



Research Centre for
Museums and Galleries

“In the past we would just be invisible”

Research into the attitudes of disabled people to museums and
heritage
Colchester Museums

Research Report

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Research Centre for Museums and Galleries
Department of Museum Studies
University of Leicester
105 Princess Road East
Leicester
LE1 7LG

Jocelyn Dodd
Eilean Hooper-Greenhill
Annie Delin
Ceri Jones



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Contents

	Key findings	i-ii
	Summary	iii-xii
	Introduction: The wider implications for society	1
	How to read this report	2
one	The background to the research	3
	1.0 Introduction	3
	1.1 The museum context for the research	3
	1.2 The aims of the research project (research questions)	4
	1.3 Research methodologies	4
	1.4 The approach to the research	5
	1.5 Research team	10
	1.6 Research ethics	11
	1.7 Disability or disabled?: A note on the use of terms in this report	11
two	Researching the context: disability, history and critical theory	15
	2.0 Introduction	15
	2.1 The literature review: researching disability	16
	2.2 Attitudes towards history, heritage and the past	18
	2.3 Discourse: shaping history and attitudes to history	19
	2.4 Deconstructing attitudes	21
	2.5 Identity: the key concept for this research	23
	2.6 Disabled people, identity and the body	24
	2.7 Excluded from history – the experiences of those on the margins	24
	2.8 Historical agency	26
	2.9 An uncomfortable and contentious history	27
	2.10 Implications from this section	28
three	Accessing groups for the research	29
	3.0 Challenges presented during the research process	29
	3.1 The need for local knowledge	29

3.2	People with complex lives	30
3.3	Disabled people as 'dependent'	30
3.4	The inadequacy of labels	30
3.5	Disabled people within the mainstream	31
3.6	Categorising disabled people	31
3.7	The motives of the research	32
3.8	Self-selection of participants and the impact on research	32
3.9	To name or not to name?	32
3.10	Defeating stereotypes	33
3.11	The impact upon our research process	33
3.12	Implications from this section	34
four	The PORTAL group	37
4.0	Introduction	37
4.1	The need for advisory groups in museums	37
4.2	The meeting with PORTAL	39
4.3	The unquestioned importance of history	39
4.4	Deaf cultural identity	40
4.5	Disability as a negative discourse	41
4.6	Objects and what they can reveal about identity	44
4.7	Different perceptions of the experience of being a disabled person	44
4.8	Museums as part of the concealment of disability	45
4.9	Disability and its representation in the museum – finding a balance	46
4.10	Some stories are not meant to be told	47
4.11	Conclusion	47
4.12	Implications from this section	49
five	Young disabled people	51
5.0	Introduction	51
5.1	Young people and museums – the context	51
5.2	The Thomas, Lord Audley School and Language College, Colchester	54
5.3	Young people and history: challenging the assumptions	54
5.4	Disabled people hidden from history	56
5.5	The oppression of disabled people – then and now	56
5.6	The impact on identity	58
5.7	The personal experience of disability	59

5.8	Museums and the representation of disability	60
5.9	Overcoming barriers	61
5.10	A collective interest?	61
5.11	Museums are about the past, present and future	62
5.12	Conclusion	63
5.13	Implications from this section	64
six	Older people	67
6.0	Introduction	67
6.1	Older people and their relationship with history – an overview	67
6.2	Grymes Dyke Tenant’s Association	69
6.3	Heritage and history – interest and curiosity	70
6.4	The absolute importance of history	71
6.5	Not quite nostalgia	73
6.6	Disabled people as ‘Other’	74
6.7	The shadow of the First and Second World Wars	75
6.8	The role of the museum in the presentation of disabled people and their history	76
6.9	The influence of age upon identity and attitude	76
6.10	Public history and the validation of experience	77
6.11	Conclusion	78
6.12	Implications from this section	79
seven	The Deaf Community	81
7.0	Introduction	81
7.1	The Deaf community and history: background and context	81
7.2	Engaging with the Deaf community: finding an entry-point	83
7.3	Returning to the literature review	86
7.4	Seeking to understand the Deaf community – interviews with Tom Fenton and Simon Hesselberg of the RAD	88
7.5	The interviews	88
7.6	To be Deaf is not to be disabled	89
7.7	Deaf people are not a homogenous group	90
7.8	Realising the Deaf community	91
7.9	Deaf history: waiting to be uncovered	93
7.10	Museums: the importance of communication	94
7.11	Conclusion	96

7.12	Implications from this section	96
eight	Conclusions	97
8.0	Introduction	97
8.1	To what extent did the research participants find history, archaeology, museums and monuments relevant to their lives?	98
8.2	How far is the relevance of history, archaeology, museums and monuments to disabled people shaped by their experience of disability?	100
8.3	What part do disabled people feel museums can play in the representation of disabled people in the past and today?	103
8.4	Additional findings	107
	Conclusions	111
	Appendices	
1	Report references	113
2	Lists of research participants	118
3	Research tools	121

Key findings

Defining disability

- It is others - disability campaigners, charities, governments, museums - who have defined disabled people as a distinct group. Individual disabled people will not automatically relate to these definitions.
- Self-identification by groups is of crucial importance, even if others may find it uncomfortable or challenging.
- Deaf 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.

Making contact

- The difficulties and complexities of engaging with different audiences and groups that museums categorise as disabled must not be underestimated.
- There is a need to recognise the 'everydayness' of disability whereby the margin becomes part of the mainstream.

How far are disability and identity linked?

- The relationship between disability and identity was complex and often directly related to personal experience.
- A political identity is the preserve of a minority. We did not feel that participants in this research study felt a strong identity as disabled people except for those participants from the Deaf community.

Attitudes towards history, heritage and museums

- Our participants took it as 'given' that history was important; however there was not an exact relationship between the value of history and its relevance to the individual. Interest in history was seen as more of a personal choice
- The 'newness' of such research for participants needs to be considered when analysing their responses; this research deals with issues that people have not been asked to think about before nor do they think about on a daily basis

(Mis) Representation of disabled people in museums

- Disabled people are invisible or misrepresented in museum collections.
- Commonly recurring stereotypes that see disabled people as pitiable and pathetic, as freaks, as objects of ridicule, as a burden or as incapable can be identified.
- There was not a single collective viewpoint from our participants, nor were they were altogether confident or assertive about presenting the history of disabled people in museums.
- The lack of a strong identification with the political meaning of 'disabled' tended to be linked with a lack of clarity and confidence about how disabled people should be represented in museums.
- For those participants who demonstrated a strong, collective identity, like the Deaf community, there was a greater clarity in terms of the role that museums could play in representing their culture and history.

Addressing the imbalance

- Participants had no models of what museums could do to show the history and culture of disabled people.
- No easy answers have been revealed from our research into how disabled people view the roles of museums in representing their history. The greatest challenge for museums is negotiating between diverse positions.

Summary

Colchester Museums commissioned this research project. It was funded by the Museums, Libraries and Archives Council (MLA) through the Designation Challenge Fund and the East of England Museum Hub Specialisms Fund. Colchester Borough Council also contributed to the funding.

Introduction – the wider implications for society

It is not only within museums that disabled people are invisible or misrepresented, society as a whole continues to find it difficult to deal with disability. Disabled people continue to be discriminated against¹ and public attitudes see disability, largely, as a private tragedy.² Extreme and misleading stereotypes continue to predominate in the media.³ Disabled people are not expected to work but this creates further problems when “to live off the welfare state is perceived as parasitic.”⁴ No-one chooses to become disabled yet they are faced with a multitude of barriers and ambivalence about their identity as a disabled person:

“If you’re going for a job, you’re going to emphasise your nearness to normality, to physical normality, or medical normality as the case may be. If you’re campaigning for better provision for your disability, then you’re going to emphasise the disadvantages of it.”⁵

Even though the Disability Discrimination Act (DDA) is acknowledged as a step forwards, there are still ‘natural’ and ‘common sense’ beliefs about disability that can be challenged by museums. Through this research we found examples of disabled people living active lives and presenting complex personal stories that did not fall into the stereotypes expressed elsewhere. Although our respondents did not identify with a common identity as disabled people, all of them were positive about making disabled people visible within the museum. This opens up the possibilities for museums to lead the way in challenging current representations of disabled people, taking into account that there is not always one viewpoint, nor is there an easy and quick approach.

1. The background to the research

¹ Miller, P., Parker, S., and Gillinson, S., *Disablism: How to tackle the last prejudice*, Demos, London, 2004, <http://www.demos.co.uk> [accessed 21/03/2006]

² For instance in a 1998 survey most people (73%) believed that if they became disabled they would experience a drop in living standards, Knight, J. and Brent, M., *Access denied: Disabled peoples’ experiences of social exclusion*, Leonard Cheshire, London, May 1998:15

³ See Barnes, C., *Disabling Imagery and the Media: An exploration of the principles for media representations of disabled people*, BCODOP/Ryburn Publishing, Halifax, 1992 and Darke, P., *Introductory essay on normality theory*, Outside centre, 2004: <http://www.outside-centre.com/darke/mycv/writings/bookchap/Colin%20Barnes.html> [accessed 21/03/2006]

⁴ Colin Barnes, interview 01/03/2006

⁵ Focus group with PORTAL, Colchester Museum’s advisory group, 17/03/2006

At present in society there is a lively debate about what it means to be a disabled person and how society treats those with impairments. As public institutions, museums are increasingly conscious that disabled people are part of their audiences and Colchester Museums have a considerable national reputation in terms of disability access and consultation. Having adopted a holistic institution-wide approach to the understanding of issues related to disabled people, the organisation wished to go beyond the now contested 'common sense' ways in which disabled people have been exhibited or ignored in the past and, from the basis of research, look for conceptual pointers and ideas that will help them to build upon existing ideas and develop new work in this area.

Carried out by the Research Centre for Museums and Galleries (RCMG), this research was designed to explore the perceptions and attitudes to heritage and the past of disabled people who live in and around Colchester. How far is the relevance of history and the past shaped by their experience of disability? What part do disabled people feel museums can play in the representation of disabled people in the past and today?

Qualitative research methods including interviews and discussions formed the basis of this research, producing a rich and geographically grounded portrayal of the attitudes of a particular group towards history, heritage and museums.

Implications:

- Do not expect to find a single unified view of the value of the heritage and the past to disabled people because there is no single group of disabled people.
- Disability may be a matter of context, for example educational, employment or political reasons, may be controlled by individuals or by others.
- There were no 'ready-made' groups of disabled people felt to be suitable for the needs of the research.
- In language, the words used are not innocent or naïve, but carry values, shape perceptions, and produce expectations.
- There are a variety of ways in which disabled people refer to disability and themselves as disabled people.

2. Researching the context: disability, history and critical theory

The challenging nature of the concepts that underlie this study entailed the formation of a sound theoretical and conceptual framework for the research. For this purpose, a review of existing research into attitudes to heritage, museums, monuments and the past of disabled and non-disabled people was undertaken, as well as an exploration of any relevant work on the specific groups to be the focus of

this research. Secondly a review of texts related to identity and culture was undertaken, particularly in the context of Disability Studies. We found that there has been limited work within the field of disability studies which focuses on museums, but, at the same time, within museum/heritage studies, we could find few research studies that focused on the subject that we wished to explore.

This research focuses on identity and representation. In developing a critical framework that offers relevant analytical tools for this piece of research, we drew on ideas from postmodernism, post-structuralism, interpretive sociology and social constructivism. These are diverse but linked theoretical positions within critical theory which have already been used to challenge social practice and to build new ways of understanding. Although difficult and demanding at times, these ideas greatly enhanced our understanding. Together, they provided analytical tools which enabled us to question and 'deconstruct' everyday social practices and ideas, many of which disadvantage disabled people. In exposing the contingency of the everyday and of the identities that are offered to individuals within social life, a deeper understanding emerges of the roles played by social institutions such as museums and heritage organisations.

Implications:

- History, and attitudes towards history, are shaped and presented through powerful discourses and meta-narratives that exclude as much as they include.
- Individual attitudes can be understood as a product or construct of the position which the individual takes within a discourse or discursive field.
- Understanding how discourses operate can reveal the constructed and contingent nature of social relations and of ways of thinking and doing that we often take for granted (common sense)
- Specific research into the attitudes of disabled people towards history, heritage and museums is conspicuous by its absence.
- History is a growing importance for the disability movement and in disability studies for explaining attitudes and understanding discrimination.
- The emphasis is on the writing of history that presents disabled people, and the Deaf community, as active participants in history rather than passive victims of their impairments.
- The study of disabled people within history must be negotiated within established discourses, stereotypes and archetypes created about disability, which are reproduced in public media, public attitudes and other aspects of society including museums.
- The proliferation of negative imagery often presumes their correction with positive imagery; however this can lead to equally unrealistic images.

The theory shaped our thinking for the next stage of the research process, making contact with research participants. Reinforced by the assertion that identities are fluid, multiple and complex, we sought to make contact with a five very diverse groups which, on the basis of our findings, we felt would approach history and museums in very different ways and have very different attitudes.

3. Contacting groups for the research: issues and challenges

There were a number of challenges that were unexpected and necessitated some changes being made to the research design in terms of the groups we could contact. As we found, it was not possible to locate within the Colchester area 'ready-made' groups of disabled people that fulfilled the requirements of the research project as initially agreed with Colchester Museums. There was much negotiation and it required a very flexible approach.

Other barriers were created by the realities of the research process. The timescale for when groups met was not always conducive to the tight demands of a research schedule. People have complex lives and disabled people may have things to manage additional to everyday demands, particularly access and/or health issues.

Above all it is the responsibility of organisations to understand the needs of their audiences. There are a number of resources and guides available that can aid in this process, for example the Museum, Library and Archive Council's *Disability Portfolio* and a number of other organisations which can provide help and support.⁶

Implications:

- There should be the expectation that disabled people are in the mainstream. Organised groups tend to work with the most dependent and disability care structures are less in touch with relatively autonomous disabled people.
- It is necessary to identify contacts who would be able to grasp the subtlety and nature of the research for the mutual benefit of the researcher and the researched.

⁶ The *Disability Portfolio* is a "collection of 12 guides on how best to meet the needs of disabled people as users and staff in museums, archives and libraries" and is available to download from the publications section of the MLA website <http://www.mla.gov.uk> [accessed 24/04/2006]. The New Audiences website has a number of resources concerned with developing new audiences, including disabled people: <http://www.newaudiences.org.uk/index.php> [accessed 24/04/2006]. At the time of writing the Arts Councils resources *Not for the Likes of You* are unavailable but their website has details of their publications <http://www.artscouncil.org.uk/> [accessed 24/04/2006]. The Directgov website has a useful database of organisations that can give information and advice: <http://www.direct.gov.uk/DI1/Directorys/UsefulContactsByCategory/DisabledPeopleContacts/fs/en> [accessed 24/04/2006].

- Relatively simplistic 'marketing' categorisations need to be avoided where possible. These do not take into account the complexity of identity or how people manage their lives.
- A complex and subtle understanding of the disability landscape is crucial. A local understanding should not be underestimated because it might be different to the national picture.

4. The PORTAL group

PORTAL is the access advisory group for Colchester Museums. Advisory groups are established in museums and galleries to focus on the needs of specific groups, particularly those that are under-represented in museum audiences. There are few reports in the public domain, however, which identify the benefits of these groups.

The group were mature in their age, which ranged from 40s to late 70s, and tended to be conventional in their approach to and experience of disability. They were not political in their thinking or part of the disability movement, nor were they used to thinking about issues of representation and history. One participant readily admitted on behalf of them all that the focus group had raised new ways of thinking for them about disability "because they're things you don't really think about yourself."

The participants tended to express the unquestioned importance of history, although they were also aware that history is an interpretation and can, therefore, be manipulated. However there was no voluntary link made between their identity as disabled people and the relevance of history and heritage to their lives. Neither was their interest in history apparently conditioned by the fact of their being disabled. They positioned themselves, until encouraged otherwise, as people with identities other than as disabled people. An exception to this non-identification was made by a person from within the Deaf community, a community that has a strong and assertive cultural identity.

When the link between history and disability was made, the participants expressed the assumption, although presented by them as 'fact,' that life in the past for disabled people would have been inherently negative. This appeared in part to be based on personal experience. It was felt by the participants that life for disabled people would always be a struggle and this should not be forgotten. Participants felt disabled people should be identified in museum displays, but they were cautious, and maybe a little uncertain, about the stories that they felt museums should tell about disabled people. This related to their own desire to be seen as 'ordinary' people first, and as disabled people second.

Implications:

- The importance of history seems to be taken as 'given', as a fact, although an interest in history is presented as more of a personal choice.

- Keep things complex. Disability is only one element of an identity which is multiple and changing.
- Language is an essential clue to an individual's position within a discourse or discursive field.
- Questions about history, identity and disability are not questions that people are normally asked to think about. We need to let people's thinking develop.
- In many or most human stories there will be an element or connection with disability. Museum practice may privilege some types of 'story' over others which will potentially influence what disabled people feel they can offer. In the context of the museum, stories of complexity may become reductive if there is no 'alternative' model.

5. Young disabled people

Teenagers and young people aged 14 – 25 years were chosen as a suitable group for this research project because they represent a new audience for museums, and were thought likely to have a high level of awareness of their rights as disabled people. Defining young people as an identifiable social group at risk of exclusion has found that like other groups excluded from museums, young people do not feel that most institutions acknowledge or reflect their specific cultural interests. It is suggested that young people have a limited interest in, and limited knowledge and understanding of history, unless they can relate it to their own lives.

However the young people we spoke to did not completely reject history; even one participant who at first stated that history was "rubbish" turned out later to be very articulate about the subject. The responses of the young people seemed to reinforce that they accepted the importance of history but that did not necessarily mean that they were interested in it. However, the young people did not make the link between history and their identity as disabled people independently. They admitted that it was impossible for them to even think about disabled people in the past because largely, museums and history were silent about disability. Furthermore, they perceived that life for disabled people in the past was very different to theirs. This appeared to create a barrier to identification with disabled people in the past, although their own experience of disability had not always been positive. All of them had experienced some difficulties or discrimination as a result of their disability, or experienced it through family members. But like PORTAL they wished to be seen as 'normal' like other young people of their age and this, along with the usual teenage/young adult enthusiasms and interests, drove them.

The young people were enthusiastic about the role museums could play in representing the past and present of disabled people. They felt that recognition of disabled people and their history would encourage greater pride and validate their existence through breaking the silence that persists. They were confident about presenting disability explicitly. They felt museums could raise awareness that there

are many different and diverse ways of experiencing the world and at the same time broaden the category of what it means to be 'normal.'

Implications:

- Role models could help young people to be proud of being a disabled person and help them to cope with more negative aspects.
- Showing how barriers can be overcome was an important narrative; that anything can be achieved if you put your mind to it.
- The use of the museum as a time capsule, to capture people's hopes and help to actively shape their future, was appealing.
- There is merit in showing that there are many different ways of experiencing the world because it could help to challenge stereotypes or 'common sense' views.

6. Older people

Older people are, like young people, recognized as a specific social group with identifiable attitudes. However, at present, the available research is at best ambiguous. More research is needed in order to understand the strength of the connection between old age and history, and why older people may have a particular view of the past.

We had intended to speak to two groups of older people. In the end it proved very difficult to make contact with a group that defined themselves as disabled. We spoke to a group of older people had a variety of impairments but did not identify themselves as disabled. Although they acknowledged their ailments and signs of ageing, the participants generally considered that they had little to complain about.

The men in the group established their interest in history right from the beginning: "That's why we came, we knew what you wanted." From a research perspective this has significant implications. These participants were self-selecting, already interested in the topic which inevitably shaped their responses. That they tended to dominate the discussions also means we must hesitate to see their responses as representative.

The experience of being a 'disabled person' was, however, not one which these participants could relate to. Their conception of 'disabled people' was that being a disabled person is a tragic and difficult experience. In terms of representing disabled people and their history in museums, their lack of identification with this within their identity meant that there was no specific discussion regarding this during the focus group. It was not until the end of the focus group that one of the participants was able to bring all the elements discussed together, and state their conviction that museums could play a role in the presentation of disabled people, a reminder that we were asking people to engage with complex issues that few people are ever asked to think about.

Implications:

- Do not expect to find a unified group of 'disabled people.'
- Link public and private narratives.
- Male and female histories might not be the same.
- Self-selecting groups may not necessarily be representative of other older people (or even disabled people).
- Individuals who acquire impairments will not always recognize themselves as disabled.

7. The Deaf Community

The Deaf community have their own rich heritage as a cultural-linguistic minority with values and beliefs that are distinct from the 'hearing' society. The desire for autonomy is reinforced by the emergence of a growing interest in Deaf history and a justification of the right for Deaf people to exist as a separate cultural and linguistic community.

In our original conception of the 'disabled community' (a coherent group of people who identify as disabled) we conceived the Deaf community as a distinct group within it. However in practice contacting the Deaf community proved to be problematic, essentially because we were basing our research on categories that the Deaf community did not identify with, in this case 'disabled.' Our task therefore became to attempt to understand the Deaf community in more depth in order to ensure that the research was relevant to them. This learning process became increasingly significant to the research process as a whole.

Interviews with Tom Fenton, the (hearing) Chief Executive, and Simon Hesselberg, (Deaf) Head of Community Development, both of the Royal Association for Deaf people (RAD) confirmed for us that Deaf people do not define themselves as disabled. They outlined the growing importance attached to the preservation of Deaf history and culture, and were enthusiastic for the Deaf community and their history to be represented in museums but highlighted the need for museums to be more aware of communication issues as many Deaf people currently do not find museums accessible or relevant to them.

Implications:

- The Deaf community is a cultural-linguistic minority, not based on impairment.
- Deafness is a highly politicised issue to the community.

- Some Deaf people will identify themselves as disabled but others will not so understanding the local context is crucial.
- The Deaf community is a complex, not a unified, community.
- Exhibitions are seen as a useful way to communicate the history and culture of Deaf people to all audiences.
- Words are not enough. Communication needs to be comprehensive and multiple.
- Co-curation and partnerships with the Deaf community are essential for exhibition development.

8. Research findings

We considered the responses from the four focus groups against the three research aims we identified at the beginning of the study:

- To what extent did the research participants find history, archaeology, museums and monuments relevant to their lives?
- How far is the relevance of history, archaeology, museums and monuments to disabled people shaped by their experience of disability?
- What part do disabled people feel museums can play in the representation of disabled people in the past and today?

We found that all the research participants took it as 'given' that history was important, although an interest in history was seen as more of a personal choice. They had visited and were able to cite heritage sites and museums, indicating that personal experience of disability, and any social barriers this might induce, were not strongly limiting factors on their visiting habits.

Our findings point to some similarities in the attitudes of disabled people towards history and heritage, namely that identity as a disabled person does not impact upon attitudes towards history and heritage as much as other factors such as demographics, biography and culture. However due to the lack of understanding about how attitudes towards history and heritage are shaped by these other factors we cannot say for certain what a 'general' or accepted attitude may be. We certainly found instances where participants did not display the generally accepted relationship with the past as suggested by available sources, for example not all our older participants demonstrated nostalgia for the past nor did all our young people express a disinterest in history and in fact seemed quite knowledgeable about disabled people in history. Therefore more research is needed to understand our relationship with the past and how attitudes towards it are determined by different facets of our identity.

Participants had to be prompted to make the connection between history and the experience of disabled people in the past; they could not make it voluntarily. They

could not see immediately how the experiences of disabled people in the past could have any relevance to the lives of disabled people now. One reason for this is that they felt that attitudes towards disabled people were much better now so "what do we need to show?"

It was clear from the focus groups that individuals construct their identity in various and multiple ways. Whereas the Deaf people we spoke to expressed a strong and assertive identity, with a specific culture and language, this was not true for the majority of our participants. Even those for whom being disabled was a strong part of their identity tended to perceive themselves as young people, as older people, or as 'normal' people who happened to have impairments. This construction of identity seemed to have a clear impact on the approach that participants felt museums should take. Where group identity was strong, participants saw museums as vital for the transmission of that group's history and culture. Where identity was less strong, the approach was more cautious and individuals either lacked a clear concept of the role that museums should take or only advocated inclusion where it was 'appropriate.'

Museums however can, and should, challenge the 'common sense' perception that disabled people are passive, a tragedy or a burden. This kind of research tells us what people think but not necessarily what should be done. Just because individuals are cautious doesn't mean museums have to be. As the conclusion to *Buried in the Footnotes* argues:

"If museums remain reluctant to engage with disability as a cultural issue, they run the risk of positioning themselves in opposition to a society which is elsewhere ready for change."⁷

Critical theory provides useful tools for understanding how the values and assumptions that underpin social and cultural practices, and continue to shape our attitudes, can be deconstructed and understood as contingent in time and place. So instead of seeking to overlay current practices, the potential for reconstruction of how disabled people are presented in museums, with its implications for the past, present and future, is an exciting potential for museums to embrace.

The key findings, which emerged in the conclusions to this report, are presented at the beginning of this summary (p.i-ii).

⁷ RCMG, *Buried in the Footnotes: The representation of disabled people in museum and gallery collections*, University of Leicester, 2004:10

Introduction

The wider implications for society

It is not only within museums that disabled people are invisible or misrepresented, society as a whole continues to find it difficult to deal with disability. Disabled people continue to be discriminated against¹ and public attitudes see disability, largely, as a private tragedy.² Extreme and misleading stereotypes continue to predominate in the media.³ Disabled people are not expected to work but this creates further problems when "to live off the welfare state is perceived as parasitic."⁴ No-one chooses to become disabled yet they are faced with a multitude of barriers and ambivalence about their identity as a disabled person:

"If you're going for a job, you're going to emphasise your nearness to normality, to physical normality, or medical normality as the case may be. If you're campaigning for better provision for your disability, then you're going to emphasise the disadvantages of it."⁵

Even though the Disability Discrimination Act (DDA) is acknowledged as a step forwards, there are still 'natural' and 'common sense' beliefs about disability that can be challenged by museums. In our focus groups we found examples of disabled people living active lives and presenting complex personal stories that did not fall into the stereotypes expressed elsewhere. Although our respondents did not identify with a common identity as disabled people, all of them were positive about making disabled people visible within the museum. This opens up the possibilities for museums to lead the way in challenging current representations of disabled people, taking into account that there is not always one viewpoint, nor is there an easy and quick approach.

¹ Miller, P., Parker, S., and Gillinson, S., *Disablism: How to tackle the last prejudice*, Demos, London, 2004, <http://www.demos.co.uk> [accessed 21/03/2006]

² For instance a report in 1998 found that most people (73%) believed that if they became disabled they would experience a drop in living standards, Knight, J. and Brent, M., *Access denied: Disabled peoples' experiences of social exclusion*, Leonard Cheshire, London, May 1998: 15

³ See Barnes, C., *Disabling Imagery and the Media: An exploration of the principles for media representations of disabled people*, BCODOP/Ryburn Publishing, Halifax, 1992 and Darke, P., *Introductory essay on normality theory*, Outside centre, 2004: <http://www.outside-centre.com/darke/mycv/writings/bookchap/Colin%20Barnes.html> [accessed 21/03/2006]

⁴ Colin Barnes, interview 01/03/2006

⁵ Focus group with PORTAL, Colchester Museum's advisory group, 17/03/2006

How to read this report

This report consists of eight sections and a summary of the main findings.

Section one outlines the background to this research project, the interest of Colchester Museums in issues of access and representation of disabled people, and an outline of the research process and the methods we used. We define the terminology that we use in order to create some consistency throughout the report as currently language to describe disabled people and their experience is in a state of flux.

Section two is an unapologetically demanding section. It outlines the critical theory which informs the basis for our research and introduces a number of challenging concepts which we used to deconstruct the ways in which disabled people find history, heritage and museums relevant and how that relates to their identity as disabled people. Alongside the theory is an overview of available research related to attitudes and perceptions of history and heritage, and how disabled writers and researchers are using history, to highlight their exclusion, and for various political and cultural purposes.

The third Section outlines the challenges we faced in securing participants for our research, which had not been anticipated in the original research design stage. It highlights the need for a complex understanding of the ways in which disabled people control and manage their lives, and the realisation that apparently coherent and 'definite' groups may only exist as categories as defined by museums, educational and social welfare institutions or for marketing purposes.

Sections four to seven discuss in detail the findings of the four focus groups we held with individuals and groups that were drawn together from criteria we established during the research design. Each group has been analysed separately and the implications for museums identified from this analysis presented at the end of each section.

Section eight outlines our overall conclusions from the project and draws together the themes that we identified from the analysis of each focus group. It is here that we seek to understand the relationship between the participants' responses and the research aims that frame this study. Last of all we conclude with the implications from the research that we feel museum practice can benefit from and draw upon and highlight the need for future research in order to understand the relationship between individuals/groups and the past in greater depth.

Section one

The background to the research

1.0 Introduction

At present in society there is a lively debate about what it means to be a disabled person and how society treats those with impairments. As public institutions, museums are increasingly conscious that disabled people are part of their audiences and Colchester Museums have a considerable national reputation in terms of disability access and consultation. Having adopted a holistic institution-wide approach to the understanding of issues related to disabled people, the organisation wished to go beyond the now contested 'common sense' ways in which disabled people have been exhibited or ignored in the past and, from the basis of research, look for conceptual pointers and ideas that will help them to build upon existing ideas and develop new work in this area.

Carried out by the Research Centre for Museums and Galleries (RCMG), this research was designed to explore the perceptions and attitudes to heritage and the past of disabled people who live in and around Colchester. How far is the relevance of history and the past shaped by their experience of disability? What part do disabled people feel museums can play in the representation of disabled people in the past and today?

This section outlines the context for the research and the background to its development, the research questions that framed our investigation and an outline of the research process. As the debate regarding the place of disabled people in society and their exclusion from it continues, we feel this research should contribute to both the improvement of museum practice and also to a deepening of understanding of these issues within the academic field.

1.1 The museum context for the research

Colchester Museums commissioned this research project. It was funded by the Museums, Libraries and Archives Council (MLA) through the Designation Challenge Fund and the East of England Museum Hub Specialisms Fund. Colchester Borough Council also contributed to the funding.

Colchester Museums have a considerable national reputation in terms of disability access and consultation. Having adopted a holistic institution-wide approach to the understanding of issues related to disabled people, the organisation has undertaken ground-breaking work into access, consultation and the representation of disabled people in museums.

In parallel with other initiatives, the Designation Challenge Fund is funding a piece of stand-alone research into the attitudes of disabled people to museums and heritage. This research promises to be highly innovative and, while focusing on people in and around Colchester, it will provide a new dimension in understanding the attitudes of disabled people in relation to museums and heritage as a whole. This research report is designed for Colchester Museums, but can be used as a generic starting point for linked research in other locations.

Colchester Museums wished to go beyond the now contested 'common sense' ways in which disabled people have been exhibited or ignored in the past. In doing so, they wished to take account of the ways in which disabled people conceive of the current and potential practices of museums and the relevance they place on the importance of history to their lives as disabled people. More specifically, museum staff were looking for conceptual pointers and ideas that will help them to build upon existing ideas and develop new work. At the moment there is very much a sense that there is limited information to work with; they are "scrabbling about in the dark."⁶

1.2 The aims of the research project (research questions)

This research was designed to explore the perceptions of and attitudes to heritage and the past of disabled people who live in and around Colchester. Within this, our attention was focused on the following aims:

- To what extent, and how, do disabled people find history, archaeology, museums and monuments relevant to their lives?
- How far is this relevance shaped by their experience of disability?
- What part do disabled people feel museums can play in the representation of disabled people in the past and today?

Throughout the course of the research, however, new issues related to the understanding of these aims were encountered which were felt to have some importance within the research context.

1.3 Research methodologies

The research methodology was designed prior to the research project as a series of distinct but interdependent stages. The findings of each stage were designed to influence each subsequent stage. Over the course of the research, the research design was subject to change as unexpected factors and contexts presented barriers and challenges to our original intentions.

This is frequently found in qualitative research. The research aims required us to establish the context of how disabled people find history, heritage and museums

⁶ Focus group with Colchester Museums Staff, 27/02/2006

relevant to their lives. Within this, our research methods were purposefully open-ended and designed to enable the research agenda to develop in response to the ongoing fieldwork. Qualitative research methodologies enable a flexible and responsive approach to research that is not possible using quantitative research methods.

Qualitative research has an emphasis on the holistic understanding of events in their context and a focus on meanings and actions. Qualitative research is based on interpretive philosophies where the focus is on understanding specific events in specific settings.⁷ It is recognised that there are multiple interpretations of events and diverse responses to social settings and so has a particular concern with the meanings accorded to situations – it seeks to understand what have been called “intellectual puzzles.”⁸ While there are many forms of qualitative research, three key aspects of the research process are:

- description (context, processes, intentions, events, multiple meanings)
- classification (breaking up the data, categorising it, and reassembling it through appropriate conceptualisation)
- connections (finding patterns in the data, linking the evidence to broader themes, patterns or theories).

Through progressive focusing, as the contexts, actors and issues within the research context become familiar, themes begin to emerge and the research puzzles are progressively refined to enable a deeper understanding of the research material.

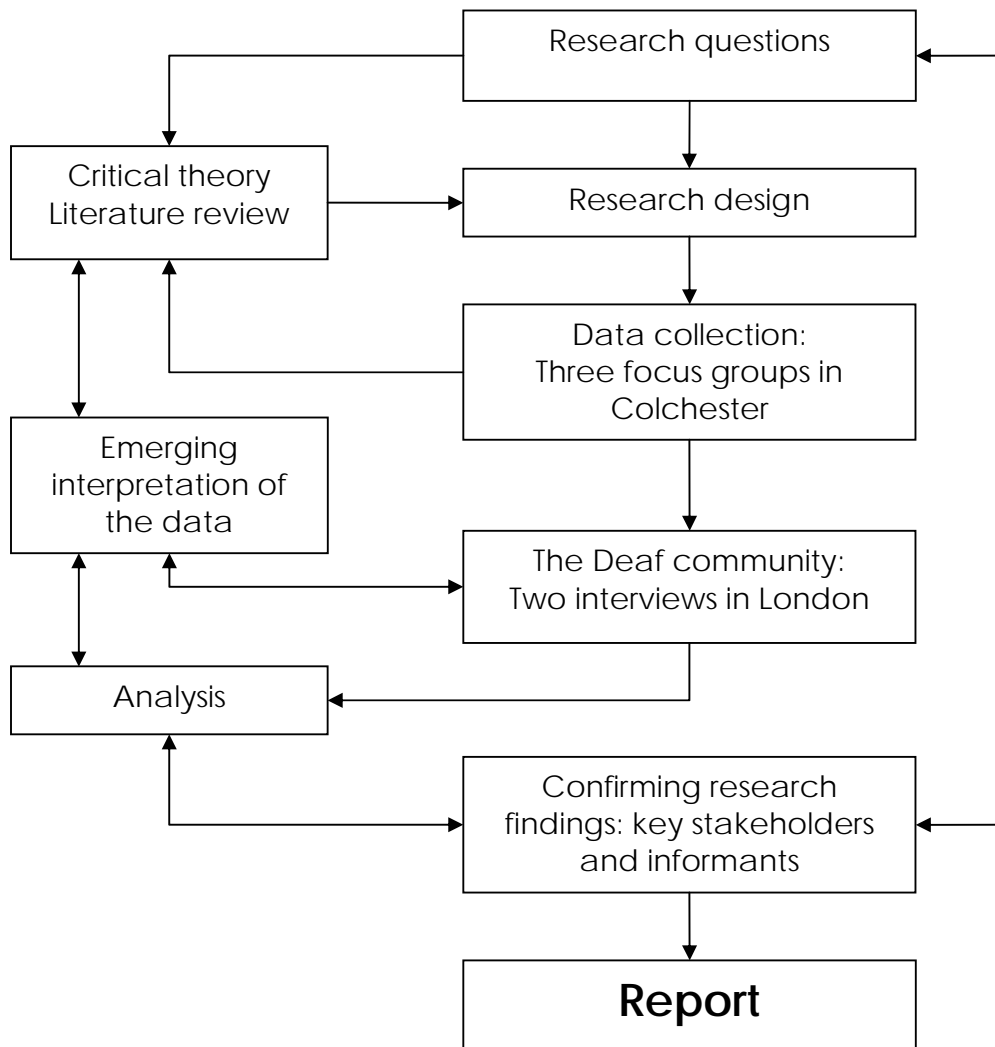
1.4 The approach to the research

The research methodologies entailed a series of interrelated, but not fixed, stages which were then developed and refined in relation to the findings of the prior stage. Each stage of the research was carefully planned and checked before proceeding to the next stage. In this manner changes could be made to the original research design, which was found to be necessary as the project progressed. Figure 1 reflects the interaction between the various stages of the research; these were not always sequential.

⁷ Glesne, C., and Peshkin, A., *Becoming qualitative researchers: an introduction*, Longman, 1992

⁸ Mason, J., *Qualitative Researching*, Sage, 1996

Figure 1: Diagram of the research process



1.4.1 Desk research and literature reviews to establish the research context and theoretical framework

A literature review established the conceptual and theoretical framework from which the detail of the specific research methods were derived, for example the questions to be asked in interviews and focus groups. There were two components to the literature review.

Firstly there was a review of existing research into the attitudes to heritage, museums, monuments and the past of disabled and non-disabled people, any relevant work on the specific groups to be the focus of this research (teenagers and young people,

elderly people, the Deaf community and museum advisory groups) and the findings of *Buried in the Footnotes*, a research report undertaken by RCMG in 2004 to ascertain the extent to which disabled people are represented in museum and gallery collections.

Secondly, a review was undertaken of texts on identity and culture, in the context of Disability Studies. This formed the theoretical and conceptual framework for the research and would enable a robust analysis of the empirical data to be generated through interviews and other methods.

During this stage we also sought to identify potential research participants in collaboration with Colchester Museums based on their experience of working with groups of disabled people, including their advisory group PORTAL, and from contact with local groups in and around Colchester.

1.4.2 Data collection: three focus groups in Colchester

During discussions for the research design, it was decided to focus on the recruitment of five distinct groups of disabled people. The intention was to gain a broad range and diversity of views from those whose disability defines their identity in a major way to those to whom disability is a lesser element of their self-image. The five groups were defined as:

Teenagers and young people (14–25 years): this group is an under-represented audience for the museums, and was thought likely to have a high level of awareness of their rights as disabled people.

Older people (60+ years): this is a more familiar museum audience, but has specific needs. People of this age-range were felt to be less aware of their rights and entitlements. We aimed to talk to two groups; one group who defined themselves as disabled people and a second group who had impairments, but who would not define themselves as disabled people.

Members of the Deaf community: the museum service had already worked with members of the Deaf community and they were felt to be assertive and well-informed as to what they might expect from museums.

The PORTAL group: this is the museums' access advisory group. They were felt likely to have well-developed views on the subjects under discussion.

During the process of recruiting participants for the focus groups it became clear that there were unanticipated challenges to obtaining participants from these categories as defined during initial discussions with the museum. These challenges are discussed in detail in Section three but in summary, they necessitated changes to the research design, particularly as there were no 'ready-made' groups of disabled people felt to be suitable for the needs of the research. After a period of negotiation and an examination of the local context in Colchester, we were able to carry out three focus groups with the following:

- The PORTAL group (focus group 21/06/2005)
- Teenagers and young people (14–25 years) (focus group 21/06/2005)
- A group of older people (65-75 years) with impairments (focus group 22/06/2005)

The interview schedule was designed on the basis of the literature review and to encompass the main themes of the research, taking into account the needs of each particular group. A list of participants can be found at Appendix 2 and the research tools at Appendix 3.

1.4.3 Desk research and interviews with the Deaf community

It had originally been intended to convene a focus group drawn from members of the Deaf community in Colchester during the initial research period but this was not found to be possible. After a lack of interest from the Deaf community in the premise of the research, and from further discussions with the museum, it emerged that a different approach would need to be taken if meaningful dialogue was to be made with the Deaf community in Colchester. Returning to the literature and contacting various members of Deaf societies resulted in the setting up of two interviews which enabled us to explore our research aims with the Deaf community and to gain an understanding of the reasons for the challenges which we had faced. This process is discussed in greater detail in Section seven.

1.4.4 Discussion of the research findings

During, and towards the end of the process of analysis and interpretation of the evidence, the findings were reviewed and tested through a series of focused discussions with a mixture of specialists, thinkers and museum practitioners (Figure 2). The original intention was to convene a colloquium but in the event it proved more practical and beneficial due to the challenging nature of the data collected to organise a number of smaller, more in-depth discussions. Participants were chosen carefully on the basis of their specific, relevant expertise. Through this exposition of the findings, we sought to challenge, confirm, and contextualise the issues and concepts that had emerged from our analysis. This ensured that the qualitative evidence was reviewed from a range of different perspectives and helped to eliminate any unseen bias in the interpretation.

Figure 2: The findings were reviewed with the following groups

Date	Location	Participants
27/02/2006	Hollytrees Museum, Colchester	Colchester Museums Staff: Peter Berridge Anne-Maria Bojko Lynette Burgess Georgina Colthorpe Tom Hodgson Caroline MacDonald Sophie Weaver

01/03/2006	Centre for Disability Studies, University of Leeds	Colin Barnes Professor of Disability Studies and Director of the Centre
10/03/2006	Department of Museum Studies, University of Leicester	Museum professionals: Heather Hollins, Access and inclusion, The Holocaust Centre, Nottinghamshire Jane Montgomery, Access Officer, NE Regional Museum Hub Alison Plumridge, Director of Bury St Edmunds Art Gallery
15/10/2006	Dis:cover, Colchester Museums Conference	Mixed discussion group
17/10/2006	Hollytrees Museum, Colchester	PORTAL, Colchester Museums: Andrew Brian Chris Dorothy Richard Robert

1.4.5 Analysis and interpretation of the evidence

Throughout each distinct stage of the research process we carried out a careful analysis and interpretation of the emerging research material. The focus groups and interviews were taped and transcribed⁹ in order to facilitate this process. We looked for patterns in the data and assessed their significance, on the basis of the theories of identity that we are using, the issues that have been identified within the literature review, and the use to which the findings will be put.

We did not expect to find a single unified view of the value of the heritage and the past to disabled people; rather we expected to find a range of perspectives that were derived from combinations of demographic characteristics (such as age, gender and education) with experience of specific disabilities and individual personalities. The research is not intended to produce guidelines from which the museum may work, but may provide a deeper picture of the ways in which disabled people perceive and use heritage, the past and museums.

1.4.6 Report

A final report was produced that took into account of all relevant comments, challenges, and confirmations of the research findings. The research should contribute to both the improvement of museum practice and also to a deepening of understanding of these issues within the academic field.

⁹ Transcription was undertaken by an external company, Kath's Keying Services Limited of Chaddesden, near Derby to whom we are very grateful

Figure 3: Timeline for the research

Activity	2005												2006			
	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A
Literature review and theory development	Orange	Orange	Orange													
Making arrangements for interviews				Blue	Blue											
Statement of research progress				Yellow												
Preparation of research tools				Pink												
Data collection; interviews in Colchester					Green	Green										
Analysis of the focus groups							Teal	Teal	Teal							
Statement of research progress									Orange							
Contact and interviews with Deaf community										Cyan	Cyan	Cyan	Cyan			
Analysis and first report draft													Light Orange			
Dissemination with museum and PORTAL group														Yellow		
Series of interviews to test the findings															Pink	
Conference															Cyan	
Final report															Blue	Blue

1.5 Research team

To carry out the research RCMG brought together a research team with a range of pertinent skills and expertise.

Jocelyn Dodd, Director, RCMG
 Eilean Hooper Greenhill, Professor of Museum Studies
 Annie Delin, Consultant
 Ceri Jones, Research Associate, RCMG

1.6 Research ethics

All research was carried out within the University of Leicester's code of conduct for Research and Data Protection.

The following guidelines provide an ethical context for the research:

British Sociological Association, 2002, *Statement of ethical practice for the British Sociological Association*,
http://www.britsoc.co.uk/new_site/index.php?area=equality&id=63 [accessed 13/03/2006]

Social Research Association, 2003, *Ethical Guidelines*,
<http://www.the-sra.org.uk/ethicals.htm> [accessed 13/03/2006]

British Educational Research Association, 2004, *Revised Ethical Guidelines for Educational Research*, <http://www.bera.ac.uk/publications/guides.php> [accessed 13/03/2006]

Economic and Social Data Service, *Ethical and legal considerations*,
<http://www.esds.ac.uk/aandp/create/ethical.asp> [accessed 13/03/2006]

The Market Research Society, *Standards and Guidelines*,
<http://www.mrs.org.uk/standards/guidelines.htm> [accessed 13/03/2006]

1.7 Disability or disabled?: A note on the use of terms in this report

At present there is a lively debate about what it means to be a disabled person and how society treats those with impairments. There is the 'medical' or 'personal tragedy' model of explanation which focuses on the impairment and how the individual must cope with that impairment. This model has been strongly criticised for portraying disabled people as inert, acted upon rather than acting for themselves. The 'social model' of disability makes the distinction between 'disability' and 'impairment', seeing the disability as socially created, constructed on top of impairment.¹⁰

"Disability describes how society responds to people with impairments; it is not a description of a personal characteristic."¹¹

The social model has been widely influential within the politics of disability because it unifies disabled people through their oppression by a non-disabled society. There is increasing recognition of the misrepresentation of disabled people within the media and how they have been reduced them to a set of unnecessary and unwanted

¹⁰ Corker, M., and Shakespeare, T., (eds), *Disability/postmodernity: embodying disability theory*, Continuum, London and New York, 2002:3

¹¹ Miller, Parker, and Gillinson, 2004: 28

stereotypes.¹² The term 'disablism' has been coined to describe discriminatory or abusive behaviour that arises from the belief that disabled people are somehow inferior.¹³

In language, the words used are not innocent or naive, but carry values, shape perceptions, and produce expectations. Decisions are made about what to emphasise and what to ignore. Words mean different things in different social configurations. Debates over terminology are familiar within discussions of disability and have been central to critiques of the traditional medical model and social science approaches.¹⁴ We noticed however that when talking to disabled people there was a variety of ways in which they referred to disability and themselves as disabled people. Use of the term 'disabled people' did not always signify agreement with the social model, nor was their clarity over its meaning:

"Can you just explain the two differences, I'm a little bit confused. Can you just explain the difference between actually disabled and disability?"¹⁵

Neither is one position favoured over the other; an analysis of the BBC website magazine *Ouch!*, written by disabled people, found that the approach of their writers lay somewhere in-between the social and the medical model:

"While the authors of *Ouch!* viewed disability as a result of societal oppression on impairment, they instead choose to illustrate this oppression and disablement mainly through writing about personal experience."¹⁶

Language and terminology is in a state of continual flux.

Our view is that there is no single group of disabled people; disabled people are found in any social group, whether defined by age, class, education, gender, culture or religion, and attitudes and responses to the experience of disability will vary across social groups. Disability may be a matter of context, for example educational, employment or political reasons, may be controlled by individuals or by others.

We therefore use the term 'disabled people' throughout the report to identify with this position. We reject terms such as 'disabled persons' because it suggests nervousness and a lack of confidence in defining disabled people as a distinct group. We will not refer to 'people with disabilities' because it suggests that disabilities are 'owned' rather than created by society.

¹² For example see Barnes, C., *Disabling Imagery and the Media: An exploration of the principles for media representations of disabled people*, BCODOP/Ryburn Publishing, Halifax, 1992

¹³ Miller, Parker and Gillinson, 2004: 28

¹⁴ Barnes, C., Mercer, G., and Shakespeare, T., *Exploring disability: a sociological introduction*, Polity Press, Cambridge, 1999:6.

¹⁵ Focus group with PORTAL, 17/03/2006

¹⁶ Thoreau, E., 'Ouch!: An examination of the self-representation of disabled people on the Internet, *Journal of computer-mediated communication*, 11 (2), 2006, <http://jcmc.indiana.edu/vol11/issue2/thoreau.html> [accessed 7/03/2006]

We will use Deaf with a capital D in order to represent those who identify with Deaf culture and use British Sign Language (BSL).

We use the word 'access' in the sense that it is a political issue of disability culture. Disabled people use the term to symbolise how in the past, and in the present, they have been excluded from society, and this is the context in which we will use it.

However, where people we have interviewed or source material we have referenced have used other terms, these are quoted directly and are not intended to cause offence.

1.8 Implications from section one

- Do not expect to find a single unified view of the value of the heritage and the past to disabled people because there is no single group of disabled people.
- Disability may be a matter of context, for example educational, employment or political reasons, may be controlled by individuals or by others.
- There were no 'ready-made' groups of disabled people felt to be suitable for the needs of the research.
- In language, the words used are not innocent or naïve, but carry values, shape perceptions, and produce expectations.
- There are a variety of ways in which disabled people refer to disability and themselves as disabled people.

Section two

Researching the context: disability, history and critical theory

2.0 Introduction

The challenging nature of the concepts that underlie this study entailed the formation of a sound theoretical and conceptual framework for the research. For this purpose, a review of existing research into attitudes to heritage, museums, monuments and the past of disabled and non-disabled people was undertaken, as well as an exploration of any relevant work on the specific groups to be the focus of this research. Secondly a review of texts related to identity and culture was undertaken, particularly in the context of Disability Studies. We found that there has been limited work within the field of disability studies which focuses on museums, but, at the same time, within museum/heritage studies, we could find few research studies that focused on the subject that we wished to explore.

This research focuses on identity and representation. In developing a critical framework that offers relevant analytical tools for this piece of research, we drew on ideas from postmodernism, post-structuralism, interpretive sociology and social constructivism. These are diverse but linked theoretical positions within critical theory which have already been used to challenge social practice and to build new ways of understanding. Although difficult and demanding at times, these ideas greatly enhanced our understanding. Together, they provided analytical tools which enabled us to question and 'deconstruct' everyday social practices and ideas, many of which disadvantage disabled people. In exposing the contingency of the everyday and of the identities that are offered to individuals within social life, a deeper understanding emerges of the roles played by social institutions such as museums and heritage organisations.

In this Section, we first describe the rationale for undertaking the two literature reviews and give an explanation of the two fields of disability studies and museum studies, between which this report falls. In order to make them more digestible, the two literature reviews have been edited and synthesised together in a manner which we hope will make the theory-heavy passages less daunting. It gives an overview of the analytical concepts we drew upon and how current research and literature address the main questions that frame our research; what are the general attitudes towards history and heritage? Is there any evidence that shows how disabled people feel about their exclusion from history and do they feel that museums can play a role in creating more affirmative discourses and representations of the past, present and future?

2.1 The literature review: researching disability

A literature review established the conceptual and theoretical framework from which the detail of the specific research methods was derived. There were two components to the literature review, a review of existing research into attitudes to heritage, museums, monuments and the past of disabled and non-disabled people; an exploration of any relevant work on the specific groups to be the focus of this research (teenagers and young people, older people, the Deaf community and museum advisory groups) and the findings of *Buried in the Footnotes*.¹⁷ Secondly a review of texts related to identity and culture was undertaken, particularly in the context of Disability Studies. This formed the theoretical and conceptual framework for the research.

The two literature reviews have been edited and synthesised for the purposes of this report and are contained in full in Appendices 4 and 5.

The research for Colchester Museums falls between museum studies and disability studies, both of which increasingly call on ideas from sociology and cultural studies. Disability studies is a highly specialised field with its own experts, many of whom speak from their own experience. It has been slow to adopt the theoretical perspectives that have provided useful conceptual tools for studies carried out within the fields of sociology and cultural studies.¹⁸ Equally, however, sociologists have been slow to acknowledge disability as a field for study, and where sociological work has been done, it has generally been on the basis of an 'individual', 'medical', or 'personal tragedy' model of explanation.¹⁹ The 'medical model' has been strongly criticised within disability studies²⁰, particularly the presumption within this model that disabled people are inert, acted upon rather than acting for themselves.²¹ The 'social model' of disability aims to go beyond the medical model in that it makes a distinction between 'disability' and 'impairment', seeing disability as socially created, constructed 'on top of' impairment.²² However, the social model, while having been widely influential within the politics of disability, is now regarded as in need of development.²³ It suggests a simple model of 'society', does not take account of important social divisions such as gender, race, age and sexuality²⁴, and while having considerable conceptual power, lacks a strong theoretical framework. Thus it has had limited influence within mainstream social theory.²⁵ Academics working in

¹⁷ RCMG, *Buried in the Footnotes: The representation of disabled people in museum and gallery collections*, University of Leicester, 2004. Both the research summary, which is publicly available, <http://www.le.ac.uk/museumstudies/rcmg/BITF2.pdf> [accessed 24/04/2006], and the more in-depth internal report were consulted (not available).

¹⁸ Corker and Shakespeare, 2002:1, 13

¹⁹ Barnes, Mercer and Shakespeare, 1999:3

²⁰ See, for example, Barnes, Mercer and Shakespeare, 1999:25-27

²¹ Barnes, Mercer and Shakespeare, 1999:26

²² Corker and Shakespeare, 2002:3.

²³ See Barnes, Mercer and Shakespeare, 1999: 29-30 for a useful breakdown of the characteristics of both models (p.30, Table 2.1) and for examples of the kinds of research questions that might be asked by researchers using these models.

²⁴ Barnes, Mercer and Shakespeare, 1999:8

²⁵ Corker and Shakespeare, 2002:13.

this field now consider that disability studies will be enhanced by drawing on the insights of critical theorists.

There has been limited work within the field of disability studies which focuses on museums. At the same time, within museum/heritage studies, we could find few research studies that focused on the subject that we wished to explore. Like disability studies, museum studies is a highly specialised field which seeks to understand the development of the museum and its role as a social and cultural institution, both in terms of its collections and the use to which these collections are put.²⁶ As public institutions, the relationship between museums and social agency has become increasingly scrutinised in recent decades and museums and galleries are seen as having the potential to “contribute towards the combating of social inequality and [have] a responsibility to do so.”²⁷ This belief that museums have a responsibility to engage with the representation of those at present misrepresented or excluded on the margins of society underpinned the AHRB-funded research project *Buried in the Footnotes: The representation of disabled people in museum and gallery collections* undertaken by RCMG 2003-2004. The report concluded that there was not a lack of material relating to disabled people in museum and gallery collections but that it was often poorly understood or museums had not engaged with challenging issues and difficult stories for fear of causing offence. There was “perceived the need for an authoritative voice on the representation of disability” and for further research to guide museums forward.²⁸

This research focuses on identity and representation and so introduces some challenging concepts. It will take account of both how disabled people understand themselves (perceive their own identities) and how disabled people understand, respond to and have expectations of museums and heritage institutions. The research requires a view of how identities are produced, maintained and changed, and equally, how representations are produced, maintained and changed. In developing a critical framework that offers relevant analytical tools for this piece of research, we have drawn on ideas from postmodernism, post-structuralism, interpretive sociology and social constructivism.²⁹ These are diverse but linked theoretical positions within critical theory which have already been used to challenge social practice and to build new ways of understanding. Together, they provide analytical tools which enable the questioning of everyday social practices and ideas, many of which disadvantage disabled people.

Critical theory offers conceptual tools (ideas, concepts, language) that enable us to dig underneath the everyday to expose how everyday life, and the position of individuals within everyday life, is brought into being and maintained over time. In exposing the contingency of the everyday and of the identities that are offered to

²⁶ Hooper-Greenhill, E., *Museums and the Interpretation of Visual Culture*, Routledge, London and New York, 2000:x

²⁷ Sandell, R, ‘Museums and the combating of social inequality: roles, responsibilities, resistance,’ in Sandell, R. (ed), *Museums, Society, Inequality*, Routledge, London and New York, 2002:3

²⁸ RCMG, 2004

²⁹ Fay, B., *Contemporary philosophy of social science*, Blackwell, Oxford, 1996; Hutcheon, L., *The politics of postmodernism*, Routledge, London and New York, 1989

individuals within social life, a deeper understanding emerges of the roles played by social institutions such as museums and heritage organisations.

The literature review focused on the following questions. What subject positions do museums and heritage organisations construct for disabled people at present and what do disabled people in and around Colchester think about this? What would they like to see? What can museums and heritage organisations do to empower disabled people through more affirmative discourses and representations of the past, present and future?

2.2 Attitudes towards history, heritage and the past

During the past decades, there has been conflict over the value of history and heritage in contemporary western societies. To many, heritage has removed our link with the 'true' past, our cultures are "amnesiac cultures: societies beset by spectacle and immediacy but lacking any sense of history."³⁰ Public history has come under attack for, conversely, making history more accessible, its meanings and complexity being reduced to a series of generalisations, and easily digestible assumptions.³¹

However, despite the pessimism there has been simultaneously an "unprecedented interest in history... from the general public who, it seemed, could not get enough of it".³² History is more available than ever before. We are equally more aware of how history is produced. An awareness that history, and that attitudes towards and interpretations of history, are shaped and presented through powerful discourses and **meta-narratives** that exclude as much as they include has emerged at the same time as marginalised groups have sought to create their own history, linked to ideas of identity and empowerment.³³

Within social formations large-scale unified stories of public life are produced that purport to tell the story of that society – such as the story of the nation, the history of Britain, or what counts as 'normality.' These are **meta-narratives**, created in public spheres. The story of the nation, for example, may be disseminated through the education system, in text books, school curricula, and through the public media. They are produced from particular perspectives which emphasise some aspects while remaining silent about others.

Museums and heritage sites have examined attitudes to the past and history but an emphasis on commercial or marketing needs that are used to frame such research

³⁰ Baer, A., 'Consuming history and memory through mass media products,' *European Journal of Cultural Studies*, 4 (4), 2001:491

³¹ Jordanova, L., *History in practice*, Arnold, London, 2000

³² Cannadine, D., 'Introduction,' in *History and the Media*, Palgrave Macmillan, Basingstoke, 2004:1

³³ Jordanova, 2000

has been criticised.³⁴ Where researchers have been proactive it has been those especially interested in cultural influences and social status.³⁵ The growth in minority history means there have been a few targeted explorations of minority group attitudes to history, particularly in relation to Black and minority ethnic communities in the UK.³⁶ But specific research into the attitudes of disabled people is conspicuous by its absence.

2.3 Discourse: shaping history and attitudes to history

Our research for Colchester Museums will be alert to discourses about disability. We will be aware of how the knowledge that a particular discourse produces connects with power, regulates conduct, makes up identities and subjectivities and defines the way things are thought about, practiced and studied. The discursive approach emphasises historical specificity, how knowledge is produced and the effects and consequences within specific practices.

Discourse is the social process of making and reproducing sense.³⁷ A 'discourse' is a means of both producing and organising meaning within a social context³⁸, a way of speaking about social life, a 'domain of language-use'.³⁹ Discourse includes language, practices and institutions; these are constituted through and situated within forms of discourse. Ways of thinking about and relating to people are produced through the language used to talk about them and the institutions that are established for their use; at the same time, language and practice makes a discourse concrete – it produces a way of thinking and acting.

Understanding how discourses operate can reveal the constructed and contingent nature of social relations and of ways of thinking and doing that we often take for granted, for instance '**common sense**.'

³⁴ Merriman, N, *Beyond the Glass Case: The past, the heritage and the public in Britain*, Leicester University Press, Leicester, London and New York, 1991; Davies, S, *By popular demand: A strategic analysis of the market potential for museums and art galleries in the UK*, Museums and Galleries Commissions, London, 1994

³⁵ Davies, 1994

³⁶ For example, Desai, P and Thomas, A, *Cultural Diversity: attitudes of ethnic minority populations towards museums and galleries*, Museums and Galleries Commission, London, 1998

³⁷ O'Sullivan, T., Hartley, J., Saunders, D., Montgomery, M., and Fiske, J., *Key concepts in communication and cultural studies*, Routledge, London and New York, second edition, 1994:93

³⁸ Edgar, A., and Sedgwick, P., (eds) *Key concepts in cultural theory*, Routledge, London and New York, 1999:117

³⁹ Belsey, C., *Critical practice*, Methuen, London and New York, 1980:5

Common sense is identified as a category of knowledge which is taken as obvious, natural, inevitable, eternal, unarguable.⁴⁰ Recent critical theory has shown how 'common sense' is not obvious or natural, but is produced within specific historical situations and in conjunction with specific social formations.⁴¹ Truths are not universal and unchanging, but are contingent, produced at a particular time in a particular culture with a particular characteristic. The everyday world of common sense ideas and actions is produced and maintained through language and through discourse. Today's common sense arrangements frequently disadvantage those who are not highly educated, 'able-bodied', white and well off.

Social formations are produced and sustained through discourse. Within these social arrangements individuals are offered identity positions, and although these offered positions do not *determine* the identity of individuals, they do provide frameworks within which people must operate. Discourses can be shaped by power relations and much of the sense-making we are exposed to is a struggle between competing discourses (a **discursive field**).⁴²

A '**discursive field**' is used to indicate an arena within which several competing discourses may be operating. They produce different subject positions and forms of identity.⁴³ 'Disability' can be seen as an active discursive field at present, one where language is challenged, along with social arrangements. Museums frequently deal with discursive fields where systems of thought and knowledge are in contest with each other.

Individual attitudes can therefore be understood as a product or construct of the position which the individual takes within the discourse or discursive field. Attitudes are not 'natural' but historically contingent or "sustained and modified by human action."⁴⁴ Attitudes are not innate but effectively learnt:

"...everything I write talks about the past, everything. Because we're not born, I mean some people say you are, but I do not believe that we are born with innate prejudice, you know, that's not what humans are about... we're taught prejudice."⁴⁵

⁴⁰ O'Sullivan, Hartley, Saunders, Montgomery and Fiske, 1994:49

⁴¹ Belsey, 1980:3. 'Social formation' is used to signal the complexity of social arrangements in specific global/local configurations and to highlight the necessity of analysing these configurations rather than accepting them as given (as 'society') Belsey, 1980:5

⁴² O'Sullivan, Hartley, Saunders, Montgomery and Fiske, 1994:94

⁴³ Weedon, C., *Identity and culture: narratives of difference and belonging*, Open University Press, Berkshire, 2004:17

⁴⁴ Barnes, Mercer and Shakespeare, 1999:12-13

⁴⁵ Colin Barnes, interview 01/03/2006

2.4 Deconstructing attitudes

We can link individual attitudes with wider social categories such as age, class, gender and race. It is argued that disability is a key defining social category on par with these.⁴⁶ This would suggest therefore that attitudes of disabled people towards history would be different to those of non-disabled people. Yet on the other hand, disability crosses all social categories, indiscriminate of gender, age, class and race.⁴⁷

Post-modern theories suggest that individuals 'are spoken' by their positions within discourse. That is, the position offered to an individual through their position within discourse enables them to speak in certain ways, but not in others. Possible forms of identity, meaning, attitudes, action, subject positions – where 'subject' means 'individual within discourse' – are set out in advance. Disabled people for example may feel that they have to 'pass' as non-disabled to be acceptable to society and avoid stigma and isolation. This has implications for the individual's attitudes, self-image and identity but also means a loss to the development of minority culture and history.⁴⁸ In recognising that identities, social customs and beliefs are established, maintained and changed through discourse, strategies of engagement with matters that are apparently fixed become possible. The establishment of new discourses offers the possibility of changed subject positions and modification of identity.

The relationship between the constitution of **representation** – through discourse, narratives, image – and the concomitant constitution of **identity** offers subject positions to disabled people. These subject positions – ways of thinking about the self and acting – may be accepted or rejected, negotiated or modified. By subjecting apparently common-sense ideas and actions to critical analysis, and by developing an understanding of how social life is produced and maintained, the possibility arises of alternative ideas and practices.

Representation is the social process of representing [things], the process of putting into concrete form an abstract concept.⁴⁹ 'Representation' can also be seen as key to the production of meaning.⁵⁰ It is through representation, which is brought about through language, visual symbols, narratives and discourses, that meanings about the world and its people are constructed. Ideas, people, objects can be represented in multiple ways with different meanings. Different representations have different effects in the social world.

⁴⁶ Kudlick, C., 'Review essay: Disability history; why we need another 'other'', in *American Historical Review*, 108 (3), June 2003:763-793

⁴⁷ Candlin, F., 'Blindness, art and exclusion in museums and galleries' in *International Journal of Art and Design Education*, Vol 22, (1), February 2003:100-110

⁴⁸ RCMG, 2004:145-146

⁴⁹ O'Sullivan, Hartley, Saunders, Montgomery and Fiske, 1994:265

⁵⁰ Hall, S., *Representation: cultural representations and signifying practices*, Sage Publications, London, Thousand Oaks, New Delhi, in association with The Open University, 1997:5-7

Such issues urge us to be cautious when looking at attitudes towards history and how they are shaped, what they mean to the individual. Gerber illustrates this point well when discussing the history of the freak shows. Although freaks are seen by some as having the 'choice' to perform on stage and were in control of their performance, Gerber questions if this can really be considered as a free 'choice.'⁵¹ If we do not look at how attitudes are shaped and constrained by wider contexts, can we really claim that people's attitudes are 'freely' developed?

The study of disability history must therefore be negotiated within established discourses, stereotypes and archetypes created about disability which are reproduced in public media, public attitudes and other aspects of life. There is a growing awareness that "media distortions of the experience of disability contribute significantly to the discriminatory process."⁵² However there are disagreements over the nature of representation and the extent to which it colludes in the disempowerment of disabled people, which Paul Darke feels continues to obscure the past and continuing oppression of disabled people within society:

"The original intent and meaning of political correctness in relation to the social model of disability – an understanding of the genealogy of oppression through culture – is what has been negated and replaced by... the sanitisation of past unpleasanties or objections to extreme examples of abuse against impaired individuals."⁵³

⁵¹ Gerber, D.A., 'Volition and valorization in the analysis of the 'Careers' of people exhibited in freak shows,' in *Disability, handicap and society*, 7 (1), 1992:53-69

⁵² Barnes, 1992:5

⁵³ Darke, 2004 <http://www.outside-centre.com/darke/mycv/writings/bookchap/Colin%20Barnes.html>

2.5 Identity: the key concept for this research

There has been a great deal written about **identity** and culture in recent times and it has become one of the most popular fields for research.⁵⁴ Identity gives a stable core to the individuality of a person. Meaning is central to identity, as it gives us our sense of who we are and where we belong.⁵⁵

Identity is central to the desire to be a knowing subject, in control of meaning.⁵⁶ Identity, meaning and self-determination are key issues in the production of a powerful sense of an active self. A person is active when what she says and does stems from her own beliefs and convictions; she is reactive when she acts or chooses what to do on the basis of what others want her to say and do. In being active, actions are generated from within; in being reactive, actions are a response to something outside you. Only by being active are you self-determining rather than passive, an independent agent.⁵⁷

Identity is produced within discourse, but responses to specific discourse will be diverse. Each of us lives with a variety of potentially contradictory identities, but at the core of our identities are values that we wish to share with others.⁵⁸ Identity is a production that is never complete, always in progress and always constituted within representation.⁵⁹ Identity is multiple rather than mono-dimensional, fluid rather than static, and constituted through language, image, action.

Personal narratives may be used in the construction of identity. We make sense of ourselves and our daily lives through narrative strategies, through structures and well-established forms⁶⁰ that organise and make our lives coherent. In the stories we tell about ourselves, like the larger public narratives in museums, some things are included and remembered and others are ignored or forgotten. The whole has a plot, a storyline and a purpose.

Identity is reinforced when public narratives, such as those found in museums, involve strong and positive representation that can be recognised as relating to or belonging 'to me'. Non-recognition and non-identification leaves the individual in a state of non-subjectivity and lack of agency.⁶¹ Individual constructions of identity are affirmed by seeing something of oneself and one's forebears in constructions of the

⁵⁴ Du Gay, P., Evans, J. and Redman, P., *Identity: a reader*, Open University Press, 2000; Weedon, 2004; Woodward, K., *Understanding Identity*, Hodder, London, 2002; Woodward, K., (ed) *Identity and difference*, Sage Publications, London, 1997

⁵⁵ Hall, 1997:3.

⁵⁶ Weedon, 2004:21.

⁵⁷ Fay 1996:19.

⁵⁸ Weeks quoted in Weedon, 2004:1.

⁵⁹ Hall, 1990:222, quoted in Weedon, 2004:5.

⁶⁰ O'Sullivan, Hartley, Saunders, Montgomery and Fiske, 1994:195

⁶¹ Weedon, 2004:7.

nation, where history and tradition interpellate the subject and induce a sense of identity and belonging.⁶²

2.6 Disabled people, identity and the body

The body (and its meaning and interpretation) is central to identity. Bodies have long been subject to inspection and judgement and this has a particular pertinence to disabled people who may find themselves defined by the shape or functionality of their bodies or fall outside what is deemed 'acceptable' by society. Classifying and hierarchising bodies is highly contentious, with overtones of the practice of eugenics.⁶³ At the very least, the (still) prevailing western view of science sets up standards of perfection to which people are supposed to conform. It is subject to on-going debates, for example in relation to young girls and women.

However, how we see 'bodies' is an effect of the discursive field within which we are located, where competing regimes of meaning seek to define bodies according to gender, skin colour, norms of beauty and ugliness, age and physical ability.⁶⁴ Therefore we recognise that while bodies are materialised through discourse, this is always in progress and always on-going.⁶⁵ Shapes or capacities of bodies do not *necessarily* determine identity and identity/bodily relations may fluctuate and change:

"I'm not walking around thinking I'm partially sighted, it's not part of my identity anymore if you see what I mean, but it was. I mean impairment is a real issue when you're young because... the important things for people in their formative years are peer groups, fashion and sex, because if you're outside those three because of impairment, you've got a real problem."⁶⁶

2.7 Excluded from history – the experiences of those on the margins

So what happens when one is excluded from the museum and from history? Museum and heritage visiting is generally associated with the white, middle class and non-disabled.⁶⁷ This can be explained by referring to structural and cultural barriers which prevent people from visiting museums, which can include physical barriers or social and educational status.⁶⁸ Most of the research agrees that groups excluded

⁶² Weedon, 2004:26.

⁶³ Shakespeare, T., *Lessons from history*, 2005:

http://www.bbc.co.uk/print/ouch/columnists/tom/170105_index.shtml

⁶⁴ Weedon, 2004:14.

⁶⁵ Price, J., and Shildrick, M., 'Bodies together: touch, ethics and disability,' in Corker and Shakespeare, 2002: 63

⁶⁶ Colin Barnes, interview 01/03/2006

⁶⁷ See, for example, Merriman, 1991; Eckstein, J, and Feist, A, 1992, *Cultural Trends* 1991:12, Policy Studies Institute, London; English Heritage, *State of the Historic Environment Report*, London, 2002. The white, middle class, male, conservative perspective can also be seen as crucial in the construction of history

⁶⁸ Merriman, 1991

from museums include the elderly, ethnic communities, disabled people, those of low economic status and young people.

Museums and heritage sites are increasingly realising that not only does the environment create barriers but the history presented does not adequately reflect the multiplicity of experiences within contemporary society. The credibility of meta-narratives as a means of explaining our world and existence are increasingly contested. Postmodernists argue that meta-narratives have lost their power to explain and their authority to justify social practices.⁶⁹ This is because they work on the basis of an a-historical standpoint from which to understand people, knowledge, society and history. So-called universal truths do not appreciate or explain diversity or create respect for difference. Postmodernists propose that **local narratives** are more useful than meta-narratives. A resistance to single explanations and to monolithic world-views can encourage a respect for difference and a celebration of the local and the particular.

Local narratives may be individual personal narratives or specific community narratives. They acknowledge that reality is grasped in multiple ways. This opens up the possibility of acknowledging multiple histories, and/or more than one category of 'normal'. Diverse ways of operating become the norm rather than the exception. It becomes possible to do things in individualistic ways without this being seen as unusual, different, abnormal. Multiple ways of managing the social and material world become possible.

A growing recognition and acceptance of diversity can be seen in changes in the treatment and status of minority groups, and coupled with this a growing interest in their history and development.⁷⁰ The idea that the individual, and by extension the group to which the individual belongs, can actively create history and thereby give justification to existence – linked to having sense of place in the world and historical continuum, a sense of destiny and the creation of identity – is a powerful belief that permeates contemporary society. Only by having a past can we have a future. The impact this has on individual attitudes to history, heritage and the past is as yet unclear, and this research is one example of how we can investigate that impact.

However these ideas about the multiple ways of being social and the diverse approach to history are not always being used: "Multi-ethnic, post-colonial societies may officially subscribe to discourses of tolerance and possibly the celebration of cultural diversity, but they remain fractured by racism and ethnocentrism."⁷¹ *Buried in the Footnotes* found that despite the emphasis on increasing access for disabled people to museums, limited attention has been paid to how disabled people have

⁶⁹ Corker and Shakespeare, 2002:5

⁷⁰ Hirsch J., and Hirsch, K., 'Disability in the family?: New questions about the southern mill village,' *Journal of social history*, 35 (4), 2002, p920-933

⁷¹ Weedon, 2004:18

been excluded from museums in narratives and displays. Furthermore, where disabled people were included in museum displays this often conformed to limited and reductive stereotypes.⁷²

2.8 Historical agency

Disabled writers are harnessing history in order to demonstrate how disabled people have contributed to and helped shape and structure the social order. The presentation of history from the margins is a call for the right for disabled people to shape their own history in the future. This is connected to developments in disabled activism, the right to independent living and advocacy and the need to combat stereotypes prevalent in all areas of society that present disabled people other than they wish to be presented.

However, as Catherine Kudlick demonstrates, there is still a problematic relationship between disability and historical agency – disabled people rarely have a leading role in history:

“Like the sidekick who never gets the girl but who causes the romantic lead to discover love, disability is all too often the unacknowledged enabler that helps define and construct the social order.”⁷³

The status of marginalized groups within society influences their relationship with history. Thus, the concealment of disabled people from society, and the stigma attached to being disabled, has contributed to their invisibility:

“If disability remains an area that interviewers shy away from, it is not simply because it is part of private life, but because it is a part of private life that most social historians have not yet treated as having a history connected to activities in the public sphere... The way history is conceptualised constructs histories that not only include, but also exclude, various topics.”⁷⁴

The growth of disability studies in itself reflects recent improvements in the political and social status of disabled people. It is only the “poverty of our historical imaginations”⁷⁵ that hinders the discovery of disabled people’s role in history and society:

“Don’t we all know deep down that disability and able-bodiedness exist in a dialectical relationship that all of us have experienced, and that if we can explore the history of that experience we will understand both the past and ourselves better?”⁷⁶

⁷² RCMG 2004; also see Delin, A., ‘Buried in the Footnotes: the absence of disabled people in the collective imagery of our past,’ in Sandell, 2002

⁷³ Kudlick, 2003:789

⁷⁴ Hirsch and Hirsch, 2002:929

⁷⁵ Ibid:930

⁷⁶ Ibid:930

The study of disability history is therefore seen as one way in which to enrich our understanding of present society. It represents a compelling argument and one which is connected to our understanding and learning of history. For if we ignore a large section of our society, how can we suppose to be telling the 'truth' about the past?

"We have so little real history of ordinary disabled people... But we have always been here, part of life, part of society large or small. We must then make sure we dig ourselves out of these local legends, like tiny treasures to tell to the present and future generations of disabled people."⁷⁷

Parallels can be drawn here with other marginalised groups who have fought to have their voices heard, and be seen as active creators of history, not its passive victims. Through emphasising the right to have a history, communities and groups define their right to exist and to define, on their terms, how they wish to live:

"All these cultures, I mean even youth cultures... they were all about a particular lifestyle if you like and the assertion of the need for society to recognise that lifestyle in its own right."⁷⁸

2.9 An uncomfortable and contentious history

The experience of disabled people throughout history is characterised by emotive and often challenging images which create further issues in terms of their presentation. Robert Bogdan felt he could present the history of freak shows justifiably in a detached and 'objective' manner but a second author, David Gerber, objected to this on the grounds it disregarded the need to make a judgement about what many historians now regard as an unacceptable activity. However Bogdan argued that:

"The author [Gerber] confused my *writing about* the topic of freak shows with *advocating for* and defending the practice. This mistake is common among people who hold strong beliefs about the prohibition of practices they deem offensive and/or immoral."⁷⁹

Buried in the Footnotes found that museums too shied away from engaging with uncomfortable stories or ideas of their presentation because, amongst other factors, the fear of causing offence as the Gerber/Bogdan argument exemplifies. All too often the proliferation of negative imagery presumes their correction with positive imagery, which can lead to equally unrealistic images. There is a need however to confront these fears, and "to construct a narrative which accepts and integrates difficult stories."⁸⁰

⁷⁷ Penny Pepper writing in the *Sue Napolitano Social Club* newsletter, July 2000, <http://www.johnnypops.demon.co.uk/poetry/snsc/> [accessed 17/02/2006]

⁷⁸ Colin Barnes, interview 01/03/2006

⁷⁹ Bogdan, R., 'In defence of the freak show,' *Disability, Handicap and Society*, 8 (1):91

⁸⁰ RCMG, 2004:76

Disability and history have a somewhat uneasy relationship with each other as it stands. It is crucial for many disabled writers to identify the disabled person's place in history but research is hampered by constraints and challenging issues to be confronted. However to do nothing is to continue the silence and prevent disabled people from finding out about their relationship to history. "[The] ability to recall and identify with our own past gives existence meaning, purpose and value"⁸¹; history legitimises and gives a sense of purpose.

2.10 Implications from this section

- History, and attitudes towards history, are shaped and presented through powerful discourses and meta-narratives that exclude as much as they include.
- Individual attitudes can be understood as a product or construct of the position which the individual takes within a discourse or discursive field.
- Understanding how discourses operate can reveal the constructed and contingent nature of social relations and of ways of thinking and doing that we often take for granted (common sense)
- Specific research into the attitudes of disabled people towards history, heritage and museums is conspicuous by its absence.
- History is a growing importance for the disability movement and in disability studies for explaining attitudes and understanding discrimination.
- The emphasis is on the writing of history that presents disabled people, and the Deaf community, as active participants in history rather than passive victims of their impairments.
- The study of disabled people within history must be negotiated within established discourses, stereotypes and archetypes created about disability, which are reproduced in public media, public attitudes and other aspects of society including museums.
- The proliferation of negative imagery often presumes their correction with positive imagery, however this can lead to equally unrealistic images.

These main points drawn from the two literature reviews shaped our thinking towards the next stage of the research process, making contact with research participants. Reinforced by the assertion that identities are fluid, multiple and complex, we sought to make contact with five very diverse groups which, on the basis of our findings, we felt would approach history and museums in very different ways and have very different attitudes. The next section outlines the unexpected challenges that presented themselves when we sought to make contact with these groups.

⁸¹ Lowenthal, *The Past is a foreign country*, Cambridge University Press, Cambridge, 1985:41

Section three

Contacting groups for the research: issues and challenges

3.0 Challenges presented during the research process

There were a number of challenges that were unexpected and necessitated some changes being made to the research design in terms of the groups we could contact. As we found, it was not possible to locate within the Colchester area 'ready-made' groups of disabled people that fulfilled the requirements of the research project as initially agreed with Colchester Museums. There was much negotiation and it required a very flexible approach.

Other barriers were created by the realities of the research process. The timescale for when groups met was not always conducive to the tight demands of a research schedule. People have complex lives and disabled people may have things to manage additional to everyday demands, particularly access and/or health issues.

These challenges to recruitment and other issues that can be highlighted from the research process in relation to the suitability of research participants are outlined within this section. They potentially could come in use as guidelines for museums and other organisations wishing to work with disabled people, or for prompting a greater understanding of the issues around recruiting participants for research.

3.1 The need for local knowledge

Details for a large number of groups and organisations were collected for the research but understanding the purpose of these groups and who they enabled us to contact was not always obvious or straightforward. The names of groups could sometimes be misleading. PHAB (Physically handicapped and able-bodied) groups, for example, were suggested as a means of contacting young disabled people but in reality, the Colchester PHAB group had a membership age of up to sixty and most of their members were actually middle aged. Support services often centralised to specific venues so some groups of disabled people met outside of Colchester area because this is where the club or service is. Other organisations offered advice rather than membership.

The timescale for when groups met was not always conducive to the tight demands of a research schedule. They often met only 1 or 2 times a month which can make establishing contact and fixing up a focus group a long-term process.

The casual nature of some proposed arrangements conflicted with the researchers need to plan and identify the likely profile of the participants. For example, the Deaf group contacted resisted a formal meeting in favour of a more informal encounter at a Deaf club or public meeting place. The short notice also clashed with the need to book an interpreter well in advance due to a local shortage. In the future such approaches would need to be considered and require integration into the research plan, and build-in time.

3.2 People with complex lives

The 'ordinary' demands of life may intrude upon any research process and people will always have things to manage within their lives which may create barriers to their participation in research projects. However, disabled people may have things to manage additional to the everyday demands, particularly access and/or health issues. Health management issues may prevent attendance at interview, such as two students from the Colchester Institute who were unable to attend the focus group at Thomas Lord Audley School. General issues such as transport may become more acute because taxis need to be booked at specific times. Communication needs become paramount when a BSL interpreter is required and it is difficult to obtain one at the last minute.

3.3 Disabled people as "dependent"

Services and support structures were felt to be heavily biased towards more 'dependent' groups of disabled people, for example learning disabilities, challenging behaviour or severe multiple disability. Reliance on such networks therefore leads towards far greater numbers than is desirable of participants who may have less ability or find it inappropriate to participate in discussion-based research. They are more likely to be institutionalised and give conditioned responses that they feel the museum wishes to hear.

Furthermore, gatekeepers of groups, who are often non-disabled and can include parents, may wish to talk 'for' the group potentially stifling the voice of the individual.

3.4 The inadequacy of labels

In conversation with Colin Barnes of the Centre for Disability Studies⁸² it was identified that many disabled people do not want to belong to clubs that solely exist for them. They desire to be integrated into mainstream society. Therefore how these clubs and societies are labelled can also create a barrier. Returning to the PHAB club, its initials stand for "Physically handicapped and able-bodied" which is quite an outdated use of language which suggests negative and stereotypical connotations:

⁸² Located within the Faculty of Social Sciences at the University of Leeds

“Referring to disabled people as ‘handicapped’ stems from the notion that the whole of life is a competition... and implies that they will not do well. Also ‘handicap’ has allusions to ‘cap in hand’ and begging.”⁸³

3.5 Disabled people within the mainstream

Young disabled people are becoming more integrated into mainstream society so gaining access is increasingly problematic. Yet conversely, young disabled people are not extensively engaged in mainstream development or representation networks despite the protestations of organisers. They may be less visible in structured networks and it was found that there was only one disabled person on the Duke of Edinburgh scheme for example and none on Essex Young people’s forum.

Integration into mainstream education will have an impact on identifying young disabled people. Essex County Council has adopted a policy of special units in schools but during the research process, the contact at Thomas, Lord Audley School mentioned that there would be a winding down of the special support unit in education. The reason for this was parent/student preference, and increasing rights, to attend mainstream school closer to home rather than benefit from a centralised support service in a designated school. The implications are that this will make it harder to reach young disabled people for research purposes.

3.6 Categorising disabled people

The abstract categories of the research plan were not readily translated into people who could be contactable or define themselves as disabled. There was some difficulty in preserving the rigour that was necessary in defining disabled people as participants, particularly when some participants proposed were in categories defined as disabled for educational purposes only. Negotiating the different classifications as defined by museums, social services, education and importantly, disabled people, was a lengthier task than anticipated.

In the event, it became clear that some of the organisations contacted had too specific an agenda to be helpful to the research. They were too easily influenced by organisational issues or by the medical model, or they focused on single impairments. As well as categories imposed upon disabled people, disabled people might also choose to define themselves. They may choose to define themselves by their disability, for example Colchester Deaf football club, or by their interest, for example the Phoenix amateur swimming club. Such sports groups and special interest groups may be a more effective way of selecting people for research rather than groups defined by their impairment.

⁸³ Barnes, 1992: 20

3.7 The motives of the research

Within specific education organisations there was sometimes suspicion or fatigue regarding the research motives and the demands it would make on their time. Several enquiries were closed down at the preliminary stage.

The motives of some very eager organisers we made contact with were also queried as it was felt they were possibly seeing the research as an opportunity for activity as a benefit to the participants. These organisers were unclear about what the research demanded from participants and that it was not activity-based. It was necessary to identify contacts who would be able to grasp the subtlety and nature of the research for the mutual benefit of the researcher and the researched.

3.8 Self-selection of participants and the impact on research

The ability to make generalizations from research data depends on the strategies of selection of research participants. It may not always be as important in qualitative research to make generalisations⁸⁴ but still, researchers must be wary of participants who are 'self-selecting', in other words individuals who take part in the research because of a prior interest in the topic or they feel they know what the researchers want in terms of answers. This may conflict with the need to capture a representative sample of the 'research population' because, as many studies show, certain types of people are more likely than others to select themselves for research, and this may result in a biased, rather than a representative, sample.⁸⁵ Therefore we must be wary with our findings from the participants who took part in the focus group at Grime's Dyke, where three men volunteered themselves for the research because of their interest in history. Since their views also tended to dominate the research, we must be wary in drawing too many general conclusions from this.

3.9 To name or not to name?

An issue that emerged from the analysis and report-writing process was the decision whether to give voice to our research participants by including their names where they had been quoted. General ethics guidelines suggest that anonymity is more appropriate but we felt it was important to use real names, as in the past disabled people are more likely to have been presented in the museum in a way that reinforced their exclusion from history:

"Disabled people displayed are more likely to be depersonalised than non-disabled people. Failing to name people as they appear in pictures, as wearers of clothing or users of aids contributes to one of the most effective forms of disempowerment – invisibility."⁸⁶

⁸⁴ Flick, U., *An introduction to Qualitative Research*, Sage Publications, London, Thousand Oaks, New Delhi, 1998:70

⁸⁵ De Vaus, D., *Surveys in Social Research*, 5th edition, Routledge, London, 2002:59

⁸⁶ RCMG, 2004:61

However, when we came to discuss this with some research participants different attitudes emerged. Some participants felt names should be used: "Isn't it a bit impersonal if you don't put a name?" Others were more hesitant. Participants felt that their responses could be taken out of context or it might present them in a way that could be damaging for benefits or pensions claims:

"I just think we've got to be careful where people, if they're on any form of benefits or pensions, that they can't really be identified cos they may have made a statement, such as I have personally this morning, which could be used against you at a later date."

Therefore we made the decision that it was safer to persist with anonymity, particularly as some of our participants were part of an identifiable group.

3.10 Defeating stereotypes

The barriers we came up against highlight the potential inadequacies of categorisations developed for marketing and audience development purposes, which in reality may be radically different to how people manage and organise their lives. However, through investigating alternative avenues of contact we were able to involve participants who we feel challenge the stereotype that disabled people are inert, passive and make no valuable contribution to society.

Instead, our participants were making a social contribution; two of the members of PORTAL were involved in committees in their local community and PORTAL, as the advisory group for Colchester Museums, as a whole were working actively to effect change within the organisation. The older people interviewed at Gryme's Dyke sheltered housing were involved with the Royal British Legion and a reminiscence project with local schools. The young people involved in the research especially recognised their dual identity as 'disabled' and as 'normal.' They were ambitious and desired to integrate within society, driven by 'normal' teenage and young adult enthusiasms and attitudes.

All participants talked about their social lives and their active participation in various interests, which included sailing, swimming, amateur dramatics, photography and travel. Participants engaged with the questions we asked them, seemed interested in the subjects under discussion and, despite the difficulties they admitted to in comprehending some of our questions, were reflective and articulate.

3.11 The impact upon our research process

As a consequence of the issues outlined above, three of the categories that were selected for research had to be amended so that instead of interviewing five groups we interviewed four. The eventual groups we established for the purposes of the research were:

PORTAL – the advisory group for Colchester Museums

There were few challenges in inviting the PORTAL group to participate in our research project and no amendments to this research group were made.

Teenagers and young people (14-25 years)

It was originally intended that the group of young people would come from one organisation; however individual organisations seemed to have too specific an agenda for the purposes of our research. In the event, six young disabled people were selected from very diverse sources and mainly from schools and education establishments: Thomas, Lord Audley School and Language College and the Colchester Institute, and a graduate who made contact via email. Essex County Council has adopted a policy of special units in schools, for example visually impaired and Deaf units, which facilitated this approach.

Older people (60+ years)

Initially it was intended to carry out research with two groups, one group who identified themselves as disabled people and a second group who did not identify themselves as disabled people. In the end it proved very difficult to find a group of older people who identified themselves as disabled people. There were a whole range of organisations available but few were relevant to the research. The planning for the focus group was facilitated through deciding that sheltered housing should be the focus, and after that decision was taken it was relatively straightforward to set up.

The Deaf community

Prior to the visit to Colchester several Deaf groups were contacted. It was found that there were lots of activities and groups and very helpful staff but it was very difficult to get a firm response from key workers. The process of making contact with the Deaf community is outlined in more detail in Section seven as it proved to be a significant challenge.

3.12 Implications from this section

- There should be the expectation that disabled people are in the mainstream. Organised groups tend to work with the most dependent and disability care structures are less in touch with relatively autonomous disabled people.
- Through investigating alternative avenues of contact we were able to involve participants who we feel challenge the stereotype that disabled people are inert, passive and make no valuable contribution to society.
- It is necessary to identify contacts that would be able to grasp the subtlety and nature of the research for the mutual benefit of the researcher and the researched.
- Relatively simplistic 'marketing' categorisations need to be avoided where possible. These do not take into account the complexity of identity or how people manage their lives.

- A complex and subtle understanding of the disability landscape is crucial. A local understanding should not be underestimated because it might be different to the national picture.

Above all it is the responsibility of organisations to understand the needs of their audiences. There are a number of resources and guides available that can aid in this process, for example the Museum, Library and Archive Council's *Disability Portfolio* and a number of other organisations which can provide help and support.⁸⁷

The next four sections go through individually the responses and analysis of the four focus groups we conducted. Each section begins with the findings from the literature review specifically related to the group in question, which presented some preliminary assessment of their relationship with museums, history and heritage, then moves on to a discussion of the responses to the research questions and the main conclusions that can be identified.

⁸⁷ The *Disability Portfolio* is a "collection of 12 guides on how best to meet the needs of disabled people as users and staff in museums, archives and libraries" and is available to download from the publications section of the MLA website <http://www.mla.gov.uk> [accessed 24/04/2006]. The New Audiences website has a number of resources concerned with developing new audiences, including disabled people: <http://www.newaudiences.org.uk/index.php> [accessed 24/04/2006]. At the time of writing the Arts Councils resources *Not for the Likes of You* are unavailable but their website has details of their publications <http://www.artscouncil.org.uk/> [accessed 24/04/2006]. The Directgov website has a useful database of organisations that can give information and advice: <http://www.direct.gov.uk/DI1/Directories/UsefulContactsByCategory/DisabledPeopleContacts/fs/en> [accessed 24/04/2006].

Section four

The PORTAL group

4.0 Introduction

PORTAL is the access advisory group for Colchester Museums. Advisory groups are established in museums and galleries to focus on the needs of specific groups, particularly those that are under-represented in museum audiences. There are few reports in the public domain, however, which identify the benefits of these groups.

The group were mature in their age, which ranged from 40s to late 70s, and tended to be conventional in their approach to and experience of disability. They were not political in their thinking or part of the disability movement, nor were they used to thinking about issues of representation and history. One participant readily admitted on behalf of them all that the focus group had raised new ways of thinking for them about disability "because they're things you don't really think about yourself."

The participants tended to express the unquestioned importance of history, although they were also aware that history is an interpretation and can, therefore, be manipulated. However there was no voluntary link made between their identity as disabled people and the relevance of history and heritage to their lives. Neither was their interest in history apparently conditioned by the fact of their being disabled. They positioned themselves, until encouraged otherwise, as people with identities other than as disabled people. An exception to this non-identification was made by a person from within the Deaf community, a community that has a strong and assertive cultural identity.

When the link between history and disability was made, the participants expressed the assumption, although presented by them as 'fact,' that life in the past for disabled people would have been inherently negative. This appeared in part to be based on personal experience. It was felt by the participants that life for disabled people would always be a struggle and this should not be forgotten. Participants felt disabled people should be identified in museum displays, but they were cautious, and maybe a little uncertain, about the stories that they felt museums should tell about disabled people. This related to their own desire to be seen as 'ordinary' people first, and as disabled people second.

4.1 The need for advisory groups in museums

PORTAL is the access advisory group for Colchester Museums and as such is a group constituted because the members identify themselves as disabled people. It was also felt they would be familiar with the subjects under discussion.

Advisory groups are established in museums and galleries to focus on the needs of specific groups, particularly those that are under-represented in museum audiences. There are few reports in the public domain, however, which identify the benefits of such groups. Where the benefits have been explored, it has been demonstrated that an advisory group can have a profound impact upon the whole organisation as well as the group participants. This was the experience of Drawbridge, established by Nottingham City Museum and Galleries Marketing Department in 1995 to develop the museum and gallery through consultation with disabled people. As well as the impact upon the Castle Museum, Drawbridge:

“...exposed the truth that disability is an area which is infinitely variable and which cannot be “solved” through a few physical alterations... It also becomes clear, however, that in many of these areas the inclusion of disabled people generates an open, inclusive and creative approach which results in a more people-friendly and attractive museum serving more of the public without targeting or marginalising them by ability status”⁸⁸

Such groups as Drawbridge, or PORTAL at Colchester Museums, are still relatively rare and few are long-term advisory groups. Many are put together for particular projects and then disbanded. Where activities do take place, these may be designed to open up the museum to all sections of the community, not just disabled people:

“The activities don’t say anything in particular about disability, except that disabled people can be stimulated and educated by activities around museum collections. They do, however, recognise the existence of disabled people in society and the need to cater for them.”⁸⁹

This distance between museums and galleries and their disabled audiences is recognised by the existence of external, independent advisory groups, which have also been established to inform and provide advice regarding access issues for disabled people. The Museums Libraries and Archives Council produces a number of publications and MAGDA, the Museums and Galleries Disability Association provides information and advice on access and educational issues. Independent groups such as INTACT (Intellectual Access Trust) raise awareness of related issues such as ensuring that displays in museums and galleries and historic properties are made more accessible to people with learning or communication disabilities.⁹⁰

There is evidence that museums have been working closer with communities and specific ‘social groups’ as part of wider audience development and social inclusion objectives. Part of this work may involve the establishment of a specific advisory group but there are still relatively few examples of permanent groups established in museums which meet regularly.

⁸⁸ Delin, A, *Drawbridge: A model for consultation with disabled people, Evaluation report* commissioned by Nottingham City Museum and Galleries Marketing Department, Funded by Resource, March 2001:83

⁸⁹ RCMG, 2004:131

⁹⁰ Rayner, A, *Access in mind: towards the inclusive museum*, The Intellectual Access Trust, NMS Publishing, Edinburgh, 1998

4.2 The meeting with PORTAL

Contact was made with PORTAL through normal museum channels of communication. The then eight members of PORTAL took part in the focus group held in the Charles Gray room at Colchester Castle, a large and spacious room familiar to them. There was some disruption part way through the focus group as one of the members arrived late but overall the focus group ran smoothly and lasted about two hours. The participants had a variety of impairments, including physically disabled people, one wheelchair user and some walking-aid users, visually-impaired people and some with hidden impairments which emerged during the course of the discussion. One participant was Deaf and used British Sign Language (BSL) and an interpreter was present during the interview.

Participants were local to Colchester, were predominantly male (six males and two females) and white. They gave the impression of living active lives, demonstrating a variety of interests such as sailing, travel and photography, and, as well as acting to effect change in the museum. The group were mature in their age, which ranged from 40s to late 70s, and tended to be conventional in their approach to and experience of disability. They were non-political in their thinking (not part of the disability movement). They were very traditionally minded; one speaking in an authoritative voice for the group said:

“And I think the last thing to sum up would be we’re not disabled people, we’re people with a disability.”

The most comfortable subject they could relate to as disabled people was access to museums. This tended to embrace sensory and intellectual access as well as physical:

“Well I suppose the activities of PORTAL would be about saying that many curators have thought about the problems of making museums accessible to disabled people and I don’t mean from an access point of view and wide doors for wheelchairs, but from the intellectual information that you get and the audio information that could be brought into museums.”

They were not used to thinking about issues of representation and history, although they raised some interesting points during the discussion. One participant readily admitted on behalf of them all that the focus group had raised new ways of thinking for them about disability:

“I think most of us will have found it a little bit difficult to focus our thoughts to answer the questions you asked; because they’re things you don’t really think about yourself.”

4.3 The unquestioned importance of history

To begin with, PORTAL did not question the importance of history; it was taken as a ‘given’, a fact. This was a perception common across all the focus groups we

carried out, even if individuals expressed their own lack of interest in history. Reasons for its importance expressed by participants from PORTAL included the fact that it was interesting and that it enabled them to understand how both society, and individuals, had come to exist at a particular point in time:

"It's just interesting."

"Today is tomorrow's past."

"[We can] appreciate how civilisation has developed from feudal society to more open, democratic society."

Knowing the history of a place or of people helped some of the participants to feel a part of that history or stimulated a deeper, emotional connection:

"I sit at home sometimes and I think where I live, the Romans were here, they had housing here. It's just the fact that all these people lived here so many thousands of years before."

"In the family stories get passed on... compare how things used to be. We have a blood link to all these people. [It is] almost spiritual, feels connected."

Another participant felt that knowing about history was essential as part of a learning process:

"History is about looking back, like life... [You] make mistakes and try not to do it again"

The group were aware that history is constructed by others and can, therefore, be manipulated, but that did not diminish its importance:

"History is written by the winners."

"You have to be analytical, decide for yourself what is true."

However there was no voluntary link made between their identity as disabled people to the importance of history or the relevance of history and heritage to their lives. Neither was their interest in history apparently conditioned by the fact of their being disabled. They positioned themselves, until encouraged otherwise, as people with identities other than as disabled people.

4.4 Deaf cultural identity

Although participants in the PORTAL group did not immediately make the connection between disability and history, the exception was that of a Deaf individual who, early on in the focus group, volunteered a descriptive narrative of a visit to a churchyard where she had found evidence for Deaf people in history:

"...there's an old church there and we were looking around, it was really interesting. And for the first time I saw a tiny, tiny grave and it had a husband and wife's names engraved on it and it was really small and it was covered by a tree and at the bottom it said that they were Deaf and it really stuck me cos it was the first time I've seen Deaf on a tombstone. And it was really odd, and it was the first time I'd ever seen that, you know, we don't see it on graves do we if someone's Deaf or if they're hearing, it just says about them and their family and that really struck me because I felt connected cos I thought, you know, as a Deaf person, you know, that's my link to history... I was really struck, you know, there were Deaf people in history and it was so important to them they put it on a tombstone."

It seemed significant that the exception to this non-identification between history and disability was made by a person from within the Deaf community, which we found later to have a strong and assertive cultural identity. She desired to self-define in an active, non-oppressed way with an identity and this contrasts to the more general responses of other disabled people present.

4.5 Disability as a negative discourse

In disability studies there is the general agreement that within the media, past and present, the representation of disabled people is limited, often reductive and stereotypical. Disabled people are presented in both factual and fictional storylines as "victims, passive, sexless, low achieving, poor and non-contributing."⁹¹ Or they are presented as "exotic and other, worthy of public display only because of their bodily difference."⁹² One of our participants described, for example, how blind people were seen as 'exotic' because they were seen as having special powers:

"But the other thing, sometimes disabled but certainly blind and some other... disability, were thought to include special powers... and [would] therefore be highly respected or possibly feared, might be accused of witchcraft."

These limited subject positions offered to disabled people are evident within history and within museums. Disability is seen as a "is a signifier of ugliness, tragedy, asexuality, invalidity and frailty."⁹³ It is a signifier that has been absorbed into the minds of our participants but it represented more than a stereotype to them. That life in the past for disabled people would have been inherently negative was an assumption made by our participants but they presented it as undeniable fact:

"You would get a group of blind people paraded... playing musical instruments to earn a few coppers in the street and being ridiculed and jeered at because of their disability."

⁹¹ RCMG, 2004:55

⁹² RCMG, 2004:9

⁹³ Hughes, B., Russell, R. and Paterson, K., 'Nothing to be had 'off the peg': consumption, identity and the immobilization of young disabled people,' *Disability and Society*, 20, 1, January 2005:12

"The ones who would probably be regarded as some sort of punishment or liability and were often hidden away and not acknowledged and hidden away from the world and never had an opportunity to do anything."

"Lonely, they probably would have lived in the village, perhaps they might have been just the only two Deaf people in the village."

"I mean if somebody's different or different way back, that in some certain areas it's some form of entertainment."

"... maybe a household had... a dwarf or a jester who was deformed in some way for their entertainment, rather than regarded as a normal human being"

"A lot of the disabled would probably have died before they got particularly old."

Partly this certainty was determined by their individual experiences of disability. As participants opened up to the possibility of linking disability with history, they used their own experiences as a means of projecting back and creating opinions of how they viewed the past.⁹⁴ One participant equated the ridicule he had experienced as a child directly with the experience of disabled people in general:

"There's definitely ridicule, I mean when I was younger and when I had my injuries, I had one leg nearly four inches shorter than the other, so obviously I ... was quite immobile as a child... Then that was misery... [But] yeah there's always ridicule of some sort, yes..."

A second participant compared and contrasted the lives of Deaf people in the present and in the past:

"I don't know really, I can't imagine it, perhaps, you know, now we have travel, you know, Deaf people travel everywhere, but perhaps back then it was just the two of them, you know, they really would have needed each other for communication. Perhaps their families would have hidden them, I don't know if they would have been supported, I don't know. Very different from now though I think..."

Being a disabled person was therefore described as a largely negative existence, both materially and in terms of peoples' attitudes. It was felt by the participants that life for disabled people had always been a struggle and this should not be forgotten:

"I think to get a proper perspective; you need to indicate that by and large it has always been very negative for disabled people, for the majority of

⁹⁴ This is a recognised approach to making meaning from history or the past for example Merriman comments that "Images of the past are an important personal way in which individuals come to terms with themselves and their circumstances," 1991:4. Aside from PORTAL we found evidence of this in the focus groups with the younger and older people.

disabled people. Partly because of attitude, partly because of the sheer facts of disability..."

So the individuals we spoke to were speaking from the position determined in society that to be disabled is a negative experience, not only from how society treats disability but also in terms of the loss and impairment it represents.

4.6 Objects and what they can reveal about identity

Already we have seen that this group did not immediately make the link between their identity as a disabled person and disabled people within history. This suggested that our participants did not have a strong sense of themselves as disabled people in the sense of being an "oppressed" minority sharing a common culture and history. This also emerged when we asked participants to tell us something about the objects they felt were important to them. Here they particularly demonstrated the presence of conflicting discourses in the messages they wished to communicate about themselves, their identity and their experiences.

Contrast these two statements made by a male participant who is visually-impaired. At first he talks in a general way about an object that is important to him because of its sentimental value. It has no direct connection to his impairment:

"I'm very much attached to an old watch which is on the blink at the moment; it's an old fashioned wind up one which I sometimes forget to wind up. But I value it partly because I've had it such a long time and also the bracelet attached was bought for me by one of my daughters..."

However when asked about an object that he would give to a museum to convey his life and experiences, his immediate reaction was to offer something directly related to his impairment. The private 'offer' was something personal and intimate, but the public 'offer' was something that might well be seen in a museum and helped him to 'cope' with his impairment:

"I suppose I would bring in things like old Braille writing equipment... that would be a large thing, that's part of my education."

Further specific references were made to themes and experiences felt to be special and unique to disabled individuals that they felt the museum would be interested in. This included objects specific to being disabled:

"I've got a selection of spare parts at home, I've got spare hip units, all the metal work and bits and pieces... the bits I've got actually were in me and I could relate from having been injured."

Another participant talked about the struggle of being disabled in terms of social structures that are supposed to help not actually being very useful:

"It's not something I've actually got now but... [an] old NHS wheelchair... it was one of these old heavy bulky ones which when you first start using wheelchairs, bloody difficult to manoeuvre cos they're heavy and bulky and getting up and down kerbs and stuff... The old NHS ones, they should have them all scrapped and have something better"

Other participants echoed the sentiment that you had to keep on going despite such difficulties:

"...show that if you're determined enough you can still keep going"

Even where more general themes were introduced, there was a dimension of the disability experience in the way in which they were presented:

"I think in my case it would be objects to do with travel and my travels all over the world. And in particular, apart from objects, there would be the tape recordings which I made on these journeys which were very evocative... more so than [photographs]... my friends tell me." [Use of sound memories by a visually-impaired participant]

"...because it was because of the Lord Nelson [Jubilee Trust sailing ship] being built in Wivenhoe that changed my life actually." [Participant who was involved in a specialist activity for disabled people]

These themes were suggested despite the fact that earlier discussions had ranged widely over life experiences, relationships and everyday objects, with little overt reference to disability. Respondents were therefore demonstrating a dissonance between their personal and public narratives about disability. Their personal stories were ones of complexity which featured ordinary (uniquely experienced) relationships, experiences and emotions; the public story for the museum offered a reductive account focusing on the presumed interest in the exceptional experience of being a disabled person. For all objects however the importance was the human story behind the object that brought it to life and gave it a meaning.

4.7 Different perceptions of the experience of being a disabled person

Despite the absorption of the idea that disability is largely a negative state or experience, there were some distinctions made. One participant commented on the importance of social context to the experience of being disabled. He felt that class and wealth distribution would have a direct impact on the quality of life and opportunities available to individuals:

"I think there's a difference between the poor disabled or blind people and the ones who were wealthy. I think the ones who were wealthy had an easier time, would have probably have been incorporated into the family."

This same participant also believed that some types of impairment could be treated positively by society:

“And they seem to think that the dwarves or limited stature or whatever people were actually well looked after and they assumed that they weren’t treated badly...”

Our participants acknowledged then that attitudes are not something fixed and enduring. The participants felt there were some benefits to examining how attitudes towards disability have changed over time:

“Well you don’t see anything much in the museum relating to the sort of general population, what their disabilities were... cos obviously the attitudes have changed over the years... back in ancient history, however far back that is, attitudes were obviously a lot different then.”

However, some participants were tentative about how this could be presented, preferring low-key additions to existing displays rather than specific exhibitions. Drawing too much attention to the issue was likened by one participant to “putting in a token disabled bit.” He desired displays to be sensitive and appropriate:

“...if you’re going to have these displays, yes put in disability aspects as and when they crop up...”

For this participant, it was important to educate others (non-disabled people) about disabled people so that negative attitudes could be challenged. However he was sceptical that everyone could be reached in this manner:

“But it is all about education and unfortunately there will always be areas where specifically with individuals where you will never get through.”

4.8 Museums as part of the concealment of disability

The initial response from PORTAL was emphatically that disability is not represented in museum collections in general:

“I mean it’s starting to come in now but the curators, and the museum people and the general public felt uncomfortable with disability. I feel that they haven’t been able to actually handle it, it’s been one of those subjects which is sort of shoved under the carpet.”

These reasons align very closely with the findings from the *Buried in the Footnotes* research which describes the reasons for museums’ lack of engagement with issues of disability, chiefly because of fear:

“...fear of offence, of making mistakes, of transgressing unknown codes. In common with some other sectors, this fear has contributed to inertia.”⁹⁵

⁹⁵ RCMG, 2004:10

4.9 Disability and its representation in the museum – finding a balance

PORTAL were cautious, and maybe a little uncertain, about the stories that they felt museums should tell about disabled people; as a consequence they seemed much more comfortable when discussing physical, sensory and intellectual access issues.

Overcoming the physical struggles presented by impairments was a common thread to the participants' responses, not only to reflect the realities of a disabled person's life but also to act as a motivating example for others:

"Yeah I think one of the things you could emphasise is going through anybody's particular life and how you cope with life, how they've overcome the difficulties... once they see how you cope it becomes an incentive because if he can do that then I can do this, you see, and it's very important."

There were concerns however that if the story was too exceptional it would create a false impression and impossible standards to live up to for disabled people:

"[You can tell] the story of exceptional achievement but you'd want it balanced by information of contemporary treatment of similarly disabled people and you might even be able to reflect that in the, as part of the story of the achievement, despite the prevalent attitudes and conditions, but I think you've got to balance that..."

Within literature and media representations disabled people are often presented as abnormal, "stripped of fundamental human capacities such as thinking, acting, willing and taking responsibility,"⁹⁶ or at the opposite extreme as 'Super Cripples' where they are "praised excessively for relatively ordinary achievements."⁹⁷ For PORTAL it was important to find a middle ground which they articulated as representing disabled people as 'normal':

"I think you've got to focus on the ordinary problems of disabled people and at a normal level rather than the exceptional."

Nor did our participants wish for disabled people to be made the centre of attention but to introduce disability as part of the 'mainstream' of displays, echoing a desire to be part of the mainstream of society. They did not want to be seen as 'special' or as the 'Other' but as the 'Same':

"Just treat us like everybody else, that's it."

"And I think the last thing to sum up would be we're not disabled people, we're people with a disability."

⁹⁶ Evans, J., 'Feeble monsters: making up disabled people,' *The media: an introduction*, Briggs, A., and Cobley, P. (eds), Longman, Harlow, 1998:276

⁹⁷ Barnes, 1992: 12

This confirmed for us that the PORTAL group are not political in their construction of themselves as disabled people. The political position states that people have impairments, they do not have disabilities and in the emergence of the disability rights movement using the term 'disabled people' has come to signify identification with this movement.⁹⁸ However PORTAL did not, appearing to use disability interchangeably with impairment without making the distinction.

However, within this desire to be seen as 'normal' there was the need to recognise difference and the diversity of impairments:

"...all these hidden [impairments] which are very difficult to deal with because it's a common assumption 'oh you're disabled, you're in a wheelchair,' well we all know this is not... at all"

Telling stories about disabled people therefore requires us to "acknowledge, name and respect differences, rather than try to erase them."⁹⁹

4.10 Some stories are not meant to be told

During the discussion with PORTAL it was generally considered that telling stories about experiences as a disabled person in museums was a good thing. However there was an alternative viewpoint expressed by one participant which offered some caution against such an approach:

"...you've asked about showing people our history, but sometimes it's private, it's personal. Some people like to share it, others don't. Some people are guarded and I think we have to respect that, you know, I don't know. Sometimes it's nice just to keep things for yourself; perhaps that needs to be considered as well."

This view strikes a balance in relation to the idea that individuals need to see themselves reflected in the museum or in other representations in order to feel validated or 'real', presenting the alternate view that identity and self are in fact very personal. The evident emotional connection that this same participant gained from seeing her identity as a Deaf person reflected in a gravestone suggests it is important to see oneself represented but it is the individual that needs to make that decision, whether it is declaring their Deaf identity or donating an object to a museum.

4.11 Conclusion

The relationship of PORTAL with history was initially one of unquestioned importance, an assumption that was presented as fact. This was not unique to PORTAL and it suggests that the importance of history is taken as a 'given', although an interest in

⁹⁸ Barnes, 1992: 20

⁹⁹ Marks, 1999: 619

history is presented as more of a personal choice. PORTAL articulated their understanding of history's importance in a number of ways: highlighting the progression of a society, making an individual connection with people in the past or as a learning process. They visited museums and demonstrated knowledge of different periods and events in time. However they did not relate this in any way to their identity as disabled people and links were not made explicitly between disability and history until prompted.

There was no sense that the participants felt or saw themselves as part of a disability community with a common identity and culture, which we feel led to the presentation of themselves, at first, as people with a general interest in history. The exception was from a member of the Deaf community who linked herself to other Deaf people in the past through a narrative about a visit to a graveyard. This experience, elicited without prompting from the researchers, happened only within this focus group and can possibly be linked directly to the participant's strong identification as a Deaf person. However, when the rest of the group did begin to overtly identify as disabled people, after encouragement from the researchers, opinions that directly linked disability with history began to emerge.

The theme emerged that suggested that life as a disabled person was inherently negative in the past or depended on the whim of the "non-disabled" society. This offers a clue as to why participants did not immediately identify as a disabled person. It would mean to identify with something negative; as someone to pity or as a burden on society. This negative perspective was largely created through the attitudes of others, as well as the actual impairment itself. Furthermore participants saw themselves, and wanted others to see them, as 'normal' people with 'disabilities.' The stigma and negativity attached to disability may have discouraged them from feeling a 'right' to talk about their history as disabled people, instead to present themselves as 'normal' people with a 'normal' interest in history. It suggested to us that people need time to begin thinking about the questions we asked them. They don't know about the history of disabled people nor are they clear about it.

There was a dissonance between the private stories that participants communicated and the public story that they wished to see in museums. In terms of the private, individuals presented more complex identities but in public they tended to offer up stories and objects linked to what they assume museums would find interesting for instance stories of struggling to overcome an impairment, technology that has helped or hasn't helped. In doing so, our participants may be mirroring the display priorities of museums as currently seen:

"...many museums identified material in their collections which indicated similarly stereotypical roles for disabled people in history. There were comparatively few 'ordinary' disabled people represented through everyday objects."¹⁰⁰

¹⁰⁰ RCMG, *Buried in the Footnotes: the representation of disabled people in museums and galleries*, summary report, 2004:13

Such “medical” related objects may serve to identify disabled people through their impairment and disregard the role that society has played in creating disability.

There was felt to be some merit by participants in using history to explain the position of disabled people today and show how attitudes had been shaped over the centuries. However they were uncertain about how this might be done. There was some concern over the representation of disabled people within museum displays and one participant’s comment that some stories might not want to be told. Participants urged the presentation of disability as ‘normal’ and as part of mainstream museum displays, which also extends as a plea for disabled people to become a part of mainstream society. They were vocal about the struggles disabled people faced but it was largely the struggle to be accepted as normal not as a minority oppressed by society.

Disability was a part of the participants’ identity and they recognised that they were ‘disabled people’. However they preferred to construct themselves as ‘people with disabilities’, they were people who “just happen to have impairments.”¹⁰¹ This did not necessarily conflict with the pursuit of an active life, although for participants it was a fact that disabled people would have to overcome their impairment, however there were structures in place to facilitate this. Several members of PORTAL had overcome their own impairments to succeed so they felt that others could do the same. PORTAL were aware that discriminatory attitudes existed towards disabled people but they did not see how museums could play a role in challenging these. Except for one member of the Deaf community they had no strong political or cultural concept of disability. The history presented in museums was ‘their’ history because they saw themselves first and foremost as ‘ordinary’ people and they saw little reason to change this history.

4.12 Implications from this section

- The importance of history seems to be taken as ‘given’, as a fact, although an interest in history is presented as more of a personal choice.
- Keep things complex. Disability is only one element of an identity which is multiple and changing.
- Language is an essential clue to an individual’s position within a discourse or discursive field.
- Questions about history, identity and disability are not questions that people are normally asked to think about. We need to let people’s thinking develop.
- In many or most human stories there will be an element or connection with disability. Museum practice may privilege some types of ‘story’ over others which will potentially influence what disabled people feel they can offer. In the

¹⁰¹ Barnes, 1992:18

context of the museum, stories of complexity may become reductive if there is no 'alternative' model.

Section five

Young disabled people

5.0 Introduction

Teenagers and young people aged 14 – 25 years were chosen as a suitable group for this research project because they represent an under-developed audience for museums, and were thought likely to have a high level of awareness of their rights as disabled people. Defining young people as an identifiable social group at risk of exclusion has found that like other groups excluded from museums, young people do not feel that most institutions acknowledge or reflect their specific cultural interests. It is suggested that young people have a limited interest in, and limited knowledge and understanding of history, unless they can relate it to their own lives.

However the young people we spoke to did not completely reject history; even one participant who at first stated that history was “rubbish” turned out later to be very articulate about the subject. The responses of the young people seemed to reinforce that they accepted the importance of history but that did not necessarily mean that they were interested in it. However, the young people did not make the link between history and their identity as disabled people independently. They admitted that it was impossible for them to even think about disabled people in the past because largely, museums and history were silent about disability. Furthermore, they perceived that life for disabled people in the past was very different to theirs. This appeared to create a barrier to identification with disabled people in the past, although their own experience of disability had not always been positive. All of them had experienced some difficulties or discrimination as a result of their disability, or experienced it through family members. But like PORTAL they wished to be seen as ‘normal’ like other young people of their age and this, along with the usual teenage/young adult enthusiasms and interests, drove them.

The young people were enthusiastic about the role museums could play in representing the past and present of disabled people. They felt that recognition of disabled people and their history would encourage greater pride and validate their existence through breaking the silence that persists. They were confident about presenting disability explicitly. They felt museums could raise awareness that there are many different and diverse ways of experiencing the world and at the same time broaden the category of what it means to be ‘normal.’

5.1 Young people and museums – the context

Teenagers and young people aged 14 – 25 years were chosen as a suitable group for this research project because they represent a new audience for museums, and were thought likely to have a high level of awareness of their rights as disabled

people. Young people tend to be identified as a specific group with definable characteristics and expectations which museums 'need' skills and experience to work with.¹⁰² Until recently, museums and galleries have not always been proactive in understanding the attitudes of young people, concerned more with audience development in general than addressing their needs. However, defining young people as an identifiable social group at risk of exclusion has found that like other groups excluded from museums, young people do not feel that most institutions acknowledge or reflect their specific cultural interests. They often have preconceived and negative views of museums and art galleries.¹⁰³

Young people define culture in different ways and the importance of context and background in shaping these attitudes is stressed. Biographical context is felt by some researchers to be crucial in explaining young people's attitudes and motivations.¹⁰⁴ *Start with the child* identifies that children and young people exist within and are influenced by a multiplicity of environments and relationships throughout their lives. Young people need to see their own identity, which is in a process of continual reinvention, reflected in the museum, their local circumstances, needs and customs. They especially need to feel empowered, valued and involved with the museum and that their voice is being heard.¹⁰⁵ Young people aged 16-25 face particular challenges as their lives change rapidly and dramatically in the move towards independence and adulthood. Evidence suggests that too few arrangements exist to support young people making this transition¹⁰⁶ but these challenges may be compounded for young disabled people, not least in the limited subject positions offered by society and the way in which images of disability in society may be perceived as the antithesis of images of youth.¹⁰⁷ Young disabled people may be aware of "the ways in which their difference, far from being celebrated as diversity, is used to stereotype them as tragic figures"¹⁰⁸ and may lead to constraints in the formation of a positive self-identity and in awareness of the opportunities available to them.¹⁰⁹

¹⁰² Rider, S and Illingworth, S, *Museums and Young People*, Artsworld for The Museums Association, London, 1997

¹⁰³ Selwood, S, Clive, S, and Irving, D, *An enquiry into young people and art galleries*, Art and Society, 1995

¹⁰⁴ Harland, J, Kinder, K and Hartley, K, *Arts in their view: a study of youth participation in the arts*, National Foundation for Educational Research, Slough, 1995; also Roker, D, and Richardson, H, *Young People and Heritage: a review of current literature*, Heritage Lottery Fund, June 2003; Johnsson, E, *In-between two worlds: London teenagers' ideas about identity, cultural belonging and black history*, London Museums Hub Research, July 2004

¹⁰⁵ Morris Hargreaves McIntyre, *Start with the Child: The needs and motivations of young people*, Resource and the Chartered Institute of Library and Information Professionals, November 2002:85

¹⁰⁶ Social Exclusion Unit, *Transitions: young adults with complex needs*, A Social Exclusion Unit final report, Office of the Deputy Prime Minister, London, November 2005a

¹⁰⁷ Hughes, Russell and Paterson, 2005

¹⁰⁸ Ibid: 7

¹⁰⁹ Miller, Parker and Gillinson, 2004

The positive impact of the arts and sport upon communities and individuals has long been recognised.¹¹⁰ However, in terms of young people's attitudes of and perceptions towards cultural activities, at the time of this study there was felt to be a limited amount of research specifically undertaken in relation to heritage or history. Age is felt to play a crucial distinction in attitude towards heritage, with the elderly and the more traditional groups tending to see heritage in a more positive light whilst those with a more 'internationalist' outlook and younger people being less enthusiastic.¹¹¹ Roker and Richardson have qualified this evidence, concluding that although the majority of young people appear to have a negative view of heritage as conventionally defined, by broadening the definition of heritage to include less tangible concepts such as identity, culture, roots and local history this could make heritage relevant to more young people.¹¹²

In terms of young people's attitudes towards history, currently there is a lot of debate around the lack of knowledge that young people have about their heritage, particularly in the 15-24 age group. Tristram Hunt presents the paradox that although the British are viewed as "nostalgia-ridden [and] heritage-crazed" we are the only country in Europe where history is not compulsory after the age of fourteen.¹¹³ For Hunt this is exacerbated by a "confusingly episodic and disjointed approach to learning [history] where few lessons can be drawn or any manageable view of the past developed... no idea of how Britain and Europe have come to be what they are today."¹¹⁴ However it was found that few attempts have been made to examine how young people feel about history. The material that has been found appears to show that young people do not always feel that the history conceived important by historians and the National Curriculum is relevant to their lives. Recent research in London with young people from ethnic communities shows that the majority of respondents thought it was important to learn about Black or Asian British history, but not European history and participants with a White British background felt Black and Asian history would not be relevant to their lives. Their own knowledge about history, for example slavery, was found to be limited and confused¹¹⁵ perhaps supporting the concerns of the historians after all.

In the light of available information, it is possible to determine that young people will have a particular view of history, but one which will be influenced by their social position, cultural heritage and education. It is assumed that young people on the whole have a limited interest in, and limited knowledge and understanding of any history, unless they can relate it to their own lives. It is also likely that because young people, particularly those aged 16-24 years, are coping with a period of rapid change and development it is unlikely that they are thinking much about history or heritage particularly when they are concerned with making decisions about their future.

¹¹⁰ For example see Matarasso, F, *'Use or ornament: the social impact of participation in the arts'*, Comedia, London, 1997

¹¹¹ English Heritage, *Attitudes towards the heritage*, London, 2000

¹¹² Roker and Richardson, 2003

¹¹³ Hunt, T., 'How does television enhance history?' in *History and the Media*, Palgrave Macmillan, Basingstoke, 2004:96

¹¹⁴ Ibid, 2004:97

¹¹⁵ Johnsson, 2004

5.2 The Thomas, Lord Audley School and Language College, Colchester

A group of young people were brought together at Thomas, Lord Audley School and Language College, a large mixed comprehensive on the southern outskirts of Colchester.¹¹⁶ The school has a visual impairment unit, with ten places,¹¹⁷ and three of the young people who attend this unit took part in the focus group. They were joined by an older graduate who had been contacted via email and by two students from the Colchester Institute. Unfortunately due to illness related to the hot weather and some anxiety about transport to the school, the two students from the Institute were not able to attend on the day.

All four participants had visual impairments. The three students from the school were all aged 15, two of which were female and the third male. One of the females had a hearing impairment. The graduate was older (aged 24) and used a wheelchair. Most of the participants lived around Colchester but the male participant travelled to the school from Ipswich.

The discussion with the group lasted about one and a half hours and was held in the library, a public space which was relatively quiet for the duration of the focus group. However the discussion was interrupted several times, first by a fire alarm in the early stages and later on when one of the students was reminded that they needed to attend an interview. The necessity for the four participants to return home in pre-booked taxis also meant that the focus group adhered to strict time limits. However the group worked really well together during the time allowed and were very dynamic and thoughtful.

There was a connection with the PORTAL group at the Museum as one of the students is the daughter of a member of PORTAL and the graduate had also been approached to become a member of the group.

The young people accepted that being disabled was part of their identity but it was not always a positive element. All of them had experienced some difficulties or discrimination as a result of their disability, or experienced it through family members. There was a strong element of wanting to be “normal” teenagers like other young people of their age.

5.3 Young people and history: challenging the assumptions

As discussed in the literature review, there is a fear that young people have become disconnected from their history:

“[The] destruction of the past, or rather of the social mechanisms that link one’s contemporary experience to that of earlier generations, is one of the most characteristic and eerie phenomena of the late twentieth century. Most young men and women at the century’s end grow up in a sort of permanent

¹¹⁶ <http://www.tla.essex.sch.uk/> [accessed 19/04/2006]

¹¹⁷ <http://www.ofsted.gov.uk/reports/115/115207.pdf> [accessed 19/04/2006]

present lacking any organic relation to the public past of the times they live in.”¹¹⁸

As we will see later, this was an assumption echoed in the comments made by the older participants in our research.¹¹⁹ However the young people we spoke to did not completely reject history; even one participant who at first stated that history was “rubbish. A load of nonsense” turned out later to be very articulate about the subject. Neither did the young people we talked to question that history was important; most of them agreed that it was. Like PORTAL it appeared to be taken as a ‘given.’ In terms of interest however, their responses suggested that an interest in history or heritage was conditional on the type of history being presented and whether it was relevant in some way to their personal interests:

“I’m not really interested in what kings and queens came after who and what happened in what specific year or whatever. I’m more interested in general social history, what people’s lives were like in the past, what kind of work they did and what food they ate and things like that.”

They also felt that thinking about the present was more important than the past:

“I think history’s good and I think you should learn history, but I also think that people should take more notice of the... now more than... history.”

Only one young person actively made trips to museums and heritage sites. For the younger participants, visiting heritage was connected with family or school trips. Since youth culture often “depends upon freedom from adult control”¹²⁰ the young people were keen to assert their independence in their descriptions:

“I got dragged around a load of places when I go out with my mum and dad. If we go on holiday then ... we haven’t got no time to go shopping or nothing, it’s all to do with history.”

But despite their apparent disinterest, the young people actually found much to value in visiting heritage sites as the conversation progressed:

“I think if you’re in a building (castle), you can really start to imagine what it would be like to be there in the past... You just find out more about, you know, your identity and... it just makes things seem more real...”

As well as the connection made with identity, visits could also be meaningful when strong emotions were stimulated. A visit to a war cemetery was memorable because it evoked empathy for those who had suffered:

“When I went to Belgium we went to the English graveyard, the amount of unnamed graves, it just sticks in your head... I can’t really remember any of

¹¹⁸ Eric Hobsbawm, quoted in Hunt, 2004:97

¹¹⁹ See Section six

¹²⁰ Hughes, Russell and Paterson, 2004: 9

the names that I read on the graves just because there just so many people that are probably looking for their husband or son or brother or whatever.”

Where young people could find relevance with history it stimulated their interest. However, the link between history and their identity as disabled people was not made independently by the young people and had to be prompted by the researchers.

5.4 Disabled people hidden from history

“They were there somewhere obviously”

At first there was a sense that it was impossible for the young people to make the connection between disability and history. Like the PORTAL group the participants struggled with the concepts raised at the focus group because it was something they had not previously considered. They were able to give a few examples of disabled people in history:

“One of the kings or something in world war one, he had to build up an empire, he had balance disabilities, he couldn’t balance properly. He had limp in his arm and his leg and everything and he couldn’t see out of one eye properly.”

Such aspects of history may be remembered because they engender a sense of identification with that person (in this case Kaiser Wilhelm of Germany) as a result of a shared impairment(s). But the young people agreed that museums and heritage sites are largely silent about disability:

“Every now and then you do hear about disabled people when you hear about history but I’ve never seen anything in a museum or you know in a place where I’ve been.”

It seems that this enduring silence is so strongly embedded that our participants could not even begin to imagine disabled people in the past:

“...it’s impossible to even think about disability, because it seems like in the past like they would just be invisible. I wouldn’t even think about it in a museum or anything cos it’s just so different. I can’t even think like that, you know?”

5.5 The oppression of disabled people – then and now

There was a lively debate amongst the young people about the treatment of disabled people in general, establishing as we expected that the notion of ‘disability’ is a discursive field with many contested interpretations. There were also debates about the oppression that disabled people have experienced now and in

the past, highlighting the diversity of opinion of individuals and reflecting their different experiences.

The general feeling emerged during discussions that life for disabled people was worse in the past than in the present, mainly because there was a sense that society was now more advanced, both in terms of technology and knowledge:

“I actually think they know a lot more now than they used to in the past. There’s things like glasses and laser surgery and stuff and they didn’t know all of that in the past. So they were too scared.”

“Like disabilities could be like locked away, treated like, cos in the olden days they used to like believe in witchcraft and stuff like that, believe in they’d been cursed by witches and stuff like that, that kind of thing.”

However, both the past and the present were presented in complex ways by the young people. There was not a clear-cut distinction between the past as “bad” and the present as “good.” One of the participants mentioned how disabled people were expected to work in the past, something which was not expected today:

“Like I know in the past like, not that I agree with this, but in the past like blind people would be sort of trained from a very young age to do particular jobs and stuff, even though those jobs were quite sort of repetitive, boring jobs, they was still the expectation that they would work and they should work, and I think that’s like different than today.”

The young people recognised that disabled people are still discriminated against in contemporary society, the difference being that there are now mechanisms in place to prevent it happening:

“...now we’ve got this idea of rights, people’s rights, and I don’t think in the past, you know, people thought like that. So like the way we experience like discrimination and, you know, bad treatment today, I think that’s a different feeling than we maybe would have had in the past...”

The young people were ‘speaking’ from the social model of disability in the sense that they identified that barriers to disabled people were created externally in society. There was the implication that it is society’s responsibility to remove these barriers but there were disagreements over the extent to which disabled people are oppressed. This appeared to relate directly to personal experience. One participant, for example, held that disabled people face “abuse” because of negative attitudes:

“I think they try and hide away the disabilities don’t they? The Government tries to hide them away... it feels like he’s [*sic*] trying to hide them away and he didn’t like them that much”

For this participant, his position seemed to be influenced by the experiences of his sister who had been sacked and prevented from working because of her disability:

“My sister’s half blind like me and she couldn’t see the print on the paper so they sacked her... They denied her cos she had a disability and... because they didn’t want the hard work.”

This was an assertion which was agreed with by some of the other participants, “Yeah there’s loads of things happen all the time like that”. However these comments were challenged by another participant who felt society was helping disabled people:

“I don’t agree with that... if somebody works in London then you can get allowances can’t you, like money given to you and things like that. And I think it’s something to do with law or something that you have to have at least one disabled person working for you, something like that. So they’re not trying to shut us away, they’re trying to encourage disabled people to work.”

There was a lack of consensus, and practical knowledge, of the legal and economic position of disabled people. It seems generally that the young people are still developing an understanding of their rights and entitlements as disabled people.

5.6 The impact on identity

For the young people, their still-developing understanding of themselves as disabled people was coupled with the lack of a politically motivated awareness. They did not explicitly identify with disabled people collectively through their language, for example the young people talked about disabled people as “they” rather than as “we” or “us.”¹²¹ Disabled peoples’ experiences in the past were described as very different:

“No it’s like when you, if you have a disability and you go into somewhere where it’s talking about disability people in the ancient days, and you don’t really think... because most of them would die young wouldn’t they? With a disability cos you couldn’t help it could you? But nowadays you could help it, so they live longer and everything.”

This discussion of difference may explain why the young people did not make the connection with disabled people in the past except for a few examples which had personal relevance in relation to impairment. They did not identify with disabled people as a coherent group, and the concept of a coherent group of ‘disabled people’ as envisaged, for example, for this research did not materialise at any time during the research. The individuals we spoke saw themselves as disabled, and it

¹²¹ In all groups, when describing disabled people in the past, the pronoun ‘they’ was used. Within disability culture there is an emerging presence of the use of the pronoun ‘we’ to signify identification with cultural antecedents and to establish a political position in discussion. This was not evident in our research, even among those who did use expressions such as ‘people like me.’

was part of their identity, however they did not conceive the existence of a united community of disabled people that shared a present and a past.

5.7 The personal experience of disability

The complexity of society and its approach to disabled people was mirrored in the young peoples' own relationship and experience of disability. Like most young people "young disabled people want to participate in mainstream leisure activities and describe their interests as being no different to young people in general".¹²² This was true for our participants, who talked about their interests in music, film, going out with friends, swimming, shopping and their appearance. However there were some instances where they talked about how their impairment impacted upon the pursuit of these interests:

"I think I lead quite a perfectly normal life, if I can't do something then I just my friends would change and do something else."

"...sometimes I feel down about it... not being able to do what my mates can do like go down town by themselves and everything like that."

They talked about the difficulties they faced and the personal experience of living with their impairment:

"I'm going back to the age of seven, cos that's when, no I would go back before the age of seven actually, cos at the age of seven I figured out that I had my eyesight."

"I used to get bullied. If they saw like you actually find it and how, stuff like that, then they would actually realise then it's not your fault and it's not like you're doing it on purpose..."

The desire to be seen as 'normal' permeated their conversation. One participant talked about how she was able to hide the fact that she is different from her friends:

"I don't really like making an issue of anything cos so many people have like not noticed that there's anything wrong with me cos of the way that I act and they think that I'm just perfectly normal, if you could compare me to normal."

This desire to be seen as normal and deny disability is noticed elsewhere amongst disabled young people, a reaction to the negative connotations attached to disability in a society "dominated by able-bodied assumptions":

¹²² Hughes, Russell and Paterson, 2005: 8

"Nobody wants to be disabled... as soon as you can pass¹²³ in Goffman's terms and get away with it, you will, not because you want to necessarily, but because you have to if you want to get a job, if you want to get a girlfriend, you know, you have to be normal, whatever that is, you know."¹²⁴

5.8 Museums and the representation of disability

"I see my identity as all sorts of things, but partly as a disabled person and it is interesting to find out about the past and it does help me have more of a sense of who I am and where I am now."

The young people were very articulate about how they felt the museum could present and reflect the complex identities that they wished to share. They felt that recognition of disabled people and their history would encourage greater pride and validate their existence through breaking the silence that persists:

"It would actually make me aware... cos you don't even think about it... That there were people that had disabilities and they weren't just all like passed aside or anything."

"If I saw a pair of glasses in a museum which was 200 years old I would take a picture of it and frame it and put it in my bedroom."

However there was some incredulity at the ability of the museum to counter the years of silence as there was already so much that negated the existence of disabled people:

"It would take millions of artefacts to show people that there are disabilities out there and to stop abusing it..."

One participant talked about how collective experiences could generate for her a sense of belonging, particularly if she knew that people in the past had been through the same experiences that she had:

"It would probably make me feel a little bit better... Like cos when people take the mick and when people are horrible, you just feel like you're on your own and then no one else doing it to anyone else. But if you heard that all these other people done it to other people, then you would think no I'm not on my own."

The museum could also play an educative role in raising awareness that disabled people are the same as everyone else:

¹²³ The concept of 'passing' originated in racially segregated states of the American Deep South where, in this environment, to pass as 'white' led to increased privileges, RCMG, 2004:144

¹²⁴ Colin Barnes, interview 01/03/2006, which contains a reference to Erving Goffman's book, *The presentation of the self in everyday life*, published in 1969 by Penguin Press.

“Well I think it would be good, I mean cos we’re still all like normal people and feel like, I just think it might make people a bit more aware...”

5.9 Overcoming barriers

For the young people we talked to, it emerged that an important belief they shared was that anything can be achieved if you put your mind to it. This was partly from a consideration of the barriers that they, and others, faced as disabled people and how they could overcome them but also a more general preoccupation with achieving their dreams. They were enthusiastic to have role models who were disabled people and who had achieved in their chosen field:

“I would love to see someone with the same ability as mine... and they got somewhere making films and being like a president or something, I would respect them.”

Role models could help young people to be proud of being a disabled person and help them to cope with more negative aspects:

“I read this story and there was things like this singer who wore hearing aids but she tried to hide them. And I so badly wanted to write a letter and say why.”

“Yeah, it would make me feel very proud and everything, because then it would boost up my abilities to like think of myself that I’m pretty good and everything, I’d feel good about it, about my eyesight...”

In this respect, the young people were less cautious than PORTAL and did not consider that ‘exceptional’ examples might create unrealistic expectations for disabled people. Instead it would inspire them. Also, the young disabled people we spoke to did not define themselves according to the ‘stereotypical’ subject positions seen as offered by society, where disabled people are seen as dependent, passive or tragic. There was an element of acknowledging that certain barriers may face them but they were certain about having a career and they admired people ‘like them’ with high aspirations.

5.10 A collective interest?

The young people were interested in how the museum could represent issues of disability history. However it was evident from some of the participants that their interest was very focused on encountering their impairment in the museum or people with impairments similar to theirs:

“Because I know there is a violin player who’s purely blind and everything and she’s one of the best violin players you can get...”

"You could do sort of a film on, you could have this film on what they can see is different to what you can see. Like this is a view from a person who isn't visually impaired and this is a view of one who is."

There was an exception to this where one young person talked about acknowledging the benefits of identifying with the achievements of all disabled people, conveying that there are shared barriers that all disabled people face:

"Whatever you do, whatever you try to do, you know, work or subject or whatever it is hard one way or the other, you're going to have barriers and I really respect any disabled person who gets to the top of whatever they do."

There seems to be articulated here an understanding one of the basic tenets of the social model, that disabled people are unified through the barriers they face. However the participant did not identify how these barriers are caused, whether as a result of society or the impairment.

5.11 Museums are about the past, present and future

For the young people museums were not only about the past, although they agreed that you needed to know about the past in order to have a future:

"...it gives you like more of a sense of how you got to where you are now and like, you know, maybe where you can go in the future and stuff."

They were creative in the ways in which they felt museums could be used to explore the experience of being a young disabled person. One idea put forward was the use of the museum as a time capsule, to capture their hopes and help to actively shape their future:

"I think it would be quite interesting because with my friends and everything from my family, you talk about what you want to do when you're older. So if you put something in saying that you want to do, then say in like 10, 20 years time you go back and see if you've actually accomplished any of that."

One young person was interested in using the museum as a place to raise awareness and to share the different ways in which people experience the world:

"You could have this film on what they can see is different to what you can see. Like this is a view from a person who isn't visually impaired and this is a view of one who is..."

For this participant it was very much about enabling people to understand what it is to be 'different' in the hope it would engender greater tolerance, and related to her own desire to understand her own difference:

"I can't see how someone with better eyesight than me can actually see things. I'd actually like to have that."

Being open about difference, and challenging the existence of 'normal', is one way in which the young people felt museums could incorporate the experiences of disabled people. It was important however to try to capture the diversity rather than trying to make generalisations. They felt there couldn't be a single distillation of how people encounter the world:

"So in a way you can't vary out what someone can see because what I can see is what I can see, you can like see differently and stuff like that."

They could see the merit of showing that there are many different ways of 'seeing' because it could help to challenge stereotypes or 'common sense' views:

"There's a lot of like misconceptions about people with visual impairment, cos they automatically think that it's all like blurry don't they?... But it's not, it's like it can be loads of different things that you can see."

The young people were confident about presenting disability explicitly. They felt museums could inspire pride and raise awareness that there are many different and diverse ways of experiencing the world, and at the same time broadening the category of what it means to be 'normal.'

5.12 Conclusion

The young people we talked to challenge the assumption that young people are disinterested in history or reject its importance. Despite positioning themselves at first as lukewarm towards the subject, throughout they demonstrated knowledge of history in general although they did not immediately identify history and disability until prompted by the researchers. One participant admitted that she found it almost impossible to think about disabled people when visiting museums and heritage sites; one explanation for this was that they had always been hidden. The young people were able to see the positive impact of making disabled people and their history explicit within museums as a way of breaking this silence.

Although there was a lively debate about the meaning of disability both present and past, there did not emerge from the discussion a sense of unity amongst the young people that stemmed from a shared, collective identity as disabled people. They tended to see themselves very much as individuals and their interest in the museum related to the stories it could tell about individuals in the past, present and future. Two participants saw the value of a collective position and a sense of belonging through the sharing of 'oppression' in the form of bullying and the barriers that disabled people experience but generally participants did not appear to identify strongly with a political position. However they presented a complex perspective of being young disabled people, with a range of interests, highly articulate and with high aspirations for their future.

The young people appeared keen to have museums play quite an important role in the representation of the experiences of disabled people. They could see how

history could play a role within this and there was identified a need amongst the young people for validation of their experiences. They talked about the challenges they expected to face and the value of seeing how others had overcome these barriers. In the literature there is a concern that the concept of “achieving against the odds” is a familiar story in the presentation of disabled peoples’ experiences that is not always desirable¹²⁵, however for these young people it was something that could inspire them and enable them to feel a sense of pride about their difference.

The young people perceived that in some cases society ‘creates’ disability through excluding disabled people through negative attitudes towards them or making assumptions about their capabilities. However they reached no conclusion about the extent to which this occurred and it was largely dependent upon their own experiences of disability. The way in which some disabled people in practice move in-between an understanding of how society discriminates against disabled people, whilst retaining a sense of the personal experience of impairment, is a growing consideration for those who feel that neither the medical nor the social model are an adequate “explanation of reality” for disabled people.¹²⁶

Our participants articulated the complex relationship between disability and society, and between their impairment and their position as young people. They saw themselves as ‘normal,’ with similar hobbies and interests like other young people. Although being disabled was a strong part of their identity, they were still developing an understanding of their rights and did not seem to have a political concept of disability. They felt that the experience of disabled people in the past was far removed from their own experiences and so could not always relate to them. However they were aware that they were different to other young people and talked openly about some of the challenges they faced in their desire to be accepted as ‘normal.’ But their experiences had made them aware that there were many diverse ways of experiencing the world, with the potential for challenging the concept society has of what it means to be ‘normal.’

5.12 Implications from this section

- A lack of interest in history does not always determine a rejection of its importance.
- Where young people could find relevance with history it stimulated their interest.
- Recognition of disabled people and their history would encourage greater pride and validate their existence through breaking the silence that persists.
- Role models could help young people to be proud of being a disabled person and help them to cope with more negative aspects.

¹²⁵ RCMG, 2004:40

¹²⁶ Corker, M., ‘Differences, confluences and foundations: the limits to ‘accurate’ theoretical representation of disabled people’s experience?’ *Disability and Society*, 14 (5), 1999: 627

- Showing how barriers can be overcome was an important narrative; that anything can be achieved if you put your mind to it.
- The use of the museum as a time capsule, to capture people's hopes and help to actively shape their future, was appealing to the young people.
- There was felt to be merit in showing that there are many different ways of experiencing the world because it could help to challenge stereotypes or 'common sense' views.
- Exhibitions can be used to show a range of ways of being 'normal' - broadening the category of what it means to be 'normal.'

Section six

Older people

6.0 Introduction

Older people are, like young people, recognized as a specific social group with identifiable attitudes. However, at present, the available research is at best ambiguous. More research is needed in order to understand the strength of the connection between old age and history, and why older people may have a particular view of the past.

We had intended to speak to two groups of older people. In the end it proved very difficult to make contact with a group that defined themselves as disabled. We spoke to a group of older people who had a variety of impairments but did not identify themselves as disabled. Although they acknowledged their ailments and signs of ageing, the participants generally considered that they had little to complain about.

The men in the group established their interest in history right from the beginning: "That's why we came, we knew what you wanted." From a research perspective this has significant implications. These participants were self-selecting, already interested in the topic which inevitably shaped their responses. That they tended to dominate the discussions also means we must hesitate to see their responses as representative.

The experience of being a 'disabled person' was, however, not one which these participants could relate to. Their conception of 'disabled people' was that being a disabled person is a tragic and difficult experience. In terms of representing disabled people and their history in museums, their lack of identification with this within their identity meant that there was no specific discussion regarding this during the focus group. It was not until the end of the focus group that one of the participants was able to bring all the elements discussed together, and state their conviction that museums could play a role in the presentation of disabled people, a reminder that we were asking people to engage with complex issues that few people are ever asked to think about.

6.1 Older people and their relationship with history – an overview

Older people are, like young people, recognized as a specific social group with identifiable attitudes. Like young people, they may be at risk from exclusion:

"[The] experience of old age should be a positive one. But whilst many older people enjoy the chance for more leisure, learning new things, or spending time with friends and family, others experience isolation and exclusion."¹²⁷

The elderly and people aged 55 and over are also found to be under-represented in museum audiences; although this assumption has been questioned as together young people and the elderly make up one-third of museum visits.¹²⁸ Certainly, older people are an increasingly important group. Continued population ageing is seen as inevitable during the first half of this century. The numbers of elderly people are rising as the relatively large numbers of people born after the Second World War, and during the 1960s baby boom, become older. The working age population will also fall in size as relatively smaller numbers of people have been born since the mid-1970s.¹²⁹ Lowenthal (1985) identified the effect he believed this would have on our approach to the past:

"Today's lengthened life spans extend both the remembered and historical past and promote their convergence... the old show a particular interest in the past... so do societies with large proportions of elderly people... [who] tend to focus on their own private, more manipulable past, substituting relics and recollections for history."¹³⁰

Lowenthal and other writers believe that this private and individual past/memory has become confused with, and even substituted, history in the minds of the public. Heritage is perceived as a reaction against the traditional approach to (scholarly) history, replaced, amongst other things, by a "visual artefactual heritage"¹³¹ and leading to the "commodification of history [and] the loss of authority of the past..."¹³²

Most available research relating to older people and their views of the past has reached the conclusion that older people tend to be interested in history and are 'nostalgic' for a golden past. Trevelyan and Merriman qualify this by stating that generally older people are interested in the recent past (*their* past) and the lives of everyday people. Merriman, whose research goes into depth, concluded that although older people are most likely to have a positive view of the past, they were also least likely to visit museums. He attributes this to old age and retirement, which are often accompanied by a withdrawal from many previously practised social activities.¹³³ Merriman also found that older people and those of low status¹³⁴ tended to be nostalgic for 'their past' because they conceived it in terms of things that they lack in the present. Since more elderly people are, for example, likely to

¹²⁷ Social Exclusion Unit, *Excluded Older People: Social Exclusion Unit Interim Report*, Office of the Deputy Prime Minister, London, March 2005b

¹²⁸ Davies, 1994

¹²⁹ <http://www.statistics.gov.uk/cci/nugget.asp?id=949> [accessed 13/02/2006]

¹³⁰ Lowenthal, 1985:256

¹³¹ Hewison, quoted in Urry, J., 'How societies remember the past,' Macdonald, S. and Fyfe, G. (eds) *Theorizing Museums: representing identity and diversity in a changing world*, Blackwell Publishers / The Sociological Review, Oxford, 1996: 52

¹³² Urry, 1996:52

¹³³ Merriman, 1991:57-58

¹³⁴ Identified as tenants with no access to a car and who left school as early as possible

experience ill-health or have a greater fear of crime, they are more likely to view the opposite about the past. There is often the perception that personal values were higher. Therefore they view the past as a haven of peace and security from their present worries. Research undertaken by Trevelyan in the same decade found that older people were keen for the young generation to understand the circumstances of this past but tended not to visit museums to find out about it.¹³⁵ More recently, Davies has questioned the assumption that few older people visit museums¹³⁶, and research undertaken by MORI for English Heritage in 2000 continues in the same vein that older people are more likely to be positive about heritage and history than the younger generation.¹³⁷

The period in which today's older people were born is also likely to have a significant impact on their values and behaviour, something which is not readily explored in the literature. Context, in terms of broader social developments and history such as the First and Second World Wars, immigration, as well as immediate background, is therefore as important to explaining the views and attitudes of older people as young people, which is likely to be more valuable than relying solely on age to distinguish between attitudes. For example, older people who have been displaced by war or life experience may have a greater sense of history and interest: "particularly when your family changes countries, awareness of another place, another past has a particular intensity to it."¹³⁸

At present, we cannot conclude from the literature that it is 'inevitable' and 'natural' that once an individual reaches old age, they become more interested in history. The available research is not only dated, but at best ambiguous. More research is needed in order to understand the strength of the connection between old age and history, and why older people may have a particular view of the past.

6.2 Grymes Dyke Tenants' Association

At first we had intended to speak to two groups of older people; one whom identified themselves as disabled and a group that did not. In the end it proved very difficult to make contact with a group that defined themselves as disabled, again highlighting the difficulties of imposing our categories onto individuals.¹³⁹ We were able to make contact with a group of older people who had a variety of impairments but whom did not define themselves as disabled. The numbers of older people who do not identify as disabled are currently growing within society as the demographic shift towards an ageing population means that more and more people will be covered by the far-reaching terms of the DDA.¹⁴⁰

¹³⁵ Trevelyan, V, *"Dingy places with different kinds of bits: an attitudes survey amongst non-visitors"*, London Museums Consultative Committee, London, 1991

¹³⁶ Davies, 1994

¹³⁷ English Heritage, 2000

¹³⁸ Tusa, J., 'A deep and continuing use of history,' in *History and the Media*, ed. Cannadine, D., Palgrave Macmillan, Basingstoke, 2004:125

¹³⁹ Section 3 details the barriers that we faced in recruiting research groups

¹⁴⁰ Miller, Parker and Gillinson, 2004: 27

Grymes Dyke is a collection of residential flats (sheltered housing) in Stanway, a suburb of Colchester. There is a warden and residents remain relatively independent. The focus group took place with seven participants, three women and four men, and the scheme manager [warden], who also had an impairment which she identified during the discussion. The focus group took place in a spacious central meeting space with comfortable chairs. The environment was pleasant, the buildings were relatively modern and surrounded by flowers and plants outside. The room was familiar to the old people and social events were commonly held there.

Not all of the participants were originally from Colchester but most of them had been born in the area. The four men were not from Grymes Dyke but had been invited to the group by the scheme manager in order to address an imbalance in favour of the women. Unfortunately they tended to dominate the discussion at times especially as they all had a strong interest in history, particularly military history.

In terms of age the participants were around 60 to 80 years of age and although they had a history of operations and illness the participants would not be described as frail nor did they use wheelchairs or other aids whilst indoors. They did not identify themselves as disabled people at all although they acknowledged their ailments and signs of ageing. However, generally they considered they had little to complain about:

“I’ve reached the age of 78, I’ve never had an operation, I’ll go and see my doctor once a year. I haven’t been near a hospital till I went for my eye... so I consider myself very, very lucky.”

6.3 Heritage and history – interest and curiosity

From our discussions with this group it emerged that visiting heritage sites was an important leisure interest, in contrast to Merriman’s assertion that older people tend to visit fewer historical and heritage sites.¹⁴¹ There was an interest and curiosity in finding out about national, local and family history. But there was a definite gender bias with the male participants being more active in seeking out opportunities for visiting historical sites. The male participants established their interest in history right from the beginning:

“That’s why we came, we knew what you wanted.”

From a research perspective this has significant implications. These participants were self-selecting, already interested in the topic which will inevitably shape their responses. Their opinions cannot be taken as representative of older people as a ‘group’.

Visiting museums and heritage sites was viewed as a worthwhile activity for themselves and for families, or to provide an alternative to other, less preferable, leisure pursuits:

¹⁴¹ Merriman, 1991

"I don't want to go shopping, that's not my cup of tea, so therefore I get my book out... and I say to my wife, see you in three hours time or whatever it is and I go to that museum or museums and I find it interesting."

Museums and heritage sites could be relevant according to interest but there was the potential for more personal connections to be made:

"Well last year and this year I've been over to Belgium and France and looked at these World War One cemeteries and I've got family buried over there, which was the reason for going."

Emotional responses to history or heritage often led to memorable experiences, described vividly by our participants. For one participant, the representation of labour at the National Coalmining Museum for England evoked empathy with the past experience of a family member and sparked an intense, emotional response:

"...And then he said to us all turn your light off, and we turned our lights off and it was total blackness and that is what they worked in. And I just stood there and cried cos my granddad went in... and I just couldn't stop crying, there was a lot of people doing the same as well."

It was often these human stories that participants were interested in, especially stories which could provoke strong emotions such as revulsion, sympathy or fear:

"[Serving on the Victory] was purgatory, I mean the first thing they did was sanded the gun decks and everything so you didn't slip over on your comrades' guts and blood and gore."

There was a definite emphasis in their descriptions of sites visited of an interest in war and social history, particularly the latter for the women.

6.4 The absolute importance of history

The findings of the literature review suggested that this age group is the most likely to show an interest in the past,¹⁴² and older participants did tend to assert the absolute importance of history:

"People like us have not realised how important history is until we're older..."

However, we found that both previous focus groups had also assumed the importance of history and that it was taken as 'given' by all our participants. The men also tended to dominate the discussion about history, making it difficult to understand the perspective of the female participants as they were often subordinate and tended to repeat the points made by the men. They appeared to position themselves along very traditional male/female gender roles.

¹⁴² Lowenthal, 1985; Merriman, 1991

The older people saw history as providing a mirror by which "to assess life in the present"¹⁴³ and to help place circumstances into perspective:

"Well possibly knowing the deprivation that our forefathers had to live through... Looking back and thinking today, we think we're hard done by but we are not. And I think if a lot more people thought about that, looked back, there wouldn't be so much strife I think these days. That's my opinion."

There were moral implications and lessons to be learned implicit within this approach to history. For the male participants, whose interest in the two World Wars played a major role in the construction of their identity and their lives, it is a means of commemorating and remembering the sacrifices others have made for us:

"...it's appalling, you know, what the sacrifice of our forbears done... and if it wasn't for them we wouldn't be sitting here today. That's why we've got to remember them and of course the heroes of the Second World War."

There was a need to examine and understand the past; to find patterns, see why wars happened and prevent them from recurring.

"Well my time of history is the First and Second World Wars and if we could do more to stop these wars and come to realise what causes most of the wars... I think it would be a better world to be in."

History is crucial to understanding the present and in helping to shape the future. That they conceived history in this manner and recognised its importance led to a certain amount of pride, both for national and for local history:

"Well you're now sitting on Grimes Dyke. It dates back to the Roman times and as we all know that we live in the oldest recorded town, allegedly so in the United Kingdom and it's absolutely steeped in history and unfortunately a lot of the locals don't know a thing about it."

At times they talked about how the past was under 'attack' or in danger of being forgotten, either from ignorance or from political correctness:

"...people don't look at our history if they live here, but we look at others as well and it brings a lot to you."

"You can't put a flag up.... Nelson's day, Trafalgar day we used to celebrate Trafalgar day, no longer do we celebrate these days because it would offend..."

Therefore they held the belief that it was vital for history, and learning about that history, to be shared between the generations:

¹⁴³ Merriman, 1991:39

“Yes I mean I think children should be taught about these wars, which some of them do at schools, we’ve even been to some of the schools with the groups and say as grandfathers and that, to tell them...”

“I’ve noticed that if you go into a museum on a weekday, you quite often see quite young toddlers with their grandparents, which is nice to see.”

In general, these participants positioned themselves as individuals who not only valued history but saw its importance for society as a whole. However there was a feeling that history was in danger of being neglected so it was important to communicate this to younger generations. Some of them, the men especially, had been active in this respect going into schools and talking to pupils about the war. The participants had also been involved in a reminiscence-type project with school children, sharing stories about their lives during the war:

“[The Record Project] with the children, [they] talked to the elderly people, talked about things that they had, the kind of lives they had and uniforms they wore in the war and that was fantastic...”

6.5 Not quite nostalgia

In the literature older people are often described as having a particular view of the past, connected to nostalgia for their younger days or as a ‘haven’ of peace and security from their present worries.¹⁴⁴ However, in talking to the participants at Gryme’s Dyke this image of older people as harking back to a ‘golden age’ was not so definitive. There were the expected nostalgic views of the past presented in opposition to a perceived ‘lack’ in the present, for example the alleged disappearance of particular values and traditions from today’s society:

“I shouldn’t say this I know, but they’re not strict enough with the children now, they seem to get away with, you know, the victim’s in the wrong, where the one that did it is in the right.”

Such views however were not held unanimously by all the participants:

“It’s alright being strict with them but some of the kids years ago got abused quite a lot didn’t they... very antiquated things happened in those days and we wouldn’t want those back again.”

There was a more complex relationship described between the past and the present from our participants. There were elements of the past that we should not be allowed to forget but there were parts of the past that we should not return to.

¹⁴⁴ Merriman, 1991:31-33

6.6 Disabled people as 'Other'

In their discussions about history and the past, at no time did the older people relate to their identity as a disabled person. Their relationship with their ageing bodies was only referred to in passing:

"...you see our minds are still fairly young in some ways, but you can't do what you want to do."

The experience of being a 'disabled person' was not one which these participants could relate to. Their conception of 'disabled people' conformed very closely to the medical model; the sense that impairments are something to be treated by professionals such as doctors and in hospitals and that being a disabled person is a tragic and difficult experience. Disabled people in the past were institutionalised, kept separate from society and deprived of opportunity:

"I think that's where they were put. In the workhouse or things like that because they couldn't work. Had to be kept somehow, that's what the workhouses were for."

"And the very bad ones used to be quietly put to sleep."

It was emphasised how terrible it must have been for the families who cared for them as well as for disabled people:

"It must have been very difficult for people [who] were looked after mainly by families... [the wheelchairs] must have been very, very heavy to push around. And people who were disabled, often from polio had these big callipers on their legs... It must have been terrible, terrible times."

The participants recognised that they have infirmities yet they accept that these are an inevitable part of ageing. Impairments / infirmities are personal and to be dealt with privately by the individual. In their experience it was not something you admitted to without negative consequences:

"Where in my time, probably in his time, especially with me, mind your own business and you just carried on didn't you? Well I felt a bit ill one day but you had to carry on, otherwise you didn't get your money..."

This serves effectively as a barrier to identifying as a disabled person:

"...the whole ideology of Western society increasingly is moving down this traditional liberal Unitarian road of, you know, pull yourself up by your boot straps lad, you know, if you can't look after yourself you're not really a man or whatever, do you know what I mean? So most people get sucked into that before they become disabled..."¹⁴⁵

¹⁴⁵ Colin Barnes, interview 01/03/2006

This attitude had been fully absorbed by the older people in our focus group. Throughout the discussion they wanted to give the impression of being very active, very fortunate in their circumstances. However later on in the discussions one of the participants was able to draw a limited parallel between their circumstances in sheltered housing and with disabled people who might have lived in an institution in the past:

Eddie - A lot of them used to end up in the spike.

Interviewer - What's the spike?

Eddie - One of these... [A] workhouse.

At a much later point in the discussion the participants were able to make further links and deduce how life might have been for them as 'disabled people' in the past:

"Well I know what I've got, I'd be blind now, but it's because of drugs that I am reasonably well. I've got glaucoma and I'm a diabetic, but my great grandmother died blind because they didn't know what the problem was."

"I mean you go and you think well if I lived even 50 years ago, I wouldn't be here now with my condition you see, cos my father he died when he was 60."

Yet this identification was still solely based on the 'medical model' of disability, with the understanding that infirmities can be 'cured' rather than recognition of the societal construction of disability.

6.7 The shadow of the First and Second World Wars

Throughout the discussions, a topic that dominated the older participants' discussion was the First and Second World Wars. Their interest and admiration for the ordinary 'heroes' of the war played a significant role in the construction of their identity and their interest in ensuring that this history was communicated to others. Their position was informed predominately through this perspective.

One link was made between war and the creation of disability:

"I've got a little wallet at home, it's all got my grandfather's discharge papers in it from the First World War cos he was wounded and he landed up in Eastbourne Military Hospital and... [at] 16 he was invalided out. I've got his silver badge that they wore and all the papers where he was wounded in his knees and to me... well I remember him so, but I was alive when he was alive but to think what he went through, you know."

However the individual did not explore this connection even when they were given the opportunity to consider how it might have been for soldiers when they returned from the war. Instead it translated into a personal recognition of how close family members had suffered in the past for the security of the nation. For the purposes of

this focus group, this was the part of his identity that he predominantly wished to share with us.

6.8 The role of the museum in the presentation of disabled people and their history

The participants at Grymes Dyke were very positive about museums as places to learn about history. In terms of representing disabled people and their history, their lack of identification with this within their identity meant that there was no specific discussion regarding this during the focus group. However there was a tentative realisation that museums could play a public role in helping people to learn about their health and being more open in regards to illness or impairment:

“It would make people... more aware to go to the doctors and get it treated and nipped in the bud you see.”

It was not until the end of the focus group that one of the participants was able to bring all the elements discussed together, and state their conviction that museums could play a role in the presentation of disabled people. This role was articulated as one of awareness raising, that disabled people are ‘normal’ and part of society:

“Because people with disabilities were institutionalised years ago, nobody actually thought about them because they were out of sight. Where now... it’s normal to live with people with disabilities. We all live together, we’re all the same people. So I think they are being more aware and maybe the museums would be good for that.”

6.9 The influence of age upon identity and attitude

The participants were much more comfortable talking about how the museum could represent their own past and represented a contrast to the discussion with the young people at Thomas, Lord Audley School. Their differing approach to the presentation of their lives suggests that age was a significant determinant in their responses. The young people were more interested in seeing the museum as a possible time capsule for their future plans, or a place for role-models to inspire them, whereas the older participants were more interested in representing their past life in the museum.

There were clear differences in how an individual’s perception of their past influenced the story that they wanted to tell. Those participants who felt that their life now was “worse” or who had experienced a loss, for example of family members, were more likely to look on the past as a positive time. One participant talked about how she enjoyed her time during the war “...because everybody was friendly in spite of the bombs and the aeroplanes and god knows what.” She was less confident about her current life, which she connected to the loss of her husband:

“Well sometimes you can feel very, very lonely can’t you, even if you’re amongst a crowd, cos I miss him terribly, but we were very good friends my

husband, he had a rotten childhood and I didn't have a very nice one, so it made us very close."

It was not necessarily that they saw the world now as a categorically "worse" place, but they seemed less certain about it:

"If I could have put a stop I would have stopped in 1964... everything was more peaceful than it is now, you could go out without fear of being attacked or whatever. "

For those who felt history communicated a message, this perspective also influenced the personal story they wished to tell. One participant felt his experience would serve as an example of how 'wasted some things in your life are', a contrast to the story that the young people wanted to tell with its theme that 'anything is possible if you put your mind to it':

"I think I should have done other things in my life, but I came out the army, went on the railway and I stayed there, I think I should have spread out a little bit further. I had good times to a certain extent and I done quite well, but looking back over life, I think certain parts of it are wasted..."

As a means of assessing life in the present, history was seen as vital on both a broad and local scale.

6.10 Public history and the validation of experience

History can be huge and impersonal – the 'foreign country' so far outside of our experience.¹⁴⁶ Our participants emphasised the role that individuals can play within the larger frameworks of history in their stories of soldiers and family members who served in the wars or worked down the mines. The men in particular were keen to see their experience represented within museums. One individual reproduced his own personal narrative in order to illustrate his own development alongside the development and progress of the Post Office telephones, for which he worked for many years:

"Well I suppose mine would be being brought up during the war, especially in this village, going to the local school and then going to the senior school and not doing very well at all, you know, 'could do better' every report. And then obviously National Service... but then when I started on the Post Office telephones, that was still in the days, well it was archaic really, because you had the main overhead lines and you had the operators on the switchboard who ruled all... there is no comparison, from a small exchange this size which was full of ladies sitting at desks and pushing things in the holes and telling you three minutes is up, till now you've got a fully automatic electronic exchange which would serve that size... but it would be just nice to see it set out and say I did that, I dug that hole, I went up that pole."

¹⁴⁶ Lowenthal, 1985

By seeing his story encapsulated in a public display in a museum he felt it could demonstrate the positive contribution by an individual as part of a larger story and locate himself within history.

6.11 Conclusion

In contrast to the limited literature available, it appears that older people have a more complex relationship with the past than is otherwise accounted for. Certainly there were elements of nostalgia and longing for the past but this was countered by alternative viewpoints which suggests that the past was not the "golden age" that is often attributed:

"Yes but don't forget in them days in '64 and a bit earlier, there was a lot of crime, they were hanging people every other week, so I mean these things happened."

Even within individuals there was a dissonance between the present and the past, with some elements valued and other elements seen as undesirable. This suggests that although there is scope for generalising visions of the past based on factors such as age, an individual's construction of identity is also important in conditioning their attitude towards history. This can help us to understand seemingly contradictory statements made.

There was the strong belief that history was important. Although the nature of the past was contested vigorously, there was no question about the need to recognise our history. This was tied into moral arguments that closely align with the dictum that "Those who cannot remember the past are condemned to repeat it."¹⁴⁷ However, with this group it was a very particular version of history based upon the significance and tragedy of the two World Wars. They responded to personal stories of history and remembered sites more vividly when a personal or emotional connection was made.

Our participants did not construct themselves as disabled people, nor did they come to recognise themselves as such during the discussion. They constructed themselves as older people with infirmities but it was something that they kept private and did not dwell upon. They regarded disability in the same way as the 'medical model'; impairments are personal and private, something to be 'cured' or cared for by professionals. Their construction of disability prevented them from identifying themselves as disabled people; disabled people were hidden from society or to be pitied. This was not how they saw themselves and they were keen to demonstrate that they were still active and fortunate to be well. They had no political concept of disability nor did they appear aware of their rights under the DDA. Even when stories of disability were uncovered the connection was not made and terms like 'health' and 'invalid' indicated their absorption of the medical model.

¹⁴⁷ Lowenthal, 1985:47

During the discussions, the participants 'spoke' from their identities as older people, as males and females, as white, English or assimilated immigrant and their social (working) class. They did not question their present circumstances, although there were elements of nostalgia in their discussions and one participant expressed dissatisfaction with his life in general. They appreciated that they had a safe and comfortable place to live and they had no need for anything else.

They agreed that museums and heritage sites could play an educative role although they were not so certain of how museums could raise awareness of health matters. It was not until the very end of the discussion that one of the participants was able to relate the concepts talked about to disabled people and the role that the museum could play in 'normalising' disability and showing that it is a part of mainstream society.

So what does this tell us about disability? It tells us that there are people whom the DDA recognizes as disabled and museums recognize as disabled but are adamant themselves that they are not disabled. In fact some people may even be offended to be called disabled such are the negative and tragic connotations connected with the term.¹⁴⁸

6.12 Implications from this section

- Do not expect to find a unified group of 'disabled people.'
- Link public and private narratives.
- Male and female histories might not be the same.
- You may find yourself researching a self-selecting group that is not necessarily representative of other older people (or even disabled people).
- Individuals who acquire impairments will not always recognize themselves as disabled.

¹⁴⁸ This suggestion emerged from the discussion of the findings with the group of museum professionals, based on the experiences of Tyne and Wear Museums (10/03/2006)

Section seven

The Deaf Community

7.0 Introduction

The Deaf community have their own rich heritage as a cultural-linguistic minority with values and beliefs that are distinct from the 'hearing' society. The desire for autonomy is reinforced by the emergence of a growing interest in Deaf history and a justification of the right for Deaf people to exist as a separate cultural and linguistic community.

In our original conception of the 'disabled community' (a coherent group of people who identify as disabled) we conceived the Deaf community as a distinct group within it. However in practice contacting the Deaf community proved to be problematic, essentially because we were basing our research on categories that the Deaf community did not identify with, in this case 'disabled.' Our task therefore became to attempt to understand the Deaf community in more depth in order to ensure that the research was relevant to them. This learning process became increasingly significant to the research process as a whole.

Interviews with Tom Fenton, the (hearing) Chief Executive, and Simon Hesselberg, (Deaf) Head of Community Development, both of the Royal Association for Deaf people (RAD) confirmed for us that Deaf people do not define themselves as disabled. They outlined the growing importance attached to the preservation of Deaf history and culture, and were enthusiastic for the Deaf community and their history to be represented in museums but highlighted the need for museums to be more aware of communication issues as many Deaf people currently do not find museums accessible or relevant to them.

7.1 The Deaf community and history: background and context

The Deaf community is split between those who believe the Deaf should have their own culture and language (British Sign Language or equivalent) and those who believe they should be integrated into society as much as possible and learn English (oralist). For many Deaf writers the history of the Deaf community is presented as a struggle against a hearing society which desires them to conform. A need for autonomy is reinforced by the emergence of a growing interest in Deaf history and a justification of the right for Deaf people to exist as a separate cultural and linguistic community. The themes behind these histories are manifold; the desire to show how the Deaf world co-exists alongside the hearing world, not hidden from it as general history suggests; Deaf people's oppression by hearing society, as exemplified by the conflict between signing and oralism, and now cochlear implants; the complexity of historical change which has affected the development of a 'Deaf consciousness'

and Deaf self-determination which enables Deaf people to play a larger role in their own history than previously recognised.¹⁴⁹

Deaf people have their own rich cultural heritage and should be in control of their own lives and destinies. In the past Deaf people have been treated badly, but to be Deaf:

“is not traumatic... The real tragedy lies in the consequences of deafness. Almost everything is geared up to the orientation of what the ears perceive. Societies relying heavily on what is heard, intentionally or unintentionally, create barriers that confront Deaf people.”¹⁵⁰

Paddy Ladd challenges the inclusion of ‘Deaf’ within disability. He cites that Deafhood “is not... a static medical condition like deafness. Instead it represents a process – the struggle by each Deaf child, Deaf family and Deaf adult to explain to themselves and each other their own existence in the world.”¹⁵¹ There is a ‘Deaf way’ or ways of thinking about and viewing the world. These values and beliefs are distinct from the ‘hearing’ society. Ladd feels there is the need to distinguish between Deaf signing communities and those who are hearing impaired, for example the elderly, in later life. He claims these boundaries have been blurred intentionally by the hearing society to deny the existence of a distinct Deaf culture.

The Deaf community should be seen as a language minority rather than a disabled group. Many Deaf are “uncomfortable with their inclusion in the disability social model because, however it might try to construct itself to assimilate them, the criterion used for including Deaf communities in their ranks is that of physical deafness... the medical concept”¹⁵² which limits how they are treated and understood by hearing society. From this perspective, Ladd views the experiences of the Deaf as akin to colonialism – “the destruction and replacement of indigenous cultures by Western cultures.”¹⁵³ This is demonstrated by the conflict between signing and those who advocate oralism in order for Deaf people to assimilate into hearing society. The controversy over cochlear implants and the isolation of genes that “cause” deafness are also perceived as threats against the Deaf community.

Ladd outlines the importance of culture in achieving recognition and change for the Deaf community, first through a greater appreciation and cultural literacy rather than seeing them as objects to be “pitied or cured.” History plays an important role in this but only in how it can impact upon the future:

“Where human beings stand right now at this point in time is simply and exactly that... the point we humans have evolved to in our long journey

¹⁴⁹ Vickery Van Cleve, J. (ed), *Deaf history unveiled: interpretations from the new scholarship*, Gallaudet University Press, Washington DC, 1993

¹⁵⁰ Dimmock, A.F., *Cruel legacy: an introduction to the record of deaf people in history*, Scottish workshops publications, Edinburgh, 2nd edition, 2000:64

¹⁵¹ Ladd, P., *Understanding Deaf culture: in search of Deafhood*, Multilingual matters Ltd, Clevedon, 2003:3

¹⁵² Ladd, 2003:15

¹⁵³ Ladd, 2003:17

through historical understanding. This journey through life, not simply through our own lives but historical lifetimes as well, is all we have. If we are able to grasp the full implications of this, we can transcend feelings of guilt and hopelessness and know that an exciting journey still lies ahead, one in which we can play our part and lay down our own markers for future generations to walk upon..."¹⁵⁴

Deaf history is much more developed than most other forms of disability history. Kudlick hopes this "will help scholars move from thinking about disability as an individual's pathological characteristic to considering it as a social category."¹⁵⁵ Although she feels that positions such as that advocated by Ladd are extreme and "few would seek to create the separatist world advocated by some Deaf activists," an important message is that "seemingly timeless ideas can be changed."¹⁵⁶ Existing discourses about history and disability can therefore be challenged.

The struggle between oralism and signing permeates most Deaf history, and most history is seen as essentially negative and oppressive to Deaf people. There are also issues raised by the definitions of disability and deafness, probably because these are understandings imposed upon the Deaf by the hearing rather than the Deaf defining themselves in their own terms. Therefore there is the need to distinguish between the minority Deaf community (signing) and those hard of hearing / deaf because of illness or old age.

Attitudes towards history for the Deaf are therefore likely to be affected by individual identity and connection to the Deaf community, whether they sign or have been taught to 'speak' as well as other social categories such as age, class, gender and race.

7.2 Engaging with the Deaf community: finding an entry-point

The original intention of the research project was to work with a group "who define themselves as part of a disabled community" (i.e. members of the Deaf community)." In our conception of the 'disabled community' (e.g. a coherent group of people who identify as disabled) we conceived the Deaf community as a distinct group within it. It was felt that because Colchester museum service had already worked with members of the Deaf community, and the Deaf community were felt to be assertive and well-informed as to what they might expect from museums, there would be a readily identifiable "group" whom we could contact regarding the aims of the research.

However in practice contacting the Deaf community proved to be problematic – there was, essentially, no "ready-made" group of Deaf people willing to be involved in the research. It is therefore important to outline in detail the process we worked through in order to make contact with the Deaf community as it portrays the pitfalls

¹⁵⁴ Ladd, 2003:23

¹⁵⁵ Kudlick, 2003:781

¹⁵⁶ Kudlick, 2003:782

of trying to make contact with groups through making assumptions about those groups based on categories that they may not inherently identify with (in this case "disabled"). Our task therefore became to attempt to understand the Deaf community in more depth in order to ensure that the research was relevant to them. This learning process became increasingly significant to the research process as a whole.

Prior to this piece of research, Colchester Museums had worked with the Deaf community on the "Twinkle Twinkle Little Star" project, but they had found it difficult to recruit Deaf adults:

"The majority of the participants in the Twinkle project, because it was based around a children's poem, were young children. It proved almost impossible to recruit adults and most of the children's parents were hearing."¹⁵⁷

It was hoped that this new piece of research would be able to make contact with participants that had not been possible for this earlier project.

During early attempts to contact the Deaf community it became clear that we needed to understand in greater detail the nuances of Deaf cultural territory. Contact with the Deaf Centre in Colchester presented an array of different groups that may or may not have been suitable for our research:

- a life skills and learning disabilities group who used Makaton¹⁵⁸
- a lunch club, some of whose participants signed and some of whom lip-read
- a sign club, mainly students learning BSL
- the Deaf club, mainly families and older people taking place on a Saturday, both Deaf and hearing, a very social group
- a hard of hearing group for people who had become deaf (deafened)

It was not until further investigation that we came to understand how profoundly different these groups really are; not only in terms of their experience of being Deaf or hard of hearing / deafened but also in terms of identity.

Contact with the Deaf Centre did not lead to any fruitful decisions being made about having access to a group of research participants, although we attempted to establish email contact with Deaf members of the RAD, whose headquarters are based in Colchester, as well as acting as the venue for local area's Deaf club. After more investigation of groups in the Colchester area we eventually made contact with the local Deaf Football Club, run through the YMCA. A group agreed to meet us in informal setting in Colchester on 19 June but it came too late for us (reply was

¹⁵⁷ Email dated 07 June 2005 from Georgina Colthorpe of Colchester Museums to Jocelyn Dodd, RCMG. Paddy Ladd in *Understanding Deaf Culture* indicates that only 5% of Deaf people are born to Deaf parents, a further 5% have one parent who is Deaf, 2003:42. Thus the majority of Deaf children are indeed born to hearing parents.

¹⁵⁸ "Makaton is a unique language programme offering a structured, multi-modal approach, using signs and symbols, for the teaching of communication, language and literacy skills for people with communication and learning difficulties" <http://www.makaton.org/index.htm> [accessed 20/03/2006]

made by email 15 June) to be able to organise the practical elements of the focus group, mainly the need for a BSL interpreter which ideally needs to be booked weeks in advance. We were constrained by the needs of the research project and in arranging time to meet other groups whilst in Colchester which curtailed our own availability.

The education system was another means through which we could have encountered young Deaf participants. We had already made successful contact through this route with a unit for visually impaired pupils at Thomas, Lord Audley School in Colchester and we felt that by contacting a second unit we would overly represent individuals defined as 'impaired' for educational reasons, rather than self-selecting members of a Deaf community.

The difficulty we encountered was not unusual. As noted above, Colchester Museums had experienced some challenge in engaging Deaf adults in a museum-based project and a member of PORTAL who is Deaf, suggested in our meeting with that group that relationships with the Deaf community would take time and be difficult to establish.¹⁵⁹ Furthermore, communication was difficult with contact via email being relatively slow and therefore not conducive to the advance planning that was necessary. Practical issues over the organisation of meetings and the ownership of the project might also have played a role. This was the experience of the *Hands Up!* project, developing access for Deaf audiences to arts events and venues in Derby, which faced challenges in setting up a Deaf consultative group:

"The Deaf consultative group did not succeed as part of the structure of Hands Up because of irregular attendance and the consequent difficulty of planning to include the group's input... some ideas suggested were that people found it uncomfortable being asked to attend formal meetings, and that they had no strong reason to appreciate the importance of their participation..."¹⁶⁰

On reflection however, we found that it was not only practical barriers that created problems in contacting the Deaf community. Our underlying approach to the research was creating a barrier to our engagement with the Deaf community, which was compounded by a lack of experience and in-depth knowledge of the Deaf community. In order to explain how this insight occurred, we must return to the starting point for the research; the literature review.

¹⁵⁹ Our informant gave the example of the Deaf Ramblers Club who meet once a month and could be one group to contact. However it would have entailed a three month lead in to build relationships and in the end the group might not be interested in participating in the research project.

¹⁶⁰ Delin, A., *The Hands Up project: developing access for Deaf audiences to arts events and venues in the city of Derby*, November 2001 – March 2003, Funded by the New Audience Programme (Arts Council of England), East Midlands Arts and Derby City Council, hosted and managed by Q Arts, Derby, March 2003:21

http://www.newaudiences2.org.uk/downloads/btp_handsup_report.doc

7.3 Returning to the literature review

During the construction of the literature review, reference had been made to the work of Deaf writers and historians who talk about the Deaf community as a community separate from the disabled community. However it was not until our first, unfruitful attempts in making contact with the Deaf community that we began to understand what this meant in practice and how it necessitated a change in our original research plan.

We returned to *Understanding Deaf Culture* by Paddy Ladd in order to obtain a greater sense of how the Deaf community might view themselves. In subsequent discussions with Tom Fenton and Simon Hesselberg of the Royal Association for Deaf people (RAD) in January 2006, it emerged that the vision of Deafhood that Ladd outlines is indeed that, a radical vision and intellectual framework for understanding what it means to be Deaf, realised in the notion of "Deafhood." Although Ladd is a visionary and, as our interviewees suggested, presents an extreme view that is not yet common currency amongst the Deaf community, it is a useful starting point for beginning to understand why the Deaf community is different and why it must be treated as separately from disability. This means Deaf with a capital "D" which is distinct from deafened, partially deaf or hearing impaired as constructed in the main by the medical and social models of disability.

The first difference to reiterate is that Deaf is not a disability because Deaf people do not experience a "lack". They are a cultural-linguistic community. The social model, whilst used to realise emancipatory goals for disabled people, fails to identify with the Deaf experience:

"[The social model] has failed to realise the extent to which it is still medically constructed. Even though it places an emphasis on the commonality of experience of social oppression, all the groups within its aegis are undeniably those who are characterised by having a physical impairment. It is also conceived around the tenets of individualism – that is the social and political barriers facing individual disabled people in their attempts to gain full access to society. Thus it has been unable to cope with the collectivist life experience that characterises Deaf communities."¹⁶¹

Ladd feels it is the emphasis on disability that ensures that Deaf communities continue to be misunderstood. Deaf people are not individuals that need to be helped but "their collective life and language embodies principles and patterns that can assist us in tackling deficiencies in our own social beliefs, theories and policies."¹⁶²

Defining 'Deaf' is at present contested, and therefore hotly debated. Ladd quotes Baker and Padden who, although writing in 1978 prior to the adoption of Deaf with a "D" offer (in his view) the most "succinct" definition:

¹⁶¹ Ladd, 2003:268

¹⁶² Ladd, 2003:269

"The most basic factor determining who is a member of the deaf [*sic*] community seems to be what is called "attitudinal deafness." This occurs when a person identifies himself / herself as a member of the deaf community, and other members accept that person as part of the community."¹⁶³

This does not therefore mean one has to be born profoundly Deaf to be a part of the community. Ladd was himself born partially deaf to hearing parents and "gradually came to be accepted by Deaf people, and simultaneously begin to accept their very different world-view and history, thus moving from 'deaf' ... to 'Deaf' (situating it around cultural and linguistic perspectives)."¹⁶⁴ He outlines three routes to membership of the Deaf community:

- a Deaf person born to Deaf parents (or one parent who is Deaf)
- graduate from a Deaf school
- mainstreamed Deaf children "finding" their Deaf identity¹⁶⁵

Partial membership may also be extended to others including hearing children of Deaf parents, hearing people who marry a Deaf person or are parents to a Deaf child, those who become deaf in their early working lives or have worked in the Deaf community. Much of this will depend upon the degree to which they sign or socialise in Deaf environments.¹⁶⁶

From the literature review we arrived at the conclusion that we had had no response from the Deaf community to our research, amongst other things, because it was couched in terms of disability. As it stood, the research was not perceived as related to them, to their experiences or to their lives.

Key themes that emerged as part of our own learning process regarding the Deaf community can be summarised thus:

- Deaf people do not define themselves as disabled but as a cultural-linguistic minority with a specific language, culture and way of looking at the world that are different to the majority, hearing world and culture of "English"
- There is a need to appreciate the complexity of those who are termed "Deaf" and to distinguish between those who are "Deaf," "deafened", "partially deaf", "hard of hearing" or "hearing impaired". However, as Ladd notes, Deafhood is not a fixed entity but a "process" which can be (re)claimed by those who may have been denied access to the Deaf community through "oppressive" education practices¹⁶⁷

¹⁶³ Ladd, 2003:42

¹⁶⁴ Ladd, 2003:277

¹⁶⁵ This perspective was confirmed by both Tom Fenton and Simon Hesselberg in their interviews

¹⁶⁶ Ladd, 2003:42

¹⁶⁷ As Ladd himself experienced as a child - "Isolated from contact with other Deaf people, the experience resulted in 'academic success' but was traumatic both socially and emotionally", 2003:277

- “Deaf” is a politically contested term as defined in the struggles between BSL and oralism, the right for Deaf people to have their own culture and language recognised rather than absorption into hearing society. They want to define themselves on their own terms, not have it imposed by the “hearing”

Armed with our new grasp of what it means to be Deaf, insofar we could gauge such an understanding from texts, we began to realise that the premise of our research was influencing some of the challenges that we faced. We needed however to discuss this assertion with the Deaf community itself to ensure the validity of our supposition.

7.4 Seeking to understand the Deaf community – interviews with Tom Fenton and Simon Hesselberg of the RAD

As noted above, Paddy Ladd’s book gave us a useful insight into the Deaf community and the notion of Deafhood but we felt that it was very much a vision, developing ideas of how the Deaf community *should* look and *should* be defined. We felt there was a need to engage with Deaf people from a grass roots level or to speak to those who could communicate to us their views. This led us to the Royal Association for Deaf people (RAD), a national charity with its headquarters in Colchester which also act as the venue for the local area’s Deaf club. Thus the centre has both a national / local perspective, similar to how Paddy Ladd describes the idea of Deaf consciousness:

“A cultural trait peculiar to Deaf community life is the national orientation of its consciousness. The trips to other clubs and participation in regional or national social and sporting events created a sense of Deaf nationhood which helped to create a larger Deaf identity which, in turn, reinforced unity at local level.”¹⁶⁸

We felt the RAD would enable a local perspective of the Deaf community in and around Colchester but framed within a broader national context.

7.5 The interviews

Contact was made with Tom Fenton, the (hearing) Chief Executive of the RAD, and Simon Hesselberg, (Deaf) Head of Community Development who works in London. Both interviews were held in London at different venues; Tom Fenton was interviewed on the 17 January 2006 at RSA, John Adam Street and Simon Hesselberg was interviewed on 27 January 2006 at Congress Centre, Great Russell Street. The interview with Simon necessitated the use of an interpreter who was booked through the RAD.

¹⁶⁸ Ladd, 2003:363

Both interviews were conducted with two researchers present and were taped and later transcribed by an external company.¹⁶⁹ Our questions focused on establishing if the premise of the research, that Deaf people identify themselves collectively with disabled people, had created barriers in relation to recruiting Deaf people to the project. We took the opportunity to explore the meaning of history to the Deaf community and ask how museums might begin to engage with them; what would be the characteristics of an effective partnership between the Deaf and the hearing communities?

7.6 To be Deaf is not to be disabled

Both Tom Fenton and Simon Hesselberg confirmed for us that Deaf people do not define themselves as disabled. The crucial difference is that being Deaf is to be part of a minority language group rather than defined by the status of the body as is implied in being “disabled”:

“Yeah, I mean it’s a commonplace in our organisation that Deaf people and disabled people are two completely different groups. We think of Deaf people as a linguistic minority and our T-shirts used to say ‘Deaf people do everything except hear’, and so you know, certainly I’d be astonished if any of our group thought of themselves as disabled.” [Tom Fenton]

“Now Deaf people look at themselves as a linguistic minority group. Disabled people, well we’re not a part of that group generally speaking people who are Deaf don’t... [identify with] that group.” [Simon Hesselberg]

It was acknowledged that there were elements that are shared between being disabled and Deaf, although concentrating on deafness as a condition “to be cured”, as Ladd suggests, denies the existence of a separate identity:

“Discrimination yes, we feel a part of that. We are discriminated by society in that way, but not disabled people... we’re a minority language group... certainly society has labelled us as being disabled which is discriminatory and creates barriers.” [Simon Hesselberg]

The social model of disability therefore goes some way to explaining the experiences of marginalised groups who are excluded from society, but it is too simplistic to give any definite answers:

“The social models of disability can apply to any disability, so you can apply it to people with learning disabilities or people with physical disabilities and so on, as well as sensory disabilities. But really all it does is say look the problem doesn’t lie in the person, the problem lies in the way society presents itself to that person. And so, but that doesn’t take you terribly far because then the answers that you find are completely different with every, with every specific group.” [Tom Fenton]

¹⁶⁹ Kath’s Keying Services Limited of Chaddesden, Derby

It was recognised that there were some contexts in which Deaf people might define themselves as disabled, for instance in using the Disability Discrimination Act (DDA) to their advantage. This was an opportunistic use rather than a close identification with the term:

“I’d be astonished if any of our group... would ever entertain the term except [to] claim benefits... [Deaf people] can claim rights under the DDA, which you know. It may be slightly a two-edged sword, but people are sensible enough to take advantage of the rights it offers.” [Tom Fenton]

7.7 The Deaf are not a homogenous group

The Deaf community needs to be distinguished from other groups recognised as having a “sensory impairment,” but by no means is this a homogenous group, nor do the different groups “naturally” interact:

“I mean when I say Deaf people, you should hear a capital D and that denotes cultural, culturally Deaf... And I’ll say hard of hearing if I meant small D deaf probably... there’s very little interplay between hard of hearing people and Deaf people. There happens to be a hard of hearing club in Colchester, some of its members come to, will mix with the Deaf club as well, but by no means all.” [Tom Fenton]

Simon Hesselberg reiterated this viewpoint, elaborating on the cultural, rather than pathological (e.g. their “impairment”) differences between the Deaf and the deafened:

“Very, very different things, completely different really. Culturally very different, a very, very wide gap between the two. You have Sign Language users have perhaps grown up Signing, and you have ... in there, you have to think about congenitally Deaf or who are Deaf at a very early age, exposed to Sign Language in any case from an early age. Now deafened people, later in life they’ve become Deaf. Their first language would be English and spoken English, so their processing is in English whether they think it’s in English. BSL on the other hand is an individual language, the processing is very different, but both have a grammar, a structure, a syntax... but in the case of the deafened people, do we link to them? No it’s a very different culture. Perhaps at the end, you know, there’s something there that’s very similar, but is there a link between them? No, that’s very difficult to say.”

There is some crossover but the essential difference is one of communication. The gulf between Deaf and deafened appears to be similar in scope to that between hearing and Deaf, although in effect they share the same term (Deaf):

“Sometimes you’ll have people cross over that, occasionally, but they wouldn’t kind of be absorbed into it, you know, they might take a visit there into that community, but clearly you’ve got congenitally Deaf Sign Language

users in that group who are Signers, and then you've got the deafened who really struggle with communication, who don't understand Sign Language, you know, and maybe I can't lip-read them at the same time. So we've not got a lot in common really."

The difference cannot be underestimated, at both a national and a local context. Tom Fenton describes differences at local level between the different types of Sign language:

"I think it's the cultural thing that should be the key issue there, that there is a rich Deaf culture and it's not perhaps as rich in Essex, some would say, as elsewhere because within the language itself, there are variations as you probably know, and there's full British Sign Language, which is very unlike English, as far away from English as you can get. And then there is Sign Supported English which uses the signs, but uses the structure of English. And in Essex the language is much more towards Sign Supported English than it is towards BSL and that poses problems for people too cos I've been at events that we've organised where Deaf people have said they couldn't understand what was going on cos it was all in BSL. So that causes some problems."

7.8 Realising the Deaf community

It emerged that there are significant differences between the Deaf experience and the experience of a hearing or deafened person. One of the most striking differences is the importance of school and education in creating the sense of Deaf identity as opposed to family or similar bonds:

"It's also worth pointing out, I mean you'll probably pick this up, that about 80, some people say 90% of Deaf children, profoundly Deaf children, are born to hearing parents, so there isn't as much transmission of culture between the generations. A lot of the creation of Deaf culture therefore came from Deaf boarding schools, to which some Deaf people went at the age of three I was astonished to discover. Some of the people like the chair of the Colchester Deaf Club, he was sent off to boarding school at the age of three, and now that we have mainstreaming for the vast majority of Deaf children, there is an issue about how they acquire Deaf culture and how they join Deaf culture."
[Tom Fenton]

For the Deaf, school was a unifying and uniting experience because it brought them into contact with other people like them, perhaps after being "isolated" at home and they were able to communicate with other Deaf children for perhaps the first time. Relationships endure long into adulthood, often centred around the Deaf club:

"Opened the door and their mother would take them in and say bye-bye, and they'd be so what's going on now, where's mummy and daddy gone? And they remember it now, you know, at 80 or 90 years old they remember this, and they'll tell me exactly what happened, very specifically in fine detail. And their school had become like a second family to them, you know, they

mixed with each other, they were like family. They celebrated things together and met together, they went to the same school and carried on being friends forever. But when you meet a Deaf person for the first time, they won't say hello, they'd say which school did you come from. Oh I went to this school. And they say on crikey you know my friend so and so, he went to that school. And then later you'll talk about something different, you know. But the most important thing, like where are you from, put into a context like that. I mean that's quite interesting in itself, you know, I mean I ask the same question myself, you know. I say what school did you go to? Oh right okay, well I know all the people that you know. It is like one big family..." [Simon Hesselberg]

However there is a sense that this form of the Deaf community is changing, caused by a multiplicity of factors. There was much discussion about how technology such as mobile phones is changing how the Deaf community is structured, particularly the decline of the Deaf club. There was a sense that the maintaining of Deaf identity, despite the advances made, is still under threat. Partly it is through the mainstreaming of Deaf children and young people in schools and partly through poor standards of education that often prevents or hampers young people in learning BSL, essential to be part of the Deaf community:

"...you have poor education basically for Deaf people at school, they had to, you know, if they went to an oral school, they'd have to lip-read the teacher and perhaps they wouldn't understand how to translate the English into BSL... When they're reading English, right the reading age of a Deaf person is perhaps six or seven to a nine/ten year old who is hearing, that would be the comparison for English ... quite different cos it's their second language." [Simon Hesselberg]

"There are big concerns among leaders of the Deaf community in England, in Britain, about the level of language they're acquiring and one of the problems that we are addressing is that in their sort of late teens, kids are using a real subset of BSL, it's rather like, you know, very poor English skills, you know, in a hearing person, and so we are concerned to help develop their language skills." [Tom Fenton]

It tends to be later in life that young people are realising their Deaf identity:

"But it's interesting that roughly in their teens, Deaf children gravitate to Deaf culture, or young Deaf adults, gravitate to Deaf culture very powerfully, they're very strongly drawn to it, and it's because of the language, it's because the huge relief, that sort of sense of coming home they report of acquiring the language." [Tom Fenton]

Despite the challenge presented by poor education, there is a real sense that the Deaf community is becoming more 'upwardly mobile' after years of oppression:

"Deaf people now, you know, say by our rights under the DDA, I have the right to use the communication I want, to have my, you know, to have my own identity. And they feel more empowered, but before, no they were just like

puppies and just do what they're told, you know, very passive really. But now, you know, with the DDA, much more assertive. Deaf people have become professionals at work, they're moving up at work up the ladder. Before Deaf people would only be allowed to be doing, they'd be doing sewing, working in the printing trade or repairing things or decorating, not anymore, now Deaf people have got degrees, you have Deaf professionals, Deaf executives, Deaf bosses." [Simon Hesselberg]

So whereas in the past Deaf people had to fit in with society and accept a limited range of subject positions from the hearing, Simon both represents, and describes, an increasingly confident Deaf community. However the past is still close. It was not so long ago that Simon was forced to deny his "Deafness" by learning English:

"It would be rude, you know, and we'd be told off at school. My school, if we were caught Signing, we'd get the cane, that's what would happen, it was just not allowed to Sign. Or they'd make you sit on your hands and just lip-read and speak, that's what they'd make you do, Signing was just not allowed."

And there is still today the conflict referred to between schools that encourage Signing and those that refuse to engender a sense of Deaf identity, and as Simon alludes to, change in this respect is slow:

"Like in some educational institution policies, you're not allowed to use Sign Language even now in some schools, oh yes it's true, yes it is." [Simon Hesselberg]

7.9 Deaf history: waiting to be uncovered

In our conversations it emerged that there was a growing importance attached to the preservation of Deaf history and culture, both tangible and intangible, perhaps partly as a response to the developments that were changing the structure of the Deaf community, as described above. Simon was involved in a project that was collecting testimonies from Deaf elders as a series of "signing histories" to record aspects of their lives and experiences that are seen as important to the community:

"Right we have a number of different areas or a number of different groups. The first related to school, their schooling educational experience, and one related to work, one related to families, another topic, and another one related to Deaf (clubs). One more related to Deaf sports and another one related to international events..."

One of the reasons behind it was to document Deaf history for young Deaf and future generations who, as a result of the education system, may be less aware of their history as a Deaf person:

"I have an awful lot, a great number of Deaf elders, Deaf older people, their Sign Language... younger Deaf people are using less, perhaps they go to a

mainstream school more often nowadays where they're not allowed to Sign as I've already said. And they're not aware of their kind of history. It's the same now with talking about Black history, people coming on the boat from Jamaica and Windrush."

There was a desire for the Deaf community, and Deaf history, to be represented in the mainstream, in the media as well as in museums. In terms of museums, Simon was very keen on creating an exhibition that would communicate Deaf history and identity to both Deaf and hearing communities, to make a powerful statement:

"It would be lovely to have an exhibition, a show in a museum, focusing on Deaf history. That would be lovely for Deaf and hearing people to visit."

He mentioned, with great enthusiasm, sources of Deaf history that were waiting to be uncovered or could be incorporated into an exhibition:

"I mean children will be fascinated by that [a collection of hearing aids from past to present], crikey that's the old stuff and this is the new stuff, they'd see a link. And also old films, you know, for the Deaf community there are videos, home videos, all a bit shaky and so on cos they're all amateur. And I've got an awful lot of old photographs I just found recently in fact."

Tom Fenton too could see the merit in having an exhibition about the Deaf community, and mentioned that Colchester Museum had previously worked with them on the "Twinkle Twinkle Little Star" project:

"However there is a community which does have a history and a tradition, that history and tradition is so much of a minority because we're talking one in a thousand of the population... But there are a lot of other minority interest groups represented in Colchester museums, there's Tymperleys Museum, which is the clock museum. Well if you can have a history of clocks, why can't we have a history of Deaf people?"

7.10 Museums: the importance of communication

There was an enthusiasm for working with museums from both Simon and Tom, however there was a sense that museums needed to be more "communication" friendly in order to enable Deaf people to enjoy them:

"I mean you do see the displays, but you hear things and you read things and all the explanation is presented in ways that are completely, I mean just completely inaccessible to profoundly Deaf people. My client group will not read if there's any excuse not to read English, they don't want stuff presented in English and, you know, you go in from one area to another and some sensor picks up your presence and immediately, you know, you hear the clash of steel, a thwack of leather on willow or whatever it is, but all of that would be missed totally." [Tom Fenton]

"I would love to visit more museums, when I was younger I would love to visit them, it was visual, but nowadays you go to a museum and they give you one of these things to stick to your ear and listen to. I'm a Deaf person, what am I going to do with that? That's just no help." [Simon Hesselberg]

In order for museums to work more successfully with the Deaf community it was felt that it was important to make the gesture to communicate more successfully in their language. Being aware that Deaf people do not necessarily speak English, or want to, was an important distinction:

"I mean I can read, obviously I can write, some Deaf people couldn't even write a note... other people just want to Sign... I mean you get a lot of different ways of communication and it would help them [museum staff] recognise and know what to do, and everybody should have that. It's a public body after all you see." [Simon Hesselberg]

There was also the need to take into account local differences and contexts which, as outlined previously, might be very different:

"You need to work with the Deaf community in Colchester, specifically ask questions to them to perhaps ... about their history, about their past."

It is important to involve the Deaf community in the project from the beginning and establish communication networks:

"And then they'd be involved in the steering group perhaps because of course they would like to be involved from the start, you know, not at the end of the project. It's like they would tell you, if you include people from the start they will tell you what to do, how it should look, rather than make some mistakes and have to make changes at the end."

Equally, the relationship of power between the museum and the Deaf community was crucial:

"I think it depends entirely on their perception of what relevance it will have to them and in a way, who's leading, who's presenting. If something is hearing led, it's not really so likely to get engagement at all."

In terms of representation within the museum, Tom Fenton talked about particular subjects that are over-explored within the Deaf community, for example cochlear implants and the concern over genetic modification, and that it was time to move away from the representation of Deaf people as victims:

"What we would really value is some sense that the whole community values, genuinely values diversity and is proud of having a Sign Language subculture within it, that's the sort of thing that would be great. And so, you know, what would be wonderful would be to find out more about what British Sign Language [was] like in the 17th and 18th and 19th centuries, you know, when did British Sign Language [begin?]"

7.11 Conclusion

From discussions with Tom Fenton and Simon Hesselberg we can see that Paddy Ladd's vision of "Deafhood" is very much a 'utopian' vision, an extreme view that the Deaf community would not immediately relate to but one which serves as an important intellectual framework and reference for the construction of a Deaf community:

"I mean I think that I would with him that objectively there is an oppression, but that's very much in academic speak, it's not, you know, so it's not cruel torture, it's not slavery or anything like that. But there is a terrible undervaluing as there is a huge assumption among well-meaning hearing people who don't know anything about Deafness, that actually Deaf people would be better off if they were able to access English things better, you know, so people think naturally that things like cochlear implants must be a good idea and, you know, better signage and so on..."

From our conversation we find that not only does the term "disabled" naively mask a huge range of people with profound and different experiences, so does the term "Deaf". It is crucial that differences between "Deaf", "deafened", "hard of hearing" etc. are taken into account. We still have much to learn about the best ways in which to contact groups whose experiences are so vastly different to our own but from our interviews with the RAD we can begin to see a way into entering the Deaf community.

7.11 Implications

- The Deaf community is a cultural-linguistic minority, not based on impairment.
- Deafness is a highly politicised issue to the community.
- Some Deaf people will identify themselves as disabled but others will not so understanding the local context is crucial.
- The Deaf community is complex, not a unified community.
- Exhibitions are seen as a useful way to communicate the history and culture of Deaf people to all audiences.
- Words are not enough. Communication needs to be comprehensive and multiple.
- Co-curation and partnerships with the Deaf community are essential for exhibition development

Section eight

Research findings

8.0 Introduction

This section pulls together the findings from the four focus groups and considers their responses against the three research aims we identified at the beginning of the study:

- To what extent did the research participants find history, archaeology, museums and monuments relevant to their lives?
- How far is the relevance of history, archaeology, museums and monuments shaped by their experience of disability?
- What part do disabled people feel museums can play in the representation of disabled people in the past and today?

We found that all the research participants took it as 'given' that history was important, although an interest in history was seen as more of a personal choice. All of the respondents we talked to had visited and were able to cite heritage sites and museums, indicating that personal experience of disability, and any social barriers this might induce, were not strongly limiting factors on their visiting habits.

Participants had to be prompted to make the connection between history and the experience of disabled people in the past; they could not make it voluntarily. They could not see immediately how the experiences of disabled people in the past could have any relevance to the lives of disabled people now. One reason for this is that they felt that attitudes towards disabled people were much better now so "what do we need to show?"

It was clear from the focus groups that individuals construct their identity in various and multiple ways. Whereas the Deaf people we spoke to expressed a strong and assertive sense of themselves as Deaf with a specific culture and language, this was not true for the majority of our participants. Even those for whom being disabled was a strong part of their identity tended to perceive themselves as young people, as older people, or as 'normal' people who happened to have impairments. This construction of identity seemed to have a clear impact on the approach that participants felt museums should take. Where group identity was strong, participants saw museums as vital for the transmission of that group's history and culture. Where identity was less strong, the approach was more cautious and individuals either lacked a clear concept of the role that museums should take or only advocated inclusion where it was 'appropriate.'

Finally we include here some further findings of the research that fell outside these research aims but which we feel are crucial in understanding the complexities of the

process we went through and raise a number of related questions for future development.

8.1 To what extent did the research participants find history, archaeology, museums and monuments relevant to their lives?

The research questions purposefully did not lead interviewees into regarding what period what might be defined as 'past' or 'history' and between them the respondents covered a broad scope of history. In general our participants took it as 'given' that history was important, corresponding with Merriman's belief that the majority of the population attaches some value to knowing about the past.¹⁷⁰ However there was not an exact relationship between the value of history and its relevance to the individual. Interest in history was seen as more of a personal choice. Young people for example described history as important yet did not always see its immediate relevance for *them*. The older generation were also apt to see the relevance of history in terms of the moral lessons that could be drawn, particularly to be transmitted to the younger generation, but not for *them* because they already understood the importance of history. Some participants felt a more personal connection with the past when it helped them to understand their own place in history, it engendered significant emotions, or they were able to connect with a strong part of their identity for example as a Deaf person.

8.1.1. A range of sites visited

The range of site types given as examples of heritage locations visited by participants was diverse. Most of them were in the UK apart from war cemeteries in Europe mentioned as part of a school trip. However the range of sites mentioned by participants can be seen as quite conventional in the sense that they have been identified as "heritage" by establishment bodies such as English Heritage or the National Trust and preserved as a museum or visitor attraction.

All of the respondents we talked to had visited and were able to cite heritage sites and museums. The breadth of such sites appears to indicate that personal experience of disability, and any social barriers this might induce, were not strongly limiting factors on disabled individuals' visiting habits. However, this has to be taken in context of the relatively autonomous, mobile and educated profile of those participating in discussion-based research groups.

For many respondents the most meaning was communicated by human circumstances with which they could empathise, imagining what it would have been like at a certain period based on direct contact with objects or environments linked to real events. The descriptions given of these scenes were among the most animated and detailed in each of the focus groups, and demonstrated imaginative engagement with experiences.

¹⁷⁰ Merriman, 1991:4

8.1.2 No link between attitudes and identity as a disabled person

Participants had to be prompted to make the connection between history and the experience of disabled people in the past; they could not make it voluntarily. There appeared to be a barrier to seeing how the importance of understanding history could be linked to disability even though at times they came close:

“The only time it’s relevant is the history of how disabled people were treated through the ages and how we came to the DDA and it became more socially acceptable.”¹⁷¹

This seems very relevant to the fact that the majority of our participants did not engage with the social model of disability, although they accepted that disabled people were discriminated against in the past. They could not see immediately how the experiences of disabled people in the past could have any relevance to the lives of disabled people now. They could not see how museums could determine attitudes from material evidence but, more tellingly, they felt that attitudes towards disabled people were much better now so “what do we need to show?”

This was a very different approach to Colin Barnes who believes firmly in the importance of history in understanding the experiences of disabled people in the present. As with much of the literature, only when we understand the past can we understand the present and shape the future:

“I think most disability writers, academics, you know, or sort of social modelists if you like, whatever you want to call them, look to history to understand today... I mean if you look at Mike Oliver’s books and his writings, he is probably the best known writer on disability, he’s a materialist and he focuses on, you know, the transitions from feudalism to capitalism as being a big factor in shaping our understanding of disability... but for me of course it goes further back than that, you have to explain it with reference to religion and Middle Ages and understandings of Christianity and what was good and what was bad...”¹⁷²

8.1.3 The need for more research

Our findings point to some similarities in the attitudes of disabled people towards history and heritage, namely that identity as a disabled person does not impact upon attitudes towards history and heritage as much as other factors such as demographics, biography and culture. However due to the lack of understanding about how attitudes towards history and heritage are shaped by these other factors we cannot say for certain what a ‘general’ or accepted attitude may be. We certainly found instances where participants did not display the generally accepted relationship with the past as suggested by available sources, for example not all our older participants demonstrated nostalgia for the past nor did all our young people express a disinterest in history and in fact seemed quite knowledgeable about disabled people in history. Therefore more research is needed to understand our

¹⁷¹ Focus group with PORTAL 17/03/2006

¹⁷² Colin Barnes, interview 01/03/2006

relationship with the past and how attitudes towards it are determined by different facets of our identity.

8.2 How far is the relevance of history, archaeology, museums and monuments shaped by their experience of disability?

It was clear from our focus groups that disabled people construct their identity in various and multiple ways. They may or may not identify with the concept that disabled people share a commonality in the form of social oppression. They may not use terms in common currency; they may not directly identify with disabled people in the past or refer to them as “we” but as “they” even if they identify as a disabled person. It is others - disability campaigners, charities, governments, museums - who have defined disabled people as a distinct group. Disabled people will not automatically relate to these definitions.

8.2.1 Experience of disability is not immediately relevant to attitudes about history

Initial responses to the question - *why is history important?* - were unconditioned by personal experience of disability. All the respondents placed themselves outside their disabled identity (however strongly they held it) and responded with reference to established narratives such as war and its lessons or social change or constitutional/monarchic history. From our evidence we felt that participants positioned themselves, until encouraged otherwise, as people with identities other than as disabled people, as teenagers, older people, or ‘normal’ people.

Individuals have multiple identities. Rather than locating ‘meaning’ within individual minds, post-modern theory suggests that meaning is produced through discourse and discursive fields, where individuals ‘are spoken’ by their positions within discourse. The research appeared to show most disabled people positioned themselves as not perceiving themselves to have a right to a culturally-specific opinion on ‘history’ or ‘the past’. Therefore when asked about the past they initially adopted a generalised, non-disabled identity to gain authority for holding an opinion.

8.2.2 Not a political identity

The disabled people who participated in this research did not express an overtly political identity or explicitly refer to themselves as members of a community of disabled people, united through “marginalization and oppression.”¹⁷³ Whereas the Deaf individuals we spoke to expressed a strong and assertive sense of themselves as Deaf with a specific culture and language, this was not true for the majority of our participants, even those who identified themselves as disabled. One of the participants from PORTAL summed up the majority position when he said:

“ [Disabled people] think of themselves as a normal person who’s in some way impaired from functioning properly because of his disability. So a disability is a secondary thing to how a disabled person thinks of themselves...”

¹⁷³ Miller and Branson, 2002:xiii

There was also incredulity expressed about the social model which one visually impaired participant felt over-emphasised the role of society in the creation of disability:

"I think it's exaggerated, not the difference is exaggerated but the conclusions drawn from emphasis on the social model is rather overdone. I mean no other approach by society will enable me to see. And the way some people talk about the social model I think it suggests that that's all there is... Well, my impairments impose limitations on me, which I fail to see how you can say they are limitations primarily imposed by society."

We did not feel therefore that participants had a strong identity as disabled people. Talking to Colin Barnes it is likely that this is the case for many disabled people, a political identity the preserve of a minority:

"If you're talking about disability activists, they all know about disability culture, and they probably are a minority, you know, in the disabled population as a whole, because we live in a culture which is like dominated by able-bodied assumptions..."

There were many reasons for why people would not identify as a disabled person in the political sense, for example oppression is hard for people to quantify when it appears that society is helping rather than discriminating against disabled people:

"I mean, I do find it rather strange that people expect disabled people to sort of be any different to anybody else, it's like, you know, feminists talk about women generally, but, you know, most of women don't particularly have interest in feminism until, you know, they experience abuse in one way or another."¹⁷⁴

8.2.3 Negative representations of disability create a barrier

The shame and stigma attached to being disabled is another barrier to identifying as a disabled person. In *The Sexual Politics of Disability: Untold Desires*, an interviewee talks about not identifying with the disability "label" because:

"... the predominant images of people who fit that label have little to do with me. Negative images which focus on dependence, guilt, pity and fear are perpetuated by the media... A typical disabled person is seen as having little control over his or her life, is dependent on others, has no rights and is not considered to be actively sexual, or have sexual desires and feelings."¹⁷⁵

Most of our participants, mostly the older ones, did not identify with the term disabled in a positive way. They talked about being 'people with disabilities' or 'ability' and

¹⁷⁴ Colin Barnes, interview 01/03/2006

¹⁷⁵ Shakespeare, T., Gillespie-Sells, K. and Davies, D., *The Sexual Politics of Disability: Untold Desires* Cassell, 1996:49-86

the oldest participants referred to their 'infirmities' or health. They did not identify themselves with disabled people in the past, because the experiences of disabled people in the past, described as largely negative, were seen as alien to their own experiences.

This implicit negative perception of disability has been likened to the history of slavery, which has developed from a personal stigma and shame to being recognised as something which society needs to be accountable for and confront openly.¹⁷⁶ By keeping disability hidden and unchallenged it is likely the negative perceptions will continue to predominate.

8.2.4 Normalisation

Throughout the focus groups, our participants expressed the need for disabled people to be recognised as 'normal' or as 'people with disabilities.' This desire to be seen as normal is identified within the political movement as part of the oppression of able-bodied society because it:

"...tends to obscure the need for change. Logic dictates that if disabled people are perceived as normal then there is little need for policies to bring about a society free from disablism."¹⁷⁷

Disabled people are also put under pressure to appear normal and deny their disability, leading potentially to feelings of shame or low self-esteem.¹⁷⁸ However for our participants being normal was perhaps one way of coping with their 'impairment' and, as more and more disabled young people are incorporated into the mainstream for education purposes, it becomes an important issue to those who may be bullied or singled out because of their difference; an experience to which several of the participants in this research had been subjected.

A different way to examine the issue is to deconstruct what it means to be normal. For our participants it meant being a part of mainstream society and being accepted as the 'same' rather than as the 'other.' Paul Darke however postulates that normality as currently defined is the antithesis of being disabled. We define 'normal' by what we are not rather than by what we are and this has impacted upon the acceptance of disabled people within society:

"Normality – the belief that there is an essentially correct way to have been born, look like and be – the belief in normality, has defined the nature of the representation of disability and impairment (and non-disability) by formulating it as the basis upon which otherness (abject humanity bordering on inhumanity) has been defined in all figurative representation of humanity."¹⁷⁹

¹⁷⁶ Heather Hollins, museum professionals, interview, 10/03/2006

¹⁷⁷ Barnes, 1992: 18-19

¹⁷⁸ Miller, Parker and Gillinson, 2004: 21

¹⁷⁹ Darke, 2004, <http://www.outside-centre.com/darke/mycv/writings/bookchap/Colin%20Barnes.html>

Therefore if we are to have a 'normality' that accepts disabled people, there must be a recognition of difference, not as something which to define ourselves against but as something to be incorporated. This can be identified most strongly in the responses of the young disabled people at Thomas, Audley School who were keen to raise awareness and be open about the many different ways in which individuals see the world. There is a need to recognise the 'everydayness' of disability whereby the margin becomes part of the mainstream:

"I mean, the more successful we are at bringing disability into mainstream culture, the less we have to do..."¹⁸⁰

8.2.5 Recognition of exclusion

When considering the relevance of museums, history and heritage sites to disabled people we must consider notions of exclusion and difference and the impact these have had upon individual declaration of disabled identity. As disability activists assert, exclusion and marginalisation in society can create the desire to become 'normal' and the denial of disability rather than to challenge that oppression. The diversity of those incorporated within the term 'disabled people' also implies a diversity of expression and opinion rather than a common viewpoint. The complexity of the relationships between disability, identity and personal experience do not present easy answers to the questions around the recognition of exclusion in museums.

This was true of the people we spoke to in Colchester. There was not a single collective viewpoint, nor were they altogether confident or assertive about presenting the history of disabled people in museums. In many ways it seemed they did they not even expect to see disabled people represented in museums and heritage sites. It was only when the exclusion was made explicit that they felt less comfortable with it and began to see ways in which museums could help shape the recognition of exclusion. However the lack of political identification as disabled people meant perhaps, ultimately, they did not see themselves as excluded from society and could not always see the need to raise the issue within the museum. Our participants did not engage with abstract concepts of exclusion and oppression and there were varying degrees of acceptance of the social model. An understanding of themselves as 'normal' therefore indirectly influenced their attitudes towards heritage. As we saw, immediate responses to history and heritage were from a general position, not connected in any way with their disability. They were speaking about how they saw themselves, and how they desired, to be represented as 'people' first and as 'disabled' second.

8.3 What part do disabled people feel museums can play in the representation of disabled people in the past and today?

This kind of research has indicated how individuals think about how museums can play a role in the representation of disabled people in the past and today. It has revealed that on the whole, the individuals we spoke to were cautious and not clear how

¹⁸⁰ Colin Barnes, interview 01/03/2006

museums could present disabled people, partly because museums have been silent for so long about disability people have no model or 'concept' from which to draw on. Secondly, there was a direct link between strength of identity as a disabled person and belonging to a community in the approach that museums should take. Where identity was strong, museums were seen as vital for the transmission of a group or community's history and culture. Where identity was less strong, the approach was more cautious and individuals advocated inclusion where it was 'appropriate.'

However, this kind of research tells us what people think but not necessarily what should be done. Just because individuals are cautious does not mean museums have to be. As the conclusion to *Buried in the Footnotes* argues:

"If museums remain reluctant to engage with disability as a cultural issue, they run the risk of positioning themselves in opposition to a society which is elsewhere ready for change."¹⁸¹

8.3.1 Museums as part of the structure of concealment

The initial response from all participants was emphatically that disability is not represented in museum collections. Disabled people were invisible. However it also emerged that most disabled people we talked to did not visit museums or heritage sites to look at the history of disabled people; to some extent they 'expected' them to be invisible or it was not something that they had previously thought about or questioned. One participant from PORTAL was incredulous that it would be otherwise:

"Well that's not the sort of thing I'd look for when I go to a museum, when you go to museums you look at the general historical themes in the museum, not on individuals who may or may not have been disabled, so it's not something I'd look for. I wouldn't look for any disabled themes just cos I'm disabled..."¹⁸²

So what does history currently tell us about the experience of disability? From the responses of participants it tells us that being a disabled person is negative, that disabled people have always been singled out as different and are socially unacceptable. It does not offer relevant subject positions for individuals but instead reinforces that disabled people are passive, a tragedy or a burden. There is the potential for museums to challenge this view but it must be noted that some of our respondents were adamant that such a view of disability was to be expected, it was 'common sense':

"It would be incredible if it were otherwise wouldn't it?"¹⁸³

¹⁸¹ *Buried in the Footnotes*, 2004:10

¹⁸² Second focus group with PORTAL 17/03/2006

¹⁸³ Second focus group with PORTAL 17/03/2006

8.3.2 A cautious approach to representing disability

Drawing on the responses from the different groups that we spoke to, there was no consensus over how representation of disabled people could be addressed in museums. The relationship between disability and identity, as explored above, was complex and often directly related to personal experience. Also there was not detected a strong identification with the political meaning of 'disabled.' As a consequence, there was a lack of clarity and confidence about how disabled people should be represented in museums. This was contrasted with individuals or groups who demonstrated a strong and assertive collective identity. For the Deaf community there was a greater sense of clarity over the role that museums could play in representing their culture and history through exhibitions or even a museum solely devoted to the history of Deaf culture. For Colin Barnes museums had an important social role in recognising the exclusion of disabled people and creating a more honest representation of difference in society:

“And this is important because what’s happening is, that we’re normalising a particular view of reality which is not what being alive and being human’s all about. And I think museums could play a real role in this kind of sort of education process, cos that’s one of the roles of museums isn’t it?”¹⁸⁴

Participants instead were more cautious. They could see the potential to include stories about disabled people within the museum but only where they felt it to be appropriate rather than singled out as a “token disability bit.” The older participants struggled with the concept most of all because they had no concept of themselves as disabled people.

8.3.3 A difference in age: younger participants’ vision of the museum

Even in the literature, the creation of relevant representation of disabled people remains a contentious issue. Images remain loaded with values; even the desire to normalise disability - “mainstreaming’ or sanitising impairment” - has led to socially acceptable images of the “valued disabled person who is physically able, educationally competent and striving to achieve a ‘normal’ wealthy life(style).”¹⁸⁵ Such images are seen as continuing to exclude those who cannot fulfil this ideal and are therefore viewed as no better than more negative images.

When looking at how individuals or groups conceived the role of the museum, one clear difference that emerged was between those who had a strong identity as disabled or Deaf, and those who saw themselves as people first and disabled second. Another difference that emerged was between the approach of young participants and older participants. The young people were keen for the museum to be aspirational, to establish role models that would inspire and challenge them to achieve their dreams. Such high expectations were considered damaging by PORTAL who felt that exceptional role models would only create difficult standards for disabled people to live up to. For PORTAL there needed to be a balance

¹⁸⁴ Colin Barnes, interview 01/03/2006

¹⁸⁵ Darke, 2004, <http://www.outside-centre.com/darke/mycv/writings/bookchap/Colin%20Barnes.html>

whereby 'ordinary' experiences of disabled people were incorporated. And although all groups could see the potential of the museum for raising awareness about the experiences of disabled people, the teenagers seemed to be more enthusiastic about this particularly in relation to understanding how they were different as perceived by others. Some participants felt that it was impossible to reproduce individual experience within the museum. The greatest challenge for museums is negotiating between these diverse positions.

8.3.4 No model that the participants could identify with

It was felt that most participants struggled with the role the museum can play in representing the history of disabled people not only because they lacked confidence in their identity but also because they had no model of what museums could do. In their own experience disabled people have been invisible in museums so it was difficult to begin to think about how it could be presented. Where participants did have a model, coupled with a strong sense of identity, the opposite was true. Simon Hesselberg of the RAD for instance could refer to the Smithsonian museum in Washington as an example of an exhibition on Deaf history and culture which he would like to recreate:

"They have one area completely focusing on Deaf history there, they don't have the same thing in this country. I would love to see that, I would really like to have something like that here."

8.3.5 "You should tell things how they are"

This comment by one of the participants from the research proved challenging when we came to test the findings:

"You've asked about showing people our history, but sometimes it's private, it's personal. Some people like to share it, others don't. Some people are guarded and I think we have to respect that. Sometimes it's nice just to keep things for yourself, perhaps that needs to be considered as well."

Most responses were noncommittal apart from the PORTAL group who, when we spoke to them a second time, were adamant that censorship should be avoided at all costs:

"Once you decide to start hiding things you get into all sorts of difficulties."

They really engaged with this question and were keen to talk about how it should be made obvious where impairment had impacted upon the creator or author of a work as it would help to explain how that person saw the world. It was felt that if something was public then anything was relevant; "you should tell things how they are."

8.3.6 Telling stories in museums – from where are we speaking?

The complexity of identity and the different positions that individuals assumes leads to apparent contradictions in the ways in which people express themselves. We asked about the types of stories and objects which disabled people wished to see about themselves in museums. The responses varied strikingly between the different discussion groups. With a few exceptions, each group had a particular slant on what type of story could be told by a museum seeking to represent disabled people. In questioning why this might be, we can return to the way in which possible forms of identity and subject positions may be set out in advance. Disabled people are influenced by discourses which set out what is expected of them, and the notion that their impairment or disability experience is what makes them 'special' has been strongly internalised. This can show, for example, in the type of object offered when museums open their collections process. Objects offered by (and accepted from) disabled people often include symbols of achievement such as certificates and Paralympic medals, or iconic objects of impairment such as crutches, hearing-aids and prosthetics.

In some of the responses, respondents demonstrated a dissonance between personal and public narratives about disability. The personal was a story of complexity which featured ordinary (uniquely experienced) relationships, experiences and emotions; the public was a more reductive account focusing on presumed interest in the exceptional experience of being a disabled person.

8.3.7 Museums need to break the silence

No easy answers have been revealed from our research into how disabled people view the roles of museums in representing their history. Barriers towards this realisation include the strength of the silence around disability, a questioning and uncertainty of the motives behind such a purpose and often the lack of a strong and confident sense of identity as a disabled person which translates into the desire to ensure the past experiences of disabled people are used as determining present and future. There is a difference between young and older participants, between Deaf people and most of the disabled people we spoke to. These are considerations that the museum must take into account.

However there was unanimous agreement that it is essential that the silence in museums about disabled people should be broken even if the way in which this is achieved is not always clear at present.

8.4 Additional findings

During the research process we found that we opened up many more considerations when researching the attitudes of disabled people that could not be easily answered within the three research aims. However they are important for understanding the complexities of the process we went through and raise a number of related questions for future development. By developing an awareness of how to deconstruct what is normally 'given' or seen as 'common sense' museums can encourage greater interrogation and probing of what people take for granted. In this way museums can

develop new ideas and ways of doing things which will enable disabled people to engage more effectively with their history and play a role in challenging the preconceived notions of disability that exist within society.

8.4.1 The newness of the research

It was felt that one of the barriers to the research was the 'newness' to the research participants, these are questions that people have not been asked to consider before. We were asking people to engage with complex issues that, outside of an academic context perhaps, few people are ever asked to think about. They often had to take a big leap in terms of concepts they were comfortable with and it was therefore unsurprising that participants were hesitant and uncertain about the representation of disabled people in museums. However we found that our respondents were, on the whole, very articulate and able to form opinions on these challenging subjects.

8.4.2 Barriers to accessing disabled people for research purposes

The difficulties and complexities of engaging with different audiences and groups that museums categorise as disabled must not be underestimated and were a crucial finding of this research. The challenges presented to accessing disabled people as research participants sheds light upon the limitations of creating categories for research and marketing purposes that do not relate convincingly to how people manage and organise their own lives – or how their lives are managed for them in some cases.

8.4.3 The use of labels – groups must be allowed to identify themselves

Language and terminology are always changing. The labels that individuals and groups use to define themselves are crucial and may be very different to that expressed in the literature. An understanding of the local context is therefore vital for engaging with different groups and respecting that different individuals have different, often radically different, opinions over how they wish to be defined.

“One of the main problems with disabling imagery and disabling attitudes was that they lumped all disabled people together and treated them the same.”¹⁸⁶

For example the Deaf individuals we spoke to were clear about their status as non-disabled people. They saw Deaf cultural identity as a cultural-linguistic minority, with communication being the main difference between the hearing and the Deaf community rather than experiencing a 'lack' of hearing. It is an important political point; Deaf people would like to be recognised as a group in their own right and on their own terms:

¹⁸⁶ Shakespeare, Gillespie-Sells and Davies, 1996:49-86

“What we would really value is some sense that the whole community values, genuinely values diversity and is proud of having a Sign Language subculture within it, that’s the sort of thing that would be great.”

This was confirmed by our experience of contacting the Deaf community using the framework of disability and is also reflected in the experience of Tyne and Wear Museums. They found that Deaf people in the North East did not wish to identify with the term ‘disabled’ or even with the term ‘Deaf’ but wished to be represented as ‘BSL users’ to demonstrate that the common link is their language.¹⁸⁷ This approach has been questioned by those who feel that because Deaf people use the DDA to assert their rights in society they should identify as disabled. However, self-identification by groups is of crucial importance, even if others may find it uncomfortable or challenging.

8.4.4 Museums need to explore how they collude in the social construction of disability

Museums themselves need to identify how their practices in the past and present continue to influence disabling attitudes and stereotypes:

“Through the persistent production of certain images and the suppression of others, and through controlling the way images are viewed or artefacts are preserved, visual representations can be used to produce a view of the nation’s history”¹⁸⁸

This is a history that has excluded disabled people. Commonly recurring stereotypes that see disabled people as pitiable and pathetic, as freaks, as objects of ridicule, as a burden or as incapable can be identified within museum displays.¹⁸⁹ Museum practice continues to reinforce stereotypes that relate to the disabled person as the ‘other’, the conception that they are ‘primitive’ and ‘subhuman’ because they demonstrate characteristics which are the opposite to our conception of a model human being. The museum and its practices evolved largely in the nineteenth century, its master narratives seeking to “enable mastery of the messy and complicated real world”¹⁹⁰ which do not represent the world in which we live at present. Now we live with the ‘other’ and yet museums do not reflect this. Disabled people continue to be defined through language and concepts developed in the nineteenth century, to be represented by the ‘tragic’ or medical model or as curiosities to gawp at:

“I can’t remember where it was, but it was like this special exhibition, and all it had on disability, as it was called then, was pictures of deformed people and models of deformed children and stuff like that, like some freak show. You know, I mean is that what this is about? It’s not about that at all. It should be

¹⁸⁷ Jane Montgomery, museum professionals interview 10/03/2006

¹⁸⁸ Hooper-Greenhill, E., *Museums and the interpretation of visual culture*, Routledge, London and New York, 2000:25

¹⁸⁹ RCMG, 2004

¹⁹⁰ Hooper-Greenhill, 2000:24

contextualised within the fact that this is human experience, you know, not something that's to be looked at..."¹⁹¹

As we have seen in this report, critical theory provides useful tools for understanding how the values and assumptions that underpin these practices, and continue to shape our attitudes, can be deconstructed and understood as contingent in time and place. So instead of seeking to overlay current practices, the potential for reconstruction of how disabled people are presented in museums, with its implications for the past, present and future, is an exciting potential for museums to embrace.

¹⁹¹ Colin Barnes, interview 01/03/2006

Conclusions

Defining disability

- It is others - disability campaigners, charities, governments, museums - who have defined disabled people as a distinct group. Individual disabled people will not automatically relate to these definitions.
- Self-identification by groups is of crucial importance, even if others may find it uncomfortable or challenging.
- Deaf 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.

Making contact

- The difficulties and complexities of engaging with different audiences and groups that museums categorise as disabled must not be underestimated.
- There is a need to recognise the 'everydayness' of disability whereby the margin becomes part of the mainstream.

How far are disability and identity linked?

- The relationship between disability and identity was complex and often directly related to personal experience.
- A political identity is the preserve of a minority. We did not feel that participants in this research study felt a strong identity as disabled people except for those participants from the Deaf community.

Attitudes towards history, heritage and museums

- Our participants took it as 'given' that history was important; however there was not an exact relationship between the value of history and its relevance to the individual. Interest in history was seen as more of a personal choice
- The 'newness' of such research for participants needs to be considered when analysing their responses; this research deals with issues that people have not been asked to think about before nor do they think about on a daily basis

(Mis) Representation of disabled people in museums

- Disabled people are invisible or misrepresented in museum collections.
- Commonly recurring stereotypes that see disabled people as pitiable and pathetic, as freaks, as objects of ridicule, as a burden or as incapable can be identified.
- There was not a single collective viewpoint from our participants, nor were they altogether confident or assertive about presenting the history of disabled people in museums.
- The lack of a strong identification with the political meaning of 'disabled' tended to be linked with a lack of clarity and confidence about how disabled people should be represented in museums.
- For those participants who demonstrated a strong, collective identity, like the Deaf community, there was a greater clarity in terms of the role that museums could play in representing their culture and history.

Addressing the imbalance

- Participants had no models of what museums could do to show the history and culture of disabled people.
- No easy answers have been revealed from our research into how disabled people view the roles of museums in representing their history. The greatest challenge for museums is negotiating between diverse positions.