



Rethinking Disability Representation in Museums and Galleries

Edited by Jocelyn Dodd, Richard Sandell, Debbie Jolly and Ceri Jones

Front cover image: Life Beyond the Label exhibition at Colchester Castle Museum
Photograph by Julian Anderson



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This publication reports and reflects on **Rethinking Disability Representation**, a large scale, experimental project which developed new approaches to the interpretation of disability-related themes and narratives and to the representation of disabled people's lives within museums and galleries.

Copies of this publication, and related resources, can be downloaded from
<http://www.le.ac.uk/museumstudies/research/rcmg.html>

Edited by:
Jocelyn Dodd
Richard Sandell
Debbie Jolly
Ceri Jones

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

Tel: 0116 252 3995
Email: rcmg@le.ac.uk
<http://www.le.ac.uk/museumstudies/research/rcmg.html>

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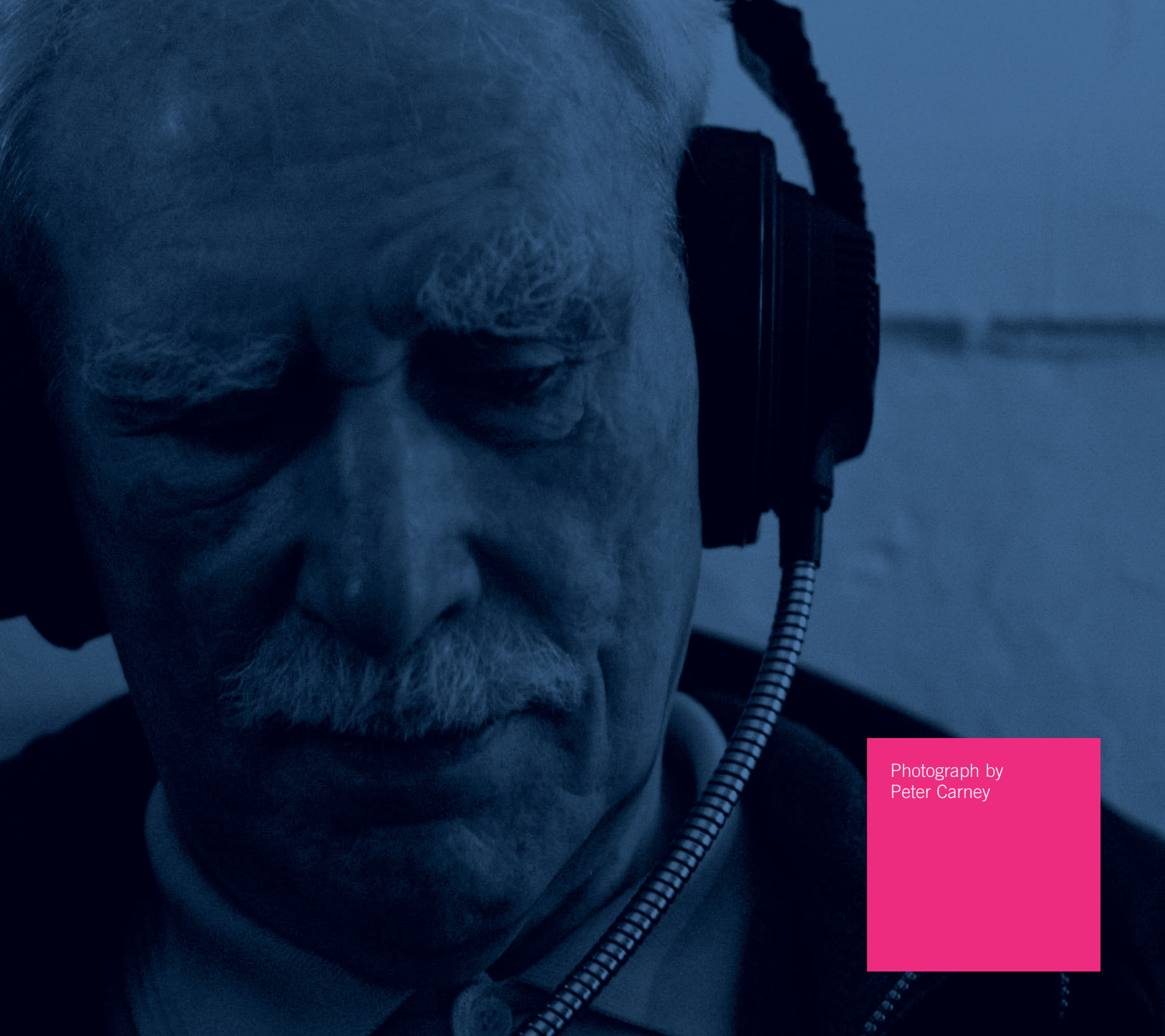
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This publication is also available in alternative formats on request from RCMG



Photograph by
Peter Carney

Contents

The Social Model of Disability	07	Part 2 Museum Experiments	33
Introduction: Rethinking Disability Representation	08	Life Beyond the Label,	35
Part 1 Perspectives on Disability Representation	15	Colchester and Ipswich Museums Service	
Shaping Representation: the Role of Disabled People ..	16	One in Four: Exploring Experiences	
Rachel Hurst		and Attitudes Surrounding Disability,	39
Why Does Representation Matter?	20	Tyne and Wear Museums	
Jackie Gay with Mat Fraser		Lives in Motion: Transport and Disability,	43
Advancing Museum Practice	28	Glasgow Museum of Transport	
Mark O'Neill		Behind the Shadow of Merrick,	46
		Royal London Hospital Archives and Museum	
		Daniel Lambert: An Exalted and Convivial Mind,	48
		Stamford Museum	
		Talking about... Disability and Art,	51
		Birmingham Museum and Art Gallery	
		I Stand Corrected?	
		New Perspectives on Orthopaedic Footwear,	55
		Northampton Museum and Art Gallery	
		Conflict and Disability,	57
		Imperial War Museum London	
		A Whitby Fisherman's Life:	
		'Stumper' Dryden through the lens	
		of Frank Meadow Sutcliffe,	60
		Whitby Museum	

Part 3 Reflections on Practice	63
New Ways of Seeing Collections	
Conflict and Disability, Katie Potter and Sarah Ballard	65
I Stand Corrected?, Rebecca Shawcross	73
Framing the Project	
One in Four, Kylea Little	79
Disabled People's Voices	
Talking about... Disability and Art, Liz Braby and Melissa Strauss	83
A Whitby Fisherman's Life, Jackie Gay and Mark Edwards	95
Countering Stereotypical Representations of Disabled People	
Daniel Lambert, Claire Jacques	99
Approaches to Interpretation	
Lives in Motion, John Ferry	103
A Place for Debate	
One in Four, Kylea Little	113
Challenging Visitors' Perceptions	
Life Beyond the Label, Sophie Weaver and Ciara Canning	117
Conflict and Disability, Katie Potter	124
Behind the Shadow of Merrick, David Hevey	131

Part 4 Visitor Responses	139
General Reactions and Responses	143
Changing Attitudes Towards Disability?	153
Getting Started	164
Rethinking Disability Representation Team	168
DVD – Behind the Shadow of Merrick	169

The Social Model of Disability

The disability studies literature inevitably contains a diversity of opinions and viewpoints but there is nevertheless a degree of consensus around certain principles and conceptual approaches to understanding disability. In particular, the social model of disability has been widely recognised as a key conceptual tool for the advancement of the rights of disabled people. The social model rejects an individualist, medicalised understanding of disability and instead locates the issue (and the need for action) not with the individual (and their impairment) but with society and the barriers which restrict and oppress disabled people. The basis for what has become the social model of disability was a document produced in 1976 by The Union of Physically Impaired Against Segregation (UPIAS) entitled **Fundamental Principles of Disability**.

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS, 1976:3)

There is a large body of literature discussing the emergence and significance of the social model and, whilst its contemporary relevance is increasingly debated, there nevertheless remains widespread consensus on its value as a means of articulating a progressive understanding of disability, as bound up in social context, and the implications this has for advancing the rights of disabled people. The social model of disability was taken as a starting point for **Rethinking Disability Representation** for framing the wide-ranging interpretive approaches used in each of the nine museum projects and repeatedly drawn upon – as the projects evolved and developed – to steer the choice of objects displayed and the tone and content of interpretive materials.

Introduction

Rethinking Disability Representation

Disabled people have often been portrayed within broadcast and news media, literature, advertising and film, in negative ways which rely on a handful of demeaning and dehumanising stereotypes. The prevalence and persistence of this negative imagery as well as the paucity of representations of 'ordinary' disabled people can be viewed as both a symptom and cause of the lack of equality for disabled people. This issue has generated considerable discussion in the field of disability studies and inspired a range of activist initiatives from within the disabled people's movement.

The social model of disability provides a powerful lens through which to challenge and reconfigure such negative representations by highlighting the environmental, attitudinal and social barriers that disabled people face in struggles for equality and basic human rights. Using the social model as a starting point, the Research Centre for Museums and Galleries (RCMG) at the University of Leicester initiated an ambitious action research project which set out to explore – through collaboration, experimentation and evaluation – alternative approaches to representing disability in museums and galleries. A critical feature of the project was the establishment of a 'Think Tank' comprised of disabled activists, artists, and cultural practitioners who played a leading role in shaping the content and tone of the different interpretive interventions that eventually appeared in nine different museums in the UK across 2007 and 2008.

The aims of the project were to:

Uncover material evidence held within wide-ranging collections that could contribute to a broader public understanding of disability

Develop narratives that draw on historical and contemporary material to engage audiences in rethinking attitudes towards disability and open up possibilities for engaging with contemporary, disability-related issues and debates

Evaluate the impact of these displays on audiences, both disabled and non-disabled

Disseminate the findings in ways which could inform mainstream practice in museums and help to develop practitioner confidence in working in these largely uncharted areas.

RCMG and the project's Think Tank worked in partnership with a range of museums. These were of different sizes and types of governance and with different levels of experience of tackling disability issues, working with communities to co-produce interpretation and engaging visitors in debates pertaining to contemporary social issues. The resulting interventions took a variety of forms – displays, touring exhibitions, films and educational sessions – and were tremendously diverse in theme and approach. All museums were accessible and provided information in a range of formats.

Background and rationale

Rethinking Disability Representation (RDR) grew from the findings of an earlier research project, funded by an Innovation Award from the Arts and Humanities Research Board. This project, entitled **Buried in the Footnotes**¹, had investigated the reasons behind the paucity of disability-related narratives and representations of disabled people in museums and galleries in the UK. What material might exist in museum collections that related to disabled people's lives and histories? Why, at a time when museums were increasingly concerned to research and present 'hidden histories', was disability rarely, if ever, considered?

The research identified a wealth of material in wide-ranging museum and gallery collections. However, much of this was in store, not on display. Where objects and artworks were displayed, their connection with disability was rarely made explicit or interpreted to visitors. Representations of disabled people in displays and exhibitions, though relatively few in number, most often conformed to prevalent stereotypes found in other media – in film, literature, television and charity advertising. These stereotypes included disabled people as freaks, as passive and dependent recipients of charity, care or biblical miracle cure; and as heroes who somehow transcend disability by overcoming the challenges presented by their impairments. Depictions of disabled people in everyday life were practically non-existent.

Interviews conducted with curators helped to explain this situation. Many we spoke with were open to the idea of including representations of disabled people in exhibitions and displays but voiced a set of concerns relating to how this might be achieved. Most significantly, we encountered a fear of causing offence, of making mistakes. The history of the freak-show, in particular, appeared to cast a powerful shadow over contemporary practice. In their display of objects related to disability, curators were anxious not to be seen to promote freak-show approaches through displaying 'difference' in ways which might encourage staring or other inappropriate forms of looking. Other display dilemmas emerged during the research which also contributed both to anxiety and inertia. Should we tell (and if so how?) the difficult stories around disability – of asylum history, industrial and war injury and mutilation, holocaust, freak-show history, people's personal experiences of pain and distress? In what circumstances should an object's link with disability be made explicit where it might not otherwise be obvious to the audience? How can the material in collections be interpreted in ways which reflect and incorporate perspectives and insights from disabled people themselves? The research team concluded that further work was needed to develop new ways of representing disabled people that could begin to move practice forward.

Disabled people's voices, experience and expertise

The Think Tank of disabled activists, artists and cultural practitioners, established at the outset of the project, played a key role in the process of guiding and supporting museums in their experimental practice. This group met with staff from the nine partner museums at intensive residential sessions at the beginning, middle and towards the end of the two-year project to exchange ideas and resolve challenges as they arose. This process of collaboration was supported by further work, carried out by each museum, with disabled people at a local level. The role of the Think Tank was to offer constructive criticism, knowledge and advice to museum partners, whilst museum staff developed each of the projects drawing on their collections-knowledge and expertise in modes of display, interpretation and audience engagement.

The central importance of working with disabled people in RDR chimed with recent legislative changes in the UK. The Disability Discrimination Act (1995) followed on from legislation relating to gender and race discrimination introduced many years earlier. Whilst there are differences of opinion on how effective the Disability Discrimination Act has been in alleviating discrimination and inequality, it nevertheless marks an important development in the legislation. In December 2006 the Disability Equality Duty and the duty to produce Disability Equality Schemes with measurable impacts was brought into the legislative framework. Part of this included a duty for public-funded sectors to include disabled people and disability equality into all of their functions and policies from the outset.

These legal imperatives to actively involve disabled people (and organisations run by disabled people) in all issues that affect their lives had consistently been called for by disabled activists for many years. One of the legacies of RDR is a strengthened understanding, within the museum sector, of the importance of this process of genuine collaboration.

Ultimately, RDR set out to explore the role that museums and galleries can play in shaping and framing the conversations which visitors have about disability and difference. Taken together, the nine experimental interventions that were created seek to address the cultural invisibility of disabled people in current museum narratives and to offer alternative ways of understanding disability which challenge negative representations.

The museum staff at each of the nine partner museums, the research team at RCMG and all members of the Think Tank undertook a collaborative journey which set out to explore new ways of working to move practice forward in this largely uncharted territory. This publication contributes to a mapping of that journey by bringing together the experiences and viewpoints of those involved, reflecting on the challenges encountered and discussing the means by which these were tackled. Part 1 presents the views of disabled activist, Rachel Hurst, (a member of the Think Tank) on the importance of working collaboratively with disabled people whilst writer Jackie Gay and actor Mat Fraser consider why issues surrounding representation warrant further attention. Mark O'Neill (Head of Arts and Museums, Culture and Sport Glasgow) considers the potential significance of the project for advancing museum practice. Part 2 outlines the different interpretive interventions developed by each of the nine museum partners involved whilst in Part 3 museum practitioners reflect on some of the issues involved in bringing these to fruition. In conclusion, Part 4 reports on the findings of the evaluation carried out by RCMG to explore the different ways in which visitors engaged with the projects they encountered.

Jocelyn Dodd

Richard Sandell

Debbie Jolly

Ceri Jones

¹ The findings of the research are available online at <http://www.le.ac.uk/ms/research/pub1114.html>



Which model do you follow?

'Which model do you follow?' Part of an interactive display in the One in Four exhibition, Tyne and Wear Museums

Photograph by
Peter Carney

Seeing Things Differently



How I see myself:
A person up with the best. I have great skills.



How I think others see me:
I am happy to sit at a desk with the crowd looking like an average young man.



How I would like to be seen:
Confident, outgoing and able.

Kristopher



How I think others see me:
A person who is on my
police in my garden.



How I would like to be
seen:
A soldier like my dad.

Gillian



How I see myself:
Thoughtful.



How I think others see me:
A person who is clever.

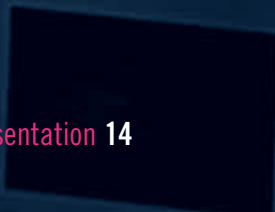


How I would like to be seen:
A person who is able.

Aimee



How I see myself:



How I see myself:

Photograph by
Peter Carney

PART 1

Perspectives on Disability Representation

Shaping Representation: the Role of Disabled People

Rachel Hurst

The United Nations Convention on the Rights of Disabled People, adopted on 13th December 2006, recognises the crucial importance of ‘promoting positive perceptions and greater social awareness toward disabled people’ [Article 8, 2a(ii)] in order to foster respect for the rights and dignity of disabled people. The Convention also stipulates that all public policies and programmes, particularly those concerning disability, should consult with disabled people and their representative organisations.

In the UK, the Disability Equality Duty in the Disability Discrimination Act 2005 (DDA) requires all public bodies to ensure that disabled people are treated equally in the provision of, or participation in, both services and employment. The need to eliminate discrimination, to promote greater equality of opportunity, to promote positive images and participation in public life, is also specifically referred to.

On top of these legal obligations there is a clear moral perspective. Can you imagine a project entitled **Rethinking Women's Representation in Museums and Galleries** that was led by men? Traditionally excluded groups – such as women, black and ethnic minorities, children, older people and those of different faiths – are increasingly evident in images of ‘the public’, and there is a growing awareness that each group should be consulted on the content of those images. Disabled people must be part of this list; images must be included and the content debated.

Despite these broader societal developments, one of the findings from **Buried in the Footnotes**, the research report that preceded **Rethinking Disability Representation** (RDR), was that only 21% of the museums and galleries surveyed had worked directly with disabled people, whilst 52% had displays that included disabled people.

RCMG were keen to ensure the inclusion of disabled people from the inception of the project. Firstly, a Think Tank was convened, with a brief to assist each of the nine partner museums in shaping their exhibitions, advise on difficult issues and encourage positive, creative and empowering images. The Think Tank members – with disabled people in the majority – were professionals with specific expertise relevant to the project.

An initial meeting between RCMG and the Think Tank immediately demonstrated the need for flexible ways of working to ensure the full involvement of disabled people in the project. It was clarified that there were disabled staff on the RCMG team, and that, ideally, consultation with local disabled users of museums and galleries would be an integral part of each project. However it was recognised that museums would be at different stages in their understanding of, and involvement with, issues of disability representation and the institutional challenges involved; therefore a complex and sensitive approach needed to be taken to the project as a whole.

A three day residential meeting between the Think Tank and partner museums followed. This was a great opportunity to review initial ideas and to discuss issues and challenges that were common to all. Most of the museums had complied with requirements under the DDA for physical accessibility but the more rigorous access requirements for visually and hearing-impaired people and for those with learning disabilities often needed considerable development in both understanding and implementation.

Additionally, museums' understanding of definitions of disability and the implications of the social model of disability were varied and challenging, especially for those museums holding medical exhibits or those emphasising one person and their impairment.

The partners were aware of the need for consultation with disabled people but did not necessarily have contacts amongst disabled professionals who had studied disability imagery and had articulated the social model of disability in relation to their own identity and their full human rights. The Think Tank bridged this gap and gave museums the confidence to overcome institutional barriers and fears.

With regard to local consultation, some of the museums had already established formal contacts with groups of disabled people. Colchester and Ipswich Museums Service employed a disabled access officer and had strong links with disabled local people. Tyne and Wear Museums employed several disabled members of staff and had a culture of consultation.

Think Tank members Rachel Hurst and David Hevey visited many of the galleries and museums along with the RCMG team to advise on the progression of specific ideas and plans. We were also able to broaden the perspective of museum staff by alerting them to relevant contacts and supportive material devised by disabled people.

A final residential meeting to evaluate the project illustrated the importance of the inclusion of disabled people in the process. For example Birmingham Museum and Art Gallery felt that the disabled artists involved in their project had brought in a 'critical and engaging perspective' and hoped to develop more work with them in the future; Glasgow Museum of Transport used images showing the vital role of disability activism in the struggle for more accessible transport; Stamford gained the confidence to shape interpretation of the images and objects held by the museum; and the Royal London Hospital Archives and Museum produced an emotive video by David Hevey on Merrick, the 'Elephant Man', using the experiences of people with disfigurements to illustrate disabling attitudes towards them.

We live in a world which is slowly becoming aware of the social construction of disability. The scales are falling – or being nudged – from our eyes, disabled people are full human beings with rights, and one corollary of this is that disabled people must be involved in all matters that concern them; debating, discussing, making choices and taking control over their own lives, and images of those lives. This has not been easy work for any of the parties involved.

Museum partners have had to relinquish some of their institutional and individual power and tackle personal attitudes they may have wished to avoid. All the museums have met these challenges with creativity and commitment. Now the important message – and the involvement of disabled people in that message – can be widely disseminated. As Helen Keller said: **"Ideas make the world we live in, and impressions furnish ideas."** Disabled people's involvement in RDR has ensured that the impressions gained from imagery are based on real understanding and experience.

Who Am I?

Who am I?

We all have many labels, those that we give ourselves and those that we give each other.



'Who am I?' Part of the Life Beyond the Label exhibition at Colchester Castle Museum

Photograph by Peter Carney

...want to be and understood. ...important to ...we are and ...live our lives. No two people are alike. ...we find it so hard to look Beyond the Label. ...if one of them happens to be disability!

This word can be isolating, yet it has to be used to access the support services which can make life easier.

...a funny thing because it categorises people. ...their user because of

Why Does Representation Matter?

Jackie Gay with Mat Fraser

'Representation (noun)... the description or portrayal of someone or something in a particular way or as being of a certain nature'

The New Oxford Dictionary of English

Representation is a tricky business. We all wish to see ourselves, or aspects of ourselves, in the full range of cultural media: film, television, radio, theatre, literature, advertising, dance, art, museums. Art and culture are two of the ways we attempt to understand our humanity, so naturally we want to be part of that, to participate and to recognise ourselves in the portrayals. However, phrases such as 'a certain nature' or representation in a 'particular way' have obvious pitfalls. Everyone will have experienced irritation or frustration when encountering cultural stereotyping: 'chavs', women, Brummies or Scousers – we all have our own examples; and many of us will have felt excluded by certain art forms because our class, culture, or ethnicity is missing or poorly portrayed. Representation is deeply personal and individual and our relationship with how we are represented on the 'big screen' of cultural life is dynamic – changing as we grow personally and in conjunction with broad developments in society.

So now try to map these complications on to the cultural representation – both historical and contemporary – of disabled people. Were we even there, in the past? Are we now? Disabled people throughout the world are engaged with a long and complicated struggle with the way we are portrayed and the meanings attached to these portrayals that include disability as stigma, as a sign of a damaged soul, as being less than human, as dependent, weak, sexless, valueless. Oh yes, and we're invisible, or should make ourselves so. This may appear an extreme interpretation in a culture where (now) a short actor can play a teacher in **EastEnders** and amputee runner Oscar Pistorius thrills us in the Nike adverts but many societies, including ours, have held long-standing prejudices against the disabled and in many parts of the world the basic rights of disabled people still have to be addressed. Representation can reinforce these prejudices or help tackle them; visibility matters and so does positive representation – in China the 2008 Paralympics is seen as an opportunity to change attitudes. Swimming coach Li Ke-qiang took silver and bronze medals for China in Athens. He says that when the Chinese public see disabled athletes succeed in the Olympics, that might really change their image of disabled people. **"In the past... people despised the disabled. They thought they were all beggars, just asking for money."**¹

Oh yes, and we're beggars, blighted by poverty. Think of Dickens, Rembrandt's paintings, de Maupassant's beggar 'always limping... hunger gnawing at his innards'², any number of cartoons and roadside ballads.

So, representation is both a highly personal and widely significant aspect of culture. When considering how best to approach writing this piece I thought that the experiences and insights of individuals would powerfully illustrate the issues: real people equals real lives. At the launch of the Rethinking Disability Representation (RDR) project in 2006 myself and actor Mat Fraser were asked to talk about our personal perspectives on our artistic practice and its development within the broad cultural framework. Mat told of his experiences of growing up as the son of actors, doing line runs and sitting in on rehearsals as a youngster, and how the feel, smell and ways of the theatre felt natural. **"It never occurred to me I wouldn't be wanted when I came back to [acting] as an adult,"** he said, until:

"I went to the auditions for the school play when I was 17, and as I was doing my monologue, I noticed the perplexed, almost terrified, fixed smile of my supportive English teacher as he wrangled with his and society's mindset – that disabled people don't belong on the stage – versus his empathy for a favoured pupil."

Mat was ‘instantaneously deterred’ from an acting career as a result, knowing that audience embarrassment is the death of entertainment. This was 1978 and there were no disabled actors to be seen in British theatre or screen, apart from Sandy on **Crossroads**³.

Mat became a drummer for 16 years, and the rock and roll lifestyle enabled him to ignore and sidestep his impairment. It still nagged, however, that it had been OK, somehow, to flatly refuse him a part in the school play. In 1994, he went to see Graeae Theatre Company, the all-disabled theatre company that he’d heard about but avoided, and witnessed their seminal production of **Ubu Roi** and his life took another dramatic turn:

“Watching a largely non-disabled audience laugh, groan and generally thrill to the bawdy antics of Jamie Beddard [an actor with cerebral palsy] completely revolutionised the way I perceived disabled actors, disability theatre, and my future.”

Representation – seeing ourselves in cultural forms – matters; it changes people’s lives.

Mat auditioned for Graeae and a successful career in disability arts followed. He had an agent, a track record and growing confidence and determination. Time to tackle the mainstream. His agent quickly arranged castings with directors in theatre, TV and film.

“Then, reality bit my ass. The pleasant assurances from well-meaning but naive casting directors – well, either that or they were lying – faded in my memory as no work came along. The naivety of my expectations – a level playing field – came back to taunt me as I realised that I was just NOT going to get mainstream stage work.”

A few years later, Mat appeared in an episode of **Doctors**, and had a small role in a docu-drama as a social worker, the only roles he’d ever played where his impairment wasn’t specific to the character. The one really good lead role he’s had was in a BBC 2 drama, **Etylam**, made possible by disabled producer Ewan Marshall collaring the Head of Drama and complaining about lack of representation.

Mat has engaged with the battle to participate equally in mainstream culture head on, and the situation is slowly changing. **Holby City** features an anaesthetist who is a wheelchair user; but this can be set against endless ‘freak’ documentaries about the boy whose skin fell off. As Mat says:

“We need to see dramas that show how we were part of history, to have our characters reclaimed and given their proper status... to see scenarios of contemporary inclusive living, and all of this needs to be written by someone who has knowledge of our experiences, and finally of course the parts need to be played by disabled actors, who can act.”

In 2003 the BBC, the Broadcasting Standards Commission (BSC) and Independent Television Commission (ITC) commissioned a report **Disabling Prejudice** to examine attitudes towards disability, and the representation of disability on television, by both disabled and non-disabled viewers, and by broadcasting-industry professionals. The report confirms Mat’s personal experience of caution within the industry. Professionals were concerned about perceived audience prejudices, ratings and other possible constraints including the assumption that viewers expected actors and presenters to be traditionally good-looking, and how audiences might respond to more ‘severely’ disabled actors or presenters. Content analysis of the representation also highlighted problems: disability was rarely portrayed as incidental or everyday, and representations were highly clustered among the more easily recognised forms. We don’t appear on cookery or DIY programmes, or gameshows; the programmes with big audiences where incidental occurrences could neatly undermine stereotypes. As one respondent quoted in the report says: ‘I’d really like to be on **The Weakest Link** to show what knowledge disabled people have.’⁴

My own experience is different, but just as illustrative. Mat was born with his impairment whereas I lost my leg above the knee in a car accident in Africa at the age of 30. Everything changed for me, at that one specific moment. The leg was ripped right off – I knew immediately it had gone forever and despite all we hear about grafting pigs’ ears on to mice, we are nowhere near to successfully re-growing or replacing human limbs. Prior to my accident my experience of disabled people was minimal, but subconsciously I must have been aware of their (and since that moment ‘our’) lack of status and visibility because I clearly felt myself sliding irrevocably down a ladder; the ladder of opportunity, status, power, attractiveness, control, right down into a murky pit which I knew nothing about and which I had no means to orientate myself within.

Able-bodied people know, perhaps not overtly, that disability means, or can mean, poverty, struggle, pain, a lack of value. They also know that physical deformity or difference is equated with mental, social and sexual ‘inadequacy’ and even criminal tendencies, and have a deep-seated anxiety that we, given the chance, will take our terrible revenge for the way we’ve been treated. In those early months I felt that if I had any manners I should retire from the world and hide myself away forever.

It wasn’t long before I started to wonder where these ideas had come from. ‘I’, the essential me, didn’t feel any different, but it was clear from the start that I was perceived differently by society. On one occasion I went to a herbalist because I hoped he might be able to help with recurring skin issues on my stump. This man – who was a middle-class, middle-aged, liberal, New Age type – took a cursory look at my skin and then bombarded me with questions about my accident. I ignored them, and told him instead that I was a writer and had just published my first novel. ‘How marvellous!’ he said. ‘You can go through all that and then write a book!’ I insisted that the book was a work of fiction, not a self-help manual or autobiographical ‘triumph over tragedy’ piece, that the accident had not affected my brain, I had a respectable publisher and the novel had garnered favourable reviews, but he wouldn’t – perhaps couldn’t – hear what I was saying and smiled patronisingly – literally saying ‘ahhh’ and patting me on the shoulder.

I had to find out what all this was about, where these assumptions had come from, and as a writer I naturally started with research into representations of disability in literature. In children’s literature writers are fond of miracle cures and ‘second fiddle’ stories, where the disabled character is an inspiration to the main character. **Heidi**⁵ fits both bills. Clara is an ‘invalid’, dependent and resigned to her status as a victim, delighted by bright, lively Heidi from the mountains. When Clara visits the mountain she is encouraged to stand by Grandfather, and then, when Peter the goatherd jealously steals her wheelchair she ‘ventured one step upon the ground and then another’. ‘You have made the effort and you have won,’ says Grandfather. She is cured miraculously by ‘God’s sunshine and mountain air’. What message does this story give? (that disabled people don’t try, that a bit of effort and some mountain air could sort everything out). In **What Katy Did**,⁶ Katy falls off the swing and injures her back. The injury (which turns out to be temporary) is treated as a lesson in life. Katy has to learn the Lesson of Patience, the Lesson of Cheerfulness, the Lesson of Making the Best of Things, the Lesson of Neatness... and the story includes this memorable line, ‘A sick woman who isn’t neat is a disagreeable object’.⁷

In adult fiction, there have been attempts to categorise representations of disabled people,⁸ for example: the demonic cripple (Richard III, Captain Ahab) who is warped by his deformity; the Charity Cripple (Tiny Tim) an angelic victim; the Realistic Cripple, whose disability is neither singular nor significant; and the Survivor Cripple who triumphs against his or her misfortune. Another common representation is the disabled person 'trapped', not only in their wheelchair, but also as the physical embodiment of other problems, human metaphors for dependency or vulnerability.

In film, it is still common for disabled people to be portrayed as monsters and/or criminal – expressing to varying degrees the notion that disability involves the loss of an essential part of one's humanity. Think how many villains in films are hunchbacks or wheelchair users or facially scarred. In contrast, the Survivor Cripple is an image for our times. Individual grit and determination against adversity is used to appeal and inspire. The wounded person is still an outsider but has a role in boosting society's feel-good factor; s/he is the new hero, the super-crip, and the experience of disability is individualised and thus distanced from the 'normal' world.

In my own writing my concern is with creating believable, faceted characters who may or may not have a disability. Incidental occurrence and individual complexity are my bywords. My characters may be disabled but this is not always the focus of the story and is certainly not all that is going on in their lives. As my own experience shows, we have inherited a deadening weight of notions about what disability signifies and these notions will not vanish in a puff of smoke even if I **did** get on **The Weakest Link**. The struggle is long, varied and difficult but the essence of the issue is that the way disabled people are portrayed, in any type of medium, or setting, **matters**. It affects people's lives, and resisting, avoiding or challenging the deeply embedded stereotypes is difficult, important work which can be approached both on an individual and collective basis. We need to tackle the difficult question of how change happens, and the best ways to achieve results over time.

So where does RDR fit into this picture? Along with seeing ourselves represented in film, television and other cultural media, we need to understand our history and our place in the development of the society we now live in. Museums and heritage sites play a central role in constructing social and national identities, and over the last few decades museums in many parts of the world have become increasingly concerned with the challenges of representing experiences and histories outside the 'norm'. Earlier research carried out by the University of Leicester identified that disabled people were either invisible or, to a large extent, stereotyped within museums, and many challenges were revealed, including controversial material held in museum stores. This material tells our stories, but the profession had similar concerns to their colleagues in television – what would the visitors/viewers think?

The project was designed to generate a greater understanding of the ways in which museums can engage with potentially challenging topics and we hope that the project's most significant, long-term impact will be to act as catalyst and resource for change within the museum and heritage sector.

The significance of this cannot be underestimated. Change **has** started, but it is slow to spread and has inherent difficulties especially when we are dealing with deep-rooted attitudes, perceptions, preconceptions and in some cases, outright fear. Cultural organisations and bureaucracies can be cautious, reluctant to tackle 'difficult' subjects. But the benefits of rounded, nuanced representation cannot be underestimated. Mat Fraser tells of being approached by a young lad who asked for his autograph. The boy, who was also disabled, had seen Mat's work on TV and treated him like any other celebrity.

"It was huge to me because I was reminded that without any examples of one's self on TV or in public view, you can feel different, unwanted, weird, unattractive and undeserving ... That was my experience as I grew up, nothing on my life, or my experience."

RDR is also a timely project. Society has progressed and there is more visibility and integration for disabled people, although this is partial and can be tokenistic. A recent DEMOS report⁹ argues that while many legal and institutional barriers to integration have been tackled, the necessary cultural change is yet to come, and that although there is a lot Government can do to change people's attitude to disabled people, they can't do it alone. How we look at, how we perceive disability is crucial to tackling stereotypes, and museums are just one of the rungs on the ladder that disabled people need to help them climb out of the institutions, the murky pits, the barriers erected by society and sometimes their own families and cultures, to realise their full potential for the benefit of all society. Changing perceptions changes lives and all disabled people know this. As Tara Flood, paralympic gold medallist says:

"I had a sudden realisation that everything that's happened was because of how people look at impairment – as different, less acceptable."¹⁰

RDR challenges this viewpoint with real stories from history and contemporary experience.

- 1 <http://news.bbc.co.uk/1/hi/world/asia-pacific/7556652.stm> Accessed 25.8.08
- 2 Guy de Maupassant **The Beggar** <http://www.online-literature.com/maupassant/194/> Accessed 1.9.08
- 3 An early British soap opera; Sandy was the son of the motel owner Meg and was paralysed in a car accident, the first regular paraplegic character in a British soap, see [http://en.wikipedia.org/wiki/Crossroads_\(TV_series\)](http://en.wikipedia.org/wiki/Crossroads_(TV_series)) Accessed 1.9.08
- 4 **Disabling Prejudice, P38**, Available from <http://www.ofcom.org.uk/static/archive/bsc/pdfs/research/disability.pdf> Accessed 25.8.08
- 5 **Heidi**, Johanna Spyr, Puffin Classics, 1995
- 6 **What Katy Did**, Susan Coolidge, Wordsworth Children's Classics, 1994
- 7 ibid
- 8 **The Cripple in Literature**, Leonard Kriegel, in **Images of the Disabled, Disabling Images**, Eds A Gartner and T Joe, Praeger Publishers, 1986
- 9 **Disablism, How to tackle the last prejudice**, Miller, Parker, Gillinson, DEMOS, 2004
- 10 ibid

Advancing Museum Practice

Mark O'Neill

Anyone who has worked in public institutions in the past twenty or thirty years has learned a great deal about disability. For some this was in response to their own commitment to improving access, for others it was a response to pressure from activists, charities and funding agencies, such as the Heritage Lottery Fund; and everyone had to comply with new legal requirements. This process revealed that, contrary to what might have been expected in expert institutions, the institutional learning involved was often difficult for museums. For museums did not have to accumulate or assimilate new information, but learn to see the world in new ways and think about displays and collections within a new paradigm – the relationship between museums and their (potential) audiences. The sequence of learning started with the relatively simple idea of disabled access, i.e. enabling people in wheelchairs to enter buildings. Some institutions have never gone beyond this. The next, crucial, stage was the transition from seeing the person in the wheelchair as an access problem to seeing them as a person with an impairment for whom the museum had created an access problem. Museums had to learn to take responsibility for the problems created by steps even if the physical environment dated back many decades. From this starting point, museums began to learn about other disabilities, other impairments, including much less visible disabilities, learning disabilities and mental health problems. This was part of a wider process of learning about, and responding to, audiences in all their variety and complexity, a process which once begun can never end. Looking back on this process can teach us many lessons about how museums do and don't learn. The indications are that we need new processes for institutional learning in museums, of which **Rethinking Disability Representation** (RDR) is a powerful and significant example.

Learning about the issues of access for disabled people may have appeared to museum staff to be about sympathy or, in the words of the great satirical songwriter, Tom Lehrer, **'being nice to people who are inferior to you'**. It has however always been about the obligations of public institutions in a democracy, obligations to provide services that reflect the realities of people's lives. Democratising public institutions is never complete and each new stage involves changing patterns of thought and work which can be difficult, even for those who are really committed. Democratic gains may appear obvious and quickly be taken for granted – with self-congratulatory hindsight we wonder how people could have opposed the abolition of slavery, the introduction of universal male suffrage, the granting of votes to women, the old-age pension.

But at each of these turning points, the 'next stage' was not so obvious. Every individual (including the slaves and the disenfranchised) had to rethink the assumptions they were brought up with, while those with power had to make choices that many in their social group resisted. And all of this for changes whose consequences were, by definition, unknown. Two hundred years of humane and democratic reform has been accompanied by unintended and counter-productive consequences – from welfare dependency to advertising campaigns which glamorise drug consumption– and this has made identifying the next stage of democratisation more difficult and resistance easier. In the face of the mockery of 'political correctness gone mad' and libertarian arguments as well as genuine difficulties of analysis, the next step only becomes obvious after it has been taken and seen to work.

We are now justifiably wary of sympathy as a motivation for democratisation; however, the capacity for empathy has been and remains an important element of discovering the next stage of democratisation. To be able to imagine that other people's experience is different from yours is an essential trait of anyone working to provide a public service. Recognising that other people may experience the world differently and speculating in imagination what that might be like is, however, only the first step. No one can imagine another's life well enough to develop services for them without involving them directly in that development. This fundamental principle again may appear obvious, but at each time the issue has emerged, staff have felt threatened, that their 'professional' judgement and status is in question. It can also appear as a specific threat to museum workers of all disciplines – curators, conservators, educators and front of house staff. Learning more about an artist, an object, learning new skills or more about a target audience within your current framework is exciting and can be difficult, but essentially it means learning more of the same. As knowledge-workers, staff experience an intimate link between their personal identity and the work they do. To be welcoming to visitors, to present the results of your research or conservation treatment in an exhibition involves elements of your self. This sense of personal engagement is tied up with a sense of (professional) service – to the discipline, to the public, to posterity and the wider society. But it is also tied up with self-esteem, with being an expert, perhaps with being a member of an elite or high status group. Even, or perhaps especially, for staff who embark on democratisation projects and direct learning from the public with enthusiasm and goodwill, the process may reveal gaps in knowledge, and expose some elements of the self to the difficulties of realising that previous assumptions may have been naive, misguided or even prejudiced. True empathy means being aware of the limits of empathy and the need to learn from witnesses. Applied to one's profession it means emotional as well as cognitive learning.

As we move beyond the simplistic understanding that disability equals wheelchairs and access equals ramps, and engage with impairments that are not so visible (and which do not give the illusion of being easy to understand) we face a huge increase in the complexity of how we understand visitors. Learning how the lives of people with physical and mental impairments are affected by institutions providing services requires an in-depth exploration of how those services are experienced and how they need to be modified to be genuinely available to potential users. The need for awareness and the complexity of issues multiply when the question of representation of disabled people's lives within museums is addressed. In a society pervaded by stereotypes and unrepresentative images, it is virtually impossible not to absorb the prevailing perceptions and attitudes. The result of this is that in arenas where society is depicted (television, radio, film, newspapers, magazines, advertisements – and museums) most minority groups have been invisible. Where representation has occurred the depictions have been stereotyped or clichéd. Changing this involves anxieties about 'getting it wrong', along with a need to overcome resistance – often expressed as opposition to 'tokenism' (but often a block to any first step). RDR demonstrated two important things. The first is that there are ways of greatly reducing the risk of 'getting it wrong'. The second is that 'getting it wrong' is part of the expert paradigm in which prestige is based on accurate information. The democratising paradigm recognises that in many situations it is difficult if not impossible to get a right answer and the important thing is for the museum to engage, consult, act and learn.

While the point of the exercise is service to the public and not the internal intellectual and emotional difficulties faced by museums during the learning process, it is vital that these issues are addressed. Otherwise defensiveness, blind spots and poor awareness can keep barriers to services in place. RDR set out to improve services to, and the representation of, disabled people in museums by seeking to create a process that would support organisational learning. Each of the key ingredients of RDR contributed to this process. The individual museums were able to create projects which were most relevant to their collections and target audiences, but also worked in parallel so that museums were able to learn from each other. While most museum staff have colleagues and networks they can draw on, the formal sharing of experience in developing and implementing their projects meant that many of the isolating effects of learning new ways of seeing were greatly reduced. The visits by University of Leicester staff and some of the Think Tank members to individual projects enabled bespoke detailed advice (and encouragement) to be provided in-between meetings.

The Think Tank had both disabled and non-disabled members with a range of expertise in representing disabled people and of communication about disability. Feedback to the projects at each stage helped the projects focus and realise their aims, but perhaps the Think Tank's most important function was supporting the teams in developing their confidence in relation to the authority of the museum vis-à-vis consultation processes. This can be an especially troubling issue for novices in public engagement, where goodwill and a desire to listen can lead to a sense of being overwhelmed with contradictory advice, or to community partners being disempowered by being expected to take on roles which are properly the museum's. Individual and group consultees are experts in their own experience and on how they want to be represented in displays, but the

museum is the expert on communication with the public. Even in an exhibition which enables a group to represent itself in its own terms, the museum, as a publicly funded institution representing society, must take responsibility for the communication of the display and, for example, ensure that the questions that the public would expect to be asked are raised. This is a very different kind of authority from that derived from the expertise of the curator or the education officer and is something that all the participants in RDR had to explore. This understanding also reinforced one of the key points learned by anyone who has engaged with disability seriously over recent decades – that any service improvements put in place for disabled people improve things for all visitors. This is true not just in terms of specifics (labels and signs that are easier for the visually impaired to read work better for all visitors), but of a more responsive and nuanced understanding of visitors in general. It is remarkable in how many museums Victorian assumptions about human psychology linger so that their imagined visitor is a solitary male who passively receives impressions and information and whose motivation to visit is a pure desire for aesthetic experiences or learning new information. The RDR project made clear the importance of increased awareness of and respect for visitors as complex, active human beings with a wide range of intellectual, physical, emotional and social attributes, needs and motivations to visit museums. While this recognition does not reduce museums' authority as expert institutions with responsibilities to disciplinary rigour, it does require them to share authority with and learn from visitors in a joint project of creating meaningful experiences.

RDR came to a conclusion just prior to the publication of **McMaster Review: Supporting excellence in the arts – from measurement to judgement**.¹ Many museum professionals would agree with the report's critique of excessively detailed targets and micromanagement by Government of museums, but the document completely fails to offer an alternative process of accountability, and as such is little more than a bid for professional autonomy, disguised as a commitment to quality. It seems a bit lame for a document celebrating intellectual excellence to claim that it is too difficult for cultural organizations to produce high quality work at the same time as democratising their service by removing barriers to participation in a systematic and planned way. In 2008 even the most powerful professions (including the law and medicine, shaken by major scandals which have made the public less trusting of experts) are working hard to demonstrate how they sustain the highest level of expertise and are simultaneously democratising their relationships with their clients and society as a whole. RDR demonstrates a different way forward for institutions, a different model of excellence in which the cultural expertise of the staff is still vital but is combined with a process of considering the realities of people who have had different life experiences from those of the staff when planning services. RDR represents a genuine step forward in democratising cultural institutions. To take this step museums need commitment, intelligence, maturity and above all courage – the courage to overcome institutional complacency and defensiveness and see themselves through the eyes of others, and the courage to change in response to what they learn about themselves and the world.

¹ Supporting excellence in the arts – from measurement to judgement', 'Department for Culture, Media and Sport, January 2008, <http://www.culture.gov.uk/images/publications/supportingexcellenceinthearts.pdf> Accessed 21.11.08



Copyright Royal
London Hospital
Archives and
Museum, University
of Leicester and film
maker David Hevey

PART 2

Museum Experiments

Photograph by
Peter Carney

Life Beyond the Label

Before you make up your mind, open it...

Life Beyond the Label

Colchester Castle Museum

17th October 2007 – 19th May 2008

Colchester and Ipswich Museums Service

Life Beyond the Label was a temporary exhibition held at Colchester Castle Museum which used objects, personal testimonies, film and artworks to reveal the lives of disabled people in Colchester, past and present. The project aimed to explore current and historical perceptions of disability and to prompt visitors to think beyond the labels often associated with disabled people by making their stories more visible.

To facilitate these ideas, the Museum made a public appeal for objects and stories. This 'Disability Roadshow' gave the public an opportunity to look at some of the objects the Museum had already collected and encouraged people to bring in their own objects, photos and stories. This successful campaign provided invaluable contacts and provided insightful and inspiring objects for the exhibition.

Initially we were offered a great deal of medical equipment and objects, but gradually we began to receive more unusual and unexpected objects, for example a tube of brightly coloured lipstick from Dorothy, who is deaf. She explained that the lipstick helped her daughter, who is visually impaired, to see her facial expressions and thus help them to communicate.

At the heart of the exhibition was a purpose-built cinema space. We commissioned a photographer and sound-artist to work with ten people with a range of impairments to help them create their own multimedia stories. Each person was encouraged to consider how they see themselves, how they feel others perceive them, and how they would like to be seen. This first-person approach proved to be a poignant and powerful way of enabling visitors to engage with difficult issues, break down stigmas and challenge inbuilt perceptions of disabled people.

Many objects were put on open display, for example an old, heavy 1960s wheelchair was displayed beside the lightweight sports wheelchair. Open displays increased physical accessibility and also demystified objects, dissociating them from a medical, clinical context and historical prejudices. An example of this was the door taken from a padded side room in Severalls Hospital. Allowing visitors to touch this powerful item made the object and issues more tangible and the stories connected to it resonate more personally.

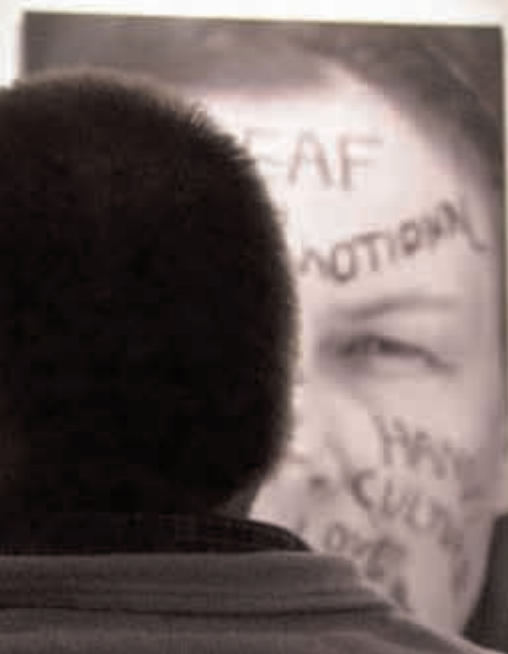
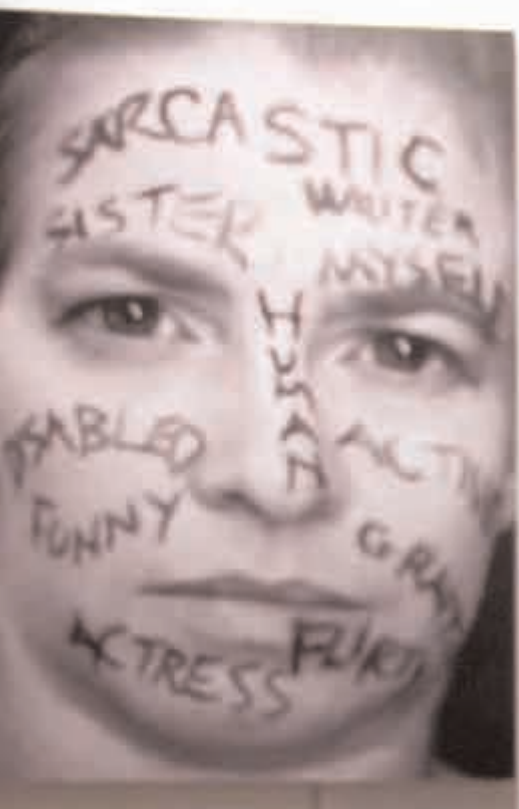
The **Who Am I?** photographs directly addressed the concept of labelling by asking five disabled people to choose a series of words to identify themselves and write them on pictures of their faces. Visitors were invited to use a mirror and write words to describe themselves on the image of their face, thus experiencing and experimenting with the idea of being labelled for themselves.

Technology was used extensively throughout the exhibition to make the displays more accessible and inclusive. The cinema incorporated a loop system and an audio description of the film. All the films used included both subtitles and British Sign Language interpretation. The oral history recordings were available in audio, written transcript and Braille, and tactile representations of images and photographs were available.

Visitors were encouraged to record or sign their comments and views in a 'vox box' video booth. We also had a blackboard comment wall and a web blog on our **Life Beyond the Label** microsite. The use of technology for accessibility proved to be very successful and has accelerated plans to incorporate similar ideas into future permanent and temporary displays.

We hope that the exhibition has helped to develop a new understanding of the everyday lives of disabled people, has triggered discussion, and that the deliberate undermining of preconceptions has enabled new ideas to be absorbed by visitors.

For further details of this project see
<http://www.le.ac.uk/museumstudies/research/pub1129.html>



Text block containing several lines of small, illegible text, likely a caption or description related to the portrait above it.



Photograph by
Peter Carney

One in Four exhibition
at Discovery Museum,
Newcastle-upon-Tyne

Photograph by
Peter Carney



One in Four: Exploring Experiences and Attitudes Surrounding Disability

Discovery Museum, Newcastle upon Tyne:
25th September – 18th November 2007

South Shields Museum and Art Gallery:
15th December 2007 – 1st March 2008

Tyne and Wear Museums

One in Four was a temporary touring exhibition which made use of material from the Tyne and Wear Museums' (TWM) social history, science and industry, and maritime collections dating from the 1800s to the present day. We also undertook some contemporary collecting to build upon existing material, including objects from a local Paralympian, Jim Richardson, and recordings of the life stories of British Sign Language users.

The exhibition took its title from the fact that one in four people in the Tyne and Wear area can be described as disabled (compared to one in five nationally). The exhibition used a variety of formats to encourage visitors to examine the histories and contemporary experiences of disabled people in the region and offered alternative models through which understandings of disability can be explored.

To contextualise the debate, we provided a timeline of relevant policy and legal changes relating to disability rights and equality issues. Local people made films describing the impact of these different policies and practices on their life experiences.


TWM formed a consultation group made up of eight local disabled people who met to debate the key messages of the exhibition. This group was presented with objects from the collection for discussion and it became clear that much of the material in TWM's collections fitted the medical model rather than the social model of disability. Few objects came with provenance. Although this understanding decreased the number of items that might have been used in the exhibition it also highlighted the strongest material – objects which related to particular and individual stories.

TWM opted for a chronological interpretation using objects that represented an aspect of everyday life that reflected attitudes towards disability; whether the attitude was negative or positive. Using a chronological and personal approach also allowed us to show that although circumstances have generally improved for disabled people, attitudes were not easily predictable; in the past some disabled people had positive experiences and today some disabled people are still treated as less than equal.

The exhibition also included responses to the exhibition brief from a group of mental health service users and a drop-in art session to mark World Mental Health Day (October 2007).

The exhibition helped the museum to think about the strengths of our collection related to disability, and examine associated language and concepts. This learning process will feed into the proposed re-display of the **Newcastle Story** in the Discovery Museum. Already, the exhibition has raised awareness of the importance of highlighting the role of disabled people in our history and the Keeper of Maritime History included a section about disabled rowers in an exhibition about the history of rowing on the River Tyne.

For further details of this project see
<http://www.le.ac.uk/museumstudies/research/pub1129.html>

A close-up photograph of a woman with short brown hair and bangs, wearing clear-framed glasses and a silver headset. She is looking upwards and to the right with a focused expression. In the background, a large display screen shows a portrait of a woman and some text, which is out of focus. The woman is wearing a white collared shirt.

Kay describes living independently after many years of living in an institution... part of the One in Four exhibition at Discovery Museum.

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Museums, Culture and
Sport Glasgow



Lives in Motion: Transport and Disability

Glasgow Museum of Transport

18th October 2007 – 31st October 2008

Lives in Motion took a close look at the ways in which transport can enable and disable people's lives. The exhibition used objects from Glasgow Museums' collections to build a broad picture of disabled people's lives and their ability to work, travel and play; along with examining the role of transport in the creation of a more accessible and inclusive society.

This exhibition combined multiple forms of interpretation including text, graphics, audiovisual, audio, an education programme, artists' residencies, film, signed interpretation and internet resources and was aimed at a broad audience of varying ability and age.

The exhibition was introduced by a BSL description of the aims and objectives of this exhibition and then consisted of a series of stories focusing on specific objects. The stories were:

Protest Movement featuring a poster calling for an end to discrimination against disabled people. **"Mary has been waiting years for the bus. Discrimination, there ought to be a law against it."**

Wheelchairs compared and contrasted two very different makes of wheelchair. The first of these could only be used indoors – large wheels at the front made it impossible to traverse raised heights such as kerbs and other obstacles. The second, an RGK sports wheelchair is a good example of recent improvements in design and technology.

Our Journey featured a slide show of captioned photographs, telling the story of Peggy Boyle and Jackie Shields' eventful journey by foot and public transport to test wheelchair accessibility.

Broadening Horizons featured the AC car – locally known as 'wee bluey'. This display featured an audiovisual interpretation by Brian Sweeney relaying his experiences as an AC driver.

Out and About used the Batricar, a powered wheelchair, which provides mobility and independence to many people. The display also included text and graphics panels which included images taken during 'street' interviews.

They Work Again consisted of a J40 pedal car, made by disabled ex-miners in 1966. The company employed only people with disabilities – 60% of them had 'the black lung'. The display was accompanied by historical film footage of the factory. Broadcaster and journalist Ian Hamilton was commissioned to contribute two revealing and amusing stories – **Travel Story** and **Am I invisible?** – of his personal experiences of using public transport as a blind person.

Balance explored the Howie Dove Therapy Tricycle, one of a range of cycles specially designed to make cycling accessible for children and adults with impairments.

The **Lives in Motion** film and events programme featured six films including the **Elegy for the Elswick Envoy** by Nancy Willis; along with an artists-in-residence programme.

Online Resources were designed to be as fully accessible as possible and included **Youtube** and **Flickr** sites to encourage further photographic and video material from participants worldwide.

http://www.flickr.com/groups/lives_in_motion/

The multiple nature of interpretation reflected the complexities of disabled people's lives and we hope that by seeking more creative and responsive methods we have enabled visitors to look again at the objects interpreted.

We aim to continue to develop this methodology to ensure our collections continue to be reflective of disabled people's experiences. Learning and Access remain at the heart of all of our interpretive development and embedded in that is recognition of different learning styles and abilities.

For further details of this project see

<http://www.le.ac.uk/museumstudies/research/pub1129.html>



The challenges of travelling around Glasgow, images from the Lives in Motion exhibition
Copyright Glasgow Museums, Culture and Sport Glasgow

Behind the Shadow of Merrick

Royal London Hospital Archives and Museum

For the Rethinking Disability Representation (RDR) project Royal London Hospital Archives and Museum (RLHAM) created a short film entitled **Behind the Shadow of Merrick**. The film used objects, documents and stories related to Joseph Merrick (more widely known as the 'Elephant Man') to examine issues and attitudes surrounding disability both in the past and in the present day. It prompts the viewer to consider challenging issues including the objectification of disabled people and social attitudes to difference.

RLHAM holds a collection of artefacts left by Joseph Merrick after he lived in rooms at the Hospital. The Museum has always perceived Merrick's story as important, and was strongly aware of the many existing tangential and fictional interpretations of Merrick's life. RDR gave the Museum an opportunity to look at Joseph Merrick's life and story in a different way; back to the facts, back to the man, not simply the medical specimen.

David Hevey, the film-maker, was employed and he immersed himself in the archive material. It was apparent early on that disabled people's voices were missing from this story, and that the stages of Merrick's life echoed the experience of millions of disabled people in the past and present.

Hevey used these stages to create a series of questions for disabled people, through which to frame a response to Merrick and facilitate a wider exposé of attitudes towards disability. The film grew out of the response of disabled people to Joseph Merrick's actual experiences and the stories that emerged were dramatic: Rowen told of how, as a child, she'd known distantly of the 'Elephant Man' and feared that she, too, would end up in a museum; Tina talked of how she, like Joseph Merrick, received visitors in the dark, wearing a hoodie instead of Merrick's veil.

The contributors were filmed handling and responding to objects related to Merrick; his (replica) veil, his carte-de-visite and a poem written by him. The aim was to reveal the truth about disability in a new and challenging way: through visual images and the participants' verbal contributions.



Museum visitors often have some familiarity with Joseph Merrick's story through existing films, books and plays. In these fictional accounts, Merrick is presented as 'other', a pathetic, childlike figure who is saved from cruelty and exploitation by the 'safe haven' offered by the London Hospital.

David Hevey's film is a completely different experience; emotive, touching and simple. By emphasising the veil, the film encouraged visitors to think about why people may hide their faces from the public gaze and what attitudes this exposes in the general public. **Behind the Shadow of Merrick** invites viewers to consider the reality behind the spectacle: the person behind the mask.

Joseph Merrick's story had clear resonance for the disabled participants; challenging museum visitors' perceptions that Merrick is merely an historical figure, long dead, and that his experiences are not something that people live with today. For most non-disabled people Merrick is 'other' and 'the outsider' but for the participants in the film he is the epitome of the insider: he knew the harsh reality of not visibly belonging and of being the eternal stranger.

For further details of this project see <http://www.le.ac.uk/museumstudies/research/pub1129.html>

A DVD of **Behind the Shadow of Merrick** is included at the back of this publication.

Images left: Copyright Royal London Hospital Archives and Museum, University of Leicester and film maker David Hevey

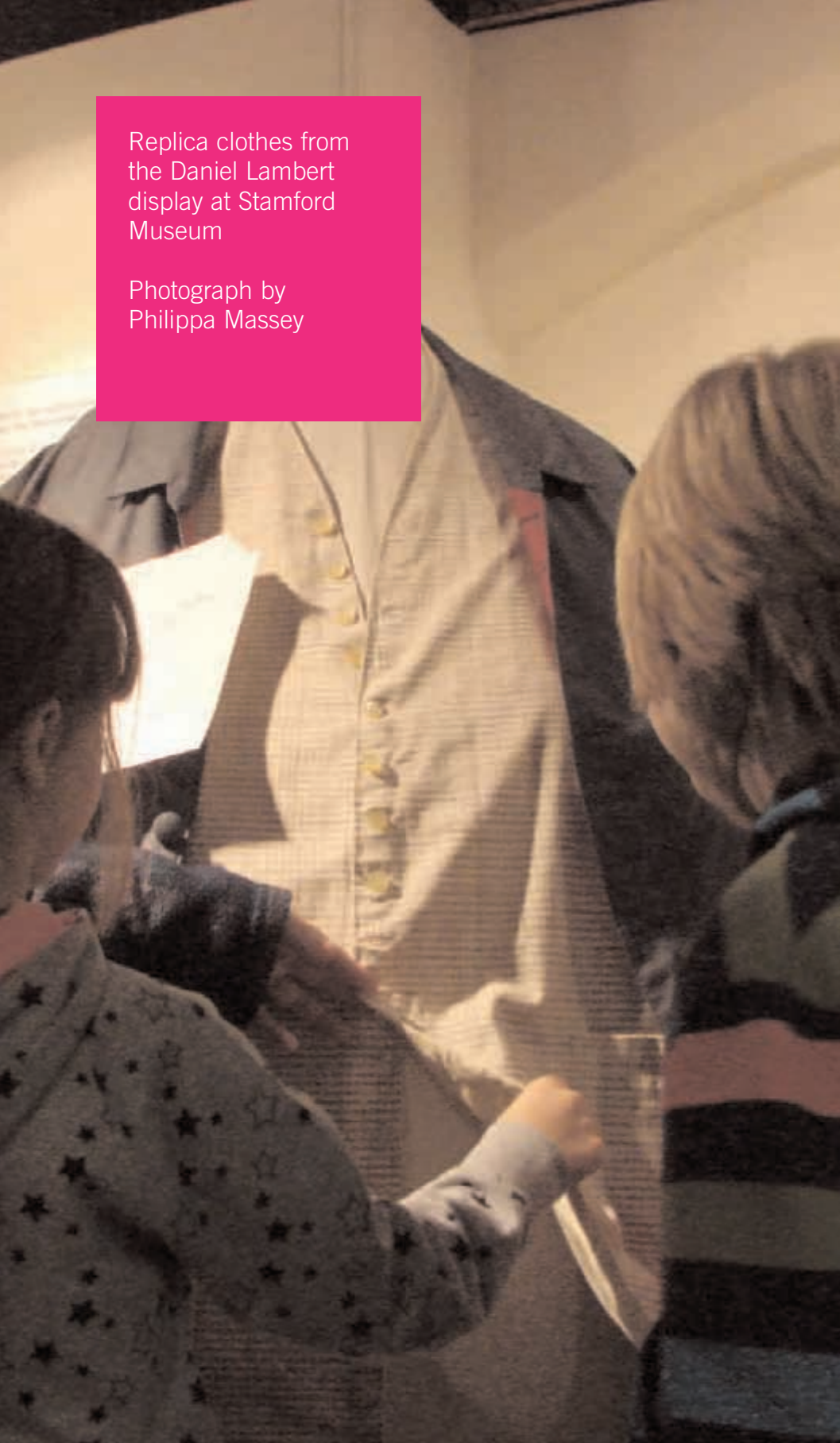
Daniel Lambert: An Exalted and Convivial Mind

Stamford Museum

Stamford Museum's project for **Rethinking Disability Representation (RDR)** involved a re-design of objects and images related to Daniel Lambert, and the gallery now offers visitors a fresh way of understanding the story of Daniel's life and personality. The project focused on how 'difference' is, and has been, perceived and represented, as well as examining the myths built around historical individuals. In his lifetime Daniel was described as having an 'exalted and convivial mind' but he became, after his death, the subject of mythology and exploitation. The new display illustrates how a man revered for his intellect and wit became objectified and represented stereotypically – for his size alone – and seeks to re-present him in a new, more personal, light.

The re-design involved a long consultation process, in order to reassess how material relating to Daniel Lambert had previously been displayed and also to examine the Museum's own attitudes and responses to him. The old (much loved) display had to be looked at honestly and critically to explore how it perpetuated outdated attitudes towards disability. The re-design moved away from the historical, familiar and comfortable, to focus on new content and themes aside from Daniel's size. The archive material was rich and it soon became clear that Daniel had many accomplishments and achievements.

We decided that the following ideas about Daniel needed to be projected: that he was a companionable man with a wide acquaintance who took care in his dress; that he wished to live his life on his own terms, and not be dictated to by the curious; and that all clothing at this time was bespoke, unlike the present day. We decided to display the replica clothes on a tailor's dummy – ready for Daniel's perusal – along with the accoutrements of a tailor's shop, to convey this.



Replica clothes from
the Daniel Lambert
display at Stamford
Museum

Photograph by
Philippa Massey

Focusing on narrative meant we had to carefully consider the meanings of objects chosen to illustrate the new story. We greatly reduced the number of objects – many of the original ones were really just about the shape and size of Daniel, in different forms – and chose those that added meaning. The story of Daniel's life was created (from the evidence) first and then appropriate objects chosen.

In addition to the re-design, there were practical considerations. Many of the objects that were previously on display, including Lambert's clothes, paper advertisements and letters, are now too fragile to be on permanent display. The new display made use of a copy of an original portrait, along with a hat and a set of 'new' replica clothes.

An abiding legacy of this project is the reaffirmation of the affection with which Daniel Lambert is regarded by staff and visitors alike. This appears to equate with the affection and respect he was held in whilst alive and is a telling tribute to the man himself. It also indicates that the new focus on his personality is appropriate, and that the attention given to his size has been an overlay to the true story of the man, built up over the 200 years since his death, when he was no longer able to control the way people responded to him. We hope we have now gone some way to restoring a balance in the many perceptions of Daniel Lambert.

For further details of this project see
<http://www.le.ac.uk/museumstudies/research/pub1129.html>

Photograph by
Peter Carney



talking about...
**DISABILITY
& ART**

Look out for the audio-visual
points located around the art
galleries or pick up a leaflet
to find out more.



Talking about...

Disability and Art

Birmingham Museum and Art Gallery

Talking about...Disability and Art explored and interrogated images of disability in paintings from Birmingham Museum and Art Gallery's displays of fine art. Disabled professionals and artists provided a range of interpretations and responses to paintings, and visitors accessed these via audio-visual points alongside the artworks.

The project focused on eight paintings in the Museum's permanent collections that showed a representation of disability. Some of the works were by very well-known artists but most had not had their connection with disability highlighted before. The paintings included very direct forms of disability representation along with others that explored visual language and the artist's personal experiences.

The paintings were:

The Blind Fiddler by Willem Van Herp, 1600/1700

The Blind Men of Jericho, a copy of a painting by Nicholas Poussin, 1650-1700

The Death of Chatterton by Henry Wallis, 1855-56

The Blind Girl by John Everett Millais, 1856

The Finding of the Saviour in the Temple by William Holman Hunt, 1854-60


Self Portrait by David Bomberg, 1937

Figures in a Landscape by Francis Bacon, 1956

Light Gathers, Several Pleasures, Pastorale, Fields: Distant Sounds by Barbara Delaney, 1995-97

The new interpretations were created through a collaborative process between the project team at the Museum, disabled artists, and other consultants. Previous research had shown non-visitors to the Museum wanted personal interaction within the galleries, and the voice of someone that they could relate to providing information. It was therefore essential that this project focused on integrating 'first person' interpretation into the art galleries, and clearly the voices had to be those of disabled people and artists themselves. The disabled participants recruited to the project were professionals who had a strong interest in art, a good understanding of disability issues and an ability to articulate issues and questions.

Through this collaborative process, four or five new levels of interpretation were created for each painting, with the aim of reaching different Museum visitors by varying the levels and methods of engagement. For example the audio-visual point for Millais' **The Blind Girl** offered visitors five different recordings to listen to:



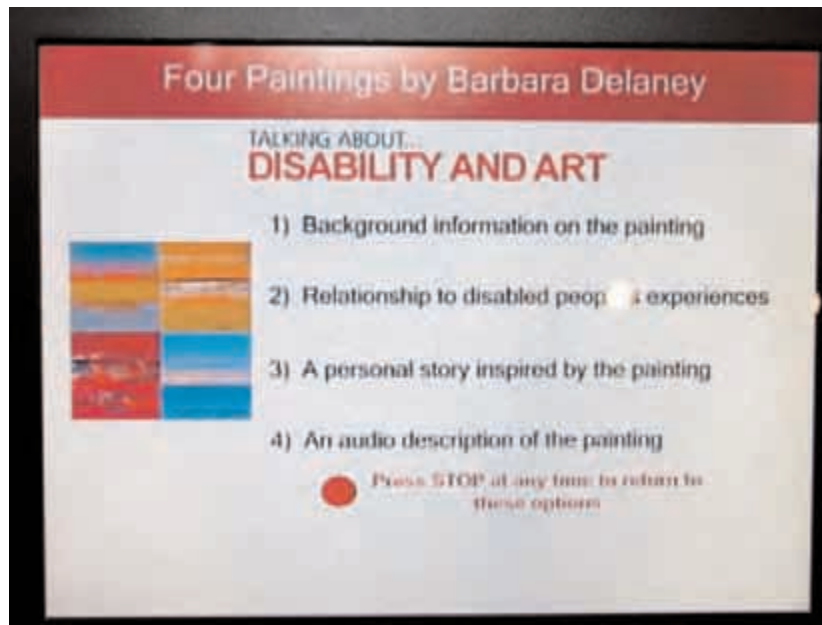
- Background information on the painting from an art curator
- Interpretation of how the painting relates to disabled people's experiences
- A personal story inspired by the painting
- A poem about the painting
- An audio description of the painting.

The content of the interpretations addressed the painting's links with disability and contemporary disability experience. Key themes which emerged were stereotyping and discrimination, the use of visual language (for example depicting emotions through artistic technique) and shared experiences.

The project created a permanent outcome, focused on disability. This has created a far-reaching legacy, for example disability has now been highlighted more clearly within the Museum's Collections Policy revisions. The Museum has also continued to develop this broader approach to interpretation and use of participatory methods to highlight and explore diversity.

The innovative and provocative series of interpretations woven through the existing painting galleries used disabled people's voices to provide new, often challenging, ways of looking at the works on display.

For further details of this project see
<http://www.le.ac.uk/museumstudies/research/pub1129.html>



Visitors can choose from a selection of commentaries from Talking about... Disability and Art
Photographs by Peter Carney



They're Actually Trendy!



I Stand Corrected!

Orthotic shoe inserts

Orthotic shoe inserts

Orthotic shoe inserts

Orthotic shoe inserts

Orthotic shoe inserts



My S...



Photograph by
Peter Carney

I Stand Corrected? New Perspectives on Orthopaedic Footwear

Northampton Museum and Art Gallery

This temporary exhibition explored themes around fashion and footwear, using oral testimonies from orthopaedic-shoe wearers and others whose choices of fashion can be limited to specially made footwear. The project encouraged visitors to look differently at Northampton's renowned shoe collection; to see the often surprising similarities between high fashion and orthopaedic footwear and also to consider the wider implications of the differences between them. Visitors were prompted to consider their own experiences and views of footwear and function through a range of shoe types and media. The project aimed to engage visitors in debates about wider issues of identity, choice and control for those considered 'nonstandard' by mass manufacturers. Elements from the completed temporary exhibition have now been incorporated into the Museum's existing permanent displays.

Northampton Museum is home to probably the largest footwear/shoemaking collection in the world. Within the collection of twelve thousand shoes there are approximately sixty examples of orthopaedic footwear dating back to the 18th Century. As a result of historical collecting practices most of the orthopaedic examples have no personal story or history attached to them.

As the main focus of the project was to highlight the views and experiences of orthopaedic-shoe users, an appeal was placed in the local paper and an article included in the **Ability Northants Newsletter**. The project was also presented to members of Northampton's Disabled People's Forum. Seven orthopaedic-shoe users made contact and were prepared to be interviewed. Extracts from their interviews were used to form the main body of the text. The text formed questions for the visitor backed up with personal quotes, with the aim of challenging the visitor to think about issues such as choice and fashion.

The exhibition also contained a section on the history of orthopaedic-shoe manufacturing, including interviews with two orthopaedic shoe makers. An opportunity was also created for some contemporary collecting. We were able to collect some of the footwear worn by those interviewed, and purchase several pairs of shoes that highlighted the parallels in style between modern designer/fetish footwear and that of orthopaedic-shoes.

The biggest personal challenge of this project was to think outside the 'shoe' box and not create simply an exhibition on shoes. In the past our exhibitions have been very much subject-based – shoes from a particular manufacturer, wedding shoes, shoes from India or people's creative responses to the collection. **I Stand Corrected?** created wholly different challenges for both curators and visitors.

To facilitate this change of approach the exhibition's content was split into three flexible themes: fashion, function and historical context/makers. All three themes were strongly linked with personal experiences and opinions.

It was important that the shoes were used as props rather than stand-alone objects. This was not an exhibition about shoes per se, but actually about the views and experiences of the people who wear them; a new mindset for the Museum.

Visitor feedback has confirmed that reading people's own experiences was what made the exhibition powerful, and that the display challenged assumptions about disabled people. The project has given the Museum confidence to be more open and flexible in thinking about future exhibitions and projects, to consider new approaches to the subject matter.

For further details of this project see
<http://www.le.ac.uk/museumstudies/research/pub1129.html>

Conflict and Disability

Imperial War Museum London

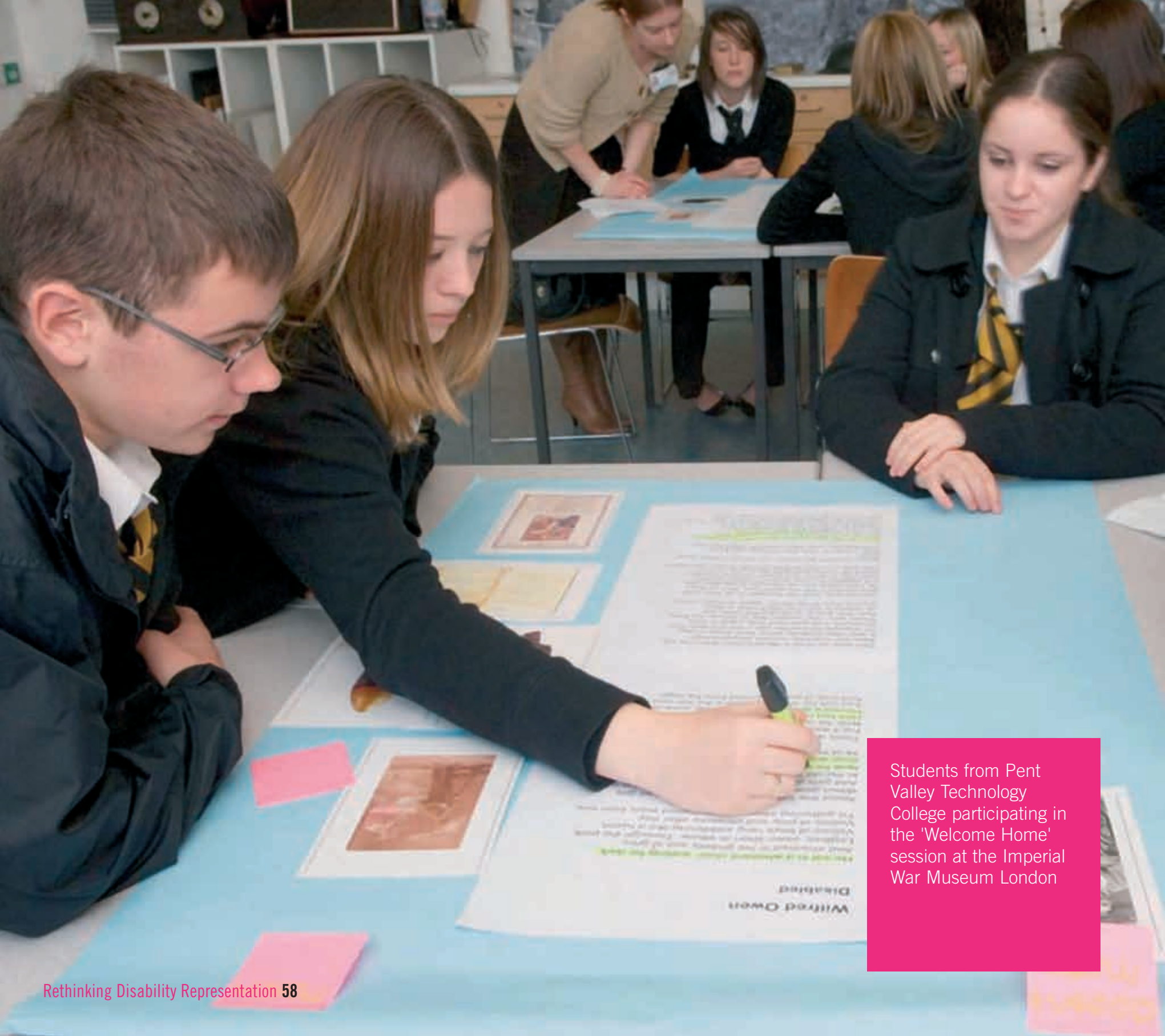
Conflict and Disability consisted of a series of educational sessions for secondary schools utilising the collections and teaching expertise of the Imperial War Museum (IWM). Each session drew on multiple themes including attitudes to disability, wartime employment, policy and rights issues with the aim of illuminating the different relationships between disability and conflict. Aims were to encourage participants to question and perhaps reassess their own attitudes to disability and to investigate new approaches to using museum collections in relation to disability.

The sessions, targeted at Key Stages 3 and 4 groups, were:

Welcome Home: students explored archive material relating to disabled veterans' experiences returning after the First World War, and compared this with the views expressed in Wilfred Owen's poem **Disabled**.

Disability Rights: students examined issues of disabled people's rights. Led by Graeae (a disabled-led theatre company) students became Disability Discrimination Act 'Inspectors' and assessed the Museum's public spaces. Following activities at IWM London, students went to the Houses of Parliament to meet their local MP and discuss the legislative process.

Necessity Breeds Invention: students explored their personal reactions to disfigurement through the story of Jack Toper, a Second World War airman treated for burns by pioneering plastic surgeon Archie McIndoe, and therefore a member of the 'Guinea Pig Club' – a social and support group formed by McIndoe's patients. Following the sessions at IWM London, students went to the Hunterian Museum to find out more about the development of surgical instruments and medical equipment and how they were used to treat injuries sustained in war.



Students from Pent Valley Technology College participating in the 'Welcome Home' session at the Imperial War Museum London

The War on Nerves: Students researched evidence of mental and emotional impact of conflict, using letters and oral history testimony, in order to curate an exhibition about the impact of war on individual soldiers. Gulf War veteran Allen Parton contributed to this workshop.

All sessions were founded on engaging young people with issues about disability through working with IWM collections items. All IWM education sessions use direct engagement with collections, however **Conflict and Disability** added to this practice by assessing or reassessing the items in the light of the social model of disability.

The project leaders made an especial effort to raise awareness of the **Conflict and Disability** project, within and without the Imperial War Museum. An example is the meetings held with the **Their Past Your Future** project team who were developing a DVD resource distributed to all UK schools in 2008 to mark the 90th anniversary of the end of the First World War. Further to these meetings collections items relating to disability were included in the resource plan. Stories of disabled soldiers were also included in the major exhibition **In Memoriam** at IWM London.

The **Rethinking Disability Representation (RDR)** programme has heightened awareness of, and confidence in addressing issues around, disability in a national museum setting. Working hard to raise awareness of the project has also fostered a determination to maintain this and extend the work where possible, e.g. **Conflict and Disability** sessions will be delivered as part of the IWM North education programme in 2009.

The national scope and gravitas of this RCMG-led programme, with the practical impetus provided by additional funding, has made RDR a significant part of the IWM learning programme in 2008 and beyond.

For further details of this project see
<http://www.le.ac.uk/museumstudies/research/pub1129.html>

A Whitby Fisherman's Life: 'Stumper' Dryden Through the Lens of Frank Meadow Sutcliffe

Whitby Museum

This display focused on the life of Robert Dryden, known locally as 'Stumper'. Robert was a 19th Century fisherman and amputee in Whitby. The display used the photographs of Frank Meadow Sutcliffe along with historical documents to bring Robert's story to life, aiming to challenge contemporary conceptions of disabled people's economic role and status historically. Examining Robert's working life and role in the fishing community of Whitby revealed new perspectives on the power of the historical image to enable rethinking about disability.

The Museum holds copies of photographs taken by renowned Victorian photographer Frank Meadow Sutcliffe, five of which feature Robert Dryden. Stumper and the Dryden family feature in many of Sutcliffe's photographs and through these family and work groupings Stumper is shown to be integrated within his family, community and working life. It is rare to find the 'incidental' occurrence of disabled people in historical material and Sutcliffe's depiction of Stumper's ordinary life contrasted powerfully with the way the historical lives of disabled people have been displayed – or more often ignored – in museums more generally. Robert Dryden was 'just another fisherman' photographed in the context of his normal life and the depictions of him resist all stereotypes; he was not photographed in any medical context and his disability is not singled out or treated as abnormal.

The Dryden family still live in Whitby and provided a family tree and memoir which included specific memories of Robert 'Uncle Bob' Dryden. We also investigated historical maps and other archive material such as newspapers, the **Whitby Directory**, census returns, dispensary records, historical records on Whitby town and the Church Street area, and the fishing industry, to build up a narrative of Stumper's life. We were keen to ensure that the text accompanying the photographs made the link with disability in a natural narrative way and this was achieved by recounting the story of

Robert's accident and amputation with equivalent emphasis on his subsequent working life as a fisherman. Robert's disability is presented as a fact – and the surviving accounts from his descendants treated the matter in much the same way.

The Museum identified an existing Victorian display case for this display and the designers 'Objectives' were contracted to produce the material. Whitby Museum does not use a lot of labelling or interpretation on its material, so to keep the display sympathetic to the feel of the Museum we decided to keep the display 'image rich' – Sutcliffe's pictures fit in perfectly with the Museum's aesthetic – and then use questions and quotations to stimulate ideas around disability. A descendant of Robert Dryden, Maureen Eves (great-great-niece), agreed to read the text for the audio description, which enabled the project to utilise both a local voice and a member of the remaining Dryden family for the reading.

The project also produced accompanying educational and interpretive material comprised of extended text leaflets, which explore the context of Stumper's life in more detail, along with the connections with wider issues of disability representation.

This project can act as an example to other museums of how high-quality, innovative work around disability can be developed from a small number of objects whilst still being rooted in the locality and character of the museum.

For further details of this project see
<http://www.le.ac.uk/museumstudies/research/pub1129.html>



Robert 'Stumper' Dryden
Photograph by Frank Meadow Sutcliffe
Copyright The Sutcliffe Gallery: www.sutcliffe-gallery.co.uk

Photograph by
Peter Carney



PART 3

Reflections on Practice

New Ways of Seeing Collections



Left: Ex-Sergeant T Phillips working a lathe to make artificial limbs for others during the Second World War, c.1944

Photograph courtesy of the Imperial War Museum, London. D17829

Right: Limbless First World War Veterans at Roehampton Military Hospital

Photograph courtesy of the Imperial War Museum, London. Q108161

Conflict and Disability

Imperial War Museum London
Katie Potter and Sarah Ballard

This account outlines the new ways of seeing the Imperial War Museum's collections which were stimulated by the **Conflict and Disability** project and as an example, uses the research, development and delivery of the **Welcome Home** session developed for schools.

Welcome Home is aimed at students in Years 10 and 11. It explores the experiences of soldiers returning home from the First World War who had acquired an impairment as a result of their service. Cohen states that 755,000 British and Irish men were 'permanently disabled'¹ by their service in the First World War – what future did they face?

In common with all IWM London schools sessions **Welcome Home** uses the education department's handling collection and draws on material from across the Museum's collection including Art, Documents, Film and Photographs. However, the approach taken to using the collection differs from existing schools sessions in two key ways.

Firstly, **Welcome Home** saw a shift of emphasis in collections research and selection – from the conditions faced during conflict to a focus on the legacy of war – in particular on those who survived rather than died. For the first time, in a schools education context, research was specifically focused on uncovering evidence of disabled veterans' experiences in the collections.

Secondly, the social model of disability informed the way we looked at and interpreted the material we discovered. This model, developed decades after the First World War, argues that it is not a person's impairment or condition that prevents them from making progress in life, but that the major disabling factors are the attitudes and barriers that society puts in their way. Using this model made us constantly question how disabled people were represented in the collections material that we uncovered. It also emphasised the importance of reflecting the diversity of disabled people's experiences as far as possible in the session whilst retaining historical accuracy.



Artist: Abben
Don't Pity a Disabled Man
lithograph on paper
762 mm x 514 mm
IWM PST 13211
Collection Imperial War Museum.

Every effort has been made to trace the copyright holder and gain permission for use of this image

Handling collection

We began by re-interpreting the First World War artefacts in the education department's handling collection, intending to draw out the 'hidden histories' of disabled people's experiences connected to them. In some ways this was a frustrating process as many of the items in this collection have little provenance and we did not want to 'invent' stories for them. However, we could see and present these items in a generic way in terms of the injuries that shrapnel, trench clubs and grenades could cause and link these to images of soldiers with amputated limbs or facial disfigurement. Indeed many of the students who handled the artefacts commented on their potential to injure and maim.

Art

Research in the art department uncovered posters produced by charities working for disabled veterans. Using these posters in the session was a shift away from the recruitment posters used in existing sessions. As one student succinctly put it: **"You always see posters from the beginning of the war, never from the end."** The posters communicated the need for post-war employment. One produced by the YMCA states **'Don't pity a disabled man, find him a job'**. Posters also highlighted the relationship between the public and disabled veterans. A poster produced by the Royal National Institute for the Blind depicts a veteran using a cane and states **'Blinded for you'**.²

Documents

Documents provided evidence of disabled veterans writing about their own lives rather than these lives being represented by the public and private agencies who worked with them: letters from Lieutenant Butlin detailed his treatment for shellshock at Craiglockhart Hospital and frustration at being discharged from the army; a handpainted certificate belonging to Henry Williams stating that he **'Served with honour and was disabled in the Great War'** was discovered tucked into the back page of his typed memoirs. Consultants and veterans we worked with highlighted different ways of 'seeing' these documents. The **Disabled Soldier's Handbook 1918** contained a table detailing pensions provisions for different percentages of 'disablement'. But how accessible was this information for soldiers with a visual impairment? Veterans drew parallels between pensions in 1918 and struggles to increase pensions for ex-service people with impairments today.

Diaries and letters reflected the men's impairments as one part of their identity meshed into stories of war service, day-to-day life, relationships and employment. However, many of the documents we discovered did not contain an accompanying photograph or enough detail about a person's life before and after the war to help engage students in the individual's story.

Film Archive

Reassessing or ‘seeing’ collections material in light of the social model of disability was at times challenging. One of the main aims of all the sessions was to contest negative stereotypes of disabled people; however, collections material frequently reinforced the medical, not social, model of disability. (This model locates the ‘problem’ of disability within the individual and sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from impairment.) The Film Archive contains film of shellshocked soldiers at Netley and Seale Hayne Hospitals, reflecting this medical model. The film highlights the soldiers’ symptoms including hysteria, disorientation, delusion, limb paralysis and loss of speech. It emphasises how quickly these symptoms could be cured by treatment (reflecting the doctors’ need to get future funding from the Government). This led to debate between education staff and teachers invited to a focus group about the most appropriate way in which this material could be shown to students.

Despite the emphasis on the men’s condition and rehabilitation, when presented in conjunction with other sources, the film can be used to reflect the lasting effects on the participants of the horror and stress of war. But it does leave voices unheard and many questions unanswered. Who were these men? Did they give their consent to be filmed? What happened to them in the years after their treatment?

Ultimately the film was not used in **Welcome Home**, but in the two-day workshop **War on Nerves** where the context in which it was filmed and the changing attitudes to what is now seen as post-traumatic stress disorder could be explored in more depth. In the **War on Nerves** session we were able to use oral testimony from the Sound Archive. Here students listened to veterans describing their experiences of service-attributable impairments, including shellshock. In order to engage students with the collection and help them to see the complexity of individuals’ experiences Allen Parton, a Gulf War veteran, campaigner and wheelchair user discussed his post-conflict experiences with the young people.

Photograph Archive

Research in the Photograph Archive uncovered images that showed the experiences of soldiers on returning home, not just in the trenches of the Western Front. Many of these photographs came from Queen Mary Hospital, Roehampton, an institution set up to fit men with artificial limbs and train them in their use. Nancy Willis, from the Think Tank, highlighted the emphasis on rehabilitation reflected in the Photograph Archive collection. Do these images reflect a desire for a return to ‘normalcy’? Between 1914 and 1921 over 41,000 men lost at least one limb as a result of their injuries, so we felt it was

important to use the photographs in the session, often including the original caption to reflect attitudes at the time they were catalogued. However, the captions gave little contextual information about who the men were, how they felt about their impairment and what happened to them in the future.

The photographs can be seen in different ways and indeed students in the **Welcome Home** session reacted in different ways to the images. Do they show the impact and waste of war? The efforts made by disabled ex-service people to get on with their lives when they returned home? Can they be interpreted as recording the Government provision for veterans whose wartime injuries were perhaps perceived as a badge of courage, a symbol of patriotism? Are the smiles forced or real? Are the men figures to be pitied?

How was the collections material used in the session?

The differing opinions expressed by the students about the photographs reflect a principle aim of **Welcome Home**: to encourage the students to see the collections material in new and different ways throughout the course of the session. At the beginning of the session the students were presented with a selection of evidence from the collections and asked to choose items which they felt most strongly conveyed the impact of war on the individual. We hoped they would respond on a personal level to the collections material. There was no right or wrong answer, just the opportunity to choose the items that made the most significant impression on them.

In a further schools education session, poetry and collections material were integrated into the material to encourage students to interrogate representations of a disabled soldier's future and challenge interpretations. A film clip of a 1960s reading of Wilfred Owen's poem, **Disabled**, was used. The poem portrays the future of a First World War veteran **limbless and sewn short at elbow**. At the end of **Disabled** Owen predicts:

**Now he will spend a few sick years in institutes,
And do what things the rules consider wise,
And take whatever pity they may dole.**

The students were asked to revisit their chosen items and think about how they supported or contested the future of the disabled soldier represented in the poem, adding their own interpretations of the poem and the collections items. As the students were working in groups there was often debate about the meaning of a particular photograph or poster, stimulating new ways of seeing the collections material.

One photograph which created much debate depicted two apparently cheerful veterans, with amputated limbs, in the grounds of the 4th London Hospital with the caption “Are we Downhearted?” To some students the veterans were genuinely happy and cheerful and proud of their war service.³ Other students felt that the men’s smiles were just for the cameras and masked depression.⁴

By creating the opportunity for students to debate the meaning of the photograph in relation to the poem, the complexity and difference of each disabled soldier’s experience could begin to be touched upon, despite the fact that the soldiers’ true experiences remain unknown.

Once the activity was completed it was clear that the majority of students interpreted the collections material in a way which did support Owen’s representation. However each group had selected at least one item they felt told a different story to the future of disabled veterans as institutionalised, unemployable and pitiable.

To conclude the session we used film and photographs of veterans with a different experience to the soldier portrayed in Owen’s poem. The need to reflect diversity and complexity of experience made us actively look for stories which challenged Owen’s representation, whilst always being mindful of historical accuracy and balance. We focused on soldiers with impairments who returned to everyday life, to family and employment. The students watched a film clip of 93 year old Fred Taylor (whose left leg was amputated one week before the end of the First World War) talking about his life after the War including his 60-year marriage.

For the first time in a First World War schools session we drew comparisons with the experiences of veterans returning home from contemporary conflicts. We showed photographs of Allen Parton, a Gulf War veteran and wheelchair user. Collections material included film from the **Back to Work** exhibition of 1944 depicting disabled soldiers working in wartime factories. The exhibition was opened by Ernest Bevin who declared **“The right of every disabled man for an independent livelihood”**.

One 15 year old student’s response card read:

“I already had a good understanding of the type of disability suffered by soldiers but it has been interesting looking at the changing attitudes between the wars. It has been a reminder that it is not just about soldiers in the past who are no longer with us.”

We found that using the collections in this way created new opportunities in school education sessions – using the Museum’s collections as a means of promoting discussion about contemporary issues. In addition to reflecting on disability issues the students were asking questions about why people go to war and what, if anything, the state and its citizens ‘owe’ service men and women for their ‘sacrifice’. Seeing the collections in new ways has led us to see existing sessions differently and we now intend to integrate the new collections material uncovered into these sessions. The importance of doing this was underlined by one 15 year old student who wrote on the pupil response card:

“yes it has changed the way I think as I didn’t think there [were] so many people being disabled through war, as you don’t hear of them, just the dead.”

Furthermore we hope to continue to work with veterans with impairments in sessions to ensure disabled people's voices are heard.

When King George V opened the Imperial War Museum at Crystal Palace on 9th June 1920 he said:

“To us it stands not for a group of trophies won from a beaten enemy but as an embodiment and a lasting memorial of common effort and common sacrifice...”

The research, development and delivery of **Welcome Home** stimulated new ways of using the collections to tell the story and analyse the legacy of that sacrifice.

1 Deborah Cohen **The War Come Home** 2001, p193 University of California Press

2 Whilst it could be argued that these posters reflect society’s awareness of the needs of disabled veterans Cohen argues “Charity was no substitute for rights”. Deborah Cohen **The War Come Home** 2001, p190 University of California Press

3 Cohen argues that “..the portrayal of ex-servicemen as unfailingly cheerful reflected the need for the public to think ‘no matter how badly injured, the war’s casualties did not regret their sacrifices’”. Deborah Cohen **The War Come Home** 2001, p130 University of California Press

4 As Cohen states: “There were many others for whom helplessness, institutional life and separation from their families proved intolerable. They got drunk and violent or retreated into an embittered isolation.” Deborah Cohen **The War Come Home** 2001, p130 University of California Press

New Ways of Seeing Collections



Orthopaedic shoe.
Copyright Shoe Collection,
Northampton Museum and Art Gallery



Photograph by Peter Carney

I Stand Corrected? New Perspectives on Orthopaedic Footwear

Northampton Museum and Art Gallery
Rebecca Shawcross

Northampton Museum and Art Gallery is home to probably the largest footwear / shoemaking collection in the world. It is also a 'Designated' collection (The Designation Scheme identifies the pre-eminent collections of national and international importance held in England's non-national museums, libraries and archives, based on their quality and significance). Within the collection of twelve thousand shoes there are approximately sixty examples (mainly singles) of orthopaedic footwear. The earliest example dates to the 18th Century, though the bulk of the collection can be roughly divided into two date-specific categories, 1900 – 1920s and 1950s – 1970s. What examples we have were collected a number of years ago and so there are few, if any, modern examples.

The orthopaedic shoe collection is largely typological as is the bulk of the main collection. Past collecting (and to a large extent the current parameters for collecting) has concentrated on building up a collection that showcases particular styles, designs and individual makers / manufacturers. This is not specific to the orthopaedic collection, but applies to many of the shoes throughout the collection. The breadth of the collection in terms of styles, design and manufacturers combines to give the collection its great strength, but as a result of this type of collecting most of the orthopaedic examples have no personal story or history attached to them. We don't know who wore them; at most we know who made them, and when.

In light of the project's aims we were faced with considerable challenges. In simple terms all we really had were the shoes. So at the very start of the project the initial thought processes involved were very difficult. How do we get that personal connection and resonance back into the collection when dealing with a very specific and, what seemed to be at the time, a very narrow and tightly defined collection? And what route could we take that would successfully combine people's own stories and experiences with the need to challenge and engage the visitor?

What we needed was to create an opportunity for those people who wear orthopaedic footwear to voice their own experiences and opinions, a voice which, in turn, would directly engage the visitor to think about and question the representation of disabled people in society.

There were three main interwoven challenges. The first was to focus on trying to get people's personal experiences not only connected to the collection, but to form the lynchpin of the exhibition. The second was to use these personal experiences coupled with the shoes to engage the visitor in thinking about the representation of disabled people. The third was to think outside the usual 'shoe' box to create an exhibition quite different to our usual shoe shows.

The fundamental element of the exhibition was to focus on people's personal experiences. We appealed locally for contributors and were contacted by seven people who wear orthopaedic footwear who were willing to be interviewed. Their candid interviews revealed a wide range of issues and experiences. These included what they feel like when wearing such footwear, now and as a child, what they perceive others think, the attitudes of medical personnel, their own expectations of what they feel they are entitled to, what other people feel they are entitled to and the reality of the lack of choice available. Interviewees also talked about how, in many cases, their impairment has impacted on their life, how they relate to the world, how the world relates to them and the strong opinions they have as a result.

The contributors' experiences formed the heart of the exhibition. A large number of very personal and individual quotes were used to illustrate not only what the shoes are like to wear, but they also highlighted and explored what it is like to be disabled. In some cases the participants talked directly about some of the shoes on display. Mr England stated about his boots: **"They're ugly boots, but they do the job."** It was this personal voice, not heard before, that not only created a new way of looking at the objects, but also the way in which the visitor was challenged to think about disability issues and those people directly involved.

There were comments on the length of the text, but apart from a short introductory panel the exhibition was created from the participants' own words and, as such, had a real relevance and a greater impact on the visitor; the bottom line being that without those who shared their experiences there would have been no way of looking at the collection in a new and meaningful way.

We also had to think outside the usual 'shoe' box and not simply create an exhibition of shoes. In the past, shoe exhibitions have been very much typologically based, a legacy from the very nature of the collection's make-up. Past exhibitions have included highlighting a specific manufacturer, themed exhibitions such as wedding shoes, shoes from other countries and even colours and those based around an individual or a group's creative response to the collection. These exhibitions have been successful, the bottom line seems to be that people like to look at shoes and most of the time seem happy without any in-depth interpretation, but what these exhibitions lacked was any depth of focus on the wearers themselves, other than perhaps the name of who wore them. This type of exhibition is fairly unchallenging, either for the curator of the exhibition or the visitor. We wanted the personal experiences coupled with the shoes to engage and question the visitor to think about the representation of disabled people.

A lot of time was spent thinking about content and it did involve a fairly radical rethink about what form the exhibition would take, what message we were wanting to get across to our visitors and what the themes would be to allow us to do that. It was hard at times not to simply fall into the comfortable position of letting the shoes become the dominating factor in the exhibition and letting them speak as objects rather than as props to explore people's very real feelings and experiences. It was important that the shoes were the jumping-off point in challenging and engaging the visitor to think about the issues and the people involved. It was the people not the shoes that had to be the dominating factor throughout.

We spent a lot of time thinking about what shoes would go into the exhibition and ended up paring down the quite extensive list that originally included Chinese bound-foot shoes, shoes worn by Charles Byrne O'Brien, the Irish Giant and Charles Sherwood Stratton's (Tom Thumb) boots. Cutting the number of shoes was in response to homing in on themes that would allow the orthopaedic shoe user's voice to be heard in an undiluted way; to get our visitors thinking in ways they haven't had to before especially within the context of the shoe collection. A mix of orthopaedic examples was chosen to be combined with examples of mainstream fashion, designer and fetish wear.

It was hoped that the chosen final combination of shoes would appeal to a broad audience and create a way for the general visitor to engage with the subject and draw parallels with their own attitudes and experiences of disability and fashion issues. Even the orthopaedic shoe wearers who contributed to the exhibition blanched at the idea of an exhibition filled entirely with orthopaedic examples.

After much discussion the exhibition's content was split into three loose and flexible themes. The themes were fashion, function and historical context / makers. All three themes had to be led by, or strongly linked to, personal experiences and opinions, ask questions and be challenging.

Orthopaedic shoe
(1920s) and fetish shoe
(2007) from the I Stand
Corrected exhibition

Photograph by
Peter Carney

Orthopaedic shoe
1920s

Fetish shoe
Xtreme Footwear
2007

One of the broad themes was fashion. It revealed how some designers / manufacturers are producing footwear with a very orthopaedic look yet are quite clearly for non-orthopaedic wearers. For example we placed the 'Super Elevated Ghillie' shoe by Vivienne Westwood, 1998, the towering boots of the Goth culture, 2007, and a wet look fetish boot, 2007, next to examples of platform orthopaedic shoes from the 1920s. The similarities were visually very clear.

This threw up a number of challenging questions for the visitor to ponder – what does this juxtaposition of high fashion and orthopaedic shoes say about the choices (and lack of choice) the fashion industry offers disabled people?

The idea to approach it this way was so it would appeal to a wider audience through creating common ground and to get people thinking about exactly what is fashion and the ideas surrounding personal choice and/or the lack of it.

The visitor in one section was asked: **Which shoes would you choose?** illustrated with a variety of different shoes. It was interesting that many people liked and thought they could wear some of the almost sculptural examples from the 1920s, but not when they found out that they were in fact orthopaedic.

One of the contributors, Barbara Hogg, made a valid comment:

"It's a perception isn't it really? If you go along and that's where it's made – oh, it's an orthopaedic shoe, then in your mind that's what it is. Whereas if you've bought it as a fashion item then you would perceive it completely differently. Yes it's a strange world, it's all in the head!"

Other sections focused on different aspects involved in wearing orthopaedic shoes, areas that visitors will never have thought about before. The sections were headed with questions and then heavily backed up with the experiences and opinions of those who were interviewed. The contributor's own words formed the bulk of the exhibition under such titles as:

I stand corrected?

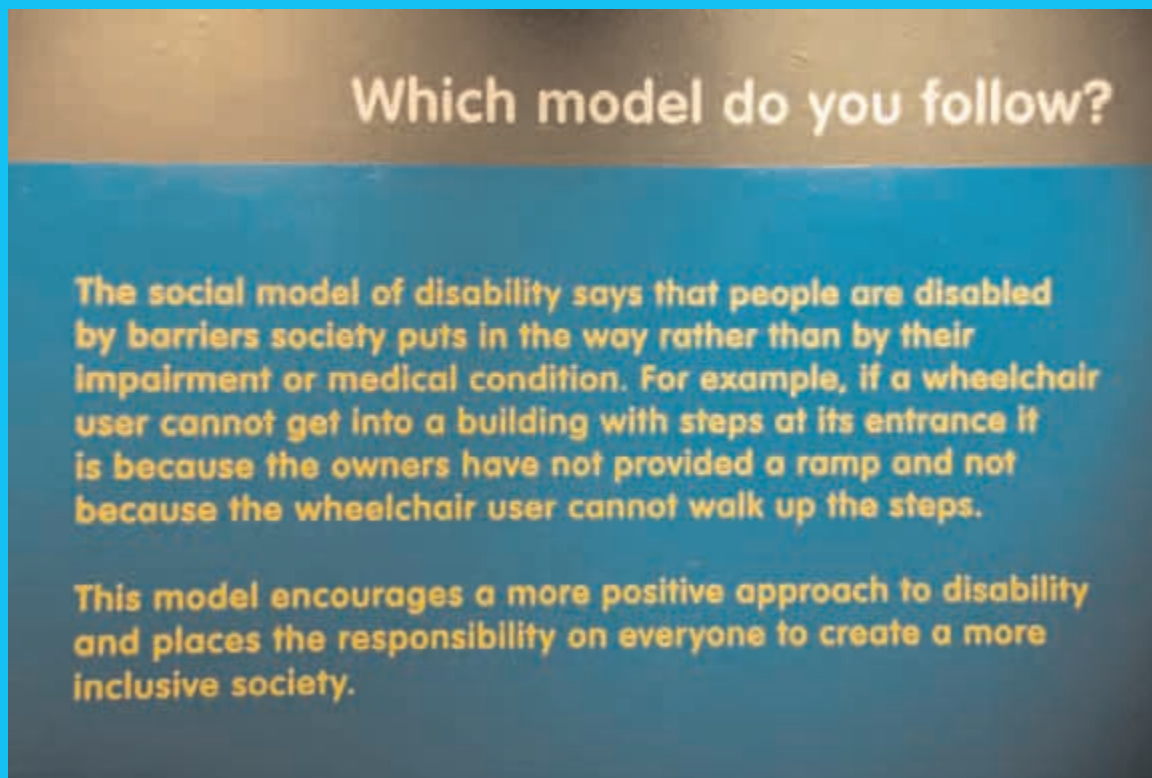
Foot doesn't bother you?

Do you have to buy the pair and throw the other away?

I hadn't noticed?

The combination of questions coupled with the very personal points of view expressed combined to create an exhibition where visitors were made to think about disability issues, how these impact on those personally involved and to question their own responses and attitudes. This new approach to interpretation created a unique 'shoe' exhibition that provided a strong voice to those who actually live with the everyday reality of wearing such footwear and the wider impact of that on the whole of their lives and informed and challenged the visitor to think about the representation of disabled people.

Framing the Project



One in Four

Tyne and Wear Museums

Kylea Little

From the very beginning of the Rethinking Disability Representation (RDR) project Tyne and Wear Museums (TWM) were committed to consulting with local disabled people in the development of their project. The gallery we intended to use for the project, then named 'People's Gallery', was a dedicated space for community groups, programmed and curated by a member of the Tyne and Wear Outreach team. The contents of exhibitions were proposed by community groups working with the Outreach team who would develop the content and install the material. The RDR project was assigned to the Keeper of Contemporary Collecting (KCC) which also ensured that consultation would be a central aspect of the project. The KCC is a post funded by the North East Regional Museums Hub and the brief includes targets to reflect the Hub programme. These targets included working with groups that had traditionally been underrepresented in the museum collections. The KCC had previously worked with a local Lesbian, Bisexual, Gay and Transgender group to co-curate an exhibition, **Private Lives, Public Battles**, in Discovery Museum and had developed a methodology for consulting with interest-groups over exhibitions.

TWM also benefited from the work of their Access team (Jane Montgomery, Access Officer and Megan de la Hunt, Access Project Officer) who were working with a specially formed 'Museums and Gallery Disabled Access Committee', a group of local disabled people who had been meeting for several years to help TWM improve access to its venues. Through this work the Access team had built useful contacts and relationships and they were keen to progress their work from a focus on physical access to consultation around issues of representation.

At the initial exhibition team meeting it was agreed that a consultation group of local disabled people would advise the KCC on the key message of the exhibition; on themes, objects and text. Using contacts from Curatorial, Outreach and Access teams an initial open day was held. Over 40 people from the disabled community attended. Three key questions were posed:

Is disability a part of your identity?

Are there any misconceptions in the way people see you?

What do you want to tell people about yourself?

The open day served two purposes; it gave staff at TWM an idea of areas of consensus and contention within the community over issues of representation and it also led to the formation of a group of eight people to consult with over the exhibition. The consultation group met five times between 2nd October 2006 and 27th November 2006. The KCC led these sessions and opened with a discussion around the key message and themes. Later, objects related to disability from the TWM collection were presented and issues of presentation and interpretation discussed.

The objects provoked some lively discussion. There were disagreements over how objects should be interpreted, and these disagreements reflected differing personal experiences and attitudes towards disability. There were concerns over balance in the exhibition and much debate over how to present the challenging aspects of disability without alienating a non-disabled audience. Some members of the group were interested in presenting positive role models whilst others were deeply concerned over access issues. In hindsight it would have been useful to have one or two introductory sessions to familiarise the group with exhibitions, collections and the behind-the-scenes aspects of museum work. Group members were at different stages in their engagement with museums and this led to some difficulties for curatorial staff. On the first presentation of museum objects, one comment was that 'it looks as if you have just found loads of random stuff in a cupboard'! A general introduction to museum work and the parameters within which displays are often developed would have helped the group to understand the potential and limitations of an exhibition.

Amidst this explosion of ideas and opinions the group drew together their ideas for the key message – **'To challenge the myths and stereotypes towards disabled people in both the past and the present – and the themes to cover were independence, language and labels, and normality'**. This brief was forwarded to the Think Tank for comment at the RDR residential in January 2007. The Think Tank felt that the brief was too complex and the key message needed refining. They raised the issue of possible over-consultation and suggested that TWM take an editorial standpoint and rewrite the brief. The Think Tank's advice was that the exhibition needed a clear key message and brief; if they weren't in place then there was a risk of sending mixed messages to visitors which could inadvertently support negative images of disability.

This advice was taken on board by TWM's exhibition team but caused some negative feelings among the local consultation group who questioned the role of the central Think Tank in making decisions on a local project. While the role of RCMG and the Think Tank had been explained verbally to the group, the process of decision-making and the different roles of various groups in the overall project should perhaps have been made more explicit from the start using a written 'contract' similar to the Memorandum of Understanding which The Manchester Museum¹ uses with their Community Advisory Panel.

Working with the consultation group helped the exhibition team to engage with many aspects of disability representation on a personal level. The process helped us to understand the diversity of experiences and opinions and to consider how each object held multiple meanings and interpretation. The sheer amount of discussion generated also led to some difficulties in deciding

what was key information, what the editorial standpoint should be and recognising that this would inevitably disappoint some of those people who had given their time to the consultation group.

The exhibition team were helped in making decisions over the editorial standpoint by the following markers:

Consideration of museum policy towards disability, i.e. the commitment to use and promote the social model of disability
The aims of the RDR project
The strengths of the collection
Key areas of concern and discussions from the consultation group.

TWM was committed to presenting the social model of disability within the exhibition. The relevant material from the social history collection was mainly medical-related equipment such as a guide dog halti, Braille watches and surgeons' instruments. However, the collection did include a few key objects that were linked to local disabled people from the past. Many of these objects represented aspects of the person's everyday life. After briefly considering using the traditional social history thematic approach – displays around work, home and leisure – we realised that the objects did not fit so neatly into these themes. Instead TWM opted for a chronological interpretation using objects that represented an aspect of everyday life that was altered for a local disabled person as a result of attitudes towards disability; whether the attitude was negative or positive. Using a chronological and personal approach also allowed us to show that, although circumstances had generally improved for disabled people, attitudes were not easily predictable; in the past some disabled people had had positive experiences while today some disabled people were still treated as less than equal.

The response of the consultation group to the exhibition was mixed. The more vocal activists of the group felt that there was not enough material representing the activism of the community and the fight to gain equal rights. Although touched upon in the exhibition, activism did not feature heavily mainly because this topic was not represented in the collection. This response will however guide the Museums' future collecting initiatives. Working with the consultation group assisted with the creation of the exhibition and also informed ideas about future consultation work. Combining the aims and ideas of many different individuals was not an easy task, made all the more challenging by the presence of two advisory boards.

Framing the project with the social model of disability helped the team to take a standpoint, to filter the information from the consultation group and to work with a clear framework for interpretation.

1 <http://www.museum.manchester.ac.uk/community/communityadvisorypanel/fileuploadmax10mb,103417,en.doc> Accessed 27.5.08

Disabled People's Voices



Talking about... Disability and Art

Birmingham Museum and Art Gallery
Liz Braby and Melissa Strauss

'Images of people with disabilities would be very different if they were designed by the people themselves.'

So said one of the participants in our project which took paintings from the Museum's fine art collections with connections to disability and invited local disabled artists to respond to them. These personalised responses, drawing on the lived experience of disability, very often used the ways in which disabled people were represented in the paintings to reflect on contemporary issues and debates pertaining to disability rights and related issues of prejudice and discrimination. The disabled artists we worked with on this project made the point that disabled people have had little control over their representation. Like many museums, Birmingham Museum and Art Gallery holds objects related to disability within its collections. Where these have been displayed, however, their significance to disabled people and the messages that they convey about disability have not been highlighted or explored. Disabled people have not been involved in their interpretation, and so – in museums as in many other public arenas – they have not had any control over how they are seen by audiences. Our project addressed this issue head-on by working collaboratively with disabled people to bring their voices, experiences and insights into the Museum.

Audio points, Talking about... Disability and Art at Birmingham Museum and Art Gallery
Photographs by Peter Carney

Photograph by
Peter Carney



Focusing on the Museum's art collections, the project looked at eight paintings from the 17th to the late 20th Century that include representations of disability. We worked in collaboration with six disabled artists to produce new and multilayered interpretations of each painting. These included an exploration of how each painting connects with disability, along with the contemporary experiences of disabled people, personal anecdotes and poems, background information to the artwork and an audio description. The collaborative process involved shared decision-making and delivery with participants, but also involved staff from across Museum teams. Visitors can find the new interpretation on audio-visual points located beside each of the paintings.

Talking about... disability and art builds on ongoing work at the Museum seeking to represent diversity, engage communities in the development of Museum activities and broaden audiences. A key aspect of this was engaging disabled artists to represent their experience of disability. The project started with audience consultation, which identified that non-visitors wanted first-person narratives told by someone that they could relate to. The results of this project progressed the Museum's work by introducing a long-term intervention exploring disability and diversity within our permanent galleries. Outcomes specific to this project and the collaborative process include new and unusual interpretation, integrating disability into the history of the paintings and promoting understanding of disabled people's experiences.

In this account, we look at the mechanisms used to bring disabled people's voices, experiences and insights into the galleries and explore the role of the collaborative process. Firstly, we outline the methods employed to enable collaborative working. Secondly, we look at the positive outcomes achieved through this process. Finally, we highlight the challenges that we encountered and opportunities for future work that have arisen.

A collaborative process

Talking about... was a collaborative project in that we shared decision-making and delivery with participants. At the start of the project we set clear parameters based on practical limitations and stakeholder expectations. The parameters outlined fixed factors – for example, the delivery media (audio) and the multilayered approach – and areas where participants could make or influence decisions – for example, the interpretative content and project title were developed by or with participants. This helped participants to focus on delivery and concentrate on the elements where boundaries could be pushed. It also made the most of everyone's time and expertise.

We selected participants carefully. All participants were disabled, but we also wanted to ensure that each person brought a perspective on disability to the project which complemented the social model of disability, along with a good understanding of art. The participants were all involved in the disability arts movement, and engaged powerfully with the broader concepts and wider experience of disability. The participants' knowledge of art not only increased their ability to make connections between disability and the paintings, but also enabled creative and varied responses.

For example, Tanya Raabe understood David Bomberg's **Self Portrait** through her own artistic practice:

"I begin to examine the way he has put the paint on the canvas. He uses solid brown background as a base colour that, to me, conveys a dark place that is quite oppressive. I have also used this painterly language in one of my own portraits..."

We took a multilayered approach, interpreting each painting through a variety of methods. This resulted in four or five audio tracks for each painting. Consequently participants could respond to the images in different ways and visitors were offered multiple approaches. The participants developed three different layers of audio interpretation: pieces created collaboratively as a group that explored the paintings' relationship with disability; pieces produced individually that recounted a personal anecdote or story inspired by one of the paintings; and pieces using creative media. The collaborative pieces provided a peer review that gave the messages about disability increased authority, while the personal pieces brought these messages to life. A performance poet wrote poems about several of the paintings, which have clearly resonated with audiences. One visitor commented, **"I got pleasure by listening to the music of Ruth Kaye's poems. Her sentences make a harmonious echo with the points, especially The Death of Chatterton"**. The participants' pieces were accompanied by background and contextual information written by art curators, and audio descriptions of the paintings.

The content of the interpretation was developed during two days of intensive workshops involving the participants, art curators, audience development staff and external museum consultants. These workshops enabled informal training for participants, along with discussion, debate, and interplay between the different areas of knowledge and expertise. External consultants built the skills of participants in reading visual images and writing accessible interpretation.

We held in-depth discussions during the first day in small break-out groups. Each group identified key themes and messages for a few of the paintings. These were then fed back to everyone for further comment and formed the basis of the collaborative pieces. The second day gave participants the opportunity to review the collaborative pieces and ensure the content could represent the views of the whole participant group. This day also looked at first drafts of the personal and



William Holman Hunt, The Finding of the Saviour in the Temple
Copyright Birmingham Museums and Art Gallery

creative pieces and the pieces written by curators. This enabled all of the interpretations to draw on the variety of skills, knowledge and experience each person brought to the process.

While the workshops allowed for the key messages to be negotiated and confirmed, an in-depth editing process was also needed to focus the messages into a clear structure, simplify language and ensure concepts were accessible for a broad audience. We were also keen to streamline themes within the layers of interpretation. For example, the curatorial piece for **The Blind Men of Jericho** explains the biblical story and the significance of Jesus's actions. The collaborative piece critiques the notion of healing. Similarly the collaborative piece for **The Blind Girl** considers disabled people's experience of rural areas, while Jayni Anderton's personal piece talks about riding motorbikes in the countryside.

Through this process disabled voices were brought into the museum – literally – with the new interpretations attributed to individual authors and the use of participants' own voices on the audio-visual points. Each track begins with an introduction. For example, Paul Darke begins by saying:

"My name is Dr Paul Darke – I'm a disabled writer and artist. I established the Wolverhampton Disability Festival and have my own radio show on WCR FM, a Community Radio Station serving the City of Wolverhampton."

This moves away from more traditional museum interpretations that use a single, authoritative, anonymous voice. It also matches with audience consultations which reported that visitors want the voice of a person they can relate to providing information in the Museum.

Project outcomes

The collaborative process resulted in a series of valuable outcomes including new perspectives and unusual interpretation. For example, while acknowledging that David Bomberg and Francis Bacon would not have identified themselves as disabled artists, the interpretation positions their work as a precursor to the disability arts movement. This movement consists of art produced by disabled people that directly relates to their experience of disability. The participants as a group felt that the visual language used by Bomberg and Bacon had inspired a mental health aesthetic.

"For example, an artist today might express feelings of depression and anguish with muddy colours, like the browns and dirty yellows in Bomberg's painting, as well as through distorted and incomplete forms."



A copy of a painting by Nicholas Poussin, The Blind Men of Jericho
Copyright Birmingham Museums and Art Gallery

Many of the artworks were by well-known artists, including famous images from the popular Pre-Raphaelite collection. This highlights the project's potential to write disability politics into mainstream art history. For example, the participants thought that **The Blind Girl** by John Everett Millais was **"an idealised image of visual impairment"** and that Millais 'wanted to connect the girl to a spiritual world and to inspire pity'. While many people might feel that this is a sympathetic portrayal, the participants pointed out that most disabled people want understanding and full access, not pity. Another piece looks at the symbolism within **The Finding of the Saviour in the Temple** by Holman Hunt. Participants examined the significance of disability in the painting, and also questioned the use of disabled people as metaphors. 'This marginalises disabled people. Disabled people are not central to the story depicted, they are only shown in order to communicate Christian ideas.'

The interpretation opened up a broad and complex discussion about disability and the experiences of disabled people. This encouraged audiences to challenge misconceptions about disability, including issues around pity and charity and stereotypes like blind people possessing heightened other senses. The interpretation also drew connections with other issues such as class, and highlighted relationships between the past and present. For example, participants felt that the Blind Fiddler's clothes **"suggest he had once been well off – presumably before he became blind"**, and that 'there is a contemporary parallel here as many people who gain a visual impairment today also experience dramatic changes to their circumstances'. Parallels were also drawn between the romantic depiction of suicide in **The Death of Chatterton** by Henry Wallis, and the contemporary 'obsession with creative or famous people who have died young or tragically'.

The project was able to incorporate personal experience, creating links between participants' everyday lives and broader issues. The personal connections bring the paintings and interpretation to life, providing a confrontation with reality. Paul Darke talked about a trip to the chemist, where 'an elderly woman put her hand on my head and said: **I shall pray for you and your father; a father's sins have made you this way**'. This story shows very clearly that some people still believe that disability is a judgement from God; simply stating this would not have the same impact. The personal stories also enable humour and emotions to come into the interpretation. Zoe Partington-Sollinger likened the tableau in **The Blind Men of Jericho**, where Jesus is depicted healing a blind man, to her annual trip to the Manchester Eye Clinic where she joins the line to see the doctor/guru.

This project provided a sense of recognition and inclusion, highlighting and exploring disability and the experiences of disabled people on a prominent platform. The interpretation is not dependent on people visiting a special area or exhibition; it is encountered by all visitors to the art galleries. One disabled visitor commented that **“at last, I am here [at the centre], not here [at the margins].”** The interpretation is also part of a large public museum, enabling the participants to communicate with a broad general audience. It made another visitor realise that disability is something that is usually hidden: **“We do not expect to see it in galleries and museums and it's not until we do that it gives us an awareness of the lack of it elsewhere.”** The participants were really keen to be involved in the project, showing that disabled people feel that the Museum should have a role in this area.

Through our involvement in this project, the Museum has developed stronger links with individuals and organisations in disability arts, and achieved a sense of legitimacy in relation to disabled people. The collaborative process and the resulting interpretation have illustrated our commitment to engaging with disability, and giving disabled people substantial opportunities to shape their own representation. We have also increased our awareness of access issues, providing a good basis for more work with disabled people. More broadly, we have gained confidence in collaborative working where the results are unpredictable, developed experience of negotiating between the views and needs of participants and audiences, and explored ways to integrate diversity into the permanent galleries through interpretation. The Museum now has increased impetus and capacity to develop more of this type of work in the future.

Challenges

As well as these significant gains, we also encountered some important challenges. **Talking about...** sought to reinterpret the existing Museum collections, and these collections posed constraints on the project. The artworks relating to disability were limited in number, and participants therefore could not actively choose the paintings to be included. They were disappointed that there were not more works by disabled artists, and that none of the works came from the contemporary disability arts movement. Apart from three paintings from the 20th Century, the representation of disability within the artworks reinforced stereotypes. The participants did positively identify with the later works, and we wished that there had been more such opportunities. For example, when talking about four artworks inspired by an artist recovering her sight, Zoe Partington-Sollinger said:

“I was thrilled by the story of Barbara Delaney and her paintings. I looked at them with fond memories of colour, light and abstract images – but also with a sense of relief! ...She must have experienced the return of colours and shapes in a similar way to my own experience.”

The narrow scope of the collection could have led to over-interpretation. We were aware that the group might have particular messages that they wanted to convey about disability, but that these might not always easily relate to the artworks. Asking the group to make specific connections between their ideas and the paintings, ensured the expansive interpretation was still clearly drawn from the artworks. The curators also worked with the group to help them to understand the broader art historical context. For example, early discussions about **The Blind Fiddler** suggested that this could be a negative portrayal of disability, with the man's slovenly appearance and drunkenness. The curators noted, however, that within the tradition of painting Dutch and Flemish tavern scenes, non-disabled figures were depicted in the same way.

We found some tensions between the need for a collective understanding of disability based on the social model and individual needs and interests. An example of this emerged while recruiting participants. A potential participant decided not to be involved as the project could not accommodate his specific interest in asylums and psychiatric repression. Different opinions were encountered and expressed in response to the pieces with both 'softer' and more politicised perspectives expressed, still within a shared approach to disability. The process did draw on the strengths of individuals. Individual participants would often have a stronger reaction to an artwork and were then able to come up with a deeper and more engaging response. Wider interests also added to the interpretation. For example, Jayni Anderton had been involved in historical re-enactments and recorded a piece imagining herself as a figure in **The Blind Fiddler**. However, we felt that we needed a strong message about disability, which, while not representing all disabled people, did reflect the views of a group of individuals well-respected within disability arts.

The interpretation had to be accessible and engaging to a broad museum audience, including people of different ages and educational backgrounds, and both disabled and non-disabled visitors. Some of the participants came from quite an intellectual background, and the points that emerged were often complex. For example, Colin Hambrook felt that **The Death of Chatterton** gave out contradictory messages about suicide, the role of the artist and the creative process. He identified associations of suicide and madness with both wasted genius and **"the idea of the artist as someone who is emotional and weak-minded"**. While we worked with participants to explain the points clearly, we sometimes felt that the ideas were too complex for our usual interpretation standards. We did simplify language, and ensured that the broader context was explained to help visitors understand the interpretation. For example, the exploration of disabled people as symbols in **The Finding of the Saviour in the Temple** relied on knowledge about symbolism in relation to Judaism and Christianity.

We had to be careful about references to other communities. The group associated Christianity and three religious-themed artworks with negative stereotypes and views, including the idea that disability was seen by some as a judgement from God, and as warranting charity and pity. We felt it was important not to offend Christian visitors, but also to engage with the issues raised and not censor the participants' views. We addressed this by making it clear that the interpretations are not 'definitive', but rather the personal, and joint, views of the participants. These views were also connected with personal experience.

For example, Paul Darke said:

"I went to a special school for people with spina bifida: a Christian faith school... My religious schooling has often made me feel that disabled people are exploited by 'ordinary' people in the furtherance of their own religious beliefs. I feel disability is seen in two ways. Firstly, as something that can be healed by faith. And secondly, that it can be exploited as a route into heaven by 'helping' disabled people."

We also avoided generalisations. For example, we did not say 'this is what all Christians believe', but instead highlighted certain historical values and principles.

Conclusion

Talking about... brings disabled people's voices, experiences and insights into the Museum. Collaboration was critical to this. The collaborative process invited new perspectives on the paintings, writing disability into their narrative in often surprising and unusual ways. It opened up complex connections between disability and wider issues, and between past and present. The interpretation challenges audiences' understanding of disability within both the paintings and broader society. These outcomes also emphasise the importance of cross-team working. Close co-operation between curators and audience development staff strengthened and embedded the project. **Talking about...** also reminded us of the pleasure of collaborative working. It introduced us to new ideas, reinvigorated our understanding of the collections and deepened our awareness of disability. We are grateful to the six participants for sharing their stories with us and our audiences, and hope that they too enjoyed the process.

Talking about... integrated disability within permanent galleries, and enabled disabled people to take control of their own representation. The project feeds into broader questions about representing diversity, the format it takes and the voices visitors find in the Museum. It has already had an impact on other projects at Birmingham Museum and Art Gallery. This includes an interpretation project in the permanent galleries that created a trail guide of artwork related to Muslim cultures with people from local Muslim communities, and an upcoming project with deaf and hearing-impaired people. It has also influenced the approach to community engagement in plans to redevelop the Birmingham history galleries. The major challenge the project highlights for the Museum, however, is the collections and how well they relate to local communities. Hopefully we will be better placed for similar work in the future, with artworks that in themselves challenge audience views and show how disabled people want to represent themselves.

If Robert 'Stumper' Dryden had been alive today how might his life have been different?

How does this photograph challenge current stereotypes of disabled people?

'A Whitby Fisherman's life'

'Stumper' Dryden through the lens of Frank Meadow Sutcliffe

This is a photograph of Robert 'Stumper' Dryden, 1855-1926, taken by Frank Meadow Sutcliffe around 1880. It shows Robert Dryden on Tate Hill Pier, Whitby, with Tom Langlands, coxswain of the Uppang Lifeboat. The wickerwork 'skep' has been baited with mussels ready for line fishing from a three-man cobbie. Cobbies were the distinctive, traditional fishing boats of the East Coast designed to be launched from Yorkshire's steeply shelved beaches.

What can we learn from this about the lives of disabled people?

A Whitby Fisherman's Life, display at Whitby Museum

Photograph by John Searby

A Whitby Fisherman's Life: 'Stumper' Dryden Through the Lens of Frank Meadow Sutcliffe

Whitby Museum

Jackie Gay with Mark Edwards

The display at Whitby Museum focused on the life of one person, Robert Dryden, a 19th Century fisherman and amputee.

Frank Meadow Sutcliffe's photographs of Dryden – he features in at least eight images – immediately caught the eye of our researchers during **Buried in the Footnotes**, the investigative project which preceded **Rethinking Disability Representation (RDR)**. The clarity, character and naturalness of the photographs are distinctive, but even more striking than this is the context. Robert 'Stumper' Dryden was photographed as a fisherman and member of the local community and Dryden family, not because he was disabled or for any medical reason, but because he was there.

It is important to note how unusual this is. Historical evidence of the lives of ordinary disabled people, especially those who were not medical examples, 'freaks', or 'characters'; those who led normal working lives, is very rare. Of course, in reality there would have been millions of Stumpers across the country, in all classes, locations and professions, but the evidence of their lives has rarely survived. What made the images even more interesting was that they were accompanied by a family history – members of the Dryden family still live in Whitby – which included memories of Stumper and anecdotes about his life.

To learn more about Robert Dryden, therefore, we researched the local fishing industry and community and built up a picture of his everyday life and activities. In Whitby the fishing community lived in the narrow streets by the harbour: Sandside and Tate Hill, Henrietta Street and Upper Church Street – all familiar addresses from Dryden census returns. The fisherfolk constituted a distinct and distinctive group, clearly identifiable and somewhat secretive. Stumper's great-niece, Mary-Jane, records this sense of community in her memoir **A Whitby Childhood:**

"We were all in the same boat. I think that's why people helped one another so much. If anybody died or was ill, everybody got around and helped because they were all alike."

Robert Dryden is listed on the census of 1891 as a 'Fisherman' and 1901 as a 'Fisherman and Head of Household'. His mother, Martha, had 13 children, 10 of whom survived childhood; his oldest brother William was lost at sea. Because the fishing industry was seasonal and insecure it would have been critically important to have a second source of income and the Drydens managed this by taking in lodgers.

We were able to obtain a family tree and other documents from Robert Dryden's great-nephew, Shaun Dryden. Another descendant, Maureen Eves (great-great-niece) agreed to read the audio description which accompanied the display. We hoped that by using the local voice of a family member, visitors would be able to make personal connections with the subject matter – Whitby is a museum grounded in the local community and history and many visitors have their own links with the fishing industry and Old Whitby town. Through the display, they could then therefore make connections with Stumper Dryden; via the streets he lived in, the seas he fished.

The incidental nature of the photographs of Stumper was important. Stumper and the Dryden family feature in many of Sutcliffe's photographs and through these family and work groupings Stumper is shown to be integrated within, and integral to, his family and working life. He was not absent, but equally it is impossible to imagine him presented separately from the Whitby community. Because Stumper's impairment is integrated visually in the photographs, we were able to make the explicit link with disability in a natural narrative way and tell the story of Robert's accident and amputation whilst giving equivalent emphasis to his subsequent working life as a fisherman. Robert's impairment is presented as a matter of fact – just as the accounts we were able to obtain from his descendants are.

The Whitby display gives an example of how disabled people from history can be presented within museums. One of the aims of the project was to enable disabled people's voices – both past and present – to be heard. By researching Robert Dryden's story and community and bringing it to life with contemporaneous photographs and a family voice, we hope to have conveyed some of the texture and qualities of his everyday existence. We have also made him present, as he was within his community. Visibility is a very important issue for disabled people in history, especially when individuals are presented with evidence not just of a presence, but a life. Here, Stumper is shown as deeply embedded in his community, commanding respect and authority.

Whilst the historical evidence, in this case, was exceptional, it is of course possible to develop similar material around any evidence of disabled people's lives in history: a shoe, a letter, a song or even a placename. The evidence is there, but we don't always see it or make the connection with disability. In all cases, the disability will only be one aspect of that person's life and we hope that the display at Whitby Museum will encourage other institutions to research and integrate the whole lives of disabled people from history into their own displays.



A Whitby Fisherman's Life, display at Whitby Museum
Photograph by John Searby

Countering Stereotypical Representations of Disabled People

Daniel Lambert: An Exalted and Convivial Mind

Stamford Museum
Claire Jacques

Stamford Museum's re-display of objects and images relating to Daniel Lambert offers visitors a fresh interpretation of the story of Daniel's life and personality. Whilst working on this project we have focused on historical and contemporary perceptions of difference and how they are represented, as well as examining the myths that are built around individuals. The new display seeks to re-examine Daniel's life and personality to present a man who was revered for his intellect and wit.

The original interpretation, which consisted of a full-size mannequin of Daniel positioned in a window, together with associated memorabilia, did nothing to resist stereotypes and reductive representations of otherness. The impact was compounded by an additional area at the side of the display, which was devoted to interactive play, focusing on weight and height. Additionally the language used to describe Daniel and his life could be viewed as patronising and pitying. The display lent itself towards myth and sensationalism as opposed to giving a rounded, balanced description of the individual character, his achievements and social and economic situation. Most importantly, the old display did indeed represent Daniel in the manner of freak-shows – showing him sitting in the window to be stared at, presenting him as a curiosity.

The process of 'rethinking' was a real challenge. At the start of the project the team experienced a level of anxiety and concern about how to display and interpret the material. As a team we had to be honest with ourselves and admit that we hadn't really reflected on how the material relating to Daniel was displayed. We had to be critical of ourselves and the way we did things, realising that we had in many ways supported and reinforced the traditional view of Daniel.

In order to overcome our apprehensions and fears we had to adopt a new approach to interpretation, whilst rethinking our practices and processes associated with exhibition-making and representation. We realised that we had 'the potential to shape, rather than simply reflect social relations and realities'.¹

This process involved examining the use of language; both Daniel's own words and other people's remarks, comments and memories of him. Crucially, we had to consider the language we would eventually use in the display. We had to unpick all the different narrative strands in his life and think about their meanings, along with the significance of objects which could help illustrate the new interpretation. We moved away from the historical, familiar and comfortable, and decided on new content and themes that did not solely focus on Daniel's size. We worked together to construct a new narrative. This involved emphasising other recorded aspects of Daniel's life – Daniel as a swimmer, gaoler, singer, as well as examining stories about him which reflect aspects of his personality. This focus resulted in us reducing the numbers of objects displayed, instead choosing material which was relevant to the new narrative, rather than displaying a plethora of objects which just record the shape and size of Daniel in different formats.

Once the elements of the text were in place, the objects could be chosen, and were eventually whittled down to three: the portrait, the hat and the set of replica clothes.

We decided the display would focus on three core ideas: that Daniel was a companionable man who took care in his dress; that he wished to live his life on his own terms, not be dictated to by curiosity seekers; and the fact that all clothing in this historical period was bespoke (in contrast to today when bespoke clothing is only made for the very rich or very unusual). To tell this story we created the replica clothes on a tailor's dummy, ready for Daniel's perusal. This process of 'narrative development' constituted a new approach for the museum team working on the project. We created the new narrative first then selected objects to help illustrate this story, rather than the other way round. Adopting this new approach was a challenging process for the team; changing the concepts behind the exhibition involved examining ideas which had been unchallenged – or perhaps unconscious – for many years, and brought to the surface politically and publicly sensitive issues. This experience constituted a real learning curve. This was particularly the case when focusing on the use of language in the display and when talking about the exhibit with other colleagues and members of the public.

Comments made during the evaluation of the project and afterwards have made it clear that many people have been made to think about the reasons behind their interest in the display of Daniel Lambert. They have also been encouraged to think about disability and otherness more broadly and to consider the experience of disability in history.

The following are examples of visitor responses:

"It reminded me to take the person as a whole and not concentrate on the disability – to celebrate what someone can do/did"

"Saw the point personality v appearance. Certainly extending remit of a museum: i.e. influencing views"

"Challenges your motives for wanting to see Daniel Lambert exhibition!"

"Excellent! I am impressed by the way you have updated the display. It is much more respectful now, and different. Well done."

It has become clear that, while the display made people think, not everyone was necessarily happy with this. Indeed some visitors wanted their comfortable old display back. Interestingly, many of these were young people who had enjoyed the interactive area dedicated to weighing and measuring. It should be noted that quite a few people were uncomfortable with having their views challenged. The team feel that this should not deter them from using the same critical approach to other displays and projects in the future. The new Daniel Lambert exhibition has developed our experience of consultation, partnership-working and working with people outside museums. Crucially, the re-display has been successful in challenging people to think about why and how they were looking at material.



Daniel Lambert: an Exalted and Convivial Mind, display at Stamford Museum

Photograph by Philippa Massey

1 Sandell, R, **Museums, Prejudice and the Reframing of Difference**, Routledge, London and New York, 2007, p139

Approaches to Interpretation



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Lives in Motion: Transport and Disability

Glasgow Museum of Transport
John Ferry

The **Lives in Motion** project was conceived as an exhibition which would utilise multiple forms of interpretation to convey stories related to transport and disability to visitors with varying abilities, ages and learning capacities, using objects from Glasgow Museums' collections.

Over a period of nine months we identified objects, produced text interpretation, acquired graphical support material, and planned the types of interpretation we hoped would successfully communicate our key messages. The process involved an extensive search of a broad range of collections including fine art, transport and social history until we had around 30 or so objects for consideration.

Ideas for a theme at this stage remained open. Through project team discussions, consultation with RCMG and various focus groups, we decided to focus on the key theme of transport – a key issue for disabled people both historically and in the present day. As our stories and key messages developed, our object selection became more concentrated and eventually seven objects were selected from our transport collection.

Lives in Motion was designed with the intention of furnishing visitors with new insights, ideas and ways of looking at and appreciating objects. Our ethos is that any form of interpretation is only meaningful if it makes the visitor look again at the object it interprets, and with greater understanding. We were also keen to provide an attractive, dynamic exhibition that would be meaningful, engaging, and fun.

Accessible Interpretation using British Sign Language (BSL)

It was a project priority to make our exhibition accessible to deaf people, and we included a short BSL description of the aims and objectives of this exhibition, produced in partnership with Deaf Connections, Glasgow. We also produced two further pieces of BSL audio-visual interpretation, along with online resources.

In order to produce this material we needed to identify professionals who could produce signed interpretation. We contacted Scottish Television and BBC Scotland to determine timescales and costings, and identified Deaf Connections as a partner.

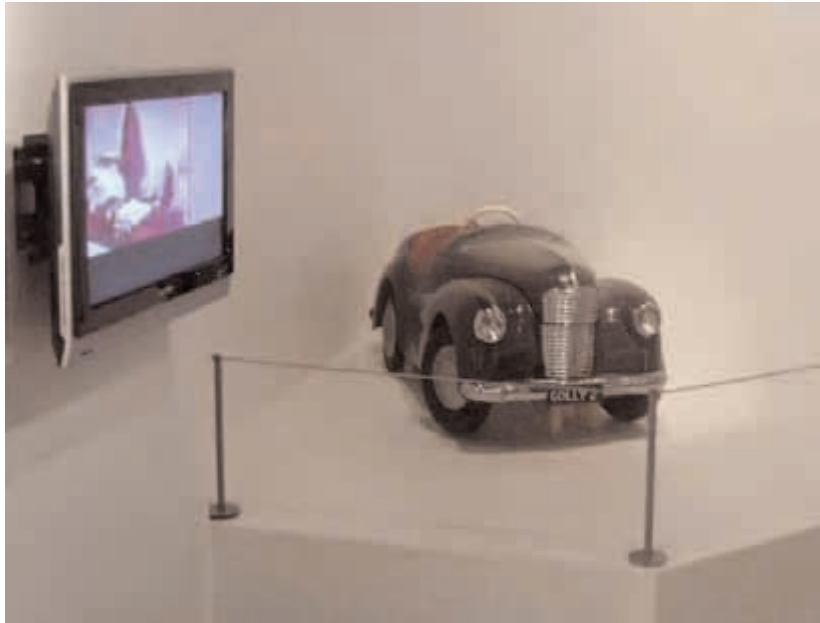
We already had a good working relationship with Deaf Connections because our Learning and Access staff had been involved with training deaf people to give signed tours of Glasgow Museums' venues during 2006. Our **Lives in Motion** project team identified where BSL would be most relevant, and text was forwarded to Deaf Connections for feedback. Deaf Connections then cut and amended the text to present their interpreter with a format that could more easily be signed. As text, this read as a condensed version of our material; however, the visual nature of BSL brought the material to life. BSL is a highly expressive language, reliant on the abilities of the interpreter as 'performer' to convey the story to their audience.

This editorial process continued until our interpreter and deaf colleagues were satisfied that the story and message were being conveyed accurately.

Developing signed interpretive material can be a lengthy process and adequate provision should be given to planning and resourcing such content. For example, interpreters are in short supply. Within Scotland the number of signed interpreters is currently estimated at 55. Finland, with a similar demographic and population size to Scotland, employs around 250 full-time interpreters.

In April 2007, CACDP (Advancing Communication Between Deaf and Hearing People) reported that 469 BSL-English interpreters were registered with them in England and Wales, which means that there is roughly 1 registered interpreter for every 106 deaf people.

Within **Lives in Motion** we examined the issues that deaf people experience with public transport, such as intercom systems in railway stations, airports and bus stations. A last minute delay or change of platform can leave a deaf person second-guessing where their train or bus is, perhaps following familiar faces using the same route to decide their next move. Some transport companies are becoming better equipped technologically to offer a broader range of communication services to the general public. However, these developments are a long way off being widely available.



Images from Lives in Motion exhibition. Copyright Glasgow Museums, Culture and Sport Glasgow



'Wee Bluey' the AC Car on display in the Lives in Motion exhibition
Copyright Glasgow Museums, Culture and Sport Glasgow

Humour and first-person interpretation

Broadening Horizons

The **Broadening Horizons** display featured an AC Car alongside audio-visual interpretation by Brian Sweeney, Disability Consultant, and an AC car driver himself in the early 1960s. Brian talked about his experiences as an AC driver in a light-hearted and entertaining way. We then employed Brian to assist us in producing our interpretation. It was crucial that the budget allocated to this project afforded us the opportunity to employ disabled people.

Our key message was that this vehicle was fun to drive and made a huge difference to Brian's life during that period, despite its dangers.

"You also had great fun in it, I mean apart from any serious things you did. You know you took them to football matches where you could get in free to a football match... And when you went there in this little vehicle and you went round the ash track, people used to shout at you, shout encouraging things at you! You felt a bit like that movie which was out at the time, with Charlton Heston in it – 'Ben Hur', there was a famous chariot race in that. And I always think that's what I felt like going round Hampden Park, like one of the chariot racers while hundreds of thousands of people were all shouting.

Anyone driving that car was identified by a member of the public as being a disabled person, someone who had an impairment. Now that's just a fact of life, you identified with that. Once people with impairments, mobility or otherwise could purchase conventional cars, then they escaped from that and they were indistinguishable from any other motorist on the road. They became 'anonymous', and that was a very welcome thing for wheelchair users. The liberating effect of a little vehicle like this to people who were wheelchair users or had mobility difficulties, was just unbelievable because your horizons were virtually limitless then."

This audio-visual material was accompanied by signed interpretation, as well as further on screen textual descriptions and text panels. A large black and white photographic panel courtesy of **Newsquest, Glasgow Herald and Evening Times** showed the AC cars trackside at a football match between Glasgow Celtic and Glasgow Rangers, 1968.

Ian Hamilton – Travel Stories

For this section of the exhibition we commissioned Ian to write and record stories for **Lives in Motion** which conveyed his experiences of using public transport as a blind person. Ian's journalistic and broadcasting work demonstrate a strong sense of humour whilst raising serious issues regarding visual impairment and disabled people's rights. These stories were presented in a space where visitors could sit and listen to the stories, alongside images of Ian beside a bus stop, accompanied by his guide dog.

Travel Story by Ian Hamilton

(Transcription of podcast for the exhibition **Lives in Motion**, Museum of Transport, 19th October 2007 – 29th February 2008.)

"As a blind person using public transport, it could be described as an extreme sport! Not only do I have to run the gauntlet of escalators, lifts, finding the right platform, and accessing ticket barriers, I also have to cope with the general public, who tend to balance between two extremes: overly helpful and won't leave me alone for a second; or they pretend I don't exist, so they don't speak to me.

Years ago, I was trying to find a particular bus stop in Union Street in Glasgow. After asking numerous people, and walking for miles, I eventually found the right one.

I was exhausted, and the noise of the bus and the traffic on the road was very loud and it made it difficult to hear people speaking to me.

All of a sudden, two little old ladies, pushed their way through the crowd. They had been observing me for some time and had decided I needed to be rescued.

When a bus arrived, they took my arms, and lifted me bodily on to it.

Now then, I'm six foot tall and over fourteen stone, however, these five-foot tall senior citizens proceeded to push, heave and drag me aboard, causing absolute mayhem.

With mothers and toddlers being pushed aside, the driver had to leave the safety of his cab to untangle buggies, shopping, walking sticks and various limbs. Shame it was the wrong bus!

I often wonder if the ladies are still patrolling that part of Union Street today?

Getting the train also brings its own challenges. Arriving at Glasgow Central Station, I headed for the exit of the train with my guide dog.

I had remembered that the buttons were on the right hand side of the automatic doors.

When the train eventually stopped, I reached out my hand to press the button, which was at shoulder height. But to my horror, I found a face!

But it was too late. I had started, so I had to finish. I continued to push the head firmly back against the button, the door slid open, not a word was exchanged, both the dog and myself shot out!

If only people would communicate, life would be so much easier!"

This material was also made available in laminated A4 large text cards and each story was produced as a podcast and made available online.



Ian Hamilton, accompanied by his guide dog, experiences public transport in Glasgow. Copyright Glasgow Museums, Culture and Sport Glasgow

Slide show and photographic interpretation

Our Journey

Our Journey featured a slide show of captioned photographs featuring Peggy Boyle and Jackie Shields from the Three Eyes Project, Knightswood, Glasgow, who went on a journey by foot and public transport to test accessibility for wheelchair users.

The images record this eventful experience and the clear interpretation proved a powerful way of communicating the message that travel presents many obstacles to a disabled person.

The slide show was situated in a seated booth where further text and graphic material was available as a handout to visitors. This material was also available online as downloadable material with additional screen resolution adaptability.

Out and About

Out and About featured a Batricar from around 1990. Since the Museum does not hold any more modern examples we decided to accompany the car with text and graphics panels including images taken during ‘street’ interviews. The resulting text panels gave examples of current Batricar users’ experiences. For instance:

“I used to have to rely on members of my family to take me out and about. This mobility car has given me a new lease of life.”

Mrs Linda Dunsmuir, East Kilbride

“This vehicle has been a great help to me as I travelled across the country from Essex to Perth, and now I’m shopping in Glasgow. I couldn’t get around without it.”

Mrs Grace Pannifer, Essex

Visitor responses captured on film

So whilst many of the stories we researched highlighted the frustrations of inaccessible transport, we also wanted to portray disabled people enjoying travel. For example, we produced a short film entitled **Waverley Journey** with the Glasgow organisation Project Ability. Members of this organisation had offered comments on our object selection and the idea to film some of their artists on a favourite journey was born. The journey was on the Waverley steam ship up the River Clyde. The resulting story, filmed and edited by James Gibson, is a warm and enjoyable journey as seen through the eyes of a Project Ability artist.

Visitors could also add their comments and responses to the exhibition and the issues it raised through further video interviews. We actively sought this material throughout the period of the exhibition, resulting in around 20, one minute, edited interviews.

"I am a volunteer for Dyslexia ScotWest. I have MS and of course dyslexia. With MS I find difficulty getting on to transport and the bus drivers move away far too quickly. With the dyslexia I have a great problem with the 24-hour clock and I have problems with timetables... I can't read when the bus is coming or if that bus is going in the direction that I want to go in... it's just very difficult altogether. As far as directions go, I use a sat nav, which has been a godsend to me really – that way you don't get lost in every city."

"But the fact that there was a sign up about able-bodied people using disabled car parking spaces. I've used that saying myself – you know, saying I really hope that you'll never need this parking space – get your van out of there son, I'm needing that parking space."

"The audio information on the blind guy was fantastic – loved it because even times when you are in a wheelchair, you're invisible. People will say 'Does she want sugar in her tea?' "

A Place for Debate



Photograph by Peter Carney

One in Four

Tyne and Wear Museums
Kylea Little

The aim of Tyne and Wear Museums' touring exhibition **One in Four** was to create an interpretive framework for our display which would challenge entrenched or subconscious attitudes by engaging non-disabled people in the exhibition. We were fully committed to presenting the exhibition from a social model of disability perspective, but also wished to make it clear that the museum does not have answers to many of the questions raised by the exhibits and the lives of individuals included in the exhibition. We wanted visitors to ask themselves questions in response to the display; the museum would host the debate and the visitors would be stimulated to participate.

Consequently, we used questions throughout the display. In the introduction to the exhibition visitors were asked if they, or any of their friends or family, were disabled. We hoped that people would recognise the relevance of the exhibition to their own lives. These questions were accompanied by a graphics panel explaining the social and medical models of disability and asking people to analyse their own modes of thinking. By responding to questions people could openly examine their attitudes within an inquiring – rather than accusatory – environment.

The object labels also used questions, formulated to highlight aspects of the social model of disability. We aimed to emphasise all aspects of the people behind, or included in, the objects, focusing on their individual lives and illustrating the variety of experiences which disability encompasses.

Example object labels

Blind Willie mugs, about 1830

William Purvis was born in Newcastle in 1752. Blind from birth, he was well known throughout the city as 'Blind Willie'. He was a fiddler, singer, and a revered dance teacher who regularly played in public houses.

Was Willie remembered for his talent as a musician or because he was blind?

Pit Disaster poster, 1866

This poster commemorates the Oaks Colliery disaster in Barnsley. Although the language used on the poster such as 'poor cripple' was typical of its day, it is not considered acceptable today as it endorses negative attitudes towards disabled people and their abilities, encouraging them to be seen as incapable and to be pitied.

How does this compare to charity today?

Some charities still encourage society to pity disabled people whereas others focus on empowering disabled people to live full lives.

Tommy on the Bridge postcard, 1870s

Tommy Ferens, born in 1841, was blind and had multiple disabilities. In the 1870s he earned a living by begging from Monday to Saturday on the middle of the Swing Bridge which spans the River Tyne. With one foot on the Gateshead side and the other in Newcastle he was able to avoid punishment for begging by either authority. Tommy became a well-known local figure.

Was it Tommy's choice to beg or was it his only option?

Cran basket rule, 1900s

The cran basket rule was used to check the size of herring baskets. The herring baskets used on North Shields Fish Quay in the early 1900s were made by blind people in a workshop in Howard Street. This work was often badly paid and carried out in poor conditions.

Opportunities for blind people at this time were often limited to this type of work.

Do you think that blind people resented doing this kind of work or do you think they valued being able to make their own living?

The exhibition featured two interactive displays which also used questions and highlighted the social model of disability. One display, an interactive computer program, asked visitors about terminology, something which had arisen in exhibition team meetings as a key area of concern. The other display raised issues of identity, asking 'What makes you you?' Visitors were invited to examine their identity, considering the various roles they undertook in life (mother, wife, teacher, carer, artist and so on). This was juxtaposed with a series of drawings by local disabled schoolchildren. The children worked with the museum on a representation project and it was interesting that very few of the children chose to draw pictures related to their impairments, instead they chose footballs, games consoles and members of their family, thus highlighting the multiple nature of their identities.

Evaluating the project was key to involving people in the debate around attitudes towards disabled people. RCMG designed response cards for visitors to complete and these were incorporated into an evaluation point at the end of the gallery. We repeated the exhibition's initial questions asking people to examine their relationship with, and attitudes towards, disability and created a space where they could sit down and record their responses. We pinned some of the responses to the wall in order to further stimulate the debate amongst visitors completing their cards – people responded to other messages and added to the display. We also worked with museum volunteers who spent time in the gallery encouraging people to complete the cards.

Challenging Visitors' Perceptions



Life Beyond the Label exhibition
Photographs by Peter Carney

Life Beyond the Label

Colchester and Ipswich Museums Service
Sophie Weaver and Ciara Canning

With the aim of challenging visitors' perceptions, the **Life Beyond the Label** exhibition was designed to:
Examine the ways in which views on disability are constructed and how they then influence identity
Give all visitors access to information and understanding of the varied lives of disabled people in the past and present.

Traditional perceptions of disability

Many historical understandings of disability have been based upon negative representations of disabled people such as the charity model, which implies that disabled people need to be looked after and pitied; or the medical model, which emphasises the physical or mental conditions that require intervention. These portrayals strip away the human, individual sides of people's lives.

To counteract such negative understandings of disability we felt that it was important to focus our exhibition on individuals and their everyday lives and experiences. As the charity and medical models of disability dehumanise people, the exhibition needed to reflect the social model. The social model recognises that the barriers that disabled people face are not related to their impairment but created by society because of the physical environment or people's attitudes, and that these attitudes are often based on limited awareness and understanding of disability.

An example of these attitudes or perceptions is the way many people equate the word disabled with wheelchairs, often with negative connotations. This is illustrated by Catherine's oral history in which she talks about her wheelchair being a liberating aspect of her life. When she was younger she was encouraged to use crutches and struggled with everyday tasks. She struggled against a view within society that using a wheelchair is negative – admitting defeat, or giving up. It was only once she started using a wheelchair that Catherine was able to live life the way she wanted. Through this story people can hear first-hand how using a wheelchair can be a positive experience once negative attitudes are exposed and removed.

Similar personal stories and perspectives throughout the exhibition give people an insight into the lives and experiences of disabled people and challenge traditional perceptions.

Labels and identity

In order to examine people's views of disability, the idea of labels and identity was explored in the section **Who am I?** Five people with different impairments were asked to use a series of words to describe themselves. This was visually represented by headshots of each person with their chosen words written across their faces. The aim of this was to challenge people to think about the way we label ourselves and the labels we give each other. Our identities may be related to personal relationships, for example husband, wife, sister, brother. Other identities may be related to the work we do – accountant, nurse, writer, athlete. However, for disabled people, once you are labelled as disabled, you are identified more by your physical or mental condition and this can overshadow and strip away any other identities or personality traits.

The five people that provided the portraits described themselves with words relating to relationships, work, and personality traits, but also included words relating to disability.

During the process of choosing her words Barbara really struggled with the idea of portraying her impairment. At first she rejected visual impairment as part of her personality. She felt it was a label that influenced people's attitudes towards her. For example she talked about her first experience of dating and how difficult it was to meet people because they were so quick to judge. As soon as they found out about her impairment they didn't want to know, which she found very frustrating and the experience affected her self-esteem. Consequently she was nervous about using the words 'visually impaired', worried that this would reinforce negative attitudes towards her and mean that other characteristics such as her independence would be overshadowed. Eventually Barbara decided to use the words but only on a less obvious area of her face.

The positioning of words was often revealing. When reading faces, the forehead and nose are read first and so they are the obvious places for more important or prominent words.

For instance, Phil positioned the initials 'A.S.' just to the side of his mouth. 'A.S.' stands for 'Asperger's Syndrome'. He positioned it almost as a beauty mark. It's not a badge of which he is ashamed. 'A.S.' is a familiar term that he uses to refer to his impairment; as a teenager it feels natural for him to shorten things down to acronyms.

When we spoke to Phil about the words he wanted to use, he had no problem in acknowledging his impairment, in fact he found it liberating for his impairment to be recognised by other people. Before his diagnosis people didn't always understand his behaviour and he was often bullied and made fun of. He talked about his diagnosis with Asperger's Syndrome as **"a challenge, but it has allowed me to make a better future"**.

Dorothy made a very bold and interesting statement by choosing to position 'Deaf' as the most prominent word on her face. She is very proud of being deaf and added that her deafness is the first thing that she wants and needs people to recognise when she meets them, otherwise she can't communicate. She is also very proud of speaking British Sign Language (BSL); as a minority language user, this makes her distinct.

Sometimes marginalised groups develop a strong sense of cultural identity within which they feel secure; being part of this intimate 'cultural unit' often contributes to a strong sense of self. Being deaf is clearly an important part of Dorothy's identity. Deaf people often identify with this community, whereas they do not necessarily identify as being disabled and indeed often reject it as a label.

It's also interesting to note that when Dorothy wrote her biography her husband Glen, who is hearing, re-wrote it for her in standard written English believing it to be more appropriate for the exhibition. Perhaps he was worried visitors may question Dorothy's intelligence because of her different use of language. Dorothy had written the biography in the way she would speak it in BSL. English is a second language for people who use BSL. In the exhibition we used Dorothy's own words, as they were a true reflection of her personality and her expressive nature.

The portraits illustrate that disabled people want to be seen as fully rounded individuals, with multiple and changing identities.

So that visitors would be further challenged to consider concepts of identity and labels, an interactive display was created inviting people to look in a mirror and choose their own identity words to write on the transparencies provided.



Life Beyond the Label exhibition
Photograph by Julian Anderson

Language and attitudes

Another important aspect of **Life Beyond the Label** was to examine the use of language around disability. Language is fluid and ‘acceptable’ terminology in relation to disability has changed historically, creating a fear of offending. So-called ‘political correctness’ may have contributed to awkwardness and uncertainty when talking about disability. In examining the language around disability it was important not to cause offence, reinforce stereotypes or use abusive language; however we did want to look at the historical use of language around disability. Use of words such as ‘overcoming’, ‘despite’ and ‘bravery’ are considered negative by many disabled people as they are indicative of sympathy and lowered expectations towards disabled people.

A number of ideas were considered and debated with PORTAL (the Museum disability consultative group), who suggested that recording a discussion with a group of disabled people would be an appropriate way to focus on language. PORTAL co-ordinator Catherine Turner recruited and led a focus group of disabled people who were filmed talking openly about disability language and the terms they use, along with their feelings on words used by other people. Disabled people were thus enabled to talk openly. We hoped that this film would give visitors an insight into the use of language and disabled people’s views on its use, and also encourage open discussion about the sensitive areas where people fear ‘getting it wrong’.

Involvement of disabled people

The involvement of disabled people was crucial to the creation of the exhibition. The people involved in the different projects were able to represent themselves in the way they chose. In so doing they felt a sense of ownership and comradeship through working with other like-minded people. Many said that this was the first opportunity they’d had to speak honestly and openly about difficult issues. This response shows that despite a general view that attitudes within society are changing, disabled people still feel marginalised.

Snapshot stories

A varied series of autobiographical films were written and produced by disabled people.

Abbie wanted to challenge people's attitudes towards disabled people. She was keen to show her many hobbies and interests, including her love of rugby and going to matches. Disabled people do not **"sit home all day watching daytime TV and twiddling our thumbs"**, she said, and this was a common theme throughout all of the films.

The films show the positive sides to people's lives but they also include some of the difficult experiences they face. Some of these relate to the physical difficulties of people's impairments, but many were caused by other peoples' attitudes.

An example of this is Kate, who talks about people's lack of understanding because her disability is not visible. She mentions that she is sometimes frowned at when using a disabled parking space to which people assume she is not entitled. In her film she asks people to think before making judgements.

Anne was keen to make a film which would educate others about Asperger's Syndrome. She talks honestly and openly about her struggles with mental health and disability and how she has found it hard to gain understanding from other people.

The film-makers felt empowered by having control over their product and the freedom to say whatever they wanted about themselves and portray chosen aspects of their lives. They felt that they were not given a voice often enough, and the experience gave them the confidence to talk openly about their experiences. The films were very honest, moving and enlightening as they were very personal and didn't shy away from some of the negative sides of people's lives, as well as highlighting the positive.

Comments

The response cards collected during the exhibition gave a good insight into visitors' current perceptions and how they might have been challenged by the exhibits.

Many felt that their perceptions had been changed, and the comments included a number of 'they are the same as us' type comments – which indicates, ironically, that there are still underlying ideas of 'otherness' and difference in relation to disabled people.

Some of the feedback used phrases such as 'I feel lucky', and 'I want to help them'. Although these were not intentionally negative, many disabled people understand these comments negatively because they reflect the idea of disabled people as needy objects of pity. Another comment from a child – 'I feel sorry for the people in wheelchairs', again indicates sympathy, which is negative to many disabled people. However, the child's use of language is less sophisticated and this could have been an expression of empathy rather than sympathy.

Looking beyond the contents of the comments, the fact that people were engaged and responsive is positive in itself. It shows that they had engaged with the personal stories, and were considering the issues presented.

We therefore consider that the exhibition was successful in challenging attitudes towards disability and can be considered a positive move forward in the area of disability representation. We also acknowledge the need to continue challenging attitudes and providing an arena for disabled people's voices.



Interactive display, part of the Life Beyond the Label exhibition
Photograph by Peter Carney

Conflict and Disability

Imperial War Museum London

Katie Potter

The **Conflict and Disability** project at the Imperial War Museum London aimed to encourage school students between the ages of 13 and 16 to question and reassess their attitudes to disability without being prescriptive and telling young people what they ‘must’ think. Each student brought their own diverse personal experiences and attitudes to the session in which they took part.

The sessions aimed to tell the stories of those affected by war in a way which did not reinforce negative stereotypes of disabled people. This was a challenging task, as some material in the collections reflected long-established stereotypes and prejudices; disabled people were portrayed in the material as being ‘charity cases’, deserving of pity, as unemployable and asexual; or the equally problematic stereotype of bravely coping or triumphing in the face of adversity.

The relationship between conflict and disability is multi-faceted and complicated; and the situation is by no means ‘resolved’. It would be wrong to assume that society’s attitudes become more inclusive and less discriminatory from 1914 onwards and present-day ex-service people with impairments are still presented with challenges similar to their First World War forebears. To ensure historical accuracy whilst attempting to challenge negative stereotypes, two approaches underpinned each session: firstly, the social model of disability framed the language used in session delivery; and secondly, as far as possible the diversity and complexity of disabled people’s lives were highlighted.

This account will examine the different relationships between disability and conflict explored in two of the four sessions developed. Response cards completed by young people, and follow-up interviews with students at two of the schools that took part will be used to reflect on the way in which visitor perceptions were challenged.

Disability Rights

The starting point for the **Disability Rights** session was the relationship between conflict and disability legislation, specifically the 1944 Disabled Persons (Employment) Act. The circumstances in which this act was passed relate directly to the Imperial War Museum collection. The large number of veterans returning from the Second World War with impairments, in addition to the labour shortage at that time, created a catalyst for legislative change. In all, a third of a million disabled people were employed in the war effort between 1939 and 1945.¹

To raise awareness of this crucial development, archive film from the 1944 **Back to Work** exhibition was used. The film shows disabled ex-service people doing, in the words of the voice-over, 'meaningful and efficient work' in factories in the Second World War. Bevin, Minister for Labour, stresses: **"The right of every disabled person to an independent livelihood"**. The impact of the film in changing attitudes is suggested by one student's comment:

"I have seen that people with a disability can have a productive job and a place in the normal working society."

Male student, aged 14

Disability Rights also aimed to raise awareness of disabled people's rights, and the discrimination faced by them. To facilitate this, students were asked to consider what rights were important to them and the impact of these rights being denied. They were then encouraged to consider rights which disabled people may have been denied. Nickie Wildin, from the disabled theatre group, Graeae, led the rights-based part of the session drawing on her own experiences of access to education, employment, transport and cultural events. Hearing Nickie's personal experiences had an impact:

"I think that disabled people should be recognised as equals and should be given equal opportunity before I thought if someone was disabled they should stay at home but my view is very different now!"

Female student, aged 13

"It makes me more aware what disabled people go through and that it's not fair. They get discriminated for something that physically happens to them."

Female student, aged 13

The impact of the Disability Discrimination Act (2005) was introduced by highlighting the role of disabled veterans' organisations in campaigning for legislative change. One student wrote:

"Before this session I thought that disability was a punishment for being bad but now I think differently. During WWI and WW2 thousands of people were disabled for protecting their country and they went through, and still are, a horrible time."

This role of veterans' groups was highlighted to the students within the broader context of disabled-led groups protesting for rights and an end to discrimination – campaigns that ultimately led to the Disability Discrimination Act. Nickie Wildin trained the students as Disability Discrimination Act 'Inspectors' and they conducted an access audit of three different parts of the Museum. This interactive activity stimulated the students to think about the disabling world and physical, sensory and intellectual barriers to access:

"I do think what I really enjoyed from doing it was the actual going round the museum. We were in the submarine section and looking at that actual part and what ways it could be improved, you know, wasn't really, you know, practical for somebody with a disability. But when you think of disabilities, most people just think a wheelchair automatically, but also thinking about in terms of vision and audio and that. So it was really, really good because we really got into it..."

In many ways **Disability Rights** was about raising students' disability awareness, as one female student, aged 14, wrote:

"I've never really thought about it before, so it makes me realise the impact it has on peoples lives."

To consolidate learning about how disabling barriers can be broken down, students made wish lists of access improvements for their own school. These were presented to their local MP in the second part of the session at the Houses of Parliament. Perhaps this quote from a member of school teaching staff best sums up the impact of the session:

"I think for me what stuck in my head is the young people's reaction because their experiences of disability around the school is not that common. I mean we do have, you know, as a mainstream school we have to take children with different educational backgrounds ... So we've had young people who have had Tourette's for example or certain mobility problems, but it's not very common and that. So for them I think it was good for them to have that exposure and look at something that was a bit different from their own lives. And what was good is that it got them really talking about things, that how the school could be different and that."

Necessity Breeds Invention

The **Necessity Breeds Invention** project investigated how the large numbers of badly burnt airmen in the Second World War led to advances in surgical techniques by Sir Archibald McIndoe and the creation of one of the first patient self-support groups, the Guinea Pig Club. The accompanying educational session aims to raise awareness of the experiences of people with facial disfigurements through the story of one member of the Guinea Pig club, Jack Toper.² An **Implicit Attitude Survey** carried out on behalf of the charity Changing Faces³ showed:

“negative bias to people with disfigurements in relation to the public’s perceptions of how happy people with disfigurements would be, their attractiveness and desirability, their social interaction skills (or sociability) and life prospects.”

We hoped to counter this negative bias with Jack’s story. This was part of the process of encouraging the students to see the ‘whole person’, not just a man with severe burns.

After Jack Toper left the Queen Victoria Hospital in common with many of the members of the Guinea Pig Club he went into full employment. He married Sybil, edited the club’s magazine and in 2003 was awarded an MBE for services to people with severe burns. The students watched documentary footage of Jack speaking about his experiences. They curated a mini-exhibition about Jack’s life, sorting facsimile archive material, including photographs of Jack from 1943 to the present day, into themes which included:



- Humour
- Social Network
- Employment
- Innovation
- Endurance
- Identity
- Friendship

Charting Jack's story from his accident and treatment, to life after the War was an important part of highlighting that people with facial disfigurements lead complex lives. Inevitably, each student interpreted the story in their own way. For many of the students 'reassessing' their attitude towards disability took the form of thinking about it for the first time. A common response was for students to express sympathy towards Jack. Many also voiced respect:

"I have a lot more respect for people with facial disfigurements because I can now understand the things they went through and the fact that they were able to overcome, and move on with their lives."

Female student, aged 15, Community College Whitstable

"After learning about Jack Toper and the Guinea Pig Club I have learnt how even severe disabilities can not affect someones capability. I now feel that a disability cannot come between what you strive for in the future."

Female student, aged 15, Community College Whitstable

A key aim of the session was to highlight the 'non-disabling' attitudes of the people of East Grinstead, which became known as 'The Town That Never Stares'. Sir Archie McIndoe understood that the psychological elements of the men's treatment were just as important as the surgical. He created a relaxed and sociable atmosphere on the hospital wards but also encouraged the airmen to move beyond the 'safe confines' of the hospital. He spent time talking to the residents of East Grinstead, explaining the airmen's stories and underlining the importance of valuing and treating them as equals. Students were shown film of the residents of East Grinstead talking about their experiences with the airmen and feedback has shown that this was key to encouraging the students to reassess their own attitudes to disability and to consider barriers less obvious than the physical.

"I thought it was all very, very good, I really did. I think the particular part where they went into Sevenoaks and they were asked to go for tea and into the fair and that sort of thing, and to be treated as though they haven't got disabilities, because people do don't they, unfortunately they do... they shy away, all sorts of things like that. And the fact of these men, they've done a lot, they've suffered for their country and the fact of just allowing them to come back into society and not to look at their disability, look past their disability. And I think that came across very, very well in the session."

History teacher, Community College Whitstable

For some students the session reinforced existing attitudes:

"I don't think this session has changed the way I think about disability, because I always tried to see disabled people as equals and I've always tried to treat them normally i.e. not stare at them. I think [it] has just reiterated the fact that disabled people are just normal people."

Male student, aged 15, Community College Whitstable

The second part of the session took place at the Hunterian Museum.⁴ Students used objects and information found in the Museum's galleries to examine how the treatment of the airmen led to pioneering advances in surgical techniques and find out about the role of Sir Archie McIndoe and his teacher Sir Harold Gillies. Through a hands-on workshop students were able to handle surgical instruments and medical equipment and learn about their development and use in treating injuries sustained in war. The two-site session built on the strengths of each collection and the specific expertise of each museum and enabled the social, psychological and medical aspects of the Guinea Pig Club story to be told whilst ensuring that the voice of the airmen remained central.

"I think [the Imperial War Museum and the Hunterian Museum] were both trying to demonstrate how these people have been through a lot and you still should treat them with the same amount of respect even though they've been through all this and maybe disfigured and scarred, but they're still people at the end of the day."

Female student, aged 15, Community College Whitstable

Disability Rights and **Necessity Breeds Invention** both had the intention of encouraging students to question and reassess their attitudes to disability. Often this reassessment was positive, although some pupil responses did not reflect a move away from attitudes we had hoped to challenge. The nature of the relationship between conflict and disability means that the students were being challenged to reassess their attitudes within the context of sessions focusing, primarily if not exclusively, on the stories of those with impairments acquired whilst fighting for their country. For many of the students the sessions provided both the opportunity to think about disability issues for the first time and also reflect on the impact of conflict on people's lives.

1 <http://news.bbc.co.uk/1/hi/health/353682.stm> Accessed 1.12.08

2 Jack Toper gave permission for his story to be used which included allowing use of personal photographs and his medical records.

3 To find out more about the work of Changing Faces and the findings of the survey go to <http://www.changingfaces.org.uk/Home> and <http://admin.changingfaces.org.uk/downloads/FE%20Campaign,%20Public%20Attitudes%20survey.pdf> Accessed 1.12.08

4 Highlighting this key part of the Guinea Pig Club's story helped to link the session to the curriculum, specifically the GCSE Medicine Through Time course. Such curriculum links are vital to ensure that teachers will book the session.

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Archives and Museum,
University of Leicester
and film maker
David Hevey



Behind the Shadow of Merrick

Royal London Hospital Archives and Museum

David Hevey

Behind the Shadow of Merrick aims to present disability in a new and challenging way. Visitors to the Royal London Hospital Archives and Museum often have some familiarity with Joseph Merrick's story. Not infrequently their familiarity derives from having seen films, notably David Lynch's 'The Elephant Man' (1980), or from having read books or seen plays that portray Merrick in a comparatively passive manner. In these fictional accounts, Merrick is usually known either as the 'Elephant Man' (the anthropomorphic identity by which Joseph first presented himself to the paying public) or by the pseudonym 'John Merrick', the name given to him by the surgeon and writer Frederick Treves in his reminiscence 'The Elephant Man' (1923). In these portrayals Joseph is presented as 'the other', a pathetic, child-like figure whose early life is obscure and who is saved from cruelty and exploitation by the 'safe haven' offered by the London Hospital and the sponsorship of the doctor Frederick Treves and hospital chairman, Francis Carr-Gomm.

There is a distinct cinematic set-up in the Museum, in which visitors have an opportunity to sit down and view a number of short medical-themed films, including some relating to Joseph Merrick. We knew, therefore, that we had an audience for **output**, but not necessarily for a new way of seeing Merrick.

"The great thing about David Hevey's film is that it's a real change from the other films, a completely different experience, much more emotive, touching and simple. It's quite hard to watch in places. Some people find the film shocking, though some watch the whole series of films, and might write comments like 'good films' or 'moving films'. We used not to get those type of comments, so they watch David's film with the rest, and they pick up the emotions of his film."

Jonathan Evans, Archivist, Barts and The London NHS Trust

Often, Merrick lived at the harsher end of humanity but he responded with humanity and humility, in part because he had a first-class brain but also, in part, because he met people who understood him beyond the ‘Elephant Man’ label. Many took an interest in Merrick, including **Royalty Times** readers of the day, not as a freak, that is to say a spectacle to be put down or diminished, but as someone who lived on the borders, in the way that explorers, soldiers and scientists lived on the borders in the late-Victorian era. The English freak-show owner for whom Merrick worked did not rob him – remembering that it was Merrick who applied for the job – and seems, like most people, to have come to respect Merrick the man, beyond Merrick the phenomenon. Subsequently people have re-freaked Merrick. My intention with **Behind the Shadow of Merrick** was to get him back to his essential humanity, truth and lived-experience, but alive now, through the empathy and identification of others. This, for me at least, is the purpose of the film.

Unsettling viewers

Behind the Shadow of Merrick is a film that shocks some viewers but what interests me is truth and how to show and tell it, not tricks, spectacle or shock. I didn’t set out to shock; I set out to uncover the long shadow of Merrick and to work out why it is still cast into our times and what he still tells us. Indeed, I was ‘shocked’ how large Merrick is in the lives of disabled people and how keen so many were to tell their tale of him.

Merrick was seen as different, just as Tina, Rowen and Tim (the disabled people whose connections with Merrick’s life feature in the film) are seen as different. Tina is a burns-survivor and an extraordinary woman, not necessarily because of her impairment but because of her articulacy about human nature, about living in the modern world and about the shortcomings of humanity, as she experienced them at the sharp end. Perhaps the ‘shock’ of the film, which I don’t see but which I understand, is that Tina, Rowen and Tim are the willing descendants of Merrick, his accomplices in turning his challenging life in the past, into challenging their world today.

Our decision to develop this project as a film (rather than any other medium) has significance for the way visitors respond. As a film, **Behind the Shadow of Merrick** is primarily **visual** and **moving**. The story moves along visually and aurally but it is not ‘radio with pictures’, the accusation so often thrown at bad TV and film. The film is a **visual** response that Tina, Rowen and Tim have to the unfolding story of Merrick in their midst and in their consciousness and, while the film’s visuals are underpinned by dramatic stories, the primary level is about changing one’s **visual** view of Merrick and, by their obvious and willing association, changing our visual view of other people who are different in the way he was different.

So, when people are shocked by the film, I wonder if it is the visualisation of Merrick-and-Tina-and-Rowen-and-Tim that actually shocks: some people might wish to have seen a more mythologizing or intellectualising film, but not one so visual, perhaps?

Tina, Tim and Rowen make this visual impact explicit by articulating their joint existence with Merrick and the huge similarities they share with him; the deep emotional detail of being 'other': the experiences of living apart, of isolation, fear and segregation. Tina, perhaps more than most, shows that Merrick was the forefather, not the freak. When Tina talks about what she would say to him, across time and space, one only has to witness the emotion to feel that transcendence.

Whilst I don't personally see **Behind the Shadow of Merrick** as shocking, the film is nevertheless unsettling. Many people hate their patterns to be broken and the film sets out to break patterns; the cinematography is 'in your face'; extreme close-ups, portrait after portrait, a few establishing wide shots, then back to portraits and eyes. The editing underscores the patterns-breaking feel by being 'off the beat'; the images cut suddenly, images which are beautifully shot on film and graded to hover in our consciousness, to be beautiful images of people who do not normally have beauty bestowed on them, as Merrick did not. Just when you get comfortable and feel safe, a cut comes in to move you to a new and unknown image.

Performing the props

We had three basic props to use in the film: a copy of Joseph Merrick's veil, his calling card and a poem.

The card – who is this man?

The first artefact was the carte-de-visite which Merrick himself had made. He wears a suit, he does not hide away. It is intriguing because it is shameless, no veil to hide behind, and no games with the focus. This image of Merrick was intriguing in that he demonstrated, dare I say it, pride. It reminds me of the freak-show archives which, far from being freaky, show images of showmen, such as Tom Thumb, who controlled their own images, who were clearly proud of themselves and who sold these cards by the tens of thousands and saw themselves as somebody, as Merrick appears to in his carte-de-visite.

And remember, in the freak-show, the 'freak-show' label was put on by the showman. To this day, horror is one of the biggest selling genres of story-telling but it was not particularly present in the photographs that the performers themselves had made. This was the same with Merrick; he did not enfreak himself. In the shots of Rowen and Tina studying the card, we see beyond their differences into their sense of self; the shots show how they identify with him, but humanise all of them at once.

The veil – inhabit that man

The second artefact was Merrick's veil; we used a copy. The museum has the original, which Joseph wore in the freak-show and, presumably, on those days when he couldn't face the staring. It is huge, but the eye-slit narrow, like a pillbox bunker. Maybe the veil also operated as an 'access tool'? Maybe it enabled Joseph to walk around, with the veil hiding his difference? Certainly, Tina very much identified with this and describes her use of long hair and a hooded jumper to do much the same.

As Tim put on Merrick's veil, as Rowen hung Merrick's veil on her wheelchair-arm, as Tina wore the veil, poking her tongue and arm through the eye-slit, they explored what hiding away meant to them. In that part of Whitechapel where the Royal London Hospital is situated, and where the presence of the burkha is supposed to hide beauty, here was a veil that was, perhaps, supposed to hide Merrick's monstrosity?

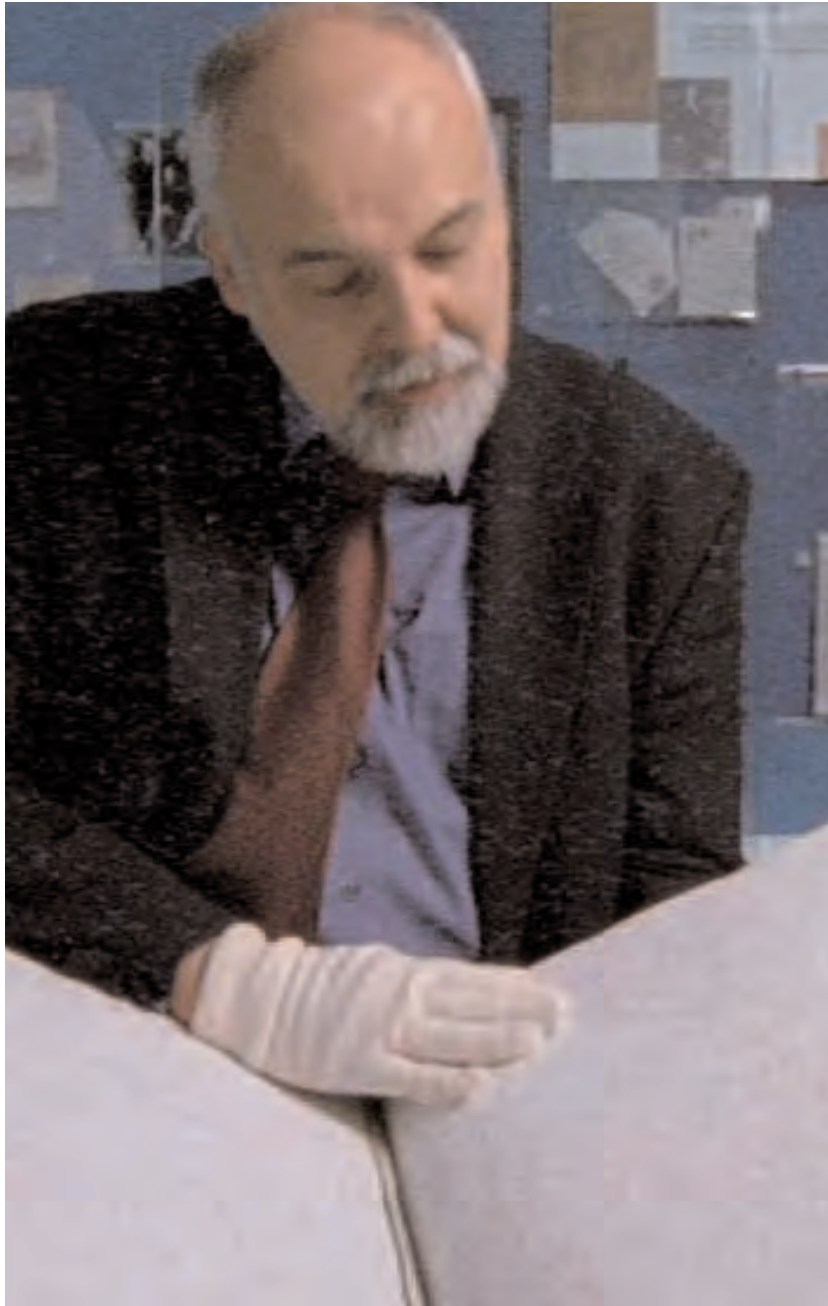
And the act of these people visually playing with the veil is itself shocking. Tina, Tim and Rowen display no special reverence for the object itself but they hold enormous reverence for Merrick. But it was important in our film for them to play with the veil, the card and poem, to physically re-inhabit Merrick, to live the world as he lived it. His life wasn't remote to them and the film shows that.

The one thing that people rarely see today in representations of disability is those who are different actively changing their image. Seeing Tim, Tina and Rowen explore Merrick's veil certainly broke notions of victimhood for them and for Merrick.

The poem – see him as he saw himself

Joseph Merrick left behind his version of a poem, which concludes, **"the mind's the standard of the man"**. I directed two of my three contributors to inhabit this poem, which they did in very different and distinct ways. Tim's performance was about the mental clarity and control which the Victorian Merrick might have felt, knowing he had such a good mind. Tina's was more emotional, a soap-box oration for change. Tim's was a command, Tina's was a plea. I could have simply had an actor read the poem, have a shot show the poem and, hey presto, the audience learns – nothing. They learn nothing because nothing would have moved them. The way we did it, with the disabled contributors entering the poem in the way that actors enter a role, brought it to life, gave the audience yet another layer of possibility about Merrick and possibility about all difference (and the toleration of difference).

People are obsessed with tracing-their-ancestors, but our ancestors live in our genes. It was as if we were using the card, the veil and the poem to trigger a sort of genetic-memory; to live-again inside Merrick, his cares, his thoughts, his passions and his strength, and him to live inside Tina, Rowen and Tim, his heirs to difference.



Copyright Royal London Hospital Archives and Museum, University of Leicester and film maker David Hevey

What the audience brings to the film

Behind the Shadow of Merrick works in layers and should be viewed several times. But, at the same time, it is also clear and up-front. It is not a dry documentary, but it uses real people, their real lives, fears and emotions. It is not a drama, but the people perform. In the end, the uses of imagery, story and editing, are all at the service of telling a new truth. If people want to learn more of the facts of Joseph Merrick's life, they might learn them here, but not dates and times. Rather, they may learn how he might have **felt**. One thing I do believe, the viewer will not be able to police it in their head and it will reverberate.

In the film, a young girl's voice-over says: **"Sometimes Joseph Merrick lived in the dark. You have to feel strong to take on the staring."**

Tina responds: **"Oh, I completely understand that, that Merrick didn't want to come out, except for at night. I went through a few years when I would only let people come to my house when the light had gone down, the light had faded or it was dusk..."**

My hope is that audiences allow themselves to feel their way through the film, and not be scared by the obvious raw authenticity of some of the contributions and how these raw and authentic contributions challenge one's pre-existing notions of those who are different.

For example, in the film, the young-girl voice-over asks:

"What would disabled people say to him now, if they could talk to him across time?"

And, as Tina plays with Merrick's veil, she responds:

"If I met Merrick today (pause, hesitation), Merrick might not like me. When I think about it, because he'd be looking for the perfect woman, the so-called perfect woman, y'know, someone who's beautiful and certainly without scars, I fear that would be the case, but if he wasn't like that, well even if he was it wouldn't matter, but I would tell him to hold his head up high. Merrick made his mark on this planet and it was a pretty good one and I think he's a role model for a lot of us crips."

What is the point of reclaiming Merrick?

Merrick did not fit, but many feel they do not fit. Merrick was different, but many believe they are different. In reality, it was the merger of two things in Merrick that gave him his historical presence: the huge 'outsiderist' body, with a huge 'insiderist' brain. It is clear he could operate in all levels of society, from the freak-show booth to the Royal booth at the opera. While there is something of the Old Testament about him; all is vanity, there is also something of the Modern about him; the striving to find a role for one's difference. There is something of the fighter in him; he kept going. There is celebrity; he featured in **The Times** and met Royalty. He pushes many buttons. But this project is the first time Joseph Merrick has been claimed by those who are the most like him: disabled people. And not just claimed fancifully but by virtue of the fact that the key-stages of Merrick's life are the archetypal key-stages of many disabled lives. **Behind the Shadow of Merrick** visually showed these connections and challenged those who enfreak disabled people today and in the past.

Ultimately, in my version of Merrick's story, he represents that shifting shoreline between mainstream and outsiderism, between beauty and the beast, between being meaningful and being meaningless in life **as judged on one's body**.

We all want to leave our mark: Merrick did and I think he knew he would.

Merrick will still be discussed and revisited in a hundred years because he casts a shadow on the nature of life: difference, fear, outsiderism, and the fight we all have – to be seen as we see ourselves. These things are classic, universal and contemporary and he represents them more than most – and so do Tina, Rowen and Tim.

What do you think?

This exhibition has explored how society's attitude towards disability has changed over time, and how it has affected the everyday lives of local Deaf and disabled people.

What are your views about disability?

Photograph by
Peter Carney

PART 4

Visitor Responses

Visitor response forms
for One in Four
exhibition, Tyne and
Wear Museums

Photograph by
Peter Carney



A key aim of **Rethinking Disability Representation (RDR)** was to offer visitors alternative, informed and unprejudiced ways of thinking about disability. Each of the nine projects, though diverse in approach and content, was designed to counter negative stereotypical representations and to engender support for the rights of disabled people. How then did visitors respond to and engage with the exhibitions, displays, films and educational sessions they encountered?

Research methods

To address this question two main research methods were used. Firstly, response cards which asked visitors how the project had changed the ways they think about disability were used across each of the nine projects. The cards were designed to elicit an overview of visitor responses with the focus on a single question. Considerable effort was put into designing the response cards and formulating a question that would be broad enough to work across all nine projects (each with their very different content and approach to disability representation), but which would be direct enough to elicit meaningful responses from visitors. A pilot study, trialling a number of different options proved useful in refining the design of the card and determining the final phrasing of the question – ‘How does this display/film/session change the way you think about disability?’ The response card also asked visitors for basic demographic information. Cards were left for visitors to pick up at the end of their visit and several museums were proactive in approaching visitors and asking them to complete one.

Secondly, to explore visitor engagement in greater depth, interviews were conducted at Colchester Castle Museum, Tyne and Wear Museums and Birmingham Museum and Art Gallery. In addition to these two primary research methods, two case-studies were undertaken with school groups at the Imperial War Museum, London (which included an observation of their visit to the Museum and follow-up interviews with a selection of pupils back at their school); observations were conducted in a number of exhibitions to gather contextual data and a small number of focus groups were conducted to explore responses to the film **Behind the Shadow of Merrick**.

The data generated by these methods was analysed with the aid of qualitative data analysis software to identify recurring themes and patterns of response and the results of this evaluation are discussed below.

A note on language

Although we recognise that the language used by participants in the research may not always conform to contemporary expectations of what is deemed appropriate, we have nevertheless presented their comments in an unedited manner, whilst acknowledging the ways in which language can be used (intentionally and unintentionally) to discriminate and stigmatise.

The task of challenging established ways of seeing disability and deeply seated attitudes towards disabled people is a substantial one – these are unlikely to be transformed by a single visit to a museum. Nevertheless, as the following discussion shows, museums have the potential to offer authoritative and credible ways of seeing that can play an important part in framing the conversations that visitors have about disability.

This section reviews the findings from the evaluation of **RDR** in two main sections. Firstly, we discuss visitors' general reactions to the nine museum projects, identifying the main ways in which they engaged with the interpretation they encountered, and the features or attributes they most frequently highlighted, and we examine their views on the appropriateness of museums as sites for presenting and discussing contemporary social issues in general, and disability in particular. The second part examines the extent to which **RDR** succeeded in informing visitors' thinking, their perceptions and attitudes. Here we examine the ways in which visitors engaged with the purposefully designed narratives and the moral standpoints, informed by disability-rights perspectives and the social model of disability, which underpinned each of the projects.

General Reactions and Responses

Although some visitors expressed concerns and discomfort with the projects they encountered, these represented a small minority of the responses that were elicited through the evaluation. The majority of visitors who completed response cards, or were interviewed, expressed their support for the displays, exhibitions, films and educational sessions they visited or took part in.

"A very worthwhile exhibition. Everybody should be aware of the challenges disabled people have to face within Society."

Colchester Castle Museum, male, aged 26-35, non-disabled

"Fantastic and engaging and truly absorbing. Thank you for making me think about this for the first time – a revelation."

Northampton Museum, female, aged 36-45, non-disabled

"I liked the promotion of the 'social model' of disability. Exhibition very well designed – hats off to the designer – it's obvious a lot of hard work went into this. Nice to have stories from people too."

Tyne and Wear Museums, female, aged 16-25, non-disabled

"Very interesting exhibition. Bought home the stigma attached to disability."

Colchester Castle Museum, female, aged 36-45, non-disabled

"The film made me more aware of people's reactions to disabled people and how those with disabilities can be affected. Even in 2008, disabled people are looked down upon, judged etc similar to Merrick was in the 19th century. Aside from looking at solely objects, the video made a strong impact, giving peoples views on disability."

Royal London Hospital Archives and Museum, female, aged 26-35, non-disabled

Methods of interpretation

Visitors often commented favourably on the variety of interpretive methods and approaches the museums used to communicate ideas and engage audiences. The use of mixed media – films, audio, interactive elements and so on – was well received.

"I loved the way that it was laid out actually. I liked the way that it led you around, led you from one part to the other. I like the way that it had the things like the earphones and the Braille books and all of that kind of tactile stuff as well, I quite liked that."

Margaret¹, Colchester Castle Museum

"I thought it was brilliant. It was so informative. And there were lots of ways that you could get the information, you know, it sort of included quite a few creative ways, sort of either hearing about it or a display."

Anne, Tyne and Wear Museums

Several projects used humour and most used disabled people's own voices and experiences to communicate ideas – approaches which were also enjoyed by visitors.

Balance and objectivity

Other visitors appreciated how the exhibitions were seen to be 'well-balanced' and 'objective', presenting disabled people more 'accurately' than other, more stereotypical, perspectives might have done. One visitor, William, particularly appreciated the approach taken at Birmingham Museum and Art Gallery:

"...the opinions were good, I enjoyed the opinions, it was nice to hear an opinion, especially a well-balanced one, cos sometimes you get ... people have some strange opinions of people with disabilities. I've disabilities myself. I've worked with a lot of people with a lot of different disabilities, but like some people have a very narrow view and don't really understand what disabilities are about ... They sort of have a label and they forget that people are behind these disabilities. So it's nice to hear quite a balanced view wasn't it?"

A number of comments suggested that the incorporation, within projects, of multiple perspectives and ‘real-life’ stories (as opposed to the single curatorial voice of the museum) enabled visitors to have a degree of autonomy in establishing their own opinions about the topic.

“It’s actually up there, open for you to get [disabled people’s] direct views as well ... you can then make your mind up about how you feel about the words and the way they describe themselves.”

Joe, Colchester Castle Museum

Challenging stereotypes?

Many supported the way in which negative stereotypes were identified and challenged by the museums, leading to the presentation of more complex and nuanced views of disabled people. For example, they responded positively to the portrayal of disabled people as active and independent, which provoked interest rather than sympathy.

“Stereotypes in which the debilitated live are quite thoroughly and unashamedly smashed away by the interpretation that is conveyed by the audio point...”

Birmingham Museum and Art Gallery, male, aged 16-25, disabled

“What I really liked about the display was how positive it was. Rather than making us feel sorry for the disabled it made me understand what people were doing about it...”

Colchester Castle Museum, female, aged 15, disabled

A small number of responses, however, questioned the approach to interpretation at some sites and believed that visitors might leave with reinforced (not challenged) stereotypical views of disabled people.

“Deeply ambivalent about portrayals – why non-speaking camera work with voice-overs? (but not the curator). If this is a strategy, it is too subtle for non-disabled viewers – reinforces romanticised – melancholic + super cripple stereotypes. Oh dear.”

Royal London Hospital Archives and Museum, female, aged 46-55, disabled

“It doesn’t really CHANGE my views or opinions on disability. I feel like the people interviewed here were picked because of their disabilities; it is the disability that defines them, and no names or anything... it’s almost perpetuating the “freak show”. I think integration is key: what ever feature sets you apart from others is what isolates you...”

Royal London Hospital Archives and Museum, female, 26-35, non-disabled

Range of disability issues and experiences

Taken together, the nine different museum projects included objects and stories linked to people with experience of a wide variety of impairments. Whilst it was recognised, during their development, that individual projects could not hope to cover the full breadth and diversity of experiences of disabled people, some visitors were nevertheless concerned that particular groups were less represented than others in the museum they visited.

“There was a little bit on learning difficulty, quite a lot of physical disability, a little bit on deafness, covered mental health very briefly, just touched on certain aspects, but some conditions were never touched on other than it gave a little overview of what the DDA 2005 said, and it talked about HIV, cancer, multiple sclerosis being covered, but never delved into conditions like that. And I think it’s too easy to think of disability in terms of those few things that were picked out.”

Julie, Tyne and Wear Museums

Personal connections

Many visitors chose to highlight their personal connections with, or experience of, disability. Some articulated their own identity as a disabled person, others referred to disabled family members and friends or talked about their professional experience of working with disabled people. Individuals with some connection to disability were generally very positive about encountering, within the museum setting, a topic that was important to them personally. Many comments suggested that, by addressing the topic of disability within an authoritative public space, the nine projects conferred value upon disabled people’s views and experiences.



"Helps open my mind even more so to disability which is something that is within my regular life, within my family. So therefore is brilliant to see things developing, makes me feel happier and better that things are changing and improving relating to something that is close to home."

Birmingham Museum and Art Gallery, female, aged 16-25, non-disabled

"I think it's wonderful. I have a disabled daughter and teach in an SEN [Special Educational Needs] unit. Please take this to as many places as you can."

Colchester Castle Museum, female, aged 46-55

Sites of learning

A number of visitors – both disabled and non-disabled – identified the role of the museum as a site of learning or a forum for the discussion of social issues. They expressed the view that museum exhibitions and displays could help to increase understanding amongst the public and impact on how disabled people are treated by society.

"By exposing all visitors to art about and art done by disabled persons it conveys the message that they are welcome and accepted members of the community, as they should be..."

Birmingham Museum and Art Gallery, male, aged 16-25, non-disabled

"...showing this exhibition it is educating people about the problems that people with disabilities face on a day to day basis and what disabled people have faced in the past. This is a great way to educate people and make people aware that people with disabilities are just the same as everyone else."

Tyne and Wear Museums, 'support worker'

"We really need more of these exhibitions, make people aware of the barriers. Anything to help people be included. Brilliant exhibitions!"

Tyne and Wear Museums, female, aged 46-55, disabled

In particular it was felt to be important to inform younger people. Their assumed lack of experience of disability and disabled people was felt, by some visitors, to contribute to ignorance and, consequently, a lack of respect. Museums were seen as a way of extending their world view in a positive manner. Such comments came from young people as well as from adults.

"I think that people my age don't really understand to a greater level to be able to respect it and it's something different and they'll either torment it or just shy away from it... I think they should be taught more. And since going I've learnt a lot more and I've got a different outlook. And I think every person my age should have that experience because you just need it."

Stacey, Imperial War Museum, London

Are museums suitable places for discussing disability?

The topic of disability in a museum context sometimes surprised visitors. For some, the unexpected nature of the content was effective because it forced people to engage with a topic that might otherwise be ignored or seen as taboo and hidden away.

"I think it's the subject matter and I think that people reject it unless they've come into contact with it. They just do not want to cope with it at all and I think it's endemic within British society."

Emma, Colchester Castle Museum

"I think it's more sort of 'in your face' then really isn't it? 'Cos you're not expecting it. It's a good space to be in, isn't it?"

Ashley, Colchester Castle Museum

"It made me feel more comfortable discussing disability. It opened up a subject that people are perhaps afraid of talking about..."

Northampton Museum, female, aged 26-35, non-disabled

"The painting, 'Figures in a landscape', shows how people in society section off disabled people or differentiate them. This is wrong. Disability is often seen as a taboo subject and is either frowned upon or pitied."

Birmingham Museum and Art Gallery, male, aged 14, non-disabled

However, the unexpected nature of the topic did not appeal to all visitors. One visitor to Colchester Castle Museum expressed their surprise, **'... that the museum is being used for a modern propaganda display'**. Other individuals found the exhibitions and films they encountered provocative and challenging. For some, this was stimulating – an effective way to prompt visitors to think differently about disability – whilst others were less comfortable with this approach. Peter, a visitor to **Life Beyond the Label**, for example, was troubled by a part of the exhibition featuring photographs of disabled people with words written on their faces representing different aspects of their identities:

"I think the pictures with – they've got the writing over their faces, I think that's a bit... I find that a little bit off-putting.... they're a little bit 'in your face', you know, that person's obviously trying to tell you something but I find the form is a little overpowering."

For some visitors, museums were seen as public spaces that could potentially reach a diverse (and perhaps, to an extent, 'captive') audience that might not otherwise be exposed to the issues raised by each of the projects.

"For me personally it hasn't changed my thinking but I do think it a very good idea as it gets the message across to people who would not normally be reached otherwise. Also good as a lot of children visit museums and again get the message they may not normally come across."

Colchester Castle Museum, female, aged 36-45, non-disabled

"And I suppose a museum is the kind of place, especially this kind of museum where you can get a whole spectrum. You're going to get the tourists, you're going to get the different age groups, children and old people etc. So I suppose in a way it probably is quite a cross section by putting it somewhere like this."

Tracey, Colchester Castle Museum

Some visitors felt strongly that museums **should** be discussing disability; they are trusted, authoritative public institutions which confer value upon such topics.

"...[the public] look upon a museum as somewhere they can go and better themselves if they like. That's terrible isn't it, that's [a] really non-PC thing to say. But yeah, it has some kind of authority stamped upon it, kind of something that's like 'not on the level' with everything outside... they'll give it more credence than if they saw it in a bar or a café or something. So it just gives it more authority and more power."

Colin, Birmingham Museum and Art Gallery

"Well museums and galleries are where you can talk about anything really, any aspect of life should be explored through art I think."

Marion, Birmingham Museum and Art Gallery

"...disabled people visit museums just the same as everybody else does and it's a good way of sort of highlighting it."

Sandra, Tyne and Wear Museums

Not all responses were so positive. Some visitors, faced with the question, 'How does this display change the way you think about disability?' were keen to point out their own (pre-existing) 'progressive' or 'enlightened' views. The two comments below, for example, suggest a resentment at the perception that the museum is attempting to prescribe the way they think about disability.

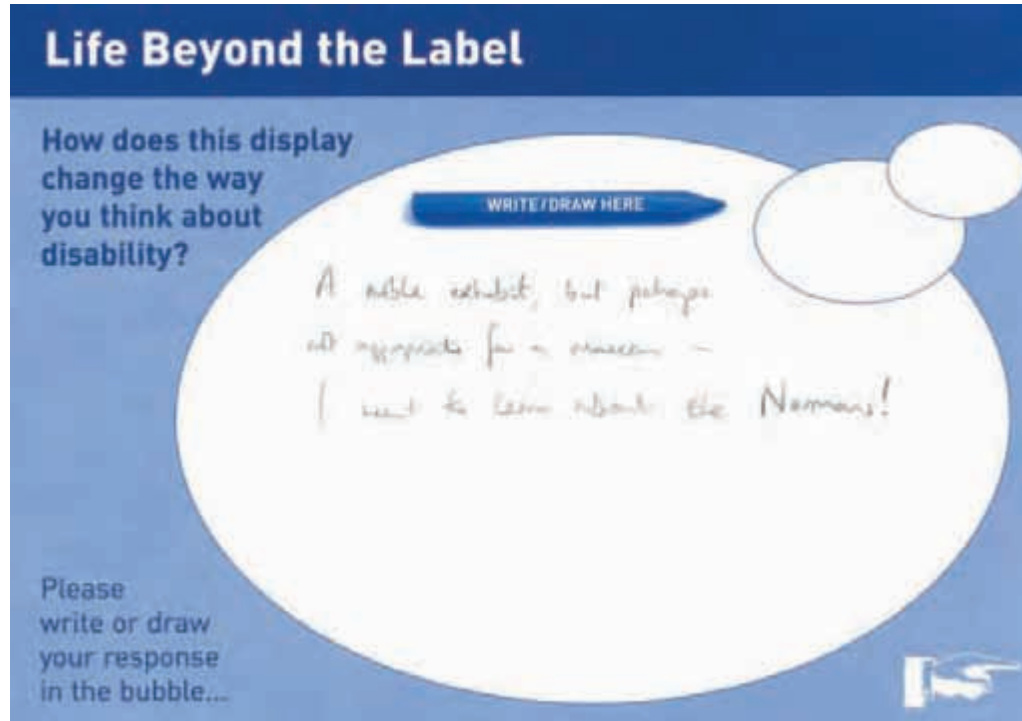
"It doesn't [change my attitude] as I'm fully signed up to the view of seeing beyond disability anyway. I don't feel this venue is appropriate for this."

Colchester Castle Museum, male, aged 46-55, non-disabled

"I am familiar with problems of mobility and find this somewhat patronising and distasteful. Stumper doesn't seem to have a problem with his peg leg and why should he?"

Whitby Museum, female, aged 66-75

Some comments reflected visitors' strong views on the role of museums. Museums, it would seem from some of these comments, were not viewed as places which should engage with contemporary issues. One man visiting Colchester Castle Museum wrote the following:



Changes to permanent galleries caused concern amongst some visitors, particularly at Stamford Museum where the existing display on Daniel Lambert was radically altered. It is clear that some respondents had been attached to the old display (and some demanded its return) or they did not find the new approach to interpreting Lambert's story to their liking.

"Why dismantle a perfectly good display? It's 'replacement' gains absolutely nothing. A waste of good representation. Backward thinking!"

Stamford Museum, male, aged 46-55, non-disabled

More visitors, however, responded positively to the changes, engaging with the new perspectives of Daniel Lambert offered through the framing of the exhibition by the social model of disability.

"Emphasis on his mind and personality is well done and his size becomes just a part of his whole being."

Stamford Museum, female, aged 56-65, non-disabled

"It reminded me to take the person as a whole and not concentrate on the disability – to celebrate what someone can do/did – not what holds/held them back."

Stamford Museum, female, aged 46-55, non-disabled

"I like the new interpretation of Daniel Lambert as a thinking man, intelligent who wasn't exploited but must have had a lot of expense, clothing, transport etc so who can blame him for making money?"

Stamford Museum, female, aged 56-65, non-disabled

Disabled people's voices

Threaded throughout visitors' responses to all nine projects elicited in the evaluation were comments which suggested that the inclusion of the voices and 'real-life' experiences of disabled people were highly significant for visitors and had considerable impact on their thinking. Visitors talked about how they valued the personal experiences of disabled people, how the inclusion of these perspectives conferred authenticity upon the content. Many were prompted to share their own experiences of disability in response, whether they themselves were disabled, had disabled family and friends or worked with disabled people. Across the nine projects, visitors responded with emotions that ranged from anger and righteous indignation, to sympathy or hopeful optimism in response to the stories told in the museum. Personalising the topic of disability – by giving faces and names to people who shared their experiences – meant that the issues raised by each of the projects were seen from the point of view of disabled people. It appeared that, for some visitors especially, this was a powerful approach, enabling them to empathise with (and understand) the topic from a new, more authentic perspective.

"Makes you look at it from their view. Makes the issue more 'human'."

Colchester Castle Museum, female, aged 26-35, non-disabled

"...if you go to a museum it gives it a much more sort of, I don't know, it appears to you as like more real and more like, you know, it actually happened. Whereas sometimes, you know, if you read something in the paper you might not take it in as much as actually being surrounded by it."

Ruby, Imperial War Museum, London

Coming into contact with individual experiences of disability turned abstract imaginings of 'disabled people' into something more real and tangible.

"Like for normal people who do come, I'd say the exhibition, I think it's like a 'wow factor' cos ... they've heard of disabled people but they've never known all about the disabled people themselves. I think it's all about they don't know the person's disability and... they get into what the persons were like. I think that's the message that gets sent out."

Alex, Tyne and Wear Museums

The power of personal stories to elicit emotional responses from visitors was evident in the evaluation. These responses suggest that people were able to engage deeply with the material on display in ways which inspired empathy, surprise, awe, horror, anger, pleasure, gratefulness, understanding and reflection. Highly emotional reactions were perhaps most frequently expressed in response to the film **Behind the Shadow of Merrick**.

"I think it has made me consider feelings more than facts. I was surprised how intensely it has affected me. I'm not hard hearted but hadn't thought about the people behind disability however this film forces you to, it's a good thing."

Female, aged 16-25, non-disabled

"It didn't make me change the way I think about disability so much as made me consider my own prejudices. The personal nature of the film made me very aware of how I usually consider a disabled person's disability before their personality (even if I think I have the best intentions / am being PC) and how frustrating I would find that if I were in their place."

Female, aged 16-25, non-disabled

It was important for visitors that disabled people had been actively involved in shaping the projects. Disabled people were speaking ‘for themselves’, not spoken for by parents, carers, charities, politicians, or pressure groups. Comments suggested that people trusted the real, authentic voice.

“...you look at how [disabled people] presented themselves in those three images. I imagine it's themselves, because the feeling I get is that ... the people involved have been active, not passive. It's not been done to them, but they've collaborated.”

Joe, Colchester Castle Museum

Changing Attitudes Towards Disability?

This next section examines in more detail the ways in which visitors were prompted to think and talk about disability as a result of their museum visit.

It is interesting to note that, whilst the evaluation found considerable evidence to suggest that people were prompted to view disability differently, some visitors were keen to point out that their views had **not** been changed.

“The display widened my appreciation of the challenges disabled people face on a daily basis. The exhibition has without doubt increased my awareness of the level of disability in society. It has not, however, altered my views or opinions.”

Tyne and Wear Museums, male, aged 16-25, non-disabled

This explicit denial of a change in attitudes may be explained, at least in part, by the character of prejudice directed towards disabled people. A recent study of prejudice in the UK found that no interviewees openly acknowledged that they held prejudiced attitudes based on disability even though the language that they used reflected perceptions of disabled people as individuals who lacked competence, were vulnerable and deserving of pity.² The study described this as ‘benevolent prejudice’ whereby individuals might strongly believe that they do not hold negative views about disabled people even if the ways in which they discuss disability reveals a different picture.

Our evaluation set out to identify what kind of impact engagement with the projects had on visitors' thinking – on their perceptions, opinions and attitudes towards disability and disabled people. In what ways did visitors endorse, challenge or subvert the messages they identified within the displays, films or educational sessions they encountered? Five predominant themes emerged from the analysis of the data. Some, as we shall see, suggest considerable influence on the part of the museum in shaping ways of thinking and talking about disability which reflect the intentions of the project. Others reveal a more complex picture and highlight some of the challenges inherent in attempts to counter deeply embedded and discriminatory understandings of disability.

Social model of disability

The most commonly occurring mode of response suggested visitors' support for an understanding of disability framed by the social model. Visitors frequently discussed the challenges and barriers facing disabled people, the impact of disabling attitudes and the stigmatising effects of language. Many comments reflected the projects' capacity to begin to move visitors' thinking away from medicalised understandings of disability – which view impairments as the source of the problem and medical intervention as the solution – towards understanding the effects of multiple social barriers on disabled people's lives.

"A very worthwhile exhibition. Everybody should be aware of the challenges disabled people have to face within Society."

Colchester Castle Museum, male, aged 26-35, non-disabled

"It helps people's awareness that disabled people are real people and that the environment disables them."

Colchester Castle Museum, female, aged 46-55, disabled

Visitors to **Lives in Motion** at Glasgow's Museum of Transport often discussed disability with reference to the barriers created both by physically inaccessible transport systems and inflexible policies and practices. Many visitors, for example, found it surprising that wheelchair users are asked to give 24 hours notice if they wish to travel by train.

"I never realised how hard it was to travel with a disability. I think its shocking that they need to give 24 hours notice to travel by train. They are not different from anyone else and shouldn't be made to feel that way."

Glasgow Museum of Transport, female, aged 16-25, non-disabled

"Everyone knows disability can make life difficult – it's disabling but, the exhibition flags up just how society fails to accommodate disabled people properly, and fails to recognize their needs properly..."

Glasgow Museum of Transport, male, aged 16-25, non-disabled

"I didn't realise the amount of obstacles there are for people with a disability! A very informative exhibition!"

Glasgow Museum of Transport, female, aged 16-25, non-disabled

"It highlights how long it took for progress to be made to include people with a disability ... in the plans for public transport and public life in general. Although great improvements have been made it is obvious that there is still a lot to be done to allow disabled people to be fully integrated into the general transport scheme in our country."

Glasgow Museum of Transport, female, aged 56-65, non-disabled

As well as highlighting the physical barriers presented by inaccessible buildings, transport systems and so on, visitors frequently referred to the disabling effects of negative attitudes towards disabled people. Significantly, comments referring to attitudes appeared in visitor responses to all of the nine projects.

"Glad that display is prominent. Helps to highlight the problems and attitudes that disabled people may face. Hopefully the public will see people with disabilities in a more positive light."

Colchester Castle Museum, female, aged 46-55, non-disabled

"But the thing that struck me most I suppose was the timeline, the history of attitudes against disabled people, from 1829 to present day and how it's taken a long time and involved a lot of people to create a lot of awareness to get where it is at the moment and it isn't perfect."

Charlie, Tyne and Wear Museums

"The exhibition was excellent. It reminds you how far society has come – but also still to go – and that it is society that causes disability i.e. not adapting to individuals."

Tyne and Wear Museums, female, aged 26-35, non-disabled

"This display challenges assumptions we all make about disabled people. It also highlights how limited resources restrict people's choices and therefore impacts so much on people's everyday lives and quality of life..."

Northampton Museum, female, aged 36-45, non-disabled

"A person is much more than a physical representation. It is quite humbling. I couldn't help but think that if I was disabled how angry I would be that people would make judgments based purely on personal appearance – I am much much more than my physical appearance. Times have changed since Merrick but frighteningly attitudes haven't."

Royal London Hospital Archives and Museum, female, aged 36-45, non-disabled

Some visitors highlighted the need for action to address the inequalities generated by physical and attitudinal barriers and called for change – on the part of individuals, society in general and governments in particular.

"I think it is amazing. It has made me to think that the powers that be need to be listening more. I am deeply concerned, but more aware from what I have seen. Excellent work."

Glasgow Museum of Transport, female, aged 46-55, non-disabled

"When you look at some of the developments over time, I think it was just after... was it after the 1960s there were like massive changes it said? And it seemed like not that many changes happened sort of in maybe 30 or 40 years, but then after the 1980s lots happened. So I think we've just got to be the ones to make sure that keeps happening."

Anne, Tyne and Wear Museums

"The present efforts to help the disabled should be continued but with a far greater input from the government to ensure that the present facilities and designated laws that affect the disabled are rigorously enforced and if possible upgraded. This goes for housing / shopping and leisure / physical aids."

Glasgow Museum of Transport, male, aged 56-65, non-disabled

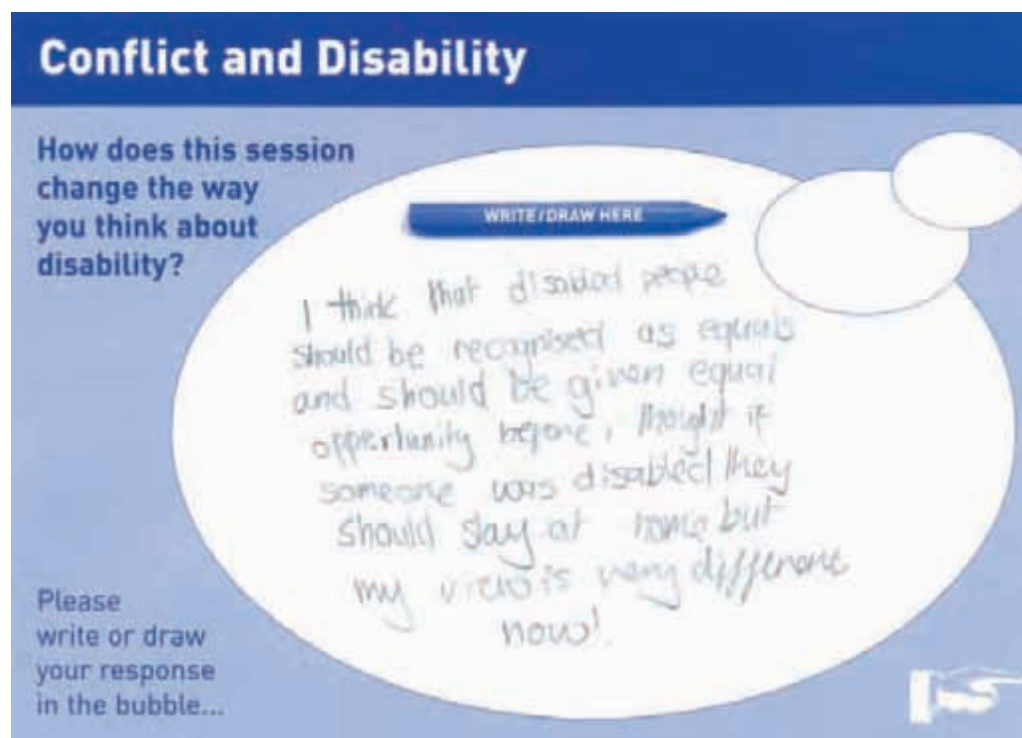
"It just strengthens my thoughts that the government [spends] more money on telling us how to treat people but does not provide the funding needed for disabled people to live full, rewarding lives without having to overcome obstacles. EVERYONE has the right to realise their full potential. We live in a wealthy country so funding should never be an issue."

Tyne and Wear Museums, female, aged 26-35, non-disabled

Equality and rights

This second largest category of response that emerged in our analysis involved visitors drawing on the language and concepts of human rights and equality to discuss disability and disabled people. This included reference to, for example, the right to equality of opportunity in the Law, equal access to services, the right to voice dissent and the right to respect and dignity. These comments, like those reflecting an understanding of disability underpinned by the social model, were generally felt by the research team and the Think Tank to reflect the aims of the project.

Typical comments on response cards included:



"Proves people should be treated as equal and not differently."

Colchester Castle Museum, female, aged 36-45, non-disabled

"My perception of disabled people has not changed as I have always considered them equal and should have the same right to employment."

Imperial War Museum, London, female, aged 15, non-disabled

Similarly, one interviewee at Tyne and Wear Museums, Patrick, when asked if the exhibition had changed his views on disability in any way, responded:

“It just basically reinforced my own feelings about it, you know, that disabled people should have the equal opportunity all the way down the line.”

Sometimes, support for equality was expressed through an emphasis on sameness – the notion that disabled people are ‘just like everyone else’.

“Their as equal as us! Shows you different aspects of disability. Well done!!”

Colchester Castle Museum, female, aged 16-25, non-disabled

“Everyone in society should be treated the same – equal opportunities for all.”

Colchester Castle Museum, female, aged 16-25, non-disabled

Discussions with members of the Think Tank revealed different opinions on the relative desirability of these comments that emphasised sameness. Some welcomed them as empathetic expressions of support for disability rights whilst others raised some concerns about the negative effects of conflating the experiences of disabled and non-disabled people (in ways which potentially denied the lived experience and distinct identity of disabled individuals). This issue re-emerges in relation to the fifth category of response – the questioning of the concept of disability – which is discussed shortly.

Despite these concerns, the identification of social barriers and equality issues by the majority of respondents in our evaluation was generally welcomed. A concern for disability rights was clearly central to the project and the social model of disability had been used as a means of framing each of the interpretive approaches. The fact that the largest categories of response were those which identified and expressed support for these ways of understanding disability was seen as powerful evidence of the potential for museums to frame and inform the ways in which visitors perceived and talked about disability. However, other significant categories of response were rather less clear-cut.

Impairment as tragedy

A key issue which regularly arose during discussions between museum staff and the Think Tank, as the nine projects were being developed, concerned the importance of resisting representations which it was felt would provoke pity, fear or patronising sympathy in visitors. Stereotypical representations of disabled people as passive victims, dependent on others, and objects of pity, prevalent in news media, were to be avoided and indeed challenged. Considerable efforts were made across the projects to avoid narratives that equated impairment with tragedy but at the same time to resist overly celebratory and naive views of disability (which could potentially negate or deny the challenges disabled people face).

Despite these efforts many visitor responses reflected the perceived tragedy of impairment.

“Makes you think how lucky we are and helps us to appreciate disabilities.”

Colchester Castle Museum, female, aged 36-45, non-disabled

“Makes me feel lucky to have the use of my legs. What I always take for granted.”

Colchester Castle Museum, male, aged 26-35, non-disabled

“I think it is good to see more being done to help all types of disabilities so that all people are helped to enjoy life without hold backs. And any more help that could be given all the better! I just feel fortunate I am not in the same situation but who knows what is round the corner of life...”

Glasgow Transport Museum, female, aged 56-65, non-disabled

These comments generated an especially lively debate within the Think Tank. Some comments were deemed offensive, oppressive, patronising and discriminatory – entirely at odds with the aims of the project. Others, however, felt that some comments which appeared to reinforce standard negative stereotypes of disabled people could not so easily be dismissed as unwelcome. Some argued that at least some of the comments might be better understood as empathetic and perhaps illustrative of the first steps towards a more respectful understanding of disability, even if the language and tone were considered problematic.

Similarly, where some visitors identified the ‘need to help’ disabled people, such views could be read either negatively – as reflective of the social construction of helplessness imposed on disabled people – or rather more positively as suggestive of an understanding of the obstacles and barriers in everyday life for disabled people. For example, one visitor to Colchester Castle Museum wrote:

“It made me realise a lot more about disabled people and how much more care and help they really need. I would love to get involved or to help to make a difference to a disabled person they are the same as non-disabled people so why treat them any differently?”

Female, aged 16-25, non-disabled

Heroic survivors (and other stereotypes)

The fourth category of response emphasises the perceived heroism of some disabled people in overcoming the apparent tragedy of their impairments. This stereotype sits well in the cultural imagination, and is widespread in news media in which disabled people are often referred to as ‘brave’, ‘cheerful’, ‘wonderful’ or ‘inspirational’. Whilst these descriptors are often kindly meant – as a compliment to the ways that people cope – they are generally part of a narrative that reflects a medicalised understanding of disability; that focuses on impairment (as the problem) and on the tragic but brave individual, rather than the myriad social barriers that disabled people are required to tackle. Sometimes, the disabled person’s strategies for overcoming the challenges presented by their impairment are offered as an inspirational lesson from which others might usefully learn.

It is perhaps not surprising, given the ubiquity of disability stereotypes within the media, that they appeared within some visitors’ responses despite efforts by the museums and Think Tank to resist and, indeed, to directly counter them.

“It was interesting to see how these people coped with their disability and got on with life and they seemed happy.”

Colchester Castle Museum, female, aged 26-35, non-disabled

“I’ve always been aware and interested in learning about disability. It’s a good idea to have this display to help people understand what these inspiring people go through and how they deal with life.”

Colchester Castle Museum, female, aged 26-35, non-disabled

“More aware of the difficulties faced by disabled people. How brave and happy all people involved are.”

Colchester Castle Museum, male, aged 36-45, non-disabled

"The display really moved me and I actually found it quite emotional. I think these people are so brave and there should certainly be more things like this to make human ignorance fade away."

Colchester Castle Museum, female, aged 36-45, non-disabled

However, as with the comments which equated impairments with tragedy, responses within this category generated a range of opinions amongst the Think Tank. For example, the following comment by a young woman (aged 16-25, non-disabled) visiting **Life Beyond the Label**, was felt, on the one hand, to conform to the negative stereotype of the 'heroic disabled individual', but on the other to demonstrate awareness of the social barriers experienced by disabled people:

"It makes me realise how hard it can be for people with disabilities. But respect how strong some individuals are, and how they over come hard day to day challenges."

In fact, many comments contained what were felt to be contradictory elements; some reflecting a medicalised, 'tragedy' perspective of disability and others demonstrating support for more respectful understandings of disabled people.

Some Think Tank members were also keen to highlight instances where stories which revealed individual disabled people's bravery should not automatically be avoided simply because of the dangers inherent in reproducing familiar stereotypes. Heroism is as much a part of disability history as it is of mainstream narratives. For example, one of the educational sessions that the Imperial War Museum developed explored the attitudes of people towards Second World War pilots who sustained severe facial injuries. A student aged 15, who had participated in that session, commented:

"The session strongly reinforces the bravery and strength of the men that were part of the Guinea Pig club. After all the horrific events they have been involved in, they still enjoy life and smile. I think that is something to be greatly admired."

The range of responses in this category highlights the importance of an understanding of the context within which visitors' comments are made when attempting to analyse their significance. Although the heroic survivor is sometimes discussed within the disability studies literature as a negative stereotype, strongly linked to the tragedy model of disability, the comments here from the Imperial War Museum project show that responses (which highlight bravery, heroism and so on) can, indeed, be viewed as positive and linked to a progressive understanding of disability issues.

Questioning the concept and use of ‘disability’

Whilst many disabled people view disability as an important part of their personal and political identity, for others the concept and associated language is confusing. For example, some visitors were clearly uncomfortable with referring to people as ‘disabled’, viewing the term as a stigmatising label which highlighted ‘otherness’.

“Hasn't really changed as I think I have a very liberal view and don't judge people on their abilities or how they look anyway.”

Colchester Castle Museum, female, aged 36-45, non-disabled

“I am not sure it does [change the way I think about disability] and I think it should be referred to as 'ability'. Thanks.”

Colchester Castle Museum, female, aged 36-45, non-disabled

“Reminder that disability has always been with us. (personally – never seen it as a problem – just not keen on the word! We're all "disabled" in some way!)”

Birmingham Museum and Art Gallery, visitor

The extent to which each of the nine projects were explicit in communicating their particular focus on disability varied quite considerably. Some museums, for example, Birmingham, used ‘disability’ in their project title whilst others, for example Whitby, wove disability-themed content into a broader interpretive framework. Some visitors objected to disability being highlighted as a separate issue, preferring instead for the subject to be mainstreamed or incidental to the wider museum and gallery exhibits. The concerns and motivations behind these comments are not clear from the evaluation. Did visitors feel that highlighting disability served to emphasise people’s differences in ways that inhibited understanding amongst non-disabled visitors? To what extent might these objections reflect a denial of disability as a positive aspect of a person’s individual identity? This is a topic that merits further investigation.

Conclusion

This overview of the evaluation carried out across the nine projects demonstrates the richness, diversity and complexity of visitors' responses to the representations of disabled people and the interpretations of disability-themed narratives that they encountered.

The majority of responses to the nine projects were overwhelmingly positive. Many welcomed the lively and innovative modes of interpretation deployed across the projects, the provision of accessible information and, in some projects, the use of humour. On the whole, the museum was seen as an appropriate, sometimes vital, place to communicate what visitors saw as important ideas about disabled people being part of society. Some visitors saw the role of the museum as a place for changing attitudes and educating the uninformed or prejudiced. Whilst there was some criticism from a minority of visitors who appeared to resent the disruption, presented by the projects, to their strong views on how museums should be, these comments tended to be directed at the institution rather than disabled people themselves.

A strong theme emerged from the evaluation regarding the inclusion, across the projects, of personal narratives and life stories of disabled people. That issues were discussed from the perspective of disabled people themselves had a powerful impact on many visitors, capturing their attention, sometimes in unexpected ways. If the museum is seen as a valued and trustworthy institution by the public (and there was evidence of this from visitor comments) then the inclusion of 'authentic' voices and stories only heightened the museum's potential to function as a forum where potentially challenging and sometimes controversial issues can be discussed.

Finally, whilst visitors responded to the exhibitions, displays, films and educational sessions in complex and diverse ways, the evaluation powerfully revealed the museum's capacity to offer ways of seeing which have considerable influence on visitors' thinking. Many left the museum talking about disability differently, in ways that reflected the project's overarching aim.

1 All interviewees' names have been changed

2 Gill Valentine and Ian Macdonald, **Understanding Prejudice: Attitudes towards Minorities**, Stonewall, 2004, www.stonewall.org.uk

Getting Started

Foundations

Framing your approach

Be mindful of the differences between the medical and social models of disability.

The social model provides a valuable starting point for developing progressive approaches to representing disabled people and interpreting disability-themed material.

Developing an ethical / moral standpoint

Be clear about the outcomes you want to achieve. What messages do you want visitors to take away from their visit?

Don't try to please everyone. Some of the ideas you will be exploring are contested and not everyone will agree on the stance that you take. Just like work with other communities, there is no single voice or unified set of opinions amongst disabled people (BUT the social model of disability, which was developed by the disabled people's movement, will help to inform a moral standpoint which many support).

A space for debate

Expose visitors to new, progressive ways of thinking about disability but avoid being didactic. It is entirely possible, though not always easy, to blend a strong moral standpoint with approaches that avoid telling people what to think. Explore interpretive devices which give opportunities for visitors to share their views and opinions with the museum, and with other visitors.

Process and Practicalities

Collaboration

Embed genuine collaborative practice with disabled people into the project.

Go further than simply consulting with community representatives – empower disabled people to play an active collaborative part in shaping the project.

Are there opportunities to employ disabled staff to work on the project?

Partnerships

When working with partner organisations, seek out those that share the museum's core values and aims.

Take time to develop these partnerships in ways that bring mutual benefit.

Work with organisations run BY (not just FOR) disabled people.

Access considerations

Ensure you commit the resources (time, expertise, money) to facilitate genuine collaborative practice with disabled people.

Work to meet the needs of people with different impairments to ensure the process, and the project's outcomes, are as accessible as possible.

Taking risks

You are likely to face some issues that are challenging and sensitive and around which there is no clear consensus. Be prepared to take risks and do not try to please everyone.

Be prepared to negotiate conflicting viewpoints.

Legacy and Sustainability

Embed practice throughout your museum

Involve and update staff across all parts of the organisation – visitor services, curatorial, education and learning, shop and café, collections management and so on.

Taking a holistic approach will help to develop a more inclusive culture and lead to more accessible experiences for disabled staff and visitors.

Further developments

Pursue opportunities to develop ongoing initiatives following on from specific projects.

How might gaps in the museum's collections be addressed through proactive contemporary collecting?

What material from temporary exhibitions and other specific projects might be incorporated into more permanent displays?

How might an object's connection with disability or disabled people's experiences be captured in existing collections management systems?

Rethinking Disability Representation Team

RCMG

Jocelyn Dodd	Co-Director
Richard Sandell	Co-Director
Debbie Jolly	Project Co-ordinator
Ceri Jones	Research Associate
Jackie Gay	Researcher, Editor
Heather Hollins	Researcher
Amy Jane Barnes	Research Assistant
Tom Partridge	Graphic Designer

Think Tank Members

Rachel Hurst	Director, Disability Awareness in Action
David Hevey	Director, screenwriter and photographer
Tony Heaton	Chief Executive, SHAPE (formerly Director, National Disability Arts Collection and Archive at Holton Lee)
Nancy Willis	Artist, film-maker
Molly Barrett	Consultant, designer
Mark O'Neill	Head of Arts and Museums, Culture and Sport Glasgow
Mark Taylor	Director, Museums Associations

Museums

Birmingham Museum and Art Gallery - BMAG

Reyahn King	(formerly) Head of Exhibitions and Interpretation
Melissa Strauss	(formerly) Community Development Officer
Liz Braby	Audience Development Officer
Victoria Osborne	Curator (Fine Art)
Brendan Flynn	Curator (Fine Art)
Anna Dolecka	Education Outreach Officer

Colchester Castle Museum

Colchester and Ipswich Museums Service

Tom Hodgson	Community History Manager
Ciara Canning	Curator of Community History
Sophie Weaver	Access Officer
Darren Stevens	Display Officer

Glasgow Museum of Transport

Glasgow Museums

John Ferry	Senior Learning & Access Curator
Crawford McGugan	Learning & Access Curator
Sam Groves	Visitor Studies Curator
Vicky Mair	Visitor Studies Curator

Imperial War Museum, London

Samantha Heywood	Project Director
	Their Past Your Future , IWM
Dan Phillips,	(formerly) Head of Corporate Education, IWM
Steve Gardam	Head of Corporate Education, IWM
Sarah Ballard	Education Officer, IWM London
Katie Potter	Education Officer, IWM London

Royal London Hospital Archives and Museum

Jonathan Evans	Archivist, Barts and The London NHS Trust
Kate Richardson	Deputy Archivist and Curator

Stamford Museum

Philippa Massey	Keeper of Visitor and Community Services
Claire Jacques	Community Engagement Manager
Tracey Crawley	(formerly) Principal Keeper, Collections Management

Tyne and Wear Museums

Kylea Little	(formerly) Keeper of Contemporary Collecting
Megan de la Hunt	Access Project Officer
Jane Montgomery	(formerly) Access Officer
Zelda Baveystock	(formerly) Senior Curator of History
Paul Bewley	Design Officer
Alisdair Wilson	Manager, South Tyneside Museums
Emma Pybus	Communications Officer
Caireen Hart	Communications Officer
Sarah Saville Evans	Learning Officer
Thomas Elwick	Assistant Learning Officer

Northampton Museum and Art Gallery

Rebecca Shawcross	Shoe Resources Officer
Debra Cox	Senior Museum Education Officer

Whitby Museum

Mark Edwards	Honorary Keeper
Sean Dryden	Family History
Christiane Kroebe	Honorary Librarian

Behind the Shadow of Merrick DVD

■ Rethinking Disability Representation ■ in Museums and Galleries

