

BURIED IN THE FOOTNOTES:

THE REPRESENTATION OF DISABLED PEOPLE
IN MUSEUM AND GALLERY COLLECTIONS



RCMG
Research Centre for
Museums and Galleries



University of
Leicester

A · H · R · B
arts and humanities research board

BURIED IN THE FOOTNOTES:

THE REPRESENTATION OF DISABLED PEOPLE IN MUSEUM AND GALLERY COLLECTIONS

Phase 1 report
September 2004

Research team

Jocelyn Dodd
Richard Sandell
Annie Delin
Jackie Gay

RESEARCH CENTRE FOR MUSEUMS AND GALLERIES (RCMG)

Department of Museum Studies
University of Leicester
105 Princess Road East
Leicester LE1 7LG

0116 252 3995
jad25@le.ac.uk

RCMG would like to thank the following:

The Arts and Humanities Research Board (AHRB)

Museum staff who contributed to the research, in particular those who participated in case studies at: Snibston Discovery Park; Manx National Heritage, Isle of Man; National Museums of Scotland, Edinburgh; Royal Pump Room, Leamington Spa Art Gallery and Museum; Whitby Museum; Royal London Hospital Museum; The Walker Art Gallery, Liverpool; Birmingham Museum and Art Gallery; National Maritime Museum, Greenwich; Colchester Museums.

Colloquium participants: Peter Berridge, Katharine Edgar, Rosalinda Hardiman, Tony Heaton, Jenny Lamb, Nicky Morgan, Mark O'Neill, Alison Plumridge, Mark Suggitt, Michèle Taylor, Diana Walters, Sophie Weaver, Marcus Weisen, Nancy Willis.

The Nottingham Regional Access to Work team (Mark Slater)

This report is also available in large print.
To request a copy please email rcmg@le.ac.uk
or telephone 0116 252 3995.

CONTENTS

1.	Background and aims	04
2.	Methodology	06
	• Questionnaire survey	
	• Case studies	
	• Colloquium	
3.	Findings	08
	• What did we find?	
	• Display in case study museums	
	• What do these findings say about disabled people?	
4.	Questions and issues raised by the research	14
	a. The need for an authoritative voice	
	b. Display dilemmas	
	c. The shadow of the freakshow	
	d. Preliminary thoughts on display practice and interpretation	
	e. The importance of context	
	f. Curatorial knowledge and specialism	
	g. What is disability?	
	h. A social role for museums?	
	i. Lack of disabled people in the sector	
5.	Conclusions and recommendations for future research	23
6.	Dissemination of findings	24

1. BACKGROUND AND AIMS

Background

Buried in the Footnotes: the representation of disabled people in museum and gallery collections was a one-year research project funded by the Arts and Humanities Research Board's Innovations Awards scheme and undertaken by the Research Centre for Museums and Galleries (RCMG), Department of Museum Studies, University of Leicester.

The project brief was to investigate evidence within UK museum and gallery collections that relates to the lives of disabled people, both historical and contemporary. We aimed to investigate how this material is displayed, interpreted, and made accessible to the public; the factors affecting how information is collected, documented and made publicly available; and the influences on curators' attitudes - both past and present - towards this information and its dissemination.

The project was informed by previous work undertaken with the Drawbridge Group at Nottingham Castle Museum and Art Gallery by three of the current research team. Drawbridge was a consultation group of disabled people who were looking at access issues, including access to collections, and this initiative created opportunities for discussion about inclusion and representation. In 1996, Annie Delin collaborated with the curator of fine art at Nottingham Castle Museum and Gallery, to approach a range of museums requesting information about the representation of disabled people in their collections. The results of the survey suggested that there was, indeed, a wide range of material relating to the lives of disabled people held by museums. This initial evidence provided the impetus for further research, alongside the ongoing debates over the impact on marginalised communities of representation or under-representation within the museum sector; critical work around cultural representation and the construction of identity; and studies of the representation of disabled people in films or other media.

The notion of representation has been explored by disability studies specialists in the context of contemporary media¹, and by museum and academic specialists in the context of gender, class, ethnicity and sexuality². In neither case has a connection been made between museums, as a repository of material evidence of culture, and disabled people as a community with hidden history. Recent studies of the role that museums can play in combating social exclusion and inequality³ suggest that collection and display are potentially critical elements in the process.

1 See, for example, Barnes, C (1992) *Disabling Imagery and the Media: an exploration of principles for media representation of disabled people* The British Council for Disabled People, Ryburn Publishing; Hevey, D. (1992) *The Creatures That Time Forgot: Photography and Disability Imagery* Routledge; Pointon, A and Davies, C (Eds.) (1997) *Framed: Interrogating Disability in the Media* BFI Publishing; Cooke, C, Daone, L and Morris, G (2000) *Stop Press! How the Press Portrays Disabled People*. London: Scope.

2 See, for example, Hall, S (1993) *Culture, Community, Nation* in Boswell, D and Evans, J (1999) *Representing the Nation, A Reader*. London: Routledge; Hallam, E and Street, B.V.(2000) *Cultural Encounters: Representing Otherness*. London: Routledge; and Porter, G (1996) *Seeing Through Solidity: a feminist perspective on museums* in Macdonald, S and Fyfe, G (1996) *Theorizing Museums*. Oxford: Blackwell.

3 Dodd, J. and Sandell R. (2001) *Including Museums: perspectives on museums, galleries and social inclusion*, Leicester: RCMG, University of Leicester; and Sandell, R (2002) 'Museums and the combating of social inequality: roles, responsibilities, resistance' in R. Sandell (ed.) *Museums, Society, Inequality*, London and New York: Routledge.

Our research questions were:

- What evidence exists within museum collections and associated documentation that relates to the lives of disabled people, both historical and contemporary?
- How, if at all, has this evidence been interpreted, displayed or otherwise made accessible to the public? If so, within what categories have disabled people been represented?
- How has evidence of the fact of disability been changed, distorted or lost during the period that the information has been held by the museum?
- What factors, historical and contemporary, have affected the way in which information about the lives of disabled people related to collections has been collected, documented and made publicly available? What factors influence, or have influenced, curators' attitudes towards this information and its dissemination?

The project's aims and objectives were:

Aims:

- To develop and test the concepts and ideas
- To produce findings that would inform a research agenda and priorities for a larger research project
- To raise awareness and levels of debate within the cultural sector and to stimulate and inform experimental approaches to representing the lives of disabled people.

Objectives:

- To survey museum collections in the UK for evidence of the lives of disabled people.
- To gauge awareness amongst curators of the existence of this evidence
- To identify how disability has been recorded and presented within the museum context
- To explore attitudes amongst curators towards the collection, documentation and presentation of evidence of the lives of disabled people.

Buried in the Footnotes started with the premise that there would be material attesting to the lives of disabled people within museum collections. Although we had no idea of the nature, quantity, or condition of that material (or of the quality of the information attached to it that related to disability), our assumption was that evidence would be found.

Our findings were that wide-ranging collections of all kinds do, indeed, contain a wealth of relevant material but that its significance to disability is not generally considered or understood by the curators who hold it in their care. This material is infrequently displayed, its link to disability is seldom made explicit or is poorly interpreted and, in only a few noteworthy cases, does the interpretation resist stereotypical and reductive representations of disabled people which are commonplace in other media. A range of factors - specific, practical, resource-based and personal ones as well as more generic societal influences - conspire to contribute to the cultural invisibility of disabled people in museums and galleries.

However, we found no evidence of deliberate attempts to suppress or distort evidence of disabled people's history in museums. There is, instead, among curators, both a lack of consensus about the significance and importance of these issues, and a level of anxiety and concern about how to display and interpret the material, which results in inertia. There is also a continuing risk that the knowledge which gives the objects meaning will be lost - including information held in archives, databases and the memories of individual curators.

2. METHODOLOGY

Buried in the Footnotes was a one-year project with six phases of research: planning, quantitative research (issue and analysis of a questionnaire), qualitative research (visits to ten case study museums), analysis and interpretation of findings, testing of findings (including organising a colloquium), and the dissemination of findings.

Questionnaire survey

A questionnaire was our principal method of collecting information about objects and attitudes to them across a broad spectrum of museums. The questions were designed to identify levels of awareness amongst curators of the existence of relevant material within collections and to gauge their attitudes towards its collection, documentation and interpretation. We would then identify a shortlist of appropriate case studies for the qualitative phase of the research.

The questionnaire was distributed to 224 museums in August 2003. The team identified museums of varied size, governance and collection type across the UK, and returns were received from all types of museums, from national collections to small, volunteer-run institutions. 73 questionnaires were returned - taking multiple returns from different curators within one organisation as a single response - resulting in a response rate of 35%. Of the 73 completed questionnaires, 12 answered 'No' to all questions ('nil returns') stating that they were not aware of any relevant material in their collections or displays. This left 61 responses from organisations stating that they did have relevant items in their collections/displays. 29 museums were willing to be involved in further research as a case study museum and case studies were selected from these.

During this period of the research some additional elements were agreed and carried out, including a survey of disabled people inviting them to identify examples of representation of disabled people in museums; visits to the *Medicine Man* exhibition at the British Museum, *Pleasurelands* at the Sheffield Millennium Galleries, *Giants: Disabled People Reaching for Equality* at the City Hall, London, and the National Fairground Archive at the University of Sheffield.

The 29 museums who agreed to participate further in research included a good spread of collection types, geography and other factors. A total of 10 museums were approached as possible case studies and all agreed to our proposal.

Case study museum	Size of museum			Collection type	Governance
	S	M	L		
Snibston Discovery Park		●		Social history	Local Authority (county council)
Manx National Heritage		●		Mixed	National
Royal Pump Rooms, Leamington Spa	●			Art (and mixed)	Local Authority (borough council)
National Museums of Scotland			●	Mixed	National
Whitby Museum	●			Mixed	Independent
Royal London Hospital Museum and Archives	●			Medical and social history	NHS trust
Walker Art Gallery			●	Fine art	National
Birmingham Museum and Art Gallery			●	Decorative art and costume	Local Authority
National Maritime Museum			●	Decorative art and social history	National
Colchester Museums	●			Mixed	Local Authority

The 29 museums who agreed to participate further in research included a good spread of collection types, geography and other factors. A total of ten museums were approached as possible case studies and all agreed to our proposal. In addition to size, geography, governance and collection type, we wanted to include known examples of good practice, museums with a potentially significant connection to disability such as medical or naval/military connections, and also those who stated they had 'nothing relevant to declare'. There were no respondents from Wales or Northern Ireland who were willing to participate in further research.

Each case study included:

- An interview with one or two named curatorial staff
- A search of database/records to identify items related to disability
- A review of galleries and displays, noting possible relevant objects
- Time with other staff to discuss displayed or collected objects
- File/desk research on specific items.

Colloquium

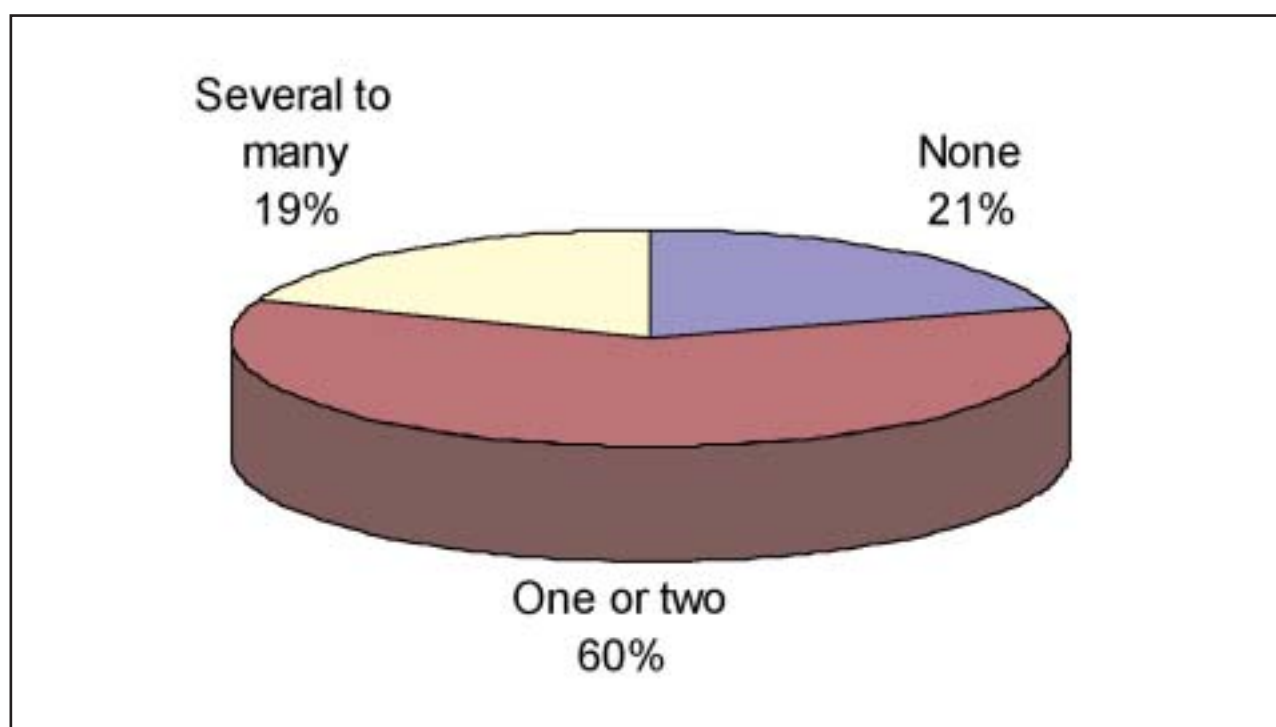
A key element of the research process towards the end of the project was a colloquium, bringing together professionals from a number of fields to discuss the emerging findings of the research. The aim of this colloquium was to test ideas and to generate new insights into the material we had identified. Participants were selected to represent the museum profession, academics, strategic bodies and representatives with disability-related cultural perspectives. 19 individuals were invited, of whom 14 were able to attend. The participants included five disabled people, each attending in a professional role.

The colloquium was highly stimulating and yielded valuable insights as well as developing our understanding of the material. Ideas, issues and specific comments from colloquium participants are integrated with the findings of the research.

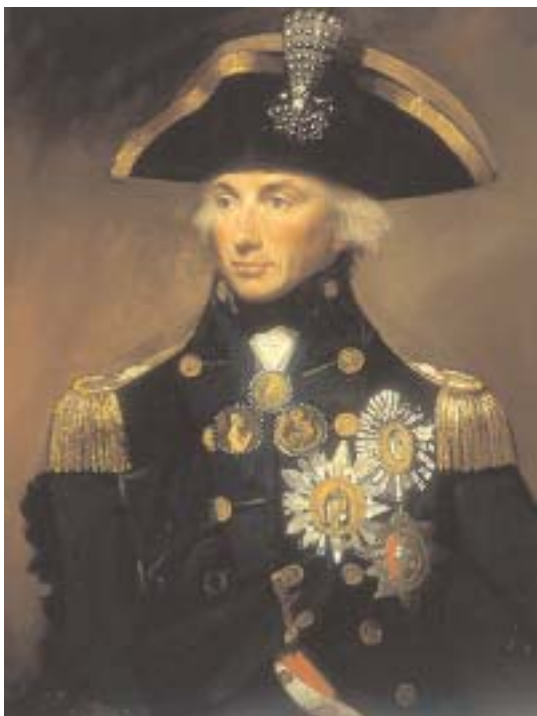
3. FINDINGS

One of the principal aims of *Buried in the Footnotes* was to discover or reveal objects that attest to the lives of disabled people. Of the 73 questionnaire respondents, 58 (79%) identified objects relevant to the search. Of these, 44 had only one or two items. The majority (81%) said that they had no objects, or only one or two.

Survey question 2.3: Are you aware of any material in your collections which relates to disability and/or the lives of disabled people?



The questionnaires posed four questions relevant to display. Just over half (52%) of respondents stated that disabled people were currently represented in their museum displays - although often by just one object. Just under half those who responded (48%) had held an exhibition which featured disabled people or their work in the past five years - almost half of these (21% of the total response) had based an exhibition on outreach work with disabled people.



Every case study museum we visited had more items (usually substantially more) than initially stated on the survey return. The case studies included one museum which gave a nil return (no items relevant to our research) and one museum holding just a single photograph. It is clear that the process of preparing for our visits triggered curators to consider the issue and identify additional items before the researcher arrived. During the case study, curators also dedicated time to thinking about their collection in the light of this research. The researchers, two of whom are disabled, brought along their particular perspective and were able to identify items which had not previously been connected with disability. Each case study revealed new items through searches of databases, using the same search words in all ten case studies:

- disabled/disability
- blind
- deaf
- lame
- surgical
- cripple
- dwarf
- giant
- lunatic
- invalid.

Additional search words were used where relevant to the collection type, including: adapted, altered, crutch and peg-leg.

Following the visit, some curators sent on additional information which had occurred to them - evidence that the interviewing and search process enabled new ways of thinking, generating fresh perspectives amongst curatorial staff.



What did we find?

The majority of objects discovered were in the following categories:

Collection type

Material identified included:

Social history

This category covers a vast range of material types - objects associated with home life, childhood, education and relationships. A large number of aids and equipment items - crutches, callipers, prosthetics, braces, spinal carriages and wheelchairs - fall into this category. Some objects had association with named individuals, but many did not. More difficult to categorise were the real disabled people who were celebrated for oddity or difference. They included celebrated individuals such as Charles Stratton (Tom Thumb) and Joseph Merrick (the Elephant Man). There were also a wide variety of local characters such as Old Katty the Ruswarp Witch (Whitby) and the Silly Annas (Colchester). Collections also included charity related items, dating as far back as the National Maritime Museum's Chatham Chest (1625).

Fine art

Numerous artworks were uncovered or offered. They included those by disabled artists, and those portraying disabled people as a subject. Disabled artists

encountered during the research were both historical and contemporary; some used unorthodox methods of working because of their disability - using shoulders, feet or mouth. Some artists explored themes of disability in their work and some are known to have been disabled through supporting material linked to the artworks. We found many drawings and sketches for stained glass panels depicting healing scenes - often lame, blind and crippled men. In paintings, blind people figured as a popular subject (blind fiddlers, pipers and beggars) some of real named individuals and others of possibly fictional characters.



Image: Colchester Museums

Archives

These were a particularly rich source of material and were held by many museums and their associated services; libraries and archives. They include material from Cripples Guilds - photographs, logs and registers, annual reports and fundraising records. Medical archives hold large quantities of information including personal medical records, records of treatment and admission registers for hospitals and asylums. There are numerous letters, journals, ships' logs and collections of ephemera in archives specialising in military and naval history, fairground history and personal collections relating to individuals.

Oral history

Where these kinds of records exist, they provide one of the richest sources of anecdote about disabled 'characters' in recent history. They also include the personal testimony of disabled people, who often feature as interviewees. Such testimony was noted at Manx National Heritage (the Folk Life survey), Colchester Museums and Leamington Spa Museum and Art Gallery.

Decorative arts

There was a wide range of decorative items, particularly ceramics, featuring beggars, war veterans or other disabled characters. Depictions of healing scenes featured on a number of items. Particularly rich were the Pinto collection at Birmingham Museum and Art Gallery (snuff boxes, cripple spoons) and the Nelson collection of decorative items at the National Maritime Museum. There were also decorative or craft items (embroidery, quilts) made by individuals who were described as invalids or cripples.



Archaeological	Items included both human remains showing evidence of life impairments and a limited number of artefacts depicting disability in decorative or symbolic form, such as mummies with amputated limbs, and Roman pottery fragments showing dwarf and hunchbacked figures.	
Costume	There were a few shoes and a small number of textile items, made for or worn by people with disabilities. Curators noted the difficulty of identifying disability in the wearer. Many costume items were associated with 'freaks' or characters, for example Charles Stratton's (Tom Thumb) suit and Arthur Caley's (the Manx Giant) boots. We also found back braces, built-up shoes and adapted items of clothing.	
Military	Items noted in armaments collections included guns and other weapons adapted for use by people with one eye or one arm/hand.	
Ethnographic	These collections included figurative pieces and other depictions showing blindness, amputation and other impairments, sometimes with connections to cultural beliefs. There were also items linked to 'intentional' disabilities - for example shoes made for Chinese women whose feet had been bound.	
Contemporary	This category includes material which has resulted from a museum's outreach projects, material relating to the Paralympics, disability action/politics and government initiatives (such as the European/International Year(s) of Disabled People) and contemporary art/craftworks.	
Photographic	This included specific collections of medical or hospital images, however disabled characters also appear in photographic social history collections such as that of Frank Meadow Sutcliffe (Whitby Museum).	

Image: Birmingham Museum and Art Gallery

Image: Whitby Museum

Display in case study museums

Objects relating to disabled people were found to be present in quantity in all the case study collections. This research also sought to identify how, if at all, the evidence had been interpreted, displayed or otherwise made accessible to the public, and if so, within what categories disabled people have been represented. A major and important category was that of **Freaks and Characters** - freaks being people who, at any stage in their lives, were exhibited or exhibited themselves to be stared at for money. Characters are people who became known as oddities in local communities, but for whom there is no direct evidence of chosen/imposed identity as a freak. Most characters were known to the curators but were not on display - partly due to concerns about how they could be displayed sensitively and accurately. In two museums where artefacts or images relating to characters were displayed, labels encouraged the viewer to note the unusual appearance of the character. We did find examples of old fashioned and reductive exposure of people as a 'freak' in a current display - although curators in these cases were sensitive to the datedness and possible inappropriateness of the display.

The case study museums included two with a direct link to the **history of medicine, treatment and cure**, and the museums were chosen partly because of the link between the experience of disability and the experience of illness and treatment. We wanted to examine the perceived 'natural' link between disability and illness and the context in which this information is displayed.

Works by **disabled artists** were displayed at three of the case study museums visited. There were also quantities of work by disabled artists identified within collections that were not currently on display. Of the artists whose work was on display, information about their disability was included (through labelling or exhibition panels) in approximately half the cases. Amongst historic artists, some had worked for part of their career as show performers, actively seeking recognition for their manner of executing work. Displaying these works raised the question of how this information might be conveyed through labelling.

The stereotype of a disabled person as super-achieving, or a hero, has been sufficiently absorbed into popular culture for some to consider it insulting to remind us that certain people were disabled.

"Following an exhibition (we held) about Nelson (which mentioned) his impairments, one complaint from a member of the public was 'He's not disabled, he's a war hero.' There is still a stigma attached to being disabled - the individual disagreed with his representation in this way:"

Colloquium participant

The research identified ways in which well-known disability was concealed or minimised in the stories of people of status and authority, for example, use of portraits which do not show the impairment, display/exhibition panels which omit known experience of disability, impairment-related artefacts omitted from display and labelling using language such as 'overcoming' impairment or achieving 'despite' it.

Distortion or loss of information about disability appears to have been common in the past and continues to be so. Issues of cataloguing - where to record a connection to disability - resources and staff time were raised frequently within the research and are not exclusive to the representation of disabled people.

However, there were also positive examples of display which integrated the experience of disability into a heroic life story. These included a detailed, factual account of an impairment and its later impact on the person's life; the use of a person's own words (letters and journals) to convey their feelings about disability; displays of artefacts giving insight into how the person lived with their impairment; and portraits showing impairment

The **incidental occurrence** of objects related to disability within displays on everyday topics, is regrettably rare. Where they do occur, the explicit link with disability is often either missing or presented in an awkward manner.

Disabled people are often **missing from the display** - the case in five of the ten case study museums visited. Absence gives a powerful (although invisible) message and may confirm assumptions among visitors that disabled people in society are exceptional and anomalous and, perhaps, without precedent in history.

In conclusion then, despite the richness of the material in museum collections, the displayed material is, with a few exceptions, limited in quantity and range. Material on display tended to confirm the stereotypical roles of disabled people in society.

What do these findings say about disabled people?

In disability studies there is a general agreement that the representation of disabled people in a variety of media is limited, often reductive, and stereotypical. Disabled people as victims, passive, sexless, low achieving, poor and non-contributing are dominant in both factual and fictional storylines. Disabled people who do not fit these moulds (by achieving or dominating) are presented as 'overcoming' their disability and becoming honorary non-disabled people. Where impairments are held to be visually extreme, there is a preoccupation with normalising through cure or surgical intervention.

In their questionnaire responses, many museums identified material in their collections which indicated similarly stereotypical roles for disabled people in history. There were comparatively few 'ordinary' disabled people represented through everyday objects. This is not to suggest that museums are actively or purposefully reinforcing stereotypes but rather that issues around disability representation are not, in most organisations, being discussed or addressed.

However the case study research was designed to draw out and reveal unexpected evidence. In addition to the stereotypical roles discussed above, we found evidence of disabled people who were teachers, coopers, miners, musicians, linguists, quilters, embroiderers, painters, naval commanders, collectors, sculptors, fundraisers, radiographers, nursing educators, politicians and merchants.

This evidence, it might be argued, gives museums the potential to engage with and challenge the expectation that disability must equal a minor contribution to society, by demonstrating how varied and influential the roles of disabled people have been in the past.

Beyond stereotypes - the real roles of disabled people

Aristocrats - *Lord Knutsford* (Sydney Holland) was known as 'the Prince of Beggars' for his fundraising abilities. He raised over £6m in his work for the Royal London Hospital. He was deaf following two accidents, and his hearing aid is displayed in the Royal London Hospital Museum.

Cripples who work - in the records of the Manx Cripples Guild, we found that some children, who were supposed to be enjoying holidays provided for cripples by a benevolent organisation, did not attend because they were too busy working on the harvest.

Naval commanders - apart from *Horatio Nelson*, a number of naval commanders lost body parts in action, and continued to serve. They include *The Hon. Charles Stewart*, Admiral of the White (1681-1740), who lost a hand as a young midshipman, and *Richard Tyrrel*, Rear Admiral of the White (1716-1766), who was wounded several times and lost three fingers from his right hand.

Medical personnel - not all disabled people in hospitals were patients. Radiographer *Ernest Harnack*, who had his hands amputated following early radiation injuries, later developed a screen made of glass impregnated with lead as a protective mechanism for other radiographers⁴. Surgeon *William Little* named his own condition (Little's disease) and researched the effect of premature birth and difficult labour on disability in children.

Collectors - *Edward Pinto* (Birmingham Museum and Art Gallery), a prolific collector, lost a leg during the Second World War while working as a fire warden. His disability is not mentioned in the gallery display.

⁴ Anon (1943) *Death of a Martyr* (Harold James Suggars) in *News Review*, March 18th 1943 p23.

4. QUESTIONS AND ISSUES RAISED BY THE RESEARCH

a. The need for an authoritative voice

There was a perceived need amongst museum staff for an authoritative voice on the representation of disability, to identify poor performance and to give guidance on preferred ways of moving forward - including specific guidance on display standards, wording and other difficult issues.

The choice of words used when discussing concerns over display was revealing. Curators wanted to avoid 'shock', 'distress', 'offence', 'upset' and 'difficulty'. One curator summarised their feelings about how to display related artefacts as "fear and confusion." This sensitivity appeared to be due to the fear of getting it wrong. Yet some curators were already developing strategies to overcome this:

"I would talk it over with colleagues. It happens (with a named freak) all the time, but it is not necessary to ask about everything."

"We have gained confidence by trying it. If we (re)did (display of disabled artist) today he would probably get a bigger space."

In common with some other sectors, this fear has contributed to inertia. This inertia, has been partly obscured by the considerable progress which the sector has made in relation to the area of access for disabled visitors. Equality of access to services and facilities for all visitors remains an important area but has, perhaps, enabled the sector to postpone the need to grapple with the more challenging issues around representation.

Yet we did encounter considerable interest in the topic from curators and other staff who participated in the research. Many welcomed the opportunities it created to discuss the presence of disabled people in museums and collections in ways which were distinct from, but complementary to, parallel discussions about disability access.

"Nobody has ever asked me to talk or think in this way about my work."

"Until you wrote to us it was an issue we had not even considered."

"We didn't realise how rich it (the Folk Life survey) was until we started looking for this research."

b. Display dilemmas

The display and representation of disability is comparatively uncharted territory for most museums in Britain. Their inability to mount more adventurous displays of material relating to disabled people is largely the result of three factors - uncertainty, lack of confidence and fear of criticism.

- *Will people stare at this?*

Museums are places where people come to look at things. The museum effect - the act of "attentive looking"⁵ - which transforms every object into something to be gazed at - legitimises and even sanctifies the act of staring. Because staring is authorised within museums, disabled people may experience a sensation of exposure when images or objects representing people "like them" are on display. They may even feel vulnerable to being perceived as part of the display.

Display of material connected with disabled people has the potential to authorise staring as a negative response to oddity. Our research indicated that most curators were acutely aware of the risk of reinforcing negative forms of staring. Some felt that the material, once out there, was vulnerable to ridicule or inappropriate responses from museum visitors.

"If we show pictures of people, we are sending them out on their own and you might get reactions like kids laughing at them. You can't write a label saying 'you mustn't laugh at these people.'"

In a few cases, freakishness still remains a legitimate topic for staring - 'high status' freaks (people who are still well-known) are understood to be a potential draw for museum audiences.

The *Pleasurelands* exhibition at the Millennium Galleries, Sheffield (Oct 2003 to January 2004), tackled the issue of staring directly by including information about the decision by one show person to turn the everyday experience of being stared at, into something he was paid for:

"I would walk around Glasgow, just ordinary fashion, and people were staring at me for free."⁶

The curators also encouraged visitors to reflect on their own feelings about being stared at. A visitor comments book had been provided which asked the question "How do you feel when people stare at you?" Words used by visitors included embarrassed, weird, paranoid, annoyed, and self-conscious.

⁵ Alpers, S (1991) *The Museum as a Way of Seeing* (pp25-27) in Karp, I and Levine, S.D *Exhibiting Cultures: the Poetics and Politics of Museum Display*. Washington and London, Smithsonian Institution.

⁶ Johnnie Osbourne (Wee McGregor) (1979) in a newspaper cutting quoted in Toulmin, V (2003) *Pleasurelands*. Catalogue of the *Pleasurelands* exhibition. (Sheffield, National Fairground Archive). (p54).

- *Should a museum 'out' someone as disabled?*

Whether or not to identify people as disabled, gay, Jewish, or as having black ancestry is a contentious issue. Factors which make it so include the ability or desire of the individual to 'pass' as 'normal', the political landscape of the day, and the personal opinions of decision makers. 'Outing' may impose on someone an identity that they may be currently unready to, or historically did not, accept. Yet a persuasive argument for outing is that it can contribute to the creation of a cultural identity based on respect for disabled people as active contributors to society. If powerful, authoritative, creative figures are known to be disabled, then respect for a new cultural identity can follow. One curator commented;

"In terms of communicating with disabled people and making a sort of bond, we might feel that the fact of disability is not well enough known.... I can see that the casual visitor might be delighted to find that the work is done by a disabled person. There are positive (educational) gains to be made from that sort of awareness-raising."

Curators invoked the risk of 'outing' a disabled person on a number of occasions, usually in connection with an artist or figure of influence or status. Several living artists with impairments (or former impairments which affected their creativity) were identified during the research. In some cases, the person concerned had clearly stated that they did not want to be identified as disabled. One curator stated;

"We have a disabled artist who vehemently does not want their disability disclosed."

In other cases, curators had made a decision not to discuss the artist's disability in displayed work because of sensitivities over whether the artist would have approved. This clearly reflects a view of disability as a naturally negative state of being. There was a consensus that it was easier, legal and more appropriate to 'out' someone if they were long-dead. One curator proposed that this was a non-issue, one which curators may be using as a 'smoke-screen' to conceal other insecurities about what to say or not to say.

Dilemmas relating to the display of work by disabled artists included:

- Is the artist living?
- Does/did the artist wish to identify as disabled?
- Did their disability influence/show in their work?
- How should their disability be described?

- *Should we name disabled people?*

Across many cultures, people's names are understood to be keys to identity and authority that can be used or misused to delineate their relative positions of power within relationships. Any differentiation between disabled and non-disabled individuals over naming or mis-naming, therefore might be seen to imply a lower status in society. Most curators were clear that naming individuals was desirable. However, in practice, a large proportion of displayed material featuring disabled people and objects related to them did not carry names.

Curators gave a range of reasons for not naming disabled people:

- Not knowing the name (records were missing or items un-named)
- Not having permission to name from individual or family
- Sensitivity about presumed family feelings if name/connection known
- Different standards apply to naming disabled people:
 - Legal and medical protocols
 - Context - are other people in the display named?

A related issue is the use of show-names or assumed/bestowed names to identify performers (freaks) with disabilities. In some cases, the popular nickname has persisted without any real name surviving. In the majority of cases, more than one name is known. In this case, it was common for the museum to use the names synonymously (e.g. Arthur Caley, the Manx Giant).

The combination of these anxieties and restrictions results in the names of disabled people rarely being used in display.



Image: Royal London Hospital Archives and Museum

- *How do we tell difficult stories?*

The history of disability is full of stories which are uncomfortable to deal with. The realities of life for disabled people in the past, the way in which society has dealt with their presence, and current prejudices towards disability are challenging themes for presentation.

We found a range of difficult stories associated with objects, and within archives, databases and history files. However, there was little evidence of engagement with ways to present and interpret these stories, which include:

- Histories of asylums, hospitals and workhouses
- War injury and mutilation, including subsequent stories (vagrancy, mental illness, poverty)
- Holocaust experience of disabled people (experimentation)
- Industrial illness and injury created by (amongst others) mining, fishing, and medical industries
- Treatment and cure - where treatments were experimental, brutal or unsuccessful
- Freakshow history
- Experience of pain and mental distress.

Following discussion at the colloquium, we concluded that it was appropriate for museums to tackle these topics. Colloquium participants talked about this in some detail and identified some of the barriers to presentation:

“(There is) censorship in museums - one elected member feels they have to safeguard family values and objects to anything that is not pretty or about education. (This) censors the display because they would not want (their children) to look at things like that.”

“All (these pictures) should be shown, but the question is how to show them and make them meaningful. There is a borderline between normal human curiosity and exploitation, voyeurism. We should be able to look at these pictures in an exploratory way, asking questions.”

- *Should we make the link to disability more explicit?*

The circumstances in which an object’s link with disability should be made explicit emerged as especially significant and problematic. Curators were only comfortable with explicit links being made when the exhibition was about disability or if an artist sees their disability as informing their work. In other cases they expressed concerns about an explicit link having a negative impact.

“The information may distract and detract from his or her work.”

“It could be thought a form of special pleading, that the work isn’t normal. If we were displaying the work purely for aesthetic reasons, we would not see the need to mention it.”

Yet there are arguments for making the link, and these were also expressed by curators during the research:

“You need to proactively mention the disability issue because there is a need for positive images.”

The explicit link can be made in other ways than just display. One museum proposed the use of its website and teaching packs to add depth to understanding, while another is working on trails and worksheets to make connections between objects and disability. While such work is welcome, care must be taken that second-layer interpretation, away from the main displays, is not simply used to sidestep the issues.

c. The shadow of the freakshow

Freakshows, where many visibly disabled people spent part or all of their lives, have a significant place in the history of disability. However the terms 'freak' and 'freakshow' are loaded with derogatory, negative and pejorative connotations which make them difficult to use objectively. Even where used in the most contextualised and accurate way, writers may feel the need to explain:

"We refer to (them) here as 'freaks', a description long used in the fairground though unacceptable in general use today, and retained for this review as an historical term."

In displaying any object or artefact related to disability, curators are anxious not to be seen as promoting freakshow approaches. In explaining why they choose not to show items, they may invoke the avoidance of a freakshow as the reason. The shadow of the freakshow has to be recognised as part of the reason why a climate of fear and nervousness pervades the discussion of display of disability. Acknowledging the historical importance and place of freakshows, and separating this from any display related to disability, is part of the future challenge for museums.



Image: Manx National Heritage

d. Preliminary thoughts on display practice and interpretation

Though it is not possible or appropriate to produce specific guidelines from this stage of the research, the following provide some preliminary thoughts which might inform consideration of display practice:

- **Is the object appropriately sited?**

Objects were sometimes positioned alongside natural history displays or together with unrelated artefacts, implying a 'curiosity' factor. Aids such as callipers, braces and prosthetics were displayed without any association with the people who wore them; labelling of surgical equipment such as amputation saws emphasised the item's technical effectiveness, rather than the human impact of its use.

- **Is there adequate narrative?**

Faced with labels which give only basic information, viewers may be encouraged to stare without consideration of contextual issues.

- **What name(s) should we use?**

We found cases where the show-name was used first, probably in response to (and perpetuating) public awareness of this. Real names should always be used in displays if it is possible and legal to do so.

- **Is it appropriate to present items for 'educational' purposes?**

This applies particularly to the display of clothing and other artefacts associated with giants and dwarves. Comparing sizes is a preoccupation for children, but curators need to be cautious about creating circumstances for possible ridicule.

- **Do we know the facts?**

This is particularly relevant to the world of showmanship, in which exaggerated size, age, scale, and fictional relationships were part of the show story. Museums may sometimes be complicit in maintaining these fabrications and have sometimes uncritically accepted material and associated information into collections. Items said to have belonged to giants had come into collections undated and unprovenanced. Rigorous research is needed to ensure that freak-related items are genuine. Museums should be careful to ensure that biographies relating to displays are as accurate as possible.

- **Would an ideas-led approach be useful?**

During the research, and especially in colloquium discussion, it became evident that disability could be placed in a more meaningful social context when the interpretation grew from ideas, themes and stories, rather than from object categories:

"It is perfectly possible to activate many areas of our collections along contemporary challenging lines. The holistic approach to museum thinking means you look more at projects or themes or displays which reflect people's concerns and interests here and now."

- **Is the display empowering or disempowering?**

The way in which an object is presented can empower or disempower the person connected with it. A prosthesis may be presented simply as a technological solution to an impairment, but the presentation becomes empowering if, for example, the voice, opinion or image of a user becomes part of the display.

- **Is the display based on the medical or social model of disability?**

These models reflect contrasting contemporary attitudes to disability within society. The medical model, which focuses attention on the impairment, places the responsibility on disabled people to adapt to their environment through their own efforts. In the social model, in which disability is treated as the result of society's failure to accommodate it, everyone has a shared responsibility to remove the social, environmental and other barriers faced by disabled people.

- **Does the display include stereotypes of disabled people?**

Stereotypes are simple reductions of dominant characteristics, perceived or present in groups of people - part of the 'self' and 'other' equation reinforcing a sense of difference/superiority among people who perceive themselves to be of the dominant culture. In museums, disabled people are often portrayed in stereotypical ways, and displays reinforce this by, for example, emphasising heroic achievements, suffering or patience. Valuable alternatives are examples of individuals who lead 'ordinary' lives as parents, workers or social influencers.

- **Is the display personalised or depersonalised?**

Within museums, disabled people are more likely to be depersonalised than non-disabled people. Failing to name people featured in pictures, as wearers of clothing or users of aids, contributes to one of the most effective forms of disempowerment - invisibility.

e. The importance of context

Many decisions for curators were cited as depending on context: whether to name, how to display, and what to say about an object/image or person were seen to be dependent on the particular set of circumstances surrounding the proposed display.

Curators cite display context as their principal area of concern, but we also need to look at how context influences our understanding of disability-related objects. For example there is a very limited socio-historical understanding of how disability was perceived in the past, and an assumption that attitudes were primitive and discriminatory.

f. Curatorial knowledge and specialism

Whilst some curators identified the potential to tell stories about disability through their collections, our research indicated that others do not readily recognise examples of material which fall outside their expectations. This may be due to a lack of knowledge or awareness about disability; influence from well-established stereotypes which suggest only certain types of material are relevant; and established ways of looking at collections, for example in terms of 'disciplinary specialism' rather than to explore 'contemporary social issues'.

g. What is disability?

The pursuit of a definition of disability was evident throughout the research, both from within the research team and from curators seeking to establish exactly what would 'count' or 'not count' in its representation. One colloquium participant argued that this concern for definition was indicative of a "curatorial need for definite knowledge" that made them uncomfortable with open boundaries of definition.

"If the question about defining disability had been asked 25 years ago, you would have had a more open response, but the focus on disability has made people more nervous about using language and definitions."

h. A social role for museums?

One possible reason for museums' limited engagement with these issues is the lack of consensus among curators of the extent to which museums should seek to address, even influence, issues of contemporary social inequality. The roles and responsibilities of museums and their potential influence on the values, attitudes and perceptions of visitors are topics which remain open to debate.

i. Lack of disabled people in the sector

A further factor which may account for the lack of attention to these issues is the small number of museum professionals with disabilities - disabled people entering the profession have to fight for access to workplaces and training opportunities, and face a daunting set of barriers to professional advancement.

5. CONCLUSIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

Buried in the Footnotes has generated a wealth of first-stage information about the presence of, and roles fulfilled by, disabled people in British (and world) history. Every museum visited had evidence of disability in the collection - indicating that there is a wealth of further material to be identified and investigated. However, the material is, in general, poorly understood and interpreted and is acutely vulnerable to loss, or change of meaning. New approaches to the display and representation of the material could enable museums to play an important role in addressing contemporary issues around disability and disability discrimination. By contesting reductive stereotypes, addressing the 'difficult stories' surrounding disability history, and demonstrating the diversity of disability experience, museums have the capacity to challenge understanding of what disability has meant to society in the past, and could mean in the future.

The research provided strong indicators for further areas of research:

- **Find the material evidence**
- **Research the evidence** - to better understand how it might be displayed to engage museum audiences with disability, and what knowledge is needed for adequate interpretation
- **Display and interpret material** - using a wide range of display techniques across wide ranging collections
- **Investigate the impact** - on audiences of both disabled and non-disabled people, to understand the ways in which visitors construct meaning from the exhibitions they encounter and how this might affect perceptions of disability.

This project has made significant progress towards finding the evidence, and provides a template for identifying the potentially huge amounts of material evidence which exist in museum collections in Britain. The research would be given greater depth by researching specific stories in detail and identifying the sources which yield the additional information both within and beyond museums. An indicative approach for subsequent work by other museums could then be developed.

Further research is also needed into: freak shows; belief systems (the the research yielded numerous examples of objects through which disability was related to belief systems worldwide); metaphor and symbolism in art (disabled people occur frequently in art, but what does their appearance signify?); contemporary collecting, and contested meanings within existing representations of disability.

A future research agenda could also include investigation into best practice in display and interpretation, and test possible new approaches, including ways to tell the 'difficult stories' identified above. An important aspect of this research would be dedicated time spent working with groups of disabled people on their response to, and interpretation of, objects, to create display materials that integrate a multiplicity of voices.

6. DISSEMINATION OF FINDINGS

The project has attracted substantial interest from academic research communities, museums, disability commentators and researchers, and mainstream media. The findings have been widely disseminated through academic, professional and media networks.

Publications

- A paper entitled 'Beggars, freaks and heroes? Museum collections and the hidden history of disability', co-authored by the research team has been submitted to the peer-reviewed, international *Journal of Museum Management and Curatorship*.
- A paper on the display of freak-related material in museum collections is in preparation for submission to a special edition of the international peer-reviewed journal *Disability Studies Quarterly*, in March 2005.
- The findings will also be featured in Chapter 5 of a forthcoming monograph, *Museums and the combating of prejudice* currently in preparation by R Sandell and due for publication in 2007.

Media coverage

The project has generated widespread interest from both museums-specific and mainstream media. The following coverage has been achieved:

- *BBC Radio Leicester* interview (13/8/03).
- *Social History Curators Group journal* (SHCG news) (December 2003, Issue 52).
- *The Guardian* newspaper, 'Access to a forgotten life: Push to get museums opening their doors to disability artwork', Wednesday March 17th 2004.
- BBC Radio 4, *You and Yours*, interview with Senior Research Associate and participating case studies (Colchester Museums and Royal London Hospital Museum, 1/4/04).
- *Museum Practice* (Summer 2004).
- *Museums Journal* (October 2004).
- *Arcady* Newsletter (AHRB), forthcoming 2004.

Seminar presentations

Papers on the emerging issues from the research have been presented at:

- Museums Association conference on the Disability Discrimination Act 2004. February 2004.
- East Midlands Museums Libraries and Archives Council seminar, March 2004.
- North East Museums, Libraries and Archives Council seminar, July 2004.
- Museums Association conference, September 2004.
- Smithsonian Institution, Washington DC: seminar on current research by Fellowship recipients, December 2003.
- Dress and Textile Specialists Annual Conference, Birmingham Museum and Art Gallery, November 2004.
- Museums and Galleries Disability Association - seminar and AGM - October 2004.

BURIED IN THE FOOTNOTES:

THE REPRESENTATION OF DISABLED PEOPLE
IN MUSEUM AND GALLERY COLLECTIONS



Marc Quinn
Catherine Long
2000
© the artist
Courtesy: Jay Jopling/White Cube (London)
Collection of the Art Gallery and Museum, The Royal Pump Rooms, Leamington

RESEARCH CENTRE FOR MUSEUMS AND GALLERIES (RCMG)

Department of Museum Studies
University of Leicester
105 Princess Road East
Leicester LE1 7LG

0116 252 3995
jad25@le.ac.uk

RCMG
Research Centre for
Museums and Galleries

 **University of
Leicester**

A · H · R · B
arts and humanities research board