Rethinking Disability Representation

The making of 'Behind the Shadow of Merrick'
Royal London Hospital Archives and Museum

Chapter 1: Inside the film, inside the Museum

The project was to make a film for the Royal London Hospital Archives and Museum and beyond, based around rethinking representation.

The Museum's perspective on the project

The point about the various Joseph Merrick interpretations – from the film by David Lynch, to the opera, to other individuals – is that each very often reveals something about themselves (the maker) in their quest for the 'Elephant Man', but the actual story is more interesting than the fictional story, especially when re-examined from the point of view of those who share Merrick's life the most – disabled people.

The Royal London Hospital Archives and Museum has a small collection of artefacts left by Joseph Merrick after he'd lived in the rooms at the hospital. The collection includes his veil and his carte-de-visite, along with medical engravings and the memoirs of Sir Frederick Treves, who wrote about 'The Elephant Man', having been Merrick's physician.

Jonathan Evans, Archivist:
"Being a hospital museum, our collection is about health and healthcare and has some associated links with disability and disability issues. We have always perceived Merrick's story as important to our museum. There are so many preconceptions about him: there are so many interpretations and people have an idea of him that is fictional or elaborated but, as archivists, we hold much of the original evidence and are well placed to find out what that tells us about him."

This is where the Rethinking Disability Representation (RDR) project comes in. It 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. It was an opportunity to look at his story less from a medical point of view and more from the point of view of a visitor who wanted to explore disability issues.

Jonathan Evans, Archivist:
"Working with David Hevey, the film-maker, it was interesting how he explored Merrick, by going into disabled people's own life-experiences and the various mental pictures they'd formed about Joseph Merrick through their own perspectives on the myths and films, etc. Because these are people who might visit the museum but might not vocalise their inner thoughts and ideas. But their clear confidence in David Hevey allowed them to open up more than they would on a questionnaire, for instance. They were willing to share – in quite a challenging way – their deepest thoughts and feelings about Joseph Merrick and make him live again."

The film-maker and archivist

Originally projected to take four months, the project stretched to six months, mainly because a key contributor, Tina Leslie, had issues over energy, health and availability. Also, the budget was very tight so, as we wanted to get the best crew (like cinematographer Chris Cox, Prix Italia winner for 'The Hunt'), we had to adapt to all their schedules, too.

David Hevey was given free rein, but on the understanding of fairly concrete parameters, which included understanding the existing films in the Museum, how they played, who the audience was, the scale of the Museum and finding the space to tell a new story about an old story. He developed more of a performed-documentary, in which the people showed some kind of power and control over the images and stories they told.

David Hevey, Film-maker:
"We set out to find a truth. Very early on, it was apparent that the one voice not heard about the Merrick story was that of those most like him – disabled people."

The beginning: projecting an idea

In the beginning, the idea was to democratise the many disabled people who'd played roles in the Royal London Hospital e.g. its growth was driven by people like Eva Luckës, who would be called disabled today. The major stumbling block to this 'voices-other-than-Merrick' strategy was that people like Eva Luckës, unlike Merrick, had not left behind disability point-of-view material.

David Hevey, Film-maker:
"The process always begins with finding the true story, somewhere beyond what one imagines the material will say. It is about immersing myself in the material, in the museum, in its needs, in the need to find a new way of showing old stories, in finding a plausible, realistic and true way of telling something anew. To find the story people know perhaps, but not from this new angle."

Jonathan Evans, Archivist:
"It was very helpful David being a film-maker and him being very able to realise if we were finding the material that made a script – we were looking for the great disabled-character quotes, but didn't find them. People like Eva Luckës – one of the key matrons who reformed so much in the hospital – didn't talk about being disabled, certainly not about acceptance or barriers, but Merrick did to some degree."

The breakthrough: finding Jonathan Evans' revelation document

Jonathan Evans, Archivist:
"I was approached sometime back by Hospital Radio to write something about Merrick. The radio volunteers were always being asked by patients for more information about Joseph Merrick, so they wanted me to write something. I thought I would like to do my own research, I would like to find out something new, and so I went back to all the books and records. I took, for instance, what was recorded at the time by people who knew Merrick. It was factual and straightforward. The piece was composed rapidly, but based on painstaking research."

David Hevey, Film-maker:
"After having ploughed through many books and articles given to me by Jonathan and Kate, Assistant Curator at the Museum, I came across that paper, which turned out to be the key, because it showed how the stages of Merrick's life echoed the stages of millions of disabled people's lives: impairment, awareness of impairment, negative response, familial ambivalence, social isolation, lack of education, medical intervention, workhouse/charity, hounding, finding peace in a place of one's own (known as 'independent living' nowadays), self-representation as a way of showing the world how you see yourself, and finally being seen by the world as one sees oneself – so do millions of disabled people. All these things happened to Merrick, they were all condensed in Jonathan's paper for the sake of clarity and truth and they reflected the line-through of disabled people's lives today."

Every project, if it's going to be original, innovative, worth doing and make an impact, has that eureka moment, when you find the new story to tell - Jonathan's paper provided that, because it showed, far from Joseph Merrick being the ultimate outsider, the freak of history, he was in fact the disabled archetype, the one-who-went-first.

The middle: rethinking the story to tell and the importance of disabled people playing a key role in the project

Once we'd realised that Merrick, far from being a strange outsider 'Super-crip' with no relevance to disabled people's lives, was in fact the archetypal disabled person, it was possible to break down Jonathan's facts-file into a series of questions with

which to interview disabled people about their lives and through which they could filter their particular feelings about Merrick, which were of course distinct and unique.

And through the interviews we began to get to the macro level of how Merrick had cast a shadow on their lives; how many had a strange affinity with him, yet kept clear of him through fear of negative association. Others were fascinated and keen to explore the Museum and Merrick's presence within it, as if they were touching the relics or mementoes of a distant relative. Again, this was a connection deeper than perhaps a non-disabled person might feel.

Merrick had clearly been imprinted on many disabled people's consciousness in subjective ways: disabled people talked about when they were children and, on learning about Merrick, dreading ending up in a museum as an exhibit; it's unlikely that a non-disabled person would take on and internalise the Merrick fable in this way.

The basic frame of the interview progressed through the following themes and questions:

Merrick, growing up, had increasing awareness of his impairment. Had you the same?
He had isolation. Had you?
He was a spectacle. Are you?
He had medical intervention. Have you?
He faced unemployment. Do you?
He found his own place. Have you?
He gained some level of acceptance. Have you?
Joseph Merrick began to be seen as he saw himself. Have you?

And so on…

This happened in his life – has it happened in yours? – was the method of enquiry, obviously adapted to each person as they responded with their own stories or views on Merrick and his life.

Then we added a second level: this happened in his life – it happened in yours – how do you think he felt during each episode? So we gained reflections on Merrick, reflections on disabled people and then a link to his life through empathy. Thus, the film grew around what Joseph Merrick went through, not based on sentiment or projection or myth, but based on disabled people who live similar aspects of the same life now, which is how it became their film, too: as he did then, they do now.

Stories in the film: Rowen's living-death in a museum

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; only she'd be there as a live specimen, not a dead one.

Stories in the film: Tim's 'Being a Merrick'

Tim Gebbels, a blind man who went to blind school, talked of how 'being a Merrick' was a school insult, it meant the lowest-of-the-low in disability terms and it was an un-PC insult he and his fellow students hurled at one another.

Stories in the film: Tina's 'Living in the dark'

Tina talked of how she, like Joseph Merrick, received visitors in the dark.
The story of Merrick mattered intensely to Tina and this changed the nature of the film, not by capitulating to one voice, but through pushing further into the archetypes. Tina knew Merrick in a way that was beyond factual and archival knowledge (though she knew a lot about him); her identification was through empathy, identity and understanding what he'd been through, because she'd been there, too.

As Merrick had lived in the dark, so had Tina. As Merrick had been hounded, so had Tina. As Merrick had worn a veil, so Tina wore hoodies. One adds levels of truth to a film if one can get to them; Tina added levels, because it was obvious she could almost transcend Time in her affinity with Joseph Merrick.

The scene we didn't shoot – Merrick's veil in Whitechapel High St

Tina had waited a long time to reclaim Merrick and explored working with Merrick's veil. We discussed the role of the veil as a barrier or as access-tool, particularly in light of the burkha and its prominence in Whitechapel Road, where the museum is located. In the event, we dropped this idea because it was gratuitous to our story and we feared Tina would become a new-freak.

The ending of the film: Tina's 'Merrick the beautiful' comment

By the end of the film, with the viewer repeatedly viewing both Merrick and Tina (and Tim and Rowen), the law-of-diminishing-returns kicks in and, by deliberately repeating similar portraits of Tina, one learned to see her as she saw herself, as one learned to see Merrick as he, perhaps, saw himself. So, at the end of the film, when Tina talks about what a hero Merrick is to her, and signs off with her 'Merrick, the beautiful' comment: it's true, it's believable and it pertains to both him and to her.

Jonathan Evans, Archivist:
"We hadn't seen David Hevey in action. There was a point when I was worried that we hadn't seen a script. I was expecting to see a documentary or factually-based script: I thought we were going to get something more prosaic, more facts-based, etc: I am very glad you didn't do dates and facts!"

David Hevey, Film-maker:
"In film, truth is delivered in two main ways: firstly, how you show it and then what the characters say within that. Once I knew what interviewees were going to say, and I knew how a few limited artefacts and a simple location would be to our advantage, the issue was then how to make something people were compelled to view, rather than moralised into viewing.

"A conventional talking-head documentary would not work, because I felt we had to show the active, conscious participation these people brought to their rediscovery of Merrick. We had to construct the event, rather than observe it, but keep it deep, emotional, moving and true. I decided that we had to see the contributors physically explore and inhabit the artefacts – put on Merrick's veil, study his photograph, reinterpret his poem, and so on – so as to convey a notion of living-again for Merrick and them through him, rather than dying again in another interpretation of Merrick-the-victim."

Jonathan Evans, Archivist:
"The use of props is interesting. The replica veil was made a long time back, because I wanted something we could show to people. The real one cannot be handled, certainly not used as a film prop in the way David used the replica."

The viewers' reactions to the film in the Museum

The film aims to present disability in a new and challenging way. Museum visitors 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 'other', a pathetic, childlike 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 can sit down in a row of seats en masse (or mini-masse) to view the various films, particularly previous Joseph Merrick films and other medical productions. We knew,

therefore, that we had an audience for output, but not necessarily for a new way of seeing Merrick.

Jonathan Evans, Archivist:
"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', 'moving films'. We used not to get those types of comments, so visitors watch David's film within the rest, and they pick up the emotions of his film. It's very different from other films."

New ways of seeing collections; how can the film help this?

The Museum and its collections are central to the film. The contributors are filmed in the Museum, in the entrance forecourt and the immediate environs. The Museum is located in a former Church of England parish church, St. Philip's, Stepney, which was rebuilt on the site of an earlier church and was opened in the year of Joseph Merrick's death, 1890. Much of The Royal London Hospital is currently being rebuilt, but St. Philip's Church survives and is now home to a Barts and The London School of Medicine library as well as The Royal London's Museum. Visitors are therefore reminded that the place they are visiting has a long history.

Joseph Merrick's hat and veil formed part of his travelling clothes which he wore before he came to the Hospital and which stayed with him until the end of his life. It is displayed in the Museum. The object features strongly in the film 'The Elephant Man' which accurately depicts the hat and veil and therefore many museum visitors are already familiar with the elements of its design – it is a peaked cap, very large in circumference with an attached veil with a single eyehole. The hat is covered in black velvet and braided around the edge; it is well made and was conserved at the Textile Conservation Centre in 1996. When the hat was being conserved the opportunity was taken to make an accurate replica. This replica is handled and donned by each of the disabled contributors in the film. Each takes off the hat in revelatory fashion to show the person concealed underneath. Jonathan Evans, as curator, shows the original hat on its mount. He wears white gloves, emphasising the curatorial role and the fact that the item on the mount is the original artefact: it is not otherwise made clear that the hat the disabled actors try on is a replica.

The hat and veil is a visual reminder of how Merrick hid his appearance from the public gaze when travelling. He combined the hat with a floor length opera cloak and oversized carpet slippers. The size of the hat reminds the visitor that Joseph's head, with its overgrowth of bone and flesh, was the circumference of a man's waist, and that he had difficultly in supporting it. Today, many women in the Whitechapel area wear a veil. Joseph Merrick's reason for wearing a veil was to hide his appearance, and by emphasising the veil in the film visitors are

encouraged to think about the reasons why people may hide their faces from the public gaze and the part that facial expression plays in visual communication.

A carte-de-visite portrait photograph of Joseph Merrick, wearing a suit, c. 1889 is also featured in the film. The contributors handle a replica of the photo, the original is part of The Royal London's collection and which has become the most familiar image of Merrick since it was first published in 1970. This is a personal item which Joseph had printed and which he gave to Reverend Tristram Valentine, the Hospital Chaplain, someone Merrick would have seen regularly when he was resident at the London Hospital. The disabled contributors look closely at the carte-de-visite and it inspires them to make revealing comments – Tina for example ponders whether Joseph would have been accepting of her appearance. The small photograph is one of the last visual representations of Merrick, taken about a year before his death when he was aging and his health was failing – it is a touching image.

New approaches to interpretation: how has the film done this?

The film is longer than a conventional museum film – the edited version of the film on the Museum's MPEG player lasts about 13 minutes – the full-length film available on DVD is 20 minutes. The pace of the film is deliberately unhurried, in places almost laconic. This is deliberate and allows the viewer time not only to listen to what the contributors have to say, but also to become more familiar with their visual appearance.

The contributions of the disabled actors are central to the film – they articulate what the film has to say. Other films may feature people with conditions that replicate some aspects of Merrick's illness, but the narration and most of the voices heard in films such as the QED film are provided by non-disabled people. The revelatory way the contributors speak gives the film a good deal of its impact and helps it feel authentic. The simplicity of approach in terms of script and presentation also helps make the film accessible to as wide an audience as possible – it is hoped that everyone can take something from it. The museum objects featured in the film are also central. They provide a very physical reminder of the life of someone who evokes strong feelings among disabled people.

Unsettling visitors' views of disability: comments and feedback

Many Museum visitors are people of faith – the Museum is situated in Whitechapel, which today is home to many people who have roots in Bangladesh, the great majority of whom are practicing Muslims. The film ends with a recitation by Tina, one of the actors, of an extract from a poem by Isaac Watts entitled 'False Greatness' (1706), which was adapted by Joseph Merrick and included in the brief 'Autobiography of Joseph Carey Merrick' (copies of which were sold in his travelling show). The poem includes the following lines:

‘Tis true my form is something odd
But blaming me is blaming God…’

These lines encourage visitors to dwell on the principle, common to many faiths and to those with ethical considerations, of accepting human life in all its forms. These lines drew a discussion from a group of visiting local teenagers when one commented: ‘That’s true’… ‘that blaming him is blaming God.’ These sentiments are echoed in the Royal London Hospital’s motto, derived from a play, ‘The Self-Tormentor’, by the Roman dramatist Terence: ‘[Homo sum] humani nihil a me alienum puto’, which translates roughly a ‘I am human so any human interest is my concern’.

Since we began running the film in the Museum the number of visitor comments mentioning the films has increased. Comments have included:

“Very interesting, good films!”'

“Interesting - the displays and the films - thanks!”

“Extremely interesting movie about the Elephant Man.”

Other comments have included “shocking” and “sad”.

The response card asked, ‘How does this display change the way you think about disability?’ The film-maker was not convinced that this was the most accurate question to trigger debate about Behind the Shadow of Merrick. The ideal question would have been: ‘how does this film change the way you see difference?’

However, there were extensive, mainly positive feedback cards, but perhaps the most illuminating response came from a Sociology student, who emailed:

“I think Behind the Shadow of Merrick is a very powerful and moving film. It has an emotional rawness that both engages the viewer and, more importantly, holds them beyond the screening... For most non-disabled people Merrick is 'the other' and 'the outsider' but for your participants in the film he is the epitome of the insider: he knows the cold, harsh reality of not visibly belonging and of being the eternal stranger.”

What’s been learnt from the process internally for the organisation?

Jonathan Evans, Archivist:
Behind the Shadow of Merrick tries to lift the veil on Joseph (literally as well as metaphorically). It seeks to draw the viewer in. It invites the museum visitor to think about the reality behind the spectacle: to think about the person behind the mask and in doing so to meditate on the human condition. It is narrated by the 9-year-old child of one of the disabled contributors. This in itself is something of a departure

from the conventional museum film, which more often than not will be narrated by an actor – someone with an adult, authoritative voice. The child's voice invites the visitor to think about the universality of disability.

"The musical introduction is simple, modern piano music: there is no hint at Victorian barrel organs, tinkling pub piano or the cries of street sellers which characterise – some might say overpower – evocations of Victorian London in museums and other visitor attractions. The narration is simple and accessible – it acknowledges the sadness in Joseph Merrick's story without straying into melodrama.

"Visually, the film dwells on the faces of the contributors who explore their feelings about their own experience of life as spectacles, living in 'the shadow of Merrick'. The contributors speak about the playground name-calling, about growing up in institutions and about being constantly stared at. The camerawork allows the viewer to maintain sustained eye contact with the contributors and the simplicity of the script means that the points the contributors make can be easily understood.

"The film's disabled contributors speak with conviction because Joseph Merrick's story has clear resonance for them. There are elements in his life that they have also experienced in their own lives and the museum visitor's perception that Merrick is an historical figure, long-dead and that his experiences are not something that people live with today are thereby called into question. People, in Joseph Merrick's day and today, are intrigued by sensation. The film does not disguise this – the startling aspects of Joseph Merrick's physical appearance are what brought him to the public's attention and remain a factor behind the continuing interest in him. The film presents a sustained view of the physical appearance of the disabled contributors – a symbol of permanence and something some visitors may find unsettling."

Beyond the ending: the legacy. How people might think about Merrick and disabled people in future

Jonathan Evans, Archivist:
"Well, Behind the Shadow of Merrick takes Joseph Merrick out of the simply biographical, telling the story through the filter of Frederick Treves' reminiscence, through the eyes of David Lynch, etc. and gives people who experience similar lives a voice; that's what's new and different and a very revealing approach. Has it been worth the time we spent on it? Yes, very much so.

"And, when visitors come in asking about the 'Elephant Man' or 'John' Merrick, they very often want to know about the fictional man, so it was good to have a project getting back to basics, but with simplicity, emotional power and truth, which Behind the Shadow of Merrick certainly delivers."

Beyond the ending: the legacy. How the Museum might do things differently as a result of this collaboration

Jonathan Evans, Archivist:
"We learnt from the process; I imagined, in my mind's eye, that David would come up with the project, but what would it be? For a long time, I was struggling with this imagined outcome. The paper was the key, because I knew the facts and David knew that those facts fitted the archetype of disability experience, even to this day."

How did this collaboration renew Merrick?

We feel it's an extremely worthwhile contribution to the scholarship and, particularly, to the facility we can offer to the public, including those people with impairments who could empathise with Joseph Merrick, by reflecting on the moments of his life and how they played out through their own lives. We were proud to be involved in something nationwide and to be linked into the whole of the RDR project.