What stories museums tell, whose stories they choose to tell, and how those stories are told really does matter. This session will explore the significance of telling overlooked stories, how these overlooked stories can shape our attitudes and challenge society to think differently.

Globally, 15% of the population are disabled. Disabled people live in every part of the world, and disability cuts across every section of society. However, despite being such a substantial section of the world’s population, every day disabled people face discrimination and oppression. Their human rights are constantly challenged. Do we remember that alongside 6 million Jews, disabled people were also exterminated during the Holocaust? The Nazis considered disabled people to be a burden and an affront to their notion of a society composed of a perfect race. The T4 programme began in 1939, it is estimated that 275,000 disabled people were murdered and even more were sterilised.

The human rights of disabled people are shaped by societies which still have a problematic relationship with disability. How can museums tell stories of disability that capture the interest of the public whilst challenging debate around the implications of a society that values some lives more than others? This session will focus on ‘Let me tell you a story,’ a dance developed for museums by artist and choreographer Mark Smith as part of a research project Exceptional and Extraordinary:
unruly bodies and minds in the medical museum. The session will examine untold stories, and unpick dominant societal models – in this instance the medical model of disability - which have led to the exclusion of certain voices. ‘Let me tell you a story’ challenges us to think differently about disability.

Disablism n. discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others.
(although you won’t find a definition in a dictionary)

Disablism: How to tackle the last prejudice, DEMOS

Disablism is a word you will not find in the dictionary. It emerged from the 2004 report by the UK Think Tank Demos How to tackle the last prejudice. Like sexism and racism it is about discrimination. Disablism is about discriminatory, oppressive or abusive behaviour which emerges from the belief that disabled people are inferior to others. The fact you will not find this word in the dictionary is significant; the concept of oppression of disabled people is still largely overlooked, an often subtle and insidious discrimination which mainstream society is all too often complicit with. Every day, disabled people experience injustice, unable to access buildings, transport and other aspects of everyday life. Disabled people are excluded from work, from decision making. Disabled children may be in mainstream education, but all too often this is lip service to inclusion. The barrier of difference is too challenging for some schools, rather than focusing on creating an environment where everyone can learn and thrive, they focus instead on the barriers of why a child may not fit into a system.

A note about language: in this paper I will refer to disabled people, this is the terminology used by the UK disability rights movement, who use this language to show they are disabled by society. Individuals are not disabled by their impairments but by society not accommodating their needs. Disabled people is a political term.

Almost a sixth of the world’s population are disabled. Disabled people live in every part of the globe, and disability cuts across all age ranges and every section of society. Impairments are wide-ranging and often changing and complex. Many are invisible like hearing loss and mental health experiences, others are visible physical impairments, like the British actor & musician Mat Fraser who featured in the Research Centre for Museums and Galleries’ Cabinet of Curiosities.¹

The integration and visibility of disabled people in mainstream society varies across the world. The Garage Museum of Contemporary Art in Moscow, for instance, is focusing on creating access to the Museum for disabled people. They are all too aware of the legacy of Russia’s Soviet past when disabled people were hidden away from society and institutionalised. The National Disability Arts Collection & Archive,² a UK initiative to be launched in 2018, illustrates how disability activists, a highly politicised group, have used art to fight for their rights and challenge outmoded models like the charity model. Disabled people have had to be vociferous and disruptive to get their voices

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¹ https://www2.le.ac.uk/departments/museumstudies/rcmg/projects/cabinet-of-curiosities [retrieved 15 01 2018]
² http://www.ndaca.org.uk/ [retrieved 15 01 2018]
heard and legal rights acknowledged, for example chaining themselves to buses in the 1990s. Eventually their actions led to the UK Disability Discrimination Act in 2005.

Despite such a substantial section of the world’s population being disabled and despite rights improving for some disabled people, every day disabled people face discrimination and oppression. Human rights are constantly being challenged. The current UK government’s austerity measures have questioned disabled people’s rights to state support for additional living costs and transport; this has resulted in increasing rates of disability hate crime, as well as the presentation and demonization of disabled people as benefit scroungers. Recently, the BBC reported the frightening increase in hate crime against disabled children (Figure 1). Families with disabled children described being targeted online and verbally abused in the street. The article explains how ‘Families often feel like they can't go into busy public spaces or post images onto social media for fear of being publicly shamed or having to be submitted to people telling them that their child must lack quality of life because of their disability.’

Figure 1: BBC News report October 2017

We have seen earlier spikes in the rise in hate crimes against disabled people. The 2012 Paralympics were the most successful to date, with greater visibility of disabled people in the media, but ironically there was also a significant increase in hate crimes.

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How can museums tell stories of disability that capture the interest of the public whilst challenging debate around the implications of a society that values some lives more than others? The dominant view is that some lives are more valued than others. Disabled people’s voices and experiences are mainly invisible: they are often not portrayed in the mainstream, are often absent from museums or presented in ways which reflect past attitudes to disabled people. However, museums are powerful places to challenge society to think and do things differently.

‘Let me tell you a story’ was part of a wider project, Exceptional & Extraordinary: Unruly bodies and minds in the medical museum, developed and led by myself and my colleague Richard Sandell in the Research Centre for Museums and Galleries (RCMG), School of Museum Studies, University of Leicester. RCMG’s research focuses on stimulating new thinking and creative practice that enables cultural organisations to become more ambitious and impactful in nurturing more equitable and inclusive societies. Like all our research, Exceptional & Extraordinary was a collaboration, in this case with museums and disability activists.

Figure 2: Exceptional & Extraordinary logo and premise

Exceptional & Extraordinary was based on the premise: Since humans first appeared on earth no two have ever been the same. Yet somewhere along the way, certain bodies and minds came to be highly valued whilst others became viewed as problematic; as deviant and unruly, deficient and requiring adjustment towards a perceived idealised norm.

Exceptional & Extraordinary invited four artists to explore behind the scenes of eight of the UK’s most renowned medical museums and - in collaboration with experts in medical history, disability and museum - to produce a series of thought provoking new commissions that examine our attitudes towards difference with the aim of stimulating debate around the implications of a society that values some lives more than others. Mark Smith and his dance company, Deaf Men Dancing, was one of those artists.

See https://www.unrulybodies.le.ac.uk/ [retrieved 15 01 2018]
Exceptional & Extraordinary emerged from 20 years of research by RCMG around disabled people and museums, including projects such as Buried in the Footnotes,6 Rethinking Disability Representation in Museums & Galleries,7 and Stories of a Different Kind8 / Cabinet of Curiosities.9 This research looks at the ways disabled people are either invisible in museums or have been represented negatively - exploring the barriers to museums engaging with this work – and has supported museums to work with disabled people to rethink their representation. Exceptional & Extraordinary specifically worked with medical museum collections, a very purposeful choice although not an easy one. The medical museum is a problematic space, containing the body parts or whole skeletons of disabled people such as Joseph Merrick.10

Disabled peoples’ lives and experiences are shaped by the expectations and barriers placed upon them by society, and also by changes in medicine, technology and biomedical science. Whilst some of these changes have been positive, biomedical perspectives have tended to see physical and mental impairments as largely negative, as deficiencies that are in need of fix or cure. These medical ways of seeing, and thinking about, difference have played a significant role in shaping the ways in which wider society also thinks about, responds to and treats disabled people – as victims, objects of pity and charity, as less than human, or as superheroes struggling to overcome the burden of their impairments.

The medical model of disability

The Medical Model sees the disabled person's impairment or health condition as 'the problem'. The focus is therefore on 'fixing' or 'curing' the individual.

The medical model of disability links the diagnosis of disability to the individual's physical body. It is a deficit model, assuming that the impairment or condition will reduce the individual's quality of life. The aim is, with medical intervention, to manage or 'cure' the impairment so that the disability will be diminished or corrected. By extension, the medical model supposes a 'compassionate' or just society invests resources in health care and related services in an attempt to cure or manage disabilities medically, and to allow disabled people a more 'normal' life. The medical profession's responsibility and potential in this area is seen as central.11 The medical museum is so framed by the medical model of disability that it is inherently challenging in the context of disability rights and social justice.

Medical museums contain a wealth of collections that are relevant to the lives of disabled people; however many of these collections are under-researched or are understood through biomedical

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5 http://www.bbc.co.uk/news/uk-41600137 [retrieved 15 01 2018]
6 https://www2.le.ac.uk/departments/museumstudies/rcmg/projects/buried-in-the-footnotes [retrieved 15 01 2018]
7 https://www2.le.ac.uk/departments/museumstudies/rcmg/projects/rethinking-disability-representation-1 [retrieved 15 01 2018]
8 https://www2.le.ac.uk/departments/museumstudies/rcmg/projects/Stories%20of%20a%20Different%20Kind %20and%20Cabinet%20of%20Curiosities [retrieved 15 01 2018]
9 https://www2.le.ac.uk/departments/museumstudies/rcmg/projects/cabinet-of-curiosities [retrieved 15 01 2018]
perspectives that do not represent the lives and experiences of disabled people through their own voices and stories, but rather through the voices of surgeons, doctors and other medical practitioners. In recent decades, disabled people, activists and researchers have fought and struggled to challenge these medical perspectives as part of a global disability rights movement, to challenge the view that physical and mental impairments are ‘deficiencies’ that need correction or cure to conform to ideas about what is ‘normal’ for the body and mind. Rather than disability being a result of impairment (body or mind), it is a product of barriers created by society (physical, sensory, attitudes) that prevent disabled people from playing a full and active contribution. It is society that disables people, not their impairment. This social model of disability is very different to the medical model, which sees the individual’s impairment as the ‘problem’ that needs intervention, fix or cure.

Certain bodies and minds came to be highly valued, whilst others became viewed as problematic; as deviant and unruly, deficient and requiring adjustment towards a perceived idealised norm.... with these words echoing in his head, choreographer Mark Smith spent hours with curators investigating the vast collections of the Science Museums stores (Figure 3) and the Thackray Medical Museum (Figure 4).

**Figure 3: Mark Smith with curator Katie Dabin, Science Museum stores**
Figure 4: Mark Smith explores the Thackray Medical Museum collections

The combination of curatorial expertise around the collections, and Mark’s perspectives, insights and experiences as a disabled person enabled the collections to be interrogated in new ways through debate, discussion and interaction. Mark was especially connected with collections related to deaf culture and hearing impairment, this is his culture. He was so excited and animated to discover nineteenth century hearing trumpets disguised as flowers, headbands and shells. There was an intimate understanding of quite how significant these items were for past lives.

Figure 5: Mark Smith shouting into a nineteenth century hearing trumpet
Exceptional & Extraordinary created a wider framework for thinking about these issues through a series of Exchanges where researchers who had framed the project came together with disability activists, advisers from the disability sector, medical historians, artists, curators and engagement staff in a process called ‘trading zones’ where equal value is given to the experiences and voices of those with lived experience as to those of professionals.

‘Let me tell you a story’ was performed by the dance group Deaf Men Dancing, an innovative all-male dance company, who, like Mark, are Deaf. Together they have created a fusion of dance styles that incorporate sign language, creating an original aesthetic. Their inspiration is drawn museum collections.¹²

Figure 6: Still from ‘Let me tell you a story’

This piece of the dance focused on the Milan Conference (Figure 6); known as the Dark Age of Deaf history, it banned the use of sign language. The banning of sign language was like a firing squad eliminating people, cutting down a community from their highly effective form of communication. The impact of the ban on the Deaf community was catastrophic, profound, reverberating, and its effects are still felt over a century later. The impact of banning Deaf culture robbed the Deaf community of their ability to communicate, isolating and disempowering people in the desire to make Deaf people ‘normal.’

What new insights did artists Mark Smith gain from this experience?

What I’ve gained from Exceptional & Extraordinary is that I feel as an artist I’ve grown so much and through researching and visiting museums and talking to professors, people who have some knowledge in the Deaf history and the Deaf culture I feel that I’ve learnt so much

¹² https://www.unrulybodies.le.ac.uk/4-extraordinary-artists/2nd-artist/ [retrieved 15 01 2018]
about myself as a Deaf person and I feel I’ve got more pride in my deafness now so and also as an artist I feel that my work have gone on new levels and new direction, become much more deeper into the whole the Deaf issues and the history and the culture...

I mean I’ve been very lucky to be given this opportunity to meet people like Lauren from Thackray Museum and who have been really incredible and supportive and helpful by providing equipment and objects in the private storeroom where I had to wear white gloves and to hold objects that belonged to Deaf people over hundred years ago, for example ear horns that belonged to Queen Victoria which is amazing to see that... and also Princess Alexandra and she had a fan but it actually disguised an ear horn which I’m really quite crazy [about]... for example they used to have the hairband with flowers but it actually disguised ear horns with the tubes inside their ears... and the sound would travel through the head and would go into their ear through the tube or sorts of things like that. It seemed to be they were being very creative enjoying something really different but obviously done through very discreet way... so they don’t appear as a person with a hearing loss or as Deaf so they were trying to find a way to make it as a fashion thing... a lot has changed since then because now children who wear hearing aids are much more open I’m more proud they either wear like blue earmoulds and pink hearing aids even with a bit of jewellery attached to their hearing aids and things like that. It’s just amazing to see how much we’ve changed that we are more open now but it’s interesting how now that children have made into a fashion thing which is over a hundred years ago they made that as a fashion but obviously in disguise and that was amazing for me to see that and for me as a Deaf person who wears hearing aids every day to hold an object or equipment that belonged to Deaf people who wore them over a hundred years ago. It felt very personal for me because... it belonged to people who wore them every day and it would be like when I go and my hearing aids be a hundred years later the next generation will be holding my hearing aids, there’s a real personal feeling about that.

There is one story that made a huge impact on me is the Milan Conference 1880 because it is actually described as the Dark Age of the Deaf history because... this is where everybody made that decision to ban sign language and to replace it with oral methods or speech therapy and also they replaced Deaf teachers with hearing teachers... and the sad thing is there was only one Deaf person who was there, his name was James Denison or something I can’t remember his name, but he was the only Deaf person there and he did not have any asset or support for him so he had no idea what’s going on. And obviously he voted for continuing sign language but he got outvoted... he was not given the chance to vote so in a way Deaf people’s rights have been taken away and especially their language have been taken away and also their lives since then for over a hundred years their lives have been organized and run through hearing authority who thought they knew better for their life but it turned out to be they were wrong. So only just recently in 2003... sign language became recognized officially so can you imagine how far back from 1880 especially how Deaf people were not allowed to sign, they had to sign in secret so that you know is also very personal for me because I went to an all Deaf school... where they banned sign language and I remember in the playground we used to sign in secret so that’s what it was like then. So that’s why the Milan Conference of 1880 made a huge impact on me and because of my experience and for Deaf people’s experience over hundred years and I just feel that it is my responsibility to retell the story for the next generation who didn’t know anything about that story like me.
I would like the audience to become more aware of the whole Deaf history and the Deaf culture and also I want them to feel and be allowed to be part of my world. In the Deaf world for example with hearing test or speech therapy and the birth of sign language it’s about the integrating experience, sensory experience of it and I want them to leave after the performance with building a new knowledge and to be educated about the Deaf history and the culture as well at the same time being entertained and to be inspired and I hope that when they meet the next Deaf person... they will be more tolerant and more understanding and be able to give more time especially on the communication side of it... I just hope that this project will change people’s perspective of Deaf people and disability as well and change their attitude towards disabled and Deaf people and I really would like them after the performance or after the project is to talk about the rights and the wrongs of for example the banning of sign language in the Milan Conference - was that right or wrong? And with speech therapy was that a good thing to help them or no? And also about the war how thousands of soldiers became Deaf but they didn't really have any support for it so I would like to create a debate about how can we improve the life for Deaf people and disabled people in the future.

‘Let me tell you a story’, along with performances by three other artists, were performed at eight museums across the UK, the events followed by a post-show discussion.

Did the performances stimulate debate?

Exceptional & Extraordinary aimed to examine our attitudes towards difference and to stimulate a debate around the implications of a society that values some lives more than others. After experiencing ‘The Wobbly Manifesto’ and ‘Let Us Tell You a Story’ at the Royal College of Physicians, this audience member (Figure 7) confidently expressed their views on how society’s attitudes towards difference are shaped. Understanding today's society to be materialistic and one that values economic worth over and above a moral and spiritual compass, they reflected on how our current societal structures and systems have had a profound impact upon how we think about and value difference.
Liz, a mum of two daughters aged 3 and 5 years, reflected on her children’s views of difference (Figure 8). Through her comments, she demonstrated that judging difference negatively is a learnt behaviour rather than innate to human thinking. She hopes for a changed world for both her and her children, where plurality is embraced, and difference is celebrated and valued.
The performances inspired respondents to think about how we as individuals and as society can change, influence or challenge negative attitudes towards difference. This comment (Figure 9) also emphasised the importance of being exposed to difference and building relationships that will, in turn, confront ignorance. By getting to know people and understanding their lives, needs and interests, individuals and society can become more open to accepting people who are ‘different.’

**Figure 9: Response card, Royal College of Physicians, 20 June 2016**

In conclusion, what stories museum tell, whose stories they choose to tell and how those stories are told really does matter. Stories come in many forms; we had not worked with a choreographer before and we had not thought how powerful, how visceral dance can be in telling difficult stories with a sense of the possibilities for the future. Museums shape as well as reflect society. We have collections which may mean very little, like serried rows of hearing aids carefully catalogued in museum stores, but these can become meaningful items which have a profound impact on the human rights of one in six of the world’s population. By working collaboratively to unpick dominating societal norms we can ignite the power of stories that museums hold, creating new insights and challenging pervading negative norms. We need to harness that power and challenge more people to think differently about disability and difference. Disability is not ‘other’, it is part of all our lives. If society accepted and understood this, and acted on it, people with impairments would be much less disabled. Museums have collections related to the lives and experiences of disabled people; how can these stories best be told with, and by, disabled people, to challenge society to think differently about unruly bodies and minds, and, in so doing, ensuring the human rights of disabled people will not be violated.

For more details of Let Me tell you a Story & Exceptional and Extraordinary:

[https://www2.le.ac.uk/departments/museumstudies/rcmg/projects/exceptional-an](https://www2.le.ac.uk/departments/museumstudies/rcmg/projects/exceptional-an)

[https://www.unrulybodies.le.ac.uk/](https://www.unrulybodies.le.ac.uk/)