

Impact case study (REF3)

Institution: University of Leicester		
Unit of Assessment: 34B		
Title of case study: Advancing disability equality: representing difference in international cultural and medical institutions		
Period when the underpinning research was undertaken: 2002–2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Jocelyn Dodd Suzanne MacLeod Richard Sandell	Role(s) (e.g. job title): Professor of Museums and Social Change Professor of Museum Studies Professor of Museum Studies	Period(s) employed by submitting HEI: 2000–2020 1997–Present 1997–Present
Period when the claimed impact occurred: 1 August 2013–2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact		
<p>University of Leicester research has enabled cultural and medical institutions across the world to develop new ethical and rights-based understandings of disability. Not only that, but the research has empowered them to apply these understandings to policy and practice; and to purposefully use them to stimulate, inform and shape public and professional debate in ways that foster support for disability rights, respect and dignity.</p> <p>This work was developed in response to growing recognition amongst disabled people and equality campaigners that, despite formal advances in the law, disabled people's daily lived experiences are still powerfully shaped by deeply entrenched negative public and professional attitudes towards physical and mental differences.</p>		
2. Underpinning research		
<p>In 2002, the Research Centre for Museums and Galleries (RCMG) at the University of Leicester secured an AHRB Innovation Award for experimental research into the representation of disability and disabled lives across the UK's museums and galleries [R1]. A follow-up research project, funded by the National Endowment for Science, Technology and the Arts and the Heritage Lottery Fund (2008), further explored the (under) representation of disabled lives in museums and the reasons behind this [R2]. Together, these projects revealed the powerful and pervasive influence of medicalised ways of viewing physical and mental differences on museum practice and the highly problematic portrayals that resulted [R3]. Disabled people and equality campaigners were highly critical of these reductive, offensive and dehumanising ways of publicly presenting and discussing disability, as inherently negative, deviant, lacking and in need of fix or cure.</p> <p>Over a period of two decades, RCMG pioneered new, participatory approaches to exploring this field, working with curators, disability equality campaigners and communities with lived experience of disability [R4]. This collaborative research process developed, tested and evaluated new ways of presenting disabled peoples' lives in cultural institutions shaped by social contextual – rather than medical – accounts of differences. These new, ethically-informed and rights-based approaches to understanding physical and mental differences have had a profound influence on the way disability is understood and represented in and through cultural institutions; helped to shape the way medics are trained; and shaped public opinion towards disabled people [R6].</p> <p>Since 2014, RCMG has focused on collaborating with medical institutions and expertise, especially medical museums and collections where negative portrayals of disabled people are most pervasive. During this time, RCMG initiated and led two distinct but related projects involving sustained collaborative research with eight of the UK's most renowned medical</p>		

museums, five artists with lived experience of disability, and advisors from the **Smithsonian Institution's National Museum of American History**, the **Royal College of Surgeons of England** and leading disability-led arts organisation **SHAPE** [G1, G2, G3, G4]. The experimental research resulted in new narratives of disability that were brought to life through five major new artworks. These were presented at 18 public events in museums across the UK – six from the first project in 2014 [G1, G2] and 12 during the summer of 2016 [G3, G4]. The events were used as a platform and stimulus for debate and dialogue, bringing together medics, disabled artists and rights activists, museum professionals and diverse public audiences to explore and challenge negative attitudes towards difference [R5, R6].

Subsequently, in 2018, the UK's most high-profile and most-visited medical museum – the **Wellcome Collection**, London – approached RCMG to develop a research collaboration which would explore how the Centre's disability-themed research over the past 15 years could be applied and extended to transform a new permanent gallery [G5]. Opening in September 2019, and in place for at least ten years, this new gallery – *Being Human* – is the first time that a major medical museum has used social contextual approaches to discussing physical and mental difference throughout its entire interpretation, public programming and external communication, to purposefully foster more empathetic and respectful attitudes towards disabled people.

This focused collaborative research with medical institutions has stimulated and informed new thinking, policy and practice in UK cultural institutions more broadly and internationally. For example, since 2018, RCMG has worked with **the National Trust** to use the Centre's research-led, ethical approach to publicly present previously untold stories of disability linked to Trust properties [G6, G7].

3. References to the research

- R1. Sandell, R., Delin, A., Dodd, J. and Gay, J. (2005).** 'Beggars, freaks and heroes: museums and the hidden history of disability'. *Journal of Management and Curatorship*, Vol.20 (1):5-19.
- R2. Dodd, J., Sandell, R., Jolly, D. and Jones, C. (2008).** *Rethinking Disability Representation in Museums and Galleries*, RCMG.
- R3. Sandell, R., Dodd, J. and Garland Thomson, R. (eds.) (2010).** *Re-Presenting Disability: activism and agency in the museum*, Routledge.
- R4. Dodd, J., Jones, C. and Sandell, R. (2017).** 'Trading Zones: collaborative ventures in disability history' in J. Gardner and P. Hamilton (eds.) *The Oxford Handbook of Public History*, Oxford University Press: 87-104.
- R5. Dodd, J. and Sandell, R. (2016).** *Unruly Bodies*, Online. www.unrulybodies.le.ac.uk
- R6. Sandell, R. (2018).** 'Museums and our understandings of difference' in S. Knell (ed.) *The Contemporary Museum*, London and New York: Routledge: 169-84.
- G1.** *New Perspectives on Disability and Medicine*. Investigators: **Richard Sandell and Jocelyn Dodd**. Wellcome Trust (2012-2014), GBP30,000.
- G2.** *Cabinet of Curiosities*. Investigators: **Richard Sandell and Jocelyn Dodd**. Arts Council England (2014), GBP30,000.
- G3.** *Exceptional and Extraordinary: unruly bodies and minds in the medical museum*. Investigators: **Richard Sandell and Jocelyn Dodd**. Wellcome Trust (2015-2017), GBP178,990
- G4.** *Exceptional and Extraordinary: unruly bodies and minds in the medical museum*. Investigators: **Richard Sandell and Jocelyn Dodd**. Arts Council England. (2015-2017), GBP49,500.
- G5.** *Disorder, dissent, disruption: making new narratives of disability in the Wellcome Collection*. Investigators: **Richard Sandell and Jocelyn Dodd**. Wellcome Collection (2018-2019), GBP33,030.
- G6.** *Isolation and loneliness - opening up new stories and interpretive experiences at Calke Abbey*. Investigators: **Suzanne MacLeod, Jocelyn Dodd and Richard Sandell**. National Trust (2018-2019), GBP124,775.

G7. Everyone Welcome. Investigators: **Suzanne MacLeod and Richard Sandell.** National Trust (2019-2022), GBP167,695.

4. Details of the impact

Impact has been achieved by building highly collaborative relationships which provide rich and varied opportunities for exchange, and which bring together different beneficiaries – museums; medical professionals; disability equality campaigners; disabled artists; cultural policy makers; and museum audiences – and which collectively foster radically different ways of understanding physical and mental differences.

Stimulating debate and informing public opinion

Since 2014, RCMG's collaborative research has generated new public narratives of disability engaging large audiences through wide-ranging museums, galleries and heritage institutions. For example, *HumanKind* at **Calke Abbey**, featuring the National Trust's first disability-focused interpretation, was seen by over 350,000 visitors in 2019. In September 2019, the new permanent gallery, *Being Human*, opened at the **Wellcome Collection**, London, and in its first four months attracted 267,161 visitors—25% more visits year-on-year than its predecessor *Medicine Now* in 2018. During this period, 12% of the audience declared themselves disabled, compared with a 5% average among benchmarked organisations. The new narratives of disability featured in *Being Human* reached large audiences beyond those who visited the **Wellcome Collection**; an outdoor advertising campaign delivered 20,300,000 impressions and paid online activity delivered 2,400,000 million impressions. The Wellcome Collection's *Being Human* webpage was viewed over 50,000 times in the first four months and the gallery was featured in 82 press articles [E1].

RCMG's research has stimulated public and professional debate through high profile media. It won the *Observer Ethical Award for Arts and Culture* in 2014 (for work which changes the way people think and behave). *Being Human* featured in a *New York Times* article that asked 'Is this the world's most accessible museum?' (6 September 2019) and in an *Apollo Magazine* special feature, 'Do museums and galleries do enough for disabled visitors?' (October 2019).

In 2016, an in-depth, mixed-methods evaluation (using self-completion response cards, filmed interviews, and social media analytics) captured and analysed responses from a sample of the 1,058 attendees to a series of events that shared the outcomes of RCMG's collaborative research with medical museums. This included the **Royal College of Physicians, Royal College of Surgeons, Science Museum, Thackray Museum of Medicine** (Leeds), and the **Smithsonian Institution's National Museum of American History**. The study generated "considerable evidence that thinking and debate was enriched by engagement with the project and its key messages, with participants taking up and discussing key ideas presented during the events. Excitingly, a number of participants were prompted by the events to express their demands for change and their intention to take some form of action to promote greater public understanding of and respect for difference" [E2].

Enriching medical professional thinking and practice

As well as stimulating and informing public opinion, RCMG also engaged medical professionals in reflecting upon their practice and, in particular, the potentially damaging implications of exclusively medicalised views of (and responses to) physical and difference that neglect to fully take account of disabled people's lived experience. The research was described as 'pioneering' in a full-page article in *The Lancet* (vol. 387, June 4, 2016). In 2016, RCMG used the research to stimulate debate and foster reflection amongst current medical professionals (working in a variety of roles across the Barts Health NHS Trust [E2]). In the same year, RCMG ran an in-depth, week-long course for 13 trainee doctors in the University of Leicester's Medical School to explore ways of supporting medical practitioners to develop more balanced and complex understandings of contemporary ethical challenges linked to disability, such as those posed by non-invasive pre-natal testing. Evaluation of these initiatives revealed that engagement with the research had prompted all participating medical professionals to make changes in their

professional thinking and inspired a commitment to change their practice, for example, by not assuming that disabled patients will automatically want interventions designed to fix or cure their differences [E2]. Subsequently, a Scientific Collaborator who teaches second- and third-year medical students at the University of Geneva used RCMG's research to support the aim of his course "to show students how important it was to cultivate nuanced and critical thinking; to challenge the idea of medical progress and even more so to challenge the belief in stable scientific truths". For him, discussing these issues with medical students is both 'necessary' and urgent' [E3].

Supporting disability rights

The research raised awareness amongst disability advocates and rights groups of the important role that museums and other cultural institutions play in framing public understandings of disability. Tony Heaton, founder of the **National Disability Arts Collection and Archive**, of which RCMG is a key partner, commented in 2019: "At a time when disability equality is in danger of moving backwards not forwards, RCMG's work is an important and powerful way to inspire and engender greater public and political support for rights for all and respect for difference" [E4]. In 2019, the UK government's **Disability Sector Champion for Countryside and Heritage**, Heather Smith, commented: "The Research Centre for Museums and Galleries has, ever since its inception, undertaken essential research to drive forward inclusive practice in the cultural sector. At the forefront of thinking in the field, the Centre's collaborative ethos and process has not only shaped the sector but also made a powerful and unique contribution to advancing equality and respect for all in the wider world" [E5].

Stimulating and informing new approaches to museum practice and policy

Our research has attracted considerable national and international attention from museum, gallery and cultural practitioners and cultural sector policy makers. The lead researchers have accepted invitations to present the research findings for practitioners and policy makers in 12 countries including Germany (German Association for Education in Museums), Argentina (Federation of International Human Rights Museums); Canada (Canadian Museums Association), Mexico (El Museo Reimaginado) and New Zealand (Te Papa Tongarewa, National Museum of New Zealand). RCMG's research features as an exemplary case study underpinning the UK **Museum Association's** major sector-wide policy since 2015, *Museums Change Lives* (E7).

An independent study of international sector professionals carried out in 2020 found that 'RCMG's disability research is highly regarded, widely considered unique in the sector and has created tangible and broad impact'. 88% (of 115 survey respondents) stated that RCMG had influenced their own organisations or individual practice and 94% agreed that RCMG had had a positive impact on the museum and heritage sector as a whole (E6). For example, the Curator of Medicine at the **Science Museum**, London, stated that the Museum's new £7m Medicine Galleries that opened in 2020, 'would not be so human-centred, so diverse, so enriched by lived experience or designed in such an inclusive way without the RCMG' (E6). Furthermore, the study revealed extensive international impact: respondents described the positive impact on their practice and their organisations as a result of engagement with RCMG work including the **Metropolitan Museum**, New York and the **Smithsonian Institution's National Museum of American History**. Subsequently, the **Wien Museum**, Austria, is using RCMG research to inform how it approaches opportunities for inclusive practice within the museum and with its communities and collaborators in its large-scale redevelopment of the entire museum (E8). **Kultur for All** (the state funded agency supporting inclusion and access across the Finnish culture sector) has translated into Finnish and shared RCMG's guidance on interpreting disability with museums, galleries and arts bodies across Finland (E9). In September 2020, the History Trust of South Australia's Migration Museum welcomed over a hundred members of the Deaf community to the opening of their exhibition 'Expressing ourselves: being Deaf in SA' citing RCMG's work with **Calke Abbey** and the **Wellcome Collection** as "groundbreaking" (E13).

RCMG was invited to present the research to staff at the UK's leading museum policy body, **Arts Council England** (ACE) where the Director of Museums Collection Development commented that RCMG's research continues to be used by ACE to embed their landmark policy, *The Creative Case for Diversity*, stating RCMG's work 'brought together innovation in research process with a bold vision for the social role and impact of museums that offered the sector a new model of public engagement' (E10). RCMG is the research partner for *Everyone Welcome*, supporting and informing the **National Trust's** major shift in policy and practice that champions inclusion and access at the heart of the organisation's work since 2019 (E6, G7).

Driving change in the museum and heritage sector

In recognition of RCMG's research in this field, the **Wellcome Collection** appointed Sandell to their Inclusion Advisory Group (2019-2021) (E11) to advise the institution on its policy and practice in the field. In 2020, Sandell also accepted an invitation to join the **Curating for Change (CfC) Strategic Disability Museums Network (E12)** which aims to support museum sector organisations across the UK to tackle the under representation of disabled people. These appointments ensure the changes driven by RCMG research will continue to be supported and embedded across the sector.

5. Sources to corroborate the impact

E1. Data supplied by Head of Marketing and Audiences, Wellcome Collection.

E2. Unruly Bodies: website including testimonies from disabled artists and museum partners; evaluation of audience responses; filmed material of medical practitioner responses; media coverage. www.unrulybodies.le.ac.uk

E3. Testimonial: Scientific Collaborator, Interfaculty Centre for Bioethics and Medical Humanities, University of Geneva.

E4. Testimonial: founder of National Disability Arts Collection and Archive.

E5. Testimonial: UK Government Disability Sector Champion for Countryside and Heritage.

E6. Shepley, E. (2020), *Advancing disability equality through cultural institutions: research impact report*.

E7. Museums Association campaign, 'Museums Change Lives'.

<https://www.museumsassociation.org/campaigns/museums-change-lives/inspiring-engagement-debate-and-reflection/university-leicester/>

E8. Testimonial: Director, Wien Museum.

E9. Kultur for All website. http://www.kulttuuriakaikille.fi/diversity_guides

E10. Director of Museums Collection Development, Arts Council England – testimonial.

E11. Wellcome Collection, letter of appointment to Inclusion Advisory Group.

E12. Curating for Change (CfC) Strategic Disability Museums Network – letter of appointment.

E13. <https://medium.com/interactions-with-history/expressing-ourselves-creating-a-deaf-exhibition-965872d4188d>