

Everywhere & Nowhere:

Guidance for ethically
researching and
interpreting
disability
histories



From a collaboration between the
Research Centre for Museums and Galleries,
University of Leicester and the National Trust



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Economic
and Social
Research Council

Ethical research and practice

Disabled people remain underrepresented, sometimes entirely invisible, within most heritage and cultural institutions' exhibitions, displays and public programmes (Sandell 2019; Dodd et al 2017; Sandell et al 2010). When disabled people from the past do appear, they are often presented in narrow, reductive and dehumanising ways and through negative stereotypes. A fresh look will often reveal those same lives filled with opportunity and autonomy, influence and adventure, love and joy.

Researching disability history is a complex endeavour. We often know less about the lives of disabled people in the past than we do about non-disabled people. Negative and stigmatising attitudes mean that archives are partial and contemporary attitudes towards disability also obscure and distort the past – historic connections to disability may be viewed as unimportant or omitted for fear of causing offense. How can we build a full picture of the lives of disabled people – in their own words – and the norms and attitudes that shaped their experience?



Shaped by the findings and learning from a research collaboration between the Research Centre for Museums and Galleries and the National Trust, this guidance shares new ethical and inclusive ways of researching and (re)presenting stories connected to disability and the lives of disabled people. It shows how we can work towards sharing richer, fuller and more honest histories and reveals how – by acknowledging and drawing attention to gaps and omissions – we can raise questions about the stories cultural institutions choose to tell and those they overlook or choose to silence.

Developed with disabled collaborators and experts in disability history, this guidance can be used to foster the enormous potential of heritage and cultural institutions of all kinds to reframe the ways in which society views disability today. It can support organisations to take this work forward, to begin to address the absence and erasure of disabled histories, to attend to the widespread unethical interpretation of disability and disabled people's lives, and to tackle contemporary ableism and discrimination.

About the project

Everywhere and Nowhere was a research collaboration between the Research Centre for Museums and Galleries (RCMG) and the National Trust which ran between 2021 and 2023. The project set out to explore the rich and multiple connections that the Trust's historic properties and landscapes across England, Wales and Northern Ireland have with previously unexplored and untold histories of disability.

We asked:

- How can we identify histories of disability across National Trust sites and present them in ethically-informed ways that enrich everyone's understanding of both our sites' histories and their contemporary resonance?
- How can we carry out this work ethically and inclusively, placing expertise derived from lived experience of disability at the heart of the process?
- How can we share disability stories in ways that reflect leading edge accessibility practice?

Methodology

We convened an international group of disability experts (including historians, researchers and artists) to work collaboratively with the Trust to investigate how stories related to the lives of disabled people in the past can be ethically researched and presented in new ways. Over 18 months we worked with Trust staff at national, regional and property-level to uncover objects, stories and sites and we received over 80 examples which our disability experts shortlisted down to ten.

As we worked together to explore and interpret these objects, sites and stories, the group generated an ethical framework to guide its work informed by scholarship as well as the varied expertise within the group. This framework sits at the centre of this document.

Based on the research and using a range of techniques, including pair writing, (interpretive text drafted by two or more people and drawing on different forms of expertise including insights derived from lived experience), we created a compelling public-facing film – [Everywhere and Nowhere](#).

Social-contextual understandings of disability

Our approach has drawn on disability studies scholarship and been informed by that scholarship's relationship to the disability rights movement. We have been influenced, in particular, by social-contextual (as opposed to medicalised) ways of understanding disability, that have been so central to underpinning rights activism across the world, to help us to frame and interpret the lives of disabled people in our museum practice. Where medicalised approaches, dominant throughout the twentieth century, have focused attention on physical and mental impairments – seeking solutions in interventions aimed at fixing, curing, or otherwise restoring individuals to a perceived idealised norm – social-contextual approaches, that emerged in the 1970s, offered a radical new way of understanding difference (Sandell 2019).

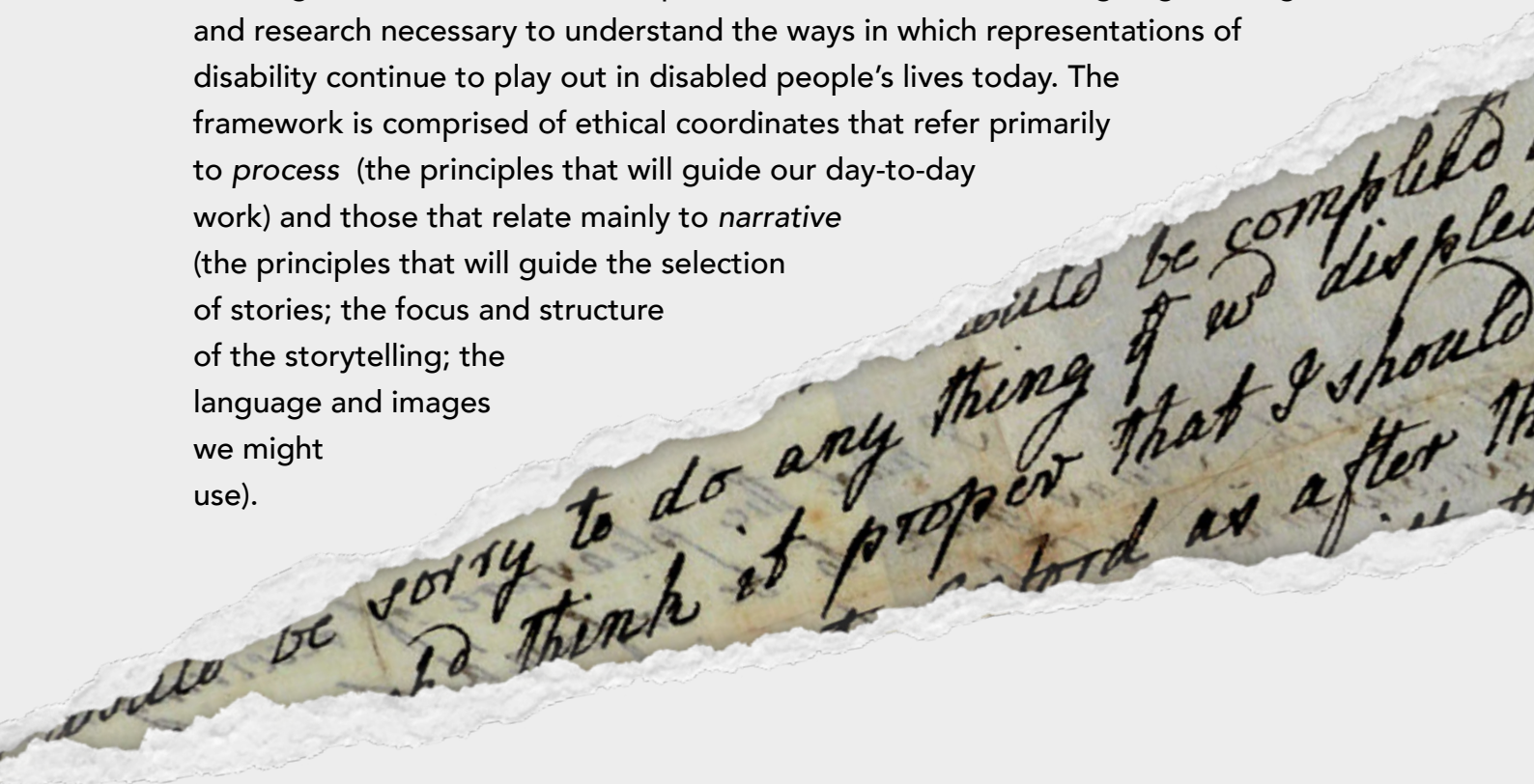
Originated by disabled scholar and activist Mike Oliver, the social model of disability is a key conceptual tool for the advancement of disabled people's rights. Rejecting an individualist, medicalised and deficit understanding of disability that primarily locates the 'issue' with the individual (and their impairment); it instead asserts that it is society (and its attitudes and environment) that disables people. The social model identifies disabling attitudes and barriers as oppressing and limiting life opportunities and constraining access to all aspects of social, political, economic and cultural life (Barnes et al 1999). The responsibility for addressing these barriers falls on society as a whole.

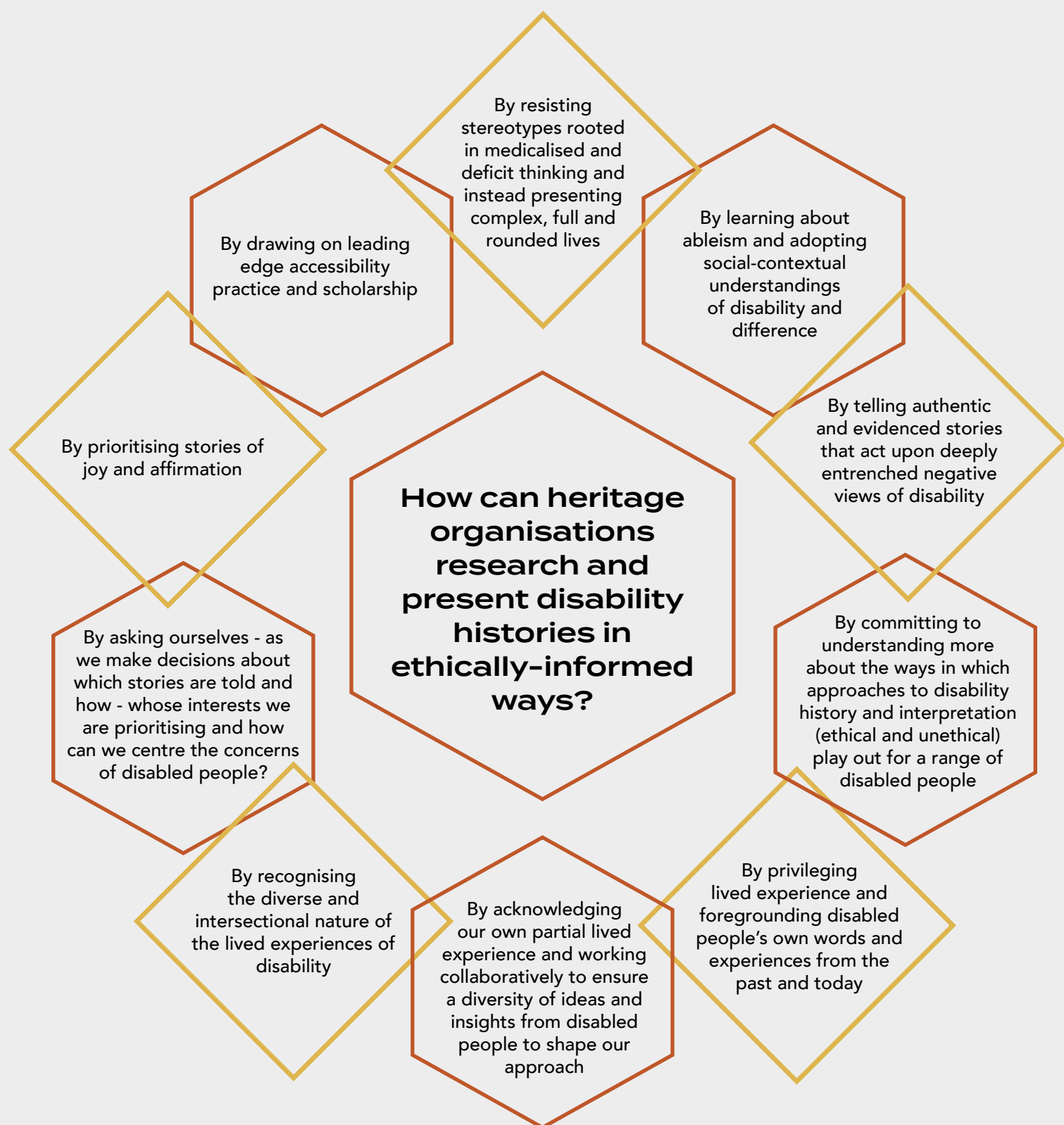
As we work to apply the social model of disability in the heritage and cultural sector, we need to undo prejudice and address silences, generate deeper, richer and more empathetic approaches to the lives of disabled people and continually work to understand, convey and respect the real lived experience of the people whose stories we tell.

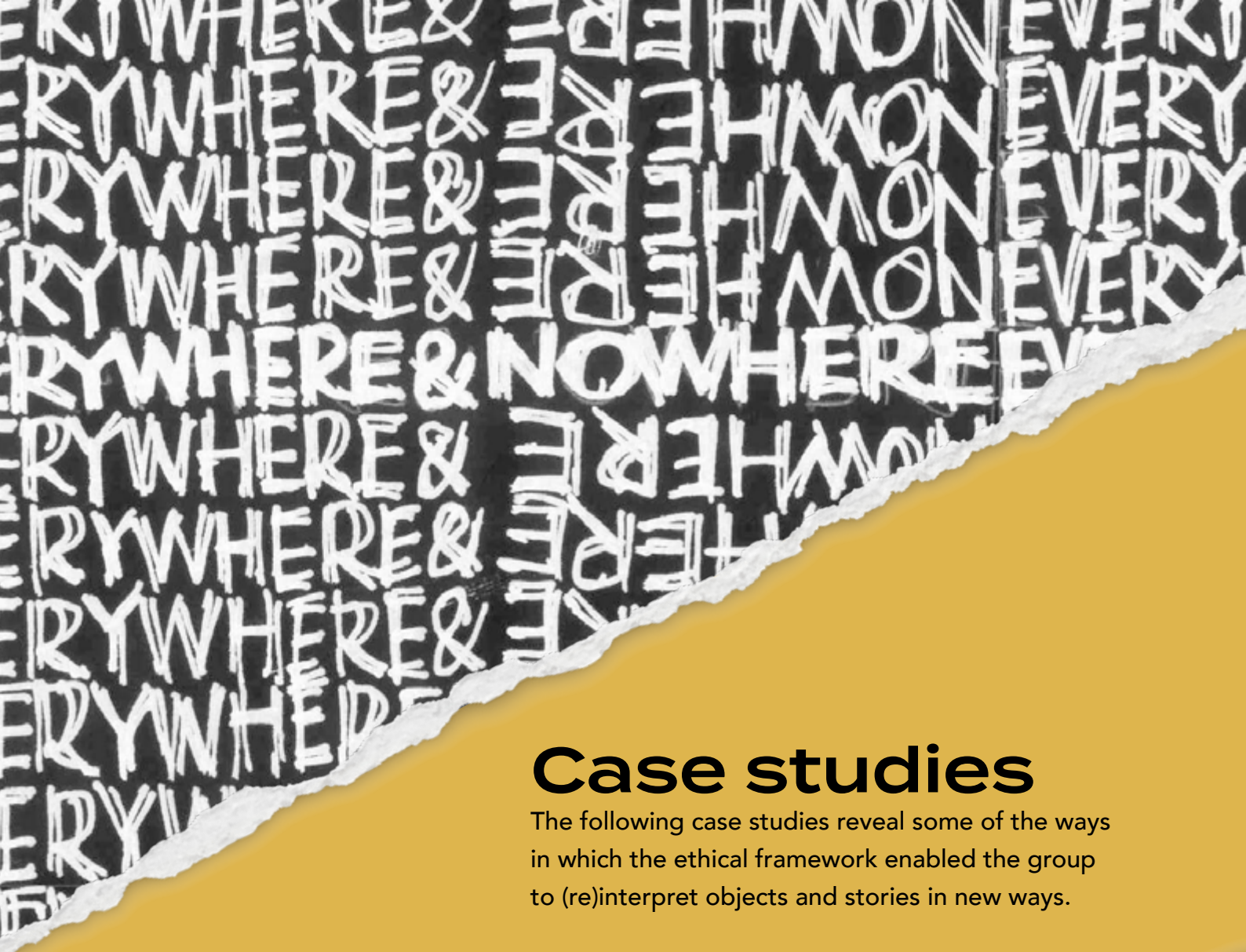
An ethical framework

RCMG is increasingly co-creating and using ethical frameworks to support our action research with cultural partners. Through the frameworks we aim to surface and make explicit the ethical issues that are sometimes tacit or overlooked and to draw out ethical coordinates to shape and guide our work and help with decision-making in day-to-day practice. These frameworks can guide our work by bringing the unseen or unacknowledged into focus (and holding it in focus); they can help us to ask questions and hold sometimes competing questions or issues in productive tension; they can support clarity of decision-making and shape interpretation in ways that prevent falling into stereotype traps or reverting into entrenched ways of working and they can challenge us to find new and creative answers or ways of working.

Rather than a straightforward formula to apply, this framework aims to support new ways of thinking. It keeps us alert to the ethical possibilities and pitfalls that arise when we look at disability histories. It recognises the central importance of working collaboratively with disability experts and critical friends and it challenges us to continue to ask questions and undertake the ongoing learning and research necessary to understand the ways in which representations of disability continue to play out in disabled people's lives today. The framework is comprised of ethical coordinates that refer primarily to *process* (the principles that will guide our day-to-day work) and those that relate mainly to *narrative* (the principles that will guide the selection of stories; the focus and structure of the storytelling; the language and images we might use).







Case studies

The following case studies reveal some of the ways in which the ethical framework enabled the group to (re)interpret objects and stories in new ways.





Sarah Biffin

We made connections across all of the coordinates of the framework to explore Sarah Biffin's story, but the principle found below became particularly important, alerting us to the dangers of commonplace interpretations rooted in medicalised thinking.

Most accounts of Sarah Biffin focus on, or open with, a medicalised and deficit description of her physical appearance and impairment. This reductive and dehumanising approach results in a level of scrutiny which is unique to the disabled experience and echoes the daily encounters of inappropriate staring and intrusive questions faced by many disabled people.

Instead we asked – why do we need to know this? Is this integral to the story we are telling? How can we tell the story of Sarah's life in full awareness of ableist assumptions and how we might resist them?

We purposefully chose not to focus primarily on her impairments. Rather, our telling of Sarah Biffin's story foregrounded her achievements and talents as an artist. She appears here because of her experiences as an artist, who happened to be disabled, rather than as someone who achieved success 'despite' their impairment. Utilising the framework, we noticed a temptation to sensationalise her story as a marvel or wonder, or as someone who 'overcame' or transcended her impairment. Again, we intentionally resisted this stereotypical interpretation, whilst acknowledging the factors that shaped her life and some of the barriers she encountered.

At the same time, we recognised the value of acknowledging and celebrating her life as a disabled person to avoid perpetuating the historic erasure of disabled lives or inadvertently reinforcing the sense that disability is a taboo subject. To achieve this, we chose to accompany our full and rounded description of her life and achievements with a self-portrait that showed how she chose to portray herself.

By resisting stereotypes rooted in medicalised and deficit thinking and instead presenting complex, full and rounded lives



Image: Watercolour portrait, The Marchioness of Abercorn at the Cottage of Industry at Llanerchaeron, Wales, by Sarah Biffin. ©National Trust Images/James Dobson

Sir Jeffrey Hudson

Historically portraiture was the principal mode of self-representation, with portrait artists revealing aspects of a sitter's life and interests through clothing, settings and props. Individuals who worked in service and enslaved people were also often depicted as symbols or props. Recent art historical scholarship and exhibitions have challenged audiences to reconsider all of the figures portrayed in portraits as individuals in their own right, with full histories and multifaceted lives.



Drawing on this scholarship and practice, we reinterpreted this painting of Queen Henrietta Maria and Sir Jeffrey Hudson, by shifting our focus towards Sir Jeffrey and his fascinating life. In the film we utilised the aesthetic and conceptual device of redaction, employed by artist and collaborator Christopher Samuel, to initially conceal and then reveal Sir Jeffrey, and in so doing highlight the 'overlookedness' of disabled people historically.

We carefully considered and adopted appropriate language throughout our interpretation, referring to Sir Jeffrey using his full title and name, rather than confining him to the offensive and dismissive category of the 'Queen's Dwarf' (Postlewait 2015). Drawing on social-contextual understandings of disability and in full recognition of the ways in which the stories we tell play out in the world today, we worked to challenge this ableist language and reveal something of Sir Jeffrey's rich life and his agency within and beyond the Royal court.

By drawing on leading edge accessibility practice and scholarship

By telling authentic and evidenced stories that act upon deeply entrenched negative views of disability

By learning about ableism and adopting social-contextual understandings of disability and difference



Image: Sir Jeffrey Hudson (1619-1682) on Horseback, after Sir Anthony Van Dyck (Antwerp 1599-London 1641).
©National Trust Images



Nicholas Ward

From researching the historic sources, it was clear that for much of his life Nicholas Ward did not have a voice and his agency had been removed. Many of the sources we were able to access relating to Nicholas Ward and existing interpretations of his life were dominated by others' views of him.

We worked hard to research and uncover a fuller and authentic story of Nicholas Ward, all the time prioritising his own words. With support from the curator at Castle Ward and Public Records Office Northern Ireland, alongside additional desk-based research, we found that his life was richer and far more complex than the long-established narrative of a 'madman' presented in the public records. We, instead, brought the framework into conversation with the archive, which enabled us to read critically across the archival material. This led us to dig deeper to find accounts of his experiences in his own words, and ensure that these were prioritised.

This more humane approach draws attention to the deeply held negative views of disability and recognises that these unethical distorted interpretations of history can be harmful to the lives of disabled people today. These principles or ethical coordinates helped us to hold ourselves accountable and provided a check to ensure that we did not fall into the trap of 'speaking for' or 'on behalf of' someone.

By telling authentic and evidenced stories that act upon deeply entrenched negative views of disability

By privileging lived experience and foregrounding disabled people's own words and experiences from the past and today

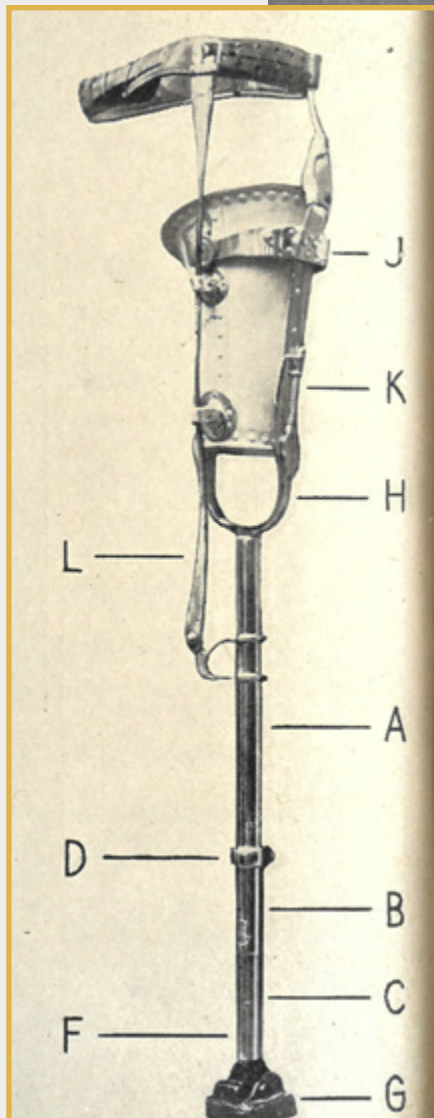
Geoffrey Winthrop Young



We prioritised and wanted to make space for stories of joy and affirmation to highlight the rich and overlooked contributions of minority groups to society and culture, and in recognition of the landscape of disability representation, which is predominantly negative.

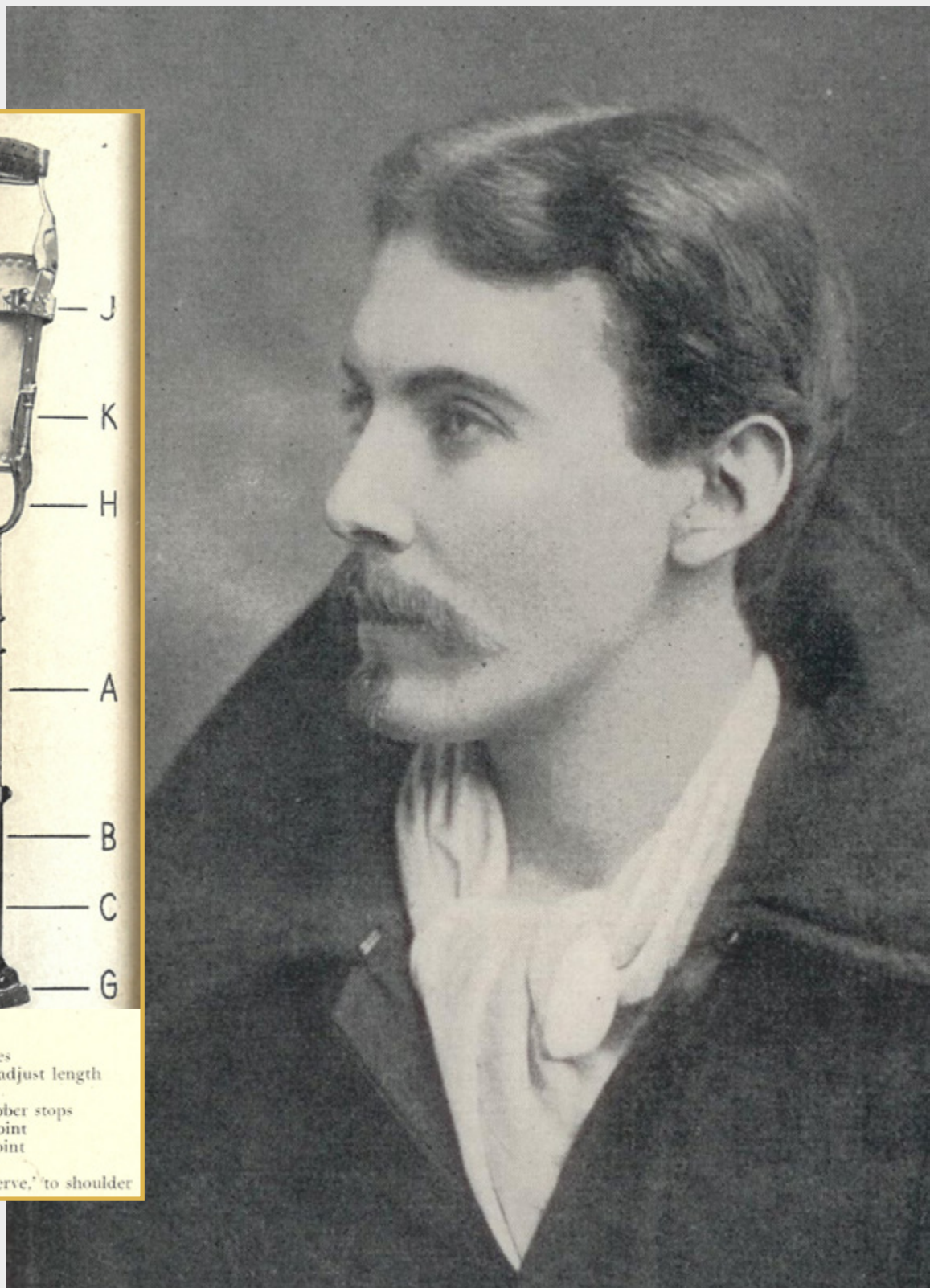
By honing in on details of Geoffrey Winthrop Young's life we were able to find a balance that acknowledged his experience of limb loss was different to many because of his privilege. Although the focus on this story is celebratory and empowering, we actively worked against common disability stereotypes, such as the 'heroic achiever', and ensured that we presented this story in full awareness of the danger of the 'overcoming adversity' narrative or an individual transcending their impairment.

By prioritising stories of
joy and affirmation



THE PEG

- A, B and C: dural tubes
- D: collar, with key, to adjust length
- F: internal spring
- G: rocking disk, on rubber stops
- H: steel crotch and Y joint
- J: Desouttar all-way joint
- K: lock
- L: control-cord and 'nerve,' to shoulder



About the partners

Research Centre for Museums and Galleries

For more than 20 years, the University of Leicester's Research Centre for Museums and Galleries (RCMG) has been at the forefront of a process of cultural transformation, working with museums, galleries and heritage sites and drawing on diverse forms of expertise to expand and enrich the social value and ethical potential of culture and heritage. Our research is recognised as world-leading both in terms of its contribution to the field of museum studies and its profound and lasting impact on wide-ranging cultural organisations and their diverse beneficiaries.

National Trust

The National Trust is a conservation charity founded in 1895 by three people: Octavia Hill, Sir Robert Hunter and Hardwicke Rawnsley, who saw the importance of the nation's heritage and open spaces and wanted to preserve them for everyone to enjoy. This mission is as vital today as it was over 125 years ago. Today, across England, Wales and Northern Ireland, we continue to look after places so people and nature can thrive. Entirely independent of Government, the National Trust looks after more than 250,000 hectares of countryside, 780 miles of coastline and 500 historic properties, gardens and nature reserves. In 2021/22 we received 20 million visitors. The National Trust is for everyone – we were founded for the benefit of the whole nation, and our 5.7 million members and over 44,000 volunteers support our work to care for nature, beauty, history for everyone, for ever.

References and further reading

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Acknowledgements

RCMG is grateful to the many individuals and disabled experts who have helped to shape the research and practice that underpins this guidance. Particular thanks are given here to: Cina Aissa, Mark Barrett, Rachel Conroy, Tate Greenhalgh, Tony Heaton, Jenni Hunt, Sally-Anne Huxtable, Isabelle Lawrence, Suzanne MacLeod, Meredith Peruzzi, Sarah Plumb, Christopher Samuel, Richard Sandell, Heather Smith and Angela Stienne.

These guidelines are a result of a wider strategic partnership between the National Trust and the University of Leicester, kindly supported by the Economic and Social Research Council Impact Acceleration Account.

Publication design: They Them Studio

Everywhere & Nowhere images: Tony Heaton

