



An ethical approach to interpreting disability and difference



Guidance from a collaboration between
the Wellcome Collection and
the Research Centre for Museums and Galleries,
University of Leicester

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Why a new approach is needed

International museum thinking and practice has come to be characterised by a desire to create inclusive narratives that draw on the cultures and contributions of previously marginalised or excluded groups. However, disabled people – sometimes referred to as the world’s largest minority – remain underrepresented, sometimes entirely invisible, within most institutions’ exhibitions, displays and public programmes (RCMG 2004, 2008; Dodd, Sandell and Garland-Thomson 2010; Sandell 2019). Where they do appear, they are often portrayed in ways that reflect deeply-held, negative attitudes towards physical and mental difference that sit uncomfortably with 21st century approaches to disability rights, equality and respect for all (Sandell 2019).

What is clear is that museums have enormous, largely untapped potential to reframe the ways in which people view disability. Museums can shape the ways in which we see the world and communicate our values – influencing and informing the kinds of conversations society has about difference (Sandell 2007; Dodd, Sandell and Garland-Thomson 2010).

An alternative way forward

A recent research collaboration between Wellcome Collection and RCMG offers a fresh perspective on what a progressive (ethical, inclusive, rights-based) museum might offer its visitors. Inspired by what has come to be widely referred to as the social model of disability, Wellcome Collection's new permanent gallery *Being Human* draws together diverse perspectives and personal stories from artists, activists, clinicians and researchers. The development of the gallery explored how curatorial and interpretive practice could create authentic portrayals of physical and mental difference and disabled people's lives.

The social model, originated by Mike Oliver, has been widely recognised as a key conceptual tool for the advancement of the rights of disabled people.¹ Rejecting an individualist, medicalised understanding of disability it instead locates the issue (and the need for action) not with the individual (and their impairment) but with society and the barriers which restrict and oppress disabled people. The guidance re-produced here was informed by this principle and used to shape both the content (the objects that were selected) and the interpretive approaches of *Being Human* – which opened in September 2019.

This guidance can be used as a starting point by museums of all kinds to address the invisibility and unethical interpretation of disability and disabled people.

¹ *The basis for what has become the social model of disability was a document produced in 1976 by the Union of Physically Impaired against Segregation (UPIAS) entitled the Fundamental Principles of Disability. It stated: 'In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society.'*

Guidance on interpreting disability-related objects and stories

Here we consider the main issues with the ways in which disability and difference have been interpreted in museums and offer guidance on how these might be addressed.

MEDICALISED APPROACHES TO INTERPRETING DISABILITY

Medicalised ways of seeing disability are dominant, not only in museums but in all areas of public life.

They powerfully shape the way disability is perceived and underpin deeply entrenched negative attitudes towards disabled people

Reductive – emphasises (and sometimes exaggerates) differences over all else

Normative – upholds body/mind norms that imply differences are deviant, undesirable, less than fully human

Uncritically celebrates and **assumes medical intervention** – a fix or cure – is necessary, desirable

SOCIAL MODEL APPROACHES TO INTERPRETING DISABILITY

Interpreting disability through a social model lens can help museums, galleries and heritage sites to present objects and stories in ways that align with (and lend support to) contemporary rights-based understandings of disability.

They enable museums to tell honest, accurate and sometimes difficult stories of oppression and discrimination – but in ways that facilitate empathy, respect, understanding and dignity.

Recognises **complex**, full and rounded lives

Challenges normative ideals by presenting **diverse** bodies, minds, experiences as part and parcel of humankind

Acknowledges there are very **different responses to medical intervention** – in some contexts, medical intervention is wholly rejected (for example where the individual rejects the idea of difference as deficit – there is nothing to fix!)

MEDICALISED APPROACHES TO INTERPRETING DISABILITY

Encourages **inappropriate staring** that reflects many disabled people's daily lived experience – disability is presented as a curiosity for the non-disabled gaze

Reinforces **negative stereotypes** – the disabled person as object of pity or charity

Presents some disabled people as **heroic achievers** who transcend or overcome their impairments – reflecting campaigns such as 'see the ability not the disability'

Pathologising – privileges the medical professional's perspective (for example, defining impairment as either 'congenital' or 'acquired')

Suggests disability is the **individual's problem** – a focus on what the person can't do

Assumes disabled people as a **homogenous group**

SOCIAL MODEL APPROACHES TO INTERPRETING DISABILITY

Encourages **respectful looking** – fosters empathy, understanding, respect, dignity

Subverts stereotypes in ways that challenge deeply held negative views of disability

Acknowledges that people can be **disabled and highly achieving** in all arenas. Recognises that such achievements are not secured *despite* an impairment or contingent upon an individual 'overcoming' their impairment

Privileges the individual's **lived experience** – in their own words and expressions – in ways that reflect their humanity, complexity and full lives

Views disability as arising from **barriers society imposes** – draws attention to society's inadequate response to difference and impairment

Recognises a **diversity of lives and experiences**

Research Centre for Museums and Galleries, University of Leicester

Since 2000, RCMG has been researching the presence/absence of disability in museum collections, displays and public programmes, working collaboratively with disabled activists, artists and campaigners – as well as museum practitioners – to develop ethical, respectful and inclusive ways of presenting disability-related narratives and the lives of disabled people, past and present. These new narratives have been used to stimulate and shape public, media and professional debate around disability and to advance disability equality (RCMG 2017).

Wellcome Collection

Wellcome Collection is a museum dedicated to challenging how we all think and feel about health. In 2018 it published its Strategic Direction for Access, Diversity and Inclusion. Setting out an ambition to effect 'significant change' over the next five years the organisation is committed to reducing barriers to access across its entire offer. Plans include making physical alterations to the building, embedding inclusive practice in workplace processes and programmes, and reckoning with the significance of a colonial-era collection.

*Embracing an inclusive approach is an iterative process and both organisations are keen to exchange learning with other museums, galleries and heritage sites embarked on similar initiatives. Please send us your feedback by contacting **Cesare Cuzzola** at cc574@leicester.ac.uk*

References and Further Reading

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