

THE MUSEUM ACCESSIBILITY SPECTRUM

RE-IMAGINING ACCESS
AND INCLUSION

EDITED BY DR ALISON F. EARDLEY
AND VANESSA E. JONES



MUSEUM MEANINGS



‘This book calls for a radical re-thinking of access programs at museums and other cultural sites. The editors argue that when access is understood merely as something the institution bestows on marginalized groups, without the active participation and collaboration of those communities, it risks preserving protocols of privilege and power. Here, a diverse collection of international authors, educators, artists, and activists describe specific projects and techniques that could be implemented in different contexts. This paradigm-shifting achievement is essential reading for anyone in the museum sector as well as anyone inspired by the potential for museums to enact meaningful social change’.

– **Georgina Kleege**, *author of More Than Meets the Eye: What Blindness Brings to Art*

‘Ensuring inclusion in education, sciences, and culture – including museums – is crucial and reaffirms our commitment to upholding human rights for everyone, as emphasized in the Universal Declaration of Human Rights. While progress has been made in many museums in terms of “Inclusion,” “Accessibility,” and “Diversity,” many others around the world are still in the process of fully embracing their social responsibilities and expanding their role beyond basic accessibility. This book offers valuable insights for practitioners, scholars, and policymakers on transforming museum practices to enhance accessibility and foster inclusion. Its release is particularly timely, coming after the World Conference on Cultural Policies and Sustainable Development (MONDIACULT 2022), which highlighted culture’s vital role in sustainable development and social cohesion, and as we approach the decade anniversary of UNESCO’s 2015 Recommendation concerning the Protection and Promotion of Museums and Collections, their Diversity and their Role in Society’.

– **Dr. Khaled El-Enany**, *Professor of Egyptology and Former Minister of Tourism and Antiquities, Egypt*



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THE MUSEUM ACCESSIBILITY SPECTRUM

The Museum Accessibility Spectrum engages with discussions around access to museums and argues that what is impairing the progress of museums towards inclusion is the current ableist model of access.

Drawing on contributors from international museum researchers, practitioners, artists, and activists, this volume challenges the notion of the core 'able' museum visitor and instead proposes all individuals are positioned on a multidimensional Accessibility Spectrum, which incorporates intersecting physical, sensory, neuro-divergent, and social and cultural dimensions. It explores the ways in which access provisions designed to enhance the experience of a minority can enhance the museum experience for all visitors. A constructively critical approach is taken to practice-based chapters, using case studies and approaches from around the globe, split into three main sections. Within the Disability Gain section, the authors consider the benefits of inclusive design, perspectives, and practice for all visitors to the museum sector. The Social and Cultural Inclusion section examines ways in which museums have broadened representation and participation to better serve audiences who have been excluded, or 'underrepresented' by the museums. Finally, the Agents of Social Change section considers how, with this work, museums are challenging systemic biases and exclusions. The international, cross-disciplinary contributions in this volume are driven by research-informed practice and will transform existing thinking to change future practice within the museum sector by challenging this ableist bias.

This book will be of interest and importance not only to museum practitioners and researchers, but also to readers with an interest in cultural studies, critical disability studies, translation studies, and inclusive and universal design.

Alison F. Eardley is an interdisciplinary researcher, trained in cognitive psychology (and employed in the School of Social Sciences at the University of Westminster, London, UK). Building on her previous work on imagery, imagination, and spatial processing in congenitally totally blind people and the sighted, her work is now focused on access, inclusion, interpretation, and evaluation within the museum sector.

Vanessa E. Jones is the Access Programs Manager at the Smithsonian National Portrait Gallery, where she has championed accessibility initiatives since 2015. With degrees in art history and museum education, she develops and implements programs that enhance the museum experience for all visitors, particularly those with disabilities. Her expertise in access and inclusion has shaped institutional practices across the museum.



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Museum Meanings

Series Editors: Richard Sandell, Christina Kreps, and Cristina Lleras

Museums have undergone enormous changes in recent decades; an ongoing process of renewal and transformation bringing with it changes in priority, practice and role as well as new expectations, philosophies, imperatives and tensions that continue to attract attention from those working in, and drawing upon, wide ranging disciplines.

Museum Meanings presents new research that explores diverse aspects of the shifting social, cultural and political significance of museums and their agency beyond, as well as within, the cultural sphere. Interdisciplinary, cross-cultural and international perspectives and empirical investigation are brought to bear on the exploration of museums' relationships with their various publics (and analysis of the ways in which museums shape – and are shaped by – such interactions).

Theoretical perspectives might be drawn from anthropology, cultural studies, art and art history, learning and communication, media studies, architecture and design **and** material culture studies amongst others. Museums are understood very broadly – to include art galleries, historic sites, and other cultural heritage institutions – as are their relationships with diverse constituencies.

The focus on the relationship of the museum to its publics shifts the emphasis from objects and collections and the study of museums as text, to studies grounded in the analysis of bodies and sites; identities and communities; ethics, moralities and politics.

The following list includes only the most-recent titles to publish within the series. A list of the full catalogue of titles is available at: <https://www.routledge.com/Museum-Meanings/book-series/SE0349>

The Museum Accessibility Spectrum

Re-imagining Access and Inclusion

Edited by Dr Alison F. Eardley and Vanessa E. Jones

THE MUSEUM ACCESSIBILITY SPECTRUM

Re-imagining Access and Inclusion

*Edited by
Dr Alison F. Eardley and Vanessa E. Jones*

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THE STORY BEHIND THE COVER IMAGE

The cover image (paperback) was taken during a performative tour, which Katie West and Fayen d'Evie developed for the exhibition *When the Other Meets the Other Other*, curated by Biljana Ciric at Belgrade's Museum of Contemporary Art in 2017. Katie is an artist and Yindjibarndi woman now based in Noongar Ballardong boodja. Fayen is an artist whose practice is oriented through blindness. The tour marked the launch of their collaborative project, *Museum Incognita*, a museum grounded in a custodial ethic, that revisits neglected, concealed or obscured histories through embodied encounters, sensory meditations, audio descriptive readings, and conversational storytelling.

Their inaugural tour brought together international and local contemporary artists, curators, art historians, and invited public, including several local women and their sighted companions. Traveling by bus, Fayen and Katie visited artworks and monuments in landscapes in and around Belgrade. Their hope was that the tour would catalyse speculation on what a museum can be, raise questions about the politics of collections, and prompt reflection on custodianship. They were interested in how memories of encounters with artworks can be conserved and cared for, individually or collectively.

The image captures a small but significant moment, amidst the ruins of a mediaeval monastery on a Kosmaj mountain, that they found down a country lane scented with jasmine and wild strawberries. Though roofless, and overgrown with ivy, the rooms were near intact. Some of the alcoves had fresh bouquets of flowers and framed pictures of saints. Exploring the architecture by touch, they traced their hands over the stone masonry, felt along the walls and windows. And then two of the women called out; they had discovered the imprints of fossilised sea creatures under their reaching fingertips. Everyone clustered around, taking turns feeling for the presence and absence of these bodies: a disappearance written through decay. They talked about tactile readings of history, traces of invisible bodies, and the transformation of material objects to immaterial stories.

SECTION 1

Introduction



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1

THE MUSEUM ACCESSIBILITY SPECTRUM

Recognising the multidimensional access needs of all museum audiences

Dr Alison F. Eardley and Vanessa E. Jones

As editors of this book, it is important to acknowledge our own positionalities and privileges, and the influences that these will have on this volume. Alison is neurodiverse, with developmental auditory dyslexia, and Vanessa is a wheelchair user. We are both white, heterosexual, cis-gender women, who grew up in middle-class homes in wealthy countries with no lived experience of conflict or war. We have higher level degrees and have had access to museums throughout our lifetimes. We are passionate about museums, inclusion and broadening participation. We work with museum professionals to explore and unpick individual and systemic biases that can mean that practitioners' good intentions may not have the desired outcomes. We seek to co-create new ways of thinking and working that deconstruct the embedded system of othering that dominates museums and society more broadly. Alison is an interdisciplinary researcher, trained in cognitive psychology (and employed in the School of Social Sciences at the University of Westminster, London, UK). Building on her previous work on imagery, imagination, and spatial processing in congenitally totally blind people and the sighted, Alison's work is now focused on access, inclusion, interpretation, and evaluation within the museum sector. With a background in art history and museum education, Vanessa has extensive expertise in access and inclusion. As the Smithsonian National Portrait Gallery's Access Programs Manager since 2015, she has advocated for accessibility and led the development of programs and initiatives to enhance the experience of all visitors, including those with disabilities.

Central to the practice of the modern museum sector are the principles of access, inclusion, diversity, sustainability, and community participation (ICOM, 2022). As the curators of our cultural and social histories, the heritage sector is morally and legally required to provide reasonable adjustments to ensure equitable access

for all people. The dictionary definition of access is the means or opportunity to approach or enter a place. However, in relation to our cultural heritage, within the Universal Declaration of Human Rights (Article 27 of the Universal Declaration of Human Rights, 1948), the concept of access was broadened to include physical, sensory, and cognitive. The human right to take part in cultural life was re-asserted and enshrined in Article 15 of the International Covenant on Economic, Social and Cultural Rights, which was adopted by the United Nations General Assembly in 1966 and has been signed by 99 countries. In the following years, these rights have been increasingly ratified within law across the globe.

The museum sector has a strong desire to improve access and inclusion. However, access initiatives still tend to take place through limited programming and/or a small number of museum exhibits. As such, the majority of disabled audiences are granted access to only small, and potentially token areas of the collection, compared to those that are available to the majority ‘abled’ audiences. Although the rights to culture are universal, and access provisions have slowly increased in many places around the world, arguably one of the significant barriers that hinders progress is the implicit bias that underpins society’s understanding of access. Specifically, this edited volume argues that the current concept of access is ableist and fundamentally flawed. The concept of ‘access’ sets up a binary distinction between the nondisabled majority, and the disabled minority. This creates an othering of disabled individuals by positing them as different to the normative majority (see Jensen, 2011). Central to the concept of othering is the subordination of a societal group (disabled) in relation to a dominant group (abled). This dichotomy sets up those who have access (the assumed normative majority) against those who do not have access (the disabled minority). From a practical perspective within museums, this can risk providing a justification for a lesser amount of resources being spent on the assumed (disabled) minority of visitors, relative to the assumed (abled) majority. However, this simple dichotomy also denies the fact that probably at least half of the global population, the majority of which are nondisabled, do not engage with museums (e.g. Mendoza, 2017). It also ignores other barriers to potential museum audiences, including, but not limited to, physical, sensory, cognitive, social, and cultural. Further, by assuming this ‘abled’ majority does have full access, this bias denies the fact that provisions created by and for the disabled community have been shown to enhance the experience of nondisabled visitors (e.g. Eardley et al., 2022; Hutchinson and Eardley, 2021, 2023; Chottin and Thompson, 2021). We use ‘abled’ in our chapters, and not ‘able-bodied’ because ‘abled’ can stand in contrast to all forms of disability, including but not only physical disability. We are also using ‘abled’ and not nondisabled in order to highlight the problematic othering of disabled communities and the implicit assumption of the lack of access and inclusion requirements for the assumed ‘abled’ majority. We consider ‘abled’ to be a fictional and biased assumption that there is some sort of normative elite (we will explore these concepts more in Chapter 2). We talk about access and inclusion as interrelated but distinct concepts. Access has both physical and conceptual

dimensions. Access most commonly describes the provisions provided by organisations or businesses to adapt their ‘normative’ offer for people excluded by core provision. Inclusion is about ensuring that all people feel they are an equal part of something, and that they are able to be themselves within any situation. Inclusion is sometimes used to describe provision for groups who are excluded from standard provision (often for social or cultural reasons), but who are not recognised as being disabled. Inclusion is not possible without access. However, implicit within both current definitions is the assumption that there is a majority who have access and who are included. The museum accessibility spectrum challenges this.

The museum accessibility spectrum

This edited volume is a collection of works by practitioners, artists, and academics who are re-imagining museums in an equitable and inclusive way. By challenging the ableist bias, our aim is to transform thinking in order to develop practice within the museum sector. We propose that access needs should be understood as a multidimensional accessibility spectrum that recognises all barriers to potential audiences, including, but not limited to, physical, sensory, emotional, cognitive, social, and cultural (Eardley et al., 2022). All people sit in different places on the different dimensions of this multistrand spectrum. Like a rainbow with multiple colour bands, or a length of string made up of its individual strands entwined together, the accessibility spectrum proposes that museum access and inclusion be re-imagined as a multifaceted spectrum of access needs. It also recognises the inter-relatedness of access, inclusion, diversity, and broadening participation. For each strand or band of needs (each of which will be an individual spectrum), individuals will sit at different points. As an example, a curator with a physical disability will sit at different points on a spectrum for physical access needs and on another for social access. Social access needs will be extremely low, because working as a curator will likely give them a facility and sense of ownership of all museums across the sector. Where a curator sits on a scale of conceptual access will depend on the type of collections – if their expertise was 19th-century art, they would sit at a different place for an exhibition on that period, compared to modern abstract art, and again on a different place for an exhibition on palaeontology in a natural history museum. Similarly, an adult with a bad back and a familiarity with museum settings but with no knowledge of fine art would sit at different points on a range of spectrums of access needs compared to a physically fit young adult visiting an art museum, who had never set foot in a museum previously. These two art museum visitors are likely to need different support within the museum setting. They may share some similar needs on a spectrum of conceptual access, but their needs in relation to feelings of belonging, ownership, and representation within the museum environment are likely to be different.

We are using audience to describe each member of society, whether they have visited a museum or not. We also use museums as a shorthand for the museum sector, including museums, galleries, and historic sites. Although all members

of the global population have the potential to be an audience member for any museum, from a practical perspective, most museums are likely to imagine their audiences within a smaller scale. We are explicitly moving away from the notion of target audiences, and core museum visitors (see Chapter 2 for more detail). Within our framework, each audience member, or individual, sits within the museum accessibility spectrum. Everyone has different places within the multiple strands that make up the museum accessibility spectrum. Each strand is an individual spectrum in its own right. It is not necessary to name each of the individual strands, but it is important to acknowledge that there are multiple strands, and people how those strands interact with each other will be different for everyone.

This inclusive approach does not suggest that all aspects of a museum can be all things to all people. Rather, this edited volume argues that we need a different approach to museum audiences because the current concept of access is ableist and fundamentally flawed in two keyways. First, by setting up a binary distinction between the ‘abled’ majority and the ‘disabled’ minority, there is an assumption that this ‘majority’ has access to collections as a result of their ‘abled’ status. This denies the fact that broad sectors of society do not engage with museum environments. Second, by assuming that the ‘abled’ majority already has full access to museums, it denies the fact that provisions created by and for the disabled community have also been shown to enhance the experience of ‘abled’ visitors.

Where an individual will sit on the different strands of the museum accessibility spectrum will partly be informed by identities. We have multiple identities, including both protected identities (such as age, race, gender, disability) and non-protected identities (which could include things such as museum goer, musician, pet lover). This multifaceted approach recognises the importance of intersectionality (Crenshaw, 1989; Cooper, 2016). Intersectionality, a theory developed by black feminist theorists acknowledges that neither our identities nor our lived experiences can be understood on a single axis. Central to this theory is an acknowledgement of the potential culminations of systemic imbalances of power, and the oppressions that results. Disabled people are not simply disabled. For example, they have differing gender identities, ages, races, economic statuses, and interests. They also have different social and cultural contexts. Similarly, ‘abled’ people are not simply nondisabled.

Museums are seeking to become relevant and appealing to broader ranges of society. An important part of this is acknowledging and addressing the systemic oppressions in which museums have been complicit. Ng, Ware and Greenberg (2017: 143) mandate an anti-oppressive framework so that museums can ensure that they are not: ‘re-inscribing and perpetuating privilege by excluding or disempowering visitors with marginalized identities’. We argue that these processes and goals will be enhanced and accelerated by taking an intersectional, or multidimensional approach (see Chapter 2 for more detail).

Towards a radical museum model: the museum accessibility spectrum in practice

This edited volume is split into five sections. As part of the introduction to the museum accessibility spectrum, Chapter 2 delves more deeply into the history of museums, access, and disability, to demonstrate why museums need to shift their ways of working if they want to become truly inclusive. The three sections that follow acknowledge both the global nature of the museum sector and that the origins and development of thinking in relation to both museum practice and disability are different around the world. Although international, it is important to acknowledge that the majority of the contributions in this volume are drawn from the global north. A conversation with only the global north is only half of a conversation, with only half of the possible solutions. We hope that this volume will provide a starting point to grow conversations. To support this, these sections take a constructively critical approach, providing some insights into the amazing work that is being carried out. The contexts of the work may be specific to a particular country; however, in each chapter, there are experiences, practices, and insights that could be transferable to other countries and contexts.

The section entitled ‘Disability Gain’ includes chapters that explore ways in which museums can be enhanced for all visitors by considering how approaches to access can be applied and imagined inclusively. All of the chapters in this section are authored or co-authored by people with lived experience of disability, deafness or neurodivergence, and/or are based around a co-creation methodology. In the first chapter in this section, *Feeling our way: Anti-ableist provocations for the future of inclusive design in Museums*, William Renel, Jessica Thom, Solomon Szekir-Papasavva, and Chloe Trainor discuss a series of in-person and online events and creative encounters co-created by disabled-led organisation Touretteshero and the Wellcome Collection (London, UK) in 2022. This chapter provides important and informative examples of the ways in which anti-ableist thinking can be practically applied within a museum setting. Alicia Teng’s chapter, *Developing the Calm Room: A Journey of Creating an Accessible Space for Inclusion and Well-being* provides an example of the way in which co-creation was used to develop an inclusive calm room at the National Gallery Singapore. It also provides important insights into the support and training needed by both neurotypical staff and audience members, to ensure that such a space can function effectively and inclusively within a museum environment. Hannah Thompson’s chapter, *French Nineteenth-Century Art Writing as Audio Description: the case of Edouard Manet*, provides a consideration of the ways in which audio description was used in the 19th Century, often by leading writers of the day, as a print-based tool to share experiences of art with sighted audiences who were unable to attend an exhibition in person. It creates a case for the use of descriptions that include references to artistic techniques, personal opinion, and the various ways a beholder looks at and responds to a work of art. Meredith Peruzzi’s chapter, *Fostering a sense of*

belonging for deaf visitors through community partnership and deaf-gain, provides insights from a Deaf museum practitioner in the US on the ways in which museums can welcome D/deaf audiences. In Chapter 7, artist Fayen d'Evie describes the ways in which she is developing access into an art form. *Blundering into Sensorial Conversations* introduces blundering, a method for grappling with the intangible, the unknown, while also affirming wayfinding through blindness. She draws on this to provide examples of her practice that could support museum practitioners to take an access-as-welcome approach, which underpins her hybrid artist-curatorial practice.

The section 'Social and Cultural Access' considers ways in which museums have considered communities and cultures that have not traditionally sat within the notion of the core museum visitor – and here we draw explicitly on the Withers' (2012) Radical Model of Disability, and his argument that, in reality, nondisabled has meant 'ideal': '...white, straight, productive, profitable and patriarchal' (2012: 6) (see Chapter 2, this volume, for further discussion). The first chapter in this section, *Social and cultural barriers to inclusion: class and race at the Bethnal Green Museum of Childhood* by Charlotte Slark, takes the V&A (Bethnal Green) Museum of Childhood in the UK (recently rebranded as The Young V&A) as a case study to consider the motivations and actions museums have taken towards building museum engagement in local strongly working-class communities. In Syrus Marcus Ware's chapter, *Going through the portal: permeable walls and immersive community engagements rooted in disability justice*, he describes the ways in which his artistic practice creates inclusive museum experiences that enable audiences to explore and engage with the intersections of aspects, including disability, race, gender, and sexual identity. In the following chapter, *What is a museum? Reframing the power dynamic between museums and audiences*, Amparo Leyman Pino considers the ways in which museums need to re-imagine their relationship with audiences, in order to become relevant and representative of all communities. She argues that museums need to move away from the deficit model, in which museums are there to fill a gap (in understanding/experience) in audiences. Instead, she advocates for museums to reframe value, to recognise the strengths of communities, and to become a service to the needs of communities. In the next chapter, *Stepping Aside: A reflection on how Museums can transfer power to communities, open up collections, and increase access through the creation of memory boxes*, Katie Cassels and Charlotte Paddock (National Maritime Museum, UK) discuss the development of memory boxes to benefit elders from the Windrush generation, who immigrated to the UK from the Caribbean. They discuss the shift in power that the collaborating communities demanded, as both sides sought to create contents that were relevant to a population who had different cultural influences and experiences to the white cultural majority in the UK at that time. In the final chapter in this section, *The Sacred Cave of Kamukuwaká: enabling digital futures for Indigenous knowledge in the Amazonian Xingu*, Thiago Jesus gives a powerful example of the ways in which museums and cultural heritage organisations can apply their

skills and understanding to serve the needs of indigenous communities, resulting in community-driven sustainable cultural heritage resources that not only can support and enrich the connectivity of the local community, but which can also serve to facilitate the ethical sharing of indigenous communities' lived experiences and heritage around the world.

The third section 'Agents of Social Change' considers ways in which museums or museum practitioners can implement or have implemented systemic change within their own practice. In the first chapter in this section, *No laughing matter? Reimagining the statuette of a 'comic' actor with dwarfism at the British Museum*, Isabelle Lawrence describes and discusses the ways in which co-creation, taking a 'contemporary lens' of disability activism, can support an ethical and relevant re-interpretation of disability-related objects in museum collections. The next chapter, *Curating for Change: How can D/deaf, disabled and neurodivergent curators drive change in museums in terms of cultural representation and inclusive interpretation?*, provides details of a highly important project in the UK, which has been working to address the under-representation of D/deaf, disabled, and neurodivergent people within curatorial practice in the UK through a programme of fellowships and placements. Esther Fox shares the details and voices of a selection of the curatorial fellows who have been working with the host museums to extend and expand interpretation of disability-related narratives within the museums' collections. In the next chapter, Corey Timpson, based in Canada, provides an insight into the development of his practice. His chapter, entitled *Inclusive design and accessibility: a methodology of perpetual evolution and innovation*, discusses how an inclusion design approach needs to be embedded into the conception of a museum or exhibition. In the next chapter, *Cultural Inclusion in Times of Crisis: Old and New Traumas*, Evgeniya Kiseleva-Afflerbach provides an insight into societal biases against disabled people in Russia, and the ways in which the Pushkin Museum, Moscow, have sought to become agents of social change through inclusive practices and representation. In her chapter, *Museums for Equality: Combating Prejudice, Promoting Human Rights and Practices of Social Inclusion in Egypt's Museums*, Nevine Nizar Zakaria discusses similar themes and the approach that Egyptian museums have taken to create inclusive accessible museum environments. She explores the ways in which Egyptian museums have sought to expand their provision and offerings beyond the tourists, to invite and support local communities. Wrapping up this section in, *Social inclusion, cultural participation and public ruptures at Iziko South African National Gallery: A close look at Our Lady and Art of Disruption*, Bongani Ndhlovu and Rooksana Omar examine the ways in which their museum has sought to expand relevance and engagement of communities related to issues of gender in South Africa. They discuss the controversies and challenges that arose from the museums' work, including the legal action which withheld their right as an institution, to freedom of speech.

In the final section, the final chapter, from the volume editors, considers the potential ways in which the museum accessibility spectrum, and the work discussed

within the examples in the book, might impact future practice. It acknowledges that while some of the thinking that underpins this book is familiar to museum access practitioners around the world, museums (and society more broadly) struggle to think beyond a dominance of vision, and access as an add-on to provision. The next chapter begins by exploring the roots of some of the systemic ableist biases that need to be changed.

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2

UNPICKING ABLEISM AND DISABLISM IN MUSEUMS

Why access should be for all

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The museum accessibility spectrum proposes that access needs to be considered not as a binary between abled and disabled, but rather as a multistrand spectrum, with each person sitting at different points on the multiple strands. Chapter 1 has given a brief explanation of the reasons why this way of thinking about access will support museums to move towards fully inclusive environments. This shift in approach requires a substantial unpicking of some of the implicit biases that influence current thinking and practice. Through an exploration of the historical origins of both the development of museums and the development of understanding around disability, this chapter highlights ways in which current understanding of both museums and disability are negatively prejudiced by some of the arguments and biases intertwined with colonialism.

This chapter will discuss the assumptions that underpin the ‘normative’ bias. As with the previous chapter, we consider ableism to refer to the assumption of a privileged nondisabled ‘normative’ ‘in-group’. Linking the origins of this normative bias to Eugenics and an ‘ideal’, the implicit bias is that this group is white, abled, neurotypical, productive, heterosexual, and patriarchal. We use disablism to refer to the prejudice and biases which disabled communities face (see Withers, 2012). For organisations to become anti-disablist, we argue that it is crucial to at once understand the roots of the implicit and explicit biases that form the core of disablism and challenge the validity of the assumption of ableism. Central to ableism, and museum practice, is the role of sensory information, and in particular, the privileging of vision. In order to unpick the fallacy of the normative museum visitor, it is necessary to examine in detail this privileging of vision. This enables us to consider the roots of ableism and disablism, in the context of museums. Drawing on models of disability that have moved beyond the false binary logic of abled and disabled, we create an argument for why the museum accessibility spectrum can provide an alternative, equitable, and inclusive way of approaching museum access.

Colonialist origins of the sensory prioritisation of the modern museum

Museums around the world are diversifying practices and looking at ways to broaden participation and enhance audience engagement. Nevertheless, exhibitions, and the ‘look and learn’ paradigm, where visitors move around an exhibition, primarily looking at collections, learning about those collections through text panels, remain core to museum identity and audience experience (Eardley et al., 2022). Both the popularisation of museums and the prioritisation of vision as a mode of experiencing have been intimately related to colonialism (e.g. Edwards, Gosden and Phillips, 2006; Classen and Howes, 2006). In fact, both have classical origins. The word ‘museum’ is drawn from the ancient Greek concept of the Muses, as the source of inspiration for art, science, and literature. As far back as the Aristotle, it has been argued that the Western cultures value seeing and hearing as the primary senses for the production of rational knowledge (Edwards, Gosden and Phillips, 2006; Classen and Howes, 2006).

Although the origins are classical, the roots of modern museums are more recent. It was in the Renaissance when the activity of collecting is thought to have begun; in the 16th and 17th centuries, museums became more strongly associated with cataloguing and learning from those collections (Findlen, 1989). Then, the Enlightenment, in the 17th and 18th centuries, saw the rise of empiricism, which argued that all ideas come from experience. This saw the growth and veneration of scientific enquiry, which was underpinned by a prioritisation of vision (Hutmacher, 2019). Observation (which was driven by an assumption of neutrality) replaced witnessing (which was based on an individuals’ first-hand perspective). At the same time, literacy and the power of the printed word, as a means of communication and learning, grew (see Garland-Thomson, 2009).

This is intimately entwined with colonialism, which, it has been argued, placed a huge emphasis on material things (e.g., Edwards, 2001). Objects became property or possession. Within the scientific paradigm, they also become evidence, to be documented, described, and explored. Collections had to be collected from somewhere. Sometimes with, sometimes without permission, wealthy explorers/colonisers acquired objects, raw materials, artefacts, foodstuffs, documents, bodies, and body parts (see Edwards, Gosden and Phillips, 2006). Classen and Howes (2006) argue that the rise in collection and preservation practices was used as an excuse or justification for taking. This practice was strongest with when imperialist and colonial practices were at their peak during the nineteenth and early 20th centuries. ‘Subject’ nations were viewed as ‘inferior’ to Western ones. Acquisition of artefacts and relics was seen as the rightful patrimony of the West, a view which gained false legitimacy through the prioritisation based on the focus on preservation and display in the Western countries to which it was taken (Said, 1994). The narratives and purpose surrounding an object became irrelevant, because these were devalued (along with the cultures they came from).

The shift from private collections to a more public visitation of collections occurred through the 18th century. Museums had been previously open to an elite public – wealthy explorers and collectors, whose experiences of collections were often through hands-on engagement (Candlin, 2006). It was in the 19th century when the modern museum really began to emerge, with the emphasis on visual experience. This period saw the growth of the national museum, with its cases of objects and artefacts available for visual inspection only, and now open to the general public. The exhibition of collections particularly enabled colonial powers to emphasise and advertise their power and authority, and indeed their ownership of the world through the materials that had been accumulated from the colonised countries (Macdonald, 2006).

This ‘broadening participation’ was also underpinned by a belief that museums as institutions, and the curated contents that they contained, could be used as a tool for social management, to civilise the masses (Bennett, 1995). These museums were intentionally established with a strict set of behavioural rules. This was intended to provide the populace with the resources to become self-educated, and the contexts that would support them to learn to self-regulate their behaviour (Bennett, 1995). Classen and Howes (2006: 208) argue that museum visitors ‘were expected to become as close to pure spectators as possible: not to touch, not to eat, not to speak loudly, or in any way to assert an intrusive multisensorial presence’. The hierarchy of sensory experience was reinforced through museums: displaying these objects in glass cases, available for visual inspection and out of context of their cultural meaning, was intended to reinforce Western ideals and superiority. Researchers have problematised the colonial and modernist empowerment of visual inspection as an experience (Edwards, Gosden and Phillips, 2006). Drawing on the writings of travellers and explorers at the time, Classen and Howes (2006) argue that Europeans used the senses to reinforce Western superiority, by presenting non-Westerners as much more sensuous than themselves. However, the sensory experiences they were applying to non-Westerners were the so-called lower senses of touch, taste, and smell. The potency of Aristotle’s thinking can be seen by the fact that his notion of humans having five senses is so powerful it is broadly considered a universal truth, despite the fact that it is incorrect (see Jarrett, 2014; Macpherson, 2011). Similarly, the existence of a sensory hierarchy has also been dismissed (Mesulam, 1998). Nevertheless, legacy of this sensory hierarchy continues to dominate museum practice.

Colonial ableism, Eugenics, and the medical model of disability

Bennett (1995) argues that to ‘civilise’ the masses, public museums were intended to be open to all. However, he goes on to highlight the limits to that conception of all: in order to create an environment to model behaviour on, only those who complied with the physical and behavioural ideals were permitted to attend. Anyone outside this idealised and civilised blueprint of the population was excluded

(Bennett, 1995). To understand the relationship of museums (and society more broadly) to disability, we need to consider some of the thinking and behaviours that are implicit in many societal attitudes towards disability around the world. Prejudice against disabled people is centuries old. In many cultures, for many years, disability was seen as an act of God, where disability represented a punishment or a curse for the wrongdoings of the individual or their family, in the present life, or in a past life (Retief and Letšosa, 2018). Although this still persists in some societies, the binary distinction between normative and nonnormative bodies was heightened with the trafficking of slaves, in which a stronger ‘able’ body became monetised and fetched a greater financial value. This created an ‘ideal’ colonised body (Grech, 2015). At the same time, disabled people were often confined and isolated from their communities through missionaries, which combined the model of disability as an act of God with the charity model of disability to reposition disability as pathology, disease, weakness, and vulnerability (Grech, 2015). The power of the concept of the ‘optimal’ human body was magnified by Eugenics theory (first published in 1865, but first named Eugenics in 1883 – see Withers, 2012). The ‘deficiencies’ of disabled people were seen as a threat to the ‘pure race’ that should not only be segregated from the essentially ‘normal’ and ‘ideal’ but also which should be eradicated. This led to the practice of genetic eradication and even the systematic murder of disabled people as part of the eugenics movement of the early 20th century (Smith, 2009).

Eugenics created a dichotomy between genetic superiority and inferiority, who was ‘fit’ and who was ‘unfit’. Withers (2012: 3) argues that the theory of Eugenics proposed by Galton was the first modern classification of disability, where the concept ‘unfit’ was all groups of people who were considered to have genetically and socially undesirable traits. This included all those who today would identify as disabled, neurodivergent, deaf, a person of colour, LBGQTQAI+, and poor or working class (Davis, 2002). In other words, Eugenics implied a scientific justification for the categorisation of an idealised subset of humans within the dominant ‘in’ group, with all other groups being ‘othered’ for being impaired, deviant, or deficient or underserving (Withers, 2012).

This binary relationship was reinforced by the medical model of disability, which also emerged towards the end of the 19th century. The medical model conceptualises disability as a functional limitation, a lack, an impairment, an abnormality, an ‘absence’ of ableness. It reinforces the othering of Eugenics, by seeking to fix or solve or eliminate the impairment or deficiency within an individual: to make people who are ‘unfit’, ‘fit’. In the medical model, it is assumed that any inability or difficulty that is experienced in daily life is a result of this deficiency or disorder (Barnes, Mercer and Shakespeare, 1999; Gill, 1999; Reich et al., 2010; Reich, 2014). Disability is defined based on medical diagnosis, traditionally based on the opinion of a nondisabled medic. The development of the medical model of disability has been linked to developments in medical practice in the late 19th century, which saw medics start aiming to ‘fix’ disability (Clapton and Fitzgerald,

1997). Once identified or diagnosed, that disability is within you, as an individual, unless there are advances in medicine which are able to reverse that disability.

The validity of Eugenics as a scientific model was rejected after the horrors of the Nazi regime in World War 2. However, the impact of the theory has arguably been more long-lasting, in particular, in relation to the notion of this assumed 'fit' (elite) group, and the othering of all groups. The medical model of disability has also persisted, in terms of both the impact of the medical model's positioning of disability being a factor of an individual and the assumption of a binary split between 'abled' and disabled.

Within museum practice, permanent and temporary exhibitions are generally created for an assumed 'abled' majority. Additional (often limited) special provision is then created for those who are not within that assumed normative majority. These will often be presented in specialist tours or upon request. This approach is based on the medical model: we don't look to fix the limitations of the broader provision, because it is assumed that that is not the problem. The problem that museum 'access' is seeking to fix, or address, concerns those groups of people who seemingly require something different to the assumed majority.

Disability as a product of society

In the 1970s, critical disability studies theorists and activists began to challenge the medical model. They argued that full participation within society is made impossible not by any impairment (lack/disorder/deficiency/illness), but by the structures and systems within society which exclude people. In other words, disability is created by societies and arises from discriminatory policies and practices (Reich et al., 2010). For example, a wheelchair user is not disabled because they cannot walk, they are disabled because society, through the use of things like stairs or steps, has imposed limits on the physical access that wheelchair users have to spaces and structures. Anything that a wheelchair user cannot do is therefore as a result of limitations within society. This has been labelled the social model of disability. Oliver (2009) explicitly distinguished between impairment, which was a medically defined reduction in ability in one area, and disability, which is the product of an unaccommodating society. He argues that the focus on impairment encouraged the ableist bias within society. Key to this is the belief that if disability is an individual tragedy (as it is within the medical model), then society is not able to or therefore responsible for rectifying this disability. However, if disability is a product of the failures of society (as it is within the social model), then there is a responsibility and a requirement to rectify those inequalities.

Subsequent critiques of the social model of disability have argued that the complete rejection of impairment risks negating the experiences of people with symptoms such as chronic pain, which are not reduced or mitigated by inclusive systems or structures within society (see Hogan, 2019). These critics call for a more holistic, embodied approach to disability that takes account of both individual lived

experience and the societal contexts in which they operate. It should also be noted that, although the social model of disability, which originated in the UK, has had a significant impact on re-framing disability worldwide, Withers (2012) suggests that the disability rights movements in Canada and the United States are more driven by a civil rights focus. Based on their experience, Withers argues that these North American organisations: ‘do not work for a rebuilding of socio-economic systems, only for them to be re-written, editing in disabled people as the main characters’ (2012: 88). Nevertheless, despite some of the issues with the social model, Withers (2012) argues it is more radical than the civil rights focus, because it moves responsibility for disability from the individual to society. Criticisms of the social model do not negate the role of societal structures and processes in creating disability, nor that these structures and practices in society can (and should) change, such that society is no longer disabling the ways in which its members can participate. Within the context of museums, the social model of disability argues that any lack of access is a failure on the part of the museum, which it is the museum’s responsibility to resolve.

New museology and museums as agents of social change

The development of a mandate to create inclusive and accessible museums is part of a larger shift in the museum sector: ‘The last century of self-examination – reinventing the museum – symbolises the general movement of dismantling the museum as an ivory tower of exclusivity and toward the construction of a more socially responsive cultural institution in service to the public’ (Anderson, 2004: 1). These shifts in museum practice have been motivated by two related but separate movements. The first was the new museology (Lumley, 1988; Vergo, 1989). This conceptual framework transformed the core purpose from collecting and storing, to one centring on audiences, with a focus on entertaining and engaging in a way that was more inclusive, and would maintain relevance to contemporary society and would continue to shape our knowledge (Hooper-Greenhill, 2000). Developing out of this was a second, more radical call for museums to become agents of social change (Sandell, 1998). Sandell (1998, 2007) advocated for museums to own and embrace their political roles and social responsibilities in the face of the ongoing changes in society, in part by helping society to achieve social justice and human rights for marginalised communities. The pressures for museums to take a much stronger role as active agents in the betterment of society have been taken up by governments and funders, such that social responsibility, social inclusion, well-being, and social change have become embedded in funding priorities (Mendoza, 2017; DCMS, 2020).

However, while ‘new museology’ has sought to create more equitable access and representation, the success of the endeavour has been challenged (Janes, 2009). McCall and Gray (2014) argue that although ‘new museology’ has provided

a useful conceptual framework for museum practitioners to operate within, the application within museums has been sporadic, and it has not transformed museum practice in ways that are likely to achieve the many expectations of the museum as an agent of social change (DCMS, 2020). Research in the UK has suggested that there has also been little shift in the way the general public view museums as a result of the ‘new museology’ (Think Britain, 2013). Within the audience sample, it was shown that attachment to history had grown, but perception of the essential purpose of a museum has remained traditional: care and preservation of heritage; holding collections and mounting displays; creating knowledge for, and about, society (in the form of public education) (Think Britain, 2013). Furthermore, the research participants did not believe that the role of museums was to foster a sense of community, except potentially in small communities that are under threat of dissolution. They also did not think that museums should aim to provide a forum for debate, nor promote social justice and human rights (Think Britain, 2013). In other words, the public’s views about the purpose of a museum not only remain traditional, it conflicts with the goals of many museum professionals and museum funders. This is the fundamental paradox of museums as agents of social change: museums can only become agents of social change if they are engaged with all communities within those societies. If communities, large numbers of individuals or governments/funders do not consider museums to be relevant to them, or if they do not consider them to be places that they wish to engage with, then the societal mission of museums cannot succeed.

Radical model of disability

The impasse between the goals of museums around access and inclusion and the reality of the ways in which audiences understand museums requires a radical re-thinking of how we are understanding the problem. There are binary splits between abled/disabled; those who go to museums/those who do not go to museums; core audiences/non-core audiences. These binary splits not only create an othering, but they also both deny the fluidity that can exist between groups and the ways in which our different identities intersect.

The radical model of disability (Withers, 2012) provides an important non-binary framework for understanding disability and has some important transferable implications or considerations for museum practice. It challenges what it describes as a ‘false binary’ in a number of key ways. Firstly, differently from the social model, the radical model does not accept that there is a biological reality that creates impairment. That isn’t to say that there is no physical, cognitive, emotional, or other dimensional reality to disability. The challenge is to the term ‘impairment’, which implies a diminishment or loss of functional ability. The model argues that while the binary split between disability and impairment shifted the blame for disability from the individual to society, this split nevertheless perpetuates the biased belief that there is something wrong with disabled people: ‘Radical disability politics is

grounded in the belief that the systems that oppress us, not us, are fundamentally flawed'. (Withers, 2012: 6).

The model also deconstructs the classification of both disabled and nondisabled in two key ways. Firstly, the model challenges who can and can't call themselves disabled. Withers (2012) questions the medically defined identification of biological impairment as the sole basis for defining membership of disabled or nondisabled categories. Withers (2012) argued that in reality, 'disabled is in constant flux' (p. 7). Withers (2012) makes the point that if people are not permitted to self-identify as disabled, it risks legitimising the medical model as the primary source of identifying 'fit' and 'unfit'. It also denies the importance and fluidity of lived experience, and the fact that some people might pass in or out of the disabled category through their lifetimes. One of the key concepts of the radical model is that determining who is and who isn't disabled has been a political act and not a biological one, which serves to marginalise and disempower certain groups.

Secondly, in questioning the validity of a binary split between disabled and nondisabled, the radical model challenges the arbitrary definition and assumption of normativity. When we think of a binary split, we are generally assuming that the two categories of difference include all members of a population – so, disabled, on the one hand, and everyone else, on the other. However, Withers (2012) argues that in Western cultures, although the definitions of disabled have changed over the past 150 years, the binary opposite to disability has remained the 'ideal': '... white, straight, productive, profitable and patriarchal' (Withers, 2012: 6). Withers uses 'ideal', the medical model uses 'fit'. We would argue that 'abled' or any other word which dichotomises the relationship between disabled people and nondisabled people can be substituted. This argument aligns with what Rosemary Garland-Thomson called 'Eugenics logic', where the systemic and societal biases in Western cultures continue to prioritise, privilege, and empower as 'normative'. If we explicitly reject the (false) binary between disabled and nondisabled, it enables us to both embrace the reality of intersectionality (Withers, 2012), and address the oppressions that can result from intersectionality. Withers (2012: 108) argues:

...one cannot choose to fight only disablism, as most disabled people experience more than one form of marginalization and, therefore, more than one form of oppression. This is why poverty, sexism, heterosexism/homophobia, transphobia, racism and agism must be fought in tandem.

The importance of taking an intersectional approach underpins the final key principle of the radical model of disability, that: '...accessibility cannot be addressed universally, rather it must be approached holistically' (Withers, 2012: 99). A universal approach arguably implies there are single solutions that would work for all members of society. It also risks erasing the value of difference. This does raise the question, what does a holistic approach look like? In the context of museum practice, in our experience, museums are not assuming that universal design will

provide solutions that will solve all access issues. However, museums, and society more broadly, have been dominated by binary thinking of ‘abled’ and ‘disabled’. In most cases, the museum sector designs for the assumed ‘abled’ majority, and then adds additional provisions for individual groups after the core design has been completed. This can include access provisions, but it can also include programmes or activities for groups who do not standardly attend museums. In addition to the problems outlined above, the reality is that this is costly and ineffective if the goal is access and inclusion for all. With the museum accessibility spectrum, we argue that the starting point in moving away from binary thinking towards intersectional thinking is an implementation of anti-exclusive design – design that takes into account at the inception the needs of multiple groups. In other words, anti-exclusive design focuses on multiplicities and embraces difference, rather than seeking any single perfect solution.

A holistic approach to museum access

Implicit in current dialogues around broadening participation and enhancing access and inclusion in the museum sector is an assumption of a core audience or visitor type who simply needs to attend the museum and engage with collections to access content. This sits within the binary logic, whether they are labelled abled and disabled, visitors and non-visitors, or core museum audience and everyone else. Drawing on research underpinned by psychology, the museum accessibility spectrum rejects this assumption.

We have already established that the core museum experience, the exhibition, has grown out of the privileging of vision as the optimum sense for observation and rational thinking. Implicit in this practice has been not only the ableist assumption that audiences are sighted, but also that the sighted visitor automatically knows what to do with that vision. Vision is standardly required to extract understanding from the museum experience. The rise of new museology has seen an expansion of multisensory museum experiences incorporating touch, sound, and sometimes smell (e.g. Levent and Pascual-Leone, 2014). However, even where there are interactives or interpretation that draw on other senses, vision is almost always required to make sense of the experience. A further assumption is that the sighted visitor is also literate.

In order to change museum practice, it is necessary to unpick and dissolve the biased belief that sight confers an automatic ability to interpret and appreciate a museum experience. We can do this by considering the behaviour of sighted people within a museum environment (see also Eardley et al., 2024). Seminal work by Serrell (1997) on the way in which typically sighted visitors pay attention in a museum (years) has shown that the majority of museum visitors are ‘non-diligent’: they don’t visit the majority of an exhibition, and the amount of time spent on average is a mere 20 minutes. This assertion of non-diligence is supported by the fact that the median amount of time visitors spend paying attention to a single

collection item (when they do stop) is only 20 seconds (Smith, Smith and Tinio, 2017). Given what a small amount of time this is, it is unsurprising that people's memories for museum visits include very little information about objects or artworks (Hutchinson, Loveday and Eardley, 2020).

We would argue that it is not that people do not want to take the time to have a potentially deeper and more memorable engagement with artworks, but rather that they simply do not know what to do with their (visual) attention. Research using eye tracking shows that the patterns of looking at artworks differ depending on the level of expertise of the viewer (Pihko et al., 2011; Koide et al., 2015). Novices are open to guidance about how to look: without being directed to, adult museum audiences will change their patterns of looking after listening to a traditional audio guide (Walker et al., 2017). Standard audio guides may refer to aspects of the physical nature of a collection item, but they are not designed as a tool for guiding attention. They will generally provide background information or additional interpretation to the collection item. However, when you ask sighted audiences to listen to an audio descriptive guide (verbal description), which can provide an opportunity for guiding visual attention around a collection item (guided looking), memory for the collection is enhanced (compared to a standard audio guide or no audio interpretation) (Hutchinson and Eardley, 2021). It is important to consider that the participants in these studies, who seemingly struggle to know how to engage with museum collections using vision alone, are mostly gathered from the members of the public who do actually make the effort to go to a museum. In the majority of countries around the world, the majority of the population do not attend museums at all (e.g. Mendoza, 2017), and the majority of those people are sighted. If museums were accessible with vision alone, we would expect different patterns of behaviour in museums, and stronger global participation. Taken together, this suggests the many museum visitors who are assumed to be able to access museums are struggling. If the implicit assumptions around the 'normative' museum experience are incorrect, it raises an important question about what we replace this with. If museums are no longer designing principally for this 'normative' audience, how do they communicate with audiences?

Disability gain

We have discussed the shift that is required to break the cycle of false binary thinking, but if the emphasis is on society, and therefore museums, to change in practice, the question becomes, how? Access provision is necessary when the ways of living, being or acting of the dominant culture prevent full participation for all. It is like a supplementary add-on to the core function of the system (in this case the museum), which provides a way to create alternative entry points for different groups. However, in so doing, it fails to question the effectiveness of the ways of living, being or acting of the dominant culture (or group). Traditionally, the 'dominant' group in museums has been a small majority of society. Crip Theory disrupts

and subverts the dominant implicit assumptions that position ‘able’ as normative and ‘disabled’ as other within a framework of impairment (Sandahl, 2003), and the theory seeks to highlight non-normativity as exposing alternative ways of living and being in the world (Thorneycroft and Asquith, 2021).

Deafness Gain is a term attributed to Aaron Williamson, a deaf performance artist, used within a presentation in which he wondered why his physician had informed him he had hearing loss, instead of telling him that he had deafness gain (Bauman and Murray, 2009). Deafness Gain represents a re-framing of deafness as a strength and a diversity which has the power to contribute to the greater human good (Bauman and Murray, 2014). It has strong links with the development of disability identity and counter-eugenic logic (Garland-Thomson, 2012). Laying out this counter-eugenic logic, Garland-Thomson (2012) identifies the core place of disability in human existence, and the ways in which disability enriches humanity.

Blindness Gain (Thompson, 2017) takes this further through the explicit recognition that the insights gained from different ways of experiencing can enhance the experience of all. Within the theory of Blindness Gain (a name which stands in direct contrast to the ableist conception of sight loss), Thompson (2017) states that it is based on three principles. The first is that blind and partially blind people benefit from access to multisensory ways of being that celebrate inventiveness, imagination, and creativity. The second is that non-visual living is an art, and the third is that workarounds and accessible approaches developed by and for blind people can benefit non-blind people. In other words, gaining blindness provides access to a richer sensory experience, and that provides opportunities for inventiveness and imagination that are not available when experience is dominated by vision. This is strongly linked to the assertion that the ways of living associated with disability should be considered an art. Intertwined with blind identity, it takes ownership and celebrates the ways of living associated with blindness, and in so doing, it denies the ‘otherness’ of access provision which is often a tack-on or an attempt to substitute or compensate for a lack of sight. Finally, and perhaps, most importantly for this book is Thompson’s (2017) statement that work-around and accessible approaches developed by and for blind people can benefit non-blind people.

Within museum practice, work on audio description (AD – known as verbal or visual description in the US) has been applying the principles of the accessibility spectrum’s anti-exclusive design approach to develop inclusive museum AD. AD practice was developed as a way in which sighted people could provide access to visual information for blind and partially blind audiences through verbal description. As with the majority of access provisions, AD has been presumed to benefit a niche blind audience. However, research has shown that it can benefit both blind and sighted museum audiences, and crucially, is enjoyed just as well by both groups (e.g. Hutchinson and Eardley, 2021, 2023; Chottin and Thompson, 2021). The key challenge to traditional AD practice has come from recent work, drawing on the principles of Blindness Gain, which has begun to challenge the

ableist assumption that vision should be necessary to produce AD (Chottin and Thompson, 2021; Eardley et al., 2022; Eardley et al., 2024).

This privileging of the visual experience in AD has been driven, in part, by the flawed assumption that vision can provide an ‘objective’ experience of museum collections, which can be described for the benefit of a blind or partially blind audience (see Eardley et al., 2024). Research from psychology and neuroscience suggests that while there are similarities in our perceptual experiences, there are significant differences in the way in which we experience sensory information (see Eardley et al., 2024). We already know there are differences in the way in which we focus our attention. If our experiences of artworks and museum collections are subjective, and influenced by our own particular lived experiences, then we should acknowledge and embrace those subjectivities. Drawing on the principles of Blindness Gain, we also need to acknowledge that blind and partially blind people will have their own experiences of museum collections, and that these experiences have the potential to be as interesting or more interesting than the experiences of fully sighted people.

Underpinned by this intersectional approach, the W-ICAD model (Workshop for Inclusive Co-created Audio Description, Eardley et al., 2024) has provided museums with a tool to co-create AD, developed by blind, partially blind, and sighted people, for blind, partially blind, and sighted audiences. This model provides one way in which museums can begin to re-imagine museum interpretation in an anti-exclusive way. It also provides an important example of a way of democratising museum interpretation by embracing different perspectives that offer an alternative interpretative experience to the one provided by the curatorial voice.

Conclusion

In this chapter, we have sought to highlight the problematic underpinning of the abled/disabled binary split in both societal thinking and more directly in museum practice. We have unpicked the prioritisation of vision within the museum sector and have used this to dismantle the concept of a normative/ideal/abled museum visitor. By designing for this assumed normative majority, in reality, museums have been designing for a fictional minority. We have argued that all people sit in different places on the different dimensions of the museum accessibility spectrum. This spectrum acknowledges that our identities are multiple and they intersect with each other.

We have considered Disability Gain as one starting point for re-thinking museum practice in an anti-exclusive way. We are imagining an approach to Disability Gain that expands out the three key points of Blindness Gain, described by Thompson (2017), across all disabilities, neurodiversity’s and deafness. The subsequent chapters of this book begin by exploring Disability Gain, with the next section exploring social and cultural inclusion. This is followed by an exploration

of ways in which an inclusive approach can support the development of museums as agents of social change.

This introduction to the theoretical underpinning of the museum accessibility spectrum has predominantly focused on the way in which museum practice and models of disability have developed in Europe and North America. The museum sector is global, and the origins and development of thinking in relation to both museum practice and disability are different around the world. Although social and cultural contexts are different in different regions and countries, the reality is that in all countries there are groups of people who remain marginalised. There are also not yet any museums around the world that speak to or for all members of their communities. Nevertheless, there are also museum professionals around the world who are working to transform their practice, their museums, their communities, so that museums can become inclusive for all.

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SECTION 2

Disability gain



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3

FEELING OUR WAY

Anti-ableist provocations for the future of inclusive design in museums

*Dr William Renel, Jessica Thom,
Solomon Szekir-Papasavva, and Dr Chloe Trainor*

Introduction

‘Feeling Our Way’ was a series of in-person and online museum events co-curated in 2022 by Touretteshero and Wellcome Collection (London, UK). The series reflected upon our relationship with touch and unapologetically centred the experiences of disabled, neurodivergent, and chronically ill people. Touretteshero is a disabled-led organisation. Using Tourette’s syndrome as a catalyst, our mission is to create an inclusive and socially just world for disabled and nondisabled people through our cultural practice (touretteshero.com). Wellcome Collection is a free museum and library based in London which explores health and human experience (wellcomecollection.org). Feeling Our Way was led at Wellcome Collection by the Public Events team, working in collaboration with Digital Editorial, Visitor Experience, Audiovisual, Design, and Marketing teams. This chapter uses Feeling Our Way as a case study to examine the current state of accessibility provisions in museums in the UK and concludes with a set of anti-ableist provocations for the future. The research methodology within this chapter is autoethnographic (Denshire, 2013), as the authors share and reflect on their personal experiences of developing and delivering the series. The authors names are used within the text to highlight when direct quotes appear. The authors identify as disabled, neurodivergent, and nondisabled people.

Feeling Our Way

In late 2021 conversations began in the Wellcome Collection Public Events team about audience interaction, safety, and COVID-19. This led to investigating the theme of touch and highlighted the importance of prioritising disabled

and neurodivergent artists and audiences. Wellcome Collection built on previous collaborations with Touretteshero and began to develop the idea of the Feeling Our Way event series. One of the starting points for the series was an acknowledgement that disabled, neurodivergent, and chronically ill people continue to be hugely underrepresented in the museum sector workforce, worldwide. Feeling Our Way was the first in-building project that Wellcome Collection developed after the initial COVID-19 lockdown. We acknowledge that for many disabled and/or clinically extremely vulnerable people, COVID was (and continues to be) a very raw and pressing issue. Research on the pandemic shows that of the total people in Britain who have lost their lives to COVID-19, approximately 60% have been disabled people, with learning disabled people as one of the groups most at risk of death (Bosworth et al., 2021; ONS, 2022). Many disabled and clinically extremely vulnerable people continue to take additional precautions to stay safe amidst growing societal perceptions that the pandemic is completely over. We write with love and solidarity for disabled people across the world who continue to navigate the complexities of systemic ableism in their everyday lives. There were three events in the series: Reaching Out (March 2022), Personal Touch (May 2022), and Invisible Touch (July 2022). Reaching Out focused on the social experience of touch. Personal Touch explored individual and personal experiences of touch. Invisible Touch was an opportunity to reflect on the relationship between touch and care.

As a clinical extremely vulnerable artist, when we started to think about the Feeling Our Way events, I felt incredibly isolated from the arts sector, I felt very invisible. But there is something amazing about the power of bringing different types of knowledge and resources together and the co-curation process with Wellcome made something possible within our communities that just wouldn't have happened otherwise.

(Jess)

Quite quickly we realised that we needed to approach Feeling Our Way in a collaborative way and to co-curate the series - to really think about our roles in the museum, about power and the decision-making process.

(Chloe)

Framing access and inclusion

Within design discourse and practice, the term access is often understood as 'who can do what' and inclusion as 'on what terms' (see Nussbaumer, 2011; Null, 2013). There is a problematic tendency for museums to frame disabled people's experiences through the limited lens of literal access to their collections and exhibitions. In this context, curatorial decisions (often made by nondisabled curators), most often foreground the technicality of accessibility provisions (e.g. can an object be seen, heard, or touched) rather than engaging with the emotional, historical,

and political aspects of what it means to be a disabled person. This engenders a curatorial culture that most often fails to represent disabled people's histories and how their stories can be understood and shared in radical and creative ways. Museum accessibility is also most often public-facing – *how can we support disabled visitors to access the museum environment* – but considering the inclusivity of the museum environment for staff, curators, and freelance practitioners working on events is a necessary expansion of this. As authors, we reflected on the terms access and inclusion while creating the Feeling Our Way events. For us, there is a clear distinction between access provisions that enable you to technically engage in museum content (as a visitor or staff member) and inclusion – where disabled people's stories, experiences and culture are visible and valued throughout a museum space. Therefore, our starting point for Feeling Our Way was to ensure the events were as technically accessible as possible, while also striving for them to be meaningfully inclusive by acknowledging the radical histories and legacies of disabled people and disabled-led movements that have come before us. We strived towards the curation of environments that nurture and celebrate a diversity of bodies and minds.

Event content

During Feeling Our Way, a cohort of disabled and neurodivergent artists created new performances, visual artwork, interactive workshops, resources, and audio pieces, each with access embedded from the outset. In total, 300 people participated in the in-person content and events within the Wellcome Collection building. There were a further 3,217 unique visitors to the Feeling Our Way web pages where the majority of the non-physical participation content was shared. Eight artists made new work for the series. During Reaching Out, BLINK Dance Theatre created two performances titled Hug-Demic and Tangled (Figure 3.1) as well as a film.

Tangled was described as a colourful sensory journey where audiences could interact with multi-sensory props designed to encourage interaction while maintaining social distancing. At the Personal Touch event, Sam Metz created a workshop titled Listening Body and a creative toolkit titled Materials That Listen (Figure 3.2). The workshop prioritised non-verbal, embodied, and neurodivergent communication and Materials That Listen considered how drawing with different materials, not just on paper, can support non-verbal body-based exploration.

For the final event – Invisible Touch – an accessible in-person and online exhibition entitled the Invisible Touch Trail was created. The exhibition shared touch diaries, audio interviews, and images created by five disabled and neurodivergent collaborators. Each collaborator kept a touch diary for 24 hours, charting episodes of touch and information such as when the touch happened and how it felt. Artist Amber Anderson visualised these diaries and the collaborators' experiences of touch draw attention to the complexities and possibilities of care in new ways.



FIGURE 3.1 ‘Tangled interactive performance by BLINK Dance Theatre, Wellcome Collection Saturday 5 March 2022’.

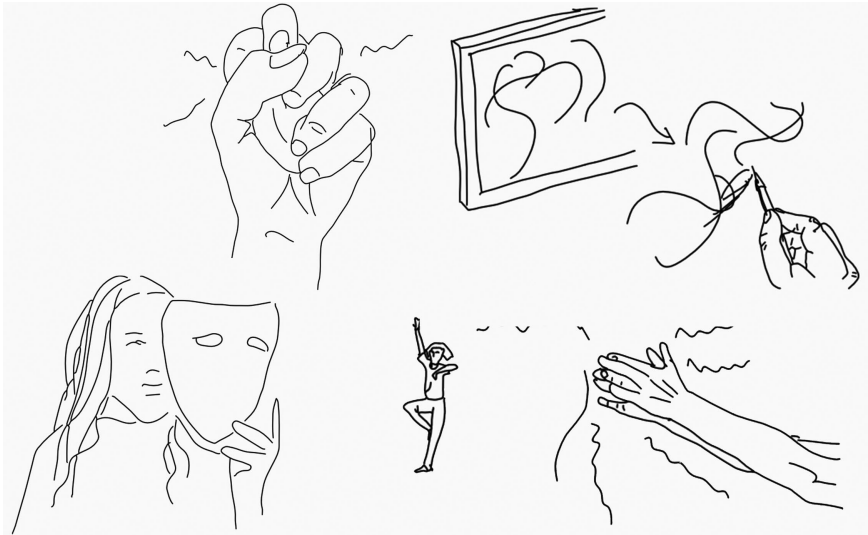


FIGURE 3.2 ‘Extract from materials that listen creative toolkit, created by Sam Metz May 2022’.

Access provisions at Feeling Our Way

The elements of the Feeling Our Way events that happened in person at Wellcome Collection benefitted from the core accessibility offer within the building. This includes accessible toilets on every floor, a Changing Places toilet, a warm welcome to assistance animals, induction loops, and captions embedded in all video content. Below are the additional access provisions that were created specifically for the Feeling Our Way events as an extension of the core provisions detailed above.

COVID access

The COVID-19 pandemic created and continues to create increased barriers to the meaningful engagement of disabled people in society. A significant part of planning Feeling Our Way was to acknowledge COVID as a new long-term barrier to access for disabled people which therefore needed new approaches and access practices. The Feeling Our Way events provided an exciting opportunity to think about COVID access provisions that allow people to be in physical spaces together as safely as possible whilst giving equal importance to non-physical participation (discussed below). The artists commissioned during the series also explored COVID access requirements as a creative provocation. For example, BLINK Dance Theatre's performance titled 'Hug-Demic' (Figure 3.3) involved interacting with



FIGURE 3.3 'Hug-Demic interactive performance by BLINK Dance Theatre, Wellcome Collection Saturday 5 March 2022'.

audiences using some very long tactile arms. The work explored how to safely pass a hug from one person to another, without actually touching. Wellcome Collection developed a 'How We Keep You Safe' page to communicate COVID-related safety considerations. The total number of people within the building was limited during the events and staff were given regular COVID briefings and training.

Non-physical participation

Non-physical participation describes the elements of an event that have been designed to support people to engage without being in the physical environment where the event is taking place. The COVID-19 pandemic and subsequent lockdowns led to an increase in digital and non-physical engagement; however, participating in cultural activity remotely was not a new experience for many disabled and chronically ill people. Unfortunately, since public spaces like theatres, galleries, and museums have reopened the care and creativity that was temporarily used to increase forms of non-physical participation during the pandemic have stopped (Walmsley et al., 2022; Marshall, 2021). For example, Misek, Leguina and Manninen (2022, p.43) note:

In the first 18 months of the pandemic, of the 219 publicly funded theatres and theatre companies in the UK, 123 (56%) streamed live performances, offered digitally native performances, or offered online workshops. For the autumn 2021 season, this figure went down to 60 (28%), and in the winter/spring 2022 season, this figure went down again to 35 (16%).

This feels like a significant missed opportunity for cultural institutions to champion non-normative ways of engaging in content. During *Feeling Our Way*, the goal was to create an equality of experience between physical and non-physical participation. This included designed activity booklets, sharing audio and video content online and curating the online and in-person multi-sensory exhibition *Invisible Touch Trail*. It was important that non-physical participation wasn't limited simply to sharing content online and included physical materials and activities that people could complete at home. An example of this was the *Feeling Our Way Activity Book* (Figure 3.4) designed by Ifeoma Orjiekwe and Amber Anderson as an accessible way for audiences to explore their own experiences of touch.

Non-physical participation was a core way of working throughout *Feeling Our Way*, with careful consideration given to how audiences that were not physically in the Wellcome Collection building could engage with the themes, questions, and activities of the series.

Budgeting for access

A dedicated budget for access was agreed at the start of the event planning. This was reviewed and discussed throughout the series. The access budget paid for

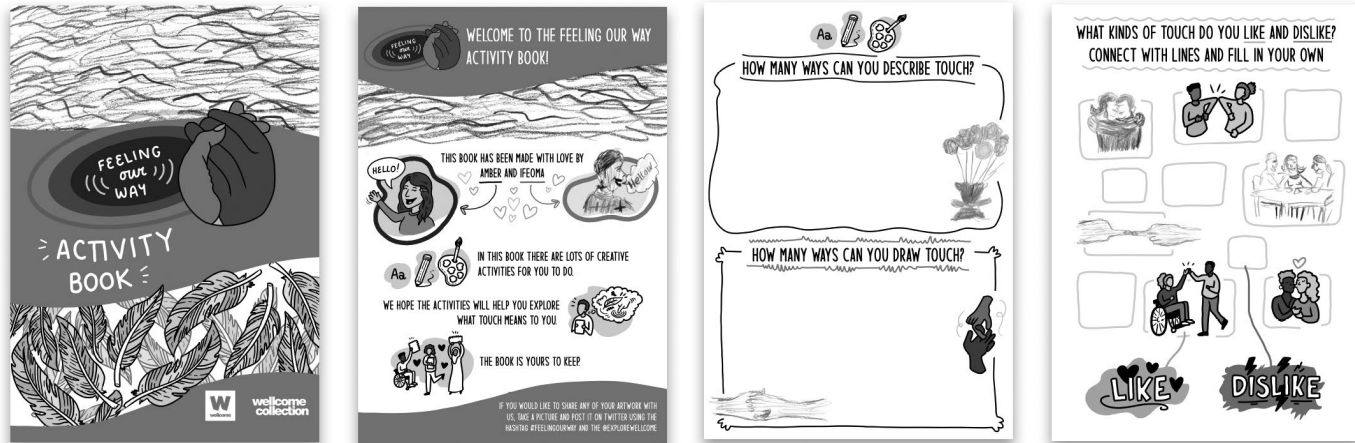


FIGURE 3.4 Extract from Feeling Our Way activity book, Ifeoma Orjiekwe and Amber Anderson.

event-specific provisions such as BSL interpretation, live speech-to-text captioning, and visual story design as well as access costs from the artists involved.

We started the events with a defined budget for access, which felt like a significant commitment. But because we were aiming for embedded access (rather than access provisions bolted on to the end of the process) one of the interesting things is that at points it was hard to separate out what was an access cost and what was a creative cost. If you're meaningfully embedding access in the creative process, it's part of the art rather than something that is separate to the art that you do at the end.

(Solomon)

Traditionally, a Wellcome Collection event would anticipate 10–15% of the event budget to relate to accessibility. For *Feeling Our Way*, 50% of the overall budget was dedicated to access. This helped shape the scale and scope of the events and made sure that access was meaningfully embedded in the series content. The Digital Team at Wellcome Collection played a key role in strengthening the visibility and accessibility of the non-physical participation activities and content. This included updating the standard Wellcome Collection web pages to increase the accessibility of how material and information were visually represented and using dedicated access resource pages and hyperlinks to create intuitive ways to find the relevant information and content for each event.

Relaxed events and venue

A 'Relaxed' event acknowledges that attention and participation will look and feel different for different bodies and minds and welcomes everyone to respond naturally to an experience. Building on Touretteshero's Relaxed Venue Methodology (Renel and Thom, 2022), all of the *Feeling Our Way* events were Relaxed. This meant that visitors could come in and out of the events freely and were encouraged to move, make noise, and respond to the content however they liked. The programme of activity repeated in the morning and afternoon each day and information was provided to show when the building was likely to be busy and noisy, and less busy and quieter. Advertising and promotional materials stated clearly that the events were Relaxed and described what this meant. Ear defenders were available for anyone to use during their visit and additional staff were present in the building. There were in-depth staff briefings on each event day.

Visual stories

A visual story is a document that provides information about an event or exhibition which visitors can use before and during their visit. A visual story is intended to give visitors all the useful information that they might need to know in advance,

in a clear and accessible format. For Feeling Our Way, the visual stories included information about the event locations and times, the artists involved and what to expect from the activities as well as the access provisions available. The pages of the visual stories were colour coded to make navigating the booklets easier and plain language and picture-supported communication were used throughout (see Figure 3.5).

Visual stories can be utilised as an accessibility provision by a wide range of people including, but not limited to, neurodivergent, learning disabled, and autistic people.

Chill-out spaces

At all of the Feeling Our Way events, dedicated chill-out spaces were available on each floor of the Wellcome Collection building where activity was taking place. These spaces had low lighting, comfortable seating, cushions, ear defenders, and sensory toys. The rooms were described as chill-out spaces (rather than quiet spaces) to avoid creating normative expectations about how the spaces should be used. The chill-out spaces were informed by the British Accessibility Standard ‘Design of an Accessible and Inclusive Built Environment Part 2’ which makes recommendations for the inclusion of a dedicated chill-out space within built environments in which ‘individuals might find peace and calm in order to manage sensory/neurological processing needs’ (BS8300–2, 2018, p.154). Visitor Experience staff were briefed on how to manage and maintain the chill-out spaces during events and careful consideration was given to how the spaces were described online – acknowledging that the physical provision is just one part of the visitor experience which also needs to be supported by Digital and Front of House teams.

Horizontal access

Horizontal access provisions are those which support people to rest and engage in events and activities in ways that work for their body and mind. This can include dedicated resting or chill-out spaces, multiple seating options that enable people to engage in content while sitting and lying down and information about events and activities that ensure people with different energy levels can make informed decisions about what to do and when. As disabled artist Raquel Meseguer describes ‘the horizontal body is not welcome in public... [it is] seen at worst as a threat, and at best as an inconvenience’ (Meseguer, 2022, p.366). Designing horizontal access provisions is therefore a radical attempt to challenge the normative expectations of ‘how to be’ in public space and an opportunity to re-frame resting, lying down, stretching out, and being comfortable as a core tenant of inclusive practice. Horizontal access provisions at Feeling Our Way included multiple seating options for each activity (e.g. beanbags and soft mats alongside chairs), a dedicated chill-out space (described above), a private sleep pod, and a resting space for artists working at the events.

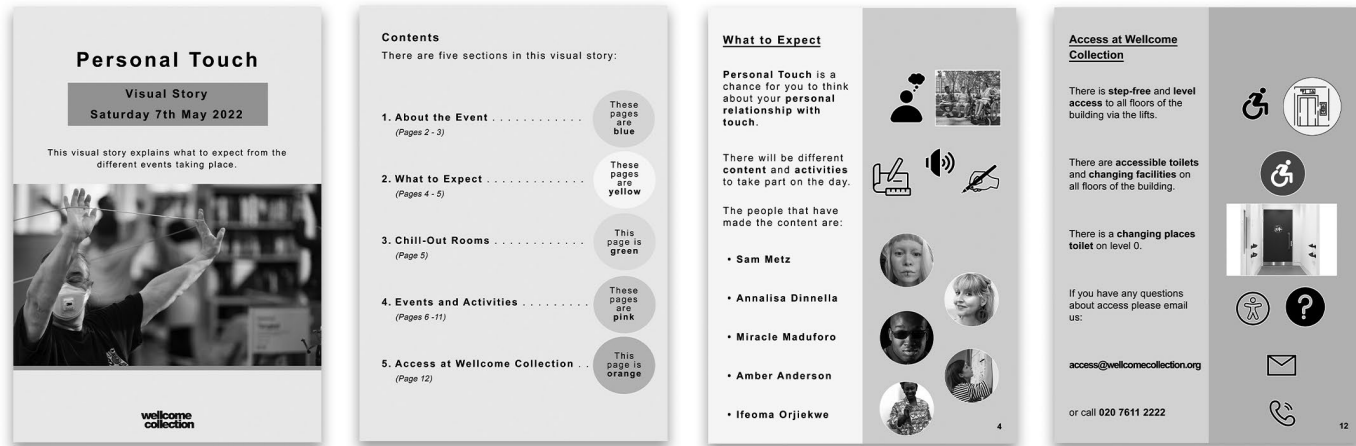


FIGURE 3.5 Extract from Feeling Our Way visual story.

Powerful ideas

The following section details six powerful ideas that informed the Feeling Our Way events, each of which was created by a disabled artist or writer. In sharing these ideas and how they were realised in the event series, we hope to contribute to new approaches to accessible and inclusive curation and programming in the museum sector.

1 ‘Crip Time’ – Alison Kafer

Kafer notes that ‘rather than bend disabled bodies and minds to meet the clock, Crip Time bends the clock to meet disabled bodies and minds’ (Kafer, 2013, p.27). The term acknowledges that some disabled people will need longer to do certain things as they are likely to encounter ableist barriers in the process. But the idea of Crip Time also moves beyond this, promoting flexibility and challenging normative assumptions about how long a certain activity ‘should’ take. Practically, this could include providing multiple event or arrival times, acknowledging that people process language and information at different speeds or making the pace of content (e.g. videos) adjustable. Feeling Our Way was purposefully designed to challenge some of the expectations around time that are embedded in museum culture. One example of this is the structure of the events in the series, which were each separated by several months, giving time for the learning from each event to inform the next. At the events themselves, the programme for each day was repeated in the morning and afternoon so people had multiple options to engage in the event content at different times. The majority of the creative content from throughout the series was also available online to engage with during and after the in-person events. There were moments when the co-curation team had to struggle against Wellcome Collection’s internal time expectations. For example, the time needed to create key provisions like visual stories was not built into standard event planning and delivery schedules. But the trusted partnership between Wellcome Collection and Touretteshero meant that many of the existing time expectations could be discussed and scrutinised.

One great thing is that, from the very beginning, some internal teams were open to challenging their own expectations and timelines – this meant that as we worked through the programme, we felt less like individuals struggling against a rigid set of institutional processes and more like a team looking to actively push boundaries. There are still barriers to our processes but the events highlighted what is possible when different teams work together towards a shared goal.

(Solomon)

2 Critical Access – Aime Hamraie

Hamraie (2017) suggests that mainstream discourses of accessible and inclusive design have turned away from addressing the histories of oppression

that disabled people have encountered. They coin the term critical access as an approach to designing accessible environments that foregrounds disability justice. Taking a critical access approach not only starts by designing an environment that supports disabled people to take up space safely and confidently but also creates the opportunity to share non-normative ideas and knowledge and challenge ableist thought processes. During *Feeling Our Way*, disabled artists and audiences were supported and encouraged to experiment with different forms of access. For example, provisions such as audio description headsets, which might be traditionally used by blind and partially sighted audiences, were also given to people resting and lying down during events so they could continue to listen and be involved. The events also created the opportunity for artists and audiences to understand and build knowledge of their access requirements and for Wellcome Collection to experiment and expand their access provisions. An example of this is that teams at Wellcome Collection who support with event set-up, such as Porters and Front of House, received training in how to set up a temporary chill-out space, so such spaces could be easily made available again at future events. Museums in this respect become important sites for the production and exchange of new forms of knowledge and critical access.

3 **Forced Intimacy and Access Intimacy – Mia Mingus**

Forced Intimacy is a term Mingus uses to ‘refer to the common, daily experience of disabled people being expected to share personal parts of ourselves to survive in an ableist world’ (Leaving Evidence, 2017a). Many disabled people will be familiar with the experience of having to share personal information about their body and mind in order to access an environment, system, or service in a way that is accessible to them. Access intimacy on the other hand is

That elusive, hard to describe feeling when someone else “gets” your access needs... Sometimes access intimacy doesn’t even mean that everything is 100% accessible. Sometimes it looks like both of you trying to create access as hard as you can with no avail in an ableist world.

(Mingus, Leaving Evidence, 2017b)

Throughout *Feeling Our Way*, we looked for opportunities to reduce forced intimacy and promote access intimacy. This included the design and distribution of visual stories to set clear expectations about the events in advance, as well as communicating the sensory landscape of the building (e.g. when it was likely to be louder or quieter) using plain language. Disabled people were involved in every stage of the events from planning and curating to designing and delivering the activities and content. This meant that disabled people were valued and visible throughout the series.

4 **Disability Justice – Sins Invalid**

Disability justice is a framework with ten principles formalised by Sins Invalid (Berne et al., 2018). The principles of disability justice seek to ‘honor the longstanding legacies of resilience and resistance which are the inheritance of all of us whose bodies and minds will not conform... a movement towards a world in which every body and mind is known as beautiful’ (sinsinvalid.org). If accessibility is only thought about and delivered as a checklist or a tick box exercise, then it is instantly depoliticised and detached from the reality of what using accessibility provisions feels like. Embedding the framework of disability justice into the curation of Feeling Our Way, and understanding that as a political act, enabled the team to hold onto the histories of ableism (alongside other forms of systemic oppression such as racism and sexism) entrenched in museum practices and strive towards experiences of collective liberation.

5 **Emotional Labour – Donna Reeve**

The term emotional labour was originally used as a description of the *work* done within social and personal relationships in ‘dealing with other people’s feelings, particularly as part of the goal of maintaining harmony with a social unit’ (Lupton, 1998, p.127). Reeve (2006) extends this by discussing emotional labour as the ‘additional emotion work’ which disabled people undertake as a way of navigating an ableist society. This can include human interactions but also interactions between disabled people and objects, systems, and services. Institutions such as museums can expect disabled people to do the work of making their environments more accessible or creating inclusive content with little thought given to how the emotional labour of those processes can be shared. During Feeling Our Way, the team were constantly looking for opportunities for Wellcome Collection as an institution to take emotional labour away from Touretteshero as co-curators and the disabled artists developing the event programmes. Examples of this include using visual minute taking (where accessible illustrations of key ideas, actions and quotes are created by an artist in real-time) at curatorial meetings so that thoughts and ideas from Touretteshero could be shared with other Wellcome Collection teams without additional input from Touretteshero. Artists were supported via dedicated access budgets and support workers were available to help with things such as navigating the Wellcome Collection building and arranging planning meetings. Wellcome Collection staff were also given training and support to manage audiences in the building so that artists could focus on delivering the creative elements of their work.

6 **Access is Love – Sandy Ho, Mia Mingus, and Alice Wong**

Sandy Ho, Mia Mingus, and Alice Wong co-created the term ‘Access is Love’ to encourage people and institutions to incorporate access into their everyday practices and ‘build a world where accessibility is understood as an act of love, instead of a burden or an after-thought’ (Disability Intersectionality Summit, 2018). Embedding access into Feeling Our Way started by

commissioning Touretteshero as a disabled-led company to co-curate the series and is exemplified in how Wellcome Collection approached the relationships with disabled artists:

A lot of museums and programming works through a linear and normative process where the institution creates a brief with specific expectations, a deadline and fee. Artists then work to fulfil that brief and, essentially, deliver what the institution has asked for. For *Feeling Our Way* we tried to approach the programming of disabled artists more as a relationship, with budget to support longer development and research time and less emphasis or expectation about the outputs.

(Solomon)

We are so often forced into working within an institutional structure which does not allow space to nurture ideas and build relationships. I think disabled people and artists are impacted more by this than non-disabled people. Working and curating with disability justice and culture at the heart of *Feeling Our Way* enabled us to work authentically and with a level of care and connection that I think is so often not the case in museums.

(Chloe)

Anti-ableist provocations

Having considered the six powerful ideas that informed the approach to the curation and delivery of the *Feeling Our Way* event series, the following section will turn towards the future. Below are six anti-ableist provocations for the future of museum studies, in sharing these our intention is to offer opportunities to think differently about the work we do, to actively seek social change and sound a call to action for museums to think beyond ‘traditional’ access provisions and towards anti-ableist practices. The title of our events – *Feeling Our Way* – was an acknowledgement that to create long-term change you have to take risks, experiment, and be open to making mistakes. We hope that by sharing these provocations, you will feel encouraged to do the same in your own work.

COVID access and clinically extremely vulnerable people

What does an ongoing and consistent offer for COVID access and clinically vulnerable people feel like?

The pandemic has exemplified existing divisions between people and emphasised how easy it is for society to turn its back on disabled people’s lives. Therefore, questioning what an ongoing and consistent access offer relating to COVID and clinically vulnerable people feels like is a more important provocation than ever.

For us, this shouldn't be limited to live streaming content or making content available online – there exists a wealth of more creative, multisensory and embodied approaches ready to be explored.

Access and autonomy

How can access provisions provide autonomy and be easy to use without lengthy explanation?

Understanding what access provisions are available, where these are and how they can be utilised takes a significant amount of time and energy. Therefore, thinking creatively about provisions which enable visitors and staff to experience environments safely, confidently and with autonomy is a significant opportunity to make museums more inclusive.

Curation and disability culture

How will museums acknowledge the historic invisibility of disabled bodies and minds and embed disability culture in new curatorial practices?

As Kafer (2013, p.169) notes, 'disabled people have more than a dream of accessible futures: we continue to define and demand our place in political discourses, political visions, and political practices'. In the arena of museums, this suggests that institutions need to continue to challenge physical and structural barriers to their environments but also own the politicised nature of a museum and find ways to make disability culture more visible and valued.

Decision-making and power

How will disabled people hold power, make decisions and lead processes?

This provocation not only requires systematic approaches to foregrounding disabled leadership, but also giving nondisabled people working in museums the confidence, expertise, and support to be led by disabled people.

Messages to disabled and nondisabled people

How will your environment send a clear message that disabled and nondisabled experiences are valued equally?

There is a well-established discourse in disability and critical disability studies about the negative messages that non-accessible environments send to disabled

people (see Guffey, 2018; Goodley, Liddiard and Runswick-Cole, 2018; Imrie, 2012; Boys, 2017; Goodley, 2016). As Hamraie (2017, p.19) notes from ‘a door-frame’s negative space to the height of shelves and cabinets, inhabitants’ bodies are simultaneously imagined, hidden, and produced by the design of built worlds’. However, a non-accessible environment also sends a message to nondisabled people that their way of doing things is correct. That their presence, time, and interaction are more valuable. Therefore, the goal of creating an inclusive environment is to challenge the sense of ownership and priority that some nondisabled people feel in museums and send clear messages that disabled and nondisabled experiences are valued equally.

New connections to knowledge

How can disability culture inform new connections to knowledge?

Often there is an assumption that the only people who benefit from an accessible environment are disabled individuals. However, by positioning disability at the centre of how we curate, programme, or interpret the museum environment and supporting different people and perspectives to access museum spaces, radical opportunities for people to connect with and exchange new forms of knowledge begin to emerge.

Conclusion

This chapter has used the Feeling Our Way event series as a case study to examine the current state of accessibility provisions in museums in the UK. It is clear that a museum is not a neutral space, it is not a blank canvas that simply holds and presents objective facts and information. Everything about a museum is politicised and subject to systemic ideas such as ableism and racism that extend way beyond the museum walls. But there is a danger that accessibility in museums has become depoliticised, concerned with ‘ticking the box’ and accountable only to goals established in lengthy non-accessible Equality Diversity and Inclusion policies. In this context, the accessibility of museums varies greatly and when a museum is accessible it can often feel like a gift, with an expectation of gratitude. We hope by sharing the powerful ideas that informed Feeling Our Way, alongside the accessibility provisions, curatorial approach and provocations for the future that we can help to orientate accessibility in the museum sector away from checklists and towards concerns of collective liberation and disability justice.

Biography

Dr Will Renel (he/him) is a practice-based researcher and Director of Research at Touretteshero CIC. Will’s work is situated between the fields of critical disability

studies and inclusive design and centres anti-ableist practices and non-normative ways of being, thinking, and doing.

Jessica Thom (she/her) is an artist and writer who co-founded Touretteshero CIC in 2010 as a creative response to her experience of living with Tourette's syndrome. Jess campaigns for disability rights and social justice and is on a mission to change the world 'one tic at a time'.

Solomon Szekir-Papasavva (he/him) is Live Programme Producer at Wellcome Collection where he works closely with partners and collaborators to co-create participatory, thoughtful, and joyful events. Sol has worked in education and museum engagement across the UK, Japan, and Brazil and is interested in surfacing and challenging the structures of power, value, and knowledge creation, which have shaped our experience of the world.

Dr Chloe Trainor (she/her) is Youth Programme Producer and Access Lead at Wellcome Collection where she works in collaboration with colleagues, partners, and audiences to reduce barriers and create opportunities for more equitable knowledge exchange. Chloe has a PhD in Disability History, and devises programmes and events that centre lived experience to surface different perspectives on health and human experience.

Summary points

- 1 The chapter uses an event series titled Feeling Our Way as a case study to examine the current state of accessibility provisions in museums in the UK.
- 2 The chapter details six powerful disabled-led ideas, each created by a disabled artist or writer, that informed the approach to the Feeling Our Way events.
- 3 The chapter shares a series of anti-ableist provocations for the future of museum practices.

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4

DEVELOPING THE GALLERY CALM ROOM

A journey of creating an accessible space for inclusion and well-being

Alicia Teng

National Gallery Singapore and its commitment to access

This chapter explores the journey taken by the National Gallery Singapore, towards the opening of our Gallery Calm Room, in June 2022. It will focus on the year-long process, which included appointing a local autistic artist-researcher as our Community Consultant, and then on the process of conducting focus groups with community stakeholders and designing a Sensory Probe Kit to enable our community members to co-create with us. This chapter unveils the power of creating inclusive spaces and the Gallery's commitment to accessibility.

Opened in November 2015, the National Gallery Singapore (Gallery) is a modern Southeast Asian art museum. Within its vision statement, inclusivity lies at its core, making access a core aspect of the Gallery's engagement with visitors (National Gallery Singapore, n.d.-a). To reinforce its commitment to accessibility, the Gallery established a dedicated Community and Access team in 2018. This specialised team takes charge of a spectrum of responsibilities encompassing access initiatives, community engagement, and volunteer management. The prime objective revolves around ensuring inclusivity for a diverse array of visitors, with a strong focus on engaging underserved communities. These communities encompass seniors, migrant communities residing in Singapore, as well as the neurodivergent and disabled communities. Collaborating closely with social service agencies, community care, and healthcare organisations in Singapore, the team seeks to increase access, aiming to provide every individual with equitable opportunities to engage meaningfully with our art, heritage, and offerings.

The team's approach in serving our visitors hinges on recognising the accessibility challenges encountered by our community partners when engaging in activities and programmes at the Gallery. We gather the insights through pre-visit discussions

with the programme coordinators from each visiting group and post-programme surveys. These insights are then integrated within the team to formulate strategies aimed at enhancing their overall experience. The considerations are also reviewed and integrated into the Gallery's staff and volunteer training when new access initiatives are introduced, ensuring the Gallery's ability in providing inclusive customer service to our diverse range of visitors.

The inception of the Gallery Calm Room emerged from consistent dialogue and understanding of the needs voiced by our visiting community groups. When serving the neurodivergent groups, a recurring concern brought up during pre-visit discussions with the group organisers was the availability of a quiet or calm room within the Gallery. Such a room would serve as a safe space in case of a meltdown situation among their service users. Not having a dedicated space for this purpose, the Gallery was often in the position of seeking out meeting rooms or any other spaces, which, regrettably, weren't always available on the day of the visit, leading to makeshift solutions. Recognising the significance of having such a dedicated facility, the Community and Access team embarked on research to develop a sensory-friendly room.

What is a calm room?

The concept of a calm room could possibly be derived from the sensory-friendly space, Snoezelen®, that was developed by two Dutch therapists, Jan Hulsegge and Ad Verhuel back in the 1970s. Their experiment yielded positive results for both verbal and non-verbal persons with developmental disabilities, leading to the travelling of this concept across various parts of Europe and the United States (Snoezelen® Multi-Sensory Environments, 2023).

In Singapore, 'The (the) terms "Calm Room" and "Quiet Room" are commonly interchangeable and refer to a purpose-build room for soothing anxiety and relieving overwhelm'. (Leong, 2023). Such facilities are commonly found within educational institutions or other establishments that serve the neurodivergent communities.

In 2019, the National Museum of Singapore (NMS) became the first cultural institution in Singapore to develop such a space, introducing the NMS Quiet Room on 1 August. Primarily designed for children with autism or sensory disorders, the room is fully padded and equipped with lights that have changeable colour settings to accommodate user preferences. (Government of Singapore, 2023).

The Gallery firmly believes that such calm and sensory-friendly spaces are beneficial to both neurodivergent and neurotypical persons. Sensory overload, a condition wherein one or more of the body's senses become overwhelmed (Leonard & Saripalli, 2023), is a phenomenon that can affect anyone. Nevertheless, it is more commonly experienced by neurodivergent persons, including those who are autistic, have sensory processing disorder, and post-traumatic stress disorder (Leonard & Saripalli, 2023). Providing a safe space for respite, sensory-friendly spaces offer

solace, relief, and recalibration for all visitors (National Gallery Singapore, n.d.-b). This belief was further strengthened during the COVID-19 pandemic when people from all walks of life grappled with heightened levels of mental stress, highlighting the immense value of having accessible sensory-friendly environments.

Designing the Gallery Calm Room

In embarking on the project of designing the Gallery Calm Room, the team was committed to ensuring the active involvement of the neurodivergent community. Their representation is essential to achieve an authentic and meaningful design of the space. Therefore, an autistic Singaporean artist-researcher, Dr Dawn-joy Leong,¹ was appointed as the project's Community Consultant, leading the research for the design of the Gallery Calm Room. Dr Leong has background in providing consultation in aspects such as the Arts and Disability, Disability Leadership, Autism, Neurodiversity and Multi-Art Applications. She has a PhD in Autism, Neurodiversity, and Multi-Art Praxis as well as her various artistic practices in developing clement spaces. Dr Leong played a pivotal role in providing valuable insights throughout the design process.

The development of the Gallery Calm Room can be categorised into the following stages: (1) information gathering, (2) design and feedback, (3) preparation and training, and (4) post-opening monitoring.

Stage 1: process of information gathering

Before commencing the information-gathering process, the team established key principles to guide the project. While the room is intended to serve the neurodivergent communities, the intention is to be able to open it for all. Therefore, the application of Inclusive Design is important. According to Microsoft Inclusive Design, the principles of Inclusive Design involves recognising exclusion, learning from diversity, and addressing the needs of one community while considering the potential extensions to benefit many (Microsoft, n.d.). Considering how the room should be easily accessible by the Gallery's visitors, it was also important that the location of the room is prominent.

Having established these principles, the Gallery launched an information-gathering process with neurodivergent communities to assess the alignment of these principles with their preferences. The neurodivergent community participants included autistic adults and children, along with their parents, individuals with Down syndrome and persons living with dementia and their caregivers.

As the primary method of research, the Gallery engaged in a series of interactions using a specially designed Sensory Probe Kit by Dr Dawn-joy Leong, along with discussion sessions or online questionnaires. The consideration to design a Sensory Probe Kit was to provide more ways for participants to share their responses as not every person may be comfortable with an in-person focus group.

In Dr Leong's experience working with neurodivergent individuals, dialogue is more fruitful when it is not restricted to lengthy or word-based communication, but when options and opportunities for other modalities are provided.

Use of a Sensory Probe Kit

The process of information gathering was divided into two parts. Part 1 involved the utilisation of a specially designed Sensory Probe Kit to obtain an initial understanding of participants' responses.

The Sensory Probe Kits, adapted from the Cultural Probes method, utilised physical objects and images to elicit immediate sensory responses rather than relying on a uniquely language-based survey-like questionnaire.

The advantage of using the Sensory Probe Kit was its self-facilitated nature. Participants received clear instructions, allowing them to independently engage with the materials, which proved particularly valuable during the height of the COVID-19 pandemic. The Sensory Probe Kit includes an instruction sheet, a black ballpoint pen, a pencil, a glue stick, a workbook, an assortment of different textured fabric samples, and four sets of images to gather inputs on colours, ambience, furniture, and chairs.

To accommodate participants' preference of remote engagement, the kits were delivered to their homes and completed kits were returned to Dr Leong for evaluation. Out of the 30 kits sent, 21 (70%) were completed and returned. This also served to support the access needs of participants who may be non-verbal as they could still participate independently without the stress of having to provide verbal responses.

Participants selected and assembled collages reflecting their perception of 'Comfortable', 'Neutral', or 'Uncomfortable' elements according to the activities outlined in the instruction sheet and provided accompanying explanations for their choices.

To assess participants' experience with the Sensory Probe Kit, feedback was gathered from 17 participants. Although only 17% of participants reported finding the kit challenging to complete, 41% were uncertain as they faced challenges in using some of the tools provided in the kit. For instance, the provided glue stick received the most comments regarding its messiness, as the glue seeped through thinner fabrics, causing the papers to stick together. Some participants with fine motor skill difficulties encountered challenges while cutting and pasting materials to create their collages. Most comments focused on the extended time required for cutting and pasting, with one participant expressing stress due to having very few items in the 'Uncomfortable' category, leading them to question whether they had made sufficiently discerning choices.

To address these issues, it is recommended to reconsider the adhesive type used and consider providing pre-cut images to minimise the need for cutting. Additionally, follow-up support, such as phone calls, could be offered to participants who may require further assistance or guidance.

41% of the participants reported no difficulties with the Sensory Probe Kit. The completed kits returned allowed Dr Leong to conduct a thorough analysis, enabling further engagement for the participants in the Part 2 process. Hence, the Sensory Probe Kit remained highly effective in fulfilling its intended purpose.

Insights derived from an analysis of the responses to the Sensory Probe Kit underscored some clear preferences for the design of the Gallery Calm Room. Smooth fabrics without any reflective sheen emerged as the top choice when it came to textures. The images that garnered the most votes depicted serene scenes – blue skies with well-defined white clouds, the warm glow of sunsets and the tranquil sea. Conversely, images featuring people, rough textures, and abstract paintings suggestive of chaotic movement were largely considered uncomfortable.

Regarding the room's ambience, a majority of the respondents expressed a preference for a mix of warm white and pastel themes complemented by natural light, as opposed to dark, windowless padded rooms. The selection of single, enclosed domed chairs was also popular among participants.

It is crucial to emphasise that the Sensory Probe Kit was not intended to yield conclusive data but rather to inspire, provide recommendations, and offer valuable insights. Consequently, Dr Leong's analysis took a sensorial approach, providing a general direction to lay the foundation for Part 2 of the information-gathering process.

In-person group discussions and online questionnaires

Part 2 comprised in-person group discussions or online questionnaires, with participants free to decide the medium they prefer to engage in. This offered Dr Leong an opportunity to gain deeper insights beyond the initial overview provided by the Sensory Probe Kits.

The interviews and questionnaires added further dimensions to the understanding gained from the Sensory Probe Kits, to substantiate the preferences for aspects of the ambience, colour scheme, furniture, and textures to apply for the design for the Gallery Calm Room. In this part, additional elements that may enhance participants' experience in the sensory-friendly space were explored, such as whether visitors should take off their shoes in the room and what other tools or items should be incorporated. The questions also delved into participants' overall experiences when visiting the Gallery and other public spaces they frequent, as well as perspectives on the importance of access facilities, such as a calming space.

25 participants provided feedback of which 21 completed it via the online questionnaire and four were done in-person. In this part of the process, majority of the participants preferred adjusting lighting between dark to bright warm white lights instead of multiple-coloured lights. There was consensus to removing their shoes upon entering the room; however, there were also concerns about possible feet odour. Privacy was important to the participants and controlled level of stimulants such as noise and lighting to reduce unnecessary discomfort.

A comprehensive evaluation of the information-gathering process necessitates consideration of both parts from the information-gathering process, as each part contributes to shaping the design brief and establishing protocols for creating a meaningful calm room experience for visitors.

The involvement of a Community Consultant, who identifies with the community, played a pivotal role in aligning the highlighted needs with potential solutions, reviewing practical considerations, resource feasibility, room space constraints, and other factors that may be overlooked by neurotypical individuals or taken for granted.

Stage 2: Design and feedback

The design process of the Gallery Calm Room is anchored in its intended purpose of providing a comfortable and soothing space. Drawing from the feedback collected from participants, the following design preferences emerged:

- Smooth and soft textures
- Warm white, off-white, and warm pastel colour schemes
- Single, partly shielded, and cosy seating arrangements
- Adjustable lighting options with a default dimmer warm white light setting

Building upon these preferences, additional elements were incorporated through design workshops involving the appointed architects, our team, and the Community Consultant. These additions included a communal area with modular furniture and elements of cool colours to balance the visual impact of the warm colour scheme. Previous focus group participants were invited back to provide feedback on the fabric selection, cushion thickness, and other room details. This iterative process ensured that the final outlook and materials of the room were comfortable and well-received by the community.

Given the room's size of approximately 36sqm, with 90% usable space, careful consideration was given to maximise its utilisation. Thoughtful visual elements were applied to create illusion of privacy, such as a clamshell-like structure around the single armchairs, as well as the use of different carpet colours to delineate spaces between the private and communal areas within the room.

Besides designing the hardware, the in-depth information-gathering process provided the basis on the software enhancements for the room. Together with Dr Leong, three light settings were pre-programmed to provide options for the different requirements of the participants. Setting 1 is a dim warm white light atmosphere that provides the general visual comfort according to the feedback received. A slightly brighter and warmer light arrangement forms Setting 2 for participants who may feel a bit cheerier and preferred a brighter atmosphere. The last setting is a comfortable blue light mode that provides the most calming and restful state, also nicknamed the melt-down mode.



FIGURE 4.1 Interior of the Gallery Calm Room with the posters featuring the breathing exercise and Slow Art Guide. Image from National Gallery Singapore.

Three royalty-free audio tracks featuring light sounds of nature such as the waves of the ocean were also selected to be played at a controlled volume within the room. The decision to include soothing soundscapes in the room was informed by participants' feedback that while they enjoy a quiet ambience, complete silence may also cause discomfort.

Recognising that not all visitors may know how to effectively calm themselves, a certified mindfulness teacher was appointed to create a 5-step breathing exercise, displayed as a poster within the room. For those seeking a more extended breathing activity, a QR code on the poster leads them to access an audio guide featuring an extended version of the breathing exercise. Additionally, the Gallery's Slow Art Guide programme was also made available, offering a solo audio guide journey inspired by the principles of slow looking and mindfulness. The programme featured three episodes, each focusing on one artwork (National Gallery Singapore, n.d.-c). Visitors were encouraged to extend their mindful engagement from the Gallery Calm Room into the exhibition galleries (Figure 4.1).

Stage 3: Preparation and training

This stage presented significant challenges as the team had to develop protocols from scratch, as there was no precedence for a calm room facility that is open to

everyone. Traditional calm or quiet rooms are typically tucked away in obscure locations, requiring visitors to seek assistance from service staff to access them.

Establishing an open room for universal use necessitated the development of internal operational protocols, logistics management, and clear messaging for the public to understand the space's intention and engage meaningfully. Being the first of its kind for the Gallery and in Singapore, the absence of case studies posed a challenge as the team navigated uncharted territory, unaware of the full extent of potential risks and repercussions.

Gallery-wide partnerships

Key insights from this process underscore the need for a whole-organisation effort and the value of close collaboration with community partners. While the project was driven by the Community and Access team, the commitment and involvement of other departments, such as Facilities Management and Visitors' Experience, were crucial in providing inputs on the room's construction and addressing service gaps to create a comprehensive and welcoming environment for visitors. One important decision made through cross-divisional collaboration was to station one front-of-house staff at the entrance of the Gallery Calm Room. The role of this staff includes setting up the room at the beginning of the day and assisting with sanitising after each use. To maintain a clutter-free environment, sensory items and kits were stored in cupboards, and the front-of-house staff would retrieve the requested items for visitors to use within the Gallery Calm Room. They would also provide information to curious passers-by about the Gallery Calm Room if they inquired and introduce the protocols using the room to visitors who expressed interest. It was important to communicate that the room may need to be vacated if someone else required urgent and private use, such as during a meltdown. We collaboratively trained a group of six front-of-house staff to support the Gallery Calm Room.

The Marketing and Communications team, along with the Content Publishing team, contributed to the review of the Gallery Calm Room's identity and messaging. While it was important to raise awareness of the Gallery Calm Room, equal attention was placed on practising sensitivity, as the room is not an exhibition or activity space intended for crowds of curious visitors. Preserving its functional purpose as a dedicated space for visitors to recalibrate and calm down was essential.

Nevertheless, being prominently located in the building's basement concourse provides an excellent opportunity to raise public awareness about neurodiversity and helps individuals discover ways to cope with sensory overload using the resources available in the Gallery Calm Room.

Gaining community buy-in

The support received from the community partners was highly encouraging. As the Gallery prepared for the room's opening, internal concerns arose regarding about

how the public may respond if asked to leave the room. Would they comply or become confrontational? The Gallery also contemplated restricting initial access to the Gallery Calm Room only to individuals who identified as neurodivergent or were experiencing distress. But that went against the grain of the intention to have an inclusive Gallery Calm Room that is open to all. Given the concerns raised, it was important that the Gallery Calm Room received buy-in from community stakeholders. Correspondingly, before the official launch, we piloted the room with visitors to the Gallery and obtained their feedback. With clear instructions and explanation about the Gallery Calm Room, visitors were not upset about being asked to leave the room. There were also supports from the various community members giving testimonials to the inclusivity of the Gallery Calm Room, therefore provided reassurance that any pushback or negative feedback from the public could be addressed appropriately. The following are two responses from our community stakeholders.

As a blind person, I am extremely sensitive to sounds and smells. Many times, I do get overwhelmed. **A calm room is not just a precaution, in case of trigger, it is an assurance to persons with disabilities that their access needs are considered and taken care of.** This allows me to feel safe and at ease in the space, encouraging me to spend more time appreciating and engaging with the artworks in the gallery. - *Vision Impaired Artist from Singapore*

Inclusivity is the main thrust of what we (the organisation) do... As part of our efforts to build a dementia-inclusive society, we seek to “normalise” dementia through creating social opportunities for persons living with dementia to continue meaningful and empowering interactions with the public, and diffusing the stigma by showing that persons with dementia are not any much different from you and I... **With the Calm Room being accessible to all, and with protocols in place to request other neurotypical individuals to leave the room for the person in need, this creates an opportunity for empathy where patrons – by knowing when to give up the room to someone else who needs it more – learn about one another’s needs, accommodate, and support one another.** That is the true spirit of inclusivity, and that will make for a better Singapore. – *Representative from a Dementia Social Service Organisation in Singapore*

Stage 4: post-opening monitoring

The Gallery Calm Room was opened in June 2022 and during the first month of its operation, Dr Leong and the Community and Access team conducted regular observations and collected feedback from users. The visitors consisted mainly of local residents, as well as some overseas visitors, including parents with autistic or neurodivergent children, small families, young adults, and elderly individuals.

Observations collected

Throughout the operating hours from 10am to 7pm, fewer visitors were observed in the mornings, while visitorship increased during the afternoons. During observations, it was noted that all the seats, both the private pods and the communal seating, were well utilised. Interestingly, some visitors chose to sit on the carpeted floor even when seats were available. Among the various types of sensory items provided in the Gallery Calm Room, the weighted blankets were the most popular. Visitors were not hesitant to request lighting changes, such as blue lighting, and one visitor even asked for a louder audio soundscape.

Visitors used various sensory descriptions to describe their experience in the Gallery Calm Room, including calm, comfortable, soothing, quiet, relaxing, peaceful, amazing, life-changing, and tranquil. Feedback regarding the design and features of the room mentioned the pleasing interior, soothing neutral colours, calming soundscape, and appreciation for the mindfulness exercises. A couple of visitors who were psychologists by profession commented that they could implement a similar design in their consultation rooms to help their clients relax and focus. Visitors also noted that the Gallery Calm Room's design was more aligned with its intended function compared to other similar calm rooms they had experienced in different facilities overseas.

The Gallery Calm Room consistently attracted a flow of visitors daily, with some learning about it through word-of-mouth, while others discovered it as they walked by. Both visitors and Gallery staff used the room, finding it relieving and helpful for recalibrating themselves. One notable observation involved a visitor who had just experienced an intense meeting at a seminar held onsite. After spending a few minutes in the Gallery Calm Room, she felt less stressed.

Wheelchair users preferred transferring from their wheelchairs to the armchairs in order to fully enjoy the Gallery Calm Room. Therefore, the design of one of the armchair, considering the height requirements for wheelchair transfer, proved beneficial. Repeat visitors were also observed returning to use the Gallery Calm Room. They were familiar with the available options and comfortably requested the room to be set with blue lighting upon entry.

Improvements suggested

While most of the feedbacks were positive, there were areas identified for improvement. One visitor felt that the room was too quiet, and others suggested the inclusion of aromatherapy. Requests were made for reclining options for the private pods and improved backrest in the modular seating. Mandarin translations for the breathing exercise were requested, and concerns were raised about the wide-opening door, which caused sound leakage. This would worsen when there were noisy activities held in the basement concourse outside the Gallery Calm Room. Additionally, visitor helped themselves to sensory kits and items stored in the cupboards which made

tracking and accounting for the items by our front-of-house staff challenging. It was also observed that some visitors scattered the sensory items around the room.

To address immediate concerns, the content of the breathing exercise was translated into Mandarin and developed as a printout for visitors who preferred it. More weighted blankets were also purchased to accommodate a more frequent laundry cycle.

Working with our front-of-house team

Approximately two months after the Gallery Calm Room's opening, a focus group session was conducted by the Community and Access team with the six trained front-of-house staff to discuss operational challenges and identify necessary improvements.

During the focus group session, the front-of-house staff openly shared incidents involving uncooperative visitors such as parents using the room as a social space while allowing their children engage in noisy play. The staff diligently introduced the purpose of the Gallery Calm Room to prepare visitors before entry, but not all visitors listened attentively and would enter the room with their shoes on. There were also cases of inappropriate behaviours observed when young couples used the room. In each case, the front-of-house staff politely reminded visitors of the room's purpose and, if suitable, directed them to other areas within the Gallery, such as the Gallery café, where they can engage in conversations with their friends.

Despite efforts to assist visitors, visitors continued to help themselves to the sensory items stored in the cupboard, causing frustration to the front-of-house staff. Additionally, the staff face the challenge of supporting visitors in the room while missing opportunities to provide information to other visitors who entered while they were preoccupied. It appeared that neurotypical visitors required the most support, as neurodivergent children were often accompanied by well-informed parents, and independent neurodivergent youths and adults were familiar with using the room.

While the pre-opening training was beneficial, the front-of-house staff expressed the need for further training to better understand neurodiversity and enhance their support for visitors at the Gallery Calm Room.

An unexpected outcome of the focus group was the immense sense of pride shared by all six of the front-of-house staff for being part of the project. They visibly observed the positive impact the Gallery Calm Room had on visitors before and after their time spent there. Assisting visitors through the Gallery Calm Room gave them a sense of purpose in their role, and they were eager to equip themselves further to serve the neurodivergent community. In response to this, the team organised training with a neurodivergent-focused social service agency in December 2022, six months after the Gallery Calm Room opened to the public. The front-of-house staff enjoyed the training and interaction they had with the neurodivergent clients, which boosted their confidence in engaging effectively with them.

Conclusion

The feedback received from the visitors and our front-of-house staff affirmed that the Gallery Calm Room was a highly valuable accessibility resource, serving as an inclusive space for all. While there are gaps to be addressed and managed, the facility was beneficial for self-care, as evidenced by its consistent usage of visitors and Gallery staff.

Moving forward

One year into its operation, the Gallery Calm Room had served over 22,000 visitors.² Over the one year, additional front-of-house staff were trained to allow for more flexible rostering. However, it was observed that the larger number of staff members trained resulted in discrepancies in the service quality, possibly due to limited time for staff members to fully grasp the principles of the room before being deployed. The training programme will be reviewed to ensure consistency in the service provided.

Internally, discussions arose regarding the effectiveness of having a single staff member manage the room and whether alternative approaches could optimise resource utilisation. Given the nascent nature of the Gallery Calm Room concept in the Singapore society, it was recognised that having someone present at all times was essential to ensure readiness to serve those in need and to facilitate broader awareness of the room's benefits.

An unexpected outcome has been the heightened recognition of the Gallery Calm Room. This led to numerous inquiries from both commercial and public service organisations and educational institutions. They sought insights into the Gallery's process for designing the Gallery Calm Room, aiming to draw upon these experiences when creating similar sensory-friendly spaces in their own establishments. In its inaugural year, the Gallery has hosted more than ten Gallery Calm Room learning journeys and numerous other engagements, further amplifying the impact of this inclusive initiative.

While exploring the concept of an inclusive calm room, the team also sought to ascertain whether a functional access space could also be a creative environment. Applying the findings that we had gathered from Stages 1–4, a similar calm room could potentially be designed and implemented in other establishments with modifications according to their establishment's requirements. So, what would make the Gallery Calm Room unique as an access facility within a museum? To expand on this concept, a Creative Residency for the Gallery Calm Room was piloted, inviting a locally based artist, Jevon Chandra³ to engage in a two-year process. The artist's task involved combining community research, physical installations, and public programmes to create a meaningful sensory experience within the Gallery Calm Room. The residency aimed not only to provide a unique experience exclusive to the Gallery Calm Room but also to foster opportunities and build artists'

capabilities to collaborate closely with neurodivergent communities as part of the artistic practice. (National Gallery Singapore, n.d.-b)

The art installation was launched in May 2023 and concluded a year after in April 2024. In the lead-up to the installation, several key challenges surfaced. These encompassed the delicate balance between preserving the room's functional integrity and the potential disruptions posed by the introduction of an art installation into an already compact space. Additional considerations revolved around training front-of-house colleagues to effectively manage not only the room but also the art installation within it, augmenting their already substantial responsibilities. The critical question of whether the installation would enhance users' calming experiences in the room remains unanswered as we were not able to gather meaningful data to analyse the engagement of participants with the art installation in the Gallery Calm Room.

Furthermore, there is pressing need for in-depth investigation to enhance the understanding of the Gallery Calm Room's impact and how its various components contribute to the overall calming experience. In collaboration with the Gallery's own Museum Research team, a study may be conducted to assess the effects of the Gallery Calm Room and provide guidance for its future direction.

Summary

The three key takeaways from the journey of creating the Gallery Calm Room are as follows:

1 *Collaboration and whole-organisation effort*

The success of the Gallery Calm Room project highlights the importance of collaboration within the organisation and with external community partners. The involvement of different departments and stakeholders across different functions within the organisation, proved crucial to create a welcoming calm room experience. The stakeholders of whom the facility is built for must be involved in the process to ensure authentic representation.

2 *User feedback and continuous improvement*

Gathering feedback from visitors and front-of-house staff allowed for ongoing evaluation and improvement of the Gallery Calm Room. By listening to visitors' needs and preferences, adjustments were made to the room's design, features, and services, ensuring a more satisfying and effective experience.

3 *Benefits and challenges of the Gallery Calm Room*

The Gallery Calm Room demonstrated its value as an inclusive space for visitors to find calm, relaxation, and tranquillity. Positive feedback from users attested to its effectiveness. However, challenges such as maintaining service quality, addressing visitor behaviour, and optimising resource utilisation remained areas for further exploration and refinement. It is also important to

consistently push boundaries and experiment new ways of audience engagement so that the museum remains welcoming to diverse audiences.

These key takeaways highlight the significance of collaboration, user-centric design, and continuous improvement in creating and sustaining an accessible and beneficial resource like the Gallery Calm Room.

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Biography

Alicia Teng heads the Community and Access team which oversees access initiatives, volunteer management, and community engagement at National Gallery Singapore. Since 2018, she led the development of various pioneering initiatives such as the Access Guide, Slow Art Programme, Art with You and the Gallery Calm Room, working in close partnership with community stakeholders to better engage diverse communities at the Gallery.

Her 14 years of art administration experience include marketing, sales, and development for the Singapore Arts Festival organised by the National Arts Council and partnership development at National Gallery Singapore – contributing to the successful solicitation of multiple major gifts, prior to her transfer to Community and Access.

Notes

- 1 Visit <https://dawnjoyleong.com/about/> to access Dr Leong's full biography.
- 2 Figure accurate as of 26 June 2023.
- 3 Jevon Chandra (b. 1991) is a transdisciplinary artist and designer. Visit jevonchandra.org to access the full biography.

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5

FRENCH 19TH-CENTURY ART WRITING AS AUDIO DESCRIPTION

The case of Edouard Manet

Prof Hannah Thompson

Introduction: blindness gain

‘Blindness Gain’ is a way of thinking about blindness that rejects the primacy of sight (Thompson, 2017, p. 55). Rather than positioning blindness as a loss of sight, it asks how blindness can be thought of as a ‘gain’ or benefit. ‘Blindness Gain’ assumes that blind and partially blind people do not suffer from what is traditionally called our ‘lack’ of sight. I use ‘our’ and ‘we’ to show that I describe myself and identify as a ‘partially blind’ person. I use ‘partially blind’ rather than ‘visually impaired’ or ‘partially sighted’ because this formulation uses a reversal of expected language to celebrate blindness and position sightedness as lack. ‘Blindness Gain’ reminds us that our non-visual senses (including touch, taste, smell, and hearing as well as less well-known ones such as proprioception) give us a different way of accessing the world. This multisensory way of being is often neglected, misunderstood, or underestimated by our ‘visually dependent’ peers. Yet, this blind way of being can stimulate inventiveness, imagination, and creativity. ‘Blindness Gain’ further argues that the best accessible approaches developed by and for blind people can and should also benefit non-blind people. When the non-blind world learns to appreciate non-visual modes of access (as has happened in the last ten years or so with the increased popularity of the digital audiobook), blind people are no longer marginalised. Instead, the way we like to access information becomes the norm rather than a costly and rare exception.

This chapter will discuss how one such access tool, audio description (henceforth AD), relates to the visual art it purports to describe. AD is increasingly – and often successfully – used by museums and galleries to provide blind and partially blind beholders with information about the visual content of displays and exhibitions. But we do not necessarily visit art galleries for information. Works of art

move, amaze, dazzle, surprise, and shock. They make us think and they make us feel. In this chapter, I will compare a ‘traditional’ AD with a ‘creative’ one to ask how museums might use AD to generate the same kinds of thoughts and feelings as the paintings they are describing. I take as my case study Edouard Manet’s 1863 masterpiece *Olympia* which was first exhibited at the 1865 Salon at the Palais des Champs-Élysées in Paris where it generated widespread outrage (Clark, 1985). You do not need to have this painting in front of you to appreciate the descriptions I discuss in this article: indeed, if you are a non-blind person, I recommend you resist the temptation to look it up so that you can appreciate what happens when you respond to the descriptions in a non-visual way. *Olympia* now hangs in the musée d’Orsay on Paris’s left bank. This former railway station in the French capital is home to the world’s largest collection of 19th-century French paintings.

In the UK and the US, AD of artworks is increasingly emerging as a literary genre, and a powerful means of creating inclusive access to art for a wide range of gallery visitors (Chottin & Thompson, 2021). In *More than Meets the Eye: What Blindness Brings to Art*, Georgina Kleege (2018) calls for a more aesthetically adventurous kind of AD; as a result, there are examples of recent ADs in both countries that have moved away from the traditional model towards descriptions that prioritise co-creation, subjectivity, and dialogue. In the UK, recent successes include the audio-described tour of the Royal Holloway Picture Gallery available on Smartify (see Eardley et al., 2022) and the audio guides that accompanied the 2022 exhibitions *In Plain Sight* (Wellcome Collection, 2022) and *Layers of Vision* (KCL, 2022). In the US, the research done at the Smithsonian National Portrait Gallery as part of the W-ICAD project (Eardley et al., in prep) shows that some blind and non-blind listeners prefer descriptions that embrace several different perspectives. Of course, there are also many blind listeners who continue to prefer traditional AD.

Traditional (functional) description

In France, museum AD is much less widespread than in the UK and the US (Reichhart & Lomo, 2019). Where AD of paintings exists, it is usually what I refer to throughout this article as traditional – or functional – ADs. Although no specific guidelines exist in France for museum AD, French describers and museum practitioners usually follow the guidelines set out in the ‘Charte de l’audiodescription’ published by the French film and television regulatory body, the *Conseil supérieur de l’audiovisuel*, in 2008. This French charter states that film and television AD should be an objective description that respects both the work of art and the needs of the listening public. It should be delivered from a neutral, third-person perspective and should not include opinion or interpretation. The information it provides should answer the four key questions: ‘Who?’, ‘Where?’, ‘When?’, and ‘What?’. The charter’s emphasis on the importance of detailed and objective

content encourages describers to concentrate on conveying information found in the painting, such as its layout and the main objects and characters depicted. The charter also recommends that the describer not mention the film's cinematographic features. This means that the crucial fifth question: 'How?' is not asked or answered by French describers; French museum ADs consequently often omit references to a painting's artistic features (such as brushstrokes or colour palette). The danger of such an approach is that it thus fails to translate, or even acknowledge, the artwork's essential 'artistic-ness'.

The musée d'Orsay's AD of *Olympia* is a paradigmatic example of traditional French AD. It is in three parts: first, a female voice gives us the 'tombstone' information usually included on a wall label next to the painting, that is, the work's title, artist, date, materials, and dimensions. Next, a male voice provides a functional description of the painting. Finally, the female voice returns with some contextual information about the painting's reception and Manet's response to it. Here is my translation of the second, functional, part of the French AD:

[Male Voice]: In a recess, a naked young woman is lying on a bed with white sheets. Her very pale complexion, barely tinged with pearl, is highlighted by the very dark background of the painting. Olympia's back rests on large pillows, her bust is slightly raised thanks to the weight she places on her right elbow; her head is almost straight, her face turned towards the spectator whom she seems to stare at. Her dark hair is held back by a headband and is decorated with a blue fabric flower above her left ear. Her left hand is resting on the top of her pubis, fingers apart. Her legs are stretched out and crossed at the ankle, echoing the modest gesture of her hand. She is wearing slippers; the only item of clothing she has on. Her neck is surrounded by a thin black ribbon, tied under her chin, and endowed with a small pendant. The right wrist wears a worked bracelet from which hangs a black pearl suspended from a chain. To the right of the painting, behind the foot of the bed and turned towards Olympia, a black servant is opening the package of a bouquet of flowers that she is handing to her mistress. This bouquet is composed with care: In the centre a large white flower stands out from an entourage of blue flowers framed by four red roses and some leaves of a deep green. The servant's face is poorly distinguished from the dark background and only the ample white shawl that is placed on her shoulders forms a large light patch that balances the mass of the pillows and the upper body of Olympia. This opposition means that the viewer's gaze is immediately drawn to the model's face and her gaze.

If this description is intended to give a blind beholder precise information about what is represented in this picture, it fails. There are at least three factual inaccuracies in this description. First, and most noticeably, the model is not wearing a headband and the flower in her hair – described by contemporary critic Ego as 'a rosette' ['un cocarde'] – a powerful symbol of revolutionary France – is red not

blue (Ego, 1865). The describer seems confident that this is a flower made of fabric, but this is not discernible from the image, and it could just as easily be a real flower. Indeed, critics have suggested the flower is an orchid (Reff, 1977, p. 108 qtd in Floyd) and a camellia (Floyd, 2004). By transforming their interpretation into fact through the confidence of their assertion, this describer does not allow the listener to experience the uncertainty which is painted into the picture. Second, Olympia is only wearing one slipper, not the two evoked in the description. While her left foot is clad in an elegant golden mule, her right foot is bare: three toes peep out from behind her shod foot and her second slipper lies empty on the coverlet just in front of her foot. Either it has just fallen off, or she is about to put it on. In both cases, the missing slipper is significant because it emphasises her state of undress. Third, the black servant is not wearing a white shawl, but a dress. (Musée d'Orsay, 2023)

It is astonishing that a description whose function seems to be, at least in part, to translate the visual into words in a factual, functional, and apparently objective way can be so inaccurate. The miscoloured flower is particularly surprising given that the bouquet to the right of the painting is the most precisely described detail in the paragraph: 31 words, or just over 10% of the entire description are devoted to these flowers, and the describer clearly considers himself something of a botanical expert because he even specifies that the red flowers are roses. This assertion is problematic because it is a personal interpretation disguised as an objective statement. It would be much more meaningful if the describer acknowledged his guesswork and embraced the potential of such subjectivity. Not only is it impossible to identify any of the flowers when we stand a traditional gallery distance – say 1–2 metres – from the painting but as with many of Manet's paintings, the closer we get to the canvas, the less identifiable its contents become. This is of course because we are presented with layers of oil paint on canvas, not an actual bouquet of flowers. And yet the description does very little to remind us that we are looking at an oil painting. Aside from the reference to the contrast between Olympia's pale skin and the painting's dark background, and the symmetry of the splayed hand and crossed ankles, this painting's painterliness is not captured here at all. There are no references to brushstrokes, texture, colour palette, or the lack of depth and perspective in the work. Instead, the describer talks about Olympia as if he is in the bedroom with her, looking at her in real life. And even this is oddly lacking in detail. While we get an accurate sense of Olympia's position on the bed, and reasonably precise descriptions of her necklace and bracelet, no attempt is made to describe her body. The only words used to describe Olympia's erogenous zones, 'pubis' and 'bust', are anatomical and prudish compared to the more explicit words that might have been chosen to reflect the model's brutal nakedness. It is as if the describer is worried about shocking, offending or even arousing his blind audience, as if we need to be protected from the painting's brutal depiction of sex work. Unlike the wall text for non-blind visitors that emphasises the 'huge scandal' caused by this 'vulgar and ugly' painting, the description captures nothing of the effect that the

painting had on visitors to the 1865 Salon. Neither are we given a sense of what it feels like to experience the painting in the Orsay today.

In the US, museum AD has become much more attentive to a painting's aesthetic qualities although these are generally mentioned after the functional description. The image description of Manet's 1866 portrait 'The Tragic Actor (Rouvière as Hamlet)' on the National Gallery of Art website gives a very detailed account of the man's physical appearance: we learn, for example, that:

He has heavy, furrowed brows and high cheekbones. His dark mustache curls up at either end over a full beard, and his wavy chestnut-brown hair is swept back from his forehead. His black jacket has puffed sleeves with narrow ruffles of white at his collar and cuffs, and a peek of the white shirt at his chest where the row of buttons are undone. His puffy pants gather at the thigh over black stockings, and he wears black slippers.

As with the description of *Olympia*, this feels more like a description of an actual person than a painting. It is only at the very end that we are told that 'The portrait is loosely painted with visible brushstrokes throughout, especially in the costume and background' (National Gallery of Art, 2023). This is a crucial piece of information that reminds us that we are beholding a painting, not the man himself. No such references to painterliness exist in the French ADs I have heard.

The description of *Olympia* ends with reference to her direct gaze, but we know nothing about her eyes' colour, shape or size, or her facial expression more generally. By contrast, we know that the actor 'turns to look off to our right from the corners of his dark brown eyes'. The final sentence of the description tells us that *Olympia*'s gaze is the first thing the beholder notices: why, then, is it only mentioned at the end, and accorded significantly fewer words (and thus less importance) than the bouquet? If the describer wanted to capture the effect the painting has on the beholder, it would be more logical to start with the penetrating stare, a stare that has attracted sustained critical attention (Brombert, 1996, p. 145). The absence of any description of the black servant is even more problematic. The describer uses nominalisation ('the servant') to dehumanise the figure: she is given no agency or significance other than her function as flower – carrier. This lack of descriptive detail problematically removes the servant from the picture. It is a symbolic gesture of erasure that points to the lack of importance historically ascribed to black people. In 2019, the musée d'Orsay included *Olympia* in a temporary exhibition entitled 'The Black Model: from Géricault to Matisse' and renamed the painting 'Laure' after the model who sat for Manet (Musée d'Orsay, 2019). However, this attempt to acknowledge the work of previously anonymous black models was short-lived and is not referenced in either the AD itself or the contextual explanation that follows it. This explanation is delivered by the same female voice that introduced the painting. It is almost the same length as the description. It explains that Manet, who had intended his painting as a homage to the Italian Masters, particularly Titian, was shocked by the scandalous reception it received, and it gives

various reasons why the painting caused such a scandal. The only visual detail it mentions is the black cat – oddly, this cat, which was the focus of critics’ outrage, as well as a significant allusion to Manet’s friend Charles Baudelaire – is not mentioned at all in the visual description.

AD in the art gallery

Perhaps, the inaccuracies in this description can be explained by the low status of AD in the art gallery. As Kleege (2018, p. 13) explains, a hierarchical gulf often exists in the art gallery between prestigious and high-status curatorial work and its much less glamorous access, education, and community provision. If AD is only ever seen as an access provision, it will not be taken seriously, or even acknowledged, by the museum’s curators. The inaccuracies we highlight here suggest that no curator at the musée d’Orsay has listened to the AD of *Olympia*. This is in part because traditionally, ADs of works of art, and audio-described visits to galleries, are created specifically for blind people and are often reserved for them: this ghettoisation makes it easy for non-blind people to fail to appreciate, or to grossly underestimate, the potential of AD. Yet, for a blind beholder, the AD can be as much a part of the artwork as any other element of it (Thompson, 2018). In addition, recent research clearly shows that all museum visitors can benefit from the kind of ‘guided looking’ enabled by AD (Hutchinson & Eardley, 2021). Indeed, AD is increasingly being incorporated into audio guides available to everyone; this is the case for example in the ‘Technicians’ Gallery at London’s Science Museum (Science Museum, 2022) where the audio descriptive guide is made available via QR code to anyone who ‘loves to listen’. The National Art Gallery in Washington DC routinely includes an ‘image description’ on the web page devoted to each artwork on display although these are not always advertised or linked to in the galleries themselves. It would be interesting to know how many non-blind people choose to read these descriptions.

The ‘blind-people-only’ approach to AD favoured by the musée d’Orsay is problematic because it positions blind people as a homogenous and marginalised group who are defined only by their blindness; it fails to acknowledge that everyone who lives in our ocularcentric society brings their own artistic and visual knowledge, experiences, and memories as well as their individual ways of seeing and not seeing. This kind of collective provision tends therefore to cater for what the non-blind provider imagines a totally blind museum visitor might need. But most blind people who visit museums either have some sight or a memory of the sight they used to have (Kleege, p. 12). Their presence both in the art gallery and online also suggests that they have the same kinds of interest in art and art history as non-blind gallery visitors.

In the musée d’Orsay, blind visitors are provided with a very limited experience compared to their non-blind peers: I found only nine paintings with AD on my most recent visit in December 2022. Compare this to the audio guide for non-blind visitors, which includes at least 200 explanations of various artworks in a range of

languages. I say ‘found’ because the museum does not have a list of the artworks whose descriptions are on the hand-held audio guide specifically designed for blind people. The only way of accessing these ADs is to wander the galleries until you notice the AD icon situated next to a painting; and to then type the corresponding number into the hand-held audio player. This effectively makes the ADs impossible to access without the help of a non-blind peer. This is acknowledged on the museum website that advises blind and partially blind beholders to visit with a companion. Even before we enter the museum, the blind visitor is placed in a position of dependency: we can only access the museum with the help of a sighted person, and we are reliant on this person’s choices (and skills of observation) to hear descriptions of paintings selected for us by the museum. In addition, these paintings are only accessible to those blind people who understand French and whose hearing is good enough to access the guide. Unlike the mainstream audio guide, available in several languages, the AD guide is only in French, and it does not include a text-based version. It is not clear why these nine paintings were chosen or who is responsible for their descriptions. This lack of autonomy and reliance on the goodwill of various sighted others echoes the problematic charity and medical models of disability where disabled people are denied agency and autonomy and are instead positioned as problems to be solved by the magnanimous non-disabled majority.

Creative (aesthetic) description

The musée d’Orsay’s AD of *Olympia* seems to have been created by a non-blind educator or access worker whose aim was to reproduce the most important elements of the painting in a way that does not shock or offend. While this traditional approach may have some value for some people, it does not capture the effect a work of art has on its audiences. My definition of ‘Creative’ AD proposes seven ways that AD might provide both blind and non-blind beholders with a sense of the painting’s artistry:

- 1 Creative AD is subjective: it acknowledges that language expresses different things for different people and that words carry a complicated network of connotation and denotation that is bound up with each person’s lived experience and cultural capital. Everyone has their unique positionality that will affect how they respond to the painting and the words they use to describe this response.
- 2 Creative AD acknowledges that different people have different relationships with the painting and that all of these are valid: it is produced in and as a dialogue with a range of voices that might include audiences of different kinds and from different periods and locations, curators, educators, the artist, and the artwork itself. As creative AD combines these voices, it seeks to avoid reproducing the hierarchical structures sometimes found in the gallery whereby curators and art historians are deemed to have more authority than educators or visitors.

- 3 In order to acknowledge this plurality of experiences, creative AD is collaborative and participatory. It uses methods such as the Workshop for Inclusive Co-created Audio Description (WICAD) (Eardley et al., submitted) to generate a range of responses and it works to incorporate different perspectives and points of view in all stages of its production.
- 4 Creative AD celebrates the painting's 'painterliness' and its own status as a creative response to a work of art: it is inventive in its own artistry and embraces creative communication. Creative AD might include poetry, stream of consciousness, dialogue, non-verbal sound, or something else altogether.
- 5 Creative AD is an inclusive approach that should be available to everyone: it should be easy to find and use and be promoted in the gallery as an experience for all.
- 6 Creative AD acknowledges that everyone sees or does not see differently. It talks about different experiences of looking and how beholders use sight to explore the painting and it does not imply that there is one 'correct' way of looking at the painting; it acknowledges that sight is never flawless, and it is attentive to the communicative potential of references to the non-visual senses.
- 7 Creative AD does not consider the artwork in isolation: it is interested in the whole gallery experience. This might include the frame, the work's position in the gallery, the use of lighting, or other design features; the sounds and smells of the gallery; other people's responses to the painting.

In his 1867 biographical and critical study of the artist Edouard Manet, novelist Emile Zola provides his own description of *Olympia* that fulfils several of the criteria listed above:

Olympia, lying on white sheets, creates a great pale patch against the black background; in this black background is the head of the black woman who is delivering a bouquet, and this infamous black cat who has so amused the public. At first glance, we distinguish only two shades in the painting, two violent shades, competing with one another. Indeed, the details have disappeared. Look at the girl's head: the lips are two thin pink lines; the eyes are reduced to a few black lines. Now see the bouquet, and up close, if you please; pink patches; blue patches; green patches. Everything is simplified. And if you want to reconstruct reality, you need to step back a few steps. And then a strange thing happens. Each object finds its place. Olympia's head stands out from the background with a striking relief, the bouquet becomes a wonder of brilliance and freshness. The accuracy of the eye and the simplicity of the hand made this miracle; the painter proceeded as nature proceeds itself, by clear masses, by large sections of light, and his work has the somewhat rough and austere appearance of nature.

(Zola & Leduc-Adine, 1991, pp. 160–161; my translation)

Unlike the traditional AD produced by the musée d'Orsay, this description includes both subjective comments and references to the painting's artistry. Zola's account is also particularly good at acknowledging that everyone sees or does not see differently. Zola's reference to his 'first glance' reminds us that sighted people have various ways of engaging with a painting. First, there is a general look, perhaps from across the room or as we enter the gallery. This captures an overall sense of the painting's construction, described here by Zola when he says, 'we distinguish only two shades in the painting, two violent shades, competing with one another'. Then, we focus more closely on something that attracts our attention: here, it is the model whose gaze draws the writer into the painting: 'Look at the girl's head: the lips are two thin pink lines; the eyes are reduced to a few black lines'. The use of the imperative here ('look') guides the beholder towards the model's face; this not only tells us that this is the focal point of the painting, but it also gives us some sense of what it might feel like to look at the painting by inviting us to share the writer's subjective point of view. Furthermore, the discussion of the bouquet reminds us that we are looking at layers of paint on canvas. The references to 'pink patches, blue patches, and green patches' tell us what the writer initially sees when he approaches the canvas, before he steps back and notices how these coloured patches transform themselves into the flowers described in the traditional AD. The reference to this transformation is crucial because it shows us how the process of observing art is not only subjective but also variable. Our perception of an artwork changes as we look at it, and this is particularly the case with the impressionist art of Manet and his followers. Zola's reference to patches of colour also foregrounds the painterliness of the painting: rather than attempting to identify types of flowers, this description of the bouquet captures how the paint appears on the canvas; it gives us the freedom to decide for ourselves what the coloured patches represent, thus replicating the process the sighted beholder goes through as they experience the transformation of the patches of colour into flowers. By presenting us with a personal response to the painting, this text is much more engaging and memorable than the Orsay AD.

AD did not exist as such in the 19th century, but this description, written for people who may not have the picture in front of them, fulfils many of its more creative functions. Unlike the Orsay AD, this description was written for a mainly non-blind audience. As such, it is not afraid to evoke the complicated process of looking. As Kleege (2018, p. 7) has shown, blind people should not be excluded from discussions of sight and seeing. *Olympia* was also described widely in the press. The annual Salon was a highlight of the French cultural calendar and the paintings selected for display were widely discussed by journalists and art critics across the country and beyond. Parisians flocked to the Salon in their thousands. But because mass reproduction of images in newspapers did not begin until around 1879 in France, anyone outside Paris who could not travel to the exhibition relied upon detailed descriptions of the paintings in the national press. Unlike the Orsay AD, contemporary descriptions of *Olympia* were not afraid to express the critics'

outrage that such a painting be hung amidst the nation's finest works of art. Several critics make unflattering comparisons between *Olympia's* body and the corpses routinely laid out in the Paris morgue for family and friends to identify. Geronte evokes a body 'exposed naked on her bed like a corpse on the slabs of the morgue'; his references to 'yellow fever'; 'a state of advanced decomposition'; and 'Its verjuice colour, sour, and acid' give us a much more accurate impression of the pallid and sickly skin tones than the Orsay describer's vague and overly romanticised reference to Olympia's lightly pearly complexion (Geronte, 1865). Ego's references to 'a courtesan with dirty hands' and 'rough feet', whose body has the 'livid complexion of a body exposed at the morgue' fills us with the same sense of the un-idealised, the sordid and the everyday that the picture was criticised for in the 1865 Salon (Ego, 1865). Ego's further point that 'her lines are drawn with coal' is particularly evocative because it puts into words exactly the kind of smudgy black outlines that seem to separate Olympia from the creamy shawl and white sheets on which she is reclining. As Zola points out, Olympia is hated by critics because she reminds them of the kind of unremarkable young sex worker seen on the streets of Paris (Zola, pp. 116–117). These contemporary descriptions of the painting, although mostly highly critical of it, are more evocative for blind beholders than the purpose-built AD provided in the Orsay. In addition to referencing the key elements in the painting – the white courtesan and bed linen; the black servant and cat; the colourful flowers; these descriptions provide us with a sense of what it might feel like to experience the painting visually.

This is a brief case study of only one AD in the musée d'Orsay. But, it nonetheless reveals that traditional ADs do not always do justice to the paintings that they are striving to make accessible, especially if they make no mention of artistic technique and thus fail to account for the painterliness of the picture. And if a visitor is visiting an art gallery, it seems plausible that they will be interested in artistic techniques to at least some extent. But, as Kleege (2018) points out: 'While it is rarely acknowledged, there seems to be an underlying assumption that blind people lack the ability to conceptualize visual phenomena in ways that will allow them to understand and grapple with art' (p. 73). Here, Kleege does not acknowledge the excellent work of those describers who are attentive to blind people's knowledge of art and visuality. Over 80% of blind people who visit museums have – or remember having – some sight. While a small minority of congenitally totally blind people might not fully comprehend uniquely visual concepts such as colour and luminescence, many other concepts that we usually think of as visual – such as space and structure – can in fact be understood with reference either to an analogy or to the non-visual senses. It is also worth remembering that even people who have never had any light or colour perception live in an ocularcentric world where they will encounter references to visual phenomena every day.

Translating images into words is a process fraught with difficulty. No AD can hope to capture every element of a painting and the multi-layered experience of viewing it in a gallery. But making better use of historic descriptions, such as those

created by 19th-century writers and journalists, offers one way of foregrounding both the subjectivity and the plurality of the ways we look at art. In the case of *Olympia*, the description purposefully created for blind beholders is much less successful than contemporary responses to the painting, written, as they were, for readers who did not have access to a reproduction and who thus had to rely on words to create their own understanding. I hope that this case study will encourage museums professionals to look again at the ADs of artworks in their galleries.

Three Key Takeaways

- The most engaging and memorable ADs are creative and subjective.
- ADs that discuss artistic techniques, the viewer's point of view and a range of responses to the artwork manage to translate the experience of viewing an artwork into words.
- Before the development of mass reproduction of images, journalists and art critics wrote descriptions of artworks that provide museums with evocative and nuanced ADs.

Biography

I am a White, cis-gendered woman. I grew up in and around museums and feel comfortable in them. I describe myself as a partially blind academic and activist. I teach French language, literature, and translation at Royal Holloway University of London and I also have a specialism in Critical Disability Studies. I am especially interested in creative ADs in cultural settings.

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6

SEEING THE DEAF VISITOR

Improving accessibility through a critical studies lens

Meredith Peruzzi

Author's Note: This chapter uses the phrase 'deaf people' to refer to anyone whose engagement with the world is affected by their hearing ability. This includes people who use sign language and those who do not; people who use hearing instruments and those who do not; people who associate with deaf community and culture and those who do not.

Introduction

In the 21st century, many countries have legislation that requires accommodations and adjustments for disabled museum visitors. Most laws, however, ignore the specific ways in which deaf people engage on a different psychological and cultural level with the world around them than hearing people and thus do not provide guidance on creating a welcoming experience for deaf museum visitors. Deaf people are not just hearing people who do not hear, but rather their unique worldview and perspectives call for deeper understanding to create a sense of belonging not considered by disability legislation.

Disability rights laws have arisen in an era of increasing awareness of social equity, with numerous organisations establishing departments and working groups focused on Diversity, Equity, Accessibility, and Inclusion. Institutions are working to confront the historical and ideological forces that have constrained them. The social model of disability of the late 20th century, which defined disabilities as reflective of societal oversights and aimed for a barrier-free utopia (Shakespeare, 2016), is beginning to give ground to Critical Disability Theory, a 21st-century framework that rejects the notion that inaccessibility is caused by the physical needs of disabled people, or that society overlooks these needs. In this theoretical framework, inaccessibility is caused by social norms that describe different ways of

interacting with the world as ‘disabilities’ in the first place, and the stigmatisation of disabled people’s different worldviews (Schalk, 2017). The signing deaf community is known for its framing of deaf lives as ‘different, not disabled’ – which has often caused friction with other disabled communities (Lane, 2005), but which nonetheless reflects the critical theory approach, positioning the *concept* of disability as a social construct, not just the *effects* of disability. According to Simi Linton (1998), the only true disability studies work is that which ‘weave[s] disabled people back into the fabric of society’ and thus depends on the deconstruction of historically distorted representations, not just the addition of *post hoc* accommodations.

In the wake of the Americans with Disabilities Act (1990), the UN Convention on the Rights of Persons with Disabilities (2007), and ongoing years of activism by disability rights advocates, many cultural institutions have joined the quest for greater inclusivity and are becoming more practised at meeting the needs of some groups of disabled visitors. In a 2023 survey, most museum staff rated the accessibility of their facilities as ‘good’, despite also describing major gaps in their accessibility in the survey’s comment sections (Fortuna et al., 2023).

As a deaf museum professional, I have observed many museums considering deaf visitors as a ‘one-and-done’ group, providing a static set of accommodations – captions, interpreters, and sometimes audio tour transcripts – rather than continuing to innovate ways of embracing the uniqueness of the deaf experience in their space. Providing only the specific accommodations outlined in legal documents makes deaf visitors feel they are no different from hearing people except for ‘broken ears’, when in actuality their entire way of experiencing the world is different from that of a hearing person. Innovating based on the visual orientation of deaf people can lead to a more diverse museum experience for all visitors.

This chapter considers a variety of museum experiences and their most common accommodations, and how staff might change their approach to create an experience in which the deaf visitor feels a sense of belonging in the galleries. Key concepts discussed include ‘deaf gain’, the importance of including visitors with lived experience in the experience creation process and the difference between accessibility and equity of experience.

People of the eye

Although medical bodies often assign decibel thresholds (World Health Organization, 2021), society at large generally assigns the term ‘deafness’ to mean *partial or complete inability to hear sounds* (Ladd, 2003). This inability to hear sounds may have a variety of different causes, some of which can be corrected with medical intervention, and some of which cannot. Some people also experience audio processing difficulties, which may not affect the volume at which they can perceive sound but affects their understanding of speech or other auditory information. This is the most basic definition of what deafness means, but it only scratches the

surface of what it means *to be deaf*. The rich literature of the field of Deaf Studies illuminates deaf lives, describing lived experience and identity in ways similar to the historical analysis of Oliver and Barnes (2010), which identified links between disability activists and academic theorists, and the identity construction work of Siebers (2008), which explored the collective action that is possible when people identify as disabled.

Humans connect with their environment through sensory orientation; for most people, this involves visual, auditory, and tactile methods of interacting with the space around them. Deaf and deafblind people also use all three methods, but frequently in different *proportions* to hearing and sighted people; the design of a space prioritising deaf sensory orientations generally privileges the visual and tactile methods of understanding over auditory methods. Indeed, understanding the meaning of deafness is not just understanding it as a ‘loss of hearing’, but realising that it changes one’s interaction with the world into a visual and tactile experience (Rosen, 2012).

Educational modes, using sign language or speech, play an important role in how deaf people learn and process information. For deaf people who are educated using sign language, they may struggle when learning a spoken language as a second language, as with American Sign Language and English (Mayer, 2009) or Japanese Sign Language and Japanese. This frequently affects reading capabilities in the second language, including on museum labels. Even for those who use speech and lipreading in school, incidental learning is generally affected, as deaf people do not overhear information in the way hearing people do (Convertino, Borgna, and Marschark, 2014). The use of visual language contributes substantially to the cohesiveness of the deaf community, as individuals can rely on each other for information sharing, but they are also othered from the hearing community, which expects information to be transmitted aurally.

These changes in deaf peoples’ patterns of thinking and perception of the world take place in the brain, but they are the result of differences in the physical auditory process. The interaction between the body and the mind is known in disability studies as the *bodymind*. The two are separate entities with their own unique characteristics, but in the theory of bodymind, they combine like two halves of a zipper, affecting each other, becoming an integrated unit, and acting together (Price, 2014).

Museums as visual experiences

Museums, generally, are designed for seeing things. Visitors examine artwork, read text, and contemplate objects – all practised through the eyes, sometimes with a patchwork of accessibility for non-sighted visitors. Science museums, children’s museums, and other facilities do often provide tactile and experiential opportunities, although these may or may not be accessible to non-sighted people, as they are often not specifically designed with accessibility in mind. It might seem at first glance that museums are ideally suited to deaf visitors; that if the museum provides

captions on films and an interpreter at events, everything within their walls is fully accessible to someone who doesn't hear. Yet, there are still many barriers for deaf museum-goers, driven largely by a lack of understanding of the depth of a deaf person's lived experience.

Most museums in the United States provide some form of accommodations to deaf visitors, at a 'reasonable' level required by the Americans with Disabilities Act (ADA); in other countries, the UN Convention on the Rights of Persons with Disabilities and/or local laws provide a framework for accommodations. These accommodations for effective communication usually require the provisioning of sign language interpreters and captioning on both pre-recorded content and for programming, both of which were groundbreaking additions to museums in the 1980s and 1990s. Museums that provide accommodations naturally look to regulatory requirements to comply with their legal responsibilities, but these laws do not mandate fully equitable and inclusive experiences for deaf people, as they focus solely on the auditory sense and visual methods of replacing it. These laws assume that the brains of deaf people are the same as those of hearing people, which countless research shows they are not: the use of signed languages creates a different way of processing verbal information than does the use of spoken language (Klima and Bellugi, 1979), and heavy reliance on visual input changes the plasticity of the visual processing centres, often resulting in superior peripheral vision and other changes (Alencar, Butler, and Lomber, 2019). Cognitively, deaf people experience differences from hearing people in executive function (Hauser, Lukomski, and Hillman, 2008), resilience (Kurz, Hauser, and Listman, 2016), and other neurological operations – but only *auditory function* is considered by disability rights laws.

Disability rights laws often create restrictions by their very nature. For most museums, their rules for 'reasonable accommodations' serve as a checklist: if they provide everything the law requires, then they have met their obligation to deaf visitors. By failing to look beyond the legal requirements and adapt for the different ways deaf people communicate, gaze, read, see, and think, museums miss opportunities to create a sense of belonging for deaf visitors. They instead perform a benevolent demonstration of being 'reasonable' rather than establishing access and equity of experience as a formal right for visitors (Prideaux, 2006, in Smith, Ginley, and Goodwin, 2012). They approach their visitors as 'hearing people who cannot hear' – not as *deaf people*.

To help readers understand the deaf perspective, I provide an illustrative example of the inequity caused by the limitations of a strict compliance with the ADA. In 2014, I visited a museum whose reasonable accommodations nonetheless created an inequitable experience for deaf visitors. In one gallery, a television screen played a video on a loop. A classic telephone-shaped handset was adjacent to the screen, with a sign 'Lift handset to hear video narrative'. There were no captions displayed on the screen, no button to push captions, and no reason for a deaf visitor to lift a telephone handset for something they could not hear. The museum provided captions, but they were only available by lifting the telephone handset.

It was not until a hearing person walked past and picked up the handset to listen that the captions appeared on the screen. There was no signage to instruct me as a deaf person, to lift the telephone handset – a tool used by hearing people. I was startled by this lack of signage and it made me feel even more invisible than I might have without captions at all. The museum was clearly following the law as written on paper, but it was not actually thinking about how deaf people exist in the real world – which is to say, dissociated from the concept of a telephone handset as non-phone users. My access needs were just a checkbox – ‘yes, we provided captions’ – and not considered from the perspective of a person who visits a museum. Displaying captions openly, or with a clear button to turn them on, benefits everyone – for example, parents with small children may not have time to stop and pick up the handset, but by watching the captions, they can experience the video’s content without their focus needing to shift fully away from their children. This type of boost to the universal experience based on creating equity of experience for deaf people is known as ‘Deaf Gain’. Named to counter the term ‘hearing loss’, Deaf Gain defines how the world is made better through the existence of deaf people (Bauman and Murray, 2014).

Another gallery featured artefacts from colonisers placed in conversation with artefacts from colonised peoples; this corner of the gallery was dark and clearly emotive. The curators elected to include ambient sound in this area, but no label provided a description of the audio recording. Many deaf visitors, including myself, have varying forms of sound perception and we are aware when sound is in use – but in this gallery, we would not be able to identify if the curators had chosen to present music, the sounds of battle between colonisers and colonised peoples, or another type of auditory information. This made me feel as though the museum rejected my bodymind as too difficult to communicate with – the burden of innovation and understanding was on me, the visitor, to piece together what I could hear and decide what it meant, rather than on the museum to find a way to tell me the information.

Elsewhere in the museum, an immersive environment was created to tell travellers’ stories, replicating the vehicles they used. The immersion included audio of the travellers’ own words, but transcripts were printed on plain white paper stored nearby. Although this gives deaf visitors access to the information contained in the recordings, the experience is othering: simple printouts seem like an afterthought in an exhibition that painstakingly recreates a traveller’s journey. My *equity of experience* did not feel prioritised: the auditory information was provided to me in a ‘lesser but equal’ fashion that the museum deemed ‘reasonable’ but which I found thoughtless. Styling the transcript like an in-flight magazine placed in the seatback pocket would have kept me immersed in the experience, while also being recognisable to hearing visitors as an even more complete recreation of the travelling environment. This example of Deaf Gain provides a fuller experience to all visitors, regardless of ability.

The message to deaf visitors from these examples is that they are an afterthought, not prioritised in the institution’s exhibition development. Visiting this museum was alienating rather than welcoming; I was reminded at every turn that I was deaf,

but hearing people could tour the exhibits without ever being reminded that they were hearing. Hughes (2007) frames this in the context of critical disability theory: ‘the normative body ... does not want to be reminded of its own vulnerability ... In this context the disabled body is troublesome[.]’

There has been some movement in the field in the years since the experiences described above. For example, *Musical Thinking: New Video Art and Sonic Strategies* at the Smithsonian American Art Museum incorporated labels to describe ambient sound and added captions to all videos, with permission of the artists; American Sign Language translations of interpretive labels were also provided via the exhibition website (Grayson, 2023).

Finding solutions

There are a number of approaches that can assist museums in developing their rationale for creating a more welcoming space for deaf visitors. The best-known of these is the social model of disability; as applied to deaf and hard-of-hearing people, the social model emphasises that they are fundamentally equal human beings, with entitlement to full citizenship and participation in society (Ladd, 2003). Where the medical model of disability proposes accommodations based on a deaf person’s inability to hear, the social model calls for accommodations based on the hearing establishment’s failure to include the needs of deaf people from the beginning (Lane, 1992). Under the social model of disability, the deaf visitor is not a problem; the problem is the museum’s assumptions about deaf people and how they interact with the world around them.

The principles of Universal Design (UD) also provide some guidance to developing an environment of belonging for deaf visitors, but Tokar (2004) finds that while some museums have staff who are familiar with UD, its implementation varies across the United States and Canada. Although its origins come from the disabled community’s own work, it has now become the territory of nondisabled architects, who largely ignore the cultural aspects of disability and are unfamiliar with critical disability theory (Hamraie, 2016). DeafSpace,¹ a design philosophy that originated in 2006 at Gallaudet University through workshops and classes led by and for deaf people, provides a user-centric framework for reimagining the physical spaces of museums. Its design process, unlike UD, is ‘rooted in an expression of d/Deaf cultural identity based around sign language, rather than as a response designed to compensate for, or minimize, impairment’ (Edwards and Harold, 2014, p. 1350). DeafSpace focuses on how deaf people move through their environment, creating adaptations such as wider walkways to allow for side-by-side signed conversations, and acoustic dampening on surfaces to reduce echoes that hearing aids cannot easily filter. By focusing specifically on what deaf people ask for, rather than trying to create a blanket one-size-fits-all space that ignores individual lived experiences, DeafSpace is a model for creating genuinely useful architectural change.

Staff training is also an essential part of making visitors feel welcome, and while front-of-house staff are used to dealing with a wide variety of visitor needs, the ‘deer-in-the-headlights’ response remains common when a deaf person approaches a staff member for information (Lehrer, 2013; Aldridge, 2017). Although sign language is a useful tool for anyone in a customer service role, most staff do not know it. Instead, they can learn to employ gestures effectively to interact with deaf visitors. Deaf people, whether they use sign language or not, are accustomed to producing and understanding gesture, as it visually augments their interactions with hearing people (Kusters, 2020). Hearing people can enhance their gestural literacy by practising and experimenting, thus replacing the scramble to find paper at the information desk with visual communication (Gallaudet University, 2020). It is incredibly rare for a hearing person to assume the burden of communication with deaf people, which makes the impact when it happens much more profound.

Auditory inclusion in museums

The following areas of museum work are full of opportunities for Deaf Gain through auditory inclusion. Making accommodations for deaf people more welcoming creates a more enjoyable experience for all visitors.

Audio tours

The barrier: Many museums offer audio tours as supplemental content, sometimes for an additional charge. The sight of an audio tour desk is often a disappointing experience for deaf visitors – they are frequently festooned with earphones and flags representing spoken languages, but there are rarely indicators that any accommodations are available.

The usual solution: Transcripts are the most frequent method of providing access to audio tour content. Frequently offered for free even if there is a charge for the audio guide, they may be single-use paper or sturdier booklets that must be returned to the desk. Transcripts are a flat, static means of interacting with content; the information is conveyed, but the audio tour’s delivery and convenience are lost as deaf visitors wander the museum head-down, gazing at the transcript.

The welcoming approach: Producing a sign language app version of an audio tour, which translates the content into a video signed by a deaf person, tells the deaf visitor they are important to the museum – they are worth the cost of the app’s development. These apps allow visitors to feel engaged with the content, and the tour can be designed with pauses to cue visitors to look up from the tour and examine the artwork or artefact. Non-signing deaf people can also be accommodated through captions being added to the video, and connectivity for hearing devices can be offered for all. Whether the app is downloaded to the visitor’s own device or offered on loaned equipment, adding signage at the audio tour desk is essential to communicate to deaf visitors that they have not been overlooked.

Key takeaway: Being exciting is the name of the game – if sign language apps are cost-prohibitive and add pictures to the printed transcript of the tour. In an art gallery, putting the artist’s photo next to the tour text is great bonus content. **Let go of relying on the printed word** as a ‘translation’ of audio content – think about visual communication, as deaf visitors do, and as visual learners of all abilities appreciate.

Videos

The barrier: Offering captions on videos is one of the most common accommodations made by museums, but best practices for caption design and access are not always followed. Sometimes, the captions are abridged from the audio content, and it may not be clear how visitors are intended to start the captions if they are not displayed with the video. In video art, captions may be omitted completely, if they were not supplied by the artist. Sometimes, artists don’t allow captions with their video if it’s not part of their artistic vision.

The usual solution: Although many museums show all their videos with open captions – displayed at all times – some rely on closed captions, which require visitor interaction to display. A clearly labelled button to start captions is essential – without clear instructions, deaf visitors will see a video and assume they are not welcome to watch it.

The welcoming approach: In addition to displaying captions for audio content, it is important to specify when there is no audio, as in a silent film. This removes doubt in the minds of deaf visitors – is this video silent, or was it simply not captioned? In the case of video art installations, some form of access should always be supplied without the need to ask staff. A brochure in a pamphlet rack, a sign on the wall, or even captions added by the museum are important, even if the artist did not include them.

Key takeaway: The visual nature of video makes it popular among people with a visual sensory orientation. Make sure all parts of a video – **spoken word, sound, and silence** – are communicated to deaf visitors in some way. Even a printed transcript is a nod to accessibility, if captions cannot be added.

Music

The barrier: Although the majority of museums remain quiet spaces of contemplation, some introduce music to create emotive experiences and add layers to their interpretation, and many music-focused museums exist. These experiences are almost always inaccessible to deaf people, perhaps because many hearing people do not realise that deaf people also enjoy music.

The usual solution: Most museums do not label music. When it is included to introduce a specific atmosphere or emotion for the visitor, this is generally deemed ‘background’ and no visual option is given. When music is part of the exhibition

content, a title and artist are often provided, but no written explanation – whether lyrics or mood – is provided; visual experiences of music are few and far between.

The welcoming approach: Any music that is included as a curatorial decision should be visually represented – if the choice has been made to include it for hearing visitors, some form should be expressed for deaf visitors, such as providing the song's title or lyrics on a label. Many deaf people experience sound, either naturally or through hearing devices, and providing visual cues allows them to understand what they are hearing. This label also makes deaf visitors feel seen by the museum's designers – open acknowledgement of deaf visitors' needs goes a long way towards creating a welcoming environment.

Key takeaway: Many deaf people love music when given a means to access it, and being left out of content you enjoy is disappointing. Bringing a balloon to a concert to feel the vibrations is quite popular, even a trope in deaf culture – holding an inflated balloon allows deaf people to have a tactile experience of the sound waves that others experience by hearing. Providing balloons not only allows access to sound but shows **an understanding of cultural norms**. In an example of Deaf Gain, hearing visitors who have never thought to experience sound as vibration would also have a more enjoyable experience by picking up a balloon and understanding a new way of processing music.

Sound effects

The barrier: Many exhibitions feature sound effects, such as a natural history museum that has a button to press to hear a bird's call, or an aerospace museum's exhibition with rocket sounds played at intervals. It can be difficult to make out these sounds in large, busy museums, as ambient visitor noise can conflict with the sound effects, and the speakers are not usually set up for optimal acoustics.

The usual solution: Visual accommodations for sound effects are rare. Although the type of sound might be explained, as with 'Press to hear the mourning dove's call', that is typically the only information supplied.

The welcoming approach: Sound should be explained as much as possible. For a mourning dove, adding 'coo-AH-coo-coo-coo' to the label explains what the bird actually sounds like; depending on label space, it is useful to add that it is called a 'mourning' dove because the bird's tone may seem haunting and sad. A mobile app that can provide the recordings directly to visitors' hearing devices can make this even more accessible.

Key takeaway: **Never assume profound deafness is the standard** – in fact, there are many more deaf people with some hearing, or who previously had hearing, than there are profoundly deaf people (Mitchell, 2005). Providing sound labels allows these visitors to feel a personal connection with the content.

Audio loops and assistive listening devices

The barrier: Although many museums have installed audio induction loops (for hearing aids to connect to) in auditoriums and at information desks and make assistive listening devices (ALDs) available for shows, they are not usually well-maintained. Their presence is often indicated by a sign, but staff frequently are unfamiliar with their operation, leaving deaf visitors responsible for troubleshooting their own accommodations.

The usual solution: At most institutions with auditory equipment, only one person is actually trained in its maintenance. Although front-of-house staff usually know the equipment exists and can provide it when it is in working condition, they are not equipped to handle problems in a timely manner. If the equipment is broken, someone might be called over to fix it (if they are in the building), but this often takes time and sometimes requires parts that are not readily available.

The welcoming approach: Whenever auditory equipment is in use, it should be checked, maintained, and replaced on a regular basis. Audio loops should be tested regularly with the appropriate equipment. ALDs should be kept charged at all times, and front-of-house staff should know how to verify they are working before handing them to a deaf visitor. Although many deaf people have become familiar with troubleshooting out of necessity, it can be exhausting and frustrating to miss part of a programme while trying to work on faulty equipment. Museum staff should be responsible for ensuring equipment works.

Key takeaway: Maintaining auditory systems for deaf people is just as important as changing the light bulbs so people can see the collections. It feels even worse to find out equipment isn't working than it does to be told it isn't installed. This happens so often that **simply making sure the equipment is functioning** creates an uplifting, memorable experience.

Tours and programmes

The barrier: Guided tours, cart experiences, and other types of gallery programmes are usually oriented to hearing people. Docents frequently walk and talk at the same time, cart staff give instructions while demonstrating, and presentations are often a speaker behind a podium with a PowerPoint. All of these are suitable for someone who can process auditory input while also doing other things, but they are ill-fitted to the needs of deaf visitors.

The usual solution: Virtually all US museums offer interpreter services for tours and programmes, usually with a required notice period, often two weeks in advance. This forces deaf visitors to plan their museum visit in ways hearing people do not have to. While interpreters can convey spoken information in sign language, they usually cannot change the style of the presentation. This results in the deaf visitor being forced to split their attention between the interpreter

(and the guide's lecture) and the material (a painting's details; a cart's contents). While deaf people are typically very practised in this, it creates a sense of feeling 'behind' – one is always trying to figure out what was just said, or where the detail under discussion is located.

The welcoming approach: Research has shown that deaf visitors, particularly those who use sign language, prefer to take tours with deaf docents, where the primary language of the tour is sign language (Roque Martins, 2016; Feyne, 2018). This allows visitors to experience the tour or programme at a suitable pace, where pauses are given to look between the docent and the object. Trained deaf docents often bring a cultural lens to their presentations, highlighting deaf stories in the collection and providing a sense of belonging for deaf visitors. These tours are frequently scheduled in advance, and as such become a social gathering – deaf visitors may plan to attend together and get a meal before or after the tour, and often social connections are made simply by meeting fellow attendees who share a language and interests. Museums that employ deaf docents also demonstrate to visitors that they value hiring and training deaf people, which further supports the visitor's sense of belonging and feeling seen by the museum's administration.

Key takeaway: The bond among deaf people is strong, enhanced not only by shared experiences of disability, but also by language and sensory orientation. **Interpreters cannot fulfil this bond, and cost money;** deaf docents serve as a direct liaison between museum and visitor and fit into a pre-existing volunteer structure.

Greeters

The barrier: When a deaf person walks into a place of business, they are walking into a hearing space. The person who greets them does so by voice; security staff give instructions verbally; the information desk staff opens with 'May I help you?' spoken aloud.

The usual solution: Deaf people are used to living in a hearing world. Watching for moving mouths is the norm; if the speaker's role seems important (such as a security guard), most deaf people will indicate their deafness by gesturing, pointing to their ear, and so on. Much of the time, a museum's greeters seem like a gauntlet to be run before getting to the museum's exhibits.

The welcoming approach: This is an instance where training in very basic sign language makes sense. While staff throughout the museum can learn to embrace gestural communication, greeters can learn to sign 'welcome,' security can learn to sign 'I need to check your bag', and so on. A few simple signs used at the museum's front door can make deaf visitors feel more welcome. For deaf visitors who don't sign, staff can give them a bit of personal attention, making sure they are looking at the visitor while speaking normally to allow for speechreading.

Key takeaway: Deaf people are quicker to identify emotions in facial expressions than hearing people (Krejtz et al, 2020), perhaps in part because of the

vigilance required to watch for someone addressing them. Staff training can **ease the work of constant attention** and processing for information – being *recognised* as being deaf, rather than having to announce it, is a relief everyone with invisible disabilities is familiar with.

Feeling welcome in a museum

A few museums are beginning to create experiences that welcome deaf visitors in the same way that hearing visitors are welcomed. The author's 2022 visit to the exhibition *Homō loquēns* (Talking Human) at National Museum of Ethnology in Osaka, Japan provides an illustrative example.

Staff at the entrance greeted visitors verbally but had pen and paper ready when deaf visitors arrived. The entire exhibition was trilingual in Japanese, English, and Japanese Sign Language – and while seeing video screens next to every label was initially surprising, it was also delightful to see the time, expense, and care taken to make the entire exhibition accessible to deaf visitors.

A key component of feeling a sense of belonging in a museum is being able to see yourself depicted in the exhibitions. *Homō loquēns* was about 'the wonders of language and languages', and signed languages were included on equal footing with spoken languages throughout the exhibition. A section showing the phrase 'thank you' demonstrated it in five spoken languages (with buttons for audio, along with written forms) and five signed languages (with illustrations of sign movements). A section on how humans form language addressed not only the lips, tongue, and vocal cords used for spoken languages but also the upper body, arms, and face used for signed languages. This integration feels empowering to deaf visitors, who are used to seeing their language and culture relegated to a sidebar, when it is included at all.

Homō loquēns also served as a social nexus for the deaf community. Despite attending just before the exhibition closed, the author encountered multiple groups of deaf Japanese visitors at the museum. One group included people who had travelled several hours to visit the exhibition, and they were excited to meet a foreign deaf museum professional. Throughout the exhibition's run, lectures and events were open to all, including presentations by the deaf researchers involved in creating *Homō loquēns*.

The experience of feeling equal in a museum was a novelty for the deaf visitors the author spoke to. In Japan, the United States, and elsewhere in the world, museums might seem accessible for deaf visitors because they are visual experiences, but the National Museum of Ethnology's work demonstrated that an exhibition that addresses the construction of deaf people's individual and social identities is more impactful than providing captions, interpreters, and audio loops.

Another illustrative example of fostering a sense of welcoming comes from the *Musical Thinking* exhibition at the Smithsonian American Art Museum, which the author visited in 2023. The museum's team worked with Gallaudet University's Motion Light Lab to develop new technological innovations that synchronised

auditory soundtracks to a haptic script. Benches and a raised dance floor platform were outfitted with vibrating devices which allowed visitors to feel the soundtrack of videos with a heavy rhythm component, such as Raven Chacon's 'Report' and Martine Gutierrez's 'Clubbing'. Both deaf and hearing visitors made use of these features, and children were especially interested in the dance floor, which also incorporated lights that flashed in time with the video. Although the exhibition's curator acknowledged that this approach would be difficult to replicate due to technical complexity and specialised skill (Grayson, 2023), it demonstrated the Deaf Gain principle of creating an enhanced experience for everyone by imagining new ways of connecting with art for deaf visitors.

Like *Homō loquēns*, *Musical Thinking* allowed deaf visitors to see themselves in the gallery space. Although an exhibition about music might seem to immediately exclude deaf visitors, the presence of works by deaf sound artist Christine Sun Kim invited deaf audiences to contemplate their own relationships with music, and appreciate seeing a fellow deaf person in a major art exhibition.

More and more museums in the United States are offering tours led by deaf docents in sign language, for example the Metropolitan Museum of Art or the Smithsonian's American Art Museum and National Portrait Gallery. For *Musical Thinking*, the Smithsonian American Art Museum's gallery talk was led by the collaborators from Gallaudet University who helped develop the exhibition's unique technology. In addition to providing a social experience and opportunity to learn from deaf experts, this event demonstrated to deaf visitors that they are truly welcome in a museum as creative partners, employees, and visitors.

Conclusion

The very essence of living as a deaf person means experiencing the world through visual and tactile means, which creates a different way of interpreting one's life. By focusing on this unique sensory approach, museums can support the self-actualisation of deaf visitors and ensure they feel they truly *belong* in the museum.

Key takeaways

- Deaf people experience the world in a fundamentally different way to hearing people. Taking steps to think about how deaf people live *as deaf people*, rather than figuring out how to 'replace' their hearing, is an essential part of becoming a welcoming space.
- Simple actions can have a profound impact. If an exhibition about the weather has a speaker playing a thunderstorm track, a discreet label reading 'Ambient sound: thunderstorm' goes a long way to building goodwill with deaf visitors.
- Get creative with sound. When you present auditory information, think about how you might represent it visually and even in tactile format. Don't assume

deaf and deafblind people don't want to know about sound – recognise another method is needed to tell them about it.

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Biography

Meredith Peruzzi is a signing deaf museum professional and accessibility activist. Her museum journey began as a young volunteer for the Baltimore City Life Museums and progressed to becoming the director of the National Deaf Life Museum at Gallaudet University, located in Washington DC. Her doctoral research at the University of Leicester focuses on how museums can look beyond the checklist of adjustments in disability legislation and move towards creating museums that are truly 'deaf friendly' creating a welcoming environment for d/Deaf visitors that provides an equitable experience and a space of belonging.

Note

- 1 Note that “DeafSpace,” the design concept, is not the same as “Deaf space,” the way in which deaf people gather and share information, often in transnational contexts (Solvang and Haualand, 2014).

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7

BLUNDERING INTO SENSORIAL CONVERSATION

Dr Fayen Ke-Xiao d'Evie

Since early childhood, I have perceived the world with fluctuating vision, mediated by a cascade of ophthalmological and neurological interactions. Despite the disorientation, fatigue, and pain that accompany these disabilities, the silver lining is the extent to which I notice, appreciate, and value perceptual variation and abundance. Within my art practice, this has flourished in the form of hybrid artist-curatorial projects, which invite collaborators and audiences to immerse in ‘sensorial improvisations, translations, and conversations.’ To explain my use of the term ‘sensorial improvisations’, I encourage artists, museum staff, and audiences alike to explore unfamiliar, sensorial ways of experiencing sites and artworks. This could involve subtle listening based on echolocation training; myopically close looking using conservators’ magnification equipment; choreographies of movement; taste, touch, and more. Second, sensorial translations relate to how we might describe a perceptual encounter, through creative mediation, such that the translated form can be experienced through another sensory reading. For example, how might sonic documentation of an encounter with an artwork in a particular site be translated into a gestural description for Deaf audiences? The third part of the invitation – to gather together in sensorial conversations – presents an alternative to common models of public programming in museum that segregate access audiences, for example, offering a gallery tour in sign language for Deaf visitors at a separate time from a touch tour for blind audiences, or a sensory tour for babies and children. Instead, my ambition is to develop structures for programming that invite people with varied perceptual experiences of exhibitions and artworks to share thoughts and sensory responses with one another, through contributing to a collective, inclusive conversation.

In this chapter, I share examples of projects that distil my thinking and methods; this is intended as an offering to museum professionals interested in engaging with

access beyond compliance, to adapt as you wish. My approach to access draws on Carmen Papalia's (2023) concept of access as a temporary, collectively held space, and also Mia Mingus' (2011) writing on access intimacy. Most simply, I conceive of access as an ethos of welcome, a platform for generosity, and as a catalyst for creative experimentation.

Access as temporary: blundering into unknown spaces

The concept of 'access as temporary' is a reaction to the problems that emerge when museums invest in access protocols that are ineffective for the audiences who were presumed to want or need such accommodations, due to uncritical adherence to standard methods of baseline compliance. Georgina Kleege, esteemed blindness scholar and my close collaborator, has described much conventional audio description, for example, as 'simply perplexing, supplying odd bits and pieces of information I can't quite imagine needing to know' (2023: 318). If access is conceived as temporary, then each exhibition or performance I develop can be approached as an unknown access scenario that will require my assumptions around audiences and communication protocols to be tested and negotiated.

Through iterative experiments, I have developed several methods that shape my wayfinding in situations of unknown and uncertainty; one of these is blundering. In a previous essay, d'Evie (2017:43), I described how blundering had emerged as a performative method, when moving within an installation of tactile artworks. Over time, it has evolved into a macro method or framework that invites improvisation and iterative experimentation:

To blunder is to stumble blindly, a method I deploy to structure (or² nstructured) writing, thinking and corporeal improvisation. Via a useful semantic doubling, stumbling may refer to a staggering or pitching movement with lurching shifts in perceptual perspective, or an unanticipated discovery. A method for grappling with the intangible, the unknown and the invisible, blundering allows for uncertainty, tenuous threads, and peripheral distractions, while also affirming wayfinding through blindness.

To give an example of blundering in practice, in 2017, I was commissioned to develop an audio descriptive artwork for *Seeing Voices*, curated by the Monash University Museum of Art, a touring exhibition that would travel regional art museums throughout Australia. My idea was to contribute a participatory and performative artwork, which would model the experimental methods I had just started developing for audio description. My intention was for the work to operate as a descriptive companion; rather than it purporting to be a neutral authority, I wanted to foreground a conversational tone. I imagined an audio tour in which I and one or more collaborators would remark on visual details of discrete works and bring attention to how the visual experience of each work was affected by its specific placement

among the constellation of works and the architecture of the site. However, I was also keen to avoid over-emphasising visuality, as I wanted blind experiences of the exhibition to be valued as well, so I imagined weaving into the descriptive script some suggestions for listening encounters.

In terms of scoping unknown elements, a key consideration was that the exhibition budget would not be sufficient to fund my travel across the vast geographic spread of the venues. Not only would the gallery architectures vary across the exhibition sites, but also the cultural and social dynamics of audiences and the access experiences of museum staff. In collaboration with sound artist Bryan Phillips, I decided to develop an audio work, to be presented to visitors on a mobile tablet that would model an improvisational, descriptive reading of the exhibition, as it was staged in the first site of the tour. I also proposed to intermingle recordings of a participatory workshop with blind and low-vision community members, who I would invite to encounter the exhibition with me.

The resulting sound work *Myopic Voices: Echoing Horsham* (2017) opens with Phillips and I narrating our entry into the first venue, with attention to the sounds and smells. As we move into the museum, our narration shifts to myopic readings of the artworks – another method I have evolved that involves extreme close investigation of the sensorial materiality of works. From our initial blundering within the exhibition, I identified possibilities for sensorial encounters with differing works. These framed my prompts to blind and low-vision participants in the community workshop, who joined us in the gallery later in the day. For example, I invited our community collaborators to gather in a certain place in the gallery, where Phillips had noticed that the audio from some of the other exhibited sound works overlaid in interesting ways. I also introduced the group to my method of myopic reading. Phillips recorded our impressions and conversations as I moved with the community collaborators through the exhibition. The structure of the final work was composed following a script that I drafted to model sensorial ways of engaging with the site and works, interspersed with fragments of the recorded impressions and conversations. The script offered implicit suggestions that the listener could adapt if they wished, as illustrated in this transcribed excerpt:

Turn. Walk towards the framed poster works by Damiano Bertoli. Walk closer towards the work than you normally would. What do you sense at this myopic distance?

Close up, I see the texture of the pigmented paper, how it's not machine perfect, how there are pencil lines and freehand marks. The pencil doesn't cover the whole field of the paper, there are underlying surfaces of whiteness...

I asked Damiano Bertoli whether close looking was something that he experienced making the work. And he said: "Through necessity, I needed to be hovering closely to address the detail. Colored pencil is most unforgiving and a high-level concentration is needed to draw areas of color without leaving a mark. It's a question of minute levels of applied pressure, that are very difficult

to sustain over large area, so... a kind of meditative zone needs to be entered, the drawings are somewhat performed...

Ethically and conceptually, I resist historical museum protocols that have positioned audiences as distant spectators. Aligned with my access-as-welcome ethos, I am drawn to creative possibilities to invite audiences into embodied encounters with artworks, and to value their perceptual, choreographic, and conversational responses as a mode of co-authoring an unfurling, collective social artwork. As *Seeing Voices* was a touring exhibition, I realised that the installation configuration would be changing between venues. Thus, in each subsequent location beyond Horsham, listening audiences would experience differing permutations of dislocation. Given that the *Seeing Voices* exhibition questioned what is heard and seen, and *Myopic Voices: Echoing Horsham* (2017) was explicitly positioned as an artwork, I reasoned that the slippages (the differences between the experience described in the audio and the experiences within the other exhibition spaces) would open space for listeners to become active participants, considering their own experiences and impressions, rather than the weakening the audio descriptive offering.

In 2022, I was commissioned to develop a series of access interventions for an exhibition *Take Hold of the Clouds*, a flagship event of Open House Melbourne's annual architecture festival, in which buildings across the city are opened to the public over a single weekend. Given the scale of uncertainty regarding installation configurations and audiences, it offered a perfect scenario to deploy blundering. In my initial briefing, I learned that *Take Hold of the Clouds* would feature site-specific responses by prominent artists, distributed across seven iconic architectural sites of Melbourne. Open House Melbourne was renowned for large crowds; the 2022 festival would later record 80,000 people attending. Due to the scale of audience, I anticipated a high degree of perceptual diversity. I also considered that the exhibition sites would largely be hosted by volunteers, with varying skills and experience in facilitating access. Many of the sites were not conventionally used for exhibitions, including a public swimming pool and a Quaker centre for study and worship. In most of these venues, the works could only be installed in the few days preceding the festival opening. Thus, there would not be sufficient time to draft and engineer pre-recorded audio descriptions of the experience of the artworks in situ. Given the temporary nature of the event, and the limited budget, I pondered how to offer audio descriptive access that might be cost effective and have a life beyond the festival weekend.

My response was twofold. First, I proposed that the texts commissioned for each site be sensorial, with each audiorecorded by the authors or their nominated narrator. In addition to the written texts being included in print catalogue, the narrated texts could be hosted on a web-based catalogue. Audiences could connect to this web-based catalogue via a dedicated, mobile-friendly website, or through QR codes available at each site and within the print catalogue. Co-curator Tara

McDowell (2022) framed the audio texts ‘as a kind of experimental wayfinding, situating the visitor, affectively, sensorially, historically and politically, as they approach and move through the site’.

Second, I considered each artwork in terms of scope for methods of participatory description. For instance, for her installation throughout a faded 19th-century mansion Villa Alba, artist Julia McNerney presented a body of photographs, sculptures, and films that dealt with the unrecorded and invisible work of women, including partial glimpses of her mother: ‘a way to circle her absence through fragments.’ She also opened certain windows, so that a soft breeze wafted through the crumbling interior spaces. The significance of the movement of air is touched on in the sensorial text, which took the form of excerpts from a recorded, long-distance conversation between the artist and Becky Beasley, a friend and artist. In one passage, McNerney notes,

I wondered what it might mean for the windows to open onto the elements outside, knowing the exhibition will take place in the wintertime... the weather becomes another material in the space. And if it’s a cold day, and the windows are open, one might question why, or what an opening is, or what does this particular window open onto.

Contemplating the significance of relationships, conversation, and attunement to the flows of weather and time, I proposed a score for a conversational audio description to be included within the print and web catalogue:

Visit in the company of another.

Stand together close to a window, listening.

Stand together close to a photographic image.

Ask: what do you see in this image, and what do you not see?

I have adopted the word ‘score’ from histories of movement and performance practices, in which textual and graphic scores have been proposed as catalysts for action or experience. Given that the exhibition budget and logistics precluded drafting and recording a description of each of McNerney’s photographs, my intention was to offer the score as an alternative, which would potentially allow all works to be described. By inviting the blind visitor and a sighted companion (whether a friend or an exhibition volunteer) to join together in a descriptive conversation, my intention was to shape an audio descriptive experience that valued the contributions of vision and blindness equally.

The web catalogue that houses the audio texts, plus other access interventions I proposed have remained online beyond the exhibition at www.takeholdoftheclouds.com. For the lifetime of that site, my invitations will reverberate, encouraging distant audiences to encounter the ephemeral exhibition via the experimental access offerings.

Sensorial abundance

Although my immersion in disability-led creative enquiry was propelled by a focus on blindness, early collaborations with Deaf, Deaf-blind, and multiply-disabled artists, designers, and poets led me swiftly into explorations of intersensorial, polylinguistic translations. For example, for the 2016 exhibition *Human Commonalities* presented in Moscow by V.A.C. and the State Museum of Vadim Sidur, I invited Deaf-blind poet and actress Irina Povolotskaya to co-guide participatory handling performances with sculptural artworks by Vadim Sidur. These performances took place within the State Museum of Vadim Sidur, and on the outskirts of the city, outside the Institute for Human Morphology, the site of a monumental sculpture by Sidur. I described the evolution of these performances in d'Evie (2017:47–50), including how I shaped the performances using a series of prompts that had emerged during my preparations, from conversation and handling explorations with Australian choreographer Shelley Lasica. During one session, Shelly and I discussed our emotive reactions and improvised choreographies as we handled of collection works from the Ian Potter Museum of Art in Melbourne, including how angles of approach, shifts in scale, and fluctuations in curiosity affected our encounters. From these interactions, I drafted lists of questions, prompts that might stir public participants to improvise with sensory attentiveness and handling choreographies, and to consider the ways that associations, memories, and emotional reverberations affect our experiences of tactile aesthetics. For example, as related in d'Evie (2017),

We reflected on whether there is comedy in touch, or strangeness, or repulsion, and how we bring weight to bear upon works individually and collectively. Through tactile exploration, we brought our attention to imprints, vibrations and entanglement, matter rearranging, and material histories.

For the performances inside the State Museum of Vadim Sidur, which handling a selection of Sidur's smaller sculptures, I had imagined parallel one-to-one performances, where Povolotskaya and I would each introduce a single audience member to tactile exploration of the sculptural works. However, during our rehearsals, a more interesting chain of translation emerged, as my spoken English prompts were translated to spoken Russian, then to Russian Sign Language, then to Russian tactile sign language, and back again. I was intrigued by the way concepts were being reinterpreted and approximated via trans-sensory vocabularies, phrasings, and embodied choreographies. This experience, arising out of pragmatic need, alerted me to the creative potential of chains of ekphrastic translation.

As Heffernan (1993) details, ekphrasis is a descriptive literary art form that dates to ancient Greece. A notable example comes from a passage in Homer's *Iliad*, detailing an ornamental shield that Hephaestus makes for Achilles. Surveying shifts in the concept of ekphrasis beyond a poetic, rhetorical, and literary

genre, Peter Wagner (1996) begins with its etymology, *ek* (from), and *phrasis* (to tell), reprising the original meaning of ‘full or vivid description’. He notes that in 1715, the Oxford English Dictionary defined ekphrasis as ‘a plain declaration or interpretation of a thing’, but by 1814, had added a secondary definition of ‘florid effeminacies of style’. This bifurcation of meaning has persisted, with ekphrasis still understood by some as explicating an image as objectively as possible, and by others, as interpreting and inscribing an image subjectively, with flair. However, in the 1990s, Wagner, Bryan Wolf, and others urged a reconsideration of ekphrasis, to account for shifts in understanding around texts, authors, readers, and representation, introduced by structuralist and post-structuralist philosophers.

Following Roland Barthes, a text is no longer constrained to a self-contained literary work. Instead, an art object, a person, performance, a practice, even a life, could be read as a text enfolding signifying systems, codes, and frames. As Barthes (1986) wrote, ‘the text is a fabric... woven of quotations, references, echoes: cultural languages... antecedent or contemporary, which traverse it through and through, in a vast stereophony’. Such multiplicity also underpins Umberto Eco’s (1989) positioning of a painting as an ‘open work’, its signs combining ‘like constellations whose structural relationships are not determined univocally’, and where the viewer (or reader) must choose points of view, connections, and directions, while excluding other possible interpretations. In relation to ekphrastic audio description, these arguments undermine the assumption that a singular, authoritative, objective description of an artwork is possible. I argue that they also liberate the descriptive act, inviting more voices, and creative mediums into descriptive practice (d’Eve 2022a). I am particularly interested in ways that disability-led practice can innovate integration of other senses and non-verbal languages into ekphrastic, approached as an experimental and participatory art form.

My collaboration with sound artist Bryan Phillips, for example, began with us discussing ways that field recordings of the processes involved in making of an artwork could offer a description of its material form as it comes into being. We also considered how an archive of recordings over time might be useful to describe transformation of that material form over the life cycle of the artwork. This led to conversations about how performative, ephemeral works could be described to blind audiences, and how audio description could trace the material degradation of artworks over time. The latter question prompted a research project with Georgina Kleege and conservators and curatorial staff at SFMOMA, audiorecording sensorial encounters with artworks from their collection.

My experience with the Vadim Sidur exhibition prompted to think more deeply about ekphrasis in poly-linguistic and inter-sensorial contexts. I began to devise hybrid artist-curatorial projects to catalyse descriptive translations among blind, deaf, and Deaf-blind artists and audiences, as well as collaborators who do not identify with perceptual disabilities. For one project, I invited blind, Chicago-based musician and sound artist Andy Slater to travel to Australia to create an audio descriptive work, composed from field recordings at the Old Castlemaine Gaol,

an historic prison located in Djaara country, near where I live. As I detail in d'Evie (2022b), the architecture and prisoner management protocols of the Castlemaine Gaol were modelled on Pentonville prison in London, which in turn was influenced by Eastern State Penitentiary in Pennsylvania, two renowned transatlantic experiments in solitary confinement and sensory exclusion. Incoming prisoners were escorted into a cell wearing eyeless hoods, a two-way functional blindness: the new prisoner could not see other inmates, nor be visible to anyone who glimpsed them entering. Radial corridors of singular cells fanned out around a central atrium, like spokes of a wheel. The walls of the cells were built with extra thickness to dampen sound, and there were no ventilation ducts shared by cells, preventing clandestine messaging. A small hole in each cell door, covered by a metal guard, was used to deliver food without visual contact. In addition to enforcing functional blindness, deafness, and muteness, Castlemaine Gaol was implicated in a brutal phase of disability history, through measurements of prisoners' bodies being used in eugenics research. I was interested in acknowledging and countering these intertwined histories of exclusion and perceptual control, by approaching the site as a space for sensorial conversation; in particular, I was keen to bringing blindness and deafness together in creative conversation.

The sound work composed by Slater, *Hauntings* (2019) is mostly non-verbal. Recurring within the sound work are the reverberations of Slater's mobility cane as he taps along prison corridors and navigates the underground prison dungeon, feeling stone surfaces and metal bars. Like echolocation navigation, vibrational echo and decay of the tapping cane provide descriptive information about the interior architecture. Mingled with cane are the creaking of cell doors and the peals of bronze bells, due to a cloud of resonant sculptures cast by blind, London-based artist Aaron McPeake that I had installed down one hallway. The only verbal language in this audio descriptive work is Slater's tentative greeting of a ghost, a voiced 'Hello?'

Next, I commissioned deaf choreographer and dancer Anna Seymour to translate Slater's audio work – the description of the Gaol site – through ekphrasis; where the language of translation would be 'gestural poetics', a term I coined for an expressive mode of signed poetry based in Seymour's native AUSLAN, Australian Sign Language. This resulted in our video work *Shape of an Echo* (2019), filmed and edited by videographer Pippa Samaya. The video includes Anna tapping out a beat with her wrist in sync with Andy's cane; a choreography of grimaces as she contorts her face in sync with the sounds of a cell door wrenching open, miming a handbell, and a curious wave of the hand, 'Hello?' I exhibited the paired sound and video works in various configurations; in one instance, I installed them in separate but neighbouring rooms, separated by a hallway; in another, I synchronised them as a single audiovisual work.

The next expansion in the ekphrastic chain was prompted by Slater's request for an audio description of Seymour's movements, so that he could understand how she had translated his composition. I thus commissioned a third link in the chain,

a narrated description of the video. This was scripted and voiced by Berkeley-based artist Hillary Goidell, whose photographic practice incorporates sensitive documentation of private, embodied processes, from behind-the-scenes development of dance works to end-of-life transitions. The following excerpts from Goidell's descriptions align with the choreographic moment that Seymour rings the handbell, as noted above:

*Right hand chimes high, left hand follows, rising dreamlike.
And more effort needed.
Crossing a threshold to lightness, Anna's expression turns melodic.
Her hands animate, sprinkling harmony here and there.
An airy seasoning of the outside.
Fingers spread and flutter undaunted, wisps of confidence, body almost daring
to follow.
(A smile, what a luxury—remember the walls around her).*

I presented Goidell's poetic audio description in the form of a video work, *To Catch a Thing in Flight* (2020), with her spoken narration synchronised with captioned text, white font on a black background. The ekphrastic chain thus culminated in a textual work that all the collaborators could access, via sound or vision. Captioned, narrated videos can operate as creative outcomes and as tools for access; like tactile sculptures, such works are able to provide shared entry points for Deaf and blind audiences to engage with artworks.

In 2023, I expanded on the concept of sensorial abundance and ekphrastic translations in the form of an immersive stage show, presented at Chunky Move dance company for the Melbourne Fringe Festival. Although this work took place outside of a museum context, the tools and methods deployed have relevance for museums, especially those that have moved towards audiovideo installations as a means of immersing visitors in thematic encounters beyond static artistic or historical objects. Titled ~~~~~ "*derelect in uncharted space*", the show paid homage to Project Communicator, a non-profit initiative of a San Francisco-based Star Trek fan club in 1974, that had aimed to bring the wonderment of Star Trek to Blind audiences through descriptive radio plays. The live performers included four bodies on stage – me, dancer Benjamin Hancock, Deaf artist Luke D. King, and Hard-of-Hearing composer Rebecca Bracewell. In addition, I integrated two distant performers: projected movement on a suspended screen from Kleege, developed in collaboration with Boston-based sound artist Nelly Kate; and an audio-described choreographic contribution from blind Sydney dancer Alex Craig, as part of the spatialised sound design.

Ekphrastic translations were prominent features of the stage design. Screens mounted high on the curtained studio walls conveyed descriptions of the spatialised sound design, which incorporated compositions by Bracewell, Kate, and Slater. The captions were developed by designers George Thomas and Lloyd Mst as

moving typographic animations, which translated the tempo and ambience of each composition. Consistent with ‘access as a collectively held space’, the descriptive vocabulary sampled in the caption videos was drafted through a collaborative writing process, with varied team members proposing poetic phrases based on our subjective interpretations of specific sounds.

To create the animated videos was time-intensive, so though achievable for all the pre-recorded sound design, an alternative approach was needed for the captioning of live sounds. Key sections of the show featured improvised solos by Bracewell, who knelt on a wooden platform, live mixing samples of quasars and pulsars, and live composing ethereal solos by manipulating feedback from her current and retired hearing aids. I wanted the live captioning to convey the dynamic shifts that occurred, with poetic and subjective authoring.

Lloyd Mst led the creation of a web-based tool that enabled instantaneous web-cast of ekphrastic descriptions of Bracewell’s sounds. During each performance, Mst listened attentively, freely drafting descriptions in a text editor, or selecting from a pre-loaded bank of descriptive words and phrases, including words sourced from collaborative listening and writing process during rehearsals. Using this web tool, Mst was able to choose font and background colours to convey mood and emotion and live publish to screens mounted along the edges of the tactile stage design. For example, on a rectangular field of soft mid-brown, he published pale lavender words on a dark chocolate background that read:

[warm. Still. Hushed. A blanket holding space].

In another sequence, on an olive-green field, cream words on a plum background read:

[TENSING and quavering emerging and dispersing]
[cane softly breathing].

Each of the five live performances was audio described by a shifting cast of trained and untrained describers, who were invited to interpret what they could see, as well as what was obscured from their vision, following the principle of ‘abundant subjectivity’. The describers stood at the stage edge, passing a microphone back and forth, following a simple choreography that indicated when a person felt moved to speak, or when describers wished to move to observe from a different location around the stage edge. Jon Tjhia led the training of describers, and also a protocol for recording descriptions each night. Excerpts sampled from his transcript of the recordings of the final audio-described performance illustrate the breadth of interpretation:

Rosemary: A moment ago was very dramatic, and now there’s a feeling of peace.
Rachel: *It feels like everyone can breathe... Georgina turns towards her wall of flowers...*

- Jon: ...*Kaleidoscopic flower figures pince outward like a crab in defence.*
- Rachel: *Looks like sea creatures. Snapping, opening, closing: there's a rhythm like my heartbeat...*
- Nilgun: *And these stamens, they're fluttering like they've just had a compliment and they're blushed...*
- Rosemary: ...*Captions in bold font, in brightly coloured screens overhead. The pulsing circulates the body of the room...*

Tjhia mixed the recorded audio descriptions from each performance with the base sound design to create a digital radio season, which he broadcast two weeks after the live season. In addition to echoing the radio play ambitions of Project Communicator, the audio descriptive broadcasts conveyed the performances to distant audiences. The final broadcast was presented as a streamed audiovideo work that experimented with bringing together the pre-recorded and live caption screens from that performance, alongside captioning of the audio describers' impressions. Similar to Goidell's *To Catch a Thing in Flight*, this streamed video provided a common entry point for collaborators and blind and deaf audiences to experience the ekphrastic work.

A review of the show in the Sydney Morning Herald concluded:

... A darkened studio looks for all the world like a '60s sci-fi TV set, as do the quartet of hypnotic performers' costumes. You can circle the space freely, observing them inhabit the spirit of season three episode *Is There in Truth No Beauty*, don headsets and listen to live narration, or read zingily poetic closed captions on a giant screen and its smaller satellites. Ethereal music and interstellar eruptions are felt in reverberation. A trippy, immersive piece, it opens with a reminder: space exploration requires a highly designed environment, so it should be accessible to all.

The framing of the stage show in relation to space exploration – including weaving excerpts of a conversation between Slater and blind AstroAccess Ambassador Sheri-Wells Jensen – reinforces arguments I have made previously. In d'Evie (2022), I described a series of experimental publishing works, that sought to communicate with post-human, alien audiences, including illustrative interpretations of Seymour's gestural poetic phrases, which I carved into bluestone. As explored in that brief essay, expanding our perceptual and sensorial imagination is not only necessary when anticipating the unknown physiology of extraterrestrial audiences, but also 'doubles as a strategy for disability justice in the present moment, inviting beyond-normative encounters within the contemporary museums and galleries'. I mention this point in response to museums that invest in access programming most intensively for disability – or sensory-themed exhibitions; my experience is that creative access can be untethered from these contexts. From the 1970s, science fiction to speculative futures, from deep time to more recent historical

movements, from poetry and literature to abstract painting, I have found that there is vast scope to innovate access as an ethos of welcome, and a catalyst for creative experimentation.

Conclusion

Consistent with my commitment to access as a platform for generosity, this chapter has introduced methods and principles that I offer for adaptation to suit the fluctuating, temporary scenarios that reader may encounter in specific museum contexts and communities. Rather than operating as blueprints, I suggest the methods and practical examples may be most useful to spark conversation, and imagination, about the possibilities for an expansion in welcome. Beyond the few approaches introduced here, I have been working in an iterative way with a constellation of other creative experiments towards enhancing access. Methods not detailed here include strategies for balancing sensorial abundance with moments of pause, as well as creating opportunities for intimacy within complex, sensorial installations, to counter the potential for overwhelm. I note these other threads to underscore the provisional nature of this conclusion, and to close with an invitation that foregrounds openness rather than closure: ‘Let us imagine your museum as a site that welcomes public and staff alike to blunder into a dustcloud of sensorial improvisations, translations, and conversation’.

Summary

- Access can be approached as disability-led, creative practice with the potential to innovate artistic, curatorial, publishing, and public programming practices.
- Access that is conceived as a platform for generosity and welcome can be responsive to fluctuating contexts, and deliver an expansion in public engagement through participatory methods.
- Access as intersensorial creative practice has the potential to radically expand the experiential and interpretive potential of artworks, exhibitions, and sites.

Biography

Dr Fayen Ke-Xiao d’Evie is an artist, publisher, and lecturer in communication design at RMIT University. Her life experience of fluctuating vision, including extreme myopia, retinal detachment, cataracts, and ocular migraines, has spurred creative research into blindness as a critical and imaginative position. Her projects are often collaborative and resist spectatorship by inviting audiences into intersensorial readings of artworks and texts. She is a co-founder of the Access Lab and Library, which approaches access as a platform for generosity, and a field for experimental creative practice. Fayen is on the Board of Directors of the Australian Centre for Contemporary Art.

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SECTION 3

Social and cultural inclusion



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8

SOCIAL AND CULTURAL BARRIERS TO INCLUSION

Class and race at the Bethnal Green Museum of Childhood

Dr Charlotte Slark

This chapter will explore the origin and impact of a visitor survey carried out in 2007 by the UK V&A Museum of Childhood (MoC). This survey aimed to identify the barriers preventing working-class and ethnic minority people from engaging with the museum. Drawing on survey results and reports from the MoC archive and supplemented by interviews (conducted in 2021–2022) with former members of MoC and V&A staff, this chapter will use the MoC as a case study to examine whether this survey was indicative of a sector-wide shift in attention away from traditional wealthy white middle-class audiences, towards a more inclusive focus on broadening participation. The chapter will argue that this interest in class and race did not necessarily herald a new age of accessibility in the museum sector but instead, it reflected a moment of time where social inclusion was valued by government and subsequently funded. It will consider what this means for systemic change going forward.

The MoC is a branch museum of the Victoria and Albert Museum (V&A), a national museum of design in the UK, situated in South Kensington, a highly affluent area in the West End of London. The MoC (or Bethnal Green Museum as it was initially known) opened in 1872 as a way to share the V&A's impressive collections with the 'cultural desert' of the East End. While this might seem like a very early attempt at broadening participation, the V&A was much more motivated by the potential for offsite storage space than they were about making the collections accessible to the 'haggard paupers' of East London (Ross, 2007, p. 30). After slowly building up a collection of toys and childhood paraphernalia, the Museum was rebranded as the MoC in 1974. Following a planned temporary closure in 2020, they reopened after an extensive renovation in July 2023 as Young V&A. This chapter discusses work carried out when it was the MoC, it will be referred to as such throughout this chapter. While working class and ethnic minority engagement

was always a more central concern of the MoC than of its parent museum (or the other cluster of national museums situated in South Kensington, London), exactly because of the location of the museum in an ethnically diverse and working-class neighbourhood, the timing of the 2007 report coincided with a larger shift towards access and inclusion in the UK museum sector.

Debates around access in museums started in earnest in the late 1980s with the rise of the so-called 'New Museology' (e.g. Lumley, 1988; Vergo, 1989). The 'old' museology focused heavily on the methods used in museums, the 'new' museology put more of a focus on the purpose of those museums (Vergo, 1989, p. 3). This new focus on the purpose of museums raised questions about who museums were for and subsequently aimed to push museum professionals away from being just caretakers of objects to considering who had access to the collections. In the early years of the new museology (the 1980s and the early 90s), conversations around access largely focused on highlighting the need for museums to prioritise the needs of the – largely at this point undifferentiated – general public over the small group of privileged elites who had previously been the core audience of most museums (Saumarez Smith, 1989; Wright, 1989). In other words, it was a broad push to broaden participation, without any focused consideration of the individual needs or interests of particular subgroups within the non-attending public.

In the UK, this interest in audience was not happening in a vacuum and instead was a reflection of the anxiety felt within the heritage sector over the threat to their funding. In the 1980s, museums were confronted by the ideology of the then Prime Minister, Margaret Thatcher, private enterprise. Museums were expected to become increasingly self-financing. Hooper-Greenhill (1999) argued that this threatened the previous certainties of the post-war funding landscape, in which UK museums had received generous government funding with little to no accountability. By the 1990s, these same museums were expected to provide justification for increasingly shrinking funds. In order to make up the shortfall, museums suddenly needed to know how to attract paying customers. Unfortunately, in the early days of the new museology, it was rare for museums to know more about their visitors than merely how many of them came through the doors each year (Hooper-Greenhill, 1988, p. 214).

While museums were thinking more about who was visiting them and why, they did not start to seriously consider who was not visiting until wider political imperatives made it essential that they do so. From the late 1990s, the New Labour government introduced Department of Culture, Media and Sport (DCMS) funding targets for museums tied to their wider agenda on social inclusion and their ideas about what they were calling 'cultural calibration' – whereby museums, archives, and libraries could and should have a vital role to play in society (Hein, 1998; Black, 2005; Hooper-Greenhill, 2007). Partly in response to research coming out of the museum sector (see, for example, Anderson, 1999), museums were no longer allowed to be mere 'focal points for cultural activity' but were instead expected to act as 'agents of social change' in the community, helping to combat social

exclusion nationwide (DCMS, 2000). However, museums could only become ‘agents of social change’ if all sectors of society were engaging with them. At the dawn of the new millennium, museums in the UK were starting to think about the class and race of their visitors in ways they had never before. Thus, the interest in access and inclusion was largely motivated by British government policy rather than being spearheaded by museum organisations (such as the Museums Association in the UK). Interestingly, a decade later a similar focus in the US was driven by the American Alliance of Museums (Moore, Paquet and Wittman, 2022).

Class and race at the MoC

Bethnal Green, where the MoC is located, is in one of the most deprived boroughs of London (Trust for London, n.d.). The area has a long and complex history of immigration and for much of its history its residents have also been predominantly working class (see, for example, Ross, 2007; Marriott, 2012). It is important to note that class and race intersect with each other, and they intersect with other identities such as gender, sexuality, and disability. Structural discrimination often has financial implications, as such discussions about class and race in the East End of London are often intertwined (see McGrath and Chynoweth, 2021). Although there may have been more awareness of the different demographics of the MoC’s local communities, they were not highly valued for much of its early history. The ethnically diverse and/or working-class local community has had a negative impact on the way in which the MoC has been viewed and valued by its parent museum, its own staff, and the general public, which subsequently impacted how the MoC has developed (Slark, 2023).

An effective way of gauging how the MoC viewed its audience in terms of race and class over time is by examining both what and how questions were asked in visitor surveys that were conducted at the museum. There were six visitor surveys conducted between 1984 and 2007. Up until the 2007 survey, all dealt with class and race on a very superficial level – often with a tick box question offering a reductive view of class and race – in either the questionnaire itself or the analysis presented in the accompanying reports.

The early surveys at the MoC also did not always offer participants a chance to self-identify. The earliest survey relied on the visual assessment of participants’ ethnic background by student researchers. (London, V&A Collections, VA55 84/1873, ‘Bethnal Green Surveys’ – Adults, p. 6) This not only gave data collectors the power to assign racial identity (something that would now be understood as inappropriate), they also required those researchers to classify everyone into a very small number of reductive ethnic categories.

Race was not remarked upon at all in the article published on the results of the 1984 survey (Gardiner and Burton, 1987). In the 1995 survey, conducted by MORI (Market and Opinion Research International – a market research consultancy), data around ‘Ethnic Origin’ was collected. However, it was not reported in

the ‘Profile of Visitors’ summary. This was despite this summary being otherwise comprehensive and covering nationality, gender, location, class, size of party, age of child visitors, rate of repeat visits, and even mode of transport used to get to the MoC. It is not until 179 pages into the report that one is able to determine that visitors to the MoC in 1995 were 91% white, 5% Black-Caribbean, 1% Black-African, 1% Chinese, and 2% other ethnic group. There were two respondents who identified as Indian and one as Bangladeshi, figures which were too low to be included in the breakdown by percentage. These numbers do not represent the demographics of the communities surrounding the MoC: 64% white, 23% Bangladeshi, and 23% other according to 1991 census data. Taken together, the low prioritisation of data around ethnic identity and the failure to acknowledge the fact that the museum visitors were not representative of the ethnic identities of the local community demonstrate the low importance placed on such information by both the MoC and MORI.

The class background of respondents was treated much the same way as race. Respondents to most, but not all, of the visitor surveys were asked about the occupation of the household’s chief income earner and this was used to determine respondent’s class identity. An omnibus survey, undertaken as part of a 2000 Visitor and General Public Review went a step further and asked how many cars households had or what their highest obtained educational or professional qualification was (MORI, 2000, computer tables p. 51). Interestingly, from a cultural capital perspective, the 2000 survey also asked respondents which newspapers they read (MORI, 2000, questionnaire p. 8). This question was then reprised for a survey the following year, which subsequently presented the results in terms of broadsheets versus tabloids (MORI, 2001, p. 58). Very little was said about class in the written reports, however, other than remarking that visitors to the MoC predominately fell into the middle and upper classes (75% of visitors in 2001 fell into the middle- and upper class category of the National Readership Survey [NRS] scale). The report did not give any information on the class breakdown of the local area but noted that the MoC had a higher percentage of lower-class visitors than the other museums and galleries which had been surveyed by MORI – 22% versus 16%, respectively (MORI, 2001, p. 58).

Arguably, the lack of focus on race and class in the 80s and 90s reflects the fact that the MoC’s diverse local audience was not highly valued at an institutional level. This changed however when the New Labour government’s DCMS targets made broadening participation central to the funding agenda, the MoC’s audience became more desirable. This, in turn, changed the way that many at the V&A and MoC viewed the importance of access and inclusion.

Changes in the MoC

Running concurrent with a major shift within the political landscape in the UK, in 2001, Diane Lees was brought on as director in order to ‘shake things up’ at the MoC (Diane Lees, interviewed by Charlotte Slark, 5 March 2021). Unlike previous

directors – who had all worked at the main V&A and had been art historians by training – Lees came from the independent museums sector, which she argues was ‘much more audience focused’ (Burton, 1999; Diane Lees, interviewed by Charlotte Slark, 5 March 2021). From the introduction of Lees as museum director, staff at the MoC started to seek answers to the question of why working class and/or people from ethnic minority backgrounds were apparently not visiting the museum. The starting point was a community strategy report in 2001, which led to the creation of a new Community Development Officer role. It was filled by Teresa Hare-Duke, who led the Community Development Project. This was largely outreach focused and based in the community. This was mostly because there was no real space in the Museum for what Hare-Duke wanted to do but also it was part of a concerted effort to reach people who were not visiting the MoC (Teresa Hare-Duke, interviewed by Charlotte Slark, 30 April 2021). It is within this context that the 2007 survey was commissioned.

Something for each imagination’

In 2007, the MoC commissioned the Insight and Strategy consultancy Morris Hargreaves McIntyre (MHM) to undertake qualitative research with ethnic minority and working-class families in order to better understand those groups and their perceptions of the MoC, barriers to visiting the MoC and museums in general, and how the MoC might deepen engagement and attract more visitors (Morris Hargreaves McIntyre, 2007, p. 5). This research was published in the 2007 report ‘Something for Each Imagination’: Qualitative Research with BME and ‘Something for Each Imagination: The Museum of Childhood Qualitative Research with BME and NS-Sec 5-8 Visiting and Non-Visiting Families’. ‘Something for each imagination’ was the first of the MoC surveys to use the term ‘Black and Minority Ethnic’ (BME). This term is now considered outdated because it does not take into account the vast cultural differences and experiences of the many people covered by such terms (Hylton, 2006), I will use this term as it was used within the 2007 report but acknowledge the problematic generalisations within it. This survey was a large step forward in terms of focus. Not only did it centre the previously ignored local audience of the MoC, but also it crucially surveyed people who were not already visiting the museum.

The use of the classification of ‘NS-SEC 5–8’ as a means of identifying class background was also a positive development. This classification came from the UK NS-Sec for determining class background rather than the NRS scale favoured by previous MoC surveys. The NRS was initially used to conduct audience research for newspaper readership based on questions about sex, age, region, and a range of other demographic and lifestyle characteristics that were used to determine social capital. The NS-Sec classification is based on the work of sociologist John Goldthorpe and takes a detailed exploration of employment status and occupation for determining class. The NS-Sec schema offers a more nuanced understanding

than the NRS, although it should be acknowledged that the sole focus on occupation does not naturally lend itself to an intersectional analysis of class (Savage, 2015, p. 40). The NS-sec schema has been in use by the UK Office for National Statistics (ONS) since 2001 (Office for National Statistics, n.d.). The shift to the NS-sec in 2007 arguably hints at how seriously staff at the museum were considering the class demographic of their audience. Despite their new role as ‘agents of social change’, museums were still trying to catch up to a society that was shifting around them (DCMS, 2000).

Given that class and race had been so neglected in previous audience research at the museum, the motivations behind an entire questionnaire devoted to examining and understanding why those groups were not visiting the MoC needs to be understood in the context of wider changes at the museum brought about by sociopolitical imperatives that arose from the shift from a Conservative to Labour government.

As part of the report, MHM ran four focus groups in September 2007 with four different groups (the report does not give details for how many participants took part in the research). Group 1 was BME families who currently visit the museum, group 2 was BME families who don’t visit but would consider it, group 3 was NS-SEC 5–8 white British families who visit now, and group 4 was NS-SEC 5–8 white British families who don’t visit but would consider it (Morris Hargreaves McIntyre, 2007, p. 6). Although they were mostly exploring the barriers to attendance among non-visitors, MHM thought it would be helpful to also talk to current MoC visitors what their experiences were so that:

...We would be able to better understand what works well, and therefore could encourage others to visit, as well as looking at how the museum could improve the product and their communications to persuade non-visitors to visit.

(Morris Hargreaves McIntyre, 2007, p. 6)

It is interesting to note here that they did not take an intersectional approach to class and race. When they are talking about NS-Sec 5–8 in their report, they are exclusively talking about white working-class people, and there does not seem to be any attempt to determine the class background of any of their ethnic minority respondents. Nevertheless, in reporting the findings, MHM do acknowledge that the responses of ethnic minority families ‘...to what the museum has to offer now, and what they would like to see more of in the future, was the same as the NS-SEC 5–8 groups’. (Morris Hargreaves McIntyre, 2007, p. 6).

MHM’s report relied on the transcriptions of the four focus groups but also drew on research that they had done across the wider sector, particularly when discussing the motivations of visitors for visiting the MoC. Many of their findings highlighted concerns that were not unique to the class and ethnic backgrounds of the participants. Respondents wanted clearer listings of activities in leaflets – ‘what the activity is, when it is (day and times), and what age group it is applicable for, ideally

this information would be “at a glance” – or just more information on what was actually on show at the museum’ (Morris Hargreaves McIntyre, 2007, p. 18). One of MHM’s suggestions on how to address this was to make the activities clearer in leaflets, which would undoubtedly have made a difference to all visitors regardless of class or ethnic background. However, they did also suggest that the MoC considers the idea of producing ‘What’s on’ information sheets in different languages such as Bengali as an active step to facilitate further participation from particular communities local to the museum (Morris Hargreaves McIntyre, 2007, p. 9).

Nevertheless, there were some key issues identified that were specific to low-income and marginalised groups. Many of the respondents made comments that touched upon themes of stuffiness or unfriendliness – although it was often noted that the MoC was not actually stuffy or unfriendly, just in danger of being perceived as such (Morris Hargreaves McIntyre, 2007, pp. 16, 46). This should not have been a surprise. A report published in 1998 had found that there was an image of museums, common across all ethnic groups, of an old building with an imposing appearance which was seen to be unpleasant and exclusively for intellectuals and posh people (Desai and Thomas, 1998).

Another key issue was the cost associated with a museum visit. The report acknowledged that one of the significant benefits of the MoC was that it is ‘accessible and local’, and that visitors can make spontaneous visits knowing that it will not cost them much money and does not require much planning (Morris Hargreaves McIntyre, 2007, p. 27). The fact that the MoC had no admission charge was undoubtedly a draw for respondents (Morris Hargreaves McIntyre, 2007, p. 28). However, Black (2005) argues that while high admission charges are often given as a reason for low attendance of people from working-class backgrounds, admission fees are only a small part of the costs associated with a museum visit (17%), the other 83% is travelling expenses, food, drinks, and sometimes accommodation costs. This was confirmed by the ‘Something for Each Imagination’ survey: one NS-Sec visitor is quoted as saying ‘I resent paying £4.50 for a little thing of macaroni cheese for me kids’ and a few respondents are noted as ‘dislik[ing] the fact that the shop is so accessible at the start [because] they have to be prepared to steer the children away from that area’ (Morris Hargreaves McIntyre, 2007, p. 45). Despite this, some of the respondents did comment on the affordability of the gift shop (Morris Hargreaves McIntyre, 2007, p. 45). Given this, it is interesting that as part of its reopening as Young V&A in 2023, the museum has introduced admission fees for their temporary exhibition programme for the first time in the museum’s history, although general admission does remain free (V&A, n.d.).

In their report, MHM raised the concern that many people from ethnic minority backgrounds might not see themselves or their childhoods reflected in the MoC galleries (Morris Hargreaves McIntyre, 2007, p. 21). This was not a new concept for the MoC. The 2001 MORI survey had already questioned whether the local community was represented within the MoC’s gallery displays. The 2001 survey, carried out by the market research agency MORI, comments that ‘The visitor

survey showed that two in five [respondents] thought that the collection focuses on a western, white culture and does not represent the history of other cultures' but went on to argue that 'it must be borne in mind that the majority of current visitors are from a western, white culture' (p. 28). Implying, whether intentionally or not, that while other cultures were not represented in the galleries, the MoC was at least representing the vast majority of their – white – visitors at that time. MORI does at least provide a suggestion for changing this, with one of their comments in a section titled 'the way forward' being to 'Move with the times, focus on childhoods of the present, particularly multicultural childhoods of the present' (MORI, 2001, p. 101).

This was not unique to the MoC. The V&A had decided to focus on highlighting objects related to the African diaspora after noticing that their own MORI surveys had shown how few of the Museum's visitors were Black. The V&A had previously assumed that there were few objects relating to the African diaspora in their collections, but Nightingale's research showed that they did in fact have more than 3,000. This could be attributed to her assertion that before this 'they thought... collections south of the Sahara Desert were not art' (Eithne Nightingale, interviewed by Charlotte Slark, 22 March 2021). A lot has clearly changed in the intervening 20 years. For example, the Maqdala collection (a series of objects from Ethiopia looted by the British Army during the 1868 Abyssinian Expedition) was heralded for the fine craftsmanship of the objects and was subject of a special temporary display in the Silver Galleries of the V&A in 2018, marking the anniversary of their removal (Hunt, 2018).

Following the 2001 survey, staff at the MoC had also started working towards addressing the lack of representation in their galleries, in large part with the World in the East End (WitEE) project (2005–2009). The WitEE project collected and displayed tangible and intangible heritage related to the histories of the Museums' diverse local communities. Although the project was first conceptualised in 2002, it officially started in 2005 as part of the V&A's wider Heritage Lottery Fund (HLF) funded Capacity Building and Cultural Ownership project (Begum, 2010; Nightingale, n.d.). This fits with wider trends, in the UK, of accessibility projects being funded externally, and short term in nature, rather than being embedded into the core institutional budget. The WitEE project was largely considered a success. The approach was popular with visitors to the museum and had a demonstrable effect on what was then referred to as 'BAME' (Black, Asian, and Minority Ethnic) visitor numbers to the MoC, rising from 36,100 in 2001/2002 (a figure which made up 20% of all visitors) to 95,700 in 2008/2009 (29%). However, reflecting an ongoing problem in the UK sector, after the HLF funding had finished and WitEE project came to an end, and collections were integrated back into the wider galleries in 2009, 'BAME' visitors dropped back down to 21% (69,100) (Nightingale, n.d., p. 99).

The MoC Community Development programme also included larger scale events, such as festivals, which became common at national museums around that

time (See for example Tate, 2005). There were also projects working with refugees or local women who wanted to improve their English-speaking skills. Community engagement projects at the MoC were spearheaded by a group of committed individuals based at both Bethnal Green and South Kensington; however, their efforts were only made possible to a certain extent by the wider cultural and political context. The push for widening participation and multiculturalism by the New Labour government through DCMS targets made diversity and equality projects more attractive at a wider institutional level and the availability of external funding, such as from the HLF, demonstrated that such projects were politically endorsed. After all, what is valued is funded.

While the focus on broadening participation in UK museums in the 2000s could be seen to be precursors to the current drive towards decolonisation of collections, I would argue that interventions, such as the ones undertaken at the MoC, were instead working within the context of the New Labour agenda surrounding multiculturalism. Despite presenting itself as ‘post-colonial’, with multiculturalism the focus was strongly on assimilation and ‘British values’, and as such, it was very much working within a colonial framework (Leonard, 1997). This is illustrated by attitudes towards the collections at the MoC. Events and temporary displays were used to increase representation, but little was done to change the permanent galleries – a practice which Nasrat Ahmed, curator of the South Asia Gallery, Manchester Museum (UK), has referred to disparagingly as ‘Diwali and done’ (Ahmed, 2023).

A new age of inclusion?

‘Something for Each Imagination’ clearly marked a shift in the way that the MoC was thinking about who was not visiting them and why, a shift which was also being reflected in the wider museum sector. While the very existence of such a report in the UK museum sector at that time could be seen as innovative, the value of the research should be questioned. It features only four focus groups, with an unreported number of participants, and fails to consider the intersectionality of class and race. The timing of the survey and its somewhat obvious findings do mean that it is debatable how much of an impact ‘Something for Each Imagination’ had on the MoC. The MoC already had a well-established and, arguably, successful community development programme by 2007 – only three years before a Conservative-led coalition government replaced the Labour government, which would herald a dramatic change in funding priorities.

The extent to which interventions such as the ‘Something for Each Imagination’ report, the WitEE project (2005–2009), and wider community development projects created truly inclusive museums is debatable. These interventions came about in response to a moment where widening access was a priority both governmentally and, as a result, institutionally in the UK. This allowed museum staff to access funding for projects such as WitEE. However, despite the proven effectiveness of the WitEE project at broadening participation among traditionally underrepresented

audiences, the gallery was dismantled in 2009 when the project funding ended, and there was no one left to advocate for its importance (Begum, 2010). This is a much wider and ongoing issue across the museum sector in the UK. So much so that 2022 saw the creation of the *Dead Dreams Club*, an online space for remembering much-loved museum projects that have fallen by the wayside after being defunded, ‘abused and misused until it is no longer what it was meant to be’ or abandoned after the project’s champion has left the institution (Dead Dreams Club, n.d.).

Conversations around access in museums have also moved on from just thinking about who is visiting museums to include who is working in them (McGrath and Taylor, 2022). The 2018 report *Panic! Social Class, Taste and Inequalities in the Creative Industries* has shown that people from ethnic minority and/or working-class backgrounds are still woefully underrepresented in the museum workforce in the UK, especially in upper-level managerial roles (O’Brien, Brook and Taylor, 2018). The follow-on publication, *Culture is bad for you*, found that there is a combination of factors which contribute to the lack of diversity in the workforce, ranging from social inequalities experienced from childhood onwards to the low pay and short-term contract endemic in the sector (Brook et al., 2020). Work is being done in the UK to try to address this from within the museum sector. Support and advocacy groups, such as Museum Detox and Museum as Muck, are working hard to raise awareness of the lack of representation of people of colour and working-class people in museums while offering support to those who are already there. It is important to note that there is a lot of cross-over in membership and allyship across the two groups, which also extends to members of other marginalised groups in museums (McGrath and Chynoweth, 2021).

There are also innovative projects taking place in museums which seek to work in a genuinely collaborative way. The National Science and Media Museum, Bradford, have implemented a project entitled ‘Bradford’s National Museum’, which involved 150 community members in an exploration of how they could become locally rooted, open, engaged, and collaborative. There has also been an acknowledgement from some museum leadership that visitors from minority backgrounds need to see themselves represented in ‘all programmes, audiences and teams’ (Casely-Hayford, 2023).

These interventions largely rely on the work of passionate individuals from working-class and/or ethnic minority backgrounds and their allies. This emphasises the importance of having a richness of lived experiences within the museum workforce. However, the burden of decolonising collections and ensuring a wider representation in exhibitions shouldn’t be placed uniquely on the individual shoulders of museum workers, volunteers, and collaborators from minority backgrounds. Without institutional support, these projects run the risk of being performative at best and exploitative at worst. This is particularly the case for so-called ‘decolonialising projects’ which are not actually given the agency to dismantle existing colonial structures and hierarchies within the museum (Minott, 2019). It is not enough to survey the people who are not visiting museums and rely on short-term projects

to promote access, it is time to include working-class and/or ethnic minority people in decision-making in museums in order to make museums truly inclusive spaces.

Museums started to think about who was visiting them and why as a result of the ‘New Museology’ in the 1980s. While this growth in theory led to an increased professionalisation of the sector, which, in turn, helped to embed audience research into museums, museums in the UK did not start to think seriously about the class and race of their audiences until wider government imperatives made it impossible for them not to do so. The government’s interest in museums as agents of social change was informed by museum theory, but it was government policy – and targets linked to funding – which motivated museums to act on an institutional level. In large part museums’ changing attitudes towards access and inclusion in the 2000s could be seen as reactive rather than proactive.

When government attention, and subsequently funding, ended so too did the institutional support for many of the access and inclusion projects. This was certainly the case at the MoC. Despite the 2007 survey showing a need for increased working class and minority ethnic representation in the galleries, the WitEE project – which did just that, along with demonstrably improving visitor numbers from previously underrepresented groups – was disbanded only two years later when the funding ended.

The UK museum sector is now slowly starting to see a more museum-led approach to access and inclusion – more in line with what is happening internationally – with an increase in co-creation projects and more embedded understanding of the importance of representation at all levels of museums. Despite this, museums are still largely inaccessible for certain people, especially at a staffing level, and accessible projects and interventions often rely on the labour of people from minority groups. However, there are innovative networks and initiatives within the sector which are currently seeking to shift the conversations around community, class, and race in museums from access to inclusion.

Summary

- Museums in the UK started to think about access as a result of the ‘New Museology’ of the 1980s which called for museum professionals to think beyond the privileged elites who had been the accepted target audience for most museums.
- Museums in the UK started to think seriously about class and race in response to shifting government imperatives tied to funding. This heralded a period of intense interest in access.
- The MoC did a lot of community-based work during this period but it was dependent on short-term external funding. A change in government saw a steep decrease in the availability of such funding.
- Today access and inclusion initiatives in the UK are more sector-led, in line with what is happening elsewhere in the world, but often rely on the emotional labour of museum workers, volunteers, and collaborators from minority backgrounds.

Biography

Charlotte is neurodiverse, with dyspraxia, and comes from a working-class background. She is a white, cis-gender woman. Charlotte grew up in a low-income single-parent household but in a wealthy country and has had access to museums throughout her lifetime. She is an interdisciplinary scholar who uses both social science and humanities methodologies to examine museums as institutions, with a particular focus on access and inclusion. She came to academia from the museum sector and has experience working both back and front of house at different museums in England. Charlotte is currently a post-doctoral research fellow in Psychology at the University at Westminster working on the Sensational Museum project.

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9

GOING THROUGH THE PORTAL

Permeable walls and immersive community engagements rooted in disability justice

Dr Syrus Marcus Ware

Disability justice is blossoming everywhere – the seeds of a freer future world are being watered by a community of activists and artists interested in transforming our social world into one that is more liveable for all of us and in which we are all rendered inherently valuable. As a disabled and Mad (a reclaimed term common in Turtle Island/North America referring to people labelled with mental health diagnoses) artist, I've been interested in the ways that disability justice shows up through disability arts practices in museums, galleries, and creative spaces. In this chapter, I will consider the creation of three exhibitions created in the past four years that bring disability front and centre and roots in disability justice organising and activism here in Tkaronto/Toronto, on Northern Turtle Island (colonially known as Canada). These three projects have allowed me to consider love, migration, community, climate justice, trans justice, and Black liberation through storytelling and performance. These projects allowed me to talk through colonialism, white supremacy and to address the race wars plaguing our communities. Through this research, I've learned that activists are primed to dream up new futures, and that this future will be full of Mad, crip brilliance – if we dare to dream that possible.

All that you touch, you change. All that you change changes you...The only lasting truth is change.

– Octavia Butler (*Butler, 2012*)

The mother of speculative fiction, Octavia Butler, wrote these words in her books *Parable of the Sower* and *Parable of the Talents*, which tells the story about a world (and its many systems – such as the economic system, ecosystem, healthcare system) going through a period of change or metamorphosis.¹ I've been drawn to her stories of change and hope and despair and possibility and of queer disabled

futures. I was really interested in this idea that we could couple a Butlerian lens – tied to speculative fiction – with an understanding of systems-thinking to consider where we are societally, during this current moment of social upheaval and change-making. I'm interested in Sankofa, in the idea that we can go back to the past to understand our present in order to know where we're going in the future. This knowledge comes from the Ashanti people in Ghana and is supported by scientific research. Research on autobiographic memory suggests that our past memories help influence how and in what ways we play for the future (Gadassi, 2020). I'm interested in rooting our Black queer futures in an understanding of the past, and am curious about what might happen if we leaned into wild futures full of more freedom than we have dared dream of. Butler suggested that change would be the only constraint in the future. She offered speculative fiction as a way of understanding the world we are emerging into. In Octavia's Brood (Imarisha, 2015), Walidah Imarisha says that, 'All activism is speculative fiction', all of it, because we're daring to dream that another world is possible. She says,

Whenever we try to envision a world without war, without violence, without prisons, without capitalism, we are engaging in speculative fiction, all organizing is speculative fiction. What better venue for organizers to explore their work than science fiction stories?

I knew after reading this that I had found my home in speculative fiction. I wanted to make speculative fiction work that dared to dream of new possibilities for our world. I drew on this idea of systems change and the possibility of creating a new world together. I thought of Adrienne Marie Brown's assertion that speculative fiction was a way of 'practicing the future' (Brown, 2017). I wanted us to practise a future together, through my creative practice. I started to think of the seeds we were planting for a freer future and began to think of mycelial networks and spores also being planted in the seeds of change. Rebecca Solnit (Solnit, 2016, page 195) said,

After rain, mushrooms appear on the earth as if from nowhere. Many do so from a vast underground fungus that remains invisible and unknown. What we call mushrooms, mycologists call, "The fruiting body of the larger, less visible fungus." Uprisings and revolutions are often considered to be spontaneous.

(Solnit, 2016, page 195)

What would it mean to see revolutionary action as part of a larger interconnected series of uprisings that together could bring about widespread systems change? I want us to feel these words from Solnit dance across our skin. I want to breathe in these words and I want to stretch upwards like mushrooms fruiting mini revolutions spreading across communities.

Going through the portal: mushrooms, mycelial networks and disabled, Deaf, and mad interdimensional beings

In the 2022 Tangled Art + Disability solo show I created, disability was everywhere. Entitled *Random Access Memory: A Portal to the Multidimensions*, this immersive gallery show filled the space with expansive portraits, a sound room, wallworks, interactive activities, and spaces to lie, sit, and rest (Figure 9.1).

Random Access Memory was a collaboration with my grandmother, Gwen Irons, a 93-year-old artist who wrote several children's stories for me and my twin in the late 1970s. One of these stories, *The Mouse and the Magic Mushroom*, stood out in our memories. And this was no small feat – my grandmother has dementia and I have a memory impairment – we both remember little from the last 30 years, but the story of a little mouse who meets a fairy in the woods after biting a magic mushroom stood out to both of us. In the spring of 2022, we began working on this story. We had a printed copy of the story written down years ago before my grandmother's dementia. Working with this copy, we created audio recordings of us both reading the story aloud. We recorded a conversation between us about the story and its impact on our childhood – it is a story about unconditional and lasting love and safety, something she wanted to provide for us kids in our lifetimes. Based on her story, I created one of my own – a short story fragment set two centuries in the future in a meeting place of a multidimensional portal that connected various dimensions to each other – activated by the audio recordings of *The Mouse and the Magic Mushroom* story. Together, my grandmother and I planned the exhibition – we imagined that viewers would enter the gallery, and would hear the story, or watch the Black Deaf interpreted story and they, too, would take a bite of the proverbial mushroom and tumble as Alice did down the rabbit hole and into the portal space. Crossing into the gallery would mean crossing the portal and would open the viewer to an encounter with the images of a variety of multidimensional beings. We planned together.

What is memory? What is forgetting? How do we access the past and the future – maybe even other dimensions, through our memories and our intergenerational bonds?

My grandmother Gwen Irons wrote us a story full of love and hope for the future. We were the mice, and in so many ways, my grandmother was loving us, cloaking us in protection. She was whispering to the fairy in the story to help her give us good dreams for a wild future – vast and full of possibilities. Together we went back to this story and read it anew in a 2022 context. Now, in a moment when mushrooms are everywhere – sprouting fruits of future revolutions. Now when so many disabled, Deaf, and Mad folks are using the medicine in mushrooms to care for themselves. Now, when we need a portal to another set of possibilities.

And so I read the story with her. We both took a proverbial bite as Molly does, and we tumbled into this portal of multi-dimensional beings.



FIGURE 9.1 (1) A close-up of the poem painted on Tangled wall during Random Access Memory. Photograph by the author. (2) A close up of the photocollage on Tangled wall during Random Access Memory. Photograph by the author. Eight mirrored images of multidimensional beings stand and sit in the mural – all are smiling out at the viewer (3) Close-up of the photocollage on Tangled wall during Random Access Memory. Photograph by the author. Eight mirrored images of two multidimensional beings stand in the mural – all are smiling out at the viewer. (4) Gallery view of the four murals on Tangled walls, the three-black plinths holding lavender envelopes of seeds, and the piles of rich black soil on the ground around the plinths. In the middle of the gallery floor are two very large full body pillows to lie or sit down on during Random Access Memory. Photograph by the author.

In September we installed our vision. Visitors entered the accessible gallery and were greeted with a text panel translated through Deaf interpretation by a multidimensionally decked-out interpreter. Visitors then entered the story room and could sit on mushroom stools while they experienced the audio of the story being read and of our conversation. We had printouts in large print with transcripts of all audio. After experiencing the story room visitors were invited to enter the main gallery by passing through a metallic portal made up of tinsel strands. Once in the gallery visitors encountered the new story – written on the wall of the gallery and Deaf interpreted. The story read as follows:

We were once stardust, as you once were, years ago.
Before you came there to your dimension and we came here to ours.
We travel like spores falling on the tails of comets streaking across your sky.
 Two generations ago Gwen Irons wrote the story with the recipe that brought
 you here
and now that we are together there is so much we want to tell you.
Mushrooms, warm summer air, water, sun: hands in your deep black earth.
Dig deeply, get dirt in every crevasse. Feel the coolness of the soil.
Remember that you are of this earth, as much as you are stardust.
Feel the bubbles of joy in your torso, and experience the joyous sound of your
own laughter.
We want you to remember that you get to love love love yourself wholly.
We want you to remember that you get to love love love yourself holy.
And that you deserve to be free.
Rebecca Solnit said “After a rain mushrooms appear on the surface of the
earth as if from nowhere. Many do so from a vast underground fungus that
remains invisible and unknown
 What we call mushrooms, mycologists call the fruiting body of the larger, less
 visible fungus
(Uprisings and revolutions are often considered to be spontaneous)”.

Feel those words dance across your skin. Breath in these words, and stretch upwards like mushrooms fruiting- mini revolutions in the self spreading across communities.

Sylvia Plath said in her poem, Mushrooms, that “We are edible. In spite of ourselves, our kind multiplies. We shall by morning, inherit the earth”

We are all the flowering fruit of a vast underground network of change waves flowing through this multiverse. Take some seeds and cast them into the stars, plant pathways for your future generations to get to the free.

We are edible. We are together. We are free.

Lining the gallery walls were expansive wallworks: on the east and west walls of the gallery I had created mushroom landscapes mixed with muted pasted patterning

reminiscent of toile wallpaper. On the north and south walls were the brightly coloured multidimensional beings – Black, Indigenous, and white, fat, queer, trans, Mad sick, and disabled organisers and artists dressed in queer resplendency with Ankara fabrics and other nods to afrofuturism peppered through.

In the centre of the gallery were places to sit/lie down, and there was an installation of dark rich soil and lavender seed packets with wildflower seeds and mushroom spores for people to plant in their home communities.

This exhibition allowed me to dream into interconnected webs of care, like the care my grandmother hoped to provide us in our lifetimes. It allowed me to dream into a multi-verse where there were fat, Black, Indigenous, queer, Mad, sick, and disabled beings throughout its realms. This exhibition allowed me a chance to activate my community, by inviting them to plant the seeds they collected in the gallery – they were metaphorically seeding forward their own dreams for a better, more just future. As the poem on the wall tied into my story read, we were like the mushrooms bursting forth after a rain – the fruiting body of a much larger fungus – spores of revolution bursting forth into the world. People came to the exhibition daily, and thousands poured in over the all-night art event *Nuit Blanche*. Visitors spent a lot of time with the poem; this was regular feedback from the gallery.

Antarctica and MBL Freedom: or how the Toronto Biennial became an abolitionist semi-autonomous zone with portals to the future

In 2018, I was approached by the Toronto Biennial of Art (TBA) team to talk through potential projects for the 2019 inaugural biennial. I spoke about my drawing practice, and my performance artworks, until they asked me, ‘Is there any project that you’d love to work on but haven’t had the time to create?’ I knew what it was immediately – a short story I’d been writing about Antarctica: specifically about the attempted colonisation of Antarctica by The Company. Based on the real fact that 11 people have been born in Antarctica, ten of them were sent there to be born, to stake a future land claim. I wondered, in a changing future, would we ever carry out these plans for land claims/colonisation of the ‘wide white continent’, as it’s sometimes called. I wondered what conditions might drive us to Antarctica and considered if humans would ever realise that colonisation is never a good plan. The TBA wanted to support further exploration of this project, and I began dreaming up what would become a five-year creative engagement spanning two biennials, in 2019 and 2022 (Figure 9.2).

I created an immersive installation for the 2019 Biennial, with rows and rows of Antarctic rations lining huge grey metal shelving, large-scale textile works and tarps hung everywhere. Within this environment, there were three zones, representing the living quarters of three BIPOC (Black, Indigenous, and People of Colour) Antarcticans: Jessica, Marcus, and Sabian. Within this setting, we performed a 30-minute play I’d written based on my short story that explores disability and



FIGURE 9.2 (1) Close-up of Ravyn Wngz as Sabian in *Antarctica* in the Toronto Biennial. Photograph by the author. (2) Close-up of *Antarctica* rations lining grey metal shelves in the *Antarctica* installation in the Toronto Biennial. Photograph by the author. (3) Biennial Instagram ad for the play and *Antarctica* installation in the Toronto Biennial. Photograph by the author. (4) Three actors from *MBL Freedom* stand in character in white paper suits facing towards the water on a beach. The Toronto Biennial. Photograph by the author. (5) Director and film and sound crew on set behind the camera while shooting *MBL Freedom* on Toronto Island in 2021. (6) Two Ankara fabric covered geodesic domes from the set of *MBL Freedom*.

trans justice, white supremacy, climate change and climate justice. The play was set in an all-white installation, a colour scheme that referenced the cold and isolation of Antarctica, but also spoke to the white supremacy that was ever present in their world. The Antarcticans wore white paper suits; the set had stacks of blue and white Antarctic ration jars everywhere; and there were fabrics that hung from the ceiling that represented icebergs, but that also eerily looked like Klu Klux Klan robes. The immersive installation and set really emphasised the white supremacy that was fuelling further colonisation.

Performed by actors Dainty Smith, Yousef Kadoura and Ravyn Wngz, respectively, the characters exemplified several vantage points on social issues like abolition, climate justice, and when to go along with a plan, versus when to revolt. Sabian is a Black trans woman who is an activist before she comes to Antarctica's icy shores. Marcus is a Lebanese queer disabled mycologist and botanist who comes willingly to the continent because he has nothing else left for him back home. Jessica is a Black cis woman who believes she is doing what's best for her community and family back home by carrying out The Company's wishes and setting up her colony. The three become unlikely allies, and eventually beloveds as they embark on a throuple (a three-person intimate bond) relationship and plot ways to escape from The Company's grip at Sabian's coaxing. By the end of the play, the characters have set off for the one part of Antarctica not yet claimed by a continent, Mary Byrd Land (MBL), to set up a free abolitionist community rooted in justice. They each have their own reasons for going along on the adventure, not the least of which is their love for each other and hope for a future for their growing family.

The play was performed inside the installation with the audience peppered throughout the set. The audience were in the space alongside the actors, and the performance happened around the audience. In the end, several audience members came multiple times throughout the run of the Biennial and witnessed the play from different vantage points depending on where they were seated. I am left curious about this opportunity to connect with the audience in this way. I'm eager to experiment with what might be possible in a future show wherein we intentionally share different information about the storyline/plot in ways that are only audience/accessible if you are in a certain zone of the story – as a way to make site-specific experiences of the play. As a team, the actors grew close, and we joked that the throuple was on the precipice of becoming a real relationship. We all became more aware of our own positionality and its relationship to colonialism, disability, trans justice, environmental justice, and polyamorous love.

For the 2022 Biennial, as a follow-up to Antarctica, I created *MBL:Freedom*. I told the story of what happens when they decide to break free and venture to MBL to start a new community. They want to set up a world where abolition is possible, and they want to invite activists to come down to join them in a place where they all get to make it. But to the three BIPOC Antarcticans' surprise, when they arrive in this free territory, someone is already there. Even in the future, there is no such thing as Terra Nullius.

Heath Salazar took on the role of non-binary queer scientist Eugenio, the charismatic stranger the Antarciticans meet in MBL. For this set, we worked with brightly coloured Ankara and wax print textiles. There were two large multicoloured domes in the forest that they discovered off the shores of MBL. There is moss, lichen, sphagnum, life, everywhere. There are plant pots with mushrooms growing, and everywhere there is life, and so much possibility.

MBL Freedom allowed me to imagine what might be possible if we actually had space, time, availability, and resources to create an abolitionist society from scratch. The Antarciticans arrive in MBL hoping to do just that and have to put their abolitionist values to the test when they find themselves in conflict with Eugenio, the enigmatic stranger with their own plans for what to do with the territory.

In all, Antarctica and MBL Freedom are queer, poly, trans, and disability justice love stories that are rooted in abolitionist activism and dreaming. We created a film that told the story of their journey to MBL featuring the breathtaking animations of Cindy Mochizuki. The actors land on the shore of MBL, shot on Toronto Island's Gibraltar Point beach and art space, and the film follows their arrival and encounters with Eugenio.

While the original story had a different cinematic ending, we had to adjust the end of the film due to COVID in the cast. Instead of filming Jessica's labour as planned, we shifted to film self-taped monologues about abolition and their conflicts going forward. The film was shot as three-channel video work and was displayed on three TVs resting on the floor of the installation. The multicoloured dome houses were there and allowed for deep exploration – each was filled with treasures and props from the storyline that audience could pick up and engage with.

Telling this story allowed me to talk about future possibilities through the speculative fiction imaginings. MBL Freedom is an artwork, but also a type of activism because it's daring to dream that another world is possible.

Community programming was an essential part of both of these projects – we held workshops exploring emergency preparedness and how to survive the apocalypse during the 2019 Biennial in collaboration with C Magazine. Working with artists Leah Lakshmi Piepzna-Samrasinha, Rodney Diverlus, J Wallace, and activist Giselle Dias, we held four weeks of workshops exploring survival at the beginning of a new era on Earth. These workshops were incredibly powerful and took place right before the pandemic isolation period began in 2020. I received messages from most of the participants when the isolation period began, as people engaged with and began to use the skills we learned in these workshops. During the workshops, we were preparing for an unknown eventual future reality. After learning from the facilitators and roundtable speakers, including j and Leah, and the roundtable of speakers, we knew how to home can, how to prepare seeds for storage and future germination, how to be crip in an apocalypse, and how to build a future world with all human diversity in it. We grew confident in our ability to survive an apocalyptic moment, together. In 2020, we faced an apocalyptic moment with these new skills, though we were isolated, not together.

For the 2022 Biennial, we held three workshops, on the first Sunday of every Month of the Biennial. Each workshop was set at a different point in the future – starting with an abolition 301 workshop taught by Sandy Hudson and Giselle Dias, set in the year 2050. Participants arrived for the workshop and traversed a portal which brought them to 2050 and to a training centre where activists and community members were prepared for their journey to MBL Freedom. The first thing in their training? Learning the ins and outs of abolition, and how to respond differently to conflict, crisis, and harm. Held in circle format, the workshop held space for the Land, with plants and rocks sitting on chairs in the circle, and given equal time on the microphone as the rest of the participants. The second workshop was a cabaret at the end of the world – a futuristic musical and performative exploration set in 2060 in MBL Freedom. With LAL, Troy Jackson and his three-year-old son Tajali, youth Aeshna Ware-Huff, and Janice Jo Lee, the intergenerational line-up imagined future worlds not yet manifested. Lastly, we held a workshop with performances by Dainty Smith and Ravyn Wngz in their roles as Jessica and Sabian, respectively. In this session, each read lines from unseen parts of the film/storyline.

I've decided that working in speculative futures, working in multidimensional futures, these are ways that I can help people to imagine something new. To return to Bambara, these stories are ways of making revolutionary change seem so doable that we can't help but want to get involved. Creative practice is helping us to move towards another greater future – a life for generations to come after us, a promise of freedom for those next kin ready to keep seeding the future. These creative projects have offered glimpses into possibilities we get to manifest together.

Conclusion

Portals have been a way for me to invite people to step through into a new reality with me. Through the Random Access Memory project and both Biennial offerings, I have invited portals to dimensions and times where we are so much freer than we currently are. By rooting my work in disability justice, I've been able to tell stories about disabled futures, about disability Deaf and Mad lives throughout the multiverse, as a way of writing us into the future. As activists, as artists, and as folks who have been underrecognised – now is the time to scrawl notes about the future on napkins, to tell stories with friends over the bonfire, and to dream up new worlds through creative practices. We get to dream of accessible futures, and of futures wherein disabled, Deaf, and Mad people are able to thrive. These works offer potential futures for those having difficulty imagining us in, perhaps, 2050. I followed the path of human history and imagined where we might be if we didn't change direction. I've spoken to countless viewers and exhibition visitors about these three works, respectively, and I've heard back that the chance to imagine the future and to see ourselves in other dimensions created a sense of power for the viewer from the margins. Yes, there are fat people in other dimensions, yes there are trans people in the future, and yes disabled, Deaf, and Mad people get

to have full lives with complex stories and narratives. All of these get to be possible. These stories allowed me to talk about life at the end of an old system and the beginning of a new one. I engaged in speculative fiction because I was daring to dream that another world was possible (Imarisha, 2015), and this dream was generated by my organising and activism and systems change work. Revolution is possible, probably, in our lifetime. Revolution is not a one-time event but rather a process that we continue to keep nurturing over times and through ups and downs in the movements.

I will keep exploring these stories and I am in the process of writing about what happens when the free community takes shape in MBL Freedom, specifically a story about migration and travel to find hope and possibility in MBL. I look forward to continuing to dream into possible futures and planting seeds of irresistible revolutions, mushrooming eruptions springing forth from deep rich earth.

Biography

Syrus Marcus Ware is a Vanier Scholar, visual artist, activist, curator, and educator. Syrus is Assistant Professor at the School of the Arts, McMaster University. Using drawing, installation, and performance, Syrus works with and explores social justice frameworks and Black activist culture. His work has been shown widely, including solo shows at Tangled Art + Disability in 2022 (Random Access Memory), Grunt Gallery in 2018 (2068: Touch Change), and Wil Aballe Art Projects in 2021 (Irresistible Revolutions). His work has been featured as part of the inaugural TBA in both 2019 and 2022 in conjunction with the Ryerson Image Centre (Antarctica and Ancestors, Do You Read Us? [Dispatches from the Future and MBL:Freedom]), as well as for the Bentway's Safety in Public Spaces Initiative in 2020 (Radical Love).

He is part of the PDA (Performance Disability Art) Collective and co-programmed Crip Your World: An Intergalactic Queer/POC Sick and Disabled Extravaganza as part of Mayworks 2014. Syrus' recent curatorial projects include That's So Gay (Gladstone Hotel, 2016–2019), Re:Purpose (Robert McLaughlin Gallery, 2014) and The Church Street Mural Project (Church-Wellesley Village, 2013). Syrus is also co-curator of The Cycle, a two-year disability arts performance initiative of the National Arts Centre.

Syrus is a co-founder of Black Lives Matter – Canada and the Wildseed Centre for Art & Activism. Syrus is a past co-curator of Blackness Yes!/Blockorama and the Wildseed Black Arts Fellowship. Syrus has won several awards, including the TD Diversity Award in 2017. Syrus was voted 'Best Queer Activist' by NOW Magazine (2005) and was awarded the Steinert and Ferreiro Award (2012). Syrus holds a doctorate from York University in the Faculty of Environmental Studies. He is the co-editor of the best-selling *Until We Are Free: Reflections on Black Lives Matter in Canada* (URP, 2020), *Marvellous Grounds: Queen of Colour Formations* (BTL, 2018), and *Queering Urban Justice* (UTP, 2018).

Note

- 1 Indeed, these books eerily predict a 2024 late-stage capital moment much like the one we are currently living.

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10

WHAT IS A MUSEUM? REFRAMING THE POWER DYNAMIC BETWEEN MUSEUMS AND AUDIENCES

Amparo Leyman Pino

Museums have been tasked with becoming institutions that serve society, underpinned by the participation of communities (ICOM, 2022). However, this principle presents significant challenges to the ways in which museums have traditionally existed. This raises questions: are museums part of the community, or are they isolated from society? Are museums community-driven, or are they content-focused solely?

Before these challenges can be considered, it is necessary to better understand what is meant by community. Society is comprised of many communities. Community is a group of people who share common interests, activities, beliefs, among others, that provide a sense of belonging (Block, 2009). For the purpose of this chapter, the terms society and community will be used interchangeably, as we are discussing the way museums relate to society and their communities. The intent is to erase the mindset of ‘**us** (the museum) and **them** (the visitors/audience/community)’, where museums exist as an entity apart from their communities, and to offer a new way of thinking about society, its communities, and their institutions (including museums) as a whole.

This is not how community is always understood within the museum sector. The word community is sometimes used to refer to the people who do not visit the museums, the ones who do not belong to the museum: the underrepresented, the underserved, and the ones with ‘diverse’ backgrounds. Sadly, ‘community becomes code for discussing black and brown visitors’ (Moore, 2015), or low-income, disabled, immigrant, or indigenous groups, to mention a few. This notion of community excludes those who attend museums. It implicitly assumes those who attend museums are part of a special or elite group of museumgoers, who are entitled to belong to the museum as visitors, volunteers, staff, patrons, and board members. Now, the term core museum visitor is code for Caucasian/white, and in some cases ‘educated’. In other words, this discourse is perpetuating ‘us – them’.

This chapter challenges museums to reframe their understanding of their authority and role within society and their communities. It urges museums to improve the way they perceive and build relationships with their communities, so that communities in turn shift their perspective from museums being simply nice, to being necessary.

The urgency to reframe the discourse

In 2010, the Centre for the Future of Museums (Farrel et al.,) published a report called the Demographic Transformation and the Future of Museums which analysed the demographic shifts in the United States and how this will impact visitorship in museums. The report sparked conversations in the field about new ways to engage the exponentially growing so-called ‘minorities’. At the time of this report, these minority groups represented 10% of museum visitors in the United States (p. 5). The data revealed that museums are disconnected from many communities, and yet are/were comfortable doing business as usual, meaning engaging the same groups/communities. Such changes in the demographics are also a growing reality in other regions of the Global North (ONS, 2023; Vinter, 2022); therefore, society is shifting but the visitors of museums remain largely unchanged. This is despite many years of attempting to broaden participation. An exemplary organisation is the Monterey Bay Aquarium, with whom I created the Blended Language Programming to broaden and deepen their engagement with Spanish-speaking and bilingual audiences. In the Guest and Community Highlights, report (Monterey Bay Aquarium, 2019) is noticeable how the visitorship of the aquarium reflects more closely the diverse population of the State of California. The Aquarium has invested in programmes and strategies to be a welcoming place for people from every given background (Leyman Pino et al., 2019) and will continue in alignment with their mission until the visitorship reflects the demographics.

Museums are urged to analyse the way they relate to society and bring themselves up to speed to match the dynamics and evolution of the society they belong to. In other words, it is urgent to burst the bubble the museums live in, and work towards their seamless inclusion within society. It is also vital to move our conception of museums and communities as separate entities. Museums are thought of as organisations who must reach out to these external communities. This notion nurtures the concept ‘us – them’, that implies that museums are segregated from the community, and the community is not part of the museum. This invitation is to think how the museum will be *part of* the community and society, and not how to include communities to the museum. The museums have done a great job to perpetuate their elitism, instead of opening their doors to be places for the community to meet.

This is also an invitation to allow us to address the biases in our language, where those who do not come to the museum or need to be outreached are under-represented, underserved, marginalised, or a minority, among other deficit-based

terms (Ukaegbu, 2017). These terms make us think that these communities are at a disadvantage and therefore, we need to provide what they are lacking or subsidise them. Therefore, it is implied that the museum is in a position of power over these communities, which feeds the idea of superiority, authority, with an undertone of condescendence. This is a symbolic barrier that focuses the attention to the perceived deficits of these communities, feeding the idea or notion that the museum is the one who knows and is able to provide, and the others need to receive to compensate for that deficit. Museums are the ones who have alienated themselves from being part of the lives of all the communities of society and museums are the ones who need to transform internally to be perceived as friendly, welcoming, accessible, present, and places for everyone.

Understanding community

Asset perspective

Every community – whether they come or do not come to the museum – is rich in virtues, skills, values, knowledge, culture, and with a high potential to succeed. When we learn more about communities that are different to ours, it is easier to value and appreciate their assets, with an understanding that some of them are at the end *communities at-promise* (Swadener & Lubeck, 1995). When museums understand the assets, these groups have and can then see these groups as part of the museum's assets, they are able to identify opportunities for collaboration, finding ways to incorporate their members to the dynamics of the museum, participating not only from the outside-in, but also from the inside. The participation is translated as consultants, co-creators, volunteers, staff, board members, and advocates. Museums are urged to be community-centred institutions, improving their customer service, and the experiences people will encounter at the museum or beyond the walls.

Museums can undergo a process to look outwards and start analysing what is going on outside their realm. It is highly recommended to conduct a *Community Asset Assessment* (McKnight et al., 2021), which is a method for collecting information about a community, to identify the strengths, assets, and resources they have. Assessing a community's assets means identifying, supporting, and mobilising existing community resources and capacities for the purpose of creating and achieving a shared vision. In the process of doing a self-assessment, community members also identify challenges and barriers that must be addressed in order to achieve their goal of a healthy community.

Asset Maps (McKnight et al., 2021) should contain information about the people, the local associations, and institutions, as well as businesses and physical resources, that are part of the town, city, county, where the museum is located. The Asset Map reveals multiple layers of society museums should be interconnected with, these are the potential partnerships the museum could build to diversify their audiences, staff, and board.

Asset Mapping includes walking the neighbourhoods, shopping in the local stores, and trying the local cafes and restaurants, making connections, and having conversations. The conversations start to be casual and then more intentional, meaning, community members are invited to sit down and participate in a facilitated conversation where people talk about their aspirations, the most pressing concerns, thinking what is keeping the community to make the progress they want, how the museum and the community could try that might make a difference, and who is trustworthy to take action (Hastings & Leigh, 2023).

In my practice, when I conduct a *Community Asset Assessment* with museums and science centres, I try to do it in two parallel processes:

- With the staff: we map out the institutions that they know and others they would like to get in touch. We do neighbourhood walks, talk to people, observe. This exercise informs the *Asset Assessment* and allows us to identify who we can invite to have a listening session with people from the community/ies we want to learn from and engage. Staff members go through a listening training to participate in the conversations with the community members.
- With actual and potential community partners, community-driven organisations, and members of different communities (LGTB, diasporas, low-income residents, to mention a few): once the members of the community are identified and invited to a listening session/s, staff members lead this space. The goal is to learn about their habits, interests, values, and listen carefully what is important to them.

These exercises are quite helpful to understand better the communities and make the connections between their assets and what the museum or science centre potentially create with them. For example, in one of my projects with a children's museum, it was very powerful to discover how many organisations they are already connected with, yet when we had the conversation with their stakeholders, we discovered that the programmes and initiatives to connect with them were not diverse at all. This exercise allowed the children's museum to think creatively on how to cater better programmes to match the needs of the community and continue strengthening the partnerships they have. On the other hand, when I worked with a mid-size science centre, their relationships with the community were almost in-existent, a board member stepped up and invited two persons who have a lot of connections within the black and Latin-American communities to the diversity and inclusion committee, their input in the *Asset Assessment* was crucial to identify the stakeholders for the listening sessions, which was the first steps in building strong relationships with them.

Communities at-promise and their community cultural wealth

It is a reality that the Communities of Colour and Latinos – among other diasporas – struggle with oppression, and other consequences of the social inequities, in the

United States and other countries of the Global North. This systemic problem can be addressed from an asset perspective. This requires thinking about what these communities can do, what and how they do/can contribute, and foremost what can be learnt from them. This also applies to people with disabilities, or any other situation where society has created barriers to that community's ability to thrive. These members of society have so much wealth. Ukaegbu (2017) uses the term untapped, meaning, 'the presence of undiscovered invaluable resources; resources of latent potency'. In my practice, I called them at-promise, which provides a clear focus of my work carving their potential, their assets, strengths, and knowledge. 'This view does not naively dismiss the realities of circumstances. Rather it incorporates an aggressive, pro-active assets-based approach' (Rodríguez & Villarreal, 2000). It is the guiding star of my practice and how I design effective learning environments and strategies that hopefully will benefit these communities and provoke change.

A useful theoretical framework to shift the understanding of communities at-promise from a deficit perspective to an asset-based one is Community Cultural Wealth (Yosso, 2005). This framework was created to challenge the perspective of Communities of Colour and Latin-Americans in the United States and analyses the funds of knowledge they (and every community) have.

This framework is based on Critical Race Theory (Crenshaw et al., 1995), which critiques deficit theorising and data that may be limited by its omission of the voices of people of colour, shifting the centre of focus from notions of White, middle-class culture (understood as predominant, or the point of comparison) to the cultures of Communities of Colour. Yosso (2005) explains that '...community cultural wealth is an array of knowledge, skills, abilities and contacts possessed and utilized by Communities of Colour to survive and resist macro and micro-forms of oppression'. Yosso (2005, pp. 77–81) describes 6 forms of capital through which Communities of Colour nurture their wealth:

1. ***Aspirational capital*** refers to the ability to preserve the hopes and dreams for the future, even when facing real and perceived barriers and/or challenges. 'This resiliency is evidenced in those who allow themselves and their children to dream of possibilities beyond their present circumstances, often without the objective means to attain those goals'. It is admirable how families maintain high aspirations for their children's future, even though they see the achievement gap they face. The stories nurture a culture of possibility, working hard to break the cycle, and live a new reality which is more promising.
2. ***Linguistic capital*** includes the intellectual and social skills attained through communication experiences in more than one language and/or style. Linguistic capital reflects the idea that Students of Colour arrive at school with multiple language and communication skills. In addition, these children most often have been engaged participants in a storytelling tradition that may include listening to and recounting oral histories, parables, stories (cuentos), and proverbs (dichos). This repertoire of storytelling skills may include memorisation, attention to

detail, dramatic pauses, comedic timing, facial affect, vocal tone, volume, rhythm, and rhyme. Linguistic capital also refers to the ability to communicate via visual art, music, or poetry. Just as students may utilise different vocal registers to whisper, whistle, or sing, they must often develop and draw on various language registers, or styles, to communicate with different audiences.

3. **Familial capital** refers to those cultural knowledges nurtured among familia (kin) that carry a sense of community history, memory, and cultural intuition. This form of cultural wealth engages a commitment to community well-being and expands the concept of family to include a broader understanding of kinship. Acknowledging the racialised, classed, and *heterosexualised* inferences that comprise traditional understandings of ‘family’, familial capital is nurtured by our ‘extended family’, which may include immediate family (living or long passed on) and aunts, uncles, grandparents, and friends who we might consider part of our familia. From these kinship ties, we learn the importance of maintaining a healthy connection to our community and its resources. Our kin also model lessons of caring, coping and providing (educación), which inform our emotional, moral, educational, and occupational consciousness (Reese, 1992; Auerbach, 2001, 2004; Elenes et al., 2001; Lopez, 2003). This consciousness can be fostered within and between families, as well as through sports, school, religious gatherings, and other social community settings. Isolation is minimised as families ‘become connected with others around common issues’ and realise they are ‘not alone in dealing with their problems’ (Delgado-Gaitan, 2001, p. 54).
4. **Social capital** can be understood as networks of people and community resources. These peer and other social contacts can provide both instrumental and emotional support to navigate through society’s institutions. For example, drawing on social contacts and community resources may help a student identify and attain a college scholarship. These networks may help a student in preparing the scholarship application itself, while also reassuring the student emotionally that she/he is not alone in the process of pursuing higher education. Scholars note that historically, People of Colour have utilised their social capital to attain education, legal justice, employment, and health care. In turn, these Communities of Colour gave the information and resources they gained through these institutions back to their social networks.
5. **Navigational capital** refers to skills of manoeuvring through social institutions. Historically, this infers the ability to manoeuvre through institutions not created with Communities of Colour in mind. For example, strategies to navigate through racially hostile university campuses draw on the concept of academic invulnerability, or students’ ability to ‘sustain high levels of achievement, despite the presence of stressful events and conditions that place them at risk of doing poorly at school and, ultimately, dropping out of school’ (Alva, 1991, p. 19; see also Allen & Solórzano, 2001; Solórzano et al., 2000; Auerbach, 2001). Scholars have examined individual, family, and community factors that support Mexican American students’ academic invulnerability – their

successful navigation through the educational. In addition, resilience has been recognised as ‘a set of inner resources, social competencies and cultural strategies that permit individuals to not only survive, recover, or even thrive after stressful events, but also to draw from the experience to enhance subsequent functioning’. Indeed, People of Colour draw on various social and psychological ‘critical navigational skills’ to manoeuvre through structures of inequality permeated by racism (see Pierce, 1974, 1989, 1995). Navigational capital thus acknowledges individual agency within institutional constraints, but it also connects to social networks that facilitate community navigation through places and spaces, including schools, the job market, the health care, and judicial systems.

6. **Resistant capital** refers those knowledges and skills fostered through oppositional behaviour that challenges inequality (Freire, 1970, 1973; Giroux, 1983; McLaren, 1994; Delgado Bernal, 1997; Solórzano & Delgado Bernal, 2001). This form of cultural wealth is grounded in the legacy of resistance to subordination exhibited by Communities of Colour (Deloria, 1969). Furthermore, maintaining and passing on the multiple dimensions of community cultural wealth is also part of the knowledge base of resistant capital. Research shows that Parents of Colour are consciously instructing their children to engage in behaviours and maintain attitudes that challenge the status quo. Transformative-resistant capital includes cultural knowledge of the structures of racism and motivation to transform such oppressive structures (Pizarro, 1998; Villenas & Deyhle, 1999).

These six capitals inform and comprise the cultural capital of these communities. The capitals not only describe the strengths of these communities, but also the way they conduct themselves in the society they live in. As an immigrant myself, I can attest that these capitals emerged once I moved to the US in my mid-thirties, and I was able to see them in action. Meaning, when living in my country-of-origin Mexico, I acquired, developed, and used them, but I was living in the culture and society that where these capitals are the norm. When I moved to the United States and now to Spain, I can tell that these capitals emerge as tools and, at the same time, provide an awareness of my identity: this is the way we do things in Mexico.

Serving society

Who do you work with?

An assets-based approach provides a revised framework for thinking about and communicating with your communities. Visitor studies provide you with a starting point for thinking about the directions in which you need to transform. Gathering these details can provide you with the data to reveal if the demographic of the locality matches the ones of the museum’s visitorship, staff, and board. Organisations can implement an exit survey (COVES, 2023), a summative evaluation of their programming and/or exhibits, conduct focus groups, and listening sessions.

These tools will yield data about the people who are participating at the museum, even though it is a single visit, the first and the only. The data will allow the museum to identify as well, who is **not** at the museum. Is the museum missing a specific age group, or families from the LGTB community? Perhaps, it is missing people from specific diasporas settled in the area. The local census would be a great source to compare the results of the instruments of evaluation, that way the museum can conduct an Asset Map.

Building transformational partnerships

Having established who is missing in your museum, you can draw on the asset-based approach to support sustainable, long-lasting, transformative, and impactful relationships with communities, that are not driven by an *outreach* mentality. This will start building relationships that will allow the museum and communities to become one team, one big community, partners who share responsibilities and leadership. No more, *us and them*, this is an opportunity to think of the museum as part of the community, and the communities as part of the museum, one community, shared goals, with a collaborative spirit.

Building partnerships allows museums to deeply learn about their communities, asking questions to understand their habits, routines, priorities, and needs requires time to gain trust, and identify how much they can commit, not only their time, also their human resources, and other assets. Reaching out to communities is a good first step, especially when the museum meets people where they live and spend time with them on their own terms. This requires becoming *porous* (Gorman, 2020), thinking of the museum beyond the walls. These encounters can provide a better understanding of the landscape and context of such communities.

Because museums want to build a partnership, while learning how to become stronger together, the outreach phase evolves into a consulting one. Trust increases while the communities are listened to, plus they provide feedback and ideas on how to move forward with the partnership that is potentially being built.

As trust builds, and the community gets involved more and more with the museum and starts seeing their ideas become tangible programmes, or initiatives, then the community starts to be involved in other issues, topics, formats, and content. The partnership starts to be bidirectional, and the culture of partnering with each other starts to take place.

When the community and the museum have established two or more projects together, the partnership is also becoming more solid and stronger. Transformational engagement of communities happens when museums and communities share leadership, the partnership is clear, there is a sense of belonging and ownership over the projects (experiences and learnings); therefore, the museum and the community are one strong community. Even the language changes, one can hear people saying: our project, our ideas, our museum.

While serving as an advisor for the Oregon Museum of Science and Industry, for the creation of their exhibition *Creatividad Silvestre*, *Wild Creativity*, I witnessed how this science centre has relationships with the communities in every stage, meaning, while they need to continue strengthening the relationships with those communities they have partnered with, at the same time the project required them to build new ones, and start all over again from outreach to transformational partnerships. This project, other examples, and details on how museums and science centres drive their partnerships can be found in the NISE Network Diversity, Equity, Accessibility, and Inclusion Booklet: *Tools for Engaging Communities and Incorporating DEAI Practices into Informal STEM Projects* (2022). All these case studies can be transferrable to your own institution and practice.

Engagement beyond exhibits and programming

According to Bergeron and Tuttle (2013) *magnetic museums* – engaging and engaged places – are the ones that practice 360 engagement, which consists of ‘involving internal and external stakeholders in meaningful experiences that make a difference for both the individual and the institution’ (p. 29), thus creating a ripple effect to draw more people in, or even better, allowing the museums to be more out, and beyond the walls, ingrained in the community, becoming part of the community.

It has been mentioned before the importance of building transformative partnerships, where the museum and the community become one entity, no longer ‘us versus them’. To push the boundaries a little bit farther – and amplify our understanding of the shared leadership due to the transformational partnerships – consider that the whole purpose is to have the members of the communities participating actively in the museum instead of keeping them acting and influencing from the outside. This means that they become members of the board, staff, and the team of volunteers.

Participation

Nina Simon (2010) disrupted the concept of participation in the Museum 2.0 blog, which later became *The Participatory Museum* book. Participation at museums is commonly understood when visitors or audiences are at the museum. In her book, Simon presented a wide variety of strategies to move the audiences to mere spectators to active participants in the exhibits and programmes. Examples range from visible polling to collecting visitor’s thoughts and emotions.

The participatory concept moved further to co-creation of the content of the exhibitions, distributing the power of curators and exhibit developers with the audience, who by the way are also experts in certain topics. Gorman (2020) explains this perspective as a dichotomy between being *dative (to/for)* visitors versus *ablative (by, with, from)* the visitors. Both Simon and Gorman walked the talk, in their tenure as Executive Directors of Santa Cruz MAH and Science Gallery

respectively, they led their institution's efforts to co-create with the communities (foster children, teens, elders, surfers, among others) treating them as equals and partners of unique exhibits and programmes.

In my work shifting cultures of museums, science centres, and other cultural and educational institutions, I try to challenge their leadership and gatekeepers to lower their places of power and allow others to come to the table and co-create. My hope is that this exercise allows people who are not in the field to consider a career in this field, and the institutions to consider these talented persons from their community as staff or board members.

I hear quite often organisations asking me to help them diversify their audiences, this is not going to happen unless they don't diversify the people in-house: board, staff, and volunteers. The safe route to achieve the diversification of the people in-house is building transformative partnerships with the different communities of the society they belong to. Museums need to reflect the demographics of their society, by including them in the whole operation, top-bottom, bottom-up, and across the organisation.

Hiring people from certain communities for specific low-level jobs, it is not inclusion, rather stigmatisation, discrimination, and segregation. It is imperative to acknowledge the intersectionalities of human beings (Crenshaw, 1989) and think broader about hiring and involvement. It requires a profound understanding of every community within the museum's radius and to connect with them, finding things to do together, and evolve the relationship until the museum is part of the community and the community contributes with the museum in many roles, capacities, and levels within the organisation.

Organisations frequently ask me: *where to start? Should we do an exhibit for a specific community and then for others?* In the chapter, *Breaking the Silos: Science Communication for Everyone* (Leyman Pino, 2023), I provide new perspectives, strategies, approaches, and frameworks to break this idea of designing for one community at a time – preferably, find ways to incorporate as many voices as possible. It is like the amazing OXO® kitchen gadgets, which were originally designed for people with arthritis, and able to develop innovative products that benefit all users.

It all starts with accessibility

When we talk about accessibility, we are forced to talk about its multidimensional characteristic, which will help to identify and understand the barriers and properly address them. An accessible museum is one within reach by either distance, price, location, visitor hours, or closeness to public transportation. Think of a children's museum in the Bay Area located in a historic place where no public transportation passes by and the closest bus stop is a few kilometres away, the entrance fee is in the mid-range, and the hours are from 10 am to 4 pm. In other words, this museum is accessible only to people who own a car or can pay for a cab, who have the day off work, flexible work hours, or do not work. Other examples are museums whose

entrance fees are too high for a family of three or more members, or their buildings are intimidating to a degree that not all the people feel they belong inside its walls. Therefore, accessibility in museums is broader than offering infrastructure and programmes suitable for people with visible and non-visible disabilities. It also includes other cultural aspects such as multilingualism and food that address special diets by faith; facilities that are family-friendly; and prices that can fit any given income bracket. An accessible museum designs their spaces and experiences erasing the barriers that could impede current and potential visitors from a full museum experience.

The chain of accessibility (Sensory Trust, 2023) starts from the moment people make the decision to go, or not, to the museum; the way they are able to access, or not, the relevant information that is, or is not, on the website; the way they are able, or not, to commute to the museum; the ease of arrival; how they are greeted and welcomed; the on-site experience, and the journey back home. Is it clear what the museum offers? Is the scheduling matching people's rhythms and needs? Are people going to the museum by foot, by car, by public transportation, by bicycle? Is it easy to commute and arrive by any type of transportation? And once they arrive at the museum, is it clear where to go? How to pay (or not) to enter? Are the facilities appropriate for their needs and physical abilities (i.e. nursing nooks, all-gender bathrooms, lockers, bicycle parking)? Are all the messages communicated in the local language solely, or is it a way to have it in other languages including Braille, and sign language? Are there audio descriptions, subtitles, tactiles? Are there opportunities to engage in the museum in different ways, depending on the sensory and experiential preferences of the visitor? Will the visitor find their interests, experiences, or histories represented in the museum? Are the events designed and planned in an inclusive way? Are the staff trained to welcome and interact with all the members of the community?

Let's broaden this concept, thinking about ways the museum can expand their mission beyond the walls. Accessibility it is not only how the museum serves and attracts visitors to their campus, but also related to the strategies they can use to connect with people where they are. Here are some examples on how museums are offering opportunities for people to engage and participate off campus:

- **Mobile Museums.** Papalote Museo del Niño, the first children's museum in Mexico, realised that not every child could go to Mexico City to visit it, created since the very beginning a mobile museum. Copies of the best exhibits were designed to be easily transported and venues such as warehouses, gymnasiums, and community centres were transformed into a Papalote locally. It started with one, and then three museums were visiting every corner of Mexico. The museum stayed four to six months, generating jobs locally, opening the eyes to families with this new type of museum and ways of learning. It was a total success, to a degree that local governments started their capital campaigns to build their own museum. This initiative has created 17 new children's museums and science centres and has impacted millions of visitors.

- **Miniaturised Portable Exhibits.** Hiša Eksperimentov, a science centre in Ljubljana, Slovenia, has the Little House of Experiments, an *interactive mobile empowering centre* that visits schools and local communities transforming their campuses into science centres for a day. Hiša has all their exhibits miniaturised to the size of a briefcase, so every exhibit becomes a tabletop experiment, easy to transport, and to reach every corner of Slovenia. Schools and other community-focused organisations book the Little House of Experiments, and the team is constantly on the road bringing interactive science to classroom. A similar programme has been created at the Gwacheon National Science Centre in Korea, they also have briefcases with activities that can be done on a small school desk, and that are easy to replicate in the classroom, allowing the experience to continue after the museum staff visited the school.
- **Online Resources.** Exploratorium (San Francisco, US) offers through its website activities and experiments called ‘snack’ to either replicate the phenomena from their exhibits or expand the understanding of science and continue promoting curiosity. These activities are accessible to everyone from everywhere, plus they offer a wide variety of content in the form of blogs to continue learning science.
- **Learning Trucks.** The Bay Area Discovery Museum, the Perot Museum of Nature and Science, and UC Berkeley’s The Lawrence (US) have trucks that go to the neighbourhoods to engage with families. These trucks also allow the museums to participate in local festivals, maker fairs, libraries, and flea markets, activities, and places where people are and spend their leisure time.

Removing the barriers

There are many creative ways to become more accessible, yet it is crucial to be observant and analyse all the different barriers that need to be continuously removed, starting to design exhibitions, programmes, and experiences that take into account what people can do, including an equity lens, aiming to serve for the many and not the few, and putting in practice the lessons learned to a point where there are no more barriers to remove. This is a never-ending endeavour, until museums are completely accessible. Barriers can have many shapes and forms: staircases, distance from a bus stop or metro station, security checkpoints, prices, language/s, to mention a few. Other barriers are symbolic, for example the use of jargon, the insufficient number of stalls in a bathroom, or changing stations only in the women’s bathroom, even the way the messages are written, or how the museum refers to their audiences (Kinsley et al., 2016).

The good way to identify, learn, and understand the barriers is having conversations with those affected by these barriers; listening to understand their pain points and ideas, and visiting the neighbourhoods where they live. When having conversations, focus on listening, allow them to share with you the challenges they face,

the values they hold, identify the goals they are pursuing. This is an exercise of empathy so you can understand the commitments they can make and what success looks and feels like.

While understanding their perspective, needs, and points of view, one is also building a relationship with them, consequently, we are not strangers anymore, we start to become friends, and being part of one big community.

Nothing about us without us

This powerful phrase refers to the idea that no policy or legislation should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy. It has its origins in Central European political tradition, it has become a byword for democratic norms. This phrase has also been used during the 1990s at the international disability rights conference and has stayed to describe the values of the Convention on the Rights of Persons with Disabilities.

In the context of the museum field, this phrase is a reminder and an invitation to include those voices and ideas of those we are trying to inspire, attract, and include in our institutions. This is a great time to stop being a *dative* organisation doing things to or for the communities/audiences, and instead become more *ablative*, meaning creating with, by, from the communities/audiences (Gorman, 2020).

When institutions listen, partner, involve, and nurture the relationships of those who haven't come or participated at the museum yet, the probability, that these efforts will result in the diversification of the audiences, staff, and board is higher. They are the experts on what, how, when, which type of programmes, activities, and content will work better for them. The museum can become an expert in involving new and diverse groups if it learns first-hand from them about their likes and dislikes.

Devolving power and influence

Transforming museums to be accessible for everyone requires a constant reflection of the current and potential barriers: physical, financial, linguistic, social, and geographic, to mention a few. As advocates and changemakers, we need to focus on identifying and removing the barriers, while allowing the people we want to see at the museum, becoming part of the museum, and the museum becoming part of their community. At the end, what we are building is one big, diverse, plural, and joyful community.

Museums need to share the power they have with the communities, and even relinquish control to the communities. I say this with respect, and from time to time I receive pushbacks from colleagues who are concerned that the museum will become shallow if this happens. What I have seen in those organisations who have tried is that they are successfully connected with their communities, and their communities

are truly part of the museum. A sense of belonging provides a sense of ownership as well.

This chapter is an invitation to each and every one of us to act from our place of power and influence. We are already empowered to make this society better, stronger, and thriving. We can contribute from any place and role we play in our institutions and in society. The invitation is to ignite this power, being brave and courageous to become the change we want to witness.

Build coalitions become stronger by partnering with other like-minded colleagues. Your coalition is going to help you lead the change, and to support you when things seem like or perceived as more difficult and tough.

Collaborative partnerships and networking with other science communication institutions [or museums] that are on a similar journey to inclusion provides myriad opportunities to engender, upscale, and sustain solidarity, cooperation, transferrable skills, and knowledge sharing, as well as inspiration and encouragement, to sustain momentum and build on achievements and progressive developments across the board.

(Leyman Pino, 2023)

Summary

- Museums and the communities they belong to are the same community.
- Museums are urged to start focusing on the assets of their communities to scaffold for co-creation, co-design, collaboration, and ultimately building long-lasting and transformative partnerships.
- Museums are urged to start going where their most wanted communities/audiences are. Serving and connecting with audiences is not limited to the museum's campus. Think broadly, beyond the walls.
- Museums can share and even relinquish their power to create content that connects better with the audiences, transforming the relationship the museums have with their audiences.

Biography

Since 1994, Amparo has applied her pedagogical experience in the museum world. There she developed content and programmes and moved into institutional leadership and administration roles. After several years in the education field, she co-founded a school in Mexico City. Most recently, she has been advising museums around the world on community partnerships with services like cultural adaptation, content and curriculum development, programme and exhibit creation, and staff training in cultural capacity. She has published several articles and contributed to a book about inclusive science engagement. Amparo is an active alumnus of the Noyce Leadership Institute and a Fulbright Specialist.

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11

STEPPING ASIDE

A reflection on how museums can transfer power to communities, open up collections, and increase access through the creation of memory boxes

Katie Cassels and Charlotte Paddock

Royal Museums Greenwich (RMG) cares for over 2 million objects and archives that tell stories related to the sea, time, stars, history, and creativity. The five sites that make up the institution and are open to the public are the National Maritime Museum, the Queen's House, *Cutty Sark*, Royal Observatory Greenwich, and the Prince Philip Maritime Collections Centre. While they are all located in the Royal Borough of Greenwich in south-east London, RMG has a national remit, grounded in the knowledge that the collection belongs to everyone in the UK. At the same time, RMG maintains a commitment to be a useful resource to the local community in and around Greenwich. It is the role of the Engagement team at RMG to ensure the collection and sites continue to become more relevant, inclusive, and accessible to all. One of the key areas of interest in local and national government policy in the UK in recent years has been on health and well-being. This has been situated within a broader societal emphasis on positive living and healthy ageing. This has impacted the areas of work within museums, including RMG, not least because engaging with museums and museum collections has been associated with a positive impact on well-being.

Since 2019, RMG has developed to become a more useful, relevant, and inclusive resource for communities living with dementia by working to build relationships through trust and transfer of ownership. This chapter discusses two projects that developed memory resources for people living with dementia inspired by RMG's collection. Both projects showcase the journey taken by the Engagement Department and community partners to move from an engagement method based on consultation towards one that centred co-production and community leading. This chapter considers how this shift in practice impacted the way the organisation partners with communities, broadening access, and increasing community ownership.

Many museums around the world have been working with people living with dementia, often creating memory boxes. These will often include items from the collections that aim to stimulate the recollection of people's autobiographical memories and a group process of reminiscing. Diagnosis of dementia encompasses several diseases that impact memory, thinking, and the ability to perform daily activities. Dementia predominantly affects older people and often results in loss of short-term memory, which means more recent experiences are poorly remembered. However, long-term memories can remain intact. Long-term autobiographical memories can also have an important connection to our sense of identity. As such, using a memory box can help to stimulate recall and communication of these personal memories and events, which can have a powerful impact on well-being.

In the UK, 944,000 people are living with dementia. Based on ageing populations around the world, it has been estimated that the number of people living with dementia will increase from 55 million in 2020 to 79 million in 2030 and 139 million by 2050 (Alzheimer's Research, UK, 2022). In 2018, the Mayor of London, Sadiq Khan, pledged to make London a 'dementia-friendly capital'. He stated, a Dementia-Friendly London is 'an inclusive and compassionate city where all Londoners affected by dementia are empowered and supported to live well' (Alzheimer's Society, 2018). This includes ensuring people affected by dementia are able to 'participate in all that London has to offer in arts, culture and leisure'. This, in turn, led to the Royal Borough of Greenwich publishing its Health and Wellbeing Strategy (2019–2024) highlighting four areas of focus: 'Thrive Greenwich', 'Live Well Greenwich', 'Healthy Weight', and 'Health and Social Care System Development'. Among these were the aims of becoming a 'dementia-inclusive' borough, gaining 'dementia-friendly communities' status and running dementia-friendly organisations (Royal Borough of Greenwich, 2019).

Responding to the local call to action from the Royal Borough of Greenwich in 2019, RMG began exploring how to incorporate health and well-being support into public programmes at the National Maritime Museum. This included working alongside Dementia Inclusive Greenwich, a project set up by the Royal Borough of Greenwich to improve support for people living with dementia in the borough. Co-creation with communities living with dementia is one of the aspects of the best practice model within the Dementia Friendly Venues Charter Framework (Mayor of London). This instigated a journey of working closely with local communities and partners to find ways the collection of RMG and its sites could better support both people living with dementia and their carers and/or significant others. By focusing specifically on Londoners, who encompass a rich diversity of social, racial, and cultural groups, RMG began to question which sectors of society memory boxes were made for and as a result sought to explore the gaps in local provision and look at how the RMG collection could support this.

RMG piloted a 'Wellbeing Programme' based at the National Maritime Museum, with a strand focused on the well-being of those living with dementia. The pilot

project looked at the potential role that museum programmes and resources could have in supporting audiences' health and well-being, while aiming to remove barriers to access the Museum as an accessible and useful resource. Central to this pilot was a comprehensive programme of consultation with our local community and evaluating any work trialled, before launching new resources or programmes.

The legacies of the pilot programmes and consultation were:

- Evidence that there was very little support for people living with dementia who were not born in UK;
- A commitment from RMG to produce culturally inspired resources, filling this void in support
- A commitment to being a dementia-friendly site;
- Increased internal awareness of the importance of being a dementia-friendly organisation;
- A pledge to embed dementia awareness strategically, underpinned by staff training.

It was decided that we would draw on the collections of the National Maritime Museum to create memory boxes. The impact of staff training on dementia awareness was particularly important because it focused our thinking and approach to ensure relevant and useful resources that would not replicate resources already available from other museums.

Many of the existing reminiscence resources for people living with dementia in the UK were created with an assumption of the user having a British mainstream cultural experience. This ignores the fact that the UK is made up of multiple cultural identities which is largely due to immigration from countries that had been colonised by the British Empire. A significant part of British 20th-century history includes the call for Caribbean people to emigrate to the UK to help re-build the country following the Second World War. These people are known as the Windrush Generation and have been integral to British society since their arrival. People living with dementia who did not experience a white British cultural upbringing, like the Windrush Generation, therefore cannot access or relate to the content of these memory boxes and are excluded from participating.

This chapter will outline the motivations, methods, outputs, and learning in connection with two projects RMG undertook to better support people living with dementia. It will critically analyse the journey that RMG has taken in its learning around dementia support and will focus on how the collections and sites can be used to create culturally specific reminiscence resources for its local and national communities. Importantly, it will demonstrate that by working with community elders living with dementia and their carers to inspire reminiscence, museum collections have the potential to strengthen intergenerational understanding and connectivity, helping everyone reconnect with their own sense of self and contribute to enhanced community memory, health, and well-being.

Throughout this journey, RMG has had the privilege of working with and learning from inspirational local and national partners including the Caribbean Social Forum (CSF), Age Exchange, The Urban Dandelion, and Dementia Inclusive Greenwich. These partners have been integral to the knowledge, processes, and outputs that RMG has developed to support people living with dementia and have contributed to the development of more authentic and meaningful engagement methods. They have also heavily shaped the institutional learning and organisational resilience of RMG to find a model of working with people living with dementia and their carers that addresses the lack of culturally relevant resources from cultural organisations for global majority communities living in the UK.

In 2020, RMG was awarded funding from the Esmée Fairburn and Museums Association Sustaining Engagement with Collections Fund to deliver ‘All Aboard: Reconnecting and Building Resilience Through Collection Exploration with Isolated Groups’. The project was developed in response to the increased isolation experienced by people living with dementia and their carers due to the global COVID-19 pandemic. The Alzheimer’s Society reported in July 2020 that four in five people living with dementia were experiencing deterioration as a result of the lockdown and half were experiencing increased memory loss (Alzheimer’s Society, 2020). While all RMG sites were closed to the public during national lockdowns, the need to develop remote access to the collection for audiences was essential.

The project was run in partnership with Age Exchange, the national centre for Reminiscence Arts who have expertise in measurably improving the quality of life and well-being of those living with dementia and their carers. Age Exchange (no date) describes reminiscence arts as ‘the focus on empowering the individual, enabling them to share reminiscence through a range of arts mediums and to interact creatively and positively with others’. Memory boxes include resources with prompts and activities, as well as sensory objects to creatively stimulate memory. Age Exchange runs five dementia services for residents of the London boroughs of Lewisham and Greenwich, which together support 125 people each week, and three services for 65 residents living with dementia in Lambeth. Partnering with Age Exchange enhanced the ability of both RMG and Age Exchange to continue providing stimulating and meaningful engagement with user groups during the pandemic. Staff at RMG were trained in reminiscence arts practice and were able to learn from and work in collaboration with multiple Age Exchange staff members and workshop facilitators with years of expertise in the social care sector.

RMG and Age Exchange identified a series of travel journals from the RMG collection as the source material for the memory boxes. The travel journal collection comprises over 300 records of voyages from 1631 to 1973 and documents the experiences of passengers, sailors, naval officers, and migrants. These were selected in order to provide creative and imaginative opportunities for ‘armchair travelling’ during a period in which most were forced to stay inside their homes for weeks or months at a time. The journals provided rich material that could be used

in the resources, including text excerpts, historic photographs, and sketches, to aid participants in stimulating their own travel memories. The collection contains personal stories of physical and emotional journeys. It explores how humankind crosses geographical, social, and cultural borders, often from the outsiders' perspective, looking into a society, place, or culture that they were not part of. However, generally the journals in the collection were written by upper and middle class white men, with just a handful written by white women. The cultural background of the authors and their experiences of travel were therefore not familiar to a large proportion of the British public and especially the Royal Borough of Greenwich, which is made up of a population of people who identify as: 24% Black, 14% Asian, and 3% other ethnicities (Royal Borough of Greenwich, 2017). This proved to be a significant challenge for the project, as there was a risk the journals might not inspire connection or reminiscence for the participants. David Savill, Artistic Director at Age Exchange, explained that by creating culturally inclusive resources:

All Aboard enabled our older participants from diverse communities to engage with the project and this has been key to its success. So often working in care settings for older people these resources simply do not exist. We often see situations where elders from diverse communities are encouraged to reminisce and respond to photos and artefacts which are not relevant to their own backgrounds and heritage. This has the detrimental effect of closing them down and isolating them. The unique resource created by All Aboard is absolutely essential in enabling those of us who work to support older people with mental health needs and their carers who come from diverse backgrounds, to engage with material that is not only culturally relevant to them as individuals, but also makes them feel valued for who they are and the heritage they hold dear.

(David Savill, interview with Charlotte Paddock, 2023)

To overcome this challenge, RMG staff spent significant time searching through the journals to find photographs, sketches, and postcards of places around the world that might resonate with users from culturally diverse backgrounds. Stories about British migration to places like Australia also bore similarities to the experiences that other communities might have had when migrating to the UK. Lastly, anecdotes about the everyday, such as not liking the food on board, playing games, or catching fish, were found to be relatable to many people's experiences. Over 1,000 excerpts from the travel journal collection were digitised as part of the project and are now available for the public to view on RMG Collections Online. Although attempts were made to make the resources culturally inclusive to as many people as possible, due to the speed with which the project had to be delivered within the pandemic, to ensure emergency support was given to those most isolated, consultation with service users and those living with dementia did not occur.

The All Aboard memory boxes included a wide range of stimuli to support memory triggers in different forms to help as many users as possible find connection and engagement with the material. The boxes contained:

- An A4 sheet that introduced the project and explained how to use the resources, plus 8 resource cards that introduced a topic identified in the travel journal collection, a set of prompts to inspire personal memories around this theme, and simple creative activities to encourage imagination for both the user and their carer/significant other to complete together. The themes identified in the travel journals were chosen due to their wide-ranging relevance and recognisability.
- Sensory items that could support and build on the resource cards to trigger memories. These included smelling pots of herbs, oils, and sun lotion; tactile objects such as foam globes; visual references such as historic photographs and postcards; soundscapes of waves, storms, and sounds from the beach.
- Oral history recordings of participants recounting their memories of travel and migration.
- Materials for creative expression and personal memories in response to the resource activities, including a blank journal, pens and pencils, glue, collage materials, and watercolour painting set.

Age Exchange used the memory boxes in arts reminiscence workshops with over 50 service users, who engaged either remotely from home via online workshops or in-person in group settings once lockdowns had been lifted.

Evaluation of the project found that the boxes were used very differently in the home, via remote online workshops, compared to in-person group settings. The participants in the group setting responded with more creative reminiscence, such as drawing, painting, or sculpting their memories, whereas the participants engaging remotely mainly focused on conversational reminiscence. The participants who were able to meet in person, as well as one online participant, produced a phenomenal amount of individual and collaborative artwork. The unexpected outcome of abundant creative responses demonstrated the individuality and creativity of the participants as they felt empowered to share their memories and imagination. Their work was displayed in the National Maritime Museum for two months between 2021 and 2022 and an accompanying exhibition catalogue was produced (Royal Museums Greenwich, 2021).

All Aboard enabled Age Exchange and RMG to work in an agile way to respond to the urgent needs of people living with dementia during a national lockdown. It created culturally inclusive resources that were useful to a wide group of people, inspired imagination and fostered a sense of purpose. Nevertheless, due to the wide scope of the project and the urgency of providing support, it did not cater to all people living with dementia and did not engage in co-production processes with participants to develop the resources. The project demonstrated that this model of

production can serve a general need but did not work closely with communities to explore lived experiences and cater resources around these.

Memories of the Caribbean

Memories of the Caribbean were funded by the Windrush Fund and ran throughout 2021. Learnings from the pilot project and All Aboard were the inspiration for a new approach in Memories of the Caribbean, which aimed to centre the expertise of those with lived experience and move RMG from a position of power to a position of support. Black African and Caribbean communities in the UK have a higher prevalence of dementia, and of early onset dementia, compared with the white UK population (Race Adelman et al., 2009, pp. 657–665). This is combined with a lower early diagnosis rate, which studies hypothesise stems from the

‘Normalisation of memory problems, concerns about stigma related to dementia, belief that families rather than services are the appropriate resource, previous negative experiences of health services, concerns about the threat of receiving a diagnosis, language barriers and lack of knowledge.

(Berwald et al., 2016, p. 2)

Finally, we cannot underestimate the effect of a ‘lifetime impact of discrimination [that] reinforces a cultural expectation of endurance and resilience in the face of hardship that makes individuals reluctant to seek help for health problems.’ (Race Equality Foundation, 2018) These facts had to be central to the development of the project.

The main takeaway from the pilot project at the National Maritime Museum in 2019 was the lack of availability from cultural organisations of culturally specific reminiscence resources for the British Caribbean community. The CSF, a local community group, had been consulted as part of the pilot. During these conversations, members of the CSF both living with an early dementia diagnosis and caring for those living with dementia reflected that living with dementia meant their friends and family were sharing memories of early experiences growing up in the Caribbean and of moving to the UK as children, and of the unique impact that this context had on them. This was combined with the reflection from second- and third-generation descendants that many of their elders had experienced racism and could be sharing traumatic memories as part of memory sharing. The CSF had spoken before about how museum reminiscence resources did not accommodate these experiences and therefore were unable to spark or support memory in the way they were intended to. They also raised the important fact that the instructions with the boxes would not effectively support carers to prepare for challenging memories. This lack of culturally specific resources available for reminiscence is replicated across the museum and healthcare system across Britain and arguably reflects the paucity of research into the experience of African and Caribbean communities in

the UK (Alzheimer's Society, 2022). Another key consideration for the project was to recognise the importance of the expertise of the British Caribbean community with lived experience of dementia, ensuring that materials were created with them.

The uniqueness of the Caribbean also had to be fully understood and only a group made up of participants from across the Caribbean islands could truly understand the resulting nuances that arise from unique cultures across islands. This would be particularly important for the diaspora (Race Equality Foundation, 2018). We also needed to consider generational distinctions as dementia can be diagnosed over a wide age. The support networks and cultural references for first- and second-generation migrants could be experienced differently, as 'many first-generation migrants locate their social and support networks within their local church congregation or African-Caribbean social clubs while the second and third generation offspring often have developed their social and support networks beyond this.' (Race Equality Foundation, 2018). With these factors in mind, the project therefore aimed to:

- Use RMG collections and resources as a source of inspiration for culturally specific reminiscence resources;
- Ensure the project was driven by those from across the Caribbean community with lived experience of dementia or of caring for someone living with dementia.

In preparation for the project delivery, support from the Windrush Fund enabled RMG to digitise the Waterline Collection, a collection of 16,500 historic photographs, which includes images of some of the Caribbean islands taken between 1929 and 1949. This opened a host of photographs of Black communities in the Caribbean to the project participants. These images acted as an inspiration for the project, encouraging the participants to think about the unique context of those elders who had grown up in one country and moved to another and the impact this would have on memory.

The partnership with the CSF on this project was the culmination of a longer relationship-building process, whereby RMG sought to understand and overcome the members' distrust of the organisation. This distrust came from a pattern of large institutions, and especially museums, working with their own priorities and timeframes in mind instead of the needs of the community. RMG and the CSF have worked together since 2015 when Forum members provided their interpretation of objects within a new gallery, 'Sea Things'. Since then, their members have taken part in co-curation projects, supported the development and delivery of events such as International Slavery Remembrance Day, and provided feedback on Museum galleries, including 'Atlantic Worlds'. During this extended period, as museum staff worked to address the CSF's concerns and address the power imbalance, relationships were strengthened, and the CSF began to share where their distrust stemmed from. Largely, there was an expectation of a large, overwhelmingly white, organisation coming to take from a Black organisation – under the

guise of helping – something that is reflected in the experiences of both the CSF and many other Black-led organisations. This encompasses a perception that is not entirely invalid given the pressures on museums to work to specific objectives with short timeframes and tight budgets. These were not two organisations that felt they had equal power in a partnership. Having this honest conversation was vital in the building of the relationship and meant that by 2019, when the Wellbeing Programme consultation was taking place, the CSF felt able to challenge RMG to cede them more power and to create projects they needed, rather than being driven by projects RMG had available and wanted their input on. They wanted RMG to work explicitly for the community. In particular, they pushed to lead work to create dementia resources that would support their members.

In 2021, RMG was in a position to prioritise looking for funding to drive forward the project the CSF wanted to deliver. In proposing the partnership for this project, the CSF members challenged RMG to be a resource that responded to their needs and ideas, rather than the community coming in to participate in a project that someone at RMG thought they needed. They were in need of culturally specific dementia resources and it was time for RMG to work for them, instead of the other way around. This context was important for the project and led RMG to move from a collaborative approach to a co-production model for resources with the CSF, a first for RMG in this context.

The resources at RMG meant that we could take on the burden of researching and writing an application, enabling the CSF to access a funding pot they otherwise felt unable to reach. The initial expectation from RMG had been for RMG team to manage the funding and to recruit a facilitator who would work with members of the CSF to come up with ideas for reminiscence resources, before the group handed all content ideas back to RMG staff to create the text, organise the design, and pull together the final resource. The funding would cover a fee for the CSF to be a lead partner, to cover the cost of the facilitator, for all materials required, and for the design and production of the resources. However, the CSF's challenge to RMG necessitated that we hand over more power and fully utilise the lived experiences of their members. They knew they were the experts in this project and within the partnership and challenged the project plan.

We needed to recruit our own facilitator. We need[ed] someone who understood not just about dementia but about the culture of the people we are doing it for. Because the conversation is not just about gathering information... this was about understanding the stories that our parents told us and being able to share those stories. Being able to understand a Trinidadian accent against a Barbadian accent and a Jamaican accent and being able to blend it with laughter and joy...
(Pamela Franklin, interviewed by Katie Cassels, December 2021)

Through the CSF Urban Dandelion, a south-east London-based social enterprise that supports communities to bring about the change they want to see was brought

on board. Urban Dandelion had previously supported the CSF and came to the project as their trusted facilitator. Their primary point of contact was with the CSF, not RMG. Their role was to facilitate exploratory workshops and conversations and refine these into topics and themes for the final resource. They would then work with RMG staff to write the text and develop the resource design for the reminiscence resources. These drafts would then go back to the CSF working group for sign-off, before RMG organised printing.

The changes to the project management structure empowered the community: *'It was important we had a space that the Museum gave us and...[we had] the freedom to explore the things that we want to explore and to do it in our style'*. (Pamela Franklin, interviewed by Katie Cassels, December 2021). It also ensured that although learnings from All Aboard were considered, any preconceptions that RMG had about the content for the project were put to one side in favour of the goals and ambitions of the working group.

The CSF and Urban Dandelion decided to run a series of workshops on site at the National Maritime Museum and Prince Philip Maritime Collections Centre and invited a group of CSF members living with or caring for those living with dementia to form a working group.

We were able to have a space in the museum each time... which meant there was consistency but there's something about being in that place when you're doing this work that brings together two different worlds.

(Pamela Franklin, CSF, interview with Katie Cassels, Dec 2021)

During the initial part of the project, RMG staff provided prompts and resources as requested by Urban Dandelion, shared learnings from previous projects, organised spaces for sessions and handled the funding requirements. However, the format of the sessions and the direction of the project were led by the working group and their facilitator, with the emphasis on their lived experiences, as a driver for the project. Using some of the grant funding, the CSF provided financial recompense for the working group's involvement. This was an important recognition of the value of the expertise and time the group were giving to the process.

The working group began by exploring their connections to a selection of images from the Waterline Collection before thinking about how they could spark other memories for their community through the use of images and objects. Over a series of sessions, they started to determine what themes and topics they wanted the reminiscence resources to cover and what format they wanted the final resource to take.

The interest and focus of the working group led to additional elements being incorporated into the project. For instance, members started bringing in their own personal objects – from photographs to clothing – that sparked strong memories for them or a loved one. One impact of this sharing was the understanding or realisation that the collection at RMG could not comprehensively cover the needs of the

project, as, due to historic collecting priorities, many objects that provoked strong memories could not be found within it. This resulted in a session organised at the Prince Philip Maritime Collections Centre, where a selection of these personal objects was photographed to museum standards, providing both a personal photograph of the treasured item for the individual and enabling them to be incorporated into the final resource. RMG was also able to host the group in the paper conservation studio, where members spoke with specialists about how best to ensure the longevity of their personal collections, such as photographs and tickets from their migration journeys. While this moment did not feed directly into the resource, it was a valuable demonstration of how RMG could continue to provide useful resources to local communities with personal collections. In written feedback after the session, one of the participants commented:

The paper preservation session was very, very useful and it seems there will be people coming together to sort their paper and photo items, restoring them using the advice given with the right materials.

(Participant, interview with Katie Cassels, 2021)

Over the course of the sessions, several priorities for the resources were established by the group:

- To represent and consider as many of the Caribbean islands and their individual languages, cultures, and contexts as possible
- To provide a mixture of printed resources and handling objects that speak to a range of senses
- To incorporate personal items and images from other cultural organisations where the RMG collection is not comprehensive.

Urban Dandelion, the CSF and RMG then worked together to create that resource, take drafts back to the working group, and finally launch the resource. The final resource took the form of a vintage suitcase that held:

- An introduction booklet
- Five activity sheets with memory prompts and conversation starters
- Five themed packs of resource cards, linked to the activity sheets
- Objects linked to the activity sheets and their memory prompts.

The group piloted the resource with their peers at the CSF before the kit was launched at RMG. The kit lives with the CSF, with a copy at the National Maritime Museum available for groups to borrow, and with digital assets available online. Since launching, the resource has proved helpful to carers from other cultures, bridging understanding between carer and individual, and better supporting the individual living with dementia. Whether a white spouse, a friend, a paid carer or

someone from another Caribbean Island with different experiences, the resource has helped create starting points for conversations that allow people to build relationships across experiences and cultures. In ensuring that the resources used languages and details, such as key locations and island dishes, the CSF had ensured that the resources supported anyone to start a conversation that prompted memories for the individual living with dementia.

It has also become clear that the resource has had unexpected outcomes, beyond supporting those from the Caribbean community living with dementia and their carers. While in use at the CSF, the working group noticed the impact of the resource on intergenerational sharing. The memory prompts sparked the sharing of stories that in many cases, the user's younger family members had not heard before. Users and their network were prompted to talk about their cultural heritage and many relatives felt this helped them to better understand the unique first-generation British Caribbean experience of their loved ones. Having a working group with lived experience lead the direction of the resource also meant that the group recognised early on that producing memory prompts for first-generation British Caribbean elders could result in the sharing of difficult memories, whether that be separation from loved ones or experiences of racism. Their reflections meant that the final resource included a note about challenging conversations to ensure that those leading the conversation were prepared for what might be shared.

Conclusion

For RMG, *All Aboard* and *Memories of the Caribbean* have been a journey that has challenged the organisation to reflect on the power it holds when working with communities and to learn how to shift this power balance.

All Aboard taught RMG the importance of partnering with a healthcare provider to share expertise in how museum collections can contribute towards the improved well-being, social connection, and purpose of communities living with dementia. The project provided RMG with the essential knowledge and experience in developing reminiscence resources, and this enabled staff to approach the CSF and begin conversations about developing more culturally specific resources. It also allowed RMG to reflect on the benefits of reminiscence resource development and the limitations inherent when creating resources *for* people and not *with* them. RMG recognised the need to work more closely with groups who had lived experience of dementia to successfully develop meaningful and relevant resources for communities that lacked appropriate support. From this learning, RMG wanted to work with people who had lived experience of dementia in the development of the memory boxes. This led to RMG actively listening and responding to the desires of the CSF to take a leadership role and for RMG to transfer their power to the participants.

Working with the CSF during *Memories of the Caribbean* has generated key learning for co-production models. The importance of stepping back, transferring

power to the community, and supporting their leadership journey has been key to the success of the project. As Barbara Gray from Urban Dandelion reflected

The participants one hundred percent owned this process... It's been a fascinating journey and I think what this shows is that if you give people the space to own and tell their own story and have the freedom to do it in their own style it's an amazing journey...that you will never forget... The content that you will get is much more than you can ever imagine.

(Barbara Gray, interview with Katie Cassels, Dec 2021)

The authenticity of the resource and its ability to speak to experiences from across the Caribbean stems entirely from the co-production model. The success of the resource in supporting not just those living with dementia, but the people surrounding them to continue to build their relationships, to find new moments together, and to access those quality moments again, is the great success of this project and of the co-production model. Involving people living with dementia in every part of the process is a model RMG will continue to follow.

For RMG and the working group, the key learning has been the benefit that these resources can have for individuals beyond the person living with dementia. As the group explained in the resource introduction booklet, 'When a person shares something about their past and another shows interest or enjoyment, it is a wonderful opportunity to feel a sense of purpose and value' (Royal Museums Greenwich, 2022). This relates to everyone involved. For children, young people, peers, carers, the individual living with dementia, within the community and beyond the community, the reminiscence resources created through Memories of the Caribbean have resulted in conversations that bring about purpose, value, and joy.

Since the Memories of the Caribbean project, RMG has continued to build programmes with the CSF. The now annual Caribbean Takeover event is a physical manifestation of the shift in power, beginning with the challenge from the CSF to provide an opportunity to celebrate Black British history and culture on their own terms on a day that suits the community. Now, one of the largest festivals at the National Maritime Museum, the Caribbean Takeover is developed entirely by the CSF using the resources of the RMG. Furthermore, as RMG looks to the future, we will replicate the working model with the CSF and apply this to co-production projects with other communities to develop culturally specific reminiscence resources. RMG is currently working on the next project to co-produce reminiscence resources with the South Asian community, to work with them to understand and overcome the barriers they experience when accessing dementia support.

To conclude, as Barbara Gray (Urban Dandelion) shared at the end of the project, '*There's something about being able to bring your whole self into an environment that other people can relate to that really makes a difference.*' (Interview with Katie Cassels, Dec 2021).

Summary

- In transferring power to communities, stronger relationships and more useful resources/experiences/programmes can stem from museums moving towards models of service provision rather than commissioning bodies.
- Museum objects can connect communities, instigate conversation, and be a source of creative inspiration that centres the individual living with dementia, ensuring they are an agent of their own experience who can lead their own reminiscence journey.
- Museums can respond to a lack of culturally specific dementia care by providing access to world collections that spark connectedness and encourage greater cultural understanding.
- Reminiscence resources are invaluable to the individual living with dementia, but the benefits of their use are much more wide ranging, supporting those communities surrounding the individual, allowing communities to better appreciate and understand each other's experiences.

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Biographies

Katie Cassels (she/her) has worked in heritage for nearly a decade, across historic houses and museums. Her practice is driven by a passion for intergenerational relationship building and conversations. Her approaches look for opportunities to build confidence in communities to access and use museums on their own terms and in ways they truly need. Katie is a white, cis-gender woman who has been in the Engagement team at RMG since 2018.

Charlotte Paddock (she/her) has worked at the intersection of cultural heritage management and community engagement for almost ten years. Her practice focuses on creating high-quality participatory programmes with underrepresented audiences to challenge inequality and contribute towards social change. She focuses on working with communities to challenge the status quo and re-imagine how museums can serve everyone. Charlotte is a white, cis-gender woman and has been in the Engagement team at RMG since 2018.

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12

THE SACRED CAVE OF KAMUKUWAKÁ

Enabling digital futures for Indigenous cultural heritage in the Amazonian Xingu

Thiago Jesus

This journey began in destruction. It traces back to September 2018, when Wauja Indigenous leaders and our teams of researchers from People's Palace Projects (PPP), an arts research centre from Queen Mary University of London, and Factum Foundation for Digital Technology in Preservation, a Madrid-based non-profit organisation dedicated to heritage preservation, encountered the ancient petroglyphs of the sacred cave of Kamukuwaká laid in shattered pieces on the ground. The rock art panels, animated by the vibrant stories of the *Xinguano* creation myths for centuries, were crudely but effectively vandalised. The cave is now a record of the destructive impact of human exploitation of the environment on the borders of the Xingu Indigenous Territory in the state of Mato Grosso, the south basin of the Brazilian Amazon.

Although the exact identity of the assailant is unknown, the aggression is representative of the increasing tensions between Indigenous and agricultural communities in the region. Over the past two decades, Mato Grosso has become a global agricultural powerhouse, the leading soybean producer in the world, and the largest beef producer in Brazil (the world's second). Intensive farming, indiscriminate use of pesticides, the expansion of cattle, mining, land grabbing, deforestation, and river alteration have changed the regional hydroclimate and increased the frequency and intensity of droughts and forest fires. The vandalism was a deliberate attack on the memory, culture and rights of the Xingu Indigenous peoples, custodians of the largest remaining island of tropical forest in the Amazon's arc of deforestation.

The Xingu, pronounced *shingoo*, stands today as one of the main barriers to deforestation in the Amazon and one of the world's most ethnically and linguistically diverse Indigenous territories (Schwartzman et al., 2013). Its protected area encompasses over 2.6 million hectares, approximately the size of Belgium.

Brazil's most well-known Indigenous territory was the first to be demarcated by the government in 1961 to safeguard the lives, culture, and environment of 16 native and displaced Indigenous ethnic groups from seven linguistic families. Among them is the Wauja, an Aruak-speaking group of around 700 individuals who live in the Upper Xingu River basin. They are direct descendants of various groups who migrated from the extreme southwest of the Amazonian basin and established the first villages between 800 and 900 AD (Neto, 2002).

The journey described in this chapter provides a detailed account of our engagement in the Wauja's radical act of resistance to safeguard and access the value of their cultural heritage by combining their collective memory with digital technologies for preservation. They have led a transformative cross-cultural exchange with non-Indigenous artists, researchers, and technologists to undertake a collaborative 3D restoration of their mythological engravings. The collective effort to revive the Kamukuwaká petroglyphs enabled the materialisation of a life-size replica of the restored cave, the development of an educational virtual reality experience for their younger generations to experience visiting the cave in their local schools, and the construction of a museum in their village.

Museums have been heavily implicated in colonising Indigenous cultures, removing cultural properties and treasures from their places of importance, and destroying vital links between people, cultures, and ecosystems. They have helped to perpetuate a long and violent history of displacement, dispossession, and marginalisation of these communities by controlling their cultural heritage and interpreting its value and meaning. Moreover, museums still convey ideologies that largely shape the public perception of these groups and influence narratives of development dependent on unlimited economic growth that are the roots of climate devastation and colonial violence. Recent years have witnessed a shift around museological discourse and practice of acquisition, display, restitution, and repatriation, but 'their underlying logics of preservation, interpretation, curating, education and research remain largely unchallenged' (Harrison and Sterling, 2021, p.9).

The Wauja's resistance offers museum professionals insights into new ways of working *with* and going *to* communities rather than taking things *from* them and their lands. At a time when the adoption of a new museum definition by the International Council of Museums (2022) was marked by an extensive ideological dispute among committee members globally, such principles could fundamentally reorient the purpose of these institutions towards meeting 'inclusivity', 'accessibility', 'sustainability', and 'ethics'. These words have been included in the first significant change in the museum definition in 50 years.

The collaborative resurrection of the Kamukuwaká highlights the importance of community engagement, capacity building, empowerment, and self-determination as fundamental principles of collaborative work. By redefining their methods of participatory engagement with Indigenous communities as *partners* rather than *subjects*, museums can help to illuminate their struggles and ancestral connections to their lands by providing platforms for dialogue and collective climate justice

action. Such practices, however, should not be detached from supporting the fight of traditional communities for historical reparation and environmental regeneration of their landscapes.

Furthermore, this chapter recognises the ability of cultural practices to protect and steward places from climate change and the destructive impacts of human activities. This is especially important since the climate crisis can only be addressed by considering the cultural integrity of Indigenous peoples, who make up just 5% of the world's population but protect 80% of the remaining global biodiversity (The World Bank, 2023).

Kamukuwaká, a museum without walls

Within a region whose material culture is primarily defined by impermanent objects, the Kamukuwaká cave is a museum without walls for the Wauja, a vital cornerstone to the integrity of their cultural identity. It symbolises the symbiotic relationship between humans and the forest and preserves the ancient stories of the first Wauja ancestors engraved on its rock face. The cave is a gateway bridging the human realm and the world of the spirits of nature mediated by the Wauja elderly, who research and interpret the ancestral collective memory of the place. They are responsible for ensuring that the knowledge is translated and passed on from one generation to another, securing the future of the 'practices, skills, and moral principles that came to define the *Xinguano* culture' (Ramos et al., 2019, p.51).

It was in the Kamukuwaká cave and in the Batovi river that our ear piercing, our painting, our music, the rituals, and even the rules of our society originated. Kamukuwaká is our history, our culture, and that is why it is so important for the Wauja people.

(Waurá, 2019, p.12)

According to Akari Waurá (2019), singer, historian, and chief of the Wauja Topepeveke village, the cave was the first Indigenous settlement transformed into stone (called 'Topapoho', translated as 'rock village'), the home of the heroic Kamukuwaká and his people. The petroglyphs activate the retelling of the epic stories of heroes Kamukuwaká, Kuwiyapu, and Yunakato, the creators of the Wauja culture, which for centuries are recounted to the young generations exclusively at the walls of the cave. Embedded within these narratives is a mythology which has shaped and enriched the worldview and spiritual lives of generations and still sustains their millennia-old way of life. The site is associated with the ear-piercing initiation ritual of the young leaders, and the engravings are the source of much of the artistic repertoire widely reproduced in their body paintings, utensils, arts and crafts, agroforestry technologies, and medicinal knowledge (Waurá et al, 2019). (Figure 12.1).

The cave is located by the Batovi River on the border of the Xingu, on the outside of the demarcated territory where the mono-colour soya fields meet and the



FIGURE 12.1 Wauja children learn about the *Xinguano* creation myths at the Kamukuwaká rock art panel. Photograph by Mafalda Ramos.

rich shades of green of the forest. The border is an abrupt line, like a scar separating two opposing environments colliding through space and time. When the protected area was demarcated in the 1960s, the Kamukuwaká and part of the Batovi River were left out. At the time, the Indigenous elders could not speak Portuguese and did not understand what those arbitrary borders meant. As the younger generations grew up and learned about the land's limits, the communities understood their sacred heritage was within private farmlands.

Climate change poses a severe and likely irreversible threat to the site and landscape. The levels of deforestation at the headwaters upstream of the Batovi have resulted in increased sedimentation of the river and the rise of the water levels. These factors have exacerbated erosion, directly impacting the Kamukuwaká sacred rock art panels. Even though it was listed as a heritage site in 2010 by IPHAN (Brazil's National Institute of Historical and Artistic Heritage) in a request made by the Wauja people, the cave is increasingly threatened by planning applications for transport infrastructure. They fear that the planned extension of a highway and the implementation of a railroad to transport grains from Mato Grosso to the Atlantic ports will increase the degradation process of the archaeological complex (Socioambiental, n.d.).

More recently, farmers seeking to expand their soya production have been keen to expropriate the land located on fertile grounds between the river and the forest, intensifying the socio-environmental impacts and conflicts in the region. However, the Wauja have never stopped visiting the Kamukuwaká and claiming the right to

their ancestral territory, history, cave, and river. For years, Akari has been taking the younger members of his community on pilgrimages to the site. Akari knows how to ‘read’ the engravings, which are not a written language like cuneiform or hieroglyphs, nor do they appear to function like the ‘cup and ring’.¹ Instead, the petroglyphs in the cave appear more like a ‘memory theatre’, triggering access to packages of information established as trails in the neural network of collective memory (Lowe, 2019, p.32).

In May 2017, 18 months before we encountered the shattered pieces of the ancient petroglyphs, Indigenous filmmaker, Takumã Kuikuro, piloted an artistic residency programme at the Kuikuro’s Ipatse village in the Xingu in partnership with (PPP) and Factum. The exchange aimed to uncover the potential of digital technologies in supporting the preservation of aspects of his community’s cultural heritage. Combining traditional knowledge with cutting-edge technology, Takumã and Factum’s digital technologists created 3D maps of the village, captured digital images of artefacts and recorded a library of sounds. The experiment led to the development of *Xingu Village* (2018), an immersive installation at the Horniman Museum in London, which allowed visitors to embark on a journey to the Xingu curated by the Kuikuro using augmented reality and video technologies.

After hearing from Takumã about this collaboration, Akari invited our teams to join the Wauja’s next pilgrimage to the Kamukuwaká in September 2018. Factum’s digital experts were asked to register the Kamukuwaká cave using high-resolution 3D-imaging technologies as a preventive measure to preserve the sacred artwork from erosion. During the conversation, he shared the deep-rooted significance of the cave and expressed concern about the impact of human activity on the surrounding environment. He told us that every year, he sees more ‘garbage on the riverbanks, the sand building up in the cave and covering the engravings, the fish dwindling’ – all linked to the contamination of waters by harmful poisons from the relentless expansion of agricultural monoculture (Waurá, 2019, p.12).

We eagerly accepted the invitation and joined the group of independent archaeologists and anthropologists who have been supporting the community to safeguard the region’s heritage in the face of the intensified environmental impact for years. Little did we know at the time that the issue of preserving the Xingu cultural heritage would take a dramatic turn, nor that our work would be profoundly transformed to respond to the community’s evolving needs. The journey to the Kamukuwaká was to become a pivotal moment in the Wauja’s collective efforts to protect the cultural significance of their sacred place for generations to come.

Destruction and collaborative resurrection

Extreme sadness filled the air upon our arrival at the archaeological site. With fragments still lying on the ground, Akari discovered that the mythical stories carved into the stone by his ancestors had been deliberately destroyed with a chisel. Our team stood beside him as he touched the marks of destruction left on the cave

walls, an attempt to erase thousands of years of Indigenous cultural heritage. The unimaginable destruction was a pre-meditated act of aggression towards the Xingu communities at a time of heightened tensions with the farming communities in the borders of the protected area.

The Kamukuwaká vandalism was discovered just two weeks after the devastating fire that ripped through much of the National Museum in Rio de Janeiro on the evening of 2 September 2018. The 200-year-old building, Brazil's oldest scientific institution, was a repository of a world-renowned collection of over 90,000 Indigenous artefacts from Brazil's pre-Columbian history and more than 1,800 artefacts produced by the Indigenous peoples of the Americas. The institution housed invaluable audio recordings of Indigenous languages no longer spoken. Marina Silva, current Brazil's Minister of the Environment and Climate Change, tweeted that the tragedy is 'equivalent to a lobotomy of the Brazilian memory' (Silva, 2018). Realising that the Wauja's sacred petroglyphs would forever vanish into history alongside the National Museum's irreplaceable treasures filled our hearts with sorrow.

Camping for three days at the archaeological site, Factum's digital experts carried out laser scanning documentation activities² that allowed the capture of detailed and accurate three-dimensional information of the damaged surface, meticulously mapping its intricate features and contours. Additionally, they recorded the oral stories told by Wauja historians about the attempt to desecrate the cave as an offensive to sever the vital links between the *Xinguano* ancient cultural practices, their rights to the land, and the region's environmental protection.

After thoroughly analysing the scanned data of the damaged surface in their Madrid studio, Factum proposed restoring the lost engravings to the Wauja through a meticulous process based on visual documentation that the community, multiple researchers, and photographers made available. Skilled digital artisans dedicated months to matching hundreds of photographs to each damaged area, seeking to determine where everything belonged and what had been destroyed. Using digital sculptural techniques, they then generated 3D models of the fragments. These carefully reconstituted elements were finally re-inserted into a digital replica of the cave.

However, only those who grew up listening to the stories of the river and the Kamukuwaká landscape could reveal the inscriptions' significance and bring them back to life. Led by local teacher and filmmaker Piratá Waurá, with support from the local Indigenous Associations and an independent archaeologist, members of Piyulewene village were mobilised in the roles of artists, curators, and researchers. In an exercise of reviving collective memory through images, they re-drew the engraving from memory with pens on sheets of acetate paper laid over a mosaic of photogrammetry scans and printed images of the digital restoration, which were shipped to Xingu from Spain. Piratá recorded the stories and traditions related to each engraving as the elders debated and recalled their memories. These activities enabled the community to evaluate the digital restoration and identify and complete missing information. Their responses provided a fresh perspective on the data, and their corrections were assimilated into the model (Figure 12.2).



FIGURE 12.2 Elder Muri discusses the engraving drawings with other members of Piyulewene village. Photograph by Akaim Wauja.

The sessions stimulated the elders to share more stories with the surrounding crowd of children, who were taken through the myths of the cave for the first time. They were taught that those figures are part of the ancestral values and moral principles left by Kamukuwaká to all the Xingu peoples and are the origin of the Upper *Xinguano* body painting motifs, ceramics, and basketry decorative patterns. Piratá recalled much sadness as the process triggered difficult conversations about the disrespect experienced by the community. It was yet one more of a long list of episodes in which Indigenous sacred sites had been vandalised, profaned, and privatised, restricting people's access to their traditional knowledge and to the land on which they have lived for centuries.

After one year of intensive collaborative work with the community in a largely self-funded and volunteer-driven effort, Factum integrated the community's drawings with the digital data and built a life-size facsimile (exact copy) of the cave, measuring 6.32 m (width) x 3.30m (height) x 4.20m deep. The high-resolution details from the digital restoration were manually integrated onto the surface before applying an acrylic resin, which gave the polyurethane the appearance of the original cave. As there has been a considerable amount of interpretation from the Wauja in the process of restoration, an absolutely perfect replica was unattainable. However, the digital restorers hoped their work would allow Kamukuwaká to remain alive through this story to future generations. (Factum Foundation, 2019) (Figure 12.3).

In October 2019, with support from Queen Mary University of London, Akari and his son Yanamakuakuma travelled to Factum's Madrid studio to unveil the



FIGURE 12.3 Life-size facsimile of the restored Kamukuwaká being mounted at Factum's studio in Madrid. © Oak Taylor-Smith for Factum Foundation.

completion of the facsimile. The restored engravings were met with an immediate emotional response from Akari: 'The Kamukuwaká was in the Xingu, and now it reappeared here!' As part of the visit, Akari led a two-day symposium organised by Factum and PPP that was open to the public to discuss the next steps of the project. It was collectively decided that, before taking the cave to the Xingu, the replica should be exhibited in museums and galleries – such as the Kelvingrove Museum during COP26 in Glasgow or as part of an Indigenous pavilion at the Venice Biennale – as a platform for Indigenous leaders to talk about the devastating impacts of climate change and human activities on communities and ecosystems.

Museums were called to action by the audience members because they are seen as trusted institutions, well-placed to address the social, cultural, political, and economic dimensions of the ecological crisis. However, they were also recognised as both an instrument and a legacy of the processes – such as colonialism, imperialism, nationalism, and industrial capitalism – that have devastated Indigenous cultures. Akari Wauja summarised the importance of showing the facsimile in museums for the Wauja:

People will learn about us, about who we are, where we come from and how we live. They will learn about our history and our struggle, and perhaps they will be able to join us in the fight to protect the cave, the river and our culture.

(Waurá, 2019, p.12)

Enabling digital futures for the Kamukuwaká

Displaying the cave's rematerialisation in museums would be an invitation to address their historical entanglement with the colonisation of Indigenous cultures, which have played a significant role in removing cultural treasures from peoples and places. It would also offer an opportunity for museum practitioners, researchers, and audiences to rethink their engagement with living Indigenous populations and their heritage, encouraging direct engagement and collaboration rather than appropriation and misrepresentation. However, as the gravity and urgency of COVID-19 became apparent, we had to interrupt the plans to display the facsimile in museums and take it to the Xingu. With many museums closed, COP26 postponed, and global travel restrictions, our resources, timelines, and priorities had to be shifted.

2020 marked the second year in countless generations that Wauja children could not pilgrimage to their 'book of learning'. The Wauja's self-imposed isolation to prevent the virus from entering their villages added to the difficulty in accessing their cultural heritage. Concerned that the community's future leaders would be denied the opportunity to learn the cave's stories for an undetermined period of time, Piratá Waurá, PPP, and Factum Foundation started a new remote collaboration to recreate the restored cave in an educational virtual reality interface *with* and exclusively *for* the community.

As the Kamukuwaká's 3D data was accessible only to those with specialist equipment, within this new iteration, it was necessary to provide the Wauja with training in how to use VR hardware and software exclusively through Zoom meetings. Still, within the COVID-19 pandemic, with international funding and a partnership with a local NGO secured, in February 2021, the collaborative effort equipped four Wauja villages with solar panels and paid internet service and delivered VR equipment, laptops, and hard drives in a safe, sustainable, and culturally sensitive way.

Under the leadership of Piratá, our team carefully designed a project framework that addressed the decision-making practices central to the Wauja culture but in a virtual context. The Indigenous Associations nominated a local representative within each of the four villages to discuss the project with the communities. They organised local research and content production teams to document the narratives to feed the VR, to assemble events to trial the prototypes, and to evaluate the outcomes locally, without travel between the villages.

However, this endeavour presented a series of communication challenges and a continuous learning process for the international partners, stemming from differences in languages, disciplines, time frames, and time zones. Unlike previous cultural exchange activities with Xingu communities, which had involved fieldwork and in-person interactions, this time, all stages from co-creation to evaluation took place exclusively in virtual environments. The online workshops frequently had to be rescheduled due to weather challenges, including the unusual flash floods that

hit the Upper Xingu in the initial three months of the project. Since the community itself was the primary audience, the absence of external pressures to uphold a strict deadline allowed for flexibility and resilience in the face of unexpected challenges. This was greatly helped by the trust and sense of security we developed as a group of collaborative partners.

This profound shift in how we engaged with the communities empowered the four villages to feel greater ownership of the entire process. Moreover, it facilitated their access to cutting-edge technologies and to new educational and story-telling tools that have since been used well beyond the original project's scope in school activities and other exchange initiatives, increasing the Wauja's confidence in working digitally.

Returning to the Xingu

It is very dry in July 2022. We are driving back to the Xingu nearly four years after the Kamukuwaká's destruction discovery, 18 months after the COVID-19 immunisation campaign among Indigenous people in Brazil began, and four months before the tight presidential election that ousted far-right President Jair Bolsonaro. I am again mesmerised by the endlessly repetitive landscape of the journey – miles and miles of soy, corn, and cotton plantations – that surrounds our 4x4 as soon as we leave the asphalt roads of Canarana. The burgeoning agricultural town northeast of Mato Grosso is the final stop for long-distance coaches from the modernist capital Brasília to the villages within the forest.

There is little sign of wildlife in the scorched landscape except for heavy machinery going up and down the countless rows of identical farms. Passing lorries carry grain on the dirt roads that cut through the ocean of soya on the central plains of Brazil. Now and then, a billboard announces new drought-resistant pesticides for sale. After 6 hours of driving with windows closed to protect us from the soybean dust that insists on colouring the journey yellow, we start to see a green line rising beyond the horizon. It is a sign that will finally give way to the fullness of the Xingu lands where the desert meets the Amazonian Forest. On the border, a signboard is nailed to a cracked wooden pole. It says, 'Federal Government, Ministry of Justice, National Foundation of the Indian. Protected Territory. Forbidden access to strangers'. The rusty board has more than 15 bullet holes in it. The temperature immediately gets two or three degrees Celsius cooler as we leave the desert of deforestation behind to enter the green island stewarded by the *Xinguano* peoples.

After driving through the forest for 2 hours along the network of roads that connects its various villages, we eventually meet our host, Piratá. He greets us at the Tuatuaru riverbank before taking us to his house in the village of Piyulaga, where his wife, children, parents, and cousins await us. We set up hammocks in his family's house, covered by a gigantic plastic sheet. He tells me that the traditional *sapê*, used for the roof of the houses, 'is growing scarce because of the droughts and relentless fires'. So is the clay from the riverbed used to make traditional ceramic

artefacts because ‘the rivers are too shallow’. The urucum seed, used as body painting and protection against the sun and mosquito bites, ‘is also disappearing’. Furthermore, the fish are getting smaller because ‘the fruits of the trees that drop into the water and feed the fish are too dry and lacking in juice’.

We walk to the centre of the circular village, where we are introduced to the new Piyulaga village chief in charge of 370 people living in 30 houses. The previous leader left to open a new village along the Batovi River. This dispersion pattern reflects the Wauja’s exponential demographic growth over the last six decades and the importance of occupying the most southern limits of the territory, which in the past decades has become a strategic point of protection and surveillance of the Xingu borders.

For the first time, we try the VR of the cave together. Seeing the community’s reactions and interactions with the experience as they identify the petroglyphs and listen to the recorded stories now secured in the virtual realm is incredibly emotional. The technology, unlike anything most Wauja had ever experienced, is overwhelming for some elderly people and extremely exciting for the children and young people who are gathered in the school village for the session.

Piratá tells us that the community came to see the value of bridging their traditional cultural practices with current state-of-the-art technology, even though they were unsure of the outcome during the process. He says that a significant hurdle had been unravelling the significance behind each engraving because many elders and knowledge-holders had already passed away. ‘I was told that I should have been born earlier’ – he tells me – ‘because then I could have recorded everything that our great masters of stories were talking about’.

Piratá filmed historians, shamans, and researchers from the four villages recollecting their versions of the myths and stories, which were gathered and thoughtfully compiled with everyone’s agreement before being incorporated into the VR experience. ‘We were researching our own source of knowledge and building our museum together’. All the recorded materials are backed up in easily accessible formats on hard drives and kept within the schools of the four villages. Piratá reflects:

We are proud of having our stories inside the computer, translated into a new technology. It’s an opportunity for our people to get to know the cave that we can’t visit anymore. It shows what our grandparents fought for, for us and for the future generations. And with technology, our children and young people have even more interest in knowing our origin, in our culture. They are trying out their own identity within technology and how our culture can exist together with it.

Yakuwipu Waurá, a young female leader and teacher from Piyulewene, tells us:

We are most proud that we have managed to record our history and encourage young people to become involved. I am getting a lot of pleasure from seeing the

way that the young people are engaging with our history. Some of them cannot yet read or write, but they can use the VR equipment and are being encouraged to think about other aspects of our culture that we should try to protect and preserve. We are very pleased to have the solar panels in the video in the village for the first time.

The Kamukuwaká VR prototype was selected to be part of an incubator development programme organised by CPH:DOX, Copenhagen International Documentary Festival in 2022. For six months, Piratá was mentored by leading experts in VR technology and collaborated with other international artists who are exploring immersive storytelling and non-contact technologies as new art forms. During the lab, a new idea for an immersive VR experience for museums and galleries emerged and is currently under development. Piratá hopes people can see and feel his community's profound connection with sacred landscapes and how preserving their stories, myths, and rituals is intrinsically linked to their survival and that of the Amazon Forest and the planet. 'We believe that by sharing the story of Kamukuwaká' – Piratá tells me – 'we can help convince the white man not to destroy himself'.

Building a museum of resistance in the Xingu

According to Brazil's first Indigenous art curator, Sandra Benites, what unites Indigenous people 'is our vision of the world and how it relates to our territory' (Langlois, 2020). Indigenous communities share a long-established and non-exploitative connection to their territories and view themselves and nature as one extended family that shares ancestry and origins (Salmón, 2000). These sustainable interactions with the environments in which they have lived for centuries are guided by an intergenerational accumulation of knowledge rooted in their ancestral connections to their territories (Riamit, 2021).

The ability of cultural values and traditions to protect and steward landscapes and enhance community resilience against climate change and human-driven impacts is increasingly being recognised. This shift in perspective became evident at the 27th United Nations Climate Change Conference (COP27), where parties, for the first time, acknowledged the critical linkages between cultural heritage and the climate crisis, recognising culture as a key tool for adaptation (Climate Heritage Network, 2022). Cultural practices are fundamentally adaptive; they are human responses to ever-changing environments through a continuous process of sense-making, adjusting, and communicating the environment. While climate change responses have focused on the devastating impacts on peoples and landscapes, they have often underestimated the immense value of cultural integrity – the capacity for cultural values, beliefs, practices, and traditions to protect and steward communities and places. (Tickell, 2023).

The unrestrained destruction of the petroglyphs has been met with resistance by the Xingu people. They did not allow this erasure of their collective identity;

the culture, knowledge, and memory the petroglyphs represent remain alive in the Xingu. Their sacred land, cave, and river are integral to the Wauja identity and physical and cultural survival. And vice versa, research shows that where Indigenous peoples have collective property rights to lands, there is a significant reduction in deforestation, and the ecosystem is preserved and enhanced. (Baragwanath and Bayi, 2020).

The facsimile of the cave with its restored petroglyphs will finally return to the Xingu in the summer of 2024. In order to host the life-size replica, the Wauja are constructing a vernacular house in the village of Ulupuwene, the second largest Wauja village. With 175 inhabitants living in 19 houses, the village was strategically founded in 2010 to strengthen the Wauja presence by the margins of the Batovi River on the territory's border. The community decided that the new building will serve as a museum where the local families and their visitors can learn about the Kamukuwaká's ancestral knowledge, as well as a monitoring centre to support the community's knowledge production about the environmental changes in the region.

Unlike traditional museums, the Wauja's centre will extend beyond its walls to reveal the symbiotic entanglement between the *Xinguano* culture and the preservation of the environment. This experience will inaugurate the third Indigenous Museum in the Brazilian Amazon (Museu Magüta, inaugurated in the state of Amazonas in 1991, and Museu Kuahi, inaugurated in Amapá in 1998) and the first in the Xingu Territory. It will reimagine the role a cultural centre can play in integrating heritage with a community's daily life by fostering a collective sense of identity and shared stewardship within the local community. The local Indigenous researchers will be equipped to collect, analyse, and share information on water, soil, and air qualities and monitor deforestation levels, forest fires, and illegal invasions inside the territory. For Hukai Waurá, the president of the Ulupuwene Indigenous Association, the Wauja Cultural Centre will be more than just a building that will host the Kamukuwaká facsimile. Their museum is 'everything, it is the entire forest together with our spirituality'.

Summary

- The chapter follows the Wauja Indigenous people's efforts to resurrect the vandalised petroglyphs of the Kamukuwaká cave, the most sacred heritage site for the Xingu communities in the south basin of the Amazon. It narrates the collaborative efforts with scholars and technologists to enable the digital restoration of their cultural heritage through a facsimile of the restored cave and an educational virtual reality experience for younger generations.
- It also addresses the historical role of museums in the colonisation of Indigenous cultures and their potential to reshape discourse and practices. The text offers museum practitioners insights into establishing participatory collaborations with Indigenous communities as *partners* rather than *subjects*, emphasising the

importance of community engagement, capacity building, empowerment, and self-determination as fundamental principles.

- Moreover, the text underscores the role of Indigenous cultural heritage in safeguarding people and places from the effects of climate change and the destructive impacts of human activities. It recognises the cultural practices of the Xingu Indigenous peoples as a key barrier to deforestation in the Amazon.

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Biography

Thiago Jesus is a Brazilian creative producer and researcher. With over a decade of experience managing creative initiatives and interdisciplinary research, Thiago is Head of Climate Action at People's Palace Projects and Creative Climate Leadership Associate at Julie's Bicycle in the UK. Since 2014, he has collaborated with Indigenous peoples from the Xingu in creative exchange programmes to preserve traditional cultural practices. Thiago's doctoral research at Queen Mary University of London, funded by the AHRC, explores climate change approaches by arts-focused organisations. He holds degrees from the University of Westminster and the Federal University of Rio de Janeiro.

Notes

- 1 Prehistoric markings carved or pecked motifs found on rocks and boulders, typically associated with Neolithic and Bronze Age cultures (approximately 4500 BC–1500 BC). They consist of one or more circular depressions ('cups') and one or more concentric rings surrounding them. These markings are found in various parts of the world,

including Europe, North America, Australia, and India, and their exact purpose and meaning remain uncertain.

- 2 Photogrammetric and LiDAR (Light Detection and Ranging) laser scanning technologies were used to map the damaged surface.

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SECTION 4

Agents of social change



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13

NO LAUGHING MATTER? REIMAGINING THE STATUETTE OF A 'COMIC' ACTOR WITH DWARFISM AT THE BRITISH MUSEUM

Dr Isabelle Lawrence

Recent decades have witnessed considerable changes to the way in which access to museums is understood. The ongoing fight to remove physical, sensory, intellectual, and social barriers in museum spaces has expanded since the late 1990s to encompass issues relating to representation, initially because the prospect of increased access to museums by disabled people forced museums to consider what these visitors would find once they gained access. Whose histories, voices and perspectives would they encounter? Would they find the historical and contemporary contributions of disabled people recognised? Initially, activists, academics, and museum professionals drew attention to the underrepresentation and misrepresentation of disability in museum spaces. They argued that disability has in fact been 'buried in the footnotes' of history, while others drew attention to the role of museums in perpetuating stereotypes that shape damaging assumptions about disabled people, past and present (Delin, 2002; see also Dodd et al., 2008; Dodd et al., 2010). In response to these observations, improving disability representation has increasingly been framed as a responsibility for museums, particularly following early projects such as *Buried in the Footnotes: The Representation of Disabled People in Museum and Gallery Collections* (2003–2004) and *Rethinking Disability Representation in Museums and Galleries* (2006–2008). These early projects were led by the Research Centre for Museums and Galleries, initially evaluating the reasons underlying the lack of museum engagement with disability themes and identifying problematic representation, and later working in collaboration with a range of museums across the UK to reinterpret disability-related objects in their collections. Subsequently, advocates for change have recommended several strategies and critical frameworks to ensure ethical interpretation practice in future. Significantly, many of these strategies involve utilising concepts and methodologies derived from the disability rights movement. This includes the social model of

disability, which emphasises the impact of socially constructed barriers that restrict equal participation for disabled people (Sandell and Dodd, 2010).

These campaigns reflect shifts in how museums are envisaged, from ‘objective’ pedagogical institutions that solely exist to conserve and educate, to spaces that can be ‘useful’ to society by engaging with controversial issues, promoting social change, and acting as a platform for activist agendas (Lynch, 2021). Scrutiny of the role museums play in the ‘shaping of knowledge’ or the ‘bordering of truth’, through processes of selection and omission, has cast considerable doubt over the traditionally assumed capacity of museums to remain neutral or objective (Hooper-Greenhill, 1992). This has prompted a variety of academics and professionals to view museums as part of the sphere in which social values and attitudes are negotiated, with the capacity to perpetuate or challenge social injustice (Sandell, 2007, 2017; Janes and Sandell, 2019). This has considerable implications for museum practice, particularly in relation to the narratives they construct and whose expertise they deemed relevant. Rather than relying solely on established disciplinary knowledge, advocates for change increasingly argue for museums to employ a ‘contemporary lens’ that encourages audiences to critically engage with the histories being constructed (Knell, 2019, 2021). In fact, strategies for improving disability representation are also increasingly informed by emancipatory research, or the principle that there should be ‘Nothing About Us Without Us’, which demands that disabled people be involved in any research surrounding disability to ensure its relevance to disabled communities (see Hollins, 2010; French, 2019, 2020). This has given rise to a series of co-production projects, whereby museums are re-envisioned as ‘trading zones’, or rather spaces in which different types of expertise can be shared or placed in dialogue with each other, and in which people with lived experience of disability are therefore valued as experts (Dodd et al., 2017).

This raises an interesting question regarding disability representation in museums: what impact should these ethical frameworks have on the disability history narratives being constructed? This chapter considers this question, concentrating specifically on the potential impact of creating dialogue between people from outside the museum sector with lived experience of disability, and those within the museum sector with more traditional forms of expertise, who may or may not have lived experience of disability. It focuses on a collaborative collections research project entitled *Hidden, Revealed*, which was organised and facilitated in 2021 as part of my PhD research at the British Museum. The aim of this project was to better understand how the museum could improve the way in which it represents disability and its history, and the impact these disability history narratives could or should have on audiences. Over the course of five workshops hosted between January and November 2021, a Consultation Group of 12 participants made decisions regarding the selection and research of 15 objects. The group consisted of six British Museum employees, and six people with experience of researching or engaging audiences with disability history in their capacities as academics, activists, and/or artists. The majority of participants who disclosed lived experiences of disability

were recruited from outside of to the museum. However, multiple participants recruited internally also disclosed similar lived experiences, perhaps reflecting the artificiality of imposing a too rigid a divide between museum employees and disabled participants. Participants not employed by the museum were offered an honorarium, funded by the British Museum's research department, in compensation for sharing their expertise. Critically, more than half of the group had lived experiences of disability, including experiences of chronic illness, learning disability, neurodivergence, and physical impairment. Unfortunately, it was not possible to recruit participants with sensory impairments, an omission that should be redressed in future projects. Nevertheless, this process effectively placed collections-based and museological expertise in dialogue with expertise rooted in disability history research, lived experience, and disability politics.

Significantly, the objects selected by the group anchored discussions exploring ethical dilemmas that museums need to tackle, including risks of inadvertently reinforcing harmful stereotypes and practices. Drawing on their lived experiences of disability, awareness of disability history, or their knowledge of the collection, many participants were subsequently inspired to challenge pre-existing assumptions about disability and disabled people. Perhaps unsurprisingly, the priorities that emerged from these discussions had a significant impact on how a variety of British Museum objects were interpreted by the Consultation Group. In some cases, it completely transformed the understanding of the historical and contemporary significance of these objects. This chapter spotlights a single object: an ancient terracotta statuette that appears to represent an actor with dwarfism. This figurine inspired discussion of experiences of 'disability' in the ancient world, and the subjective and derogatory ways in which such material has typically been interpreted. Charting the way this object was reimagined, it is possible to see the potential of collaborative projects to radically transform how we understand both the significance of individual objects and the responsibilities of museums and heritage organisations.

As a result of my dual focus on both an ancient figurine and issues of disability representation in the present day, it is important to comment on the language used in this chapter. I am using the language of the social model of disability, which distinguishes between 'impairments', which refer to the implications of individual conditions and 'disability', which is created because of socially constructed barriers that restrict the ability of people with impairments to participate equitably in society. While this model and the associated language are not uncontested in the fields of disability studies and activism (see Shakespeare, 2014; Kafer, 2013), it is widely used as a lens for reframing disability within museums in the UK and is therefore a useful tool to make the content of this chapter accessible to as wide an audience as possible. Additionally, I use identity-first language when referring to disabled people in the present day, acknowledging that disability is commonly regarded as a political identity in the UK. However, I also recognise that disability is a relatively modern construct used to categorise a range of impairments and

differences, each of which has held varying social and cultural meanings among different cultures throughout time. For ease of understanding, I therefore apostrophise the category ‘disabled’ as a shorthand when referring to people in the ancient world who might otherwise have been categorised or identified as disabled had they lived in the present day.

‘Head overlarge and extremely ugly’? Archaeological interpretation of the ‘comic’ actor as an object of laughter

Standing with his feet planted on the ground, with one hand raised in the air and the other on his hip, the comic actor is represented mid-performance wearing a himation and possibly a mask (see Figures 13.1). He is one of many terracotta figurines in the collection that represent ancient actors or other types of ‘disabled’ performers. It was selected following a consultative workshop in May 2021 exploring the theme ‘Disability, Early Societies and the Archaeological Record’, during which participants selected five objects to be researched further. Purchased by the museum in 1906, the figurine was excavated from Myrina (also known as Smyrna), an ancient city located in the Izmir Province of modern-day Turkey. At the time of its creation in approximately 100 BCE, Myrina was subject to Roman occupation and ‘Hellenistic’ influences, meaning that the creation of the statuette may well have been impacted by Ancient Greek beliefs, aesthetic values, and artistic norms, which, at this time, increasingly depicted human body types that fell outside of Graeco-Roman beauty ideals. Therefore, the figurine was produced at a time when artists depicted a more diverse range of human life. At the time of the workshops, the actor was described on the museum’s online collections database as having a ‘head over-large and extremely ugly’ (Object Record, Collections Online). Although it is unknown when this description was added to the online database, it is possible that it was lifted verbatim from earlier documentation. More generally, this figurine has often been interpreted as an object intended to inspire laughter as a direct result of the actor’s appearance. In 2015, it was suggested that the artist found ‘comic effect in the contrast between the man’s appearance and his theatrical gesture’ (Jenkins et al., 2015: p. 219). Effectively, it has been assumed that this form of human physicality would have been deemed inherently ridiculous.

In many ways, this interpretation is symptomatic of how such figurines have traditionally been interpreted by archaeologists and historians. The term ‘grotesque’, an archaeological and art historical category, has evolved to refer to Graeco-Roman objects depicting body types that deviate from the classical body ideal and is associated with caricature, ridicule, and obscenity (see Morris, 2022: p. 289; Meintani, 2022: p. 80). Therefore, these ‘grotesques’ have often been categorised based on their perceived ‘ugliness’ or imperfection, as they seem to depict people with a range physical, sensory, and cognitive differences, using both literal and symbolic markers to signify ‘disability’. This categorisation, moreover, has been shaped by speculation about why these figurines were created and how they might have



FIGURE 13.1 Photograph of terracotta figurine of the ‘comic’ actor, 1906,0512.4. © The Trustees of the British Museum.

been used, and informed by how past academics envisaged ‘disabled’ people in the ancient world. For example, it has often been suggested that these objects were used as amulets to ward off misfortune or increase fertility and virility, emphasising the exaggerated features of the people represented. Another explanation is that these figurines represent comic actors of the mime or farce, and that these actors were themselves ‘disabled’ or ‘deformed’. Gisela Richter (1913) suggested that these figurines represented ‘disabled’ comic actors, and while this has been debated, it has since been widely accepted that this was true for at least some of these figurines. For example, Margarete Bieber (1939) in her history of the Graeco-Roman theatre casually suggested that the actors of the ‘farce’ often had ‘abnormally ugly bodies, excessively lean and small’ (pp. 417–419).

Underlying each of these explanations is the expectation that the impairments represented by the figurines become the object of laughter. This is tied to the understanding that Greek and Roman societies believed that images of ‘deformed’ bodies possessed apotropaic qualities which means they were thought to have the capacity to avert misfortune caused by malicious or evil influences. By inspiring the act of laughter, these objects were believed to protect against misfortune or the evil eye (Garland, 1995; Husquin, 2020). Historians have often emphasised these beliefs

to explain the prevalence of imagery depicting entertainers with various forms of dwarfism and spinal curvature in household settings. Garland has emphasised the popularity of ‘deformed’ men and women as enslaved entertainers, citing once more the ‘talismanic’ value with which ancient societies invested ‘deformed’ bodies (Garland, 1995; Husquin, 2020; Trentin, 2020).

New scholarship has, however, raised significant questions regarding the objectivity with which this accepted disciplinary knowledge has been generated. In particular, academics increasingly draw attention to what they frame as a ‘fixat[ion]’ with the idea that ‘disabled’ people *must* have been stigmatised and laughed at in the ancient world, and therefore that objects representing ‘disabled’ people *must* have ‘provided a form of sadistic amusement for the audience’ (Meintani, 2022: p. 33). As early as 2003, Martha L. Rose suggested that assumptions about disability and disabled people, that were or are contemporaneous to researchers of ancient societies, have ‘coloured’ or ‘skewed’ interpretations of the ancient world (Rose, 2003: pp. 1–2). In fact, Rose argued that these ‘skewed interpretations’ serve only to give ‘modern discriminatory attitudes...a historical precedent’ (Rose, 2003: pp. 1–2). Effectively, critiques of this bias destabilise more established interpretations of ‘disability’ in Graeco-Roman societies.

These concerns have inspired a more cautious approach among archaeologists and historians when interpreting such material. Utilising a wider array of sources to examine the treatment of ‘disability’ across textual and material cultures, revisionists have arguably generated a more robust context against which representation of ‘disabled’ people can be analysed. Critically, rather than emphasising stigma and marginalisation as in the early historiography, revisionist archaeologists instead stress that attitudes to ‘disability’ were far more varied and ‘ambivalent’ in Graeco-Roman societies (see Husquin, 2020; Sneed, 2018). This has, in turn, led scholars to strip ‘grotesques’, such as the comic actor, of their stigmatising connotations. Alexandra Morris argues that ‘it is modern day art history that chooses to label such objects as “grotesques” or “dwarfs,” rather than any negativity or caricatured features found in the depictions themselves’ (Morris, 2022: p. 289). In fact, Morris includes our ‘comic’ actor in this analysis, arguing that such figurines instead have the potential to ‘give us a glimpse into what professions could have been considered acceptable for those individuals with dwarfism’ (Morris, 2022: p. 122).

Critical approaches to recontextualising the comic actor

The aim of this chapter is not to attempt to contribute to archaeological discussions around attitudes to disability in the ancient world. Instead, this chapter aims to explore the interesting questions that this ongoing debate raises surrounding how museums could or should interpret the ‘comic’ actor in future. How far, for example, should museum interpretation simply communicate the ‘objective’ findings or theories of archaeologists and ancient historians? Is it also the museum’s

responsibility to explicitly acknowledge the impact of the subjective positionality of researchers and museum professionals on museum interpretation? And could the museum engage its audiences with this object through discussion that moves beyond ‘objective’ analysis of archaeological evidence to wider speculation about the impact of our experiences and biases in the present on how we imagine the past?

Interestingly, workshop participants repeatedly discussed the need for a dual approach to interpretation, rooted in both the past and the present. Participants emphasised the need for interpretation to be built upon ‘a historical, researched perspective’ that was ‘informative of the time and society that made this object’. (Breakout notes: comic actor, 2021). Examining Graeco-Roman attitudes to dwarfism, as well as to ‘disability’ more generally, was clearly significant to participants, who questioned how this might have impacted the statue’s real-life counterparts. There was particular interest in the opportunities and choices that would have been available to people with dwarfism, and ‘how societal infrastructure impacted their life’ (Penny, Meeting 3, 2021; Breakout notes: comic actor, 2021). Participants were particularly interested in evidencing ‘why they were actors and how the audience saw them’ and whether these opportunities would have been ‘narrow’ (Breakout notes: comic actor, 2021; Penny, Meeting 3, 2021). Participants also expressed interest in the possibility of using such research to demonstrate how these attitudes and values changed over time, suggesting that objects be presented in chronological order to better reflect societal change (Paul, Meeting 3, 2021). Clearly, rooting this object in its original sociocultural context was important to participants. Moreover, the emphasis they placed on ensuring a ‘historical, researched perspective’, signals understanding that the credibility of future interpretation requires the establishment of a sound, well-evidenced foundation.

Conversely, however, this desire to uncover lived experiences was accompanied by acknowledgement that the limited archaeological evidence available relating to these experiences has often been interpreted in reductive ways by researchers and museum professionals. Subsequently, this interest in lived experience was also complemented by the conviction that the British Museum needs to find a way to raise questions about this material that destabilise visitor expectations surrounding what life *must* have been like for ‘disabled’ performers in the ancient world. Participants approached this in a variety of ways, many of which involved situating this object within the broader legacy of theatrical traditions in which disability is associated with laughter. Ian, for example, drew attention to the ‘historical wealth of information [about] [“disabled”] individuals that we are aware of, who have been on stage’ (Ian, Meeting 3, 2021). The comic actor’s significance was thereby interpreted as part of ‘a[n] unbroken line o[r] tradition of actors with dwarfism’, that stretches to the present day (Breakout notes: comic actor, 2021). Subsequently, it became appropriate to consider how themes that emerge through examination of this tradition might be used to recontextualise this figurine. Participants repeatedly raised questions that suggested a desire to employ modern-day concepts to

theorise the limited evidence we do have about the statuette's real-life counterparts. Several were keen to explore how consideration of the themes of choice, consent, empowerment, and exploitation might shape how we interpret evidence about the ancient world.

We want to not only celebrate these people, these disabled people, but we should also look at the reason why people act the way they do, explore the reason in depth. *Paul, Meeting 3, 2021*

...it seems a complex story about someone who found a role that worked for them...it's sort of a double thing there. It's like here is a role that's available... this is playing a role in society and having some respected position. But there is also ...what are the things that were available to them? And was it quite a narrow opportunity?

Penny, Meeting 3, 2021

By asking these questions, participants demonstrated interest in engaging critically with this subject. Penny's curiosity about the opportunities that were available to these performers, for example, was expressed out of concern for the level of choice and control these individuals had regarding the professions within which they could work. This implicitly suggests that it might be useful to consider archaeological material in a manner comparable to how 19th- and 20th-century freak shows have been critiqued. Penny's line of questioning is, for example, reminiscent of analyses that examine the 'quality of consent' provided by sideshow performers, and which argue that 'free choice' can exist only in social environments in which individuals are enabled to choose from a significant range of meaningful and unrestricted choices (Gerber, 1996: p. 43).

Participants clearly envisaged the museum and its audiences actively engaging with issues that are potentially controversial and 'uncomfortable' for museum and visitor alike. By questioning the 'quality of consent' of the statuette's real-life counterparts, participants implicitly recommended that the museums play a role in challenging the assumptions made about disability and its history. This suggests a need to consider forms of collection engagement that encourage critical speculation regarding these questions of choice, consent, exploitation, and empowerment. By extension, the perceived responsibilities of the museum expand from simply relaying established disciplinary knowledge to actively encouraging radical transparency, reflexivity, and critical thinking.

'Is he actually being quite powerful?' A radical reinterpretation of the 'comic' actor

Arguably, such a desire for critical speculation also creates a mandate for more creative and inclusive approaches to interpretation. It expands, moreover, the types of expertise that are considered relevant to the interpretation of such artefacts to include expertise rooted in disability activism and ethics, but also, potentially,

expertise rooted in the lived experiences of disabled performers. Crucially, there was willingness among participants to draw upon the perspectives of people with such lived experiences, particularly as these ‘modern perspectives’ were understood to form part of the legacy of the theatrical traditions being discussed (Ian, Meeting 3, 2021). To explore this possibility further, I conducted five interviews with performance artists with lived experience of disability.¹ Strikingly, many of the themes discussed above also emerged when interviewees were asked to draw on their own experiences in response to the statuette. Interestingly, several shared a complicated mixture of positive and negative experiences, revealing a fine line between empowering performance and exploitative spectacle. Paul, for example, described performing on stage as empowering, providing performers with a ‘platform’ from which to be heard, and, critically, to ‘change people’s mindsets’ (Paul, Interview, 2021). However, other interviewees demonstrated the need to navigate the legacy of the ‘freak show’.

I was feeling this level of exposure and lack of control about how my image was being used...so it’s been a really long process basically of exploring a movement vocabulary, of exploring ways of control over my image and how I present myself on a stage or in a film or another sort of medium.

Anon., Interview, 2021

...There were five people at the front, drunk...and as soon as we came on stage, they all started laughing. So this was a laugh-at not laugh-with. And it was pure freakshow, vaudeville, all the things that we didn’t want to be. And the joy of it was each comedian taking them down. Each comedian just peppered them with something. And each time it came up, they peppered them with something else, until, in the end, we squashed them.

Simon, Interview, 2021

Effectively, interviewees drew attention to the complicated dynamics of performance, during which power relations between performer and audience are negotiated, and which performers need to navigate to maintain some control over how they are perceived. Interestingly, moreover, these very personal experiences shaped the way the interviewees responded to the comic actor, suggesting the need for a more speculative approach to the ‘comic’ actor that complicates the overly simplistic interpretation of such objects as either wholly stigmatising or, alternatively, as entirely positive.

Unlike maybe plenty of your life, when you are performing you are in charge, you are manipulating the audience, and I keep coming back to that – how does he compare, this guy on the stage? Is he actually being quite powerful in what we see here, where, in the rest of his life, he may not have that power? Or is it a bit of a Joseph Merrick situation where he is being exploited in the extreme?

Liz, Interview, 2021²

By highlighting the potential for disabled performers to either exert power through their art, or to be ‘exploited in the extreme’, interviewees raised interesting questions about whether it is possible to view the statuette as ‘actually being quite powerful’. In fact, Liz explicitly questioned the comic actor’s categorisation as ugly or ‘grotesque’, instead describing him as appearing ‘self-possessed’, which contrasts with earlier readings of the actor’s pose that emphasised the ‘comical’ juxtaposition of his physicality and dramatic gesticulation (Liz, Interview, 2021).

The inclusion of these modern perspectives in museum interpretation would therefore represent a radical reinterpretation of the ‘comic’ actor, arguably destabilising more traditional interpretations. Critically, such an approach seemed to intrigue the workshop participants when they were presented with excerpts from these interviews in the November workshop, during which participants discussed how to engage visitors with such objects in an ethical way. Participants invested these excerpts with a form of authenticity on account of the interviewees’ personal experiences. Participants repeatedly referred to the short interview excerpts provided, resolving a kind of ‘hesitancy’ among participants who seemed to feel that ‘they didn’t necessarily have the lived experience or necessarily the right to have an opinion’ (Westwood, Interview, 2021). In fact, it was suggested that several participants perceived these interviewees to have a unique ‘authority’ (Westwood, Interview, 2021). This could perhaps be due to the compatibility of these interview excerpts with the participants’ interest in centring lived experience, which arguably encompasses the more intangible, emotional aspects of performing. Effectively, the interviewees were regarded as ‘authentic experts’ with the potential to shed light on the emotional impact of navigating the fine line between empowerment and exploitation (Rasmussen, 2021: p. 91).

This reflects how lived experience is increasingly conceived of, not only as a valuable form of expertise, but also as a useful interpretative tool. In the context of museums more generally, the inclusion of personal testimony is perceived to help audiences in the present to ‘relate’ or empathise with people in the past, by engaging with the ‘emotional aspects’ of social vulnerability (Rasmussen, 2021: p. 90). Scholars, for example, increasingly emphasise the utility of these anecdotes or insights, arguing that they encourage audiences to ‘identify links and common ground’ with people temporally or culturally removed from them, particularly when discussing themes that relate to morality, social justice, and social vulnerability (Sandell, 2007: p. 114). Moreover, it is increasingly seen as expanding the interpretative potential of the museum. Knell, for example, describes the use of personal testimony as offering ‘a way to negotiate and value difference using the particularity of individual experience’ rather than relying solely on established disciplinary knowledge, which is perceived to ‘homogenise and objectify’ (Knell, 2021: p. 169).

Significantly, the potential to include such personal testimonies in British Museum interpretation seems to have been envisaged in very similar ways by participants, framing these modern perspectives almost as potential counterpoints to

more traditional interpretations. One participant emphasised the potential for these perspectives to prompt speculation about the lived experiences of the statuette's human counterparts and their role in society (Penny, Meeting 5, 2021). Importantly, these contemporary perspectives were not framed as a substitute for the disciplinary knowledge established through archaeological and historical research. Instead, they were presented as perspective that need to be presented in 'collaboration' or dialogue with more traditional, disciplinary forms of expertise (Penny, Meeting 5, November 2021). As such, the potential to use direct quotations from people with lived experience seems to have been envisaged as a creative intervention, provoking reflection on issues that continue to be relevant in the present day, while also highlighting the gaps in our knowledge with regards to the lived experiences of the 'comic' actors' real-life counterparts. This could therefore be an extremely useful approach in terms of lending weight to critiques of the way in which the 'comic' actor has previously been interpreted, while also breathing human relatability into what could otherwise be a fairly dry, even didactic, discussion of archaeological evidence, and disability ethics.

From 'extremely ugly' to 'self-possessed': reimagining disability representation for the future

Ultimately, these discussions effectively encourage contemplation of a number of tantalising opportunities for the British Museum to radically reinterpret the 'comic' actor. The consultation process raised extremely pertinent questions for which we have no answers, surrounding the choices and agency available to the statuette's human counterparts. It seems clear that such considerations should inform any major re-interpretation of this object in future, complicating any conclusions that we might draw about what life *must* have been like for 'disabled' actors in the ancient world. Essentially, this suggests a need for the British Museum to explicitly explore multivocality, or the multiple voices or meanings that objects can hold depending on the positionality of the researcher. In this case study, to do so would be to encourage audience engagement with the more philosophical question of how our attitudes, values, and experiences shape what we 'know' about 'disability' in the ancient world, and how this shapes the narratives we 'read' into the objects we study. In terms of the museum, moreover, this highlights the need for the museum to adopt a more critically engaged role when interpreting material such as this. It seems that it is not enough to simply echo the findings of archaeological research that may be 'skewed' by modern prejudices. Instead, participants framed the museum as having a responsibility to provoke self-reflection, and to inject a level of human relatability into its object interpretation that encourages speculation about the lived experiences of the statuette's human counterparts.

The prospect of such a radical reinterpretation of both an object's significance and the museum's responsibilities therefore signals the powerful impact of involving people with relevant lived experience. This could, moreover, be taken further in

a future project with greater scope and resources. The participants and interviewees who took part in *Hidden, Revealed*, as a doctoral project with limited resources, were largely restricted to the role of consultants and therefore did not have the level of control over the project they would have exerted had they been involved more extensively as researchers or co-producers. Any future projects seeking to reimagine disability representation would therefore need to consider how consultation could be transformed into true co-creation. Nonetheless, this project demonstrates the impact that such work can have, even with the relatively conservative level of participant involvement. Critically, the British Museum is actively contemplating future opportunities for such work to take place. Existing efforts have predominantly focussed on creating an audit of disability-related objects in the collection, updating museum interpretation on a case-by-case basis by removing derogatory and outdated language from labels and text-panels, and hosting further consultative workshops with people with lived experience to better understand how to proceed. However, these projects are intended to build momentum towards longer term changes, including potential exhibitions and trails, that are more critical and introspective in nature. The case study of the ‘comic’ actor therefore hints at what might be possible should emancipatory research principles be more fully embedded in museum practice, enabling organisations and communities to reclaim disability from the ‘footnotes’ of history.

Summary

- Lived experiences of disability are a form of expertise that can radically transform how objects, and the disability histories that they embody, are interpreted. It can also transform how museums understand their own responsibilities with regards to improving disability representation.
- Values and attitudes towards disability that are contemporaneous to researchers and museum professionals often shape the way in which evidence relating to past societies are interpreted. Future museum interpretation exploring the ‘comic’ actor needs to acknowledge this with transparency, not only contextualising the evidence that has been accumulated about ‘disability’ in the ancient world, but also encouraging reflexivity on how we construct historical narratives.
- The inclusion of modern perspectives and personal testimony could therefore be a useful interpretative tool to raise questions about the impact of subjective attitudes and values on how we approach evidence of ‘disability’ in the ancient world without resorting to didacticism.

Biography

At the time of publication, Isabelle was an AHRC-funded, post-viva PhD student concluding a Collaborative Doctoral Partnership with the University of Leicester and the British Museum. She organised and conducted the workshops and

interviews discussed in her chapter as part of her doctoral research project, entitled ‘Hidden, revealed: investigating representation and narratives of disability in the British Museum’. With lived experience of brain injury and Special Educational Needs, and subsequently identifying as neurodiverse, Isabelle strongly believes in the importance of representing disability histories in museums to challenge attitudes and assumptions in the present.

Notes

- 1 Two of my participants, Paul and Liz, had their own experience of performing before audiences as part of their work as disability artists, actors and activists. They were therefore involved in this project as interviewees as well as Consultation Group members.
- 2 Joseph Merrick (1862–1890) was a well-known ‘disabled’ figure in the UK who was popularly known as the ‘Elephant Man,’ and who was displayed and depicted throughout his lifetime for both medical and voyeuristic purposes.

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14

CURATING FOR CHANGE

How can D/deaf, disabled, and neurodivergent curators drive change in museums in terms of cultural representation and inclusive interpretation?

Esther Fox

Disabled people are woefully underrepresented in museums, both in their exhibitions/collections and their workforce. Without disabled people in curatorial roles, nondisabled curators struggle to tell nuanced and authentic disability history narratives. At best, there are occasional exhibitions and displays that centre on disability narratives, but they often lack a more complex reflection of disability lived experience. At worst, these perpetuate ableist ideas of deficit and charity, removing agency for disabled people and fuelling negative stereotypes and prejudice.

This chapter argues that without D/deaf, disabled, and neurodivergent people in curatorial roles, we cannot effectively challenge embedded ableist principles that manifest in museums. It draws heavily on practice-based examples taken from the work of the Accentuate scheme in the UK, which includes the Curating for Change workplace initiative for D/deaf, disabled, and neurodivergent people pursuing a curatorial career. These practice-based examples enable the exploration of two key issues: (1) the lack of artefacts and collections on display in museums that relate to disabled people's lived experience reinforces ableist ideas that disability history and identity are of a minority interest and importance and (2) traditional curatorial interpretation of objects and exhibitions within the physical space of the museum prioritises 'normal' bodies thereby excluding disabled people from fully engaging with collections and heritage. This chapter concludes that the under-representation and misinterpretation of disability narratives within museums can be more effectively challenged and addressed by disabled museum professionals and specifically disabled curators.

Screen South, a cultural development and digital creativity organisation in the UK, in 2009 set up a specialist scheme called Accentuate, which delivers projects that break new ground for D/deaf, disabled, and neurodivergent people in the cultural sector, in particular with museums, galleries, and heritage settings. As Head of

the Accentuate scheme, I have devised and delivered a range of initiatives that have sought to tackle the underrepresentation of disabled people within our shared UK national heritage. The first such initiative was History of Place (Fox, 2019). History of Place aimed to reveal the presence and place of disabled people in relation to the history of the built environment. We uncovered a wide range of stories of disabled people who had designed, inhabited, or used eight built heritage sites over 800 years of history in the UK. These buildings ranged from a Medieval Alms House on the Pilgrimage route to Canterbury (13th Century), to the first accessible housing scheme for disabled people to live independently, built in the 1970s. The stories of the disabled people behind these buildings were rich and complex and had not been previously shared. Yet, when it came time to co-curate three exhibitions and displays with M Shed in Bristol, the Museum of Liverpool, and the Victoria and Albert Museum in London, it became immediately obvious that the challenge lies in telling these stories in an authentic and complex way without disabled people in curatorial roles interpreting these narratives. For example, when writing the exhibition text and object labels, nondisabled curators often used overly medicalised language or described disabled people's experiences as 'suffering with' or 'confined to a wheelchair'. The more nuanced explanations of authentic lived experience of disability can only be expressed by a disabled person from a position of 'knowing'. Within the exhibition team on this project, the only person who could contribute the nuanced understanding that comes through the lived experience of disability was me, a non-curator. It was through the significance of this lack of curatorial expertise and experience that Curating for Change, a curatorial work placement programme for D/deaf, disabled, and neurodivergent people, was born.

We know from the statistics that disabled people are significantly underrepresented in the UK museum workforce, currently at around 7% in Arts Council England National Portfolio Organisations (Arts Council England, 2021). We also know from our previous consultation with disabled people across the UK via our surveys and online workshops (Fox and Sparkes, 2021) that disabled people feel their experiences and heritage are not reflected within museum collections or their programming.

...Show me myself and the times that we DID survive and sometimes even thrive... Not only activists. And while you're at it, let's reclaim some of the disabled figures in history for ourselves... Show me where we thrived, not as inspiration, but as evidence that we have always been here, and that we have made vital contributions to the world that non-disabled people live in today.
Curating for Change Survey Respondent 2021.

(Fox and Sparkes, 2021)

Curating for Change is a work placement programme for D/deaf, disabled, and neurodivergent people wanting to pursue a curatorial career, with eight paid Fellowships over 18 months, and eight paid shorter traineeships over 40 days. We are

working with over 20 museums across England, from small local museums like Hastings Museum and Art Gallery, to large nationals such as the Imperial War Museums and the National Railway Museum (part of the Science Museum group). Museum partners were given Disability Equality Training before the start of their hosting, and they have had continued support from the Curating for Change team, in areas such as recruitment and induction and how to work accessibly and equitably with local disabled communities. We have also provided museums with expertise and a budget to ensure the exhibitions and events delivered by our Fellows are accessible, enabling Fellows to build in features such as audio description, tactile models, and BSL-filmed interpretation.

Our Fellows have been undertaking collections research on disability narratives, uncovering many items that have been hidden or neglected, and have worked with local disabled people to co-curate exhibitions and events. Fellows have also been given professional development and training opportunities and been promoted and invited to speak at national events such as the annual Museum Association Conference. This has helped to build their confidence and their professional networks. In the next sections, I will explore in more detail two key issues, first the representation of disabled narratives within collections and, second, the impact of the problematic societal biases towards ‘normalised’ bodies within museums.

Disability narratives within museums

There are two major challenges in museums relating to the dearth of disability narratives within collections. The first is a lack of knowledge as to what material exists within collections, accompanied by an assumption that there is very little with a disability narrative or relevance. The second is a belief, which is rooted in ableism, that disability narratives are of little interest to nondisabled audiences, or in fact to disabled people themselves. This comes from an inherent stigma attached to these stories and the belief that they will make people feel uncomfortable. The first of these challenges is easier to tackle, but the second is deeply rooted in societal prejudice with the ongoing perpetuation of narratives that see disability as something to be fixed, hidden, or pitied.

During the development of Curating for Change, our museum partners expressed concerns that they had limited items within their collections of disability relevance, or that they didn’t know of any items at all. After preliminary investigation, we were able to identify some potential items of interest in all nine of our Fellowship host museum collections. These varied, from intricate drawings of prosthetic limbs found in the collection at the National Railway Museum, York, to a ‘Guinea Pig Club’ badge, issued to World War Two pilots treated for burns at the plastic surgery unit in East Grinstead, found in Hastings Museum’s collection.

Both examples were obvious because they related directly to impairment and, without care, would risk falling into the trap of medicalising disabled people’s lives. Museums often objectify people through the objects they display, where

the disabled person **is** their medical condition or impairment. We lose sight of the individual and at worse we ‘other’ this person and see them as something ‘less than’ or needing to be ‘fixed’. Whereas, if we follow an approach based on the social model of disability, we can start to understand that it is society that ‘disables’ someone, and this disabling is rooted in inequity and injustice. We can then explore more complex identities and experiences that aren’t reduced to someone’s medical diagnosis. What is often missing is the human story. Who was the person who wore the limbs, and why did they wear them? Who was the owner of the badge, and what was their story? It is these stories that add to the complexity and humanising of experience. They also help to connect people, either enabling disabled people to see themselves reflected within collections and history or encouraging nondisabled people to think more deeply about different life experiences and what this might mean for them.

We were convinced that once disabled people were placed within museums as curators, they would be able to discover and interpret the stories of disabled people in meaningful ways. The experiences of the curators support this belief:

Iris Sirendi is a Curating for Change Fellow at the Museum of Liverpool. Iris is an early-career curator of social and community history who is neurodivergent and has a chronic illness. The Museum of Liverpool is a large, modern social history museum which tells the stories of the people of Liverpool through a range of objects and artefacts. The collections are particularly strong in the areas of popular culture and entertainment, working life, labour history, politics, and public health. Iris states:

During my time as a Curatorial Fellow in the ground-breaking Curating for Change project, I have been working in a museum with a collection so extensive it fills two warehouses, and multiple on-site storerooms. I have identified around 90 objects that relate directly to disability heritage, of which only around 20 are on display. Many of the stories are hiding in plain sight. Some objects don’t even acknowledge their ties to disability history.

I have worked extremely closely with all of them, researching their history in detail. Soon, they will form a Disability History Community Trail, where visitors can follow the stories of D/deaf, disabled and neurodivergent people through our museum and through time. Its legacy will outlive my 18 months there, and hopefully, will be expanded once I’ve left.

Whilst handling these objects, I thought about how some of them might not have been looked at in over a decade. Would any of them have been considered for display before this? I’m sure that some of them would, especially with Accentuate’s ‘History of Place’ preceding my work here by only a few years. Then again, this important work was once again delivered by an initiative to promote the visibility of disabled people in museums. Would anybody be interested in these stories without disabled people championing them? Did they matter to the museum without us? They mattered to the people they came from, and especially to me, a disabled curator who sees myself in so many of them.

By not displaying objects that speak to the lived experience of disabled people, we deprive them of the chance to see themselves in our museums. And everyone deserves to experience the pure, unbridled joy of being able to see something and say: “This is for people like us. This is for me”. *Iris Sirendi, Curating for Change Fellow, The Museum of Liverpool 2023.*

Iris was able to explore the collections through a new lens, identifying items that might not otherwise have been considered as having relevance to disabled people. Alongside the disability history trail that Iris has created, there will be a new online collections page that will highlight specific items of interest to disability. The museum had produced a similar trail for LGBTQ+ audiences, but this was the first time it had been created for disabled people. I believe without Iris in this role, it is unlikely that this level of interest and research in the collection would have taken place. I also believe that the lack of knowledge about which items in the collections had relevance to disabled people is indicative of the way disabled audiences and disabled lived experiences are generally not prioritised or considered. Invisibility in collections, and within the workforce, translates into a self-fulfilling misconception that disabled audiences are largely invisible or absent too, despite making up over 20% of the UK population.

Jack Guy is our Curating for Change Fellow at Hastings Museum and Art Gallery. Jack is a neurodivergent person with dyslexia who is early in his career. Hastings Museum is a small local museum, owned and run by the local council, but with a global collection. It owns many items of significance, including important examples of majolica ware, extensive items from the North American Indian Blackfoot Tribe, as well as numerous items of local history. Jack discusses his experience and explains that Hastings Museum:

...Has been part of the Hastings community for over 100 years. During this time, the museum’s collection has grown primarily through local donations and the closure of other smaller regional museums. The acquisition of their collections has placed additional strain on our store. This process was under-planned and hurried and has caused many difficulties, such as infrequent documentation, hidden items and a crowded store. These problems are present throughout our collection but, in particular, affect our disability collection, which wasn’t a priority until the partnership with Curating for Change.

Hastings Museum has a very small collection of around 35 objects that specifically relate to the disability experience. However, many of these objects have been collected to represent a medicalised perception of disabled people. The approach in acquiring has created a collection mainly around themes of charities, disability aids, war and asylums. This has made it difficult to curate, especially for those without lived experience, and has seen the history of disabled people in Hastings generally left unseen.

The majority of disability-related objects in the collection also have no donor listed. Limited time, mistakes, and past disinterest in the person behind

the object, have seen the history of disabled people disappear as they have been seen as irrelevant to the museum and of little interest to its audiences.

To address the central gaps in the museum's collections records and to restore a disabled voice and experience to the objects we have set up a co-production group of local people who are D/deaf, disabled and neurodivergent to research disability-related objects and produce a blog post and an exhibition later this year.

The groups' work researching objects, such as the suffragettes' eugenics talk, straitjackets and workhouse boots, have filled in crucial information that the museum didn't have before. Working with a group has begun to provide a re-interpretation of the collection and has also allowed a small museum with limited space to restore a disabled voice to the objects and create a meaningful collection. We are currently also discussing as a group which new objects we should acquire to represent contemporary disability histories. We hope that by working with the community, we can acquire new perspectives, information and objects that can redress not only the gaps in the collection but also change the museum's perspective on displaying and acquiring items that relate to disability history.

*Jack Guy, Curating for Change Fellow,
Hastings Museum and Art Gallery, 2023*

Jack's experience provides evidence, not uncommon across the range of museums we are working with; that disability-related items in collections have been woefully neglected. The limited information that is found within the catalogues often relates purely to the materiality of the object rather than the story behind it. Worse still, some items do not even feature within the catalogue and are left forgotten and anonymous in the stores, with little hope of interpretation without sustained effort and time to uncover the object's history. This is a problem for cataloguing more generally, but specifically for disability heritage. When collections are not examined, considered, or interpreted by people who have the same or similar lived experiences, at best, the emotional resonance and meaning are likely to be muted or lost, and at worst, biases, prejudices, and negative stereotypes will be expressed.

Without Jack's lived experience and passion to uncover these items, and his approach of working with local disabled people, no doubt they would have continued to remain neglected and unexplored within the museum. This work with his co-production group has now galvanised local community interest, and a greater sense of belonging. The co-producers have been recognised for their contributions via 'thank you' vouchers, as well as being credited as part of the exhibition, valuing their knowledge, and lived experience in interpreting the collections.

Amelia Silver is an early-career heritage professional who became visually impaired in her mid-20s. Amelia is based at the Thackray Museum of Medicine in Leeds. Because the museum explores the history of medicine, the majority of their collection has a medical focus. Therefore, unlike the previous museum collections that had ignored or erased disability narratives, most of the items within this

collection had the potential to relate to disability. However, all of these items were currently understood within the framework of the medical model. This, therefore, represented a different challenge. Ameila describes her experiences:

People with disabilities have historically been over-medicalised, institutionalised, and treated as problems to be fixed. Something ‘other’ than the norm. So, the challenge I faced was how do we represent disability in a medical museum, surrounded by medical implements, with the caveat that the displays all have to link to medicine, without over-medicalising disability. How do we promote the voices of disabled people and highlight their lived experience?

One way is through co-production. This is relatively new at the Thackray, and I was excited to be part of the team that was trying it out for the upcoming temporary exhibition, *Private Parts*.

Private Parts is all about intimate health, identity, and intimacy. It’s a comfortable space to talk about things that can be uncomfortable – including but not limited to intimate medical exams or screenings, equal access to intimate healthcare, body image, sex, sexuality, and relationships. I reached out to various co-producers to tell us their stories, and to help us represent objects in a sensitive way. Two of these co-producers were disabled.

Enter Sarah, a wheelchair-using fashion influencer with EDS and endometriosis. We discussed the speculum, which many vagina-owners will recognise. This is an object that is not necessarily designed for someone with a disability, and the whole experience of vaginal medical check-ups are not accessible to wheelchair users. Sarah told us all about her experiences with the speculum. Most doctors’ offices don’t have adjustable beds, or leg rests that can hold the patient in the right position. The staff often aren’t trained in how to treat a patient with a disability and make them feel comfortable. This can lead to some very uncomfortable, painful, and even degrading visits to the GP, which understandably puts many people off getting their regular cervical screenings, or going to the doctor when they notice a problem.

Obviously, most of this is medical – so how do we present this information in a way that doesn’t make disabled people seem singular? Well, we also talked about sex. And not the kind of gentle, vanilla, careful sex that people may think disabled people engage in, if they even have sex at all! Basically, we’re putting a bondage whip in her case and discussing how disabled people are not only over-medicalised, but also de-sexualised. [The ableist assumptions can be] Disabled people don’t want sex, can’t have sex, are too fragile to have sex. Disabled people don’t understand sex or don’t have sexual desires, can’t have fulfilling relationships, get married, or have children. And if they do, they’re not adequate parents or they’re putting a caring burden on their children. By extension, disabled people are often not thought of as being part of the LGBTQI+ community. [These prejudices and ignorance’s are what the exhibition is trying to upturn]

Now the exhibition is live, we will input the object labels into the Content Management System so we can keep this information forever. Otherwise, all that hard work us and the co-producers put in to create this exhibition will just be lost. These are just a few of the ways we are collecting new stories for old objects, and changing our way of contemporary collecting.

*Amelia Silver, Curating for Change Fellow,
The Thackray Museum of Medicine, 2023*

Amelia's case study demonstrates that many objects, even those that are not obviously associated with disability, can tell a story about a disability experience. I posit that objects that have a shared relevance for disabled and nondisabled audiences alike (e.g. the speculum), have the power to engage with a greater number of people and change attitudes. These stories will have resonance with all and will combat the myth that disability narratives are of no interest to 'nondisabled' audiences. They also challenge the othering and stigma that is associated with a marginalised view of disability. Seeing an object that is easily recognisable for all, and then hearing a personalised perspective from a disabled person that illuminates a new way of considering the world and indeed, humanity, enables a space for connection and understanding, as opposed to fear and prejudice.

This approach, of embedding disabled people and their histories within museum collections and exhibits, is something that many of our Fellows feel passionate about. They have expressed the sense of belonging that is so important when we see our lives as disabled people reflected with authenticity and complexity.

Claudia Davies, our Fellow based at the Black Country Living Museum (Dudley) is in her early museum career, is deaf, and wears two hearing aids. The Black Country Living Museum is a living history museum which aims to bring Black Country folk back to life, from metalworkers and miners to nurses and schoolteachers. Visitors experience sight, sounds, smells, and tastes of the Black Country as they explore the shops, houses, and industrial workshops. Claudia shares her experience:

I remember visiting a museum which had a 19th Century sign language mug and although I am deaf, I am not a signer, but it really made my day as it is rare that objects represent D/deafness or tell those stories. My own reaction to this instance really highlighted the importance of representing everyone in society, regardless of who they are.

*Claudia Davies, Curating for Change Fellow,
Black Country Living Museum, 2023*

The Fellows are also, quite rightly, impatient for change and recognise the power of sharing disability narratives, to not only engage with disabled audiences but also to provide a platform to foreground ideas about what it means to be human and how we connect with each other. This is expressed by our Fellow Suchitra Chatterjee,

a wheelchair user based at the Historic Dockyard Chatham. The story of Chatham Dockyard and its people is told via exhibition galleries such as Command of the Oceans and the Ropery as well as through the exploration of three historic warships and objects related to the Dockyard and the wider maritime world from the collections of Royal Museums Greenwich and Imperial War Museums. Suchi explains:

Museums have a chance to step out of the shadows of their complacency and take on disability history and put it on display for all the public to come and see. There are plethora of stories, artefacts, objects, and images that fit in with mainstream history, however uncomfortably, they fit, and these stories need to find their place in every museum in the UK. It is easy to say that the lack of objects reflecting disability history etc in museums could enforce an ableist view of disabled people, but even non-ableist people are guilty of marginalising disabled people, with many thinking that just access to the museum itself is good enough, why would you want anything else, if you have that?

What interest is there in the life and voice of a disabled person from 200 years ago? Disability history is far from being of a minority interest or value, it is a definition of what it is to be human, and it NEEDS to have its place in museums, educating people and letting them know that our lives aren't about being inspirational, but rather about being part of the story of what makes humans, human.

*Suchitra Chatterjee, Curating for Change Fellow,
The Historic Dockyard, Chatham, 2023*

The stigma associated with disability in society, which is rooted in the deficit model, will take museums longer to address and this will only be possible if we move away from one dimensional depictions of the disability experience, which continues to 'other' the individual.

Perpetuation of the myth of normal bodies

Museums assume audiences have 'normal bodies'; experience the world in terms of 'normal' vision, hearing, and mobility; and therefore predominantly exhibit their collections and temporary displays from this position. However, we know this is a problematic assumption to make, when over 20% of the UK population identify as having an impairment or health condition. Not only does this assumption perpetuate ableist ideals of what is regarded as 'normal', othering those who do not fit this standard, but also it continues to exclude people who wish to engage with museums, their artefacts, and stories, if they cannot physically access this content due to their impairment.

The presentation of the disabled body as the 'other' also resonates with similarly marginalised and prejudiced communities; we therefore have much to learn about how this representation sits alongside other initiatives such as decolonisation. When

I first had conversations with our museum partners, they expressed reservations about focusing on disability stories, as they felt this could restrict the scope of the work our Fellows. However, what was being left unsaid was they didn't think the disability story would be of interest to audiences, and perhaps, it was best left hidden, just like disabled people themselves had been. It was only when I compared the disability narrative with other human rights movements, such as decolonisation or LGBTQ+ rights, that our partners felt more comfortable about telling these stories. It was as if before I mentioned this connection, they had not been able to consider these lived experiences and narratives from such similar perspectives. We must continue to challenge the notion that disability is the 'other', to be pitied or hidden and instead champion a narrative that puts the disability narrative centrally within the context of shared human experiences.

Our Fellow, Kyle Lewis Jordan is an early-career academic who is a wheelchair user with Cerebral Palsy. Kyle is undertaking a joint placement hosted by the Pitt Rivers and Ashmolean Museums in Oxford. The Pitt Rivers Museum was founded in 1884 and houses more than 500,000 objects, photographs, and manuscripts from all over the world and from all periods of human existence. Founded in 1683, the Ashmolean is the University of Oxford's Museum of Art and Archaeology. These two world-famous museum collections range from Egyptian mummies to contemporary art, telling human stories across cultures and time. Kyle describes his experience:

Investigating the archaeological collections of the Ashmolean and the ethnographic collections of the Pitt Rivers, I'm conscious of how the exploration and identification of disability histories in these spaces overlaps with the unravelling of their colonial legacies. Correcting ableist notions of "deformed" bodies within the Museum is crucial not only to unpacking our own social history – which saw the judgement of the human body by its capacities and capabilities in the wake of the Industrial Revolution, leading to the modern classification of "disability" – but also how these notions of "deformity" and "otherness" were created to justify the colonial practices of states and their institutions who utilised them against various indigenous populations around the world. Ergo, it quickly becomes apparent that disability histories are relevant to everyone, and an integral part of efforts to decolonise the museum.

Traditional museum interpretation relies on a neutral tone, where the one speaking is not the curator but "the Museum" at large. The problem there is that the curator will inevitably bring their own subjectivities regardless, but when the visitor reads the label, they hear only "the Museum" and thus something they feel is rooted in absolute fact. Thus, when a visitor encounters very few or no examples of disability within a display case, they may unconsciously accept that this is the reality: that there is nothing to see, or if there is anything at all, it exists only at the margins of history.

My hope with the project at the Ashmolean and the Pitt Rivers is to demonstrate not only how disability has been present in so many periods of history,

and how relevant it is to various different aspects of life in societies across the globe, but that by working with a local group of disabled co-producers we can create interpretation that does not seek to speak with a neutral tone, but rather a characterful set of dialogues that expresses the diversity of experience and our relationship to objects, making the Museum space more of an avenue for fostering understanding across society rather than solely being a repository of “things” past and present.

*Kyle L. Jordan, Curating for Change Fellow,
The Ashmolean and Pitt Rivers Museum, 2023*

If we start to see museums as radical social hubs, as a meeting place to explore human existence, both past and present, we must include and enable the plethora of human experience to be visible, present, and engaged.

Alongside diversifying the stories that are told within museums, we must also be more fluid, far-reaching, and innovative in how we display and interpret artefacts. This relates to the ‘curatorial voice’ and who has the knowledge and power to tell these stories, but it also connects to the materiality of museums and their collections. How do we experience the object, do we rely predominantly on vision or an expectation that audiences will be mobile and standing? How do we navigate the space itself and can we even get to the museum to experience their collections?

The Covid-19 pandemic proved that things could change and, in some instances, why radically re-thinking how audiences engage with museums and their artefacts is essential. Suddenly, all audiences were excluded from real-world spaces and, at this moment, many museums who wanted to remain connected to their visitors and communities embraced digital technology to open access to collections and spaces. This didn’t only benefit nondisabled audiences but was something that many disabled people had been requesting for years. Activities and collections were now accessible for people to engage with from their own homes, rather than having to negotiate inaccessible spaces, transport or dealing with pain or fatigue that can prevent physically getting to venues. Digital technology also provided opportunities to remove barriers in terms of careers within museums. Previously, disabled people had requested Zoom interviews if energy levels had made it difficult to travel long distances, but they had been told this wasn’t possible. Yet, during the pandemic, everyone was being interviewed online and meeting via Zoom. The challenge now is how to sustain what worked well during this time, not letting a flexible approach for engaging online or in-person to shift back to in-person only.

I believe we need to make the boundaries between the museum and the audience, the physical and the virtual, the body and the artefact, more porous. The digital world offers many opportunities to dismantle these boundaries. Audiences expect more from museums now, they want to find curated online collections and 3D models of artefacts to explore from home. This also potentially presents opportunities for disabled people to engage more easily. We also must ensure we are considering and implementing access within these digital experiences, such as BSL

interpretation, captioning, and audio description. This is an area that needs more work.

An initiative we piloted during the pandemic was the use of telepresence robots to provide guided tours of Hastings Contemporary, a gallery on the South Coast of England. When Covid forced Hastings Contemporary to close its doors to the public, the trustees and staff were keen to sustain the gallery's vital social role through digital means. So as a Trustee for the gallery, I teamed up with Prof. Praminda Caleb-Solly, of Robotics for Good and Hastings Contemporary to trial the use of a telepresence robot to enable access for the public whilst the gallery remained closed. Praminda and I had previously been using this technology with disabled people who were physically unable to get into museums or attend events. Suddenly, the technology, which had perhaps appeared 'niche', became a significant opportunity for all audiences in terms of engagement with museums.

During lockdown, approximately 350 participants experienced tours via the Robot, exploring the exhibitions with a 'live' guide in the gallery. Groups of five people came together via the robot to share this experience, connecting people from across the globe, whatever their background. This experience highlighted the power of telepresence technology to not only open up access to museums and their collections/displays, but also to galvanise people who may otherwise not have the opportunity to meet, through a shared visit to the gallery. At the time, we hadn't been able to consider how best to make these tours audio described or BSL interpreted. This became something we wanted to develop further in the next phase of the work.

Coming out of Covid, Hastings Contemporary secured funding from the Museums Association to further explore the possibilities of telepresence digital technology in engaging audiences, focusing on two target groups; school groups that were increasingly finding it hard to manage the resources and logistics required for in-person visits, and disabled people and those with health conditions that prevented them from visiting the gallery in-person. We created a film, interviewing gallery staff, participants, and the project team about the potential and the challenges for using this kind of technology in museums.

Robot tours provided an excellent way of dismantling boundaries by combining the convenience of being at home with placement at the heart of the museum/gallery. The most common way museums try to reach people who do not normally visit museums and galleries is through outreach, which has often failed to make the link back to the physical museum space. Robot tours – like other virtual media – are helpful because they operate in both spaces simultaneously. Also crucially, rather than offering a passive experience, robot tours allow the audience members to co-control the route and perspective of the robot. This gives a sense of agency to the person/people experiencing the tour.

Another common feeling for new visitors or those with anxiety or neurodivergence is a sense of being overwhelmed. This is also addressed in the robot tours because they give a bespoke structure to the tour, enabling the audience member/s

to choose the terms of interacting with the space and the work. The tours often took place during quiet times, so it mitigated the challenge of fighting through crowds and enabled a more intimate experience. The robot provides an opportunity for a more embodied experience, as you physically move through the space, engaging with the works at standing height. We also combined live audio description of the works, by a guide, to enable those with visual impairment to engage with the works via the telepresence robot.

Telepresence Robot Tours are just one example of how audiences can engage with museums and their collections' via digital technology. It is important to acknowledge that these kinds of tools are not of minority interest (e.g. only for disabled people) but offer transformational ways for museums to expand their audiences and remain relevant and dynamic connective spaces for all.

Museums need to move away from the myth of the normative body within the museum itself. They also need to continue to develop digital provision, in the way that they began to during Covid, in order to maintain and develop forms of access for people who are experiencing the museum remotely, who may be unable to get inside the museum. This could be because of geographical location, physical or mental capacity. Thinking about audience engagement and provision in new ways, that includes digital provision, will enable museums to be more relevant and accessible spaces, in turn increasing their resilience.

Conclusion

If we combine these approaches of re-thinking who is working in museums and telling the stories, whose stories are absent, along with more radical ways to engage audiences, dismantling the boundaries between the physical experience and the virtual one, then perhaps we will really see the potential museums offer for individuals, communities, and the wider world.

Disability stories are present throughout history and throughout collections. Existing collections can be re-interpreted through a new lens of disability experience and this can bring together disabled and nondisabled people to explore what it means to belong, see ourselves reflected, and what it means to be human. Working with local disabled communities to co-produce and re-interpret collections is an extremely useful tool in terms of widening the narrative and bringing collections to life.

Disabled people working in curatorial roles are best placed to challenge the absence of disability narratives within our museums. They understand the nuance of how to bring a disability perspective to an object and have the drive to undertake the research necessary to uncover hidden items within museum collections. Without disabled people in curatorial roles, it is unlikely this work will take place and disability will remain largely marginalised and not prioritised.

Boundaries between the physical space, the artefact, the body, and the audience need to be more porous as does the boundary between the curatorial voice

and the lived experience of audiences. Using digital technology is just one way to dismantle these barriers and encourage more wide-reaching engagement with audiences.

Summary

- Disabled people working in curatorial roles are best placed to challenge the absence of disability narratives within our museums.
- Disability stories are present throughout history and throughout collections.
- Using digital technology is just one way to dismantle the barriers between physical space, artefacts, bodies and audiences, and these technologies can encourage more wide-reaching engagement with audiences.

Biography

Esther Fox creates landmark opportunities for D/deaf, disabled, and neurodivergent people to participate and lead within the cultural sector. As Head of the Accentuate scheme, she works with cultural organisations in the UK and internationally, recently with 30 museums across England, creating fellowships for disabled people pursuing a curatorial career. As an artist and researcher, Esther explores the synapses between medicine, art, heritage, and digital. Esther identifies as a wheelchair user and believes her identity as a disabled person is the cornerstone of her professional and creative practice.

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15

INCLUSIVE DESIGN AND ACCESSIBILITY

A methodology of perpetual evolution
and innovation

Corey Timpson

This chapter will explore the foundations and ongoing evolution of Corey Timpson's inclusive design and accessibility practices. Developed in earnest at the Canadian Museum for Human Rights (CMHR) between 2009 and 2017, Corey initiated, directed, and led the inclusive design practices that saw the creation of a museum that welcomes the widest possible audience. Concurrently, developing and applying such a methodology across the enterprise of the organisation – its programming (including exhibitions), museological practices, operations, outreach, communication, media, and events – during its inaugural capital design-build was a daunting task that required an enormous amount of coordination, iteration, collaboration, and nimbleness. The approach to inclusive design and accessibility at the CMHR was ripe with preconceived incongruencies, stakeholder management complexities, community engagement ambitions, various forms and sources of rhetoric, and competing demands. And yet, this deliberate approach led to innovation in design and a museum that provides unparalleled accessibility for its audiences.

After the museum opened in late 2014, this methodology evolved and widened, and it has continued to evolve through its application on projects with museums, galleries, archives, libraries, location-based entertainment, theme parks, and sports venues, of varying staff sizes and resources since. This methodology is ongoing and forever evolving. While the contexts change – subject matter, geographic location, size and scope of project or programme, mandate of the organisation, etc. – certain aspects remain consistent. The methodology is of utmost importance, and the application of this methodology evolves, adapts, and changes based on the unique characteristics of each context. New challenges are presented daily, and in these challenges, new opportunities are yielded, and innovation is realised.

This chapter will explore the intentions and outcomes of this inclusive design methodology. Across projects large and small of varying organisational types

and mandate, the quest for radical inclusion is perpetual. Through the continual application of this methodology, lessons are learned and the opportunities for deep, meaningful, accessible, and inclusive audience engagement are rich and plentiful.

At the National Museum of African American History and Culture (NMAAHC) in Washington DC, the Greensboro Lunch Counter installation presents the story of the Greensboro Sit-In. This is a very important segregation story from the US Civil Rights Movement where four Black students in 1960 sat at the ‘whites only’ lunch counter in a Woolworth’s in Greensboro, North Carolina, US, were refused service, and were subsequently subjected to dehumanising abuse. The mixed-media installation within the museum has some access affordances such as high-contrast typography and graphic design, video captions, and forward approach for those in a seated position. The unfortunate irony is that this installation on segregation segregates the audience based on ability and disability – a wheelchair user, for example, must navigate down to the end of the counter and use the section that has been lowered, to meet the ‘Americans with Disabilities Act (ADA)’ requirements. The counter is accessible. It is not inclusive. The installation, extolling the maliciousness of segregation, segregates. Intersectional identities are inherently ubiquitous, and one need not extrapolate their thinking very far to realise the unfortunate and unintended outcome of staff at NMAAHC having to direct a Black patron in a wheelchair down to an alternate portion of the Greensboro Counter.

Rather than attempting to address abilities and disabilities individually, a better approach is to apply an inclusive design methodology and consider all vectors of human difference at the outset. The starting position must be from a place that acknowledges each individual has multiple ways of identifying (e.g. gender, race, interests, education, social status, culture, and disability), multiple ways of engaging with something, and that people are dynamic – they change from day to day. By casting the widest net possible as a prerequisite before starting, we are far less likely to inadvertently create barriers. Developing ideas of how to welcome the widest possible audience within a specific design intention is critical in establishing efficient projects that yield inclusively accessible outcomes while also delivering a greater return across strategic performance metrics such as visitation numbers, repeat visitation, audience reach, and audience demographics.

Structured beginnings

The most critical aspect in designing and developing inclusively accessible experiences or products is making informed, deliberate decisions. A simple statement, easy to perform in theory, more complicated to ensure in practice. Imagine making a decision, the outcome of which will be considered suboptimal for some reason. In the case of the deliberate decision having been made, mitigation tactics can be applied, soft tactical solutions (solutions not built natively into an experience) can be developed, expectations can be pre-managed, consistent communication language can be developed and perpetuated, and much more. If the decision is not

deliberately made, is made by default or simply not made at all, then none of these mitigation tactics will be planned for and developed, and barriers, or unexpected barriers, are more likely to exist.

In teasing out the idea of making informed decisions, emphasis is placed on ensuring decision-making is informed by a plurality of perspectives. This means ensuring feedback, insights, data, and more is captured and leveraged from diverse sources, beyond the museum team. Advisory teams and working groups, prototyping and testing participants, must be multidisciplinary, interdepartmental, diverse in subject matter expertise and professional disciplines, and include those with a range of lived experiences. Idea generation and decision-making should draw on data and analytics; however, it is equally important that this material should be from a plurality of sources, ideally those that have rigorous methodologies in ensuring diversity and drawing on analysis and interpretation frameworks that do not perpetuate bias or deficit positioning. In other words, it is important to challenge traditional data collection and interpretation frameworks that have existed to demonstrate how historically marginalised communities are at a deficit or exist within a gap – higher mortality, higher health issues, more violence, without demonstrating the strengths or different contexts of a community that may indicate difference versus deficit.

Deliberately structuring how to inform decision-making, and ensuring the processes, roles, responsibilities, and decision-making authority are well understood by all participants, is critical to having efficient and collaborative workflows and a well-functioning, informed project. Fundamental to this approach is working directly with, and building trust with the communities and community members who will help inform these projects and their development. When constructing advisory teams, clearly articulated, and mutually realised terms of reference that will govern these activities are critical to managing the expectations of all involved while ensuring useful, practical outcomes for both the project and the participants who are generously providing their time, insights, and lived experiences. Not all decisions will be arrived at via consensus, especially as the plurality of perspectives feeding into decision-making grows in diversity while subjects for contemplation increase in complexity. When decision makers inform their decision-making, it also allows for suboptimal decisions to at least be communicated, understood, mitigated, and overall, for expectations to be managed.

Ensuring inclusive design and accessibility is integrated into all phases of a project's design and development is critical to avoid schedule, budget, and/or stakeholder impacts later down the project schedule that would otherwise have been easily avoided. This means accounting for and supporting inclusive design through project management, project direction, and project administration via tactics that ensure it is consistently surfaced, addressed, and kept at the forefront of decision-making. Project schedules and planning must account for iterative design cycles of design, feedback, and iteration.

While there may be an inclusive design and accessibility champion on a team, the approach to inclusive design requires shared ownership. A patron of an experience or user of a product is not concerned with what the curator did vs the collections manager vs the designer vs the media producer vs the fabricator vs the operations manager. The audience member is concerned with having an accessible, enjoyable experience they can participate within. The delineations in roles and responsibilities are important for project accomplishment reasons, but the visitor shouldn't ever be able to glean seams in their experience based on who worked on what. All the pieces of a project must work together in concert for an experience to be inclusively accessible, and this requires a distributed, yet synchronised, effort.

The ecosystem

Getting to the tactical level of inclusive design, thinking and attention must operate at both the broad and detailed levels. Across the project, consideration needs to be given to the intentions of the project – strategic goals, curatorial intent, design intent, interpretive, and learning objectives, and so on. Just as the project has intentions, it must also meet the intentions of the audience otherwise barriers will occur.

Evaluation (front-end, formative, summative, testing, mock-ups, prototyping, etc.) is an important aspect that will validate, invalidate, and ultimately inform project intentions and design decisions. Ensuring the expectations and intentions of the audience (in its widest diversity) are accounted for when developing the experience or product creates more informed and efficient outcomes while also contributing to ambassador and audience development.

- Front-end evaluation is done at the outset of a project and uses probing questions and scenarios in an attempt to surface audience expectations, knowledge, commonly held biases or misconceptions and is used to help establish baseline in terms of starting points for stories, storytelling, content, and experience. This form of evaluation can provide important insights into usability, inclusivity, and accessibility in terms of content and experience.
- Formative evaluation takes place during design development and uses mock-up, prototyping, and testing scenarios to validate and invalidate various aspects of narrative and content development as well as design – interaction design, interface design, graphic design and presentation, media design and development, and overall experience design – to inform design processes moving forward. Formative evaluation is not only a critical aspect of an inclusive design methodology but also helps with community, stakeholder, and ambassador development.
- Summative evaluation is done at the end of a project and the beginning of the exhibition, programme, and/or product's life. Summative evaluation can lead to both remediation work and the iteration of design approaches for future projects so that they start from a position of having been informed by the previous work.

Many groups will contract specialised evaluation resources to conduct a full evaluation programme across the duration of the project. If performing evaluation in-house, the same phases of front-end, formative, and summative evaluation can be undertaken. None of these steps need to be costly or arduous activities. Be sure to follow best practices in ensuring a plurality of participants, while also ensuring internal biases, or the perceptions thereof, are counterbalanced.

Critical to evaluation work is ensuring the project schedule accounts for evaluation and subsequent iteration. There is no greater barrier to engagement than inaccessibility.

When referring to an experience design project – an exhibition, programme, event, installation, ride, etc. – the broad perspective is to consider all the various aspects that together comprise the experiential ecosystem a visitor will find themselves within. These include:

- The content and information design (how content is developed, organised, and written)
- Graphic design and presentation of information across media and space (how content is presented graphically – printed, built, digital)
- The built environment (galleries and spaces, museum infrastructure, exhibitory, scenography, props, furniture, artefact cases, seating, etc.)
- Time-based media (film, video, audio)
- Navigable media (digital interfaces, kiosks, games, tables, etc.)
- Digital systems (digital asset management systems, web content management systems, collections management systems, enterprise search, etc.)
- Humans (staff, volunteers, visitors)
- Audiovisual systems and presentations (projections, monitors, music, soundscapes, etc.),
- Service affordances (collateral, large print guides, braille guides, tactile maps, access devices)
- And more.

Each of the facets at the broad perspective needs to be designed and developed to be inclusive. Then when aggregated, everything must work together, contributing to consistently and systematically surfaced access affordances.

In the following example, the largest gallery at the CMHR is displayed (see Figure 15.1: CMHR Canadian Journeys). It contains a dense amount of content expressed through dozens of stories. It also contains various graphic design aesthetics thematically related to the stories being presented. The gallery makes use of a variety of interaction designs – passive (read, watch, listen), active (play a game), and interactive (dialogic, tell a story, respond to something). The gallery's fabric is mixed media containing various audiovisual and digital media installations, synchronised lighting programmes, tactile and touch objects, immersive set designs, video games, art installations, and more.



FIGURE 15.1 The largest gallery at the CMHR contains the greatest diversity in stories and their expression – graphic and environmental designs, scenography, interaction design, interfaces, media, and more. Yet, the ecosystem works in concert ensuring inclusive access for all.

Yet, within this space, the facets of the ecosystem work together so that while stories each have their own discrete thematic presentations and interaction designs, visitors spend more of their cognitive and physical energy on the content and the experience vs learning how to access the content and experience.

Be mindful that while the approach to designing an inclusive experiential ecosystem across a museum or exhibition is consistent across projects, the design tactics implemented within each project within that broader ecosystem are unique to the project's characteristics and context. Too passive and the audience risks being bored. Too active and the audience risks being overwhelmed. There is no formula that states x percentage of the interaction design should be passive vs active or interactive, or of style A vs style B. However, mapping out design and curatorial intentions, lining up which types of design (style, interaction, medium) work best with which stories, and many more design approaches are informed by the designer's experience, by thinking of the entirety of the experience in addition to the discreet installations, and through testing and prototyping.

In the CMHR's Canadian Journeys Gallery:

- The content is at a set reading level that has been balanced with expected dwell time and appropriate character counts and line lengths. Plain language versions are available via digital and printed materials. Some of the concepts in the content at this museum, when unpacked into simpler language, would result in much larger word counts and longer dwell times. Being subject to the Official

Languages Act of Canada, the museum also presents all content in at least two languages (English, Français) and therefore informed by testing, decided on a ‘not to exceed grade 9’ reading level for all content. Plain language versions are available as handouts when not built into the installations.

- The graphic design is accessible – from typeface selection (ensuring strong glyph distinction among letters and numbers), to colour contrast between fore and backgrounds (ensuring various colour-blindness access). Text is laid out in clear hierarchical structures to facilitate pan, scan, and dive on content, with tested and implemented size-to-distance ratios and viewing angles of content (text and image) from expected viewing positions accounted for, ensuring more comfortable viewing for all.
- The built environment includes strong edge detection between walls or cases and floors; all seating is accessible containing armrests, backs, no armrests and no backs at times, adjacency spacing, transfer seating, bariatric seating. Tactical lighting for artefact preservation and accessible pathing is in place. Audio controls for both the entire gallery (visitor services staff use) and at individual installations (user controlled) are available.
- A/V materials including a full suite of child asset access affordances – captions, signed interpretation, audio description, volume control – in both English and French are always present.
- Digital systems facilitate navigation of tangible and graphical interfaces via screen reader and keypad, as well as screen reader and mobile device.
- Braille and tactile maps are available from visitor services.
- Staff have been trained for inclusivity and accessibility.
- All content is accessible via the museum’s mobile app through both interpreted audio guides and also through simply presented multimedia assets (text, image, video, audio) allowing autonomous/unfacilitated consumption through typical web-style browsing.

The importance of this example is to demonstrate that all facets of an ecosystem must work together. A video may have captions and American Sign Language (ASL) included but if it is set into an interface that is not accessible it is not going to yield an inclusive outcome and may not yield an accessible one either. And if the media has the requisite affordances, and the interface is accessible (i.e. WCAG compliant), and it is built into a kiosk that is not reachable from a seated position, then the same scenario of segregated experiences and or inaccessibility persists. Just like in the meta example of the CMHR gallery, in these smaller examples, the kiosk, the interface, and the content must all be accessible and designed to work with one another.

Inevitably compromises must at times be made. This is why the inclusive design practice distinguishes between the development of an affordance (such as captions being a video affordance) and the surfacing of an affordance. IN a 16:9 typically video presentation, captions are surfaced along the bottom 20% of a screen, such as when watching a movie on a television. Yet when a video is being presented

in a non-typical scenario, such as on a surface in a gallery that spans across two walls, and from floor to ceiling, surfacing the captions along the bottom 20% of the picture may no longer be an accessible solution, since that would place them at ankle height – a non-accessible viewing height because they would risk being frequently obscured by others in the space or create difficult viewing angles for some. In this case, the surfacing of the captions requires some design effort to have them (the affordance) be surfaced in a manner that is most accessible and appropriate to the context in which they are being presented. Such a solution may imply reaching a compromise that ensures design intent meets inclusive design, in a way that does not perpetuate exclusion – perhaps, the captions are surfaced at the top of the image, or mid-image built into scenography, or surfaced on a mobile device, or any other various options.

Multisensory vs multimodality

Immersion has become a popular term over the past few years. Often ‘immersive experiences’ have been distilled down to projection-mapped rooms or virtual reality experiences. Both simple instances of immersive experiences leverage multisensory design tactics. In the projection-mapped spaces, audio and visual stimulation is immersive in its 360° presentation, and the same scenario exists in the virtual environment. Yet, the multisensory qualities are typically rather thin with most stimulating only sight and hearing. So how immersive are these experiences for anyone not at the top range of either sight or hearing spectrums?

Thinking beyond these two examples towards more robust immersive design, the same leveraging exists – stimulating more senses can lead to greater feelings of immersion and can contribute to engagement. There are, however, many more senses that can be affected within multisensory design scenarios and the tactics of engaging these senses can be designed in a way that creates a multimodal system of consumption and interaction while also providing simple stimulation.

Multiple senses

Beyond audio and visual systems, when thinking through how the engagement of more senses might contribute to inclusive accessibility, consider touch (tactility, haptics), scent, temperature, and proprioceptive effects like equilibrium, to name a few. Each one of these senses can be stimulated to increase immersion while also serving accessibility. When more modalities are simultaneously engaged within an inclusive design approach, it means what provides accessibility for one person will provide augmentation for another. It also means people using different primary modalities for engagement are far more likely to be able to participate together.

For example, mobile devices today are likely the most common example to recognise multimodal interactions. Take a user receiving an alert on their iPhone.

It might be a text message, a news alert, a calendar invite, an indication from the phone's operating system or from a linked device like an AirTag, or a number of other alert types. The alert may be surfaced visually on the lock screen, Siri may read it to the user via AirPods, and the mobile device may vibrate in a specific pattern. When a phone is in someone's pocket, or if someone cannot see their lock screen, the vibrotactile (vibration) pattern can surface meaning. Different patterns can, for example, specify 'news alert' with a double pulse, 'message from mom' with a triple beat, 'AirPods left behind' with a long vibration, etc. The exact same techniques can be used to convey meaning within experience design and also provide multimodal interaction and interface designs.

In the Web Slingers Spider-Man Experience at Disneyland, Los Angeles, the interface and interaction design is rich with multisensory stimulation. The experience is interactive in that the game play has users sitting in a 'vehicle' that moves and shakes while users perform physical gestures to 'shoot' web out of their imaginary web shooters. The user gestures are tracked as virtual webs shoot out of the vehicle in the direction of digitally projected enemies. The video is surfaced on a large screen that fills the visitor's field of view, and 360° audio is leveraged for immersion. The vehicle rotates and vibrates on events. It is an immersive experience and multiple senses are being engaged concurrently. Yet all of the multisensory components only serve to embellish the themed setting and feelings of immersion. Audio does not render success or failure of task completion (or at least not obviously), vibrations are not meaningfully clear as to what they mean other than something must have happened or 'it feels like we're actually moving'. The display screen that serves as a command console surfaces the leaderboard and various statistics but through a visual medium only. The 360° audio is all-encompassing yet provides few if any directional cues, or task feedback.

All the ingredients that could render this experience truly inclusive are present in this multisensory soup, yet they are not being used in this way. A blind or low-vision user, for example, simply becomes bombarded with sound effects, music, narration, vibrations, blinking lights, and more, yet without purposeful functionality behind these elements, they just become a cacophony of competing, non-integrated effects. With some deliberate design thinking the creators of this experience could exploit the already present multisensory design tactics to facilitate multimodal interface and interaction design in addition to contributing to the theme and deepening immersion.

Mapping

What is most important when designing and applying multisensory tactics is that they are conceptualised to provide both content and interaction design meaning in addition to multisensory scenographic, or themed, purposes. This often implies the mapping of one modality of engagement to another, for example, mapping the different colours in painting to different textural patterns, for a tactile relief of the



FIGURE 15.2 At the California Science Center’s Fire! Exhibition, visitors can perform the door test activity by sensing the handles colour, the noise behind the door, and/or the temperature of the door and handle, facilitating three different modalities of engagement.

same painting. In many museum exhibitions, the visitor may be asked to perform an action after which feedback will be surfaced. In a very simple example, making a selection on an interface provokes a visual effect on a digital screen denoting success or failure. A multimodal experience might ask the user to perform the same task, yet the feedback might be a visual effect and an audio chime, both denoting either success or failure. Using the same example, the selection can provoke feedback that is audio (ta-da), visual (green check mark), and tactile (short pulse vibrations) for a successful outcome or audio (minor tone), visual (red X), and tactile (long, single vibration) for unsuccessful outcome.

In the below example, the exhibition about Fire Safety includes an installation that teaches kids to think cautiously before opening a door after a fire alarm has gone off. In this case, the door handle glows either red or blue (via lighting effect) and is either hot or cold (via small built-in temperature controller) (Figure 15.2).

When developing touch objects, including tactile reliefs, a mapping must occur. People do not perceive information in the same way through various modalities. What a user can see and interpret is different from what a user can feel and interpret. Therefore, it is critical to deliberately think through intentionality and how to achieve multimodality within each specific setting.

Figure 15.3 provides examples of two touch affordances (in this case both are touch objects) for the same artefact. One touch object is much smaller than the



FIGURE 15.3 At the Boise Art Museum, Mary Wott’s *Canopy (Odd One)* 2005 has two touch objects. The smaller object provides shape and size through touch, while the cross-section object provides details and dimension.

artefact and is intended to communicate the overall shape of the artwork. The other touch object is a cross-section of the artwork at 1:1 scale that communicates the details of the artwork and provides insights into how the piece was carved. The two objects are used to convey different aspects – shape of artwork, details of artwork. Often touch objects for textiles can be swatches of fabric providing visitors with an idea of the grain, texture, weave, etc. and can be paired with an embossed line drawing that provides the shape and style of the garment at a much smaller scale. Pairing both touch affordances with a description (such as a guided tactile description or visual description) can provide the salient context and assist the visitor in understand exactly what is being explored. The visual experience of viewing the garment has become a multisensory experience with audio description and touch affordances, but it has also become a multimodal experience where the artefact can be accessed through three modalities – augmentative for some, accessible for others, and explorable for everyone.

Taking all the lines in an image, and simply embossing or raising them, likely won’t yield an image that is discernable via touch. Again, a mapping must take place that addresses what to communicate, how, and how to ensure aspects of the

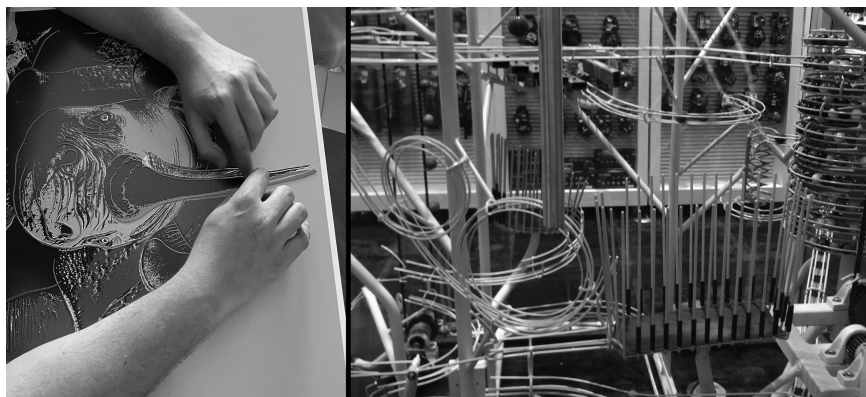


FIGURE 15.4 The Rhino print from Andy Warhol's Endangered Species Series required several iterations in production to properly map the line work and colours of the print to a discernible tactile relief.

2D object are conveyed via three-dimensional reliefs. Humans process a greater volume and fidelity of information visually than they do through touch. As such, endeavouring to surface the same kinds of data typically consumed through one modality through another modality takes interpretive effort, and a scaffolding process so visitors can find their way through the content. In the case of the previous example at the Boise Art Museum, multiple touch objects are used to provide the tactile exploration of the single artefact that might otherwise be consumed visually. In the example below, for Andy Warhol's Endangered Species prints, the tactile reliefs of the ten prints took several iterations of testing and design production refinement, in order to arrive at an outcome that allowed shape, layers, and colours to be consumable and understandable via touch. These were repeatedly produced, tested, and reproduced until the team was satisfied with the results. These reliefs were present within an installation that included the visual descriptions of the original prints (Figure 15.4).

Finally, it is not enough to simply produce a tactile relief or touch object. Associated visual descriptions, and when possible, guided tactile descriptions (an audio track that guides users in touching the relief or object), working in tandem with the touch affordance will increase the accuracy of the knowledge being obtained by the user.

Letting people know about the kinds of experiences they will be immersed within, before them encountering these experiences, is a critical step in ensuring welcoming and inclusively accessible experiences. A sensory map of the venue and experiences needs to be made available to patrons before and during their visits. Sensory maps should highlight the quiet and loud spaces and places, the areas that are cold or hot, the areas that typically have more people, and they should note how

to get to the closest quiet space. When a venue does not have a purpose-built quiet or sensory room, identifying areas of low sensory stimulation, volume, and traffic will be a key affordance for visitors.

Wayfinding

Wayfinding most commonly refers to the system and method by which people orient themselves within and navigate 3D spaces and places. When thinking through inclusive and accessible experiences, inaccessible or poorly developed wayfinding systems can immediately be identified as a potential barrier to intended outcomes – if people cannot find the content or experience, they are intended to engage with, then engagement is not going to be achieved, irrespective of how inclusively or accessibly it has been presented. Even though wayfinding is critical to providing a supported, welcoming experience, it is most often relegated to being a subject within the architecture and building scope, composed only of directional and destination signage, and is planned, designed, and installed at the beginning of a venue's existence and rarely, if ever, revisited.

Yet, wayfinding is a system that helps people feel comfortable, welcomed, and included within a specific environment. This environment can be digital, physical, or blended, and the system that can help orient and navigate people must contain more tactics than simple destination and directional signage. In fact, being a system, it can and should be expressed via multisensory design tactics, providing multimodal surfacing and consumption of those designed outputs.

Users of a wayfinding system are not just navigating through 3D space, they are also concurrently existing in digital space, they are navigating multiple information systems (building information, life safety information, interpretive content), they are navigating through programmes, and they are navigating through services. It is critical to consider just how much the audience member is being bombarded with data and information as they are attempting to engage in the designed experience. As such, identifying and exploiting the tools available within any context that are otherwise going underused can not only remove noise and clutter from obscuring the system, but they can contribute to it. Aspects of a space, including the acoustical signature of spaces, the lighting scenes within a space, materials and finishes, colour and texture, provide a rich library of tools within any contextual setting that can all be intentionally used and mapped to create a wayfinding system that provides multimodal use. Including braille on high-contrast signage, tactile floor markers, location-aware technologies, sound cues and earcons, material textures, an elaborated tactile vocabulary (using tactile affordances for hazard, path of travel, content nodes within a narrative structure, etc.) and much more can all contribute to facilitated orientation and navigation within spaces and places by composing a system that is not simply visual and that is redundant across modalities. A wayfinding direction such as 'in 2 meters turn right' can then be 'in 2 meters, when the black carpet becomes white polished concrete, turn right towards the sound of the

atrium' and suddenly multiple cues across multiple modalities can be leveraged to help ensure the path of navigation is understood simply because the materials, finishes, colours, and acoustical signatures of the building, which are already present, can be activated in service of multimodal wayfinding.

In the example below, the Corning Museum of Glass has a Rube Goldberg-like marble machine – a large, twisted, machine of rails, bells, levels, levers, spiny wheels, and more. Drop a marble in one end and watch it travel, fuelled by gravity, through the maze. It makes a very distinctive, almost musical sound. It is located in the store, by the only ATM in the building, and beside the escalator that leads back to the main museum lobby. It is an incredible audio beacon that as part of a wayfinding system can be used to help locate the ATM and the path back towards the main entrance and exit.

Digital interventions

The volume of access technology that now exists within mobile devices is impressive. Unlike a traditional hand-held device to support museum visitors, mobile devices will be set to the preferences of their owners. This is exponentially more relevant when considering that for disabled audience members, their mobile device is an amazing access tool providing functionality like magnification, spotlighting, high-contrast colour swapping, hue and saturation adjustment, text-to-speech, speech-to-text, location awareness, audio volume management, and much more. While there is often a tension between leveraging the use of a visitor's mobile device and having them fully immersed in situ, this need not be the case. Consideration of the experiential ecosystem must start from the premise that the typical visitor is concurrently navigating and participating in both a physical environment – at home, on the metro, in an exhibition – and a digital environment – the user's device is location-aware and is performing a number of computation tasks even when at 'rest'. At the outset of designing an inclusive experience, this must be considered, even when the decision is to not leverage a mobile device. At least then it is a deliberate decision and implications around access affordances and technology can be developed, mitigated, exploited, etc.

Considering all the access technology that now exists built-in to iOS and Android mobile devices, as well as so much emerging technology, digital interventions can be leveraged to facilitate more usable, accessible, and inclusive experience design. Image 6 shows 3 arpillera (brightly coloured, patchwork, burlap textiles) that are held under strict environmental control. They are behind glass in a microclimate-controlled case, under low lighting. Next to the case containing the artefacts are iPad minis. Visitors make use of the iPads or their own devices to increase not only the accessibility but also usability of the installation. The arpillera are image recognisable and through augmented reality allow visitors the opportunity to scale and zoom the artefacts, getting a better and more accessible view of their details than what is possible in the case, behind glass, under low light. The app



FIGURE 15.5 The Rube Goldberg-like marble machine at the Corning Museum of Glass has a distinct sound created by glass marbles clinking, falling, and rolling through metal traps and channels. The machine can be used as a wayfinding beacon across several parts of the building.

also provides visual descriptions of the artefacts, and clicking on the blue hotspots provokes supplemental interpretation. The artefacts are also explorable via the app from outside the gallery using any images of them, including the postcards printed and provided in gallery for educators to take back to their classrooms.

While application development can be a more complicated and arduous tactic for some organisations, several third-party systems can offer this type of functionality and web-based AR is now well supported across platforms and browsers and can help avoid the necessity of downloading an app. Not all digital interventions need to be as sophisticated and, in many cases, simple and lower tech interventions can be just as usable. The XYZ exhibition in the Toronto History Museum provides an example of a similar but simpler technical solution (see Image 15.5). A reader rail in this instance is used to surface braille and touch objects. There is also a QR code in the left, bottom corner of the rail that is locatable through tactile exploration by the fact that it is consistently placed (bottom left corner) as a raised element on the rail, and the rail itself is locatable due to the cane-detectable tactile floor markers. The QR code is also high contrast (white square on black rail) and includes a braille 'QR' just beneath its lower edge. This system is applied across the entirety of the exhibition.

In this installation, we observe the following affordances:

- Accessible typeface and high-contrast graphic design
- Braille versioning of English text

- High-contrast tactile floor markers noting the hazard of the reader rail while also providing a wayfinding cue for the location of the QR code
- High-contrast QR code that is tactily locatable
- The QR code takes the user to a WCAG-conformant website that surfaces:
 - All text (via text-to-speech)
 - Zoom
 - High-contrast colour swapping of text
 - Visual descriptions
 - Guided tactile descriptions (for touch objects)
 - Transcripts (for refreshable braille displays)
 - Much more.

The digital interventions in these cases help ensure that all persons can engage with the content at the same time, from the same, shared space.

New and existing

Remediating existing experiences and installations is a vastly different scenario than designing and developing something that is not new. The greatest impacts to new projects have to do with phase and task sequencing and less about budget and schedule. Conversely, when dealing with existing experiences or products, adjusting them to be inclusively accessible means heavier budget and schedule implications.

New projects

The most important aspects when setting up new projects are:

- Defining the structure and workflows that enable and support informed decision-making
- Ensuring the various teams working on different aspects of the project are clear on the inclusive design and accessibility intentions
- Developing success criteria that accommodate inclusive design and accessibility as mandatory criteria is objectively measurable (against standards like WCAG) and is consistently understood by the various project participants and stakeholders.
- Ensuring project schedules account for iterative design-testing scenarios accommodating the informed decision-making process across all aspects of design and development.

The impacts of sequencing can be best explained through example. When developing a piece of linear media, like a documentary film, there is a fairly consistent flow of tasks and phases. Ensuring the ASL interpreter is not recorded until a rough cut

of the film exists will mitigate needing to reshoot the interpreter because a script change happened in studio and the ASL interpreter had been recorded before the narrator was locked. These scenarios can be more complicated than this one, but the basic premise remains the same: Sequencing tasks within a project is critical to ensure being accessible doesn't become an additional schedule or budget burden.

Existing projects

When addressing remediation, the opportunities for increasing inclusion and access are more costly for the simple reason is that the product or experience has already been created and now need to be adapted, edited, or changed. Not only will remediation create the need to undo original in addition to adding new, but maintaining original design intent, aesthetics, or themes takes far more consideration. The most valuable tactic in addressing remediation is to set a roadmap and be organised in how and when certain aspects of remediation will be addressed.

Set tasks to a schedule and do not try to do everything all at once.

Recognise that in many cases, staff will be learning and need to get comfortable with new workflows and tasks. Provide time for this normalising and comfort building to take place.

Batch some tasks across installations, products, or experiences to create economies of scale and to avoid scenarios of inconsistency in presentations.

For example, adding captioning to all videos within an exhibition can be batched and produced at a time that leverages economies of scale. They can be published in gallery at a point when visitors won't become accustomed to seeing captions on one video and then ask why they're not present on another.

Leverage working groups and multidisciplinary teams so that more people can take on smaller burdens and work towards synchronised goals.

Final approach

Every project is unique, and it is important to remember inclusive design is a methodology that requires application. What works in one context is not necessarily the best solution in the next context. The methodology by which the solution is arrived at is what requires consistency.

Planning for the design and development of an access affordance should not be conflated with design and planning for how that affordance will be surfaced. This means, for example, that a project should plan, budget, and schedule for captions to be included on all video or time-based media. Yet, how the captions are surfaced requires design thinking, needing to facilitate inclusion and access while respecting project and design intentions within the unique context of this instantiation. Continuing the example, captions are most often surfaced along the bottom 20% of the moving images. But if the video is projected across a non-typical size and shape, such as two walls and ceiling, then having the captions along the bottom 20% of the



FIGURE 15.6 The Greensboro Counter installation at the NMAAHC is ADA accessible, and is not inclusive, by segregating its users based on ability and disability.

projection surface, in this case by the baseboards, is not a practical, let alone accessible solution. That doesn't mean the project shouldn't plan for captions. Just the opposite. The project needs to account for the captions being developed, and then also account for the iterative design process that will determine the best manner of surfacing the captions –across the middle of the surface? The top? On a companion mobile device? Multiple solutions?

The ADA is a remarkable piece of civil rights legislation, yet many in the field also consider it something that falls far short of ensuring equity. With the NMAAHC's Greensboro Counter Installation, it is apparent that the best of intentions and a reliance on code and regulations will only go so far. The most critical aspects of integrating inclusive design and accessibility into any project are the will to consider all vectors of human difference at the outset, and to design and develop tactics that address the full plurality of individuals that these experiences and products are being designed and developed for in the first place.

Have the will. Implement a structure to sustain the intentionality. Design tactical affordances. Test and validate the tactics with a plurality of informing sources. Implement the tactics. Evaluate them. And fail forward, always learning from the previous experiences to further inform the next.

Summary

Inclusive design is a methodology – its application can vary based on the unique context of each project, programme, or product. There is no barrier to engagement more fundamental than inaccessibility.

Curatorial, interpretive, and design intent need to be informed by audience intentions and expectations. When misalignments arise between the intentions of the project and the expectations of the audience, barriers and exclusion exist. Be mindful that a design tactic creating access for one audience member will create augmentation for another.

Projects are organised into silos and hierarchies for some very good reasons, but the entire ecosystem a visitor will find themselves in transcends these operational divisions. All aspects of the ecosystem's design, development, and ongoing management need to be congruently designed and synchronised to be inclusively accessible.

Inclusive design is a methodology that demands perpetual evolution, the development of new tactics, new applications, and a persistent need to continually involve a plurality of perspectives to inform its evolution.

Biography

Corey Timpson (He/Him) is a recognised expert in multisensory experience design, inclusive design and accessibility, and digital media and transmedia storytelling. He was Project Director for the design-build of the CMHR where, as senior vice president of Exhibitions, Research, and Design, he led the creation of the world's most inclusively designed cultural institution. Corey's focus was on collecting and interpreting difficult knowledge and presenting it through a multisensory, mixed, and inclusive transmedia storytelling approach. As one of the two principals of Prime Access Consulting, Corey leads a multidisciplinary team that works with experience-based organisations to help them sustainably welcome the widest possible audience. Among his volunteer roles, Corey serves as the Chair of the American Alliance of Museum's Media & Technology Professional Network, is an Advisory Board member of Europe's Best in Heritage, and a board member of the Portrait Gallery of Canada. Corey's design leadership has accounted for over 30 international awards in the fields of environmental, exhibition, and graphic design, digital and interactive media, digital systems, film and linear media, and universal design and accessibility.

16

CULTURAL INCLUSION IN TIMES OF CRISIS

Old and new traumas

Dr Evgeniya Kiseleva-Afflerbach

A young man is walking through the woods with a dog. He has stopped and is looking at us. His right hand, adorned with lace cuffs, is tucked into an opening in the front of his golden vest. His black waistcoat accentuates his slender figure. The young man leans on a cane with his arm, while extending his left leg forward. He is wearing a powdered wig and a tricorn hat. He looks at us openly as if he is interested.

This is how I describe Thomas Gainsborough's *Portrait of a Gentleman in the Forest*¹ (1746) to a non-seeing visitor at Moscow's Pushkin Museum in 2019. My listener smiles. He asks, 'Is this man wearing long white stockings?' – 'Yes, he is' – 'I saw pictures like that in my mother's album. We had a lot of art books, and until the age of 14, when I could see, we'd look through them. I still remember some images, including people in stockings and wigs in the Old Masters' paintings'.

No words can describe my emotions when a visual impaired visitor comes to an exhibition and connects a description of an artwork to an experience or memory from their past. It is especially surprising to meet such an interlocutor considering the still pervasive ableist attitude towards blindness in Russian society. Just eight years ago, tour guides often heard bewildered questions from visitors: '*Why would blind people be interested in painting?*' '*What can you understand about art by touching it?*' I found such questions from the public quite shocking. It always seemed to me that museum lovers tend to be progressive, open, and humanistic. But this isn't a question of the cruelty or unfeelingness of certain people; it is an ableist bias still deeply rooted in many societies.

The conceptual shift, from access to inclusion, is key to the development of the cultural heritage sector in the 21st century. However, different sociocultural contexts in the cities and countries of the world provide different challenges to

establishing these programmes. Russia is one of the least accessible countries in terms of architecture and people with disabilities there have long been excluded from cultural and social life. They have at times been absolutely invisible. With the sociocultural context in Russia as a backdrop, this chapter explores the work carried out by the Accessible Museum Program, founded by the author of this chapter, in the Pushkin Museum (Moscow, Russia) in 2016. The problems of ableist attitudes towards people with disabilities are considered, as well as the emergence of artistic practices that are aimed at challenging implicit and explicit biases and recognising human rights. This chapter considers the ways in which museums in Russia have been working as radical spaces, challenging and redefining societal norms around access and inclusion, within museum environments that are still working towards making the building physically accessible.

Through the 20th Century, many Russians were unaware of how many people with disabilities lived next to them since they were typically isolated in their homes or in special rehabilitation and neuropsychiatric institutions. After the Second World War, Joseph Stalin ordered ‘crippled’ war veterans to be removed from major cities so that they would not spoil the appearance of the victorious country. (Katushkin, 2010). Not all the soldiers who disappeared during the war died; some simply didn’t come home, so as not to be a burden. Relatives looked for them, but they could not find them (Ulitskaya, 2020). A practice of exclusion emerged. On the one hand, there was a tradition of honouring the eternal memory of nameless heroes; on the other hand, for actual heroes, there was global exclusion and oblivion. That is why, quite often, persons with disabilities in Russia find themselves in a hopeless situation. Many, living in misery and fearing that their existence complicated the lives of their loved ones, committed suicide (e.g. Bellman & Namdev, 2022). In the same period, people who were unhoused and disabled people disappeared from the big cities and moved out of public view and into special camps or buildings such as the former monasteries. They have not left any traces in the collective memory. However, it is something that begins to be considered by contemporary artists (see image 16.1).

Even in the present day, foreign visitors have expressed surprise at how many young and energetic people are out on the streets of Moscow. Unfortunately, this is not because the population is so young and healthy; it is because the elderly and people with disabilities still face many barriers to living a normal life. That is why several generations in post-Soviet Russia did not know how many of their neighbours had disabilities, were in isolation, or passed away in despair. In the relatively prosperous 2000s, some Russian tourists to the West believed that in Europe and America, residents apparently get sick very often, because on the streets and in cafes there are a lot of wheelchair users and people who behave unusually. The discovery that there are also many people with disabilities in Russia was a shock to many.

At the turn of the 21st century, most public spaces in Russia were not accessible. It was rare for train stations outside of Moscow to have a ramp-up to the platform,



FIGURE 16.1 Sculpture by Andrey Krasulin. *The War profiteer*. 2022. Cardboard, paper, mixed media. 59 x 26 x 23 cm © Evgeniya Kiseleva-Afflerbach, photo by Marcus Schneider.

and in most cities, this situation still has not changed. Basic infrastructure, including transport, hospitals, shops, libraries, and museums, often remains inaccessible. Due to a lack of contact, meeting a person with a disability evoked a feeling of embarrassment in many Russian people. The situation began to change with the advent of the federal Accessible Environment Program (2011) and after Russia ratified the UN Convention on the Rights of People with Disabilities (2012).² This agreement brought people with disabilities to the attention of the general public for the first time. Before that, there was no movement for the rights of people with disabilities in Russia, in part because many years of social isolation and suppression prevented them from thinking that they could protest or demand anything.

Some of the strongest drivers towards equity, diversity, and inclusion in Russia have come from artists, film directors, curators, and activists. In 1998, a movie starring Chulpan Khamatova and based on a book by Renata Litvinova, *Country of the Deaf*, was released (Directed by Valery Todorovsky, written by Yuriy Korotkov, Renata Litvinova, Valery Todorovsky). Although the filmmakers conflated the terms ‘deaf’ and ‘mute’ – an indication of society’s ignorance of these matters at the time – the movie was a revelation for audiences. The 1990s were a very difficult time for Russia, and the film portrayed a better world, a country where everything is better than here, something like an ‘Atlantis’. Building on the myth of the film, the term ‘leaving for the ‘country of the deaf’ has come to represent a utopian escapism in everyday conversation. Although this creates a romanticising of otherness, the film’s impact as the first positive portrayal of deafness cannot be underestimated.

In 2011 the *Chapiteau Show* was released, featuring rock star Pyotr Mamonov and deaf actor Alexey Znamensky (directed by Sergueï Loban, written by Marina Potapova). This show was created as an ode, or homage, to the uniqueness and otherness in all of us. This was the first time for many viewers that sign language speakers were portrayed not as outcasts, but as ‘normal’ members of everyday society. A year later, in 2012, writer and director Lyubov Arkus released *Anton’s Right Here*, about the life of a young man with autism. This film sat in strong contrast to *Chapiteau Show*. Where *Chapiteau Show* sought to highlight and celebrate the richness of diversity in our lived experiences, *Anton’s Right Here* was horrifying because of the truth it told about reality of the dehumanising ‘othering’ of teens and adults shut away in psychiatric institutions, and the way in which they were treated. This film has helped spur activism related to neurodiversity in Russia.

All of these films were a revelation and a shock for the public. Crucially, the messages and impact were being reiterated and reinforced by the work done in museums and galleries. In 2012, Austria’s cultural attaché in Russia, Simon Mraz, organised the exhibition *Beyond Seeing* in Moscow, featuring works by Austrian, German, and Russian artists united by the concept of multisensory perception (Braunsteiner & Mraz, 2013). The exhibition took a really pioneering approach, it was aimed at blind, partially blind, and sighted visitors alike. Exhibited in the Winzawod Centre for Contemporary Art, the exhibition showcased sculptures,

multimedia objects, photographs, and works involving Braille alphabet, which it was argued could only be deciphered all together, through a dialogue between seeing and non-seeing visitors. This focus on an inclusive and equitable experience was unique at this time. Although the impact on museum audiences was potentially not enormous – it neither received strong publicity nor attracted large visitor numbers, it had a significant impact on museum professionals, as for many it was their first contact with the topic.

In 2015, thanks to Chief Curator Kate Fowle and Director Anton Belov, the Garage Museum, Moscow, launched an Inclusive Projects Department staffed with museum volunteers who later became stars of the inclusive movement in Russia. The Garage became the first museum in Russia where inclusion and accessibility were included as key aspects of the museum mission and public image. Every year the museum held a ‘Museum of sensations’ laboratory. It also initiated many programmes and research workshops with visitors with various forms of disability.

My personal experience of exploring inclusion also began in this period. In 2015, as a participant in an internship programme for young museum leaders, I spent some time at the Museum of Modern Art (MoMa) in New York learning from different museum professionals. Drawing on the insights, I gained in New York, I returned to the Pushkin Museum with an idea that would become the Accessible Museum Program. In the first years of life, the Accessible Museum Program and its team were funded by sponsorship from Absolute-Help and from donations from Alexander Svetakov, who has always believed that ‘inclusion should be the main vector for the development of a modern museum’. Unlike film and TV, in which you are a passive observer, museums provide a space for active participation with other people. As such, museums can be an inclusive physical space, which welcomes all individuals to experience collections together in an equitable way. The core value of the Accessible Museum Program was to create an inclusive space, where visitors with disabilities were able to come to museums any day free of charge and receive accommodations, such as sign language interpretation or guided tactile experiences. For me, this was an opportunity to remove the societal barriers that have kept disabled individuals in Russia hidden and to provide a place where the needs of all visitors, disabled or not, were recognised and met. Through our inclusive approach, the aim was that the museum space would challenge the ‘othering’ of disabled individuals within Russian society on a daily basis.

Although accessing museums for free is probably the least significant barrier, it was significant for Russia because in the Soviet and post-Soviet period, theoretically people with disabilities also had opportunities to come to museums for free. However, organising such visits required an official request with stamps and signatures on behalf of the All-Russian Society of the Disabled. It was almost impossible to do this on your own. It is important that this situation has changed, and freedom to enter is genuine.

For the Accessible Museum Program to work, the Pushkin Museum ‘merely’ had to train its 700 staff members to feel comfortable and competent welcoming

visitors with disabilities, and to create visitor experiences that would provide access to a broader profile of visitor. A particular challenge was that the staff of administrators, coat check attendants, and security officers were in constant rotation. As such, it was not enough to conduct a series of trainings once; the training had to be repeated constantly and regularly so that all new employees were aware of the programmes and the associated requirements for the constantly changing temporary exhibitions.

After one of our early events in 2015, which was aimed at adults and children with Autism, and their companions, a tour guide told me: 'They don't look at the paintings, they look at the frames'. The guide went on to say: 'They are definitely not interested'; 'Why should they be tortured by the museum, they could take a walk near their house. Poor things...'. Practically every expert who has organised visits to the museum for autistic children and adults heard such things within the Russian museum sector. 'People with autism are not our target audience' was another crushing conclusion I heard from museum veterans. Prejudice is one of the biggest barriers to inclusion in the museum system. Prejudice can only be defeated by constant interaction. When visits of people on the autism spectrum to the museum become a daily routine and not an exotic event, and different ways of engaging and being become better understood, this barrier disappears.

It was an incredible stroke of luck for us that the neuroscientist and autism expert Dr. Alexander Sorokin turned out to be a great fan of the museum. In 2018, we collaborated with him to create the first sensory map of a museum space in Russia (Sorokin & Kiseleva, 2021). This took some creative thinking. After conducting an audit of the premises together with people with autism, parents, and tutors, we found out that there were no absolutely sensory-friendly zones in the Pushkin Museum. So instead, we came up with a sensory safety map that marked the less risky areas, as well as quick navigation to exits and recreation areas, which in our experience are primarily of interest to parents and those accompanying visitors with autism.

This programme, and others like it across the museum sector in Russia, supported the regular presence of people with disabilities in museum spaces. International cooperation in building the visitor experience also played an important role. Museum professionals communicated internationally, travelled, and reacted to trends. From 2017 to 2021, the Pushkin Museum hosted the annual International Festival of Inclusion, which provided an opportunity for the employees of large and small museums in Russia to get acquainted with the experience of foreign institutions, such as the Metropolitan Museum of Art, the Victoria and Albert Museum, the Uffizi Gallery, the Vienna Museum of Art History, the Rijksmuseum, the National Museum of Finland, the Royal Academy of Arts in London, the National Museum of the Royal Palace in Taipei, Palazzo Strozzi, Museum of Contemporary Art Kiasma, the Peggy Guggenheim Museum in Venice, the Ateneum Art Museum, the State Museums of Berlin, the Israel Museum, and other museums where accessibility and inclusion practices had been in place for decades (Vulnerability map, 2021).

International participation has played a very important role in raising the prestige of inclusion in the Pushkin Museum. Crucially, they also created an awareness around the importance of enhancing accessibility as a way of broadening participation to both disabled and nondisabled audiences. During the first steps of the 'Accessible Museum', these programmes experienced great resistance from custodians, classical art historians, who believe that 'art history is not for the laymen'. The speeches of the directors and staff of the world's leading classical museums, whose collections contain works of antiquity and old masters, impressed many doubters and supported the shift to a conversation about inclusion and diversifying audiences. In addition, the exchange of practical experience has also proved to be a very important source of ideas for new projects.

The impact of this work was extensive. The museum sector began to experience a boom in attendance in Moscow, St Petersburg, Perm, Ekaterinburg, Nizhny Novgorod, and many other Russian cities, as a result of a series of blockbuster exhibitions. There were entrance lines that resulted in online memes, and museums became almost as popular as movie theatres. The exhibition business was making great strides in Russia, and as a result, more and more attention was paid to accessibility and inclusion. The coinciding of these two developments meant that museums became a pioneering space for everyday inclusion in Russia.

Over time, tactile experiences, sign language interpretation, and sensory safety became important for many other museums, such as the Hermitage, the Tretyakov Gallery, the Yeltsin Center, the Russian Museum, the Jewish Museum, and the Museum of Russian Impressionism. We were all very lucky that private Absolute-Help foundation decided to support the development of Russian museums specifically in terms of inclusion, allocating considerable resources to our incentives. One might say that in the late 2010s and early 2020s, art exhibitions became one of the most likely places for equal communication with a person with a disability in Russia. The speed with which changes occurred was matched by their intensity.

Museums as inclusive environments also create an important site for mutual learning, and co-creation of ways of experiencing and understanding art. An example is my experience of guiding around the Exhibition *Picasso & Khokhlova* (2018–2019): A teenage girl touches a tactile relief based on a painting by Pablo Picasso and laughs. Before us is *Large Nude in Red Armchair* (1929), in which a female figure is spread over an armchair-like plasticine with her arm behind her head. The girl, who was blind, imitates the pose of the model in the picture and also puts her hand behind her head. She is very excited by the pose of the woman and the way the artist portrayed her. Who would have thought that analytical cubism is a fun bodily experience? She chose to physically replicate the pose in this painting, thereby translating the verbal description into a physical embodiment. This way of experiencing an artwork was unfamiliar to me and demonstrated ways of sensory engaging with a work of art that, as a practitioner, I found new and insightful.

The work on inclusion of people with disabilities within the museum spaces in Russia has focused not simply on access, but also on representation. When I started

the Accessible Museum Program at the Pushkin Museum, I could not imagine how much this experience would change my life, my views on art, and my perception of the world. Several years of active work with visually impaired visitors led me to a study of non-visual perception in art culminating in a large exhibition, *Athantor: The Haptic Eye and Non-Visual Perception* (2022), which I had the honour of curating in the halls of the Gallery of European and American Art of the 19th–20th centuries. In this project, the collection of the Pushkin Museum became a portal for opening up new perspectives on the representation of blindness in art and the history of non-visual creativity. Some of the questions it explored included: Why did Aristotle consider vision to be the most important of the senses? Why did Brueghel choose the blind as an allegory for the human being? What did Denis Diderot see as the advantage of the blind over the sighted? Why did 20th-century artists turn to blind drawing and blind chance? Can we see with our whole body?

These and other questions posed by the graphics, paintings, sculptures, and installations were met with incredible enthusiasm by the public. Several feedback albums were filled with drawings, poems, and various insights. Perhaps, this is the best evidence that many of us intuitively seek alternative perceptions and are ready to learn from people who perceive differently. ‘It was the blind who taught me to really see’, said contemporary Japanese artist Yohei Nishimura, whose multisensory sculptures were included in the *Athantor* exhibition (Athantor, 2022). Meter-high columns of unbaked clay could be hugged, smelled, listened to, or touched to feel their warmth. These works in particular, and the entire exhibition as a whole, made it possible to rethink the role of the majority and the minority in the artistic process and pursue unconventional interactions and explorations that go beyond social stereotypes or clichés.

‘This is a very beautiful girl, covered in flowers. She’s an actress’, says Andrey Pashkov, a 35-year-old artist with autism, about Auguste Renoir’s painting *Portrait of Jeanne Sammarie* (Look from the Inside, 2021). Andrey is a commissioned artist with the Pushkin Museum; the museum’s kiosk sells notepads with his drawings and signature dishes from the ceramics workshop where he works. His colleague Alena Trubikhina, a young woman with autism, in conversation with me, admitted that both her grandmother and mother brought her to the museum, but she did not easily engage with collections as a child. It turned out that she started noticing the interior of the museum on sensory-friendly tours. She saw some very beautiful ceiling paintings in the Egyptian or Pompeian style. Now, she repeats these figures in her own works on paper and in ceramics. An exhibition featuring the works of Alena, Andrey, and other artists from the ‘Special Ceramics’ group was the first exposition of art from an autistic artist in Pushkin and a rather important event for a large state institution. Both the parents of Andrey and of Alena were the first generation in Russia (in the 1970s and 80s) to reject neonatologists’ advice to leave their ‘sick’ children at an orphanage. They decided to bring them up on their own, listen to them, and accept their special needs. It is probably not surprising that these people gathered at the Pushkin Museum. It was a very organic continuation of the museum’s mission.

Pushkin is a very ‘local’ museum, where grandparents who met long ago in the Young Art Historians’ club now bring their children and grandchildren to concerts and creative workshops. Now that same spirit of community has been extended to neurodivergent people, so that they, too, can explore their creativity. My task was to maintain and strengthen this inclusive experience for all generations of visitors.

Creative projects cannot fix social and economic problems, but they can help raise public awareness of these issues. ‘Restitution of Signs’, by the German-Chilean artist Jan Vormann, was a project in which kids and teens with the Down syndrome were invited to create alternative street navigation (Vormann, 2019). At the same time, this project addresses social inequality and the restitution problem, which is an urgent topic for the Pushkin Museum. ‘Corridor of Reflections’ (2019–2020) was a performance by Elena Kovylina, in which a female lawyer in a wheelchair, positioned in front of a Sumerian column with the laws of Hammurabi, interprets the legislation for people with disabilities in Russia. Concurrently, in different halls of the museum, representatives of different disability groups comment on the monuments through the prism of their personal experiences. Both artworks (or better: performances?) were exhibited at the Pushkin Museum Festival of Inclusion. The importance of inclusion was also explored in the *Branch* exhibition in the Pushkin Museum in 2022 and 2023. As part of this exhibition, ‘Tree of Life’, a psychotherapy technique first used in Rwanda, became an element of the art mediation conducted by Ekaterina Joraniak, when many museum visitors were in shock and trauma at the outbreak of war and the sense of losing ties to the outside world.

In Russia, cultural inclusion, which became a trend for museums worldwide at the beginning of the 21st century, was in some respects inconsistent with official policies. The values of diversity and equality seemed to contradict the main guidelines of the Russian state in the 2010s, a trend that has intensified with time. All references to LGBTQ topics were incrementally banned, the media began to exploit tensions around ethnicity, and disabilities were discussed superficially and in the language of religious mercy. Human rights activists were handed prison sentences. In this context, what was happening in museums sometimes seemed like a miracle. Within the museums, nonbinary artists and curators were able to have a voice in Russia, and issues including postcolonial trauma and prison violence were discussed. At the Pushkin State Museum, the Accessible Museum Program became a platform for discussing sociocultural issues that remained outside the scope of public attention, where they had been ignored as if they did not exist at all. The International Inclusive Festival had a new theme every year: topics like ‘Experience the World My Way,’ ‘Everyone is Present’, and ‘Vulnerability Map’ were attempts to take a fresh look at society, culture, and interactions between people. Nevertheless, Russian museum professionals continued to face a number of challenges to making their museums inclusive, including architectural barriers and equal treatment of people with different life experiences.

Talking about equality has often led to conflicts, especially with older visitors who were convinced that disability is not a feature, but a bug, a life sentence.

Speaking to them about the validity of various experiences was experienced by them as hypocrisy and deceit. Russia continues to be a very inaccessible country, that is in no way adapted for people with disabilities. Nevertheless, a museum in the 21st century does not exist in isolation from its audience; the people who come to the museum become part of it and influence how art is shown and talked about. A museum is also often part of an international museum sector. This can highlight conflicts between international museum practices and sociocultural situations at home. Within Russian society, the silent absence of excluded communities from everyday life is no longer inconspicuous. For many museums, lack of access is still a barrier to starting inclusive programmes. We have been asked ‘why are you doing some kind of master classes for the deaf if you don’t have a ramp’? There is still a huge problem with accessibility, at the Puskin Museum. Some museum professionals will ask why they should do anything inclusive if they have no chance for accessible toilets or ramps (due to lack of funds, protected historical buildings etc.)? But where we struggle with access, we can still work towards inclusion. The result of these inconsistencies can become reflected in activism, performances, and exhibitions. There are still ongoing problems and challenges in making museums fully accessible, but increasingly museums in Russia are working to transform societal perceptions of disability by making inclusion, both in terms of visitors and exhibition content, normal, and expected within museum exhibitions. This work is also important even during periods of crises and wars. This text was written mainly before the Russian military invasion of Ukraine, which turned the lives of many people upside down, including mine. But, I continue to believe in mutual relations and supporting human rights through inclusive practices.

How can the barrier of access and isolation be fully overcome? Exactly how that reality is brought into being will be determined by today’s and future generations. Perhaps, it will be with the help of the memory of a museum experience that was inclusive. As more museums redefine their approaches to access and inclusion, this inevitably changes the contours of visibility and representation of traditionally marginalised communities in world culture. By comparing different national, local, and global practices, we can begin to appreciate the efforts of leading museums and individuals, dreamers, and experimenters.

Summary

- Inaccessible museum buildings can still be used to promote inclusion and inclusive societies.
- Ongoing training for staff, and being open to respond to doubts and criticisms, is crucial for the creation of an inclusive atmosphere within museums
- Welcoming people to museums needs to be mirrored by creating exhibitions that represent those people. Inclusive audiences require inclusive exhibitions.
- It is possible for museums to push forward an agenda of change, even where inclusion is limited in society outside the museum walls.

Acknowledgements

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Biography

Evgeniya is audio description writer, curator, and researcher, focusing on sensory perception in art history. Her turn to inclusion occurred while working at the Pushkin Museum in Moscow, where she initiated in 2016 the 'Accessible Museum' project. From 2017 to 2021, she curated annually International Festival of Inclusion. In 2021, Evgenia organised the first exhibition of neurodiverse artist at the Pushkin Museum. It was a 'Look from the inside' exhibition, where drawings by ASC artists were shown along with texts by minimalist poets. In 2022, Eugenia curated the exhibition 'Athanor. The Haptic Eye and Non-Visual Perception', dedicated to the representation of blindness in art and different ways of perception. Eugenia's contact with disability also occurs through her family. She believes that the shift towards inclusivity in museums around the world is driving new strategies in contemporary art and improving the visitor experience in museums. Holding a PhD in cultural studies since 2011, Evgeniya is currently researching a multisensory turn in contemporary art at the Ruhr-University of Bochum, Germany.

Notes

- 1 Thomas Gainsborough. The Pushkin State Museum of Fine Arts 03 DEC 2019 - 01 MAR 2020. <https://pushkinmuseum.art/events/archive/2019/exhibitions/gainsborough/index.php?lang=en>.
- 2 State Program of the Russian Federation "Accessible environment" for 2011–2020: zhit-vmeste.ru/gosprogramma-dostupnaya-sreda.

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17

MUSEUMS FOR EQUALITY

Combating prejudice, promoting human rights and practices of social inclusion in Egypt's museums

Dr Nevine Nizar Zakaria

Introduction

Spurred by changes in society, the museum sector is undertaking a set of developments towards advancing social inclusion and contributing to the betterment of society. The shifts in society require museums to respond to and confront the growing challenges of the present. As an essential element of the cultural sector, museums have the potential to play an important role in combating prejudice and achieving human rights for disabled people. From the management of cultural accessibility and the development of social policies to the implementation of organisational practices for removing barriers and changing disability-related narratives, the museum holds a very influential position in the direction of social reforms and the planning of a sustainable future.

Reflecting upon international views on the social dimension and the wider societal tasks placed on museums in the contemporary world, Egyptian museums have experienced major transformations in their understanding of the purposes and role of museums in society. This has had a dramatic impact on working practices over the last three decades. They have moved from being largely tourist-oriented museums, to institutions that interact and communicate with Egyptian citizens and the local community. As an example, before this shift in focus and practice, if a school-teacher had taken their pupils to the museum on a school trip, it would be up to the teacher to explain exhibits to the children. This has now changed. The political and social events that occurred during and in the aftermath of the 2011 revolution led to fundamental changes in the museums' thinking and action to be more responsive to the communities they serve. New social responsibilities have been added to the Egyptian museums to benefit the public and meet the ongoing changes in society. Furthermore, the national government has made major investments to establish

new museums across all regions and also to modernise the existing ones. Further, the museums themselves have also expanded the scope of selected topics for their exhibitions, as well as their programmes and activities, to address the needs of various population groups and be more relevant to the concerns of local communities.

Egyptian museums are very keen to expand their social roles to be relevant and contribute to the development of society. Until recently, there has been limited focus on what this might mean for disabled people. Nevertheless, given the fact that museums are keen to expand their social roles and be relevant and contribute to the development of society, there seems to be an important opportunity for the museums of Egypt to lead a shift in the public discourse and create social and institutional change that supports the rights of disabled people in Egyptian society. To understand how, this chapter will first explore the context of disability inclusion and access within Egypt. It will then discuss examples of emerging social practices in some national museums, such as the Grand Egyptian Museum (GEM), the National Museum of Egyptian Civilization (NMEC), and Egypt's Capitals Museum (EMC) to assure the potentiality of the Egyptian museums in combating prejudice and achieving human rights.

Disability and museums: Egyptian context between human rights and charity

The moral framework of human rights in which social justice and equality can be realised is one of the key elements that shaped the social inclusion work in museums (Sandell, 2012, pp. 197–199, 2017; Moore, Paquet and Wittman, 2022, p. 48). In Egypt, on a national level and in response to the 1948 Universal Declaration of Human Rights, the earliest legislative and policy framework addressing disability issues and ensuring disabled people's rights in Egypt dates back nearly to the same time when the state introduced several provisions to provide care and social security for disabled people after the 1952 revolution (Fahmy, 1995; Hagrass, 2005; Al-Gameel, 2017; Zakaria, 2020). It was not until the 1970s that all legislative measures were combined into the first comprehensive law regarding disability, namely, Law Rehabilitation Act 39 of 1975, later amended under Law 49 of 1982 (Meadows, Bamieh and Lord, 2014; Disability IN, 2023) 'see Table 1'. This Act can be seen as a counterpart to the American Disabilities Act of the US or the Disability Discrimination Act of the UK, although without any guidance on accessibility or inclusion regulation.

However, none of this legislation was sufficient to combat the discrimination and social exclusion experienced by disabled people in many aspects of life. In response, disabled people, activists, and scholars worldwide formed powerful disability rights movements during the second half of the 20th century (Barnes, Mercer and Shakespeare, 1999; Shakespeare, 2006; Oliver, 2009). The impact of these movements has been different from country to country and society to society. In Egypt, the 2014 constitution included articles that ensure equal rights for disabled people (Constitute,

2022, p. 27). Furthermore, a new law was issued in February 2018 to support disabled people's rights in Egypt. The law promotes non-discrimination principles, equal opportunities, full participation in society, and accessibility. This legal reform has led to changes in how people think about disability, such as the shift in language from 'Disabled People' to 'People with Disabilities' and then to 'Differently Abled' (Presidency Egypt, 2018). The government has increasingly used the phrase 'Differently Abled' in all media channels. This language shift is aimed at emphasising the abilities of disabled people rather than their impairments.

Although the lived experience of disabled people in Egypt has improved significantly over the last decades and continues to do so, the country – like many countries of the Middle East and North Africa – remains dominated by the individualistic medical model of disability, which is underpinned by '*ableism*' and a denial of disabled people's rights (Hagrass, 1998, 2005; Reich, 2014, p. 12; Zakaria, 2020). Disability can be understood through two different models: the medical model and the social model. The medical model sees disabled individuals as having medical deficiencies that prevent them from conforming to societal norms (Barnes, Mercer and Shakespeare, 1999; Reich et al., 2010). On the other hand, the social model distinguishes between impairment and disability. It views disability as a result of societal barriers rather than individual medical conditions. It thus places the responsibility on discriminatory policies and socio-environmental barriers that limit the opportunities of disabled individuals (Gill, 1999; Stone, 1999).

The medical model is pervasive in Egypt's national policies, discriminatory practices, and environmental barriers, leading to the social exclusion of disabled people who are often viewed through the lens of 'inability' and 'impairment' (Fahmy, 1995; Al-Gameel, 2017; Zakaria, 2020), reinforcing the medical model. This has been reinforced by the link between the medical model and '*tragedy model*', in which disabled people are seen as victims of misfortune who are in need to pity and charity (Hagrass, 2005). In Muslim countries where religion is a crucial aspect of life, such as Egypt, nondisabled people are frequently asked to support vulnerable groups, including disabled people, by a percentage of their income, known as '*Zakah*', as an obligation (Hagrass, 1998; Oliver, 2009). However, this has resulted in limiting the abilities and opportunities of disabled people – who are perceived as powerless, impaired individuals, to interact with society on equal bases as nondisabled. Therefore, most of the developed policies in the last 50 years are grown from charitable organisations, individual initiatives, and religious obligations (Lababidi and El-Arabi, 2002). The prevailing narrative still rests on negative stereotypes and prejudices (Lababidi and El-Arabi, 2002; Hagrass, 2005). It fails to recognise that disability is not inherent to an individual but rather caused by society. Therefore, society is responsible to remove the social, environmental, economic, and cultural barriers that disabled people encounter on daily basis (Zakaria, 2020).

Upon closer examination of Egypt's human rights obligations and disability-related laws, it becomes evident the museum sector is not recognised as a provider of 'social and educational services'. This means that museums are not viewed as

institutions that can provide programmes and services for the rehabilitation and sociocultural empowerment of disabled people. Despite the existence of many laws assuring the cultural rights and welfare of disabled people are on an equal basis with other citizens, the state has not yet taken any measures to ensure that disabled individuals have equal access to cultural materials.

Egyptian museums and community service: origins and development

Egypt has different types of museums, ranging in size and activity from main national museums to regional and local museums. Initially, these museums were founded during the European colonial period in the second half of the 19th century to collect and preserve archaeological materials (Reid, 2002; Mahmoud, 2012). Their primary purpose was to collect and preserve the artefacts of excavations. Today, they all operate under a centralised governmental administration, except for a few exceptions under non-governmental and private structures (Doyon, 2008). The National Museums of Egypt, also known as antiquities museums, are affiliated with the Egyptian Ministry of Tourism and Antiquities (MoTA), while other arts, biographical, historical, and specialised museums are affiliated with different governmental jurisdictions (Hassan, 2005; Doyon, 2008 Table 3). Due to the lack of museum associations in Egypt that provide technical support and formalised coordination between all the museums' institutions, additional advisory and coordination roles were assigned to the MoTA by the state (Zakaria, 2020, 2023).

Since 2014, Egypt has been experiencing a crucial phase in its history. The government has implemented a national plan to achieve the 2030 Sustainable Development Strategy (SDS) goals. The SDS' strategy was launched in 2015–2016 to lead Egypt toward sustainable development (Ministry of Planning, Monitoring and Administrative Reform, 2016, pp. 217–227). This has resulted in significant improvements in the cultural sector by establishing new museums across the country and modernising existing ones.

This unprecedented cultural agenda is remarkably ambitious but lacks a clear vision of inclusion and a demonstrable commitment to cultural accessibility and inclusive design (Zakaria, 2020). Unfortunately, most museums in Egypt pose significant accessibility challenges for individuals with physical disabilities due to various environmental and architectural barriers (Zakaria, 2020). Additionally, people with other types of disabilities still face many barriers to accessing museum programmes due to the lack of accessible services.

In recent years, special adjustments were made to make exhibitions more intellectually accessible. However, these modest adaptations have been limited to specific provisions rather than incorporating inclusive design. These adjustments include braille labels and signages, descriptive signs, touch tours, and 3D models. Videos with captions and sign language interpreters have also been included in exhibition galleries and social media channels for people with hearing disabilities.

It is worth noting that some services have emerged and thrived during the COVID-19 pandemic, providing an opportunity for Egyptian museums to adopt online activities and improve digital transformation on an unprecedented scale. Various virtual educational programmes have been designed for disabled people, particularly those with visual and hearing disabilities, to engage them remotely in virtual interaction online. These programmes include virtual tours, videos with sign language interpreters, audio descriptions, and storytelling. Some virtual tours have narrations and stories tailored to accommodate disabled people.

International collaborations have been established with specialised international museums that offer accessibility services. These collaborations include projects that cater to the needs of blind people in partnership with Homer State Tactile Museum in Italy. In 2019, MoTA worked with the Homer Museum to develop a tactile path for visually impaired people in the Egyptian Museum of Cairo (EMC). Special audio pens were provided to describe the artefacts on the path (State Information Service, 2023b). A new tactile pathway has been developed with the support of the Homer Museum for the Graeco-Roman Museum of Alexandria, which reopened in 2023. This pathway allows tactile exploration of 19 masterpieces, supplemented by Braille, relief drawings, and audio pens to enhance the experience. In addition to providing sensory books and ‘Disability Awareness Training’ to the museum’s staff (Homer State Tactile Museum, 2023).

The following section will delve into the emerging inclusive practices in three of Egypt’s latest national museums projects: the GEM, the NMEC, and ECM.

The GEM

The GEM is Egypt’s most ambitious national project and one of the largest, if not the largest, archaeological museum complexes dedicated to Ancient Egyptian/Pharaonic Culture. It is located on the Giza Plateau, near the pyramids inscribed as a World Heritage Site in 1979, away from the crowded downtown Cairo where the Egyptian Museum of Cairo – EMC exists. The GEM was constructed in several phases, initiated in 2002, with the enabling of the site and infrastructure in 2005, followed by the conservation and energy centres in 2006–2010. The final phase of the museum building began in 2012 and partially opened in 2023. The GEM has 15 permanent galleries along with the children’s museum, the HoloLens gallery, King Khufu Boats’ Museum, and other visitor facilities.

The GEM has already shown a willingness to act toward disabled people and promote social inclusion practices. As highlighted in its accessibility strategy, it is ‘centered on connectivity and inclusiveness’ and aims to be accessible to all visitors regardless of age and ability, physical, and intellectual, without requiring separate access provisions. As a result, access and inclusion were considered at all



FIGURE 17.1 Tactile map with Braille text at the GEM. Photograph by the author.

stages, from the architect's design to consultations with disability-led organisations and access specialists. The GEM has installed a wide range of different accommodations, including tactile warning floor, tactile maps (Figure 17.1), materials of 3D protruding elements, interactive exhibit elements, Braille texts, hands-on stations (Figure 17.2), replicas, diagrams, tactile routes, escalator, audio descriptions, captioning and subtitles, and much more, recognised in the GEM for its services in promoting the inclusion of disabled people.

The GEM has taken steps to ensure the inclusion of disabled people in their services. Members from disability organisations have been recruited to help plan, design, and test these services. In addition, regular meetings with the General Administration for People with Special Needs staff, affiliated with the museum sector of MoTA, were held to review inclusion issues. Further, internal policies, protocols, and international cooperation in the museum's programmes and exhibitions are currently underway to support the inclusion of disabled people. The museum's accessibility team is working on initiatives to recruit volunteers and paraprofessionals to assist with services and hands-on programmes for disabled people and other marginalised groups. Even though the GEM is not fully opened yet, it is involved in many educational programmes, art performances, drama events, and storytelling activities for disabled individuals of different ages, with a particular focus on students with disabilities.



FIGURE 17.2 Hands-on stations for visually impaired people at the GEM. Photograph by the author.

The NMEC

The NMEC is situated in Old historic Cairo, a World Heritage Site known as Al-Fustat. The museum showcases the rich and diverse history of Egyptian civilisation from prehistoric times to the present day. It demonstrates the continuity of Egypt's tangible and intangible heritage (Abdel Moniem, 2005). The foundation stone of the NMEC was laid in 2002, and as of now, only two out of the eight planned halls have been completed and opened to the public in 2021. The two halls are the core gallery and the mummy gallery, which displays 20 royal mummies. A temporary exhibition gallery has been open since 2017.

Although the construction phase of the NMEC began in 2004–2005, the museum's history and preliminary concept date back to 1981 after the UNESCO International Campaign to Save the Monuments of Nubia. The primary concept was intended to move away from the traditional collection management roles and pursue a new strategy that would enable the NMEC to become part of the local community and contribute to the civic fabric of Egyptian society (Paolini, 2005). This approach was necessary as Egyptian museums were often perceived as exclusive for the enjoyment of tourists/foreigners rather than accessible to local communities. The NMEC's primary focus is to reach out to the local community that is not traditional users of Egyptian museums, including vulnerable

groups such as those with low income and illiteracy who reside in the urban sites and slums around the museum.¹ The NMEC's inclusion agenda deliberately focuses on creating social relationships, cultural links, and communication with surrounding locals and different groups of communities not necessarily identified as disabled.

A group of experts from various organisations under the leadership of UNESCO collaborated with the Egyptian authorities to develop the programming phases of the museum. The global approach adopted at that time was to link the 'past heritage to living cultures' and value the diversity of society (Paolini, 2005, p. 59). This approach was placed at the centre of the NMEC agenda to interact with the various strata of society and surrounding urban communities, emphasising their historical development through a rich cultural agenda and social activities that link them with their ancestral cultural roots. Therefore, central to the museum policy is 'community outreach and engagement' formulated as early as 2002-2004. These notions, nowadays, are equivalence to 'access and inclusion' (Morse, 2022, p. 29). Nevertheless, this original intention does reflect the affirmance of the NMEC at that time to serve as a public space and an active interface with the Egyptian communities, offering educational, cultural, social, and recreational opportunities for all segments of society (Abdel Moniem, 2005)

Since the main objective of the NMEC was to bring diverse community groups to the museum, the overall design of the NMEC building did not prioritise accessibility standards, unlike the GEM. Most of the internal spaces were designed to accommodate different experiences for the locals, such as workshops, exhibitions, or educational places, rather than adopting design standards aimed at being inclusive for disabled people. As an example, the mummy gallery is designed to imitate the Egyptian royal tombs with narrow descending corridors and burial chambers. However, the result is inaccessible gallery to people with physical disabilities.

Where the NMEC has made positive inroads to access is by making collections and content accessible for disabled people through various programmes and workshops. Thanks to its independent management and budget, the NMEC has increasingly collaborated with disability organisations, private sector companies, and NGOs to develop social events and activities on a large scale for disabled people. These activities include inclusive educational programmes for students with disabilities (Figure 17.3) and their nondisabled peers, social performances led by disabled individuals, workshops, cultural and artistic events, and other initiatives to increase the participation of disabled people in the museum. This has been supported by many enhancements to improve the physical environment of the building. In 2022, the World Disability Union in Sharjah-UAE evaluated these improvements to ensure the building is accessible to disabled people. As a result, the NMEC was awarded the Certificate of Promoting Accessible Services for Disabled People, valid until 2025, and recognised the building's physical qualifications for welcoming disabled people.



FIGURE 17.3 Workshop for students with visual disabilities at the NMEC. Photograph by Ahmed Romeih.

ECM

In line with Egypt's urban development strategy, the government is constructing a new administrative capital that has been partially operational since 2023 to be the new capital of Egypt. It is located 45 km east of Cairo along the roads to the Suez Canal. The aim was to alleviate the overcrowding in Cairo by attracting people to the new capital, creating new job opportunities, and generating public and private investments (New Capital, 2023). The new capital is also envisioned to become one of the largest hubs of Arts and Culture in the Middle East, with a city within the city that is dedicated to Arts and Culture. The urban design includes impressive cultural buildings such as an opera house, a massive library, a central Park, contemporary museums, several theatres, cinemas, and exhibitions and venues for painting, music, crafts, and performing arts.

In 2018, the Administrative Apparatus of the New Capital entrusted the MoTA with establishing an Archaeological Museum at the heart of the City of Arts and Culture. A team of experts from the MoTA and the High Scientific Committee for Museums Scenarios has worked together to develop a new concept that differs from the traditional thematic topics commonly found in many Egyptian archaeological museums. The team has introduced a new perspective with a new narrative that has never been told in any of Egyptian museums. This is to use storytelling of

the history of Egyptian capitals throughout history, from the very first, Memphis, to the newest, which is the Administrative Capital. The author was at the forefront of key actors that sparked this concept of Egyptian capitals.

The museum building has already been constructed in a baroque-modern style to match the overall design of the city of Arts and Culture over an area of 9,000 m². The building consists of two floors, initially intended to be dedicated to the archaeological museum of Egypt's capital. However, the author suggested including other types of museums to enrich the city's offerings. As a result, the second floor has been dedicated entirely to displaying contemporary art in six main halls, including a gallery dedicated to displaying the orientalism panels, for the first time in Egypt.

The ECM has utilised advanced digital media applications to aid in interpreting its collections, which are displayed in the main building known as the 'Capitals Hall'. There are two other halls that narrate thematic topics related to the afterlife and coins (Ministry of Tourism and Antiquities, 2019a). The digital timeline includes captions and subtitles designed for people who are hard of hearing. Subtitled films are currently in progress. The 'Wall of Knowledge', developed by using augmented reality, showcases some of the wall paintings of the reconstructed tomb of 'Al-Dayabat' at the 'Afterlife Hall'. Further, the tomb has been made accessible to visitors with physical disabilities through a virtual reality component. This will allow them to explore the tomb's rooms and burial chamber. The aim is to improve public engagement with the tomb's scenes and stories by using a mobile application. This application offers interaction with the tomb's illustrations and stories through captions, sound, and commentary audio, thereby making it accessible to blind and deaf communities.

The General Administration for People with Special Needs, affiliated with the museum sector of MoTA, has made an assessment to suggest services that can further improve access for blind, partially blind, and deaf audiences. Based on these recommendations, the Administrative Apparatus is taking the lead in preparing further tools, including Braille texts, tactile replicas, tactile diagrams and maps, and audiovisual sensory experience, to enhance accessibility.

In the planning and construction of the City of Arts and Culture, physical accessibility has been a top priority. The goal is to make the infrastructure and facilities accessible to the largest spectrum of the population, including those with disabilities. To achieve this, special teams, experts, and renowned architects have been involved in promoting accessible accommodations and integrating technological and informational infrastructure. Thus, not surprisingly, the museum's building and its physical environments have been designed to support the inclusion of disabled people. Universal design recommendations have been adopted, such as accessible ramps, ground and floor surfaces, clear spaces for wheelchair users or someone using sticks, lifts for the second floor, elevators for the second level of the 'Capital Hall', and accessible toilets, among others. When the City of Arts and Culture is complete, the museum will be opened fully to the public.

Upon close examination of the GEM and NMEC, substantial changes have been captured in the management mode and system of these national museums to meet the 21st-century demands. GEM and NMEC are owned and operated by the MoTA, which assumes the ultimate legal and financial responsibility. This resulted in limited institutional independence and government control, restricting their ability to invest in museum services, raise additional funds, attract grants, or collaborate with private companies to improve visitor services. The government's control and centralisation in managing these museums have been recognised as complex and challenging, with bureaucratic processes and slow decision-making issues. Therefore, MoTA has taken a new approach to provide more flexibility in managing the GEM and NMEC. This includes forming strategic partnerships with the private sector to improve visitor services and achieve growth in the tourism industry. These partnerships allowed GEM and NMEC to outsource the operation and management of their visitor facilities to investors and private museums operators while the MoTA retains oversight and control. This collaborative model stimulated the quality of their services while preserving these major museums' identities and unique characteristics.

One of the reasons why GEM and NMEC have been able to put a strong mandate on access and inclusion is because they have been transformed from state-owned national museums to shared authority with the private sector. The significance of this in Egypt should not be underestimated. It required new laws to convert these two national museums into 'independent authorities of an economic nature' with boards of trustees (Law No. 9, 2020; Law No. 10, 2020), allowing more liberal performance beyond the governmental bureaucracy in cultural and recreational services to visitors and legitimate their partnerships with the private sector. The part of public-private ownership attracted a lot of companies and investments from the private sector to develop numerous programmes and cultural activities that serve the community on one hand, while, on the other hand, bringing more effectiveness and quality to the provided programmes. This also provides more flexibility in implementing inclusive practices and formulating partnerships with disability-related organisations to support the access and engagement of disabled people in museum programmes and activities.

Interestingly, the ECM is characterised by shared governmental management between the museums' sector of the MoTA, which is responsible for the custodianship of artefacts, and the administrative apparatus which oversees the museum's operation. Undoubtedly, the City of Arts and Culture, along with the ECM, will play a pivotal role in catalysing new social innovations and new forms of cultural engagement that can lead to a shift in mindset and perspective in tackling contemporary issues such as disability. To achieve this, a 'Commission' has been recently established for the City of Arts and Culture with a rich cultural agenda to be a platform for artistic and cultural creativity and liaising with the public and private sectors, including the community of disabled people, to share their artistic works in its cultural venues.² Fourteen governmental ministries of Egypt, including the MoTA, have relocated now to the new administrative capital and commenced their work (State Information Service, 2023).

Pathways towards promoting inclusion: actions for Egyptian museums

Egyptian Museums have significant social potentials that still need to be fully realised. They have great opportunities to support the rights of disabled people and generate cultural movements and social initiatives for addressing the exclusion and marginalisation of disabled people and other disadvantaged groups. Two significant paths will support these roles.

Developing knowledge

In order to promote social concerns in society and eliminate prejudice against disadvantaged groups, including disabled people, Egyptian museums must first understand the concept of ‘inclusion’ and enact policies and standards to incorporate it as a ‘practice’ within the museums. This requires a paradigm shift in their thinking about disability and a concerted effort to deepen their understanding of inclusion. By doing so, museums can operate as socially relevant agencies and people-centred institutions (see Dodd, 2015; Weil, 1999). However, limited research exists on disabled people in Egypt, including a need for a database or statistics related to their numbers, their types of impairment, causes, and relevance. This is in addition to the need for more research and empirical studies on the social roles of Egyptian museums, their changes towards serving society, and the expected implications. Otherwise, how can museums understand the contexts that influence the inclusion of disabled people?

It is crucial for Egyptian museums to build a platform where museum professionals, practitioners, and scholars can discuss social inclusion and disability rights. By sharing their views on how museums can counter social injustice and promote human rights for disabled people, they can inspire change and progress. An inspiring example of this approach is the international *Incluseum* project launched in 2012 as a blog to bring together museum professionals and develop ideas about ‘inclusion into practice’ (The Incluseum, n.d). This platform has since become a valuable resource for the latest theories and practices related to inclusion. It engages in digital exhibitions and activities shaped by concerns for inclusion and social justice in museums and conducts physical workshops at museums, conferences, and other collaborative projects. Therefore, it has successfully bridged the gap between theory and practice. (Moore, Paquet and Wittman, 2022).

Establishing a digital platform that connects concerned actors, personnel, and bodies in the museums’ landscape of Egypt would contribute significantly to promoting social inclusion and combating prejudice. This initiative will result in exchanging insights and ideas in the field, sharing different perceptions and reflections that will comprehensively fill gaps in the contextual framework, and supporting research in overlooked yet very significant research topics. This approach can be underpinned by the new digital transformation strategy of the MoTA that has flourished and advanced in response to the COVID-19 pandemic.

Representing and portraying disabled people in Egyptian museums

One important way to support the reduction of prejudice against disabled people in society, more broadly, is by representing them in museum exhibitions (Sandell, Dodd and Garland-Thomson, 2010; Semedo and Camacho, 2018). If disabled people are excluded from the representations of our social and cultural histories, they are excluded from not only our past but also our present museum documents. Failure to include traditionally marginalised audiences in museums perpetuates the prejudices and systemic biases that underpin that marginalisation.

A wide range of international projects, touring exhibitions, programmes, and activities have been conducted to provide a reflective understanding of the lives of disabled people, in both historical and contemporary contexts (Sandell and Dodd, 2010; Dodd, 2015; Martins et al., 2018). Examples, including *Buried in the Footnotes: The Representation of Disabled People in Museum and Gallery Collections Between 2003 and 2004* (Delin, 2002); *Hidden Histories: Discovering Disability in Norwich's Museum Collections* in 2006 (Tooke, 2006); *Rethinking Disability Representation in Museums and Galleries Between 2006 and 2009* (Sandell and Dodd, 2010; Dodd, 2015); *The Representation of Disability in Museum Collections of the General Directorate of Cultural Heritage: Discourse, Identities, and Sense of Belonging Between 2015 and 2019* (Martins, 2018), have contributed largely to prompting new conversations about disability through the lens of the social model, highlighting the social and political implications of disability.

Despite this international movement, Egyptian museums have yet to develop exhibitions tackling disablism or educate visitors on the negative attitudes and discriminatory practices against disabled people in Egypt. Only one example of a hands-on exhibition entitled '*You Can See with Your Hands*' has sought to address some of these issues. The exhibition was launched in 2016 by the EMC on the occasion of White Cane Safety Day to celebrate people who are blind and underline the barriers they face in accessing museum exhibitions. The exhibition was created in cooperation with blind people and targeted both sighted and blind visitors. The exhibits were placed into open showcases covered with black curtains, allowing sighted visitors to explore the exhibits by touch, giving insight into how blind people acquire information. Additionally, the exhibits were equipped with Braille labels and replicas, ensuring that they were accessible to blind visitors as well. Although the exhibition may have limitations in terms of inclusivity and sufficiently simulating the experience of blindness, as touching something behind a curtain is nothing like what it is like to be blind, which can contribute to discrimination, it does have a positive impact on empathic concern and a desire to help and accommodate people with disabilities. Encouraging visitors to think about the challenges blind people face can foster a greater willingness to accommodate and support them in their daily lives.

This approach needs to be widely progressed so that the representations of disability histories and narratives are woven into the museums' context of Egypt. Especially since there is a wide range of different and rich collections among the

Egyptian museums that reflect the lived experiences of disabled people in different historical periods, from ancient Egypt, the ‘Pharaonic culture’, to the Islamic period and modern era. This is reinforced by visual representations of people with various disabilities depicted in tomb paintings and art sculptures, as well as mythological figures with non-normative attributes, such as those with dwarfism (Zakrzewski, 2014; David, 2016). Even though ancient Egyptians adopted idealistic methods in representing the Egyptian rulers and tomb owners, they depicted many individuals with physical differences, including what would be considered through the lens of the medical model as limitations, deficits, or loss of their limbs. These depictions reveal that disabled individuals experienced not only social acceptance in Egyptian society thousands of centuries ago but also received special treatment, with some disabilities being viewed as a positive mark of divine blessings (David, 2016, pp. 82-85). This is underpinned by ancient Egyptian literature and moral teachings emphasising respect for all individuals, including those with disabilities, as being God’s creations (Lichtheim, 1976, p. 160).

One of the masterpieces in the EMC is the group statue of Seneb, a prominent individual with dwarfism who held a high-ranking position in the Old Kingdom (Figure 17.4). GEM possessed many artefacts for the popular God Bes, depicted as

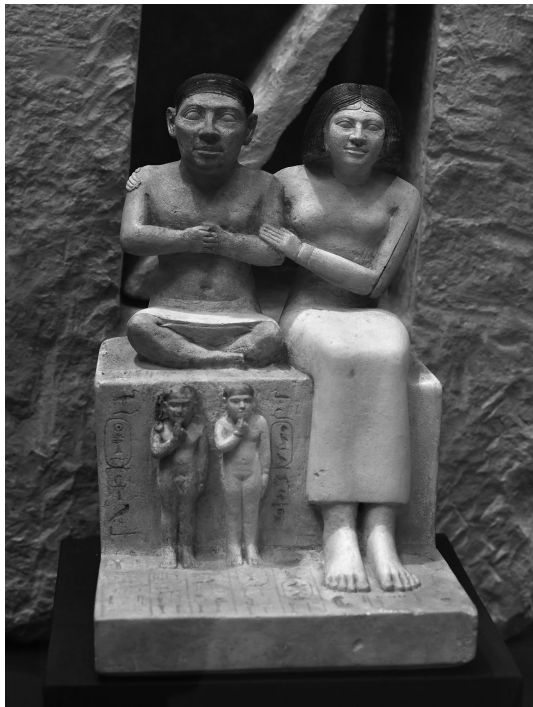


FIGURE 17.4 The statue of Seneb with his family, from the Old Kingdom at the EMC. Photograph by the author.



FIGURE 17.5 Figurine for the God Bes at GEM. Photograph by the Collection Management Department of the GEM.



FIGURE 17.6 Three wooden prostheses with leather straps were used by an Egyptian lady who amputated her big toe, from the Third Intermediate Period at the NMEC. Photograph by the author.

a dwarf, widely worshipped in ancient Egypt as a household protector (Figure 17.5). NMEC also displays some artefacts related to disabled individuals from ancient Egypt, including a prosthesis for an Egyptian lady called ‘Ta-bakt-en-mut’ who had to amputate one of her big toes due to arterial disease complications (Figure 17.6). This is not to mention the mummy of the King ‘Siptah’ from the 19th Dynasty, who has a disability in his left leg.

In addition to ancient Egyptian culture, other representations of disabled people were witnessed in subsequent periods. The Islamic period is full of many depictions of disabled people. Orientalism panels from the modern era reflect many aspects of Egyptian society in the 19th and 20th centuries, including depictions of disabled individuals. Integrating this historical context in Egyptian museums would positively influence the attitudes and social values towards disabled people. It can be presented in a series of new narratives with interpretive interventions that generate a deeper and more reflective understanding of disability issues in Egyptian society.

Conclusion

Although there have been some legal reforms and advancements in the way disability is perceived in Egyptian society, the dominant medical/charity model of disability still holds strong biases. There is an opportunity for the museums of Egypt to boldly challenge these models and push for a more inclusive and empowering approach to disability. Even though there are still limitations as they have yet to be provided full physical accessibility provisions or grasp the fundamental concepts of ‘inclusion’ and ‘access,’ they can take action in promoting social change by utilising their potential and willingness to work within governing systems and internal capacities to lead a radical shift towards changing mindsets and perspectives on disability and promoting a culture of social inclusion.

Integrating representations of disabled individuals into the social and historical narratives exhibited in Egyptian museums, which is currently lacking, can challenge the stereotyping and prejudice prevalent in our society. Reframing the way disabled people are perceived in Egyptian society can not only shed light on the negative attitudes and behaviours that have led to discriminatory and exclusive practices but also highlight the vital role museums play as direct actors in societal changes and the betterment of Egyptian society. This can energise the government towards a more equitable and just future for all.

It is time for museums to take the lead and drive this much-needed change, given the current climate and the shift in some museums’ management from state-owned towards allowing joint public-private ownership. The newer museums have already made decisive steps toward accessibility, such as GEM and NMEC, along with increasing interactions and partnerships with disability organisations, activists, and other community groups, which elicits a new perspective on disability underpinned by a concern for human rights rather than the traditional medical model that has led to prejudice against disabled individuals. It is time for the older museum institutions to follow suit, given that the national government is currently initiating this

mode of joint public-private partnership with other museums' examples to improve visitors' services and widen access to museums.

* I developed this chapter during my Alexander von Humboldt Postdoctoral Fellowship at Würzburg University, Museology Department.

Summary

- Egyptian museums have recently undergone significant changes to improve their social roles, rebuild their organisational structures, and shift from tourist-oriented museums to community engagement approach.
- Egyptian museums can challenge prejudices against disabled people, despite the current limitations in accessibility measures, by integrating narratives on disability and portraying disabled people's stories.
- The shift in management from state-owned museums to shared authority with the private sector has brought positive transformations and the much-needed flexibility to implement inclusive practices.

Biography

Nevine Nizar Zakaria, PhD, 'she/her,' is a passionate museum professional and academic lecturer. She holds Postdoctoral Fellowship in Museology and Cultural Studies at Würzburg University in Germany. She has been working in the museum field since 2001, and during this time, she has actively pursued her academic goals, obtaining her MA and PhD in Egyptology. Between 2004 and 2015, she held multiple vital positions at the Grand Egyptian Museum (GEM). With her expertise in museum work, she took on the role of Assistant to the Minister for Museums Development at the Egyptian Ministry of Tourism and Antiquities (MoTA) from 2018-2021. She played a key role in implementing several museum projects at the MoTA. As an academic lecturer, she provides the expertise and knowledge that support the teaching of museology curriculums at several universities. Her research focuses on organisational policies, cultural accessibility, and social inclusion in museums.

Note

- 1 NMEC's plan for the surrounding landscape extends beyond the museum's development. It involves a comprehensive strategy to renew the infrastructure, improve slum areas, and rehabilitate Ain Al-Sira Lake. Additionally, it aims to create more public spaces, gardens, parks, and other external green spaces with significant environmental benefits.

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18

SOCIAL INCLUSION, CULTURAL PARTICIPATION, AND PUBLIC RUPTURES AT IZIKO SOUTH AFRICAN NATIONAL GALLERY

A look at Our Lady and Art of Disruption exhibitions

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Introduction

The Iziko South African National Gallery (ISANG) has been renowned for putting on controversial shows that have sparked the uncomfortable and transformative debates, causing reactions to the work from the public (Iziko Museums Annual Reports, 2011 to 2018; Bizcommunity, 2011). This identity has resulted from the way in which ISANG has sought to transform its content by welcoming diverse views and embracing debate and discussion on difficult issues. This chapter explores how this identity has developed and considers how this worked to bring in ‘different’ audiences to the gallery, at the same time as intensifying debates in South Africa about social and cultural inclusion. We draw on examples of where debate has centred around whole exhibitions (Our Lady, which became Our Lady), and Dean Hutton’s work in the Art of Disruption exhibition. We consider how Our Lady attempted to confront representation of certain groups and how this position was productively challenged by the public. This chapter examines how this exhibition evolved from a ‘closely’ to an ‘openly’ curated exhibition. Discussing the situation that arose around ‘Art of Disruption’, we closely analyse how the museum’s act of inclusion of one artwork was challenged by a lobby group whose goal was to narrow the museum’s focus and programming. We look at how legal action reaffirmed the museum’s freedom of expression, academic research, and artistic articulation in the case of the Art of Disruption. Through these two exhibitions, we also analyse contradictions and contrasts in public responses.

The history of challenging exhibitions put on by ISANG includes Miscast (1996), which was an exhibition attempting to deal with the complexities of the indigenous Khoisan exploitation, and the 2013 centenary exhibition (in 2013) on

the Native Land Act of 1913. The exhibition on the Native Land Act was critical of how the colonial and apartheid states dispossessed Africans of their land and livelihood. However, it further criticised the democratically elected government in South Africa. The exhibition also argued that the Marikana massacre of 16 August 2012 was an indication of the state's failure to address the land question. Tretchikoff: The People's Painter (2011) was another controversial exhibition. Art critics argued that Vladimir Greigorovich Tretchikoff was not a conventional artist given that his work was mass produced, but the museum argued that the work should be seen in the context of South Africa during Tretchikoff's era.

These exhibitions were hosted by ISANG in line with its transformation mandate and as an attempt to be inclusive, intended for the sharing diverse views and to be providing a safe space that welcomes debate on difficult issues. Officially opened in 1930 as the South African National Gallery, the museum had originally catered for the needs of the select few – predominantly the white people especially the elite e.g. a previous Director of the South African National Gallery, Mr Matthys Bockhorst before becoming Director of the gallery lashed out in the press about the artistic value of Tretchikoff's work which resulted in his work not being exhibited in the South African National Gallery before amalgamation (Lamprecht, 2011, 36). Contrary to the exclusionist approach of the pre-1994 museums in South Africa, the approach of the new museum was premised on bringing 'different' audiences to the gallery and in encouraging healthy debates in South Africa about social and cultural inclusion. The focus on inclusivity and open engagement on key issues was radically different to its position during colonial and apartheid times. This aspiration was aligned with Iziko Museums vision to be an 'African museum of excellence that empowers and inspires all people to celebrate and respect our diverse heritage'.

Exhibition intent and conceptual framework for Our Lady

The Our Lady exhibition was co-curated by a curator from the ISANG and the New Church Museum, a privately funded museum whose collecting focus was on contemporary artworks produced after 1994. The curatorial team, working on Our Lady, wanted to present artworks that interrupt the current visual economy around imagery of the female form. This disruptive approach was attractive to the museum. The curatorial team, through the curatorial statement argued that the figurative painting of the female form has traditionally been painted to appease the male gaze, women were presented as sexualised objects or as symbols of the religious concept – original sin. Through Our Lady, the museum wanted to challenge this convention and to disrupt capitalist society's presentation of images of unrealistic female forms that are used as tools to sell, clothes, accessories, and the 'good' life.

Our Lady was an attempt to counter the convention by depicting empowered female capacity. This show was conceived of to reinforce positive female power

and their achievements through the works of various artists and to undermine the view that women required men to protect and map out their being and sexuality. The show also contended that the female form was not just about the fickle portrayal of women that required beautification and adornment to affirm them. The pigeon-holed woman was not going to be upheld in this exhibition. Within this prism, the exhibition was pencilled for a soft opening during women's month. Women's Day in South Africa is celebrated on August 8 annually to affirm the contribution of Women who courageously fought against Apartheid, repression, and economic injustice and exploitation that the majority of women endured. This public holiday recognises the bravery of women, fighting side by side with their male counterparts to win the freedom South Africa enjoys today. Women are celebrated in South Africa not only on the public holiday but also throughout the month of August. This month is not about the commercialisation of women's perceived interests but a concerted effort to affirm the strong role of women in the struggle against oppression and repression.

All of the artists considered for the exhibition had a strong connection to visual and performing arts on the African continent. The artworks of Bridget Baker (*The Maiden Perfect*, *The Botched Epic*, *Attempt to Escape the Maiden*), Conrad Botes, Deborah Poynton, Njideka Akunyili Crosby, Matthew Hindley, and Penny Siopis (*On Stains – Confess*, accompanied by *Delux* monograph) were in the initial exhibition list (Core Functions Minutes, 2016). Sethembile Msezane was earmarked for a performance of *iQhiya*, as a result of the iQhiya Collective's approach in engaging with and challenging power and gender dynamics. Mary Sibande's art had a potential for inclusion due to consistency in challenging gender representation, race, and class positionalities. In addition, other works of art were to be included as the research progressed, with a room left open for the inclusion of Zwelethu Mthethwa's work.

Every painting was carefully selected to reinforce the message that women were not feeble, homely, and helpless. Some of the curatorial rationale was captured in the minutes of the Core Functions meeting in 2016:

Poynton's painting *Land of Cockaigne 1* depicts empowered feminine sexuality and a female form real to blemish. Botes in his diptych *Terrorist and Anarchist* and his sculpture *The Fiscal Agent* deconstruct patriarchal stereotypes and fears as does Hindley in his painting *The Grace to Escape the Maiden* plays with ideas of what it is to be 'feminine'. Akunyili Crosby with *Mama, Mummy and Mamma* depicts a real women empowered in the role as mother, as opposed to the figurine of Mary on the table in front of her.

From the outset of discussions for this exhibition, the New Church Museum curators were aware that some of the artworks may be viewed as controversial by conservative members of the public because they challenged conventional gender and power relations in South African society. However, the view was 'We are however

secure that any controversy can be facilitated by the ISANG and New Church Museum curators into positive dialogue'. (Core Functions Minutes, 2016). This attitude was commendable as the risk of controversy was identified, although mitigating factors were highlighted at the outset. These included engagements with relevant role players, curated discussions, and debates. Such a process has a basis in the South African constitution where the freedom of association and freedom of speech are upheld. But the constitution also obliges South Africans to seek ways to negotiate differences rationally and equitably. The museum wanted the exhibition to open broader dialogue about the pervasive role representations of women can play in determining positive and negative societal attitudes towards women, and how these could be challenged and changed. At the launch of the exhibition, the curators (ISANG and the New Church Museum) had released a joint statement noting: Visual and verbal violence towards and about women are often significant markers of prevailing attitudes and ideas surrounding physical violence towards women. Within this context, the museum was seen by the curatorial team as a safe place where such difficult conversations should be hosted.

Although the exhibition had been due to open on Women's Day (August), it was eventually open to members of the public through a soft launch during 16 Days of Activism for No Violence against Women and Children (25th November–10th December). However, following this soft launch, there were objections and dissent around the exhibition. These objections and dissent were not only from 'the conservative' members of the public as initially anticipated, but also from the Sex Worker Education and Advocacy Taskforce (SWEAT) and the Sisonke National Sex Worker Movement of South Africa (Sisonke) and later from Womxn artists. The central argument of these latter groups was that the inclusion of Zwelethu Mthethwa's artwork ran against the exhibition spirit. At the time of the exhibition opening (Nov 2016), Mthethwa had been accused of murdering Nokuphila Kumalo, a sex worker. SWEAT and Sisonke saw the inclusion of his work as an amplification of patriarchy by the museum and the all-female exhibition curators. In 2017, Mthethwa was convicted of killing Nokuphila Khumalo. SWEAT and Sisonke argued we had added salt to the wound by launching the exhibition to coincide with the focus on '16 Days of Activism for No Violence Against Women and Children'. These concerns and points were articulated by SWEAT and Sisonke in meetings with Iziko Museums management, the curatorial team and with the New Church Museum. In addition, they were sharply stated in a letter dated 26 November 2016 from SWEAT and Sisonke to the museum. Through these meetings, the curatorial team sought to address the concerns. The advocacy groups argued very strongly that the choice to of a national gallery to exhibit the works of a person accused of the murder of Nokuphila, together with the silence in the exhibition around her murder was a matter of grave concern (Ndhlovu, 2019, 338). In the case of Nokuphila Kumalo, SWEAT and Sisonke argued that her sin was prostitution and that she was murdered because she did not conform to Mthethwa's mould and belief systems. In essence, they argued that the inclusion of Mthethwa's work

was an act of promoting his career at the expense of her life. SWEAT and Sisonke wanted the museum to also include narratives of women in the margins, including those who were involved in prostitution or sex work to earn a living. They argued that in interrupting ‘the current visual economy around imagery of the female form’ the exhibition should also highlight atrocities committed by the very artist whose work was on display (SWEAT and Sisonke, 2016).

However, the museums argued that far from promoting Zwelethu Mthethwa’s career the inclusion of the artwork *Untitled (from the Hope Chest series)* (2012), from the New Church Museum Collection, in *Our Lady*, was an opportunity for critical engagement for and by the public and that *Our Lady* was an opportunity to discuss these difficult issues. The work was contextualised within a theme of the exhibition that looks at portraits of ‘unnamed women’. The curators further maintained that the inherent brutality of denying a woman the right to her individuality and her name, by varying social constructs and systems was unpacked with the inclusion of five different artworks made over the course of many years by five different artists. The curators argued that not naming one’s subject was akin to the early practices of explorers, exploiters, missionaries, and collectors who were interested in collecting and commenting about the other but there was never much information about the creator of the work and the art they produced. All the collector was interested in was to ensure that they collected as many of the same pieces so that the artistic work could fall within a category and be part of a typology.

Untitled by Mthethwa, formed part of his photographic series entitled *Hope Chest*. This series explores the relationship between women and the chest she customarily receives as the final wedding present from her family before she marries. Inside are the woman’s most prized possessions, which she takes with her to her new home. His unnamed subjects read as a typological series, suggestive of early disciplinary approaches to documenting the ‘other’. Through the exhibition, the curators were therefore aiming to argue that the violence of misrepresentation has received broad criticism for portraying the subject as a type rather than an individual and that this representation needed to be challenged. However, public debates following its launch argued that the inclusion of Mthethwa’s work reinforced patriarchal practices.

Extensive discussions and open engagement between the ISANG curators, New Church Museum, Iziko Museums management, SWEAT and Sisonke focused on the ramifications around the artwork’s inclusion in the exhibition. There was an acknowledgement that not including this work and avoiding the difficult engagement associated with this artwork would have been easy, but it also would have been a betrayal of women everywhere. The point about including the controversial work of Mthethwa was not to pretend that the abuse of women does not happen, and as such the curators welcomed the dialogue about what needed to be done to support the debate, to enable audiences to understand both within what was happening within the constructs of the artwork’s ‘frame’, and the implications and significance of what was happening outside the ‘frame’.

During these meetings between museum management, the curatorial team, SWEAT and Sisonke, it was agreed that the painting by Astrid Warren should also be exhibited by ISANG. This artwork, of the late Nokuphila Kumalo, had been commissioned by SWEAT. It was based on a police mugshot, the only picture that exists of Nokuphila SWEAT and Sisonke were of the view that including this artwork would be an indication that the gallery took seriously its call to interrupt patriarchy. It argued that Warren's painting was a direct manifestation of resistance. It allowed for a representation of Nokuphila's life beyond the lenses of the state.

The work was included as a transitional work between the *Home Truths* exhibition and *Our Lady* exhibition. *Home Truths* was an exhibition at ISANG focusing on interrogating uncomfortable truths in domestic interiors. In relation to *Our Lady*, all parties further agreed that Iziko Museums would allow a peaceful protest by SWEAT and Sisonke on its premises on 15 December 2016. In addition, a performance and a panel discussion on *Our Lady* exhibition were held on 15 December 2016. The aim of this was to allow curators and members of the public to have an open discussion and engagement on the exhibition and what it represented. This exhibition brought to the museum a new kind of visitors. These were activists and artists who were interested in confronting labour and gender representations and in advocating for rights of less privileged individuals and South Africans.

Our Lady: win-win or win-lose or a compromise position?

The loose agreement was reached between the museum, SWEAT and Sisonke. It revolved around the broadening of exhibition space to include Warren's work, a peaceful protest and performance at Iziko Museums and the inclusion of text around the death of Nokuphila. However, there was an ongoing debate about the exhibition form and format beyond those who were involved in the initial discussions. There were those who strongly felt that Mthethwa's photograph should be removed from the exhibition or that their works as concerned Womxn artists should be de-installed. The majority in the Womxn's group did not want their work to be exhibited alongside Mthethwa. While other artists within Womxn argued that they were being intimidated and forced into demanding that their work be de-installed as a form of protest. These forms of disagreements continued to be points of engagements for the duration of the exhibition and the late entry into the debate by Womxn extended and deepened the controversy around this exhibition.

On 14 December 2016 in an email addressed to Executive Director Core Functions and CEO of Iziko Museums, and on the eve of the moderated public discussion, the New Church Museum informed Iziko Museums of South Africa that it was withdrawing all its works from *Our Lady* and that it was pulling out of the exhibition partnership. Its main concern was the loss of curatorial integrity, intimidation of artists who disagreed with Womxn artists and possible intimidation, and the plans to hold the panel discussion on 15 December 2016 as a moderated public dialogue and communication breakdown.² This decision was accepted by the

curators and management of the Iziko Museums. Nevertheless, it was felt that their withdrawal from the exhibition could be interpreted as an act of aggression and a withdrawal from the debate.

The de-installation of some artworks by the New Church Museum led to the renaming of the exhibition as *Our Lady*. The Iziko Museums' curatorial team adopted a curatorial approach which saw empty spaces left by de-installations as statements in themselves. The team also added as part of the exhibition, a letter signed by more than 500 artists and sent to Iziko Museums by Womxn artists. This letter had demanded that all works made by its signatories be immediately withdrawn from *Our Lady*, as a gesture of protest against the exhibition.³ Furthermore, the curators demanded that the New Church Museum should give a public account of its decision to withdraw from the *Our Lady* exhibition. Such a statement, they argued, should also be hung in the gaps left by each of the works that had been withdrawn from the exhibition. In addition, and notwithstanding the standard editorial process, there was a demand by Womxn that the video recording of the moderated public dialogue be immediately made public.

In some quarters, the museum's public gesture was viewed positively. It was seen as one of the exceedingly rare gestures where a public institution pro-actively engaged with different audiences and attempted to understand and engage with their points of view. *Our Lady* (including its different iterations) was partly seen as a radical and game-changing exhibition that embraced a discursive format and allowed voices in the margins to echo their discomfort about exhibition making. Iziko Museums also acknowledged this format change in a media statement it issued on 21 December 2016. The museum argued that *Our Lady* brought into collective consciousness a very real, current social issue and that the pain, hurt, and anger expressed during the public dialogue must be acknowledged. It further argued that the institution was grateful to have been able to support the work done by SWEAT and Sisonke in making visible the voiceless and silenced. The exhibition critics also observed that

if there is one hope that has been shared unanimously by all who have contributed to the ongoing debate thus far, it is the fervent hope that meaningful space might be created within the exhibition for the voices of the activists who have come forward to protest the inclusion of the work of Zwelethu Mthethwa in *Our Lady*...⁴

Bringing together a selection of artworks from the permanent collections of ISANG and taking into account concerns raised by the New Church Museum and input from SWEAT, Sisonke, and Womxn artists, *Our Lady* reflected on the evolving canon of artistic representations of women spanning more than 170 years. The exhibition highlighted works of selected artists who employed different strategies when depicting the female subject. The museum also included the commissioned work and the letter from Womxn artists in its gallery spaces in an attempt to

broaden the discussion. Furthermore, it hosted a moderated public dialogue where the idea of visual presentation of women by public entities was further interrogated. Following the exhibition interruptions and the panel discussion, there was an acknowledgement that in thinking about visual women representation, curators, interlocutors, visitors, and galleries are often confronted with idealised, mythologised, sexualised, or objectified images that are revealing of unequal gender relationships and that women's bodies have been used as symbolic objects, embodying political, erotic or aesthetic ideals, rather than individual female subjects. There was a need to continuously disrupt the trajectory and within the context of a disobedient museum (Message, 2018), the exhibition was able to address diverse and heterogeneous audiences and sought to produce a museum site that generated responses and public exchanges. These exchanges were seen as positive or negative or both.

The Art of Disruptions and the confrontation of white privilege

The year 2016 marked the commemoration of several key milestones in the history of South Africa. The 60th anniversary of the 1956 Women's march to the Union Building, Pretoria; 50 years since District Six was declared a whites-only area in 1966 (under the Group Areas Act of 1950); 40 years since the 1976 Soweto Youth Uprising; and 30 years since the Nationalist Government of the day, declared a state of emergency in 1986, intended to repress and curb mass action (the first was in 1985). The year 2016 will be remembered for high-profile protests, unprecedented in our young democracy. Against this backdrop of both historical and contemporary protests as well as the volatile environment permeating many of our campuses; communities, and the media following Rhodes Must Fall and Fees Must Fall protests in South Africa, Iziko resolved to curate a poignant temporary exhibition that was strategically intended to question the role of 'protest' art in society today. The exhibition titled, *The Art of Disruptions*, was thus intended to highlight some of the strategies employed in the current milieu by artists to deal with, and comment on, the various controversial and fraught issues that afflict our society today. These included racism, sexism, homophobia, inequality and privilege, migration, and environmental degradation.

The exhibition showcased works by artists who employ different methods to actively 'break apart', challenge, and complicate the traditional boundaries and hierarchies of culture and society, as represented by those in power. The chosen artworks engaged with a range of topical issues, often reflecting on our contested histories and their enduring effects. Debates around racism, sexism, homophobia, inequality, and privilege as well as migration and environmental degradation are endemic globally, but they are also very much in the foreground locally. In some way, these uncomfortable and tense issues affect all South Africans.

It is part of Iziko's mandate to engage with, and provide a platform for, these matters to be explored and understood more deeply. Thus, at its core, the *Art of Disruptions* was intended to create healthy dialogue. The exhibition also explored

the role of media and technology in expressions of freedom and justice (or the lack thereof). As such, it was inevitable that some of the more controversial works would be scrutinised – not only by the public but also by the media.

In the spirit of engagement – that this exhibition engendered – Iziko embraced the discussion across all platforms, including the media and encouraged mature and insightful rather than reactive debates. One artwork in particular that has been drawn into question was titled ‘fuckwhitepeople wall, chair and golden boots’, 2016, created by Dean Hutton.

Cognizant of the provocative nature of the language this work employs, Iziko displayed it along with an explanation (in the artist’s own words) that contextualises the artwork and makes it clear that the artist is not trying to provoke racial hatred or violence. Rather, the intention is to get the viewer’s attention so that they can engage with the concept of racism and white privilege in South Africa. This work by Dean Hutton was not intended to denigrate the dignity of a group of people on the basis of race or promotes hate speech but aimed to provoke dialogue and an improved understanding of racism in this country. The social relevance of the artwork and its insight into the current social conditions in South Africa is very important and crucial. For this reason, the work was included in this seminal exhibition.

In one of their visit to the National Gallery, the Cape Party – Kaapse Party placed a sticker over the artwork ‘*Fuck the White People*’ by Dean Hutton. The Cape Party is a separatist political Party which has been formed in 2007. It is their manifesto to make the Western Cape, Northern Cape, and some municipalities in the Eastern Cape to become independent from South Africa. They would like to have an independent government which their members strive to control as the ruling party. Dean Hutton self-identifies as gender queer, is a trans artist, and was a Master’s student at the Michaelis School of Art, University of Cape Town when their installation was on display. The sticker that the members of the Cape Party used to do deface and cover this artwork stated, ‘Love they neighbour’. In the act of defacing the artwork, the members of the Cape Party roughly manhandled the museum staff. Following this action, the Cape Party took Iziko Museums to the Equality Court where it complained that that Iziko Museums was not complying with the terms of the Promotion of Equality and Prevention of Unfair Discrimination Act, No 4 of 2000. They maintained that Iziko Museums of South Africa’s *Art of disruption* especially the ‘*Fuck White People*’ artwork by Dean Hutton unfairly discriminated against white people based on race and hate speech in violation of Sections 7, 10, and 12 of the Promotion of Equality and Prevention of Unfair Discrimination, Act (the Act from hereon) which in essence states the following, prohibition of unfair discrimination in relation to race, the prohibition of hate speech, and the dissemination of unfair discrimination. This Party wanted a declaratory order that it was hate speech to say, print, display, or communicate the word ‘*Fuck White People*’, a payment of 150, 000 South African rands by Iziko Museums for damages, restraining of further discriminatory practices and the removal of the

‘offending’ display, an unconditional public apology, an order of a deterrent nature, a referral to the Director of Public Prosecutions, and a cost to order.

Iziko Museums argued that the artwork did not fall within the sections of the Act that the complaint was based on, and that in any event the museum was protected by Section 12 of the Act. Section 12 argues that no person may (a) disseminate or broadcast any information (b) publish or display any advertisement or notice that could reasonably be construed or reasonably be understood to demonstrate a clear intention to unfairly discriminate against any person, provided that *bona fide* engagement in artistic creativity, academic and scientific inquiry, fair and accurate reporting in the public interest or publication of any information, advertisement or notice in accordance with Section 16 of the Constitution is not precluded by this section.

Section 16 of the Constitution of the Republic of South Africa, Act No. 108 of 1996, freedom of expression, states that everyone has the right to freedom of expression, which includes (a) freedom of the press and other media; (b) freedom to receive or impart information or ideas; (c) freedom of artistic creativity; and (d) academic freedom and freedom of scientific research. The museum argued that the work should be seen as expression of artistic creativity and that it was produced by a University of Cape Town Master of Arts student and as such it should be protected by freedom of scientific research. Hutton, through their work, also wanted to use their ‘whiteness’ to systematically articulate frustrations previously challenged by a black South African in challenging white privilege.

Through the *Fuckwhitepeople wall, chair and goldendean boots* as well as the installation text, Dean Hutton (b. 1976) observed as follows:

If you are white, you’re probably feeling some type of way right now. White people have been having a lot of feeling lately about ‘reverse racism’ as if it’s a thing. White people made racism and made sure it is deeply embedded in our social systems, laws, economies, institutions and individuals. So this provocation is here to make you feel that ‘white pain.’ Breathe deeply through it.

Earlier this year I photographed a student Zama Mthunzi wearing a t-shirt with the words ‘Fuck White People’ smeared in black paint. He was threatened with expulsion and a case at the Human Rights Commission. None of the complainants said anything about the front of the t-shirt which read “Being Black is Shit.”

You see, white pain demands attention all the time, while black pain flows constantly. So I made a suit to fuck white people. It began as an experiment to see what happens when a white body wears this. It makes people angry, sometimes to the point of violence. But I can do it – that is white privilege. I’m here for your pain because white people think empathy can cure racism but what we must strive for is complete dismantling of the systems of power that keep white people racist.

Learn to fuck the white in you too. Fuckwhitepeople.org #fuckwhitepeople.⁵

This context and the need to confront racism at both at an individual and institutional levels were important for the country to move forward. The museum therefore argued that the artwork should be viewed within the broader exhibition context and encouraged visitors to find meaning in the artworks beyond the passive gaze. The *Art of Disruptions* also included other artworks on loan and from Iziko Museums collections. These works included Gerald Sekoto's works on violent scenes of the 1960s Sharpeville massacre, the Russian revolutionary protests and Jane Alexander's, Butcher Boys, sculptures that represent the lack of humanity during the state of emergency during the turbulent 1980s in South Africa. In context and through its curatorial statement, the museum argued that the year 2016 marked several milestones in the history of South Africa. The 70th anniversary of the 1956 Women's March to Pretoria against pass laws, the declaration of District Six as a whites-only area in 1966 (under the Group Areas Act of 1950), the 50th anniversary of the 1976 youth protests (mainly against the introduction of Afrikaans as a medium of instruction), and the 1986 declaration of a state of emergency (the first was in 1985) by the South African government intended to repress and curb mass action.

The museum argued that in examining the strategies employed, the exhibition also explored the role of media and technology in expressions of freedom and justice or lack thereof. At its core, *the Art of Disruptions* was therefore intended to create dialogue and exhibition visitors were presented with an opportunity to participate in further disruptions like interaction with the artist Dean Hutton and a blackboard on which members of the public had an opportunity to express their views about the exhibition more broadly and their comments became part of the show and provided the platform for further interrogation. There were Facebook discussions about the value of the artwork of Dean Hutton. Some members of the public indicated that the work was not art and it should be removed from the museum. Other experts argued that the installation was an art piece and that the reaction it had elicited was necessary within the context of decoloniality and within a country that was fraught with racism and all its manifestations. This was also an opportunity to 're-think' the museum's role and the involvement of artistic communities in reshaping narratives and interrogating past behaviours (Basu and de Jong, 2016, 15–19) in that in a post-apartheid South Africa, activists saw the museum exhibitions as 'interventions' privileging not so much the legislative aspect of the museums but their transformative capacities.

The museum therefore saw the action by the Cape Party as an act of censorship that was aimed at silencing an important debate, both creative and academic, in one of the country's public galleries. It was an act that was intended to continue to marginalise communities who were excluded in such spaces, in spaces of privilege and it was an act called for a continued entrenchment of white privilege.⁶

The exhibition was designed to enhance critical debate on issues of race and discrimination and the museum argued for the dismissal of the complaint. Through its galleries, the museum wanted South Africans and its visitors to have a curated debate on these questions in a safe space. These discussions were censored by apartheid South Africa and white privilege continued to permeate in public and

private spaces. There was a need not to shy away from this complicated issue for the benefit of the museum's many publics who had hitherto to been denied a curated engagement on this question.

The court ruled that the work and the exhibition achieved its intended objective of allowing South Africans to engage publicly on the question of white privilege. Chief Magistrate DM Thulare stated as matter of fact that there was no contention that the work was an outcome of academic and artistic creativity. Through the exhibition and the artwork and in context, the museum and Hutton were able to challenge white people to reject, confront, and dismantle structures, systems, knowledge, skills, and attitudes of power that keep white people racist. The exhibition and the artwork therefore did not incite any form of racial violence or hatred. The Chief Magistrate asserted that it was the views of the select few should not be allowed to stifle public engagement around such issues. The dialogue, ruled by the Chief Magistrate, intended to contribute to the establishment of a society based on democratic values, social justice, and fundamental human right therefore needed to be allowed. This judgement which the Chief Magistrate made reiterated the intention of the Curators that the museum is not a place to stifle any one view but a forum to encourage dialogue and generate new thinking. Merely censoring and muzzling visitors to engage with the substance of the artwork belonged to a repressive era gone by.

Conclusion

Through the *Our Lady (Our Lady)* and the *Art of Disruption*, Iziko Museums were able to invite public engagements and the participation of specific groups including activists, political parties, groups in the margins as well as groups in historically protected and privileged positions to debate difficult issues through its platforms and by extensions through the courts as an extension of the public space as a sphere of engagement. This also meant that different audiences were seeing issues that affect them on a daily basis being represented and discussed in a public space like the museum and they saw that the museum was prepared to engage and be challenged in the discussions. The voices of the marginalised and downtrodden echoed through the ISANG through these two exhibitions that created a space to rethink the role of the museum as being the space for serious dialogue to practice democracy with equity, and fairness and laying the basis for challenging institutionalised racism and prejudice.

Summary

- Making presenting and representing museum research and knowledge in a manner that is none prejudicial and anti-discriminatory (Accessibility)
- Breaking barriers by giving spaces for marginalised voices which are not regarded as conventional access to museum spaces. (Inclusion)
- Equality and justice and freedom of research and artistic expression lay the foundation for ethical museum practice.

Biographies

Bongani Ndhlovu has a PhD in History from the University of the Western Cape (UWC), South Africa. He is Research Associate at the Centre for Humanities Research at UWC. He works for Iziko Museums of South Africa as the Executive Director: Core Functions and has more two decades experience in the heritage sector. He was the course co-convenor for the UCT Michaelis School of Fine Art-Iziko Honours Curatorship Course. He has served, among others, on boards of ICOM-SA, ICMAH, Memory of the World in South Africa and as President of South African Museums Association (SAMA). His peer-reviewed publications have appeared on a number of publications. Ndhlovu's academic interests are history, heritage, curatorship, and auto/biographical narratives.

Rooksana Omar has a Master's in Business Administration from the University of Durban Westville (now the University of KwaZulu-Natal). Rooksana was Chief Executive Officer of the Iziko Museums of South Africa (November 2010–August 2023). She was President of the South African Museums Association (2001–2003); President of ICOM-South Africa (2010–2013); President of the Commonwealth of Museums (2011–2017); and a board member of the International Centre for the Study of the Preservation and Restoration of Cultural Property (2019–2023). Working in museums for over three decades, Omar's passion is making museums community engaged, socially inclusive spaces with co-created programmes.

Notes

- 1 This article was written and researched during Omar's term of office as the CEO of Iziko Museums. Omar served Iziko Museums from 1 May 2010 to 31 August 2023.
- 2 Email from Kirsty Cockerill to Bongani Ndhlovu and Rooksana Omar, 14 December 2016 and City Press, 15 January 2017. <http://www.channel24.co.za/News/Local/outrage-over-our-lady-exhibition-20170114>, accessed on 14 July 2022.
- 3 This is articulated in detail by a letter that was formulated by Candice Breitz, with the support and consent of the SWEAT and several artists, 9 January 2017.
- 4 This observation is contained in a letter emailed by Candice Brietz to Iziko Museums on 19 December 2016.
- 5 The detailed wording is also contained in the equality court judgement, refer to Magistrate Court Judiciary, Republic of South Africa, In the Equality Court In the Magistrates' Courts for the District of Cape Town held in Cape Town, Case Number ECO2/2017, in the matter between Cape Party-Kaapse Party, complainant and Iziko – South African National Gallery, respondent, judgement stamped 2017 -07-04.
- 6 Chief Magistrate DM Thulare articulates this more clearly and in detail in his equality court judgement, refer to Magistrate Court Judiciary, Republic of South Africa, In the Equality Court In the Magistrates' Courts for the District of Cape Town held in Cape Town, Case Number ECO2/2017, in the matter between Cape Party-Kaapse Party, complainant and Iziko – South African National Gallery, respondent, dated 04 April 2017.

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SECTION 5

Museum futures



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19

INSTIGATORS OF CHANGE

Museums as inclusive, accessible, equitable, participatory hubs

Dr Alison F. Eardley and Vanessa E. Jones

In the opening chapters of this book, we challenged the validity of the assumed split between ‘abled’ and ‘disabled’ audiences within museum practice. This split is based on the belief that there is a majority museum audience who can automatically access museums, with only the support of written labels or wall text, by virtue of their ‘able-bodiedness’, their neurotypicality, and their inherited or acquired cultural capital. The majority of museums around the world are designed based on this ‘abled’ group as a starting point. For the disabled, museums seek to provide additional ‘accommodations’ for access to the building and/or the collections. The ableist bias has informed our collective cultural psyches for centuries and is systemic within our structures across society.

Drawing on evidence from museum studies, psychology, cognitive neuroscience, and critical disability studies, we demonstrated why this ableist assumption about the ‘majority’ museum audience is false, and therefore why museum visitors should not be simplified in these reductive ways. By considering the historical roots of both museum practice and societal understandings of disability, we are confronted by the fact that the origin of the ‘in’ group in museum visitors is in fact underpinned by the eugenics notion of the ‘ideal’. The ideal of the eugenics model was based on ability, class, race, gender identity, sexual identity, nationality, and productivity. Anyone who was not ‘able-bodied’, neurotypical, wealthy, white, cis-gender, heterosexual, and productive in ‘Western’ society was outside that ideal (see Withers, 2012). The eugenics model, and the suggestion of a ‘superior’ race or subsection of society, was explicitly rejected after the Second World War. However, the prejudices that underpinned eugenics are older than the theory itself, and these remain embedded within societies across the globe.

What, then, is the impact of this highly problematic central assumption about ‘normativity’, on the one hand, and ‘others’, on the other hand? Within the museum and

heritage sectors, we argue that not only does the assumption of this binary distinction negatively impact the provision made available to audiences with recognised access requirements, but it also leads to the failure to provide suitable access for the majority of audiences who are not targeted by these provisions. It is also important to recognise that there are many museum professionals who are working to make change.

The aim of this edited volume is to voice the systemic biases within the museum sector (and society more broadly), and to draw on work that is being carried out across the globe that re-imagines access and inclusion in a way that recognises and seeks to challenge the binary distinction between ‘abled’ and ‘disabled’. Once we accept that there is no ‘core’ visitor, we can re-imagine museum audiences. In challenging who museums exist for, we also need to challenge how a museum is experienced, and then what is the museums role. These challenges are uncomfortable. To do this, we have drawn on expertise, ideas, and actions of museum professionals, academics, and artists from around the world. Lived experience, collaboration, and co-creation are central to all of these chapters. They acknowledge that everyone has a differing array of access needs. Redefining mindsets and putting those refreshed perspectives into practice will require work. For each chapter, the authors have provided examples of some of the exciting work that is being done, to stimulate ideas and scaffold future actions. In this final chapter, we will discuss how the work described in this book helps to illustrate some core principles of the Museum Accessibility Spectrum (MAS). In doing so, we will consider the way forward for museum professionals and the museum sector more broadly.

Intersectionality

If we reject the dichotomous thinking around access, it becomes crucial to consider our multiple identities and the ways in which these identities interact to make us who we are. As humans, we are considered to have race, ethnicity, sexual orientation, gender identity, class, and other forms of identity and characteristics. In many countries around the world, some of these identities or characteristics are protected by law. However, the way in which we consider and address these characteristics has traditionally been as isolated identities. Intersectionality, on the other hand, describes the ways in which systems of inequality ‘intersect’, and emphasises the importance of recognising the negative impact of these interplays (Crenshaw, 1989; see also Cooper, 2016). It is only through acknowledging these intersections that we can really begin to understand someone’s lived experience. The multiplicities of identity, and the interactions or intersections of these identities, are central to the MAS (see also Eardley et al., 2022). The MAS describes an infinite number of strands of characteristic and identities, each of which represents a spectrum of its own. Each of these strands intersects and interacts together in a unique way for each individual.

As we acknowledge and embrace our intersectional identities, so can we accept that barriers to access can be physical, sensory, cognitive, social, and cultural or a combination of all or any of these. In Chapter 8, Charlotte Slark considers the ways

in which museums have (or have not) considered the access needs for people in relation to class and race in the UK. She discusses the impact of external motivators on long-term organisational change. She argues that when these external motivators are not matched by institutional buy-in, the impact is limited. In his Chapter 9, Syrus Marcus Ware considers disability justice within an art practice that draws on his identity as a disabled, Mad artist. His work grows from intersectional identities and takes us on a journey into worlds reframed by the possibilities of Afrofuturism. As explored within Ware's chapter, intersectionality acknowledges the interactions of needs. Needs are no longer discrete. This leads to the question of what this might mean within a museum context. We argue that it is not possible to design for all needs at once. Instead, all design should be anti-exclusive.

Anti-exclusive design

Anti-exclusive design is based on a similar conceptualisation to the MAS. In recent years, the concept of inclusion and inclusive design has been challenged by the disability rights movement. This is because it is often applied within an in-group/out-group context. In other words, inclusion is used to suggest that the out-group should be included in the in-group events and activities. A commonly used analogy is the party. Diversity is being invited to the party, and inclusion is being asked to dance. Underpinning this remains a problematic power balance, because there is no shift or relinquishing of power. It also does not challenge the appropriateness or relevance of the format in itself. Will the party take place online as well as in person, for those who may not be able to travel, for whatever reason? Will there be a silent disco? 'Belonging' is sometimes now invoked in addition to describe being able to help plan that party. However, it doesn't get away from the fact that the party was already decided. That party may be one person's ideal way of spending time, and for others, it will be an unpleasant experience. What about those who would rather go and hang out in the countryside? The core tenet of anti-exclusive design is that there should always be multiple starting points, with threads of experience that can run in parallel to each other. Those parallel pathways will have points of convergence and intersection. It is important to acknowledge that this is not universal design. Anti-exclusive design will never be perfect for all visitors. It is never possible to get all points of view at the table. However, the start point of the design process will no longer be the needs of an assumed 'majority' audience. It will no longer be possible to assume that broad swathes of the population can simply walk in and 'access'. As such, anti-exclusive design will acknowledge limitations without othering. Most importantly, the principle is that as long as design has as its starting point access for more than one group, there will be other needs which will intersect and therefore other benefits. Different from the dominant ableist design starting point, at the core of anti-exclusive design is disability gain.

Taking disability as the starting point of design means discarding our current ways of working, because we will require a new starting point for all future museum

design. In Chapter 3, William Renel, Jessica Thom, Solomon Szekir-Papasavva, and Chloe Trainor discuss the core structural aspects that should be a given within all museums and in all museum planning and budgeting: BSL interpretation, speech-to-text captioning, visual story design, and inclusive audio description (we would argue, ideally co-created, following something like the Workshop for Inclusive Co-created Audio Description, Eardley et al., 2024). Core experiences should include relaxed time, where visitors are encouraged to come and move as they wish and make noise as they wish within the space, these should be widely advertised. Likewise, ear defenders should be available. Renel et al advocate a chill-out space, with opportunities for horizontal lying. In Chapter 4, Alicia Teng provides a detailed exploration of the development and implementation of a calm room space in the National Gallery Singapore. Crucially, this isn't a space that is hidden away, or needs to be unlocked by a member of staff when needed. This is a space that sits within the centre of the museum. Each element was designed through co-creation with neurodivergent communities, and the result becomes a direct example of disability gain because it was always intended to be an inclusive space, available for anyone who needs it.

Over time, these things should become as central a provision as restrooms. However, the starting point should be beyond basic core provisions. A theme running through chapters five and six, which draw on blindness gain and Deaf gain respectively, is the negative impact of 'box-ticking' access provision, which occurs when access tools are not designed with consideration for the audiences they might benefit. In Chapter 5, Hannah Thompson discusses the differences between very poor audio description provisions created specifically for blind and partially blind people, in comparison to rich evocative language used in 19th-century descriptions, often written by authors and poets for the sighted readers of journals. She advocates for audio description as a poetic artform. In Chapter 6, Meredith Peruzzi similarly draws attention to the fact that description of sound is often neglected for D/deaf audiences, because the ableist bias is that vision is enough. She notes that it is important to describe the sounds where they are available. Similarly, she talks about the importance of recognising that sign languages are their own specific linguistic form, and in the same way, a direct word-for-word translation from English to French (as an example) would be inappropriate, so a direct translation from spoken or written word to sign language will not be helpful.

In the final chapter of this section (Chapter 7), Fayen D'Evie discusses the ways in which she has made access art. Her work not only speaks to the principles of anti-exclusive design and disability gain, but also centre on access and puts inclusive ways of experiencing at its core. In her chapter challenges traditional ways of thinking about access, and the potential of access provision. She shares insights and understandings about the ways in which access becomes art, so that museums can begin to draw from some of the creative examples within her inclusive practice.

Co-creation as default practice

We need to centre disability gain and intersectionality as the starting point for anti-exclusive design. Into the future, museums must have a workforce that is representative of the societies that they serve. In that future, museums would have a broad representation of the different access needs within the multiplicity of stands within the MAS. Projects such as Curating for Change (CfC) (Esther Fox, Chapter 9) are seeking to start to make those changes to the demographics of the museum workforce. By providing paid fellowships to disabled, D/deaf, or neurodivergent curators within museums across England, CfC provides a model for how museums can diversify workforces into the future. These fellows then draw on co-creation, working with disabled communities local to the museums, to seek out disability histories and interpretation within the museum collections. This reinforces a central point, which is that even where the museum workforce, at all levels, is representative of society, co-creation with communities is vital.

Many museums have moved towards a more participatory practice (e.g. Simon, 2010). Co-creation and co-production involve collaborative engagement between external community groups and museums from the outset of the process. It differs from consultation. Consultation can take a variety of forms, such as front-end evaluation to test an exhibition concept; bringing in disabled visitors to test a specific design product or concept; or engaging with the community to find out what they want from a museum. Consultation can involve input from the outset of the design process, or it can involve evaluation and discussion further into the process. However, the main difference between co-creation (or co-production) and consultation is the balance of power. In consultation, it remains situated wholly with the museum, whereas with co-creation, communities are equal partners, or are leading the process. Museums have struggled to create a dialogic relationship with audiences, where all parties bring their own expertise and/or experience to create a common language and a new understanding (e.g. Witcomb, 2003; Iervolino & Sandell, 2016). Many museums find it hard to create an equal relationship between themselves and their community (e.g. Lynch, 2011, 2014). Audience collaborations are often driven by short-term goals or ill-fitting agendas, shoe-horning former museum activities into new aspirational objectives and initiatives, without the right resource, planning, expertise or buy-in (Lynch, 2011; Iervolino, 2019). Furthermore, attempts to use collections to broaden belonging – or to challenge dominant ideas about history, culture, and identities – are not always successful (e.g. Smith, 2010).

One of the biggest barriers to effective co-creation within museums is the challenge that it makes to the identity of a museum as knowledge bearers and knowledge givers. Nevertheless, as a society, as museum visitors, as individuals working with or in the museum sector, unless we reach outside of ourselves, our biases perpetuate what a museum is, and how it is experienced, and therefore who it is for. Co-creation is a central theme in many of the chapters in this volume discussed

above and below. In particular, Chapter 11 (Katie Cassels and Charlotte Paddock) provides a powerful description of the benefits of enabling community consultation to transform into co-creation. Cassels and Paddock discuss a project that aimed to create memory boxes that were meaningful for the elders of the Black Caribbean community, many of whom were part of the Windrush era of migration to the UK. Intersectionality was central to this project. A core feature of memory boxes for older adults with dementia is that they aim to draw on the personal memories from the teens to the 30s, as the memories of this life period tend to remain intact the longest. As the first part of their chapter, titled ‘stepping back’, acknowledges, the community groups within this process demanded that they were the active directors of this process. They were able to draw on the expertise and support of the museum, but the process was ultimately led by the communities. This was not the process that the museum had initially imagined, but the outcomes were arguably stronger for both the museum and the community groups as a result.

Although co-creation (more or less successfully) is not uncommon within programming, where it is less common is within interpretation. In Chapter 13, Isabelle Lawrence describes the ways in which co-creation has been used in the UK to address the systemic biases that underpin traditional interpretation. She discusses the co-creation of interpretation of objects related to disability, with groups of disabled artists and activists. This type of co-creation does not dismiss the importance of previous scholarship in relation to an artefact or object, rather it recognises the importance of lived experience as a way of better understanding both the historical context and contemporary meaning of a collection item. It also reinforces the need to recognise the importance of the expertise of lived experience (see also Fox, Chapter 9).

Power shifts

A shift in the balance of power between museums and audiences is central to the work of co-creation. However, the shift of power that is required to make museums accessible and inclusive for all goes beyond co-creation and content creation in the traditional sense. The question of power also reaches into the heart of museum identity. For many museums, education or learning is at the core of their identity and purpose. Education describes the process of giving knowledge to, or receiving it from, someone else. Learning is gaining knowledge or skills through study, experience or being taught. Museums have attempted to move away from the traditional conception of them as authoritative givers of meaning (Adams, Falk, & Dierking, 2003). In many parts of the world, museums play an important role in school-based learning, and within that unique context, museums are most certainly part of a traditional education system (which also seeks to move away from authoritative learning, but which nevertheless is built on an assumption of providing active learners with an opportunity to learn) (e.g. Hooper-Greenhill, 2007). However, most museum visitors are not children on a school visit, who are there

to actively learn. There remains a huge contradiction between the explicit outward recognition that museums are not teaching institutions, and the continued focus on learning objectives or key messages that audiences are expected to learn. We are not arguing that museums are not sites of incidental learning. They most certainly are. It is clearly a reason why most people will choose to go to a museum. They are interested. However, while museum can draw on their expertise to consider what stories they might like to tell, and how they might like to tell them, what those museums cannot do is to assume or attempt to know what audiences will or should 'learn' from the experiences that they provide. Ultimately, the core issue is that the concept of museums as educators is underpinned by the deficit model, which assumes that audiences must be educated or edified. As long as museums assume that audiences are in deficit, truly inclusive museums are not possible.

The problematic nature of this deficit model is discussed in Chapter 10, where Amparo Leyman Pino advocates for a shift in core museum identity. Her chapter considers the social context of communities. Many museums seek to broadening participation by trying to attract to the museum those sections of society who do not attend. It is not generally considered to be part of the mandate of 'access', but it is widely acknowledged that sections of society struggle to access museum content on a conceptual level. These communities tend to sit on the outskirts of the 'normative' audience, alongside disabled communities (and invariably intersecting with them). These communities may struggle to access museums due to social, cultural, or economic differences (to the 'normative' core audience). Leyman Pino states that our implicit biases and prejudices tend to assume that these communities and cultures are in deficit on one or multiple levels. As such, museums do not seek to understand what the assets of these communities are, and how the museum might serve their needs and requirements, but rather they assume that these communities are in deficit. Furthermore, interaction is often based on an assumption about what is needed.

Reflecting on the ways in which museums can and do engage with their communities is not new (e.g. Watson, 2007). However, a growing number of practitioners are proposing that museums should be taking this further, by considering how to work FOR, rather than with, communities (e.g. Chamchumrus, 2019). In this approach, museums become a resource that communities can use as they would like. There is no assumption about what communities need, but rather a joint conversation to better understand how the expertise in museums might support communities towards the goals and ambitions they have already identified for themselves. Chapter 12 provides an example of this shift in dynamic. Thiago Jesus describes a collaborative project that was re-imagined in response to an act of vandalism to an important heritage site for the Wauja people, an indigenous community in the Upper Xingu region of the Amazon. This act of vandalism led to a cross-cultural collaboration, in which scholars, artists, and technologists were led by the Wauja people in the creation of a 3D restoration of their mythological engravings. The result was a preservation of the community's collective memory

through a life-size facsimile of the restored cave. This virtual reality environment has opened up a new heritage resource for the Wauja people. It has also been on tour, sharing the histories and experiences of the Wauja people internationally.

As this example illustrates, reframing the relationship between museum professionals and audiences is by no means the death of the expert. Rather, as a trained academic and an experienced museum professional, we acknowledge that these traditional brands of expertise result in both strengths and weaknesses in our thinking and decision-making. Each community is the expert on their social and cultural contexts and heritage. By serving communities, we reframe access and inclusion by redefining who is making the choice about what the core event or experience is or could be.

Systemic change

Museum collections, and the narratives within them, have the potential to link us to the past, present, and future of our planet, societies, communities, and ourselves. With that potential also comes the power to challenge problematic narratives within society, or to perpetuate them. The MAS is advocating for systemic change within cultural heritage organisations to challenge not only ableism, but also the broader legacy of ‘normativity’. Systemic change can only be achieved if it is supported by managers, trustees, policymakers, and funders. Museums need to be provided with the tools and resources to implement sustainable change that can outlast time-limited funding.

In Chapter 15, Corey Timpson advocates for a top-to-bottom re-imagining of the principles of design in museums. He considers the importance of an integrated approach. His chapter includes examples and discussion from own work, including at the Canadian Museum for Human Rights, which is one of the few examples of a museum that has sought to maintain a focused on access and inclusion from the build through to the opening. One of the central tenets of his work is that a design tool creating access for one audience member will enhance the experience for another. This echoes the philosophy of the Sensational Museum (TSM) project (UK), which aims to draw on what we know about disability to enhance the museum experience for everyone.

In some parts of the world, the mandate for change is coming at a societal level. Nevine Nizar Zakaria (Chapter 17) describes work carried out in Egypt, which has in part been stimulated by a government-level desire to increase access and inclusion to cultural heritage. Her chapter discusses the ways in which changing the mindset within a museum can challenge the perceptions and expectations of ‘abled’ museum visitors. These themes are echoed by Evgeniya Kiseleva-Afflerback in Chapter 16. However, in her chapter, the drivers for change are coming from artists, filmmakers, and activists. She discusses the ways in which the museum can be an agent for social change when it becomes a microcosm of inclusivity not seen within the larger society. Museums can also create a space within which difficult conversations can occur, at times finding themselves and their actions at the centre

of that discussion. These types of issues are explored in Chapter 18, where Bongani Ndhlovu and Rooksana Omar discuss this in the context of exhibitions discussing gender roles and women, and their representation and treatment. They provide a consider discussion of the ways in which a museum exhibition can provide a catalyst for discussion, debate, and in some instances collaborative and creative responses to controversy.

Next steps

There is a drive for museums to become inclusive. There is a drive for museums to become more accessible. Conversation and debate are no longer enough. As a sector, we need to change our approach to both access and inclusion so we are no longer othering pockets of humanity that are thought to sit outside our fictional ‘core’ museum audience. This edited volume has highlighted the ableist biases that are systemic within society and the way in which we think about museums and museum audiences. It has rejected the false binary split between ‘disabled’ and ‘abled’ and proposes we re-imagine access and inclusion as a MAS, where each individual will sit at a different point on a multitude of access spectrums. These different strands of identities will intersect and interweave, to shape our unique lived experiences and access needs.

Radical, far-reaching change is needed. Within this volume, we have drawn together a sample of some of the work that is going on around the world, in order to provide ideas and inspirations for work that can be done. This is a starting point from which we will build.

There are many other pockets of great work going on. We need to continue link and explore the ways in which we intersect. The best solutions will only come from truly collective knowledge-sharing across the Global North and the Global South. This paradigm shift also requires museums to cede their role as singular authorities bestowing knowledge. We must also reconsider our roles to become resources, by making collections, expertise, and spaces available as public assets. Rather than operating from a deficit model, we must reframe audiences and communities as partners, as co-creators. Communities and co-creation need to be put at the heart of museum practice, drawing on anti-exclusive design, and centred on intersectional understanding. Mistakes will be made, but growth will still happen. In order for museums to become truly anti-ableist, we need to push for that systemic and seismic change, that will reach every corner of museums and museum practice. Truly inclusive, anti-ableist museums are our future.

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To our readers, thank you for taking the time to engage with this book. We hope you find it useful and that it expands your thinking about the role museums can play in our society. We also hope that it empowers work you might already be doing or inspires you towards new ways of thinking and practicing.

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