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# **Neurodivergence in Museums: Making the Cultural Heritage Sector Accessible Using Participatory Practices**

**Aimee Leanne Fletcher**

**MA (Hons), MSc**

Submitted in fulfilment of the requirements for the degree of Doctor  
of Philosophy Information Studies School of Humanities College of  
Arts University of Glasgow

September 2024

This work was supported by the University of Glasgow's Lord Kelvin and  
Adam Smith studentship (2020-2024)

# Abstract

Museums and cultural heritage institutions have the potential to be engaging spaces for autistic and neurodivergent (AuND) people. However, this community continues to be under-served by these organisations. While the sector has increasingly undertaken work to make its organisations more “autism-friendly”, this tends to be primarily geared towards children or young people and lacks community involvement. The thesis focuses on three research questions:

1. What are the motivations for and barriers to museum visiting for AuND adults?
2. What do museums currently offer AuND visitors, and what are the perceived barriers museums face when addressing their accessibility issues?
3. How can museums learn from AuND adults to adapt their practices to become more engaging and accessible to this audience?

The author, an autistic researcher, answers these questions by utilising participatory and emancipatory practices. Throughout the research project, AuND people were consulted on key aspects of the research – such as the research questions, aims, survey questions, and findings analysis – to ensure that the research was driven and informed by the needs and priorities of the people or the community the project is designed to serve. The research was carried out in three key stages: 1) consultation about the research, 2) surveys of AuND adults and museum workers, and 3) workshops presenting the findings and exploring the direction of a guidance toolkit for the sector. The research received an elevated level of engagement and participation throughout the data collection process, with 466 AuND people and 130 museum workers responding to the surveys.

The results show that AuND respondents are motivated to visit museums for a variety of reasons, with most respondents indicating that they would go to museums more often if they were more accessible to their needs. The research also highlights a broad range of barriers (for example, the sensory environment and lack of understanding of neurodiversity) that impact an AuND person’s ability to visit a museum, but indicates that many of these barriers could be addressed with often straightforward actions.

The research also reveals the barriers and experiences of museum workers in developing and delivering accessibility provisions for neurodivergent audiences. A key finding was the need for accessibility considerations for AuND workers, whether paid or voluntary, to be considered alongside the needs of visitors.

The findings suggest that not only is there a need for further developments to make the cultural heritage sector more accessible to AuND people as visitors, but there is also a necessity for cultural change within the sector to prioritise accessibility for *everyone* in the organisation. The thesis also offers a model for a participatory practice that can be utilised and adapted by researchers and sector workers alike.

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# Acknowledgements

“Nothing about us, without us” is the phrase that I have used most frequently throughout my PhD, whether it is to highlight the importance of neurodivergent and disabled-led research, the need for decision-makers to actively listen to disabled people, or when teaching the leaders of tomorrow that accessibility should be a priority. While reflecting on this journey, and how much trying to make positive change for the neurodivergent community and society has shaped it, it became apparent that this thesis and research would not have been possible without so many people. Before I start naming just a few of those people, I want to acknowledge you as a reader. For showing an interest in facilitating accessibility for neurodivergent people, I appreciate you. This thesis would be nothing without the people who supported me, regardless of whether they took part, shared advice, were a shoulder to cry on during stressful periods, celebrated my successes with me, shared coffee, or simply said, “Keep going, but take care of yourself.” It takes many people to finish a project like a PhD, and I will never be able to express my thanks to everyone who contributed enough.

First, I would like to thank everyone who took the time to participate in or support this research. From the first time I shared my research, I was blown away by how many people expressed an interest, reached out to share personal stories and encouraged me to keep going. I did not expect so many people to take part in the surveys, or to approach me at events to talk about it. This research would not have been possible without the support of the autistic and neurodivergent community, or the museum, gallery, archive, and library workers who contributed in numerous ways throughout the thesis. This work is for all of you.

I would like to thank my supervisors – Maria Economou, David Simmons, and Chiara Horlin. Maria – who supported me in finding and applying for the Lord Kelvin and Adam Smith Scholarship that made completing this research possible. They always provided the advice and encouragement that I needed to write when my sense of duty and perfectionism was holding me back. David was always interested in talking about my ideas about autism, introduced me to colleagues I had not met before, and shared opportunities that enabled me to take my research to conferences in the UK and Australia. Chiara joined the team later but immediately brought a fresh perspective and different approaches to participatory practices and writing. I have learned so much from you about what it takes to be a good researcher, and I am thankful for your expertise and openness to supervise a topic that possibly wasn’t on your radar

before we met. To Johanna Green, little did I know it was you who encouraged Maria to supervise my PhD – you were, and continue to be, a researcher I admire, who always did what you could to support others no matter what, and I hope to someday do for others what you did for me.

To my PhD colleagues who I met throughout the journey. Starting a PhD can be an isolating and challenging experience at the best of times but starting it in 2020 from a bedroom taught me the importance of having people around you who have been through similar. The monthly Zoom meetings in my first year and the Information Studies PhD WhatsApp group where we could share questions and advice were, at times, lifesavers when overthinking would kick in – thank you to everyone for always having advice and meeting for coffee and words of encouragement. To Cassy Kist, who was my “buddy” from day one – our catch-ups over coffee and your reassurance that I was on track when everything felt behind helped calm my nerves on more than one occasion. To Joy Hye Lim Nam – thank you for your support in moderating the focus groups, and your time and feedback helped me to develop as a qualitative researcher. I also thank Elliot Millington – who supported me with finalising the surveys and was always there to bounce ideas off while we were planning and conducting our fieldwork. To Zein Al-Maha Oweis and Mitch – thank you for your comradery as fellow openly disabled PhD researchers. I cherish every catch-up and your joyous optimism. To Holly Sutherland and Helen Smith – meeting you at Autscope and sharing our journeys as PhD and early career researchers interested in autism helped me to find a neurodivergent researcher community that I realised I had been missing at the beginning of my PhD. This has encouraged me to want to support other neurodivergent researchers on their academic journeys.

To my student support mentor, Natalie Harries – words cannot describe how much your support meant to me when going through challenging periods. Your advice and willingness to go above and beyond (even continuing your support when you started working in Aberdeen!) helped to guide me during uncertain periods. You are a powerhouse!

To the Scottish Museum Federation, Autscope, and the Museums Association – your willingness to share my research, create space for me at your conferences and offer me platforms to disseminate and conduct research was essential. Knowing that I had your support helped me to overcome imposter syndrome and reach people I did not expect to reach, enabling me to learn more about the diverse ways this research could help different audiences beyond the neurodivergent people it was designed to serve.

To Lisa Collinson, who caught up with me frequently throughout my thesis and shared an infectious enthusiasm for my research, I appreciate each time we have met and how much of a positive impact you had on me whenever we caught up. Thank you for always picking up where we left off and sharing all the wonderful projects you do in Aberdeen.

I would also like to thank my loved ones, who have been there far longer than I have been completing my PhD. First, to my parents – Julie and David Fletcher – who have always supported me through everything and never once doubted me: from when I was diagnosed as autistic during my childhood, you have always understood me and encouraged me to do anything, loved me unconditionally, and been there for everything. Not only could I not have completed my PhD without you, but I also do not believe that I would be who I am today without you. Thank you for the many phone calls, for letting me rant when stressed, and for being the first ones I want to share good news with.

I am incredibly thankful to all my family, especially Gerald Fletcher, my grandpa, who has always supported me. My grandpa has always been an inspiration to me for his commitment to his family, and I appreciate all his support and feedback on what I do.

To all my friends who have been there through thick and thin. Whether you have been sharing words of encouragement, asking how I am getting on with the various stages, listening to me overshare about the stressful times, or helping me to do non-research-related things when I needed it most, I could not have got through these times without your support and the many side quest adventures we went on. I particularly want to thank Lucy for always being there to start a new craft activity and go for brunch and a catch-up whenever needed. To Winnie, Alex, Amanda, and Elena, my wonderful IMP gang from our Master's – I thank you all for late-night reassurance and plenty of adventures.

To Matthew Hayhow – no one has made me laugh during challenging times like you have. I am incredibly thankful for all your support, love, encouragement, and reminders to take breaks. There have been stressful times, busy times, and lots of “can you read this and make sure it makes sense?” times, but you have always been there with me no matter what.

## **Author's Declaration**

I declare that, except where explicit reference is made to the contribution of others, this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

# Abbreviations

AAM	American Alliance of Museums, formerly American Association of Museums
AASPIRE	Academic Autistic Spectrum Partnership in Research and Education
ACE	Arts Council England
ADHD	Attention Deficit Hyperactivity Disorder
Aims-2	Autism Innovative Medicine Studies-2-Trials
APA	American Psychology Association
ASD	Autism Spectrum Disorder
AuND	Autistic and Neurodivergent
BAME	Black and Minority Ethnic
CfC	Curating for Change
COVID-19	Coronavirus Disease of 2019
DCMS	Digital Culture Media and Sports
DDA	Disability Discrimination Act 1995
DSM	Diagnostic and Statistical Manual of Mental Disorders
GLAM	Galleries, Libraries, Archives and Museums
HR	Human Resources
ICD	International Classification of Diseases
ITAKOM	It Takes All Kinds of Minds conference
MA	Museums Association
MGS	Museums Galleries Scotland
NAS	National Autistic Society
ND	Neurodivergent
NICE	National Institute for Health and Care Excellence
NMS	National Museum of Scotland
NT	Neurotypical
PARC	Participatory Autism Research Collective
POC	Person of Colour
SARG	Scottish Autism Research Group
SMF	Scottish Museum Federation
SMF1	Scottish Museum Federation Workshop 1

SMF2	Scottish Museum Federation Workshop 2
STARTS	Striving to Transform Autism Research Together – Scotland
TNM	The Neurodiverse Museum network
UN	United Nations
UofG	University of Glasgow
V&A	Victoria and Albert Museum
WCAG	Web Content Accessibility Guidelines
WHO	World Health Organisation



# Chapter 1 Introduction

I did not go to museums as a child. As an autistic child with specific sensory needs, diagnosed in the early 2000s, in a town without any museums, and during a period before the creation of “autism-friendly” events, my experience was not uncommon. Only in my late teenage years, when I realised that History was my interest and direction for university, did this begin to change. Between visiting local museums and galleries around Scotland with my dad and as part of university field trips, I found a sense of peace and “autistic joy”<sup>1</sup> in the exhibition spaces I visited. This is because I was able to explore topics that interested me in a calming environment. I wondered why I had only begun visiting at an older age and the answer was simple – museums were not accessible to me.

In recent years, work has been done to enhance the accessibility of cultural heritage institutions. This work has frequently focused on physical access, considering, for example, step-free access, but has gradually expanded to consider more diverse access needs (Eardley et al., 2016). One audience that has received much attention over the past 15 years is autistic children and young people. With the majority of “autism-friendly” provisions originating in the US – and being slightly adjusted to meet local needs – the tendency has been to replicate what has already been created rather than to undertake community(-led) consultation. The “autism-friendly” label attached to organisations typically refers to the availability of a sensory bag, pre-visit booklet, and “Quiet Hour” event available in the morning and aimed at children. Exploring the Autism in Museums event calendar, which serves a UK-based audience, most events are aimed at children and young people. Since the beginning of this research, there has been an increase in programming of events and resource development for autistic adults – such as the Wellcome Collection (London)’s “relaxed” events, which occur bimonthly on alternating weekday evenings and daytime slots (Wellcome Collection, 2024) – though such programming remains is not yet widespread<sup>2</sup>. This growing area of museum practice suggests that there is an increasing awareness and interest from some parts of the museum sector. As an autistic adult,

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<sup>1</sup> The term “autistic joy” refers to the intensity of the feeling of joy, or happiness, that an autistic (or otherwise neurodivergent) person can feel. It is essentially the antithesis of a meltdown, as an AuND person experiencing autistic joy may feel energised by the experience. To date, there is limited academic literature on “autistic joy”, but it is a common phrase utilised within the community. An example of a blog on the topic is by AuND advocate and author, Emily Katy (2023).

<sup>2</sup> Other examples of events specifically for autistic adults in museums include; National Museum of Scotland (offering Relaxed Mornings once a month for any visitors who would prefer a more relaxed visiting experience) and the Science Museum in London (offering Night Owl events for people who are age 16 and over and would benefit from accessing the museum when it is closed to the general public).

I welcome this increase in resources and acknowledgement of the diverse access needs of neurodivergent people. However, it is evident that, despite having good intentions, the majority of what is available tends to be aimed at autistic children and merely duplicates the work of other organisations instead of consulting with autistic or neurodivergent people themselves. This sparks the question – where are the autistic adults’ needs and voices in all of this?

## 1.1 Research Context

Over the past 15 years, “autism-friendly” initiatives have become increasingly visible in public spaces and are starting to address a previously neglected audience. However, the study of the impact and experiences of autistic and neurodivergent visitors (hereafter AuND) visiting public spaces or accessing these initiatives remains under-researched. Approximately 1% of the UK population has a diagnosis of autism (Zeidan et al., 2022; Brugha et al, 2012) and an estimated 15% to 20% of the world’s population is neurodivergent (Bell, 2023), indicating a demand for museums to offer provisions for autistic people, as well as their families, friends, and carers.

Recent focus has fallen on making libraries more accessible to autistic people. Shea and Derry (2019) highlight that much of this research has been conducted with families and carers who support autistic people and not with AuND individuals directly. This reflects the wider under-representation of AuND people and their lack of direct involvement in projects or research intended to meet their needs. Of the limited research currently available about the experiences of autistic adults accessing cultural heritage organisations, only one paper has been published on this topic that has directly involved autistic people. In 2023, Tirill Bjørkeli Svaler published findings from a small study of 125 autistic adults in Norway conducted as part of their Master’s degree, which asked about their experiences of visiting libraries, and included museums. Svaler observed that there are barriers relating to sensory overload and expected social interactions in the venues. This gap in research directly involving neurodivergent people means that the sectoral understanding of neurodivergent interests and individuals’ need to visit is limited. Like Svaler’s research, this thesis addresses this by examining the needs of AuND people directly. However, this thesis identifies that barriers and potential solutions often overlap because of the diversity in needs and preferences within this community. This research differs as it invites neurodivergent people, both diagnosed and self-diagnosed, to share their perspectives rather than limiting the criteria to one neurotype. This project focuses on the experiences and needs of adults – a group that has been under-served as both visitors and participants in research into accessibility requirements in cultural heritage organisations. In

addition, complementing the input from AuND adults, this study also sought and examined feedback from the cultural heritage workforce about their organisation's accessibility provisions for AuND people and areas where they would benefit from receiving AuND-informed sectoral guidance.

This thesis has been primarily based on literature and examples that have occurred in countries where English is used to communicate, whether in academic journals or other forms of digital or physical print. For this reason, the majority of the examples of practice discussed have typically occurred in the UK, US, and Australia. Nevertheless, some examples of practice from other countries are available in English or where respondents to this project's survey have come from countries where English is not the dominant language. This pattern of geographic representation can be found in the findings of this thesis, as the majority of the participants were from countries where English is the primary language. It is important to acknowledge that there may be instances where practices in broader global contexts are not present in this study. This reflects a wider systemic gap in autism and neurodiversity research, where significant cultural and global perspectives remain overlooked or underrepresented. This thesis focuses on literature, experiences of the AuND community, and trends in museum practice, primarily from the UK and the US.

## 1.2 Methods and Questions

This research project, led by an autistic researcher, was initially designed to address the question “Where are the voices of autistic people in the development of provisions in museums?” As the research progressed, and with the feedback of AuND adults as part of focus group consultations, this initial question developed to encapsulate the barriers to, and motivations for, visiting museums for this group. In addition, it was equally important to understand the barriers and motivations that impact what the cultural heritage sector currently provides for AuND people – whether visitors or staff. Finally, the “autistic voices” aspect developed to become a question about how participatory and emancipatory practices can help the cultural heritage sector become more accessible to AuND people.

This research project was created and driven by the principles of emancipatory practices commonly found in the field of Disability Studies. Mike Oliver, a disability researcher and activist (1997) defines emancipatory research as a paradigm which aims to shift the power of research away from the traditional “researcher” and the “researched” dynamic, towards the

(traditionally marginalised) communities having the power to shape research in a way that serves them. Colin Barnes and Alison Sheldon (2007) identify the core principles of emancipatory research to be: 1) the application of a social model of disability in recognition that needs are not being met as a standard due to inaccessible environments, 2) the researcher and their research must be accountable to the community it is designed to serve, 3) the researcher must be clear about their positionality concerning the research. The fourth principle is that the research methods must reflect the needs of the community it is for, and the voices of the community must be heard (See also, Aldridge, 2015). In addition to these principles, for research to be considered "emancipatory", it is usually expected that there is both dissemination of findings to the communities the research is for, and that there is a form of practical outcome. Emma Stone and Mark Priestley (1996, p. 706) argue that any research that is undertaken, should be conducted only when "it will be of some practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers".

As an autistic person aiming for this research to make a difference for the autistic community, these principles guided every project decision. The primary objective, from the beginning, was to work with and for the AuND community to identify barriers and potential solutions and to ensure that the direction of the research reflected the needs and priorities of the community it was intended to serve. I thus held myself accountable for decisions made throughout the project, was open in my position as a researcher and AuND community member, and disseminated in both formal and informal settings about the research. Public engagement was an essential aspect of this practice, and – in addition to the formally recorded feedback as discussed in this thesis – I sought feedback in informal spaces at various stages throughout the project. The feedback was then incorporated into the development of the methodology and findings. The principles of the emancipatory paradigm formed the foundation for this research, and the approaches of participatory practice shaped the project's methodology.

As this research intended to be community-based and promote participatory approaches to the museum workforce, it was important to produce findings and approaches that could be utilised in practice. These emerged during a time when there was greater emphasis, both in the cultural sector and in society more broadly, on democratisation in decision-making and agency (for example, Gergen, 2014; Black, 2012; Simon, 2010; Carpentier, 2011). They are defined as a reciprocal process, which allows for mutual learning and engagement on a particular issue or project and could result in social change (Lynch, 2011; Ledwith and Springett, 2010; Billett

et al., 2006). Projects that involve participation have the potential to be forms of active engagement that allow visitors to engage in open dialogue (Arnold, 2016; Simon, 2010; Coffee, 2008). Scholars such as Alacovska (2017) and Bruns (2008) suggest that participatory practices are defined by the involvement of non-workers in collaborative projects with the shared aim of producing new outcomes or developing existing outcomes. In the context of this research, the participatory approach underpinning it actively involved AuND people at various stages of the project.

In recent years, participatory practice has become more common within the cultural heritage sector. Museums seeking to collaborate with other public services and agencies, such as health and social care, to provide social outcomes that aim to tackle social inclusion have been evident in museums within and beyond the UK (Morse, 2019; Sandell, 2003). With increasing pressure since the 1990s on the museum sector to reflect and adapt to criticisms about its relevance, it is unsurprising that it responded by adopting participatory approaches to meet its audiences' needs as a potential solution (Sandell, 2002). Nina Simon, one of the leading practitioners advocating for participatory practices in museums, is the author of *The Participatory Museum* (2010), a book that has become the most popular manifesto for how to put theory into practice. According to Simon, a participatory museum is “a place where visitors can create, share, and connect around content” (2010, ii). Simon offers a framework for organising participatory work within the sector and discusses the four distinct levels of engagement that museums can achieve by undertaking these projects. Those levels are collaboration, contribution, co-creation, and hosting of groups (2010). There are various levels of participant involvement, with co-creating being the most engaged – as museums and groups work directly together – and the least being hosting. For this research, various aspects of Simon's framework were applied: groups of neurodivergent adults and museum workers were hosted as part of focus groups and workshops, and were invited to collaborate in shaping the research and contribute to the direction of the research, with the intention of co-creating the research design and outputs. With museum conferences and publications increasingly promoting good participatory practice, or specifically highlighting current related projects, a clear shift towards adopting these approaches within the sector (Museums Association, 2021; *ibid*). However, gaps remain in the meaningful utilisation of these participatory approaches with AuND visitors and sector workers.

In addition to the cultural sector, there has been a shift towards using participatory methods in arts and humanities and social science research (Rodney, 2019; Lang et al., 2016;

Davies et al., 2013; Black, 2012; Simon, 2010; McLean and Pollok, 2007). Whether the research itself is undertaken by or with neurodivergent people as part of project teams, or there is some form of direct community involvement, participatory practices are gradually becoming more frequent practice in this field. For example, the Striving to Transform Autism Research Together – Scotland (STARTS) project launched in 2022 by a neurodiverse team of researchers has been working to identify priority research topics for the autistic people the research is designed to serve. Furthermore, academic journals and charities conducting research also require “community involvement” statements as part of their submission process. For example, the National Autistic Society (NAS) – the largest autism charity in the UK – launched its Moonshot Vision (2022), which promotes the message that the priorities and needs of autistic people (and the people who support them) should be centred in the work that the charity undertakes and supports.

However, this is not universally applied within the autism research field, as there are still papers and studies that utilise methods or have aims that perpetuate misconceptions or questionable treatments of autistic people and are *about* rather than *inclusive of* autistic people in their approach. As this research aims to promote neurodivergent voices and utilise methodologies that are in keeping with challenging perpetuating falsehoods and creating autistic-led guidance, this thesis focuses on and is driven by the perspectives and priorities of the neurodivergent people it is intended to serve. For this reason, it was important to ensure that the research conducted reflected the priorities identified by AuND people and addressed existing barriers to making visiting museums, and potentially other public spaces, more accessible. This approach also led to the use of terminology which followed community language preferences, outlined below.

### 1.3 Terminology

In recent years, changing language and terminology has been linked to changes in the understanding of autism as a condition and its social meaning (Dwyer et al., 2022; Keating et al., 2023; den Houting, 2019). There has been an increasing focus on neurodiversity and the preferences of the wider neurodivergent community. These developments in language and terminology reflect the evolution of autism and neurodiversity research, and the increasing movement for AuND advocates to contribute to and challenge historical discourse (Bottema-Beutel et al., 2021; Gillespie-Lynch et al., 2017; Kapp et al., 2013). When misused, language can be interpreted as ableist and, at worst, dehumanising (Bury et al. 2023b; Botha et al., 2021;

Bottema-Beutel et al., 2021). Furthermore, there is a greater recognition that misuse of language when addressing neurodivergence can perpetuate stigma in research and the “real world”, and increase the risk of victimisation (Vivanti, 2020; Botha et al., 2020; Griffiths et al., 2019; Gernsbacher, 2017). This thesis utilises terminology that is preferred and advocated for by the AuND community (Bottema-Beutel et al., 2021).

### 1.3.1 Person or Identity-first Language

One of the initial terminology decisions required is whether to use person-first or identity-first language when describing an individual’s relationship to their diagnosis. Traditionally, professional guidance for language has suggested the use of person-first language. For example, “person with autism” is preferred on the basis that the person should come before their diagnosed condition, meaning that the disability is only named if necessary (Bury et al., 2023a; Kenny et al., 2016; Dunn & Andrews, 2015; Milton, 2014). In contrast, the autistic community has suggested that their preference is for identity-first language – for instance, “an autistic person” – with examples of this dating back to Jim Sinclair’s (1993) paper entitled, “Why I Don’t Like Person-First Language.” Sinclair contends that autism is not an add-on to a person that can come and go, but rather a part of someone for their entire life (ibid). The preference for identity-first language can also be found in the deaf and blind communities, where advocates have argued that describing a blind/deaf person as a “person with blindness/deafness” is belittling to the individual (Vaughan, 2009). While Vivanti (2020) attributes the shift towards identity-first language to a cultural shift facilitated by the neurodiversity movement, Monique Botha et al. (2021) and Robert Chapman (2019) suggest that the change is more likely a paradigmatic movement away from pathologisation.<sup>3</sup>

The autistic and wider disability community has argued that the different uses of person-first language dependent on the disability or diagnosis are contradictory to the original purpose of these terms. Within the autism community, Kenny et al. conducted a survey in 2016 into the various uses of label application in different contexts. This study aimed to understand whether person-first or identity-first language was preferred, where these different conventions are commonly used, and whether there was a specific preference across diverse groups (for example, whether person-first language is most utilised in professional settings). This online survey of over 3,470 UK residents found that there was no agreed consensus on one overall

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<sup>3</sup> For a detailed history of the neurodiversity movement, Kapp (2020) provides an insight from the perspective of neurodivergent activists and academics into the development and impact that this movement has had since the 1990s.

preference, as a range of terms was used and the favoured term differed between autistic people and their families, who tended to use identity-first language, and professionals, who used person-first (Botha et al., 2021; Vivanti, 2020; Kenny et al., 2016). This lack of consensus demonstrates the challenge of using language that reflects the majority preference across the AuND and research communities. Furthermore, it highlights the need for more research to understand the preferences of under-represented populations within the autistic community, especially the non-speaking community, and people with co-occurring learning disabilities (Botha et al., 2021; Bury et al., 2023a; Kenny et al., 2016). However, considering Kenny et al.'s 2016 paper alongside more recent and international studies looking at language preferences within the neurodivergent community (such as Bury et al., 2023b; Dwyer et al., 2022; Keating et al., 2022), it is evident from the data collected by autistic people and their families that, while the exact terms used differed, identity-first language was most used and preferred across the groups surveyed. I have therefore decided to use identity-first language in this thesis unless a participant stated they would like to be referred to using person-first language.

### 1.3.2 Autism and Neurodiversity

Autism is a condition that is increasingly being treated as a form of natural variance rather than a disability. The neurodivergent movement – which will be discussed in more detail in the autism section of the literature review (see Chapter [2](#), [2.4](#)) – follows a social model of disability. This actively discourages medicalised language with damaging connotations, such as “deficit”, “impairment”, or “disorder”, as these terms tend to focus on the AuND individual’s characteristics as negative “symptoms” that require intervention. This also includes the use of functioning labels, such as “high” or “low” functioning, as a way of categorising autistic people based on what they can or cannot do (Rose, 2017). Instead, the movement promotes viewing neurodivergent minds as having diverse ways of thinking and recognising their strengths, using the word “traits” instead of deficit/impairment, and “condition” as a less negative label than a disorder (Kenny et al., 2016; Milton & Bracher, 2013). Within the museum sector, there has been an increase in the use of the term “neurodiverse” or “neurodivergent”, as evidenced by the creation of a UK Neurodiversity Museum Group and a “Neurodiverse Network”,<sup>4</sup> both

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<sup>4</sup> This is a “neurodiverse” network as it is open to both people who are and are not neurodivergent. The aim of this network is to identify and promote neurodiversity and the needs of neurodivergent people working in (as well as visiting) museums. It is intended that this network will be a place to promote sectoral change and allow professionals a space to learn from and with neurodivergent people to make the sector more accessible.



established in 2021, which aim to promote neurodiversity within the cultural heritage sector for museum workers who identify as neurodivergent.

While I will refer to “autism”, “neurodivergent”, and “autistic people” in this thesis, the term “AuND” and labels related to the wider neurodiversity movement will be used where the discussion pertains to more audiences than just autistic ones. These terms will be used interchangeably, which reflects the usage within the community and demonstrates the often-overlapping needs across different neurotypes.

### 1.3.3 Autism-Friendly or Neurodivergent Accessible?

Throughout this thesis, the term “neurodivergent accessible” will be used, rather than “autism-friendly”. The reason for this is simple: when we discuss accessibility regarding physical disabilities or access requirements, we observe that these are crucial conditions for a venue to be considered accessible. The term “autism-friendly” tends to refer to one-off events and provisions (e.g. in museums) that are not consistently available but are crucial for an AuND person to visit. Additionally, by only referring to autism, there is the risk that otherwise neurodivergent people may not access provisions that they require to visit the organisation. If a venue were described as “wheelchair friendly” because it was only physically accessible at certain events, this would not meet the minimum legal requirements for accessibility. With “autism-friendly” provisions not always available, or events being one-off occurrences in venues that are not always “autism-friendly”, organisations may appear tokenistic or not fully committed to accessibility. A key factor in becoming “accessible” is removing barriers and creating a more equitable environment for everyone. “Inclusion” and using inclusive design are crucial for creating accessible experiences that enable equitable participation by removing barriers for everyone (Fletcher, 2006). Therefore, for an organisation to become accessible, it must also strive to provide equitable opportunities to everyone, particularly groups who have been traditionally under-represented or marginalised. Cultural heritage institutions and wider society should therefore be striving to make sure they are always “neurodivergent accessible” and not simply “friendly”. For this reason, I utilise the phrase “neurodivergent accessible” except when discussing an event or resource labelled as “autism-friendly” by organisers, or when asking museum workers about their experiences of “autism-friendly” practices because it is the current commonly used term. This is a conscious decision and emphasises the general point that, if attitudes shift towards treating AuND people’s needs as an accessibility requirement, this could influence the development of future provisions and associated funding.

## 1.4 Research Structure

The structure of this thesis follows the key phases of the research in the sequence in which these were carried out, inviting the reader to follow the project's journey. The literature review ([Chapter 2](#)) which follows provides an overview of the development of the museum and autism fields. It highlights the similarities that exist within the two fields and shows the current gap in research into the experiences of AuND adults in the cultural heritage field.

[Chapter 3](#) focuses on the methodology adopted and explores the theoretical and practical approaches that have influenced the direction of the research. It introduces and explores the participatory and emancipatory activities undertaken as part of the research design process, highlighting the impact that community consultation had on the research objectives, questions, and methodological approach taken. It then outlines the work undertaken at each of the three phases of the project: 1) the design, launch, and analysis of the surveys for AuND and museum workers, 2) community consultation with workshops and 3) the plan for further consultation post-thesis submission to create a sectoral guidance toolkit. This chapter is intended to not only give an overview of the project's key stages, but also provide a blueprint for developing future participatory projects, either research or sectoral.

The three chapters which follow (Chapters 4–6) present the findings of the fieldwork. Each chapter discusses a) the key findings from the AuND survey ([Chapter 4](#)), the museum workers' survey ([Chapter 5](#)) and the feedback from the workshops held with both AuND adults and museum workers ([Chapter 6](#)) respectively. These findings from the various participatory points of contact with the AuND and museum worker communities illustrate the importance of direct community consultation and participatory practices when developing a resource. In the case of this thesis, these findings informed a co-designed guidance toolkit, discussed in the conclusion and recommendations chapter ([Chapter 7](#)).

# Literature Review

While Museum Studies and Psychology are two distinct disciplines, there are similarities in the trajectory of both as research fields. In particular, the shift from a top-down, academic-led practice and perception to being more participatory and community-focused occurs in both fields. This literature review provides a summary of the developments in both the museum and autism research fields. It explores some examples of practice from the cultural heritage sector to illustrate that embedding participatory practices in work to enhance accessibility for neurodivergent adults is a natural progression.

While this literature review focuses specifically on autism research rather than neurodivergent research more broadly, this approach directly responds to current research trends. To date, neurodivergent research has predominantly focused on autism, with growing recognition of trait overlaps and increasing co-diagnoses like autism and ADHD (May et al., 2018). Consequently, neurodivergent-specific research in cultural heritage has specifically been targeted at autistic audiences. In 2024, Jason Lang et al. (2024) published research on neurodivergent trait overlap, analysing 114 participants' medical records and questionnaires. They advocated for a more holistic diagnostic process, highlighting significant trait intersections that challenge traditional single-condition diagnoses. This research supports a spectrum-based understanding of neurodivergence, suggesting support for AuND people should recognize individuals as potentially multiply neurodivergent rather than confined to a single diagnostic condition. The growing understanding of “multiply neurodivergent” individuals reveals significant trait overlaps – including communication differences, sensory needs, and consequential difficulty in socialising and accessing public spaces. Given autism's prevalence and emerging research on neurodivergence, this study considers both conditions together.

## 2.1 From Cabinets of Curiosity to Cultural Living Rooms: The Shifting Roles of Museums

The modern museum, where exhibitions were intended to display selected objects for the public, has early origins in the sixteenth century. However, it did not become recognisable as the museum we understand today until the seventeenth and eighteenth centuries. Over the past 30 years, museums and their societal functions have significantly altered (Rodney, 2019; Black, 2012; Pitman, 1999; Stam, 1993). Since the 1990s there has been a substantial increase in

scholarship on museums and cultural heritage from a wide range of museum workers and scholars from a variety of different disciplinary backgrounds: for example, museum studies, psychology, visitor studies, sociology, and history (MacDonald, 2011). Much of this literature has sought to explain and understand museums from their origins through to the roles that museums play in the everyday lives of people and society today, as well as making informed projections about the future of the sector (Simmons, 2017; MacDonald, 2016).

## 2.1 Museum Definition and Shifting Public Perceptions from the Sixteenth Century to Present Day

The museum's definition and core purpose have not shifted significantly over time, despite the role that museums have in the community and their practice having adapted to meet cultural shifts (Murphy, 2019; Arnold, 2006). Like a temple, a museum was also seen as a place for people to attend, observe, and learn quietly by following its leaders' rules and as a place of contemplation. This purpose has some overlaps with a museum's main purpose: to collect, preserve, interpret, and display artefacts or objects with historical, scientific, or cultural significance for the benefit and education of the public (MA, n.d.; ICOM, 2018; Anderson, 1999). What has shifted over time is how society, particularly politicians and museum workers, have viewed the role of cultural heritage institutions. This includes how they should operate, what the museum's position should be nationally and locally, and how these organisations should run or adapt to meet the needs of society (Simmons, 2017; Ross, 2004; Pitman, 1999). Furthermore, museums are institutions that could be considered "living" because of their constant change, growth, and development within society (Watson, 2007; Spalding, 2002). This has caused a shift in the values and approaches of the cultural heritage sector to become more inclusive, adaptable, and focused on its role within society, away from the connotations of its namesake (Murphy, 2019; Stam, 1993).

Museums have traditionally been identified and understood by society as educational institutions, where visitors can go to be educated about the collections, look at objects selected for display, and read labels written by authoritative curatorial figures (Ross, 2004; Harrison, 2004; Hooper-Greenhill, 2000; Pitman, 1999; Bennett, 1995). In addition to being seen as places where meaning-making is directed by the museum, how the visitor was expected to behave was pre-determined, and any actions not consistent with the standards set by the museum were not tolerated (Stam, 1993). Museums were used as civilising tools to educate and engrain specific morals, manners, and social rules shaped by the elites within society to

control the behaviour of the lower classes (Rodney, 2019; Coffee, 2008; Witcomb, 2003; Duncan, 1995; Bennett, 1995). This societal purpose of communicating and policing behaviours often based on Foucauldian theories further emphasised the perceived elitism within the sector (Foucault, 1995; Wong, 2015; Ross, 2004; Bennett, 1995).

### 2.2.1 Shifting Roles of Museums and Visitors

The late 20<sup>th</sup> century marked the beginning of what is known as new museology (Vergo, 1989). This was described as a response to the perceived cultural failings of “old museology”, which was felt to be elitist and exclusive to specific, limited audiences, not making its collections available for public education (Heijnen, 2010; Vergo, 1989; Stam, 1993). Some scholars have suggested that “old” museology was focused primarily on its functional role of collecting, preserving, and educating, rather than considering the audience and societal role (Stam, 1993; Ross, 2004; Vergo, 1989). Peter Vergo’s essays on new museology (1989) challenged old museology and its focus on the method rather than the purpose of museums. These essays, and further work by other museologists since this publication, offer critiques of the “old” and suggest a person- or audience-focused approach that emphasises the museum’s role within society and moves away from its elitist past (Vergo, 1989; Hooper-Greenhill, 1988; Merriman, 1989; Bennett, 1988).

New museology marked a period of transformation and change within the museum sector. Some suggest that it promoted attitudinal changes within museums, emphasising the importance of their role in social justice in the late 20<sup>th</sup> century and resulting in further publications influenced by its ideas (see Karp et al., 1992; Weil, 1990). Vergo’s work was not the first of its kind within museology to promote social justice and an audience-focused approach (O’Neill, 2006; Stam, 1993). Throughout the history of museums, there have always been criticisms of practice, with notable theorists calling for museums to take on more of a social justice role from the 1930s (Stam, 1993; Riviere, 1985; Adam, 1939). By the 1970s, several noteworthy events within society accelerated change, and led to critiques of the museum’s focus on being a repository for material culture. This resulted in a crisis of identity in a changing society (Morse, 2019; Mayrand, 2018; McCall & Gray, 2013; MacDonald, 2011;; O’Neill, 2008; Harrison, 2004; Witcomb, 2003; Cameron, 1971). One change was the shift away from the industrial age towards an information age, which has seen the emergence of the importance of information and how its communication and dissemination impact society. This

underpinned the visitor-led direction of new museological theories (Rodney, 2019; Stam, 1993).

With a museological shift towards becoming more visitor-centred, and the increasing pressures on the sector to survive in a saturated cultural market and governmental pressures, museums have needed to make changes to survive (Rodney, 2019; Black, 2012; Coffee, 2008; Prior, 2002; Hooper-Greenhill, 1994). Many scholars have suggested that, while there has been some hesitation about shifting the organisational aims of museums away from education to a more audience-focused approach, the financial pressure to keep open amidst a busy leisure market has often led to museums changing their practice (Coffee, 2008; Black, 2005; Ross, 2004). Responding to the instability of the museum sector, museums have had to learn to adapt to protect their future. This has led to the extension of their role within the communities they serve (Ross, 2004; Harrison, 2004): for example, as community hubs or by promoting the benefits of visiting museums for enhancing mental health (Morse, 2019). This suggests that the recent adoption of marketing and visitor-centred projects is not only about the ideals introduced by new museology but comes from necessity (Hooper-Greenhill, 2000).

### 2.2.2 Civilising and Social Benefits: Who Are Museums For?

As museums became public bodies funded by government and local authorities, their purpose shifted from collection and conservation to civilising the public through display (Abt, 2006; Pitman, 1999). The government viewed museums as ideal places for teaching the working classes how to behave more like middle- or upper-class citizens and to discourage drunken, immoral, or illegal behaviour (Bennett, 1995 & 1997, Habermas, 2001, Ashley, 2007). There were strict social rules for how one would be expected to behave within the museum space and in everyday life, which were monitored by museum staff throughout their visits (Giebelhausen, 2006; Bennett, 1995).

Since the early 1990s, a shift has taken place away from the traditional view that museums are institutions primarily focused on civilising and educating their visitors with an emphasis on audience-focused learning (Hooper-Greenhill, 2000; Pitman, 1999; Hein, 1998). With the societal and political focus on the social benefits of culture and museums, attention has shifted from what museums can do *to* visitors to *educate* them. They are now more focused on what museums can do *for* their visitors to *benefit* and add *social value* to them (Rodney, 2019; Watson, 2007; Stam, 1993). These social benefits include programming based on the needs and interests of visitors within the local community that can promote communication

and learning and enhance physical and mental health (Rodney, 2019; Morse, 2019). Governments have invested in museums, such as the V&A in Dundee (2018), as part of wider urban renewal projects and many funding bodies require evidence of quantifiable benefits that they can have in society (Rodney, 2019; Watson, 2007; Sandell, 2003; Pitman, 1999).

### 2.2.3 Museums for Audiences: Audience Development

Museums became increasingly visitor-centred in the 1980s, which has resulted in the sector adapting its practice to become more welcoming to diverse audiences (Rodney, 2019; Murphy, 2019; McCall & Gray, 2013; Hooper-Greenhill, 1994). While Museums Galleries Scotland (MGS) do not have a specific position statement on audience development, they have emphasised in their Character Matters Report that, particularly in the last 10 years, changes have taken place in how museums have worked to engage and increase the participation of its audiences (MGS, 2023). The Character Matters Report suggests that museums and their workforces must adapt and develop new skills and approaches to meet the changing needs and preferences of their audiences (ibid). Meanwhile, the Museums Association (MA) Code of Ethics' first principle for museums emphasises that museums "should actively engage and work in partnership" with new and diverse audiences, as well as their existing ones, to treat everyone with equal respect, and support freedom of speech using the collections for the public's benefit (MA, 2016). The code explicitly emphasises the importance of collaborating with audiences to promote active engagement with the collections in a way that is beneficial to them. Indeed, both organisations highlight the importance of audience engagement as an evolving process to meet changing needs.

One of the key changes during the 21<sup>st</sup> century has been a shift away from aiming for one-off visitors, instead encouraging engaged, repeat visitors from existing and new audience groups (Lang, 2016; Black, 2012). Visitor studies and audience development have become more common in museological practice to complement this shift. Part of the reason for this shift is the realisation that there is no one type of visitor, and museums need to understand the unique needs of their audience better to develop ongoing relationships with different visitor groups (Rodney, 2019; Black, 2012; Hooper-Greenhill, 2000; Treinen, 1993). This has often involved visitor studies, observation, speaking directly to visitors, and a measurement of visitor demographics to identify patterns of who does or does not visit museums (Black, 2012; Hooper-Greenhill, 2000). One of the key areas that museums have focused on when assessing their success is whether they are meeting their audiences' needs and identifying what potential

audiences are being missed. This has resulted in the creation of new roles within museums, particularly learning, marketing, and other audience-focused positions acting as “audience advocates” within the institution (Hooper-Greenhill, 2000). Furthermore, greater emphasis on the role of front of house and visitor services in creating and maintaining a welcoming environment for and engaging all visitors means that an increase in investment into these services is a crucial part of enhancing the visitor experience (Black, 2012).

In addition, a key objective of audience development is to make museums more inclusive and accessible to under-served audiences (Black, 2012). Visitor research has demonstrated that museum visitors tend to be from middle-class, white backgrounds with higher education and/or a history of visiting museums from childhood (Rodney, 2019; Hooper-Greenhill, 1997; Hooper-Greenhill, 1994; Ross, 2004). For example, a 2015 Warwick Commission report found that 87% of museum visitors came from higher social groups, which refers to people who have had or come from families educated at university level and/or have a professional occupation (MA, 2016). In contrast, the working classes, individuals from the global majority, and disabled people have been identified as key groups who have been under-served and under-represented in visiting patterns (Rodney, 2019; Black, 2012; Bunting et al., 2007). However, as the higher and lower middle classes make up a smaller portion of wider society, there are concerns that museums are missing a sizeable portion of the population of potential visitors (Rodney, 2019). This suggests that museums must not only understand *why* these groups do not visit, but *how* they can create changes to make the institution more appealing or welcoming.

These questions have become focus points of visitor studies that have begun to identify some of the common barriers to potential visitors. One theory relates to the idea that museums are not considered accessible and welcoming to everyone. This means that people from under-represented groups have not developed a visiting pattern within cultural heritage institutions (Rodney, 2019; Black, 2012). A hypothesis often applied to this gap in visiting is that it is a result of cultural capital (Bourdieu, 1984; Fyfe, 2020; Hanquinet, 2016). Bourdieu (ibid) observed that the low visiting numbers of minority groups may be a result of not being raised with a sense of belonging or connection to museums (Watson, 2007; Blau, 1991). They suggest that people who do not have an established connection to museums may not feel comfortable in these spaces. If museums are for educating and civilising practices and are frequently seen as planning for specific, often pre-existing audiences, certain audience groups can feel excluded from museum visits by design.



Issues have been related to the absence of traditionally marginalised groups within museum collections and displays (Black, 2012; Sandell et al., 2012; Sandell et al., 2010; Delin, 2002). Historically, many potential visitors have not felt as though they belong in museums because their experiences are not represented in museum exhibits (Black, 2012; Sandell et al., 2010; Watson, 2007). Groups such as Museum Space Invaders, a UK-based movement in the museum sector, highlight the absence of women and non-binary individuals within the collections and interpretations (Museum Space Invaders, 2016). Similarly, Museum Detox, a “network for people of colour (POC)” in museums, which began in 2017, was created to support and reclaim their history (Museum Detox, n.d.). These networks demonstrate that gaps remain in representation in museums, requiring external support networks and advocacy groups. Curating for Change (CfC) is a work placement programme designed to address the under-representation of disabled people working in museums and to undertake projects in English cultural heritage organisations relating to disabled people’s histories (CfC, n.d.). As new museological theories call for interpretation to move away from representing only dominant cultures to include stories of more diverse experiences, this shows a shift from the civilising and educating approach to one that incorporates more diverse stories that are more reflective of the society we live in (Black, 2012; Stam, 1993). For museums to attract the audiences they have alienated in the past, they must therefore work to adapt their practices and reach out to engage these audience groups (Ross, 2004). This involves civil engagement and the active involvement of groups who have been under-served to address visiting and representative inequality, which could result in increasing access (Black, 2005).

### 2.2.5 Criticisms of Audience Development

Criticisms have been addressed towards the movement to undertake visitor studies and change traditional practices to meet the preferences of current or potential visitors. Bennett (1995), for example, has criticised the de-professionalisation of curators and the shift towards audience development that changes what “works” to attract a new audience (Witcomb, 2003). The concern is that changing what exists within the museum can result in a loss of established visiting groups to try and engage non-visitors. As Watson (2007) and Wong (2015) suggest, community groups are fluid and can change over time, as can their preferences. For some scholars, this is considered too large a risk, particularly with the concerns about the survival of the museum. There are concerns about curators’ perceptions of decision-making – which was historically top-down in its approach – becoming more democratic (Rodney, 2019). This process of opening dialogue and making changes based on visitor feedback can mean a shift

away from traditional methods of display or the perceived priorities and values of the institution.

Another reason for the reluctance, or inability, to undertake audience development projects is that they are often endeavours that require a lot of investment of time and finance, as well as commitment, to complete them in a way that has long-term benefits (Black, 2005). Nuala Morse (2019) argues that museums often struggle to raise and maintain non-governmental funds during periods of austerity, which can negatively impact such projects. In 2017 and 2018, sector surveys found that museums had experienced financial cuts (Morse, 2019). Despite reductions in funding, it is important to note that public-facing services during this same period reported an increase in outreach with specific groups, which may be connected to funding tied to specific bodies (such as the Arts Council) or a determination to use outreach to increase the profile of museums within the community (Morse, 2019; Black, 2012). Hooper-Greenhill (2000) asserts that, as change is a necessity for museums to survive, lack of funding makes audience development and outreach essential – without the audience, there would be no museum. This suggests that, while cuts to funding undoubtedly impact the scale of participatory and community-based practices, there are ways that museums can utilise their resources and audience development strategies to remain open.

Criticism aside, audience development practices have become more essential over the past 20 years. With the age of information, the democratisation of information, and the opening of dialogue facilitated by technology, it has become more crucial to adapt (Rodney, 2019; Stam, 1993). In recent years, more emphasis has been placed on engaging under-represented groups in the form of projects, awards (such as the MA's Museums Change Lives Award) and conferences specifically themed around promoting good social justice and inclusion work being undertaken by museums to address the gap (Morse, 2019; Black, 2012; Sandell, 2003; Pitman, 1999). This is a positive sign of museums taking on their roles as agents of change and institutions capable of promoting social inclusion, offering an important contribution to their community (Black, 2012).

In addition, significant gaps in visiting and representation within the museum workforce must be addressed (Rodney, 2019; Sandell, 2003). In the same way as within the workforce, the demographic information of the current audience shows that minority groups are still under-represented (*ibid*). Museums still have low engagement with people from ethnic minorities, working-class and disabled groups (Black, 2012; Dodd and Sandell, 1998).

This suggests that, for museums to survive, they must find ways to engage non-traditional audiences and ensure that all people feel welcome in their establishments as visitors and members of the workforce (Ross, 2004). Addressing the embedded inequality within the sector and increasing access for more diverse visitors and workforce can benefit all who access the museum (Black, 2012; Sandell & Dodd, 2005). It is important to note that this must be evaluated as an ongoing process to better understand the motivations of why some individuals or groups visit museums while others do not (Black, 2012).

## 2.3 Accessibility: Legal Framework, Social Equality and Museums

Richard Sandell (2003) describes museums as “social agents”, as they have the power to influence positive change in wider society by setting an initial example through their practice. In this context, museums are important public spaces with the potential to lead the way in developing and highlighting inclusive practices by instilling diversity and accessibility policies first within their organisations.

According to the UK government (Duggin, 2016) “accessibility means that people can do what they need to do in a similar amount of time and effort as someone that does not have a disability”. While accessibility can be explored in relation to class, race, and nationality (Cole, 2015), this literature review focuses specifically on shifts and developments in access for disabled people within cultural heritage and wider society (Black, 2012; Black, 2005). This section gives an overview of the legislative changes introduced in response to social and political shifts, which have evolved from the 1980s to the present, resulting in a legal and social obligation for cultural institutions to become more accessible (Blackie & Moncrieff, 2022; Shakespeare, 2018; Sandell & Dodd, 2010). Furthermore, it highlights current and future developments and explores why planning with accessibility in mind through universal design practices can benefit all visitors.

### 2.3.1 Overview of Legislative Changes Towards Accessibility

Accessibility has only been advocated as a priority for museums and supported by related legislation introduced for the whole society in the last 30 years (Sani, 2018; Sandell & Nightingale, 2012). Before this, the experiences and needs of disabled people were often overlooked in society, forcing disabled people to either adapt or miss rights that non-disabled people had without question (Goldman et al., 2003). Barriers to access have ranged from physical barriers, such as inaccessible buildings, to less visible obstacles including *intellectual*

(limited and difficult interpretation for people with intellectual disabilities), *financial* (cost of visiting, including cost of transport, entrance fees, personal equipment, and support needed to attend), and *psychological* (visitors' anxieties that they may not belong in the space or that their needs may not be met) obstacles (Lang, 2016; Black, 2012). The journey towards person-centred, accessible cultural institutions has been entirely necessary to meet every human being's right "to participate in the cultural life of the community, to enjoy art and to share in scientific advancement and its benefits" (Article 27, Universal Declaration of Human Rights, UN, 1948), but it has been a slow process because of enduring access barriers (Sani, 2018; Magkafa & Newbutt, 2018). Sandell (1998) highlighted that, for social inclusion to occur, there must be equal opportunities to access and participate in society. This suggests that, where an individual or group cannot have equal access to these opportunities, they are socially excluded, with their access rights denied. However, there is a growing legal and social pressure to address these disparities. This is demonstrated in the work of disability activists, government policy, research, guidance from international organisations such as the WHO and the UN, and organisations within the museum sector who identify and seek to address accessibility barriers.

At present, approximately 16% of the worldwide population (1.3 billion) is estimated to have some form of disability, and this number continues to grow daily (WHO, 2023a; TNM, 2022). According to a survey conducted between 2019 and 2020, over 14.1 million people were disabled in the UK alone, representing approximately 22% of the population (Family Resources Survey, 2021). Reports on the experiences of disabled people demonstrate elevated levels of inequality and exclusion compared to non-disabled people (Kastenholz et al., 2015; Sandell, 1998). For example, disabled people are more likely to experience poor or inadequate housing, lower employment, and poorer education opportunities, increasing their risk of living in poverty. They also experience poor medical support (WHO, 2011; UN, n.d.). Most of the societal barriers impacting disabled people's daily lives are human-made, such as buildings being designed without physical access. This is because many people take certain aspects of daily life for granted without realising that they constitute a barrier to accessibility for others (Girma, 2017; Adler, 2010). In recognition of the fact that the exclusion of disabled people stems from structural inequalities, efforts to improve accessibility have emerged through equality and equal access legislation. Structural and legislative changes were initiated in the UK and the rest of the world to improve access to services, support, and public spaces, ensuring that all visitors have equal access (Sandell, 2003; Sandell & Nightingale, 2012; Sandell, 2012;

Black, 2012 Expert Group on Cultural Heritage, 2018; UN Convention on the Rights of Persons with Disabilities, 2008).

Indeed, as societal understanding of enduring equality and access issues has improved, legislation has adapted and been updated. The collective voices of disabled activists and their allies, the mantra of “nothing about us, without us”, the pressure applied to acknowledge the right to equality in access, and human-rights-influenced policy-making has provoked public institutions such as museums to address their past failures and create opportunities for disabled people to share previously inaccessible spaces (AAM, 1998; Durbin, 1996; Smith et al., 2012).

Following the introduction of the Disability Discrimination Act (DDA) in the UK, the heritage sector was given 10 years to address its accessibility issues. This has involved developing policies and undertaking physical updates to meet the legal requirements, in recognition of the fact that adaptations would take significant financial and time investment (Reeve, 2016). For many, this meant that museums or other cultural heritage institutions had to ensure that a wheelchair user or person with limited mobility would be able to access the building and have equal rights to access facilities such as toilets. Meanwhile, the American National Endowment for the Arts handbook “Design for Accessibility” (Goldman et al., 2003) and AAM’s “Everyone’s Welcome: The Americans with Disabilities Act and Museums” (Salmen, 1998) both offer guidance on best practices for enhancing accessibility for cultural institutions. In both countries, the legislations emphasise the importance of including disabled people in the planning and evaluation of access strategies and notes that this process must be treated as ongoing rather than limited to what is legally required (Walters, 2009).

It should be noted that the legislative requirements introduced in the 1990s tended to focus on physical disabilities and were often limited by budget and expertise, which consequently impacted the ability of institutions to go beyond what they were legally required to do (Sandell et al., 2010). As a result, other disabled audience groups, such as visitors with visual, hearing, or cognitive disabilities, often slip under the radar, particularly in smaller institutions. However, while the scope of this early legislation was limited to physical access, it brought about a huge improvement to the previous circumstances where accessibility was not a priority and basic physical needs were not being met, providing a crucial foundation for developing accessibility for more diverse access needs. While it cannot be disputed that the disability rights movement and legal requirements introduced in the 1990s and the subsequent

Equality Act (2010) have had a crucial role in making accessibility a priority within the museum sector, it is therefore still an area that needs to be prioritised.

### 2.3.2 Impact and Progress in Museums

The disability movement and legislative changes have had a significant impact on accessibility in public spaces, including within the cultural heritage sector.<sup>5</sup> However, actual changes have been slow and have been driven by meeting the legal requirements as an accessibility end goal (Smith et al., 2012). With the deadline for adjustments to public spaces set to 2004 in the UK, to account for financial and structural barriers that could delay the provision of accessibility facilities, such as ramps, brail, audio loops, and accessible toilets, the real impact of these pieces of legislations has only been felt in the last 20 years. In this period, progress in enhancing the accessibility of museum spaces and programming beyond the legal requirements has been limited (Walters, 2009). There is some research, such as by Papadimitriou et al. (2016), which points to the need to identify and address accessibility barriers for the museum sector to become more socially inclusive. This section shall explore current practice, policy and gaps that impact accessibility and social inclusion within the cultural heritage sector.

### 2.3.3 Understanding and Reality of Access

To gain insight into how accessible museums and cultural heritage institutions in the UK have become, some sectoral research has been undertaken to reveal current access provision trends. One of the key British projects that has reported findings was the Museum and Heritage Access Survey (2020) and the State of Museum Access (2018), both co-organised by VocalEyes, StageText, and Autism in Museums. Each report aims to give a snapshot of what currently is, or is not, available, and to offer guidance and recommendations based on the findings of each respective project. The Museum and Heritage Access Survey (2020) and State of Museum Access (2018) are two UK-specific reports on current accessibility provisions in museums, based on analysis of related surveys of disabled people and resources available. The teams involved in the production of these reports are accessibility specialists who represent expertise and experience in several types of disability and access needs. This is important as it bridges the expertise gap of museum workers, who often have limited knowledge on the topic of accessibility and the needs of specific disabled groups. It is important to note that, while this

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<sup>5</sup> For example, in 2000, DCMS introduced a Social Inclusion Policy for Museums, Galleries and Archives, which included policy guidance to support this work. Since this policy, organisations like the MA have produced guidance on improving accessibility or inclusion with their “Inclusive Museums” work.

discussion focuses on the UK reports, similar findings to those found in the access surveys discussed are also apparent in American and European literature on accessibility within society (for example, see Sani, 2018.; Goldman et al., 2003; Equality and Human Rights Commission, 2018; European Commission, 2014). The similarities between the UK reports and those published in America and across Europe suggest widespread issues in accessibility that must be addressed going forward.

As of 2018, only 53% of UK-accredited museums included in the Museum and Heritage Access Survey (Cock et al., 2018) had ramps or level access and only 1% of museums surveyed mentioned having captioned talks or dementia-friendly or autism-friendly events. Potential reasons for this include lack of funding and training, resistance to changes to established resources or practices, and lack of confidence in addressing these shortfalls (Samuels, 2016; Rossi-Linnermann, 2010). Furthermore, as suggested previously, another factor for a restricted range of access provisions and policies may be attitudes towards accessibility and a limited understanding of what it takes to be accessible. For example, an institution may believe it is “fully accessible” simply because it has met the minimum legal requirements (Walters, 2009). As the Museum and Heritage Access Surveys conducted in 2018 and 2020 demonstrate, the availability of physical facilities as listed above and the use of subtitles and braille has improved over time. However, clear areas remain for significant improvement to be addressed across the sector. While this is an improvement on what was available 20 years previously, the same access surveys show that few museums go beyond the legal minimum requirements or fail to advertise specific accessibility features and events. This demonstrates a need to identify and begin to practically address inaccessibility within the sector.

These reports highlighted some key gaps and priorities for the museum sector to address. The Access Survey (Cock et al., 2018) revealed that disabled people’s attitudes towards museums were more positive than before – they perceived that museum commitment to accessibility was higher than for other public venues. However, there were still areas that needed substantial improvement in reducing the engagement gap for disabled people. While a museum building may be physically accessible and encourage attendance, if the museum then fails to engage disabled visitors this impacts the experience of disabled people as it is disempowering and leads to further exclusion (Chiscano & Darcy, 2020).

### 2.3.4 Changing Communication

The development of technology, allowing visitors to connect from within, or outside the physical museum, has contributed to shifting museum practices (Wong, 2015). In the last two decades, advancements in technology have shifted theories and transformed what is possible in terms of display and communication within and beyond the physical museum (Murphy, 2019). Access to technology is increasing, as is access to museums via their websites or social media to engage or be attracted to the museum (Black, 2012). The development of technology has had an impact on museums' ability to communicate knowledge to visitors in creative ways, increasing the possibilities for museums to engage different visitors and cater to a range of learning styles (Sola, 1992). The ability to use social media to engage with museums has enabled increased opportunities to engage with, but also to be held publicly accountable by, society (Wong, 2015; Black, 2012). Online content and engagement in two-way conversations between institutions and audiences have allowed for more informal and friendly discussions (Wong, 2015). The rising utilisation of technology in museums has challenged the museum to break away from its transmission-based communication model and an analogue approach to educating the visitor.

The development of technology that can be used to facilitate participatory practice in recent years has helped some museums to enable such practice and increase the potential for opening dialogues between an institution and its audience (Murphy, 2019; Marakos, 2013; Black, 2012). These practices aim to contribute to the shift away from visitors being seen as passive to becoming active in the museum (Rodney, 2019; Coffee, 2008). With many museums seeking to be more democratic in their information-sharing and gathering processes, directly communicating with diverse groups is an important approach for museum workers to take to achieve this (Marakos, 2013; Weil, 1999).

It is important to note that interactivity within the museum space is not all digital. Some scholars, such as Andrea Witcomb (2003), have critiqued the modern assumption that interactivity within museums is always through technology, or that digital displays or technology are enough to be interactive. Indeed, interactivity is about connection and engagement between people – communication and influencing each other rather than passively receiving a one-way transmission (Harrison, 2004; Hooper-Greenhill, 2000). One type of interactive approach often overlooked is multi-sensory, or touch-based, engagement using objects (Black, 2005; Witcomb, 2003; Hooper-Greenhill, 1994). Some scholars, such as



Bennett (1988) and Classen (2017), suggest that object-based engagement activities where the visitor can have hands-on experiences can be effective for engaging visitors as well as enhancing accessibility.

While technology has had a positive impact on increasing interactivity and active engagement in cultural heritage institutions, it is too simple to suggest that digital interactives are enough to create and foster engaging shared experiences within museums (Witcomb, 2003). For museums to be truly interactive, immersive, and engaging, they must identify and utilise both digital and more traditional person-to-person interaction to make museum visiting an active and collaborative experience. While many of these changes have developed out of necessity to enable museums to survive in the face of financial cuts and increasing competition from other leisure activities, often with reluctance from curatorial teams, they have resulted in a movement towards audience-led, multi-disciplinary decisions (Black, 2005; Ross, 2004; Witcomb, 2003; Hooper-Greenhill, 1994).

### 2.3.5 Online Accessibility in Museums

The State of Access Survey (Cock et al., 2018) highlighted that one in five museums offered no online access information. This is as problematic for the museum sector as it is for disabled people. Lack of information about a venue's accessibility might be seen as a lack of commitment to meeting the needs of disabled people, making them feel unwelcome and less likely to attend. This reflects Komar et al.'s (2019) argument in highlighting that a museum's online presence, accessibility information, and presentation of general information can significantly impact how accessible a museum is outside and within its physical space. Indeed, the State of Access Survey (2018) and Komar et al.'s (2019) findings suggest that, for disabled visitors in particular, visiting experiences in museums very much begin with their online presence and how they engage audiences via websites and social media platforms to communicate, demonstrating how it meets their access needs (see also, McMillen & Alter, 2017). Since the introduction of the W3C WAI web content accessibility guidelines (WCAG) – which are international guidelines intended to enhance accessibility on the World Wide Web – specific standards and expectations for websites for cultural heritage institutions have been set (Cock, 2018). By failing to meet web accessibility guidelines or to make accessibility information available online, museums risk losing potential visitors.

Respondents to the Access Survey (2020) found that 96% of disabled people wanted to visit venues more regularly and were more likely to visit venues that they were aware (via

website information, word of mouth or previous experience) were meeting their access needs and had useful resources. This demonstrates that disabled visitors appreciate and benefit from museums that prioritise accessibility, but such visitors are more likely to visit and recommend institutions that meet, or even exceed, their needs and expectations.

### 2.3.6 Community Involvement

The Museum and Heritage Access Survey conducted in 2020 shifted away from looking at what information was available online to asking the opinions of disabled people and their visiting companions who access and visit museums in the UK about their experiences in cultural heritage institutions. This survey aimed to gain insight directly from disabled people and their families, an audience group whose voices have traditionally been neglected, to inform and further shape the sector's priorities. This shift itself is crucial, as data was previously gathered from museum websites by volunteers rather than from disabled visitors themselves. As one of the recommendations from the 2018 survey was to create access panels and listen directly to the priorities of disabled people, this approach reflects the practices they are striving to promote to the sector. This demonstrates the belief that lived experience should be treated as a form of expertise, and therefore museums should actively seek to include the audiences they aim to represent in access panels or other consultation processes (Sandell, 2003; Black, 2012, Masterson, 2015). For example, Goldman et al. (2003) and Chiscano and Darcy (2020) recommend that cultural venues should have access panels or adopt co-creation practices in consultation with disabled people to initially identify and then address their needs. They also recommend that cultural institutions ensure staff training is offered as this is a necessity for making a venue welcoming (Sandell, 2003; Levent & Reich, 2013; Nightingale & Mahal, 2012).

By consulting with disabled people directly, museum workers can gain greater insights into what visitors would find useful, which helps to inform workers and engage potential visitors as their views are being listened to (Levent & Reich, 2013; Fox, 2010; Goldman et al., 2003; Ng et al., 2017). While access advisory panels are yet to be widely adopted in the cultural heritage sector because of budgetary constraints and lack of staffing to run them, there are examples of panels that have been set up on specific exhibitions or projects and long-term panels. One example is the access panel at Beamish, which has played a significant role in the development of the museum's access provisions. For example, in 2019 the museum worked with its access panel to develop its accessibility and consulted on the creation of its Changing

Places toilet. The Changing Places toilet introduction was a response to the need to have bathroom facilities that are accessible for disabled people who are unable to transfer from their wheelchairs onto a toilet safely. By working with the access panel to identify the needs of visitors with physical disabilities that impact their access to the museum and its bathroom facilities, Beamish made history by listening to its panel and designing a bathroom to meet their needs (Beamish Museum, 2019). This active inclusion of disabled people in the consultation and development of access strategies can have a positive impact as the open dialogue can lead to institutional change and the individuals involved tend to feel more welcome.

Consultation and direct involvement of the disability community can be seen in curatorial projects. An example of the collaborative involvement of disabled people in creating representative exhibition content was the Riverside Museum's Wheel project in 2012. During the planning for this exhibition, wheelchair users were consulted and involved in the interpretation and design of the exhibition space. This was to make sure the exhibition was wheelchair accessible and reflected the stories that the group wanted the audience to hear and learn from (Johnson-Symington & Robertson, 2014). Another example of an exhibition that took a multi-layered approach to making its space accessible was the British Museum's *Mummy: The Inside Story*, in which Jane Samuel (2016, p. 195) was a strong example of a learning team working as "disability advocates" in an inter-departmental manner. This enabled them to create an exhibition that considered the physical, intellectual, and sensory needs of its visitors as they created a multimedia experience with information available in a variety of different formats for its audience to engage in.

### 2.3.7 Accessibility Events

The Museum and Heritage Access Survey (2020) found that, two years on from the previous survey, there were still areas that had not improved in line with their previous recommendations. The survey showed that a need remains for more frequent events for specific audiences (for example, "autism-friendly" events) and revealed that the respondents prioritised staff awareness training as a principal factor for making them feel more welcome in museums. Indeed, the survey showed that over half of the participants changed their minds about attending a museum because of the lack of access to information or difficulty in booking tickets for themselves and their companions (Access Survey, 2020, p. 6). Considering that approximately 70% of the disabled participants in the Access Survey (2020) checked online

information before a visit, a lack of accessible events and clear information on an institution's website may contribute to low attendance.

One of the more popular accessible event types identified by the 2020 Access Survey participants was the “autism-friendly” events, which have increased in popularity across the museum sector over the last decade. Respondents felt that, during these events, their access needs were more likely to be met, and the museum was “trying their best to include me”. Indeed, according to the Access Survey (2020, pp. 22–23), 40% of the respondents “always or often attended” the museum when an accessible event was on. As the museum environment can make or break the experience for visitors and determine whether a visitor will visit in the first place or return, this suggests that museums looking to extend their audience must consider the environment they create during and beyond accessible events (Fletcher et al., 2018).

### 2.3.8 Accessibility as an Ongoing Process

Developing accessibility should not be seen as a linear process with a set end goal and instead should be treated as multi-dimensional continuous development (Goldman et al., 2003; Sandell, 2003; Samuels, 2016).

Increasingly, academic literature and recommendations by government accessibility organisations have emphasised that accessibility needs to be expanded in acknowledgement of diverse needs that have not yet been fully met (Kosmas et al., 2019; Majewski & Bunch, 1998; Sandell, 1998; Rosetti et al., 2018; Kastenholz et al., 2015; Walters, 2009). Yet the emphasis tends to be on visible disabilities, such as physical disabilities, rather than “hidden” disabilities and the importance of the sensory environment and experience within (Goldman et al., 2003). Indeed, according to Diana Walters (2009) in a survey conducted two years after museums were expected to have fulfilled the requirements of the DDA, and in which museum workers were asked if their museum was “fully accessible”, most respondents answered “yes”. However, as the survey continued to ask about specific provisions available that go beyond having an accessible entrance (for example, questions asking if the museum had disability-specific events or access to resources such as hearing loops), the percentage of respondents answering *no* increased and the number of respondents to that question decreased. In the context of cultural heritage institutions, the next step is to review the wider accessibility requirements for visitors who have not been included in the existing legal guidance as an ongoing process. Furthermore, as our understanding of disability and of how specific disabilities can impact visiting museums evolves, so should accessibility provisions.

### 2.3.9 Universal Design and Inclusive Design

Accessibility provisions benefit more than one specific audience. Goldman et al. (2003) explain that planning for accessibility in architectural and event development from the beginning has the potential to enhance the experience for disabled and non-disabled audience groups (Story et al., 1998; Goldman et al., 2003; Choscano & Darcy, 2020; Girma, 2017; Walters, 2009). For example, architectural planning that minimises the use of stairs, displays designed at a lower height, and the availability of multi-sensory resources (such as visual information and audio descriptions (Snyder, 2005) can benefit physically disabled visitors in wheelchairs, visually impaired visitors, and non-disabled visitors such as parents with prams, children, and adults who benefit from having information available in different formats (Mesquita & Carneiro, 2016; Goldman et al., 2003).

This process of planning to meet the needs of everyone from the beginning of a project is what the “universal design” principle aims to accomplish (Story et al., 1998), involving starting a project to make a space or event as accessible for as many people with diverse needs as possible. This principle promotes planning to include disabled people and their experiences to shape the development from the beginning rather than having a challenging time changing and making a non-accessible environment accessible later (Story, 2001). It is more difficult to revert and introduce accessibility later in a project than when it is considered early on.

Inclusive design can be considered the next level of universal design. Much like universal design, the principles of inclusive design are about planning for and factoring in the needs of different people from the beginning of a project to benefit a diverse range of audiences (Sensory Trust, N.D; Kendrick, 2022). However, inclusive design diverges from universal design in terms of the approach to meeting diverse needs (Waller et al., N.D; Fletcher, 2006). Universal design focuses on identifying needs and establishing a solution or approach to be accessible which can result in people with different needs still experiencing barriers (Inclusive Design Research Centre, N.D). In contrast, inclusive design intends to involve a diverse group of individuals with different needs to identify different types of support to create more nuanced solutions. Unlike universal design, inclusive design is not about claiming to create a product or approach to become accessible for all – instead, it asserts that it is unlikely that you can be fully accessible to everyone. By acknowledging that a place or product cannot be fully accessible, it is about establishing different options that help to become more equitable in access. Persson et al. (2014) argue that there is a similarity between the concepts of universal

design, inclusive design, and accessible design in that each concept strives towards the same goal of improving accessibility, and highlights that there can be a risk that less clear definitions of these concepts can have a negative impact on the practical development of accessibility. This research project utilises the principles of universal design as a starting point and the approaches and recommendations of an inclusive design model to recommend diverse adjustments and approaches to meeting the varied needs of AuND people.

### 2.3.10 Expertise by Experience: Including Lived Experiences

Another approach to enhancing disability expertise in the museum is the creation of specialist access roles in the sector. For example, John Reeve (2016, p. 188) suggests that roles such as museum learning or education coordinators have the potential to be “learning advocates” who can directly promote and address the needs of visitors by developing materials or programmes that meet a range of diverse learning and engagement requirements. Where a museum does not have specific internal teams with accessibility expertise, it can hire specific disability accessibility consultants who offer a range of services including bespoke training and create access advisory panels made up of disabled members (for example, Disability Collaborative Network, N.D.). Bringing in external experts by lived experience can potentially create opportunities for disabled, or otherwise under-served communities, to collaborate and inform institutional practices – for example, developing and delivering audience-specific training, such as dementia training or autism awareness training for museum staff (Smith et al., 2012). Recently, there have been more conferences that exclusively explore the topic of accessibility within museums as a priority (for example, MA’s “All Inclusive: Championing Accessible Museums”, a one-day conference on how to meet the needs of disabled visitors held online since 2021). The creation and demand for these roles and services show a positive sign of addressing the need for further staff training identified in the Access Survey (2018), as well as the willingness of the sector to develop further its understanding of what is needed to enhance their access and make their museums more welcoming.

It is noteworthy that the museum sector in the UK is currently reflecting on its neurodivergent population among professional staff and the museum workforce with the creation of a UK-wide Neurodiverse Museum Network (TNM). TNM is a UK-based professional network founded in 2021 by Justine Reilly, a museum professional who is also known for founding Sporting Heritage following the completion of her PhD in 2012 to change “the way museums and the cultural sector as a whole, approaches neurodiversity” (TNM, n.d.).

The network intends to improve the experiences of AuND people as both visitors and members of the workforce by centring lived experience to advocate for improved working conditions. This network and advocacy organisation has been established as a sectoral platform for promoting rights, advocating, and supporting academic and museum workers in the sector who identify as autistic or otherwise neurodivergent. The Neurodiverse Museum was founded by neurodivergent museum workers and holds meetings and events to gather neurodivergent workers to develop neuro-inclusive principles for the sector. Several of the priorities highlighted to date have been about fair recruitment, adjustments for staff, enhancing mental wellbeing, and creating a new platform for assisting all museum workers to better understand neurodivergence. This further demonstrates the need for museums and cultural heritage institutions to reflect on the accessibility provisions they provide for their neurodivergent audiences, and to ensure that they meet the access needs of their staff.

Overall, there is no “one-size-fits-all” solution to accessibility provisions, as every single visitor will have their individual or group needs when visiting and engaging within a museum. It is therefore crucial that museums consider that accessibility has a wider scope than physical access, and that they must reflect on their strategies, respond to any gaps identified or flagged by visitors, and treat the development of new provisions as an ongoing and constantly adapting process (Black, 2012; Ng et al., 2017). While some accessibility adaptations may come at a financial cost (Chiscano & Darcy, 2020), Rebecca McMillen and Frances Alter (2017) highlight that the cost of accessibility is often placed on disabled people themselves, which can result in their exclusion. This goes against the potential for museums to be participatory, inclusive, and meaningful for their visitors, as Nina Simon (2010) advocates. Rather than seeing accessibility as an expensive outgoing, museums should consider it as an investment in their audience, enhancing the institution’s cultural value (Sandell, 1998). Advocates of the universal design principle (such as Black, 2012; Goldman et al., 2003; Story et al., 2008; Connell et al., 1997), advise seeing financial investment as beneficial for a wider audience and crucial to meet audience needs and promote greater inclusivity. With the needs and priorities of disabled visitors changing, and available technologies advancing, museums and the wider public-facing sectors must strive to make their venues welcoming or risk losing out to venues that do.

Accessibility in museums, while a growing field of interest, is still limited in academic literature compared to other aspects of museum and audience development research. However, what is available shows a clear demand and illustrates the impact of enhancing accessibility

and making it a priority to engage a larger number of audiences than originally intended. Thus, making research projects that utilise principles of universal design and participatory and inclusive development in their practice, as this project aims to do, is crucial for shaping future practice and research.

## 2.4 Autism: Shifting Understandings in Society and Research

As the focus of accessibility in museums is increasingly shifting towards addressing the needs of visitors with more diverse access needs, this has led to an interest in making museums “autism-friendly”. This section provides an overview of the shifting understanding and research trends in autism. It intends to synthesise the shifts in autism research trends and to demonstrate the importance of these shifts in autism discourse both in practice and research. It also attempts to demonstrate similarities between autism, access, and museum studies and the methods they employ.

### 2.4.1 What is Autism?

Autism, or Autism Spectrum Disorder (ASD), is a lifelong developmental disability that impacts people differently (Fletcher-Watson & Happé, 2019; NAS, n.d.). Wing and Gould (1979) defined autism as a “triad of impairments”, a term that is no longer used today, which specifically highlighted “social interaction”, “communication” and “rigidity of thinking” as the core symptoms of autism, although how these manifested themselves in different individuals varied. This definition of autism went on to define how we understand autism today (Milton, 2012). According to the current diagnostic criteria for autism (Young & Rodi, 2014; Volkmar, 2013; APA, 2013; ICD-11, 2024; WHO, 2019), it is a condition that impacts an individual’s communication (verbal and body language), social interaction, relationship building, and sensory sensitivity.<sup>6</sup> Repetitive behaviours, such as repetitive body movements and intense interests are other core traits of autism (NAS, n.d.; Milton & Bracher, 2013).

Our understanding of autism has changed significantly since the term was first coined. Since then, significant changes have taken place in how researchers have conceptualised and understood the condition, as well as its impact on autistic individuals, their families/carers and society more widely. Many of the theories and early perceptions have contributed to what are now regarded as misunderstandings and built-up stigma about autistic people, their quality of

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<sup>6</sup> See Ben-Sasson et al. (2019) for an exploration of different sensory symptoms identified as part of their meta-analysis.



life, and the causes and impact of autism (Gernsbracher et al., 2017). It is important to understand that the journey to comprehend what autism is today has not been straightforward. It is a diagnosis that has been widely debated and many areas of research have caused stigma, missed diagnosis and uncertainty about what autism is.

One of the biggest challenges in understanding and explaining autism is how distinct characteristics can vary significantly from person to person and day to day (Fletcher-Watson & Happé, 2019). While on paper the diagnostic criteria may appear straightforward, the reality is that each of these traits impacts an autistic person to varying levels, which is why autism and other neurodivergent conditions are often misdiagnosed or not diagnosed (Cascio et al., 2020a & b; Fein & Rios, 2018). One of the most common inequalities debated by advocates and academics alike is the under-diagnosis of autism in non-white, non-Western communities (Travers & Krezmien, 2018; Di Pietro & Illes, 2014; Mandell et al., 2009; Begeer et al., 2009). Another common example is of an adult female who has gone through childhood without their autistic traits being noticed because they were perceived as shy or having “normal” interests for their age, potentially reaching adulthood before their difficulties in managing social interactions or communicating needs have a significant impact on their day-to-day life (Cridland et al., 2015). This variance in presentation and impact of autism on autistic people’s lives has led to misunderstandings, or in some cases missed diagnosis and consequential lack of support, making autism such a challenging condition to define (for example, Hull et al., 2017; O’Nions et al., 2023).

In the autism community, two commonly recognised phrases are used to emphasise the importance of listening to neurodivergent people directly. The first phrase recognises that the diagnostic term “autism” unites autistic people with others who have shared but not identical traits. This is a modern adaptation of the line often attributed to Dr Stephen Shore, an autistic professor, who stated that, “If you have met one person with autism, you have met one person with autism” in a presentation.<sup>7</sup> The second phrase, “nothing about us, without us” – which is commonly used by the disabled community more generally – recognises the need to include as many autistic voices as possible in any research or provision development (Milton & Bracher, 2013; Chapman, 2020; Charlton, 2004). This suggests that, like museum workers looking to expand their audiences through working collaboratively and directly with their target

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<sup>7</sup> More recent uses of this common phrase have been updated to “when you meet one autistic person, you’ve met one autistic person.” This reflects current language preferences within the community.

audiences, autism researchers must increase the scope of their projects to include autistic people directly if they are to address the needs and priorities of this group effectively.

If every individual is different, this presents a challenge for museum workers and autism researchers looking to work collaboratively or otherwise directly involving autistic people, since it calls into question whether feedback from small numbers of participants or co-creators can be generalised. However, where a professional or researcher recruits a diverse group of autistic people and acknowledges that everyone's needs are different, this approach still allows insight that is only possible when autistic people are consulted. Moreover, by including autistic people, workers, and researchers, they begin to understand and better address their wider needs. This is aimed at enhancing visitor experience (in the case of museums) and fostering trust in researchers (in the case of autism research) to address the historic issue of exclusion of this group in academic studies and practice within society (Fletcher-Watson et al., 2017).

TNM has stated that autistic people often experience discrimination. This includes reduced access to education and opportunities to participate in the wider community, which is linked to enduring stigma as a result of ongoing misconceptions about the condition (WHO, 2019). For this reason, recent researchers, such as Sue Fletcher-Watson et al. (2019) argue that it is time to shift the focus of research away from trying to adapt and make the diagnostic criteria more specific to focusing on the priorities of autistic people, such as how to address the societal, physical, and social barriers that disable their lives. This study follows this approach and aims to achieve this by working directly with autistic people to identify the types of barriers that they experience within the cultural heritage sector.

A significant trend in autism research has been the focus on young people, from infancy to adolescence, rather than on adults (Orsmond et al., 2013). Moreover, much of the literature acknowledges a focus on early identification, causes, and early intervention. This trend is unsurprising, given the tradition of autism being viewed as a childhood condition and the emphasis on biological research into causes, genetics, and identification. The focus of related research on children and young people is positively received by workers and autistic people because of its contributions to our understanding of autism today (Fletcher-Watson et al., 2017). However, this does highlight the significant disparity in research into adulthood and autistic experiences in later life stages. Researchers such as Orsmond et al., (2013) have identified a gap in research specifically relating to the lived experience of being autistic as an

adult, consequent barriers in day-to-day life, and the detrimental impact this can have on an autistic adult's mental wellbeing and access to support. Furthermore, research into adult experiences could arguably help to shape and develop evidence-based support and early interventions from childhood with more insight into potential outcomes for later life outcomes (Orsmond et al., 2013). For this reason, there has been a move towards further research into autistic adults, specifically in areas prioritised by the autistic community itself (Mueller, in Milton, 2020b; Milton et al., 2014; Milton, 2014).

### 2.4.2 Medical Model and the Shift to the Neurodiversity Paradigm

Much existing literature, particularly on funded research, has tended to be more biologically or medically based (Stahmer et al., 2017). Traditionally, autism research has utilised the medical model of disability (Woods, 2017; Graby, 2012). The “medical model” of disability is a research approach that focuses on deficits (or causes) of the individual diagnosed, and on how to change the individual (where possible) to fit the environment (Laing, 1971). The neurodivergent movement and paradigm are social models of adapting to the environment, rather than expecting neurodivergent people to change. It has helped to shift autism research away from more traditional science-focused models that exclude neurodivergent people and focus on changing behaviours to a more inclusive model that focuses on cultural understanding of what it means to be neurodivergent in a world not designed to meet their needs. This is still an under-researched area within autism research and its principles may not be universally applicable to all autistic people (for example, Woods, 2017). The neurodiversity movement can be considered a further, more specific, branch of the wider disability rights movement. Within the context of museums, with the neurodivergent movement growing and increasingly influencing research approaches, it therefore makes sense that this study reflects on this in both theory and practice.

### 2.4.3 Autism Research and Co-Production

With the autistic community increasingly vocalising their concerns on public platforms, and more autism researchers themselves critically reflecting on the impact of past research, a shift has taken place towards more autistic-inclusive research (Chown et al., 2017; Milton, 2020; Lesser et al., 2020; Kenny et al., 2016; Fletcher-Watson et al., 2018; Cusack & Sterry, 2015; Pears Foundation, 2019; Fletcher-Watson et al., 2021). The distance between the lived experiences of autistic people and their families and past research has resulted in a divergence of priorities and created a tension between different research stakeholders, specifically between

the neurodivergent community and academic researchers (Pellicano et al., 2013; Cusack & Sterry, 2015; Fletcher-Watson et al., 2021; Arnold, 2010). In 2022, a response to the Lancet Committee's Autism Research Priorities publication by a group of AuND researchers highlighted the impact of tension around lack of accountability and broken trust, as well as the common perception that the research prioritised by researchers is often distant to the priorities of the community it should be serving. As a result, greater emphasis on lived experience as expertise has increasingly been recognised in the autism research community (Meuller, 2020; Fletcher-Watson et al., 2021).

The recent increase in research challenging traditional stigmatic and dehumanising theories, such as the belief that autistic people lack empathy, is changing the field (Milton, 2012a; Gernsbacher, 2017). For example, an increase has taken place in neurodivergent-led research communities (for example, AASPIRE, n.d.; Nicholaidis et al., 2019), which has helped to shape research that is more reflective of AuND priority topics. This shifting narrative and approach within research may arguably be partly attributed to the positive impact of the increasing visibility of the autistic community and the use of public platforms by its self-advocates (such as digital communities on Twitter and autistic-led conferences such as Autscope) on growing societal understanding and the confidence of the neurodivergent community to advocate for itself. This is an affirmative move towards more emancipatory research projects, which address the priorities of autistic people in projects that have traditionally been missed. However, the inclusion of neurodivergent people in research is still not as common as participatory or advocate-led research in other disability groups and power structures favouring non-autistic researchers without personal connections to autism and their priorities remain in the majority (Brownlow et al., 2017; Fletcher-Watson et al., 2021).

There is a methodological overlap in the current trends towards the use of co-production approaches in both the autism research field and museum sector respectively, as already discussed. This overlap in the methodological research approach is a significant thread that unites disability and museum studies, suggesting a mutual priority of the community groups, in this case, museum visitors and autistic people, in their studies and practice. It makes this study a more logical and natural next step in both museum and autism research, utilising the principles and aims that drive co-production or audience-focused projects of this nature. This study therefore strives to demonstrate how both the autism and museum research fields can learn and develop their approaches to make their projects and findings more informed and directed by specific audience voices.

## 2.5 Autism in Museums

While there are numerous instances of “autistic-friendly” practices within the sector, the study and practical evaluation of the impact and experiences of autistic visitors remain under-researched. Furthermore, the experiences of neurodivergent people more broadly represent a further gap in research, with many initiatives still specifically advertised for autistic audiences (such as “autism-friendly awards” (Lee, N.D.), despite the overlap in access needs with other neurodivergent audiences. This means that existing literature and practice discussed in this section will focus on initiatives specified for autistic audiences but which are also accessed by neurodivergent people.

### 2.5.1 Current Provision Trends

The most generic form of “autism-friendly” offering by museums and art galleries involves the following:

#### 2.5.1a Pre-visit Information

Pre-visit information is one of the most common provisions. It has typically been presented in a storybook style, which has been influenced by the “Social Story” format popularised by Carol Gray (e.g., see Gray & Garand, 1993). These booklets usually consist of pages with photographs of a specific area within a venue, such as the entrance or facilities such as bathrooms, with brief but informative information written in plain English (for example, Randi Korn & Associates, 2016). These booklets intend to provide visitors with the essential information they would need to both plan and undertake a visit to the space. These resources tend to be available on museum websites, with downloadable files for visitors to use as they need (such as Glasgow Museums, n.d.; Fletcher, 2019a), as well as access in person at the institution itself (such as the National Museum of Scotland (NMS)).



*Figure 2-1 "What to Expect at The Hunterian Museum" pre-visit resource, designed and photographed by the author.*

Pre-visit information resources often use the same format in terms of their general content and layout. However, the level of detail about each collection type, how to visit the museum, its staff, sensory guidance, and the types of photographs or illustrations they include can vary significantly. This can be influenced by the size of the museum, what it displays, and how much sensory information the museum has on its specific areas. Another visual tool designed to improve the experience of visitors with specific sensory sensitivities is the “sensory map”, which is typically a map of the institution with symbols and colour coding to indicate what areas may be quieter and where interactive or busy areas tend to be. The British Museum and NMS are two examples of UK-based museums that have developed sensory maps that have influenced the work of other museums in this area (Fletcher et al., 2018; British Museum, n.d.). The availability of pre-visit information is more common than other provisions listed below and is considered crucial by the Access Survey (2020) for encouraging disabled visitors to visit museums.

### 2.5.1b “Autism-friendly” Events

These are accessible events designed specifically for autistic visitors to attend with their families. The institution usually organises these by creating a low-arousal environment during this time with less noise, lights and/or crowds, which can become overwhelming (MacDonnell,

2019; Lurio, 2016).<sup>8</sup> Autism in Museums (n.d.), a UK-based blog by Claire Madge that shares information and reviews of autism events for families taking place in museums, usually provides information about several of these events.

< > This Month June 2024 ▾

MON	TUE	WED	THU	FRI	SAT	SUN
<b>27</b> 10:15 am - 11:00 am  Morning Stars – Advanced, Relaxed Planetarium Show @ Royal Observatory, Greenwich	<b>28</b> 8:30 am - 10:00 am Relaxed Tours @ London Zoo 2:00 pm - 3:00 pm Relaxed Afternoon for Adults (autism and learning disability friendly) @ Portrait, Scotland	<b>29</b>	<b>30</b> 10:00 am - 12:00 pm  Relaxed Openings @ The Mary Rose, Portsmouth	<b>31</b> 10:15 am - 11:00 am  Morning Stars – Beginners, Relaxed Planetarium Show @ Royal Observatory, Greenwich	<b>1</b> 6:00 pm - 8:00 pm Relaxed Evening Event: Exploring Clocks and watches @ British Museum, London	<b>2</b>
<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b> 11:00 am - 12:00 pm  SENsory Social Club Online @ Prince Philip Maritime Collections Centre, Royal Museums Greenwich, Kidbrooke 1:00 pm - 2:00 pm  SENsory Social Club – onsite @ Prince Philip Maritime Collections Centre, Royal Museums Greenwich, Kidbrooke	<b>8</b> 9:15 am - 10:00 am  Early Birds @ Locomotion, Shildon 11:00 am - 12:30 pm  SENsory Sailors @ National Maritime Museum, Greenwich	<b>9</b> 10:30 am - 11:30 am Sensory Friendly Sundays for Families (autism and learning disability friendly) @ Portrait, Edinburgh
<b>10</b> 3:00 pm - 4:00 pm Relaxed Sessions @ Netwon Abbot Museum, Devon	<b>11</b>	<b>12</b> 6:00 pm - 7:00 pm Twilight Relaxed Opening @ Homiman Museum and Gardens, London	<b>13</b>	<b>14</b> 11:00 am - 12:00 pm  SENsory Social Club Online @ Prince Philip Maritime Collections Centre, Royal Museums Greenwich, Kidbrooke 1:00 pm - 2:00 pm  SENsory Social Club – onsite @ Prince Philip Maritime Collections Centre, Royal Museums Greenwich, Kidbrooke	<b>15</b>	<b>16</b> 11:00 am - 12:00 pm Family Fun Zone: Relaxed Session @ Great Exhibition Road Festival, London

Figure 2-2 Screenshot of “Autism in Museums” June 2024 calendar of events.

As is apparent in the screenshot of the calendar, these would typically be morning events or (less commonly) a “relaxed” hour at the end or beginning of the day where families could book in. The events are increasingly called “relaxed” or “sensory friendly” rather than “autism” events to keep the museum open to wider audiences, but to be clear these would be

<sup>8</sup> This type of event is increasingly found in different settings, such as theatres (see Mattaini, 2022) and supermarkets (see Manning et al., 2023).

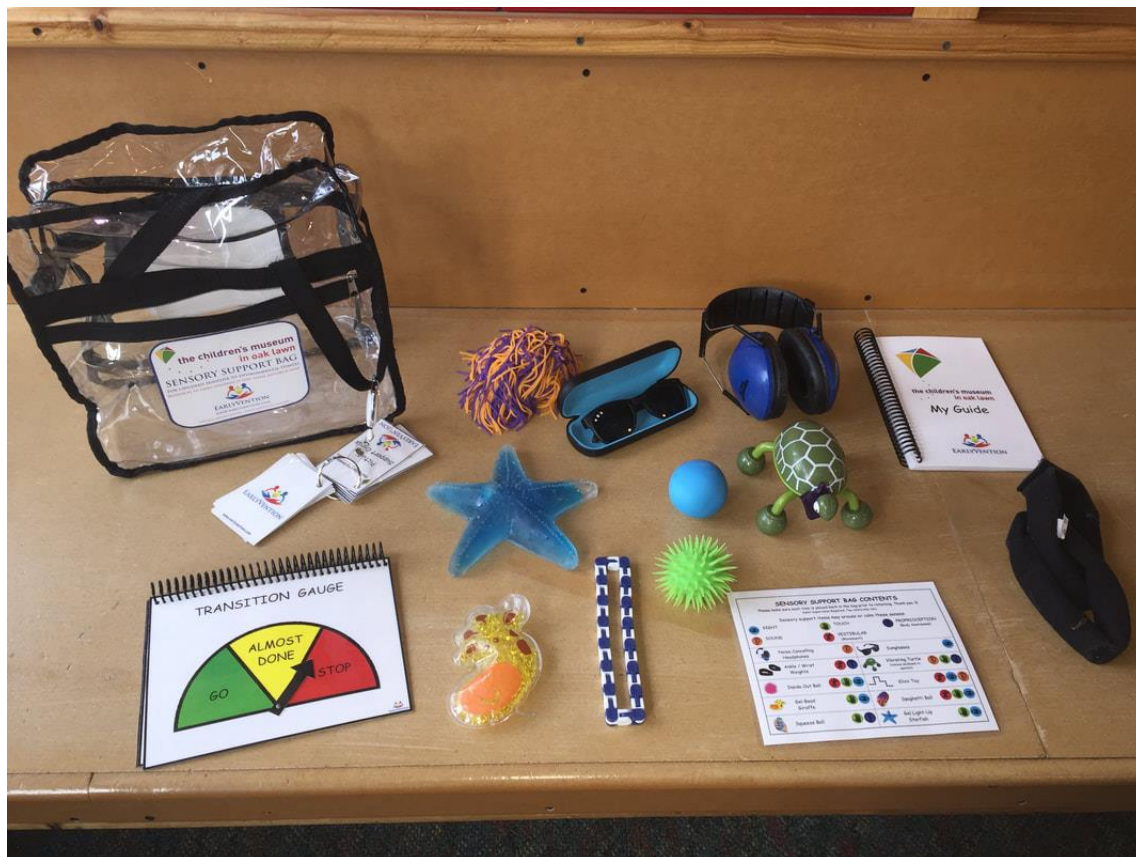


periods where common sensory triggers, such as noise and flashing lights, would be reduced. The Access Survey (2020) suggested that the availability of these events is often crucial for disabled visitors attending museums, but they are still not universally available or a frequent part of the programming.

Many autism-accessible or “relaxed” events require visitors to book in advance, often through their own websites or event booking websites, such as Eventbrite, for a set price or for free. This practice was intended to ensure that the museum could manage and limit numbers to reduce the risk of overcrowding.

### 2.5.1c Sensory Bags

A current trend in provisions is the creation of sensory bags. These bags contain objects that can help an autistic person to manage the sensory environment and to engage with what they see. The contents of the bags can vary, but often contain comparable items to other organisations. In addition, publications refer to the design of the NMS's sensory bags (Anderson, 2017) and The Hunterian's sensory backpacks (Fletcher, 2019a & b), as well as the rationale for what was chosen to go in these unrelated bags.



*Figure 2-3 Sensory bag from Children's Museum in Oak Lawn, Illinois.*





*Figure 2-4 The Hunterian sensory bag, made by the author.*

As shown in the two examples above, the bags may differ in content and theme but include the same core sensory tools: ear defenders, sensory toys, and pre-visit resources, which tend to be the most common contents as loud or busy environments can result in a person becoming overwhelmed. Sensory toys can help the autistic person to self-regulate or “stim”<sup>9</sup> to help manage this. The inclusion of the magnifying glass, as in Figure 4, is a tool for encouraging engagement with the museum’s objects while the “transition gauge” in Figure 3 is used to help an autistic child move on to a new activity or area. Sensory bags can be tailored to the theme of the museum or gallery and updated to reflect temporary exhibitions, learning programmes, and other events. Substitutions can be available, which are customisable and beneficial for different ages and learning abilities. As sensory bags are designed to contain objects and tools to help autistic people (or people with other sensory-impacted conditions, such as anxiety or dementia) manage environments that they cannot change themselves, they are crucial for making public spaces more accessible.

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<sup>9</sup> “Stim” or stimming is short for “self-stimulatory behaviours”. These behaviours are often repetitive physical movements but can involve specific senses (such as seeking visual or audio sensations). Physical stims (such as hand-flapping, spinning, rocking and hand movements) and verbal stims (repetitive sounds, patterns of speech or singing) can be noticeable in a crowd (NAS, 2020).

### 2.5.1d “Autism-friendly” Accreditation/Staff Training

There has been a recent upsurge of provisions of relevant autism training for staff. For example, the NMS organised free autism awareness training sessions aimed at helping cultural organisations target demand from this visitor group and assist institutions – particularly smaller ones – which have difficulty funding this training despite staff wanting further training to alleviate their anxieties about meeting audience needs. The NAS (Autism Friendly Award, n.d.) have introduced an accreditation award for businesses, including cultural heritage institutions, which meet autism-friendly criteria and include provision offering and training of staff. Local targeting of increasing autism awareness, such as the Scottish Government Autism Strategy (2018) and Glasgow City Council Autism Awareness Strategy (n.d.) has seen an increase in investment in autism training for the city, awarding those who participate with an “autism-friendly” accreditation (Autism Friendly City Centre Strategy, 2013–2019). This demonstrates a civic effort to address the lack of autism understanding in society, which makes accessing public places such as shops and museums difficult or impossible for some autistic people and their families. Despite this being an increasing priority in practice, there is still a gap in research that explores the availability and effectiveness of autism or neurodiversity training and accreditation schemes on a person or organisation’s understanding or approaches. This suggests that further research into the potential impact of training and accreditation on attitudes and practice, as well as the influence of the trainer’s positionality as a neurodivergent or neurotypical presenter, could influence effectiveness.

### 2.5.2 Barriers for Autistic Visitors

Research conducted by museum scholars and workers (e.g., Lam et al., 2010; Langa et al., 2013; Antonetti & Fletcher, 2016) aligns with the Access Survey (2020) to suggest that autistic people – specifically families with autistic children – want to engage in wider community leisure pursuits, such as visiting museums, but social and societal barriers can limit participation. It is worth noting that most of the literature focusing on barriers, physical and social, tends to involve studies of families with autistic children and usually comes from the parent’s perspective (e.g., Kulik & Fletcher, 2016; Langa et al., 2013, Higgins et al., 2005).

These studies have tended to be *about* autistic visiting experiences rather than co-proactively produced *with* autistic people throughout the research. However, as suggested by the increasing prevalence of participatory practices being employed in the museum sector, this approach is a natural next step in addressing the barriers to museum visiting for AuND

audiences. This section will explore autistic traits that impact museum visits, and the ways in which this study and using an emancipatory, audience-focused approach can address this.

Some of the barriers that can hinder AuND people from visiting a museum can start from the individual and the anxieties that autistic people can experience as a result of changes. As discussed in the “What is autism” section, the need for routines and certainty are two key characteristics of autism (for example, see Gotham et al., 2013). This means that, while a museum may have an exhibition or collection that fits an autistic person’s interests, an autistic person may miss this event because of the uncertainty of going somewhere outside of their routine. Higgins et al. (2005) conducted a study observing that, of the 53 parents of autistic children participating, only a quarter would take their autistic child(ren) on an unplanned visit or trip. This was because the anxiety of an unstructured or unpredictable trip caused too much stress to justify the trip.

Anxiety about visiting museums is not only experienced by autistic children or adults but also by their parents and companions. Parents of autistic children in other studies expressed their anxieties about how their children’s behaviours are perceived by other visitors or by museum staff (Adams, 2017; Antonetti & Fletcher, 2016). While anxiety about museum visiting can be found in other audience groups – for example, visitors from working-class backgrounds who may not have visited before and therefore may not feel comfortable – autistic people and their families or carers may experience heightened anxiety because it is harder to predict or mask behaviours to fit social norms in the museum.

As suggested previously, museums have traditionally been perceived to be places with specific social norms and expectations, such as being quiet places where touching objects is not permitted (O’Docherty, 1999; Bourdieu, 1977). This can indicate that parents or caregivers of autistic people – or even autistic adults themselves – may have the perception that they cannot attend these spaces if they are unable to guarantee that they will or can follow the “rules” of visiting. According to Lam et al. (2010), families with disabled children are less likely to participate in these spaces and instead tend to be isolated despite wanting to participate in wider community spaces and activities.

In my previous research on museums’ accessibility for autistic visitors (Fletcher, 2019a & b) and in other research on autistic visitors’ participation in arts community programmes (Schleien et al., 1995), parents who completed pre-visit surveys suggested that misunderstanding and lack of autism awareness were also barriers to them visiting museums

and arts programmes with their autistic children. Indeed, sensory-seeking behaviours (such as stims) and meltdowns, which can be misinterpreted as “tantrums” (important self-regulating behaviours for autistic people), can be misunderstood by others, and can even lead to AuND visitors being asked to leave (Antonetti & Fletcher, 2016; Ambitious About Autism, N.D.). The pressure that some parents or carers can face because of fear of judgement and society’s lack of autism understanding also contributes to sparse numbers of autistic visitors to museums, specifically children with their families (Langa et al., 2013; Kulik & Fletcher, 2016). This shows the significant impact that societal expectations of how people should behave in museums can have on AuND people and their families participating in museum-visiting and community-based activities (for discussions on who may feel excluded from visiting museums, see Bourdieu & Darbel, 1991).

Many modern museums offer multi-sensory experiences to enhance their engagement with existing audiences and attract new audiences interested in active learning through various sounds (Howes, 2014; Levent & Pascuel-Leone, 2017; Golding, 2009). While having a range of diverse types of displays and accompanying activities can contribute to high visitor numbers, which is a positive sign for a museum, this type of environment can be a barrier for neurodivergent visitors if found to be overwhelming. Lussenhop et al. (2016) suggest that noisy exhibits, with flashing lights and busy spaces, deter AuND visitors. This is because these types of environments can be over-stimulating for autistic visitors or visitors with other sensory processing conditions and, in some instances, can activate a “fight or flight” response of leaving the museum, or the resultant overload can lead to the visitor having a meltdown (physical, outward reaction) or shutdown (mental, inward reaction).<sup>10</sup> While this is not a major objective of this research, as part of understanding the barriers to and reasons for visiting museum spaces, the impact of multi-sensory areas or resources and technology on autistic people will be explored.

### 2.5.3 Limitations to Current Knowledge

Although not yet widespread, in recent years the development of provisions for autistic audiences in museums has increased. As an English-speaking researcher, I have focused on papers written in or translated into English, which has allowed for common trends to be identified from those papers that could be analysed. Many of these provisions started in

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<sup>10</sup> The “Too Much Information” campaign by the NAS (2015–2018) aimed to promote public understanding of the impact that sensory triggers (such as loud noises or bright lights) can have on an autistic person, and to show what meltdowns or shutdowns look like and what causes them.

American museums, specifically in New York, and have since become more common in the UK. There is a range of American papers on the topic of autism in museums. However, the majority of these tend to be doctoral theses that analyse existing case studies of local events or provisions in art galleries rather than examples of provisions that the researchers have developed and tested (e.g., Freed-Brown, 2010; Tyler, 2015; Woodruff, 2019; Hartman, 2020; Starr, 2016; Salthouse, 2017; Perry, 2016). The paper by Aliza Greenberg and Sheri Levinsky-Raskin (2017) highlights that there is a gap in practice that considers autistic people throughout their lifespan as visitors and potential workers in the field.

Some of these papers specifically focus on the introduction of digital technologies, such as virtual reality or other immersive or mobile applications, to benefit autistic visitors (e.g., Messina et al., 2018; Baradaran & Brielmaier, 2019; Swartzenberg, 2019). This has had a positive impact on the recent development in provisions, as for many museums the ability to apply existing and tested types of events or resources for their museums has reduced the task of researching and creating from scratch original concepts that meet a diverse audience's sensory and learning needs. For example, examining the resources listed in Autism in Museums, a website that reviews and advertises autism-friendly events in the UK, especially in England, it is evident that most events tend to be quiet hours, aimed at children, involving arts and crafts as part of the programme (see Figure 2). These studies have advanced our understanding of the need for accessibility developments in the museum sector and have proved to be a popular blueprint for many institutions when developing their resources and events.

It should be noted that most of the literature on autistic provisions in cultural heritage organisations is not written by or in collaboration with autistic people or related specialist workers (such as Varner, 2015, Freed-Brown, 2010; Tyler, 2015; Woodruff, 2019; Hartman, 2020; Starr, 2016; Salthouse, 2017; Perry, 2016). They analyse pre-existing resources for young autistic children and use observational or parent-survey methodologies to assess the strengths and weaknesses rather than asking the children directly. This points to a gap in the use of first-hand accounts even from children, let alone autistic adults, or the use of lived experiences to create and develop resources as part of the research project. This is evident in the existing papers through the persistence of outdated or inaccurate information and terminology about autism, such as using person-first language and terms such as *tantrums* to describe *meltdowns*. There has also been a tendency to draw autism information from sources that are not academic or reflective of lived experience, or come from controversial sources, such as Autism Speaks (Silberman, 2015). Consequently, the researchers or provision creators

risk misunderstanding the significance of the projects they undertake, or what AuND audiences truly need to address inequality and barriers within their institution.

Another common theme to existing studies (such as Varner, 2015, Freed-Brown, 2010; Tyler, 2015; Woodruff, 2019; Hartman, 2020; Starr, 2016; Salthouse, 2017; Perry, 2016) is that they tend to be designed to reflect and evaluate finished projects, rather than to contribute towards understanding the development process from initial planning to execution. This means that there are limited opportunities for them to perform formative evaluation and include the feedback of AuND people to improve provision design. One of the biggest limitations of this for determining whether the provisions are successful in meeting the needs of autistic people is that their voices are missing from the discussion and their success is often determined by the researcher's interpretation of the data. This suggests that certain data may be misinterpreted or left out depending on the researcher's bias or understanding of autism. This is not to discredit the findings to date – indeed, without these papers and their findings, it is unlikely that the common provisions (discussed below) resulting from these papers would exist at all. Moreover, without these papers, it would have been more difficult to identify the gap in the evaluation and inclusion of autistic adults in the planning of events and research.

Although existing research is crucial and has provided a foundation for understanding the types of barriers autistic people can face in museums, research that focuses only on the experiences of young people cannot be generalised. The gap in studies that focus on AuND adults implies that there is a gap in our understanding of how these obstacles may differ in adulthood. Furthermore, there is a dearth of research that directly involves autistic or otherwise neurodivergent people, regardless of their life stage.

## 2.5.4 Good Practice Case Studies

Most of the literature on the topic of autism-friendly events and provisions to date comes from the US and, most commonly, from arts-based programmes for autistic children and their families (Fletcher, 2019a & b; see Varner, 2015 for an exploration of a range of examples in America). This section will focus on two examples of good practices in Scotland that have involved autistic people and local autism charities in their project development. These examples have been selected as they are representative of the general structure and type of provisions widely available across the sector but have demonstrated a commitment to go beyond the current trend of creating and designing *for* an AuND audience *without* including

their voices and ensuring that the frequency and availability of events or resources are consistently maintained. Using these two examples as a basis for developing more participatory involvement of AuND people, it sets an expectation for the level of detail to be considered when developing provisions and guidance as part of this research.

#### 2.5.4.a National Museum of Scotland

One of the leading examples in Scotland for their commitment to increasing autism accessibility in museums is the NMS, which in 2019 organised and ran (with the charity Scottish Autism) autism training to help museum workers better understand autism and autistic visitors' experiences within museums. As a museum, NMS (N.D.) has introduced autism-friendly events and sensory bags, which are free to borrow and have influenced the design of other museums' sensory bags and online access information. In addition, NMS has created a sensory map that can assist museum visitors to plan out where they go based on sensory needs. Sensory maps are still a less common provision in museums.<sup>11</sup> This may be because many of the UK's smaller museums may not have as many areas with varying noise and interactivity as large national museums. However, it is an additional resource that has the potential to help a variety of different visitors to plan their trips.

A reason for highlighting the NMS is that their commitment to accessibility and addressing low visitor numbers in autistic audiences goes beyond their museum, as, following their national remit, they have worked to promote and address this issue across Scotland. To coincide with the opening of the Ancient Egypt section of the museum, NMS launched a national partnership with selected Scottish museums with Egyptian collections of their own to introduce further training and promote the development and implementation of "autism-friendly" events and provisions (NMS, 2019). Those museums involved in the partnership were to attend autism training sessions, develop novel resources for autistic audiences, and organise at least two events for the coming year to help increase engagement and audience attendance in their museums. NMS has demonstrated a commitment to expanding its accessibility for autistic visitors and partnering with autism trainers and charities to benefit the museum sector.

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<sup>11</sup> Other notable examples include: [The Metropolitan Museum of Art, \(2015\)](#), which produced one of the first sensory maps available and also promotes a resource for planning visits in advance; [The British Museum, \(2019\)](#), an example of a large UK museum, and [Reading Museum \(2019\)](#), a small-to-medium UK museum which has created an easy-to-read sensory map. The difference in dates suggests that UK museums are starting to use existing examples such as the Met's sensory map to influence their own provisions, which has led to a trend of other museums creating their own. This reflects trends in how accessibility provisions are developed.



### 2.5.4.b Glasgow Museums

Glasgow Museums is an organisation with a longstanding reputation for its commitment to social inclusion and developing accessibility across its venues (Johnson-Symington & Robertson, 2014; O'Neill, 2006; 2002). In recent years Glasgow Museums has developed provisions and access strategies across their venues. Since April 2018, Glasgow Museums have been working on and providing a range of autism resources, particularly “visual storyboards”. From the beginning of the process, the Learning and Access Curator responsible for this project collaborated with the Autism Resource Centre in Partick to gather feedback on what would be needed to make the resources neurodivergent accessible.<sup>12</sup> Since the project began, Glasgow Museums have completed and released seven visual storyboards (Glasgow Life, 2019) and they aim to run a monthly relaxed or “autism-friendly” event at one of their venues each month (Glasgow Life, 2024). This is an example of strong practice, as it demonstrates a collaborative and co-productive development of a resource with the audience it is intended to benefit, as well as a willingness to reflect and adapt to meet the needs of visitors.

Glasgow Museums also aims to hold at least one autism-friendly family or children’s event a month at their venues. These are often sessions that run openly, such as specific craft sessions. However, they are limited in numbers and specifically advertised as “autism-friendly”. During the run of the T-Rex exhibition at Kelvin Hall (2019) and Dippy display at the Kelvingrove Museum and Art Gallery (Natural History Museum, 2019), monthly autism-friendly sessions were held in the mornings an hour before the exhibition typically opened on the last Friday of the month. These were bookable in advance, like all the sessions for this event, and were autism-friendly as the sound of the exhibition’s interactive components was switched off, the lights were dimmer, and there was a rug with storybooks and toys (such as soft toy dinosaurs in keeping with the theme and using items available in the gift shop). All staff at these sessions were “autism aware”, having completed autism awareness training, and the capacity of the number of visitors was reduced to make the environment less busy. These adjustments to the museum, its programming, and its resources demonstrate a commitment to making the venue an accessible space for autistic visitors and those who visit with them. Having these events regularly and making the resources available throughout the year allows

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<sup>12</sup> During my 2019 Museum Studies placement at The Hunterian (University of Glasgow), I also contributed to the naming of this resource. When consulted by Glasgow Museum staff, I recommended changing the initial “Social Story” or “Storyboard” title to “Visual storyboard”. a more accurate description of the resource’s content and purpose. The Learning and Access Curator who asked for my feedback, implemented this suggestion in the final version.



neurodivergent visitors and visitors with other sensory-related needs to develop confidence and trust in the institution, potentially resulting in one-off visits becoming a recurring part of routines.

This example of an autism-friendly event is typical of how this type of event is usually structured and advertised. The sessions, while advertised as “autism-friendly” sessions, did – because of the resources added to this session – seem designed more with autistic children in mind. The biggest challenge these sessions had was low attendance numbers, as I observed during a session in June 2019 as part of my Master’s research (Fletcher, 2019a & b). This may have been because the sessions occurred during typical school and work hours on a Friday morning, limiting who could attend, and as a result of the prohibitive cost of the exhibition itself (which was part of a travelling exhibition with high implementation costs). While attending the autism-friendly session of this exhibition, which showed potential to draw in a large audience because the exhibition was a temporary one during a period (2019) where dinosaurs were a popular topic, the low attendance made it clear that there some planning issues may exist: specifically, the prioritisation of planning events to coincide with what works best for the museum’s needs over the needs of the audience it is designed to serve, as evidenced by choosing a time that is not convenient for autistic people to attend. This gap in planning events that specifically address the needs of autistic audiences – particularly of autistic teenagers and adults – rather than catering to the perceived interests of autistic children, fails to consider or plan for their changing needs and interests as they grow up. Furthermore, by fitting the provisions around what works best for the museum, such as making events for autistic audiences limited to specific periods that are quiet rather than including autistic people in decisions of when to run the sessions, museums fundamentally fail to reach potential visitors. This suggests a need for research into exactly what AuND audiences would prioritise in the planning and running of events that are designed specifically for them.

These examples of good practice, with limitations, were key case studies that informed my MSc research project (as discussed in Fletcher, 2019a & b). This project was divided into two parts. The first was to develop a pre-visit visual resource for The Hunterian Museum, Glasgow, and the second was a continuation of this project, involving creating a sensory bag and planning and executing the museum’s first “autism-friendly” event. The Hunterian’s first accessibility-enhancing projects specifically for autistic visitors. Indeed, before this event and provisions developed for this placement, The Hunterian had no specific access information on their website or events programmed at their venues. The project found that this failure to

provide for visitors with additional needs, not just potential autistic visitors, was a significant obstacle for disabled visitors and that more needs to be done by the institution to address this issue. The findings from this project showed that those who visited had positive experiences and the event had a large and encouraging response, selling out within 48 hours. The Facebook post about the new sensory bags was shared over 20,000 times in the space of one week from its launch, reflecting similar findings to those of the Access Survey (2020). This also reflects findings from other studies that suggest that parents of autistic children want the opportunity to participate and attend spaces such as museums (Lam et al., 2010; Langa et al., 2013; Antonetti & Fletcher, 2016). Museums must therefore take heed of these findings and ensure their institutions address their accessibility shortcomings to meet the needs of their current and potential visitors in their public-facing venues as well as structurally in their organisational accessibility policies.

#### 2.5.4.c Current Toolkits

One way that the GLAM sector provides peer support and shared guidance on various aspects of practice is through the creation of guidance toolkits or practice portfolios and manifestos (such as Ament, N.D.; M.A., 2023; Miles et al., 2020; Davis-Hofbauer, 2016). These toolkits often cover various topics, such as collections management or learning, and combine examples of good practice with advice for how practitioners can incorporate these approaches or values into their organisation's practice. The aim of these outputs, which are typically created by key professional bodies within the sector (such as the Museums Association in the UK and the American Museums Association in the US), is to overcome sector-wide difficulties and drive towards shared practices.

Although “autism friendly” programming and resource development are increasing in recent years, there are still limited toolkits available within the sector. Some examples of toolkits in this area include the Guggenheim for All (N.D), FRAME Museums’ report on making museums accessible for autistic audiences (Barthélémy et al., 2021), and Aide Canada’s *Neurodiversity in Cultural Institution’s* (Kozak, N.D). In these toolkits, you can find guidance on making museums more accessible for autistic (such as the Guggenheim and FRAME Museums resources) and neurodivergent audiences (Kozak, N.D.). Each of these resources provides examples of current practice, particularly within the national context in which they were created (such as the US, Canada, and France). The Guggenheim (N.D) and FRAME (Barthélémy et al., 2021) toolkits both include a section with introductory information

about what autism is, ways to adapt the sensory environment and suggested approaches to learning and programming for autistic audiences. The toolkit by Aide Canada (Kozak, N.D.) is based on examples of best practices for programming events, space design and resource development. The focus on providing best practice case studies, which can be found across these three examples, is representative of the standard format that sectoral toolkits tend to follow – prioritising examples that can support museum workers to transform theory into practice and providing background information.

While these toolkits provide a useful foundation for museum workers to begin this type of work within the field, they have limitations. Firstly, existing toolkits within the sector offer minimal evidence of neurodivergent people’s involvement in their development or creation.<sup>13</sup> This can be evidenced by the use of person-first language in the terminology section (see Barthélémy et al., 2021). Only one of the toolkits found (Guggenheim, N.D) took a neurodiversity approach, but does not go into much detail about the specific barriers that AuND people experience, and how these can overlap and differ with other AuND people and non-AuND audiences. The toolkits examined include minimal discussion about the needs and priorities of neurodivergent people within cultural heritage spaces, nor do they explain in any detail where their guidance has been drawn from in the absence of lived experience. Much of what is available in a toolkit format is not written in the UK, with the Kids in Museums and Autism in Museums guides (N.D.; see also Madge, 2020) on the experiences of autistic young people being the main UK-based resource focusing on AuND visitor experiences at the time of writing. Therefore, there are currently limited toolkits designed with AuND people that consider the overlaps in the needs. This suggests that there is a need for a museum sector-specific guidance toolkit that is informed directly by the experiences of AuND people; includes a diverse range of practice examples reflective of the barriers and priorities to museum-visiting; and ensures that research, professional practice and lived experiences are equitably balanced in its formation and recommendations.

There are guidance resources, such as the Neuk Collective (2021) in Scotland, which provides advice for removing barriers to neurodivergent artists that could be applied in some areas. In 2021, Neuk Collective published *Removing Barriers: Report on research into the experiences of neurodivergent artists in Scotland*. The report analysed insights from 43 Scottish

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<sup>13</sup> The “Guggenheim For All Toolkit” includes a link to its ‘Autistic Museumgoer Survey’, which shows the responses by autistic people, their families or carers. They do not discuss how these responses have or will be used to shape practice. They do not explain how many people took part, how the survey was recruited or any details about how many of the respondents were autistic themselves.

artists self-identifying as neurodivergent, documenting the barriers that they face and their priorities for change within the arts sector. As this project focused on the experience of neurodivergent artists in a work context, the responses tended to focus on issues related to the arts. The most common obstacles were financial insecurity, social difficulties, and difficulties with the administrative tasks required to undertake their work. While many of these barriers can be experienced regardless of neurotype, the priorities that the participants identified to make medium and long-term improvements for neurodivergent artists include: providing support with administrative tasks, having access to quiet spaces, more opportunities for rest breaks, tailored mentoring schemes, lobbying for more financial support, and the establishment of a professional network for neurodivergent artists. Many of these suggested areas to prioritise for change could improve the experiences of neurodivergent artists specifically, but could also be beneficial to artists regardless of neurotype. Many of the barriers and priorities for change could overlap with changes that would benefit AuND museum workers.

There is one example of a resource created specifically for neurodivergent museum workers by TNM, a neurodivergent-led organisation within the museum sector. *The Principles for Museums and Neurodiversity* (2022) were produced by neurodivergent museum workers using the feedback from the network, which includes approximately 150 museum workers (identifying as both neurodivergent and neurotypical) working in roles across the sector. The feedback resulted in TNM identifying five principles to inform a roadmap that helps museums adapt their current practices to become more equitable to AuND people. TNM has been run in a voluntary capacity, without funding success thus far, but they are continuing to apply for funding to enable them to develop a toolkit to improve the experiences of AuND museum workers. TNM's work is a positive sign for the direction of resource development and neurodivergent-led practice within the sector. However, TNM's limited progress due to lack of financial support shows a need for greater investment by funding bodies to enable this type of research and guidance to become and remain available across the sector.

In addition to the museum and creative arts sector, there has been a recent increase in toolkits, frameworks and guidance designed by and with AuND people in other fields. The Sensory Street principles and SPACE framework are two examples that – whilst shaped in different disciplines and contexts – have arrived at similar recommendations for creating enabling environments for neurodivergent needs, whether in work or social settings. Doherty, McCowan and Shaw (2023)'s SPACE Framework stands for Sensory needs, Predictability, Acceptance, Communication and Empathy, which they identify as the five core needs of

neurodivergent people. This framework was created to improve clinical services and promote equitable healthcare practices. Meanwhile, MacLennan et al. (2022) established the Sensory Street Principles based on their research into autistic people's experiences of sensory environments in public spaces like supermarkets. From seven focus groups conducted in 2021, they identified six themes (Sensoryscape, Space, Predictability, Understanding, Adjustments and Recovery) and 15 sub-themes. While not identical, there is clear overlap between the SPACE Framework and Sensory Street principles. Both emphasise neurodivergent people's needs for accessible sensory environments, understanding and acceptance, and predictability--regardless of whether in clinical or public spaces. The SPACE Framework is about the fundamental needs of autistic people in healthcare settings that would reduce the need for recovery, while the Sensory Street principles consider the importance of what is needed when needs are not met in public environments. Despite being developed independently, the significant similarities between these resources suggest important implications that could extend to other contexts, such as museums.

### 2.5.5 Barriers to Provision Development

Although there are clear barriers to AuND visitors and their families/carers attending cultural heritage institutions such as museums, challenges also exist for museums and their staff in attempting to address them. Lack of confidence and expertise among staff are two of the major reasons for the lack of provision development (Ng, 2017). A consequence of this lack of confidence is that many cultural heritage organisations delay, limit, or do not develop and implement access provisions because of concerns about undertaking projects without the right level of expertise. Their concern is that a lack of certainty and expertise could risk a backlash or negative response to any accessibility initiatives that could impact the institution's reputation. This anxiety about creating resources that do not meet the needs of audiences can hinder progress in meeting visitor needs and addressing accessibility requirements (Ng, 2017). While collaboration with AuND people, their families, and practitioners who have direct experience would benefit the development of provisions (Potvin et al., 2008; Access Survey 2020), inadequate finances to cover the cost of participant time and expenses can make this crucial consultation unachievable. Lack of funding, training, and staffing available to commit to dedicated access projects, especially for specific disability group experiences, is not necessarily the fault of the museum, or necessarily a reflection of the museum's aims and

priorities. Instead, it demonstrates a gap in accessibility provisions, incentivisation, and related training in the cultural sector.

One way in which some institutions in the sector have attempted to address their accessibility barriers has involved investing in the creation of access-focused positions. While some museums have specifically created roles with the responsibility of enhancing access and learning opportunities for diverse audiences, these can be limited to larger institutions able to afford to finance such roles and are often the first to be cut if an institution experiences any financial strain (for example Glasgow Museums, 2023). Furthermore, they can be restricted in scope because of the considerable number of audience groups that have specific access needs to be addressed, and it is not realistic for a single member of staff to have the level of knowledge and expertise of all access requirements, given how diverse access needs can be. The Access Survey (2020) recommended the creation of access consultation groups, which could be beneficial for museum practitioners in access-specific or engagement roles to address gaps in their knowledge and use participatory practices.

## 2.6 Conclusion, Gaps, and Contribution to Research

Our understanding of what a museum is, who it is for, and its function in society has changed significantly over the past 30 years. From their traditional “cabinet of curiosities” approach and its later influence on the approach of public museums on exhibiting the wonders of the world and educating their visitors with an authoritative voice, modern museums have shifted towards being interactive, more accessible, and more focused on visitors as users of their space and co-creators of exhibitions and programmes. This shift has enabled museum workers to learn and respond to their visitors, taking the time to develop audiences and expand the reach of their collections to previously under-represented individuals. Since the 1990s, with the growth of the disability activism movement in both the UK and the US, a greater emphasis on ensuring museums are accessible and engaging for disabled visitors has become a priority. While clear improvements have been made in the provision of cultural organisations and promising moves have enabled greater accessibility, the lack of literature on British accessibility developments in recent years shows that this is an area that needs to be further developed. Furthermore, in existing museum accessibility research, there is a distinct focus on physical disability or other traditionally marginalised groups but extremely limited research into autism or sensory-specific provisions in British museums. For this reason, there is a significant need for further research in this currently under-researched field.

At present, there is a significant gap in accessibility, autism, and museum research that specifically focuses on the priorities of autistic people – most notably adults – and resulting in tangible outcomes. Although there is a movement towards person-focused research that encompasses the autistic community in autism research, it is still in its infancy compared to other, more commonly researched areas. Furthermore, a clear shift has taken place towards more audience-focused, participatory research and practices within the museum sector, and a gap currently exists in this practice being applied as standard, particularly for neurodivergent audiences. This research project therefore intends to address the gaps in these two traditionally separate fields of study to directly design and execute research that utilises participatory practices to identify what AuND people need in museums to overcome barriers, develop provisions in response to feedback, and include autistic people throughout the project to evaluate whether barriers have been addressed and needs met. Currently, there are no existing studies in the museum field that demonstrate commitment to this level of participation and inclusion of AuND people's expertise and priorities to this scale. For this reason, this project will specifically focus on the experiences of autistic adults within cultural heritage institutions and utilise cross-disciplinary research and methods to address this gap and further the scope of what it means for a museum to be accessible and inclusive of neurodivergent audiences in its planning.

This research project responds to these movements for wider accessibility in society as a whole and within the cultural sector, as it looks to take museums beyond the minimum legal requirement for accessibility. It is motivated by the growing movement towards participatory and community-based approaches to develop and introduce a framework of recommendations for AuND accessibility. The literature highlights a need for further research into provisions for autistic visitors in cultural heritage institutions, specifically museums, with the existing literature limited to studies of autistic children visiting with families and undertaken by museum workers with little to no experience of working directly with and responding to the needs of autistic adults. Furthermore, of the existing literature – which comes from the US – there has been a clear trend in specific research approaches and methods (case study analysis, observational or parent-reported surveys) in studying visits of young children and families in art gallery settings (for example, Mulligan et al., 2013). While this research has been crucial in the initial development and introduction of autism-specific provisions in museums, increasing the visibility of the needs of autistic visitors and offering a tested framework to replicate, it is now time to progress beyond this model. This research project intends to advance the visibility

of neurodivergent needs by contributing research that specifically includes AuND adults who are traditionally marginalised or left out of research, to produce tangible guidance for the cultural heritage sector. This research offers a unique opportunity to address the gap in existing provisions and provide a framework enabling museum workers to utilise the findings to develop their practice and provisions without the anxiety of creation without expertise. Overall, it intends to open the door to future accessibility projects that prioritise the needs and experiences of disabled and under-represented voices, demonstrating how the active inclusion of such audiences at all stages of design can help us to better understand the barriers.



## Chapter 3 Methodology

This thesis investigates how museums and cultural institutions can become neurodivergent accessible using social research methods.<sup>14</sup> It focuses specifically on AuND adults utilising emancipatory, participatory, and co-creation practices to better understand the needs of AuND people and what would make the museum visiting experience more accessible and enjoyable to this audience.

Using emancipatory and participatory research practices and actively involving AuND adults and museum workers, this study aims to identify and address currently existing barriers to museum visiting, asking AuND people for their input on what would make the experience more accessible for them. Emancipatory practices in research, including autistic-led autism research, have been used to promote the active inclusion of traditionally marginalised groups and ensure that their needs and preferences are met at various stages of the research (Grant & Kara, 2021; Nind, 2017; Cotterell & Morris, 2012). Emancipatory practices are increasingly used in disability research (Noel, 2016). According to Danieli and Woodham (2007), the key principles associated with them are “openness, participation, accountability, empowerment and reciprocity”. Throughout the data collection, the needs and feedback of all participants shaped the research process and the outcomes to ensure that the study met participant priorities and access requirements. The data gathered through surveys, focus groups, and workshops will be used to create a sectoral guidance toolkit following the submission of this thesis. This will be developed and evaluated with both AuND adults and the museum workforce.

As an autistic researcher, and following the increasing practice of undertaking participatory research and drawing from lived experiences (for example Botha et al., 2021; Fletcher-Watson et al., 2019; Fletcher-Watson et al, 2021), I intended to draw from lived experiences of barriers to conduct research where AuND adults would be meaningfully involved at various stages of the project. This focus comes from a personal and professional background, where, before this research project, I witnessed the disconnect between well-intended accessibility measures in museums that would have benefitted from the direct involvement of AuND people in its development.

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<sup>14</sup> Closely linked to how this was understood and applied in the thesis, Alan Bryman (2008) defines social research as research that draws from different fields within social sciences, such as sociology, and is motivated by the potential to create changes in society that are beneficial to people. Additionally, Bryman indicates that this type of research should highlight ways to bring about the changes that have been identified by the research.

This research contributes to the growing literature from AuND researchers who openly challenge misconceptions about AuND researchers by undertaking high-quality, community-focused practices in the field (Grant & Kara, 2021; Gillespie-Lynch et al., 2017). This personal perspective and experience, interwoven with the study of existing research in the museum and autism fields respectively, has played an integral part in all levels of the development of this research. From its conception, this research has put the needs and priorities of AuND people at its core, and all methods used and adaptations to the study will be made to ensure that the thesis and its findings can capture as many experiences and views as possible (Nicholaidis et al., 2019; Woods et al., 2018). Historically, AuND people have considered their involvement in research as tokenistic or felt that they have been treated as “guinea pigs” (den Houting et al., 2021). This demonstrates the importance of a methodological approach that prioritises individual needs with clear outcome intentions (Poulsen et al., 2022; Grant & Kara, 2021; Gillespie-Lynch et al., 2017). As such, this methodology and the findings discussed include auto-ethnographic approaches – such as reflexive practices and explanations for decisions or thought processes that have been shaped by my personal, professional and research experiences as an autistic person (Fletcher-Watson et al., 2019; Berger, 2015).

This chapter focuses on the planning and methods employed throughout the study. It highlights the considerations involved in creating a project that was reflective and adaptive to specific access requirements for its participants and co-producers.

### 3.1. Study Aims and Questions

The methodology has been designed with the research aims as a guide for practice. The four aims and the phases these relate to in this research are as follows:

1. To better understand the motivations of AuND people who wish to visit museums, and the barriers that prevent them from visiting Scottish museums. **(Phase 1 and 2)**
2. To evaluate the effectiveness of what museums currently offer AuND audiences, and better understand the barriers to progress in accessibility for this audience. **(Phase 1 and 2)**
3. To demonstrate the benefits and challenges of working with AuND audiences using participatory and emancipatory methods to enhance accessibility for traditionally under-served audiences. **(Phase 2 and 3)**

4. To create sectoral guidance to help make museums more accessible to AuND audiences. **(Post-thesis submission)**

## 3.2 Methodological Framework

The research was developed with the following principles in mind. The research must:

- Have the best interests, wellbeing and needs of AuND people considered at all stages of the research.
- Actively involve AuND adults throughout the various stages of research and do so in a meaningful (non-tokenistic) way.
- Ensure that AuND people feel valued during the research.
- Be reflective and adaptive to ensure that the above principles are followed.

This research project utilised a range of community-focused methodologies and approaches (Johnson, 2019; Jason & Glenwick, 2016). This means that, at each stage of the research, AuND people were consulted both formally and informally (for example, via one-to-one conversations, email exchanges and discussions outside of the set methodology) to ensure that all aspects of the research – from the development of the research direction through to the final theme identification from the surveys – were shaped using AuND community and museum worker insights. In contrast to the types of autism and neurodiversity research that have historically dominated the field, this project incorporated collaborative and community-informed theories and practices. This section provides insight into the theoretical basis and key principles that led to the methodological framework and approaches employed in the project.

### 3.2.1 Community-focused

The presence of the voices of AuND people in research on “us” has traditionally been absent (Keating, 2021; Fletcher-Watson et al., 2019; Gowen et al., 2019; Milton & Bracher, 2013; Chown et al., 2017). This same absence has also been found in services designed for autistic people, which organisations like Scottish Autism have been working to address in recent years (Long et. al., 2017). Consequences of the research lacking insight from the AuND community include community dissatisfaction with the type of research conducted, lack of impactful research findings and exclusion from the processes, and dissemination of findings resulting in disengagement from and distrust of research (Pellicano et al., 2014; Gowen et al., 2019).

Although this had historically been accepted as (at best) standard and (at least) preferred, a recent shift has taken place away from this expectation (Chown, 2013). In recent years – as introduced in the literature review – there has been a significant movement within some parts of the autism research field. With more openly AuND researchers publishing high-quality research within the field (such as Botha et al., 2021; Milton, 2012b), traditionally accepted research practices have been challenged. This has consequently led to shifts towards requirements for “community involvement statements” by leading journals (such as the Autism Journal by Sage Publications) before acceptance for publication and by charities, such as the NAS for consideration for support or partnerships. This increasing emphasis has led to the creation of guidelines for participatory and community-based research, further demonstrating the shift towards this practice (Keating, 2021; Fletcher-Watson et al., 2019; Pellicano et al., 2017; Hampton & Fletcher-Watson, 2016). The shift in the field has enabled autistic researchers from more diverse research backgrounds to not only contribute to but lead or co-lead research that combines lived experiences and different research disciplines. This can be seen clearly in the projects showcased by the Participatory Autism Research Collective (PARC), which features multi-disciplinary work with a high level of AuND-led initiatives. These shifts in neurodiversity research priorities have enabled this research project to take place and be welcomed into the field. This was an interdisciplinary endeavour, which benefitted from theoretical and practical insights from both the humanities and psychology fields to create a participatory framework.

### 3.2.2 Co-Creation and Co-Production: A Theoretical Starting Point

The first theoretical concept that initially shaped this research was co-creation, a widespread practice in recent research on cultural heritage (Barnes, 2019). Within the museum sector, this practice is utilised when referring to the inclusion and active engagement of local communities and audiences in participatory practices, such as idea exchange and open dialogue between museum workers and museum audiences (Barnes, 2019; Simon, 2010). Co-production can also be found in autism research, with Stark et al. (2020) reflecting on the experience of using this method with autistic adults. Similarly, co-creation in research is the process of active collaboration and knowledge exchange between the researcher and the potential audience or community in the creation of a product, such as research findings or a new service of value to the community involved (Anton et al., 2017; Suntikul & Jachna, 2016). It is considered a form of impactful practice, as, rather than a researcher “translating” knowledge to and from a community, they work together to create new knowledge (Greenhaugh et al., 2016). One of the

key principles of co-creation as a process is that the needs and experiences of the individuals involved in a project are at the centre of the project – from research proposal to practice (Langley & Cooke, 2018). It is often intended that the co-creative process seeks to engage under-represented, or “hard-to-reach” (Barnes, 2019, p. 4.) groups in activities such as consultation to inform practice as part of the research or project undertaken. In the context of this research, the research questions and aims were co-created with two focus groups.

Co-production, while similar to co-creation in intention and often used interchangeably within the museum sector, differs in execution and the level of contribution of the communities it involves (Voorberg et al., 2014; Craig et al., 2016). While co-creation is about the collaboration of groups in a project, often related to the design and implementation of a project, such as the development of a new service, co-production often occurs after the design stage. This means that the involvement of a community or group comes at a stage where a new service or product has been designed to gain feedback to shape the “product” of the research (Brandsen & Honingh, 2018). After further research into the differences between co-creation and co-production, it emerged that there is a clear difference in the levels of meaningful involvement of communities in research and projects. This is reflective of Arnstein’s (1969) Ladder of Participation, a hierarchical system designed to measure the level of involvement and power of those participating in a process or decision. While co-production is a useful starting point for understanding the involvement of AuND people in research, only including AuND individuals at the “implementation” stage of the project felt too late to be meaningful. Meanwhile, co-creation showed more promise of being able to have an impact on the AuND community this research seeks to serve as it is more clearly community-focused. Although Arnstein’s model remains influential, it has been critiqued for its linear and normative assumptions, which may not always reflect the diverse ways communities engage with research. These critiques are explored further in Section 3.2.3, where the limitations of hierarchical participation models are considered in relation to neurodivergent inclusion and museum practice.

As an autistic researcher, it was important to me that the needs, experiences, and insights of other AuND people were at the heart of the research I conducted, particularly since this was a gap in existing research. Utilising co-creative strategies thus became a core aspect of the initial proposal for this research. These complemented the participatory and emancipatory principles of the research design.

### 3.2.3 Participatory and Emancipatory Research

At the core of this research project are participatory and emancipatory practices and principles. Like co-creation, these principles are about putting communities – in this case the AuND community – at the heart of research and assisting them in communicating and advocating from their experiences. Participatory research methods – particularly within the health, autism, and research fields – have been increasing in frequency, as has research into their values and limitations (see Keating, 2021; Pickard et al., 2021; Fletcher-Watson et al., 2019; Martin, 2014; Hollins, 2010; Cargo & Mercer, 2008). Although similar in principle, the actions taken in participatory and emancipatory research differ in practice. While both participatory and emancipatory research often have overlapping ideological principles surrounding the involvement of specific groups – and often involve a mixed methods approach – the intended impact of the output on the community differs (Barton, 2006; Cornwall & Jewkes, 1995). Participatory research may involve working with a community group to identify an issue, while emancipatory research is intended to continue beyond the identification of an issue by working *with* the community group to generate social change (Rosqvist et al., 2019; Waltz, 2009). In the context of this project, the methodological approach – including focus group consultation and adapting practice to reflect feedback – is a form of participatory practice. The dissemination practices and intended guidance toolkit are examples of emancipatory practice as they are intended to result in changes that benefit the AuND community as both visitors and museum workers.

As discussed in the introduction to this thesis, one of the greatest limitations of both participatory and emancipatory research is the impact of poorly conducted practice. When designed without meaningful involvement and clear outputs for those involved, these practices can be detrimental to the research project, the community involved, and the trust in the researcher. One of the biggest risks of these is projects being tokenistic or lacking in impactful benefits for those involved, which can result in breakdowns in trust in the researcher or harm to the community more broadly (Keating, 2021; Pickard, 2021; Milton, 2020a & 2019). Until the last 15 years, autism research was traditionally top-down, as explored in the literature review (Michael, 2021; Fletcher-Watson et al., 2019; Pellicano et al., 2014; Pellicano et al., 2013). This has meant that communities can feel hesitant to participate in research, particularly if they are aware of past failures in involvement, or can even actively engage in a campaign against the project. Recent examples of this include Aims-2 Trials and Spectrum 10K, which both boasted some level of AuND involvement, but have received negative responses from the

autistic community because of harmful research methods. For some, the impact of such research projects can have traumatic consequences, resulting in trauma for those directly involved (for example, Aims-2 Trial) and damaging the reputation of the researchers and/or organisations involved in said research (for example, Crusack, 2021). Once a damaging piece of research has been conducted, it is incredibly challenging to rebuild the trust and reputation of the researcher or research group with the community (Keating, 2021). As many AuND people have experienced trauma and minority stress because of their neurodivergent identity – particularly because of stigmatisation, unsuitable environments, and increased risk of exposure to abuse – researchers and practitioners undertaking any form of research or project must be mindful of the impact that they can have if their practice is not carefully designed (Botha & Frost, 2020). With the development of research frameworks for participatory practices (most notably Fletcher-Watson et al.'s 2019 framework developed using community insight) and consequential examples of good practice in new research projects (see Keating 2021 for a list of recent examples), there is potential to advance community-focused research. In this project, each stage of the methodology was carefully considered and planned to identify and address potential safeguarding concerns, and signpost mental health support to participants.

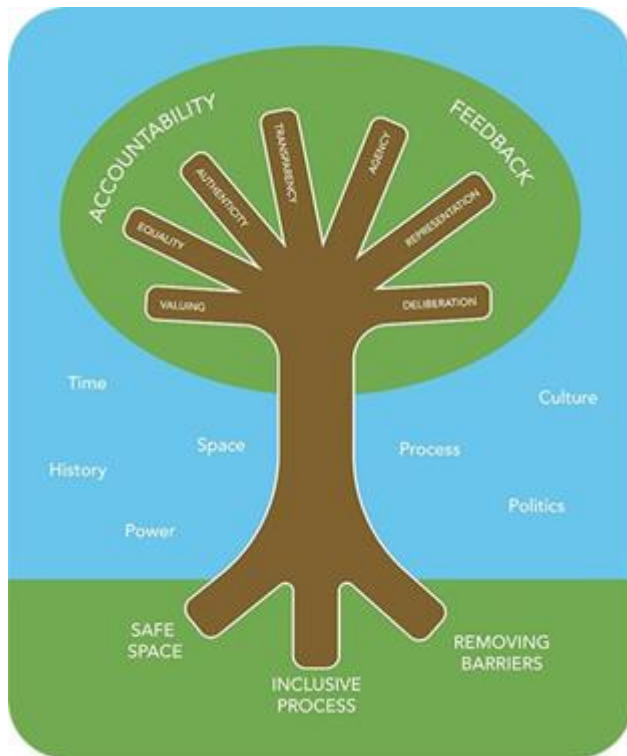
Some critiques of participatory methods include the risk of normative assumptions when applying this theory into practice, particularly for AuND people. The Durham Community Research Team (2012) highlighted that community-based participatory research can be viewed by some as being a more “ethical” form of research due to there being a less firm distinction between a researcher and the community being researched. However, they suggest that the relationship is usually less straightforward than this. Indeed, they identify that the power balance between the “researcher” and “researched” community can remain less balanced and, consequently, tokenistic or be impacted by the level of trust established. Participatory approaches can sometimes be disadvantageous when they incorrectly assume that all members of a community share the same views or needs, leading to an oversimplification of the community's diverse reality.

In her work on community engagement, Nuala Morse (2020) draws on earlier research (such as Lynch, 2011 & 2014) to highlight power imbalances between museums and the community groups they serve. She argues that museums typically implement only those participatory approaches that they feel comfortable with to fulfil their own institutional goals. These normative approaches to participation and engagement, Morse (2020) argues, can

undermine the intended goal of community empowerment, as marginalised groups may view these approaches as serving institutional interests rather than their own needs.

This critique aligns with broader concerns about the limitations of hierarchical models of participation, such as Arnstein's (1969) Ladder of Participation. While influential, Arnstein's model has been critiqued for its linear and normative assumptions, which may not suit all contexts—particularly those involving neurodivergent communities. Consultation, for instance, may be more appropriate or empowering than full control, depending on the community's needs, preferences, and capacity to engage, as was the case with this project. In response to these limitations, Bell and Reed's (2022) "Tree of Participation" offers a more flexible, non-linear model that better reflects the diverse ways communities can meaningfully engage with research and decision-making processes. Its emphasis on accountability and feedback—rooted in creating a safe space, implementing an inclusive process, and removing barriers (see fig. 3.1)—closely aligned with how consultation was employed throughout this research to centre the voices of the AuND community. In a context where little prior research has explored the experiences and barriers faced by AuND people in museums, consultation was not only appropriate but necessary. It provided a foundation for future, more collaborative practices by initiating dialogue and building trust. This research is therefore positioned not as an endpoint, but as a starting point—a call to action for museums to engage more meaningfully with AuND communities in ways that reflect their specific needs and definitions of participation.





*Figure 3-1 The Tree of Participation by Kate Bell and Mark Reed (2022).*

This shift toward more flexible and context-sensitive models of participation highlights the importance of critically examining how participatory practices are implemented in real-world settings. While theoretical models can offer valuable guidance, their application often reveals complexities and tensions that challenge idealised notions of inclusion and empowerment. The Durham Community Research Team (2012), for instance, explores these challenges in their examination of community-based participatory research, drawing attention to the ethical and practical difficulties that can arise when attempting to balance power between researchers and communities. Some of the difficulties they identify include defining what constitutes a community, identifying legitimate community representatives, which risks excluding voices that do not fit these predetermined categories, and managing discussions when community perspectives differ. This illustrates the difficulties that researchers can encounter when trying to apply standardised theoretical approaches to communities with diverse experiences and needs.

A further risk to participatory and emancipatory research is the promise of transforming society, structures, and understanding that is not feasible within the scope of the research. Jo Alderidge (2015) cautions that researchers should not “get too carried away” with the belief that, with their project, they can necessarily trigger long-term, large-scale changes. Many researchers can fall into the trap of over-promising their participants with changes beyond their

control. This has the potential to result in disappointment or be seen as misleading. To avoid breaking the trust of participants, Alderidge suggests that researchers do not over-promise, and instead focus on what is possible on a smaller, individual scale. It is not accurate to say that the research being conducted is not capable of causing societal or structural changes, for instance within a sector or organisation, but that it is scaled to a more realistic outcome. This is one of the biggest risks that this research project carries and, while I intended to conduct sector-changing research, I remain realistic that not all museums or cultural heritage organisations will be a) receptive to the guidance or b) able to action all recommendations that come from this project. Nevertheless, conducting the research to make a sectoral change and taking part in engagement work to communicate the benefits of this research was a useful goal guiding the approaches of this project.

### 3.2.4 Auto-ethnography

As an autistic researcher, I acknowledge that one of the greatest strengths and potential limitations of my role has been the impact of my own subjective experiences on the project. As a researcher, it is my responsibility – and ethical duty – to ensure that the research I conduct is based on data, the views of AuND adults, and the museum workforce, and that this is accurately captured and analysed. However, it is important that, as a member of the community that this research is intended to benefit from, I can reflect critically and personally on the project and findings from my perspective as an autistic person. My involvement as a researcher, while a strength in my ability to understand and relate to participants, can result in challenges around boundaries – being a community member researching a community I belong to – and potentially causing misinterpretation of data. For this purpose, utilising auto-ethnographic practices and actively ensuring that personal interpretation and reflections were included – and not overshadowing – those of the participants was a means to manage this risk. One of the ways of incorporating these views in a controlled way was to include an auto-ethnographic approach to discussing the findings.

Auto-ethnography is a qualitative method and academic writing approach that involves the author(s) analysing, interpreting, and communicating their own lived or shared experiences in a way that connects the researcher to the subject (Poulos, 2021; Ellis et al., 2011; Patton, 2002). This is a method that requires the researcher to be actively reflexive and rational in their reflections and observations (Tracy, 2020; Adams & Herrmann, 2023; Adams, 2017). Historically, auto-ethnography has been viewed as a weaker form of analysis within the science

and psychology research fields (Poulos, 2021; Gergen, 2014). This may be because of criticism of using researchers' viewpoints and experiences to influence the interpretation of findings in a way that reflects their agendas, thus creating biased research. In recent years, a movement has taken place towards more acceptance of auto-ethnographic practices within the research field, which has resulted in publications of academic guidance to support researchers in developing ethical practices. The post-modernist reform in the social sciences since the 1980s saw a rise in scepticism towards what would be considered a "universally accepted fact" despite a lack of personal insight (Ellis & Bochner, 2000).

During this period, a shift began towards seeing social sciences as not purely "scientific" (more quantitative and data-specific), and a recognition that more consideration of the narratives and literature related to the social element of the field is needed. It was no longer enough to accept the "science" as black-and-white truth without considering the literature that could provide colour to the metaphorical picture through personal reflection (Bochner, 1994). It is important to note that "auto-ethnography" is different from "autobiography". This is because the auto-ethnographic process is intended to be data-driven, as it is typically a method used in conjunction with other data forms – such as interviews, focus groups, or surveys – as part of the analysis of these findings (Poulos, 2021). While there are areas where auto-ethnographic writing may relate to autobiographical elements – such as the role of personal narrative, potentially describing emotions or views – auto-ethnography seeks to take these personal insights and critically analyse and process them (Ellis, 2004).

Some researchers have highlighted that, as part of any qualitative data analysis, there is a form of interaction between the original narrative, as presented by participants in their responses, and the researcher's interpretation and analysis of the insight (Alderidge, 2015; Baldwin, 2013). This "voice" of the researcher analysing data and presenting it should be in conjunction with the direct perspectives and experiences of the participants to create a more reflective, participative approach and not override their voices and perspectives (Alderidge, 2015). Problems with auto-ethnographic approaches, as well as of analysis that lacks a participatory component, are that they can become more about the researcher and their own experiences or interpretations than those whose experiences should be represented in the findings (Patai, 1994). The potential disparity between the views or experiences of the community who the research is being conducted for and a researcher's understanding of the topic – or "self-truth" – could result in conflict. In these circumstances, it is the researcher's responsibility to ensure that the views and "truth" of the community are fairly represented, and,

where possible, to be transparent in their views separately to these findings to maintain the integrity of the research.

### 3.3 Data Collection: Focus Groups, Surveys, and Workshops

This research employed a variety of different methods of data collection to answer the research questions and achieve its objectives. The project was divided into three key phases of data collection, with two initial focus groups, formal and informal consultation conducted before each stage to gather community feedback to adapt these processes to ensure their accessibility, and workshops to gather feedback on the findings analysis. Once the focus group consultation was completed and the feedback incorporated into the research design, Phase 1 of data collection was online surveys for 1) AuND adults and 2) the museum workforce. Phase 2, building on the findings of the first phase, was about conducting follow-up workshops with both AuND and museum workers to shape guidance for the sector. Phase 3 was intended to be a period of analysis of all the findings from Phases 1 and 2 to revisit the survey findings and provide the basis for developing sectoral guidance after the thesis submission. While originally intended to include the completion of an initial draft of the guidance toolkit, it was decided that – to meaningfully involve the AuND community and museum workers in the creation and development – it should be a separate project, with the thesis focusing on answering the research questions. The three phases of the research addressed the research questions in the following way:

<b>Research Question</b>	<b>Phase</b>	<b>Actions</b>
1. <i>What are the motivations for, and barriers to, visiting museums for AuND adults?</i>	Phase 1 and 2	<ul style="list-style-type: none"> <li>• Focus groups that fed into the design of the study (e.g. research questions, methodology and development of the surveys)</li> <li>• Online surveys (one for AuND adults and one for museum workers)</li> </ul>
2. <i>What do museums currently offer AuND visitors, and what are the barriers museums face when addressing their accessibility issues?</i>	Phase 1 and 2	<ul style="list-style-type: none"> <li>• Online surveys</li> <li>• Feedback workshops</li> </ul>
3. <i>How can museums learn from AuND adults to adapt their practices to become more accessible to this audience?</i>	Phase 2 and 3	<ul style="list-style-type: none"> <li>• Analysis of the survey findings</li> <li>• Workshops</li> <li>• Creation of a guidance toolkit</li> </ul>

*Figure 3-2 Research questions and relevant phases.*

### 3.3.1 Research Design

The data collection methods were selected to best suit the type of information required, the access needs of the participants and the most appropriate way of ensuring that the selected approach complemented these requirements. The methods chosen had to be appropriate for gathering information from AuND people and museum workers to enable thematic and pattern analysis of a wide range of information. As a result, focus groups, interviews, and surveys were originally selected as the most appropriate methods for collecting this information. However, as the research progressed and the number of respondents increased, a shift took place from interviews to organising workshops, enabling more people to share their views to shape the research. The decisions made regarding the practice and focus of this research were shaped by feedback from AuND people and museum workers, which reflects the recommendations made by Cascio and Racine (2018) when undertaking person-oriented research.

All the data collection methods used in the project are common in research—both within the museum field and in social science research in fields such as psychology – and have well-known benefits and implications for their use (see Flick, 2018; Barbour, 2018; Allen et al.,

2017; Jamshed, 2014; Guest et al., 2013; Groves et al., 2009). However, a gap currently exists in the literature about how these methods are used (and appropriately adapted) in research involving AuND adults, except for some articles suggesting frameworks for research and ways to adapt questionnaires to meet the needs of AuND people (Stacey & Cage, 2022; Fletcher-Watson et al., 2019). For this reason, the following sections present how these traditional data-collecting approaches were adapted by an autistic researcher as part of this research project to ensure that they were as neurodivergent accessible as possible.

### 3.3.2 Surveys

Surveys and questionnaires are some of the most common methods for data collection in research that involves humans (Ponto, 2015; Singleton & Straits, 2009). These methods are particularly suitable when a research project is intended to be quantitative with qualitative components. Surveys are used to identify demographic information that can be quantified and use a variety of types of questions to generate insight into a topic. With technological advances allowing for surveys and questionnaires to be published online, with several different survey hosting platforms now available, researchers have increased capacity to collect data from far larger samples than other methods, which rely on in-person or local engagement (Toepoel, 2016). Surveys can therefore be a cost- and time-effective means of collecting a high volume of responses able to be used to inform research. As many AuND people utilise online platforms and communities as a way of connecting with others and undertaking their own research, publishing an online survey and sharing it within these spaces was a useful way of reaching the community.

Additionally, most surveys include open-ended questions or allow for free-text responses in some way. These enable the capturing of information about the individual participating in the study and provide a new perspective and context on topics. However, the data collected from open-ended questions may reduce the level of generalisation that can be applied to a survey. Further, extended use of open-ended questions could result in misinterpretations of the questions or survey drop-out (Stacey & Cage, 2022; Nicolaidis et. al., 2020). Using the feedback from the initial focus groups, the survey for AuND adults was designed to have both open-ended and closed questions to enable respondents to choose the response method they felt was most appropriate or comfortable for them. Efforts were taken to write questions that were clear and concise, which were tested with AuND adults, my supervisors, and other PhD researchers, who were provided with contact details for sharing any

feedback or questions that might occur while participating in the survey. The final versions of the surveys can be found in Appendix [C](#).

### 3.3.3 Focus Groups and Workshops

Another approach to qualitative research common in participatory practices is to include some form of direct involvement with participants (Robson, 2011). Focus groups and workshops are useful methods that, when executed well, can provide insight into social issues and feedback on research projects (Barbour, 2018). A focus group is a moderated discussion involving a group of people (on average, six to 12 members, plus the interviewer/moderator) who usually have a shared experience they can discuss (Stewart, 2018). The moderator is responsible for coordinating the group, leading the discussion by setting up questions or topics of discussion, and moderating to ensure the environment and conversation remain safe and on-topic. Unlike interviews, the structure of focus groups is more likely to be directed by the conversation between members.

There are clear benefits to a focus group approach. For example, the more free-flowing and open approach to the conversation can reveal even more about a topic or potential experience than an interview may be able to uncover. This may be because the group can respond to and comprehend a personal experience as shared by another member and know the most appropriate questions to ask (Leung & Savithiri, 2009). For example, a focus group with victims of abuse may be able to relate directly to experiences, creating a “safe space” to share these incidents and openness to discuss more specific details that they may not feel as comfortable discussing in a one-to-one conversation, especially if there is no established relationship or trust between the interviewer and interviewee. When a safe environment has been established and focus group members feel comfortable sharing within the space, it can result in detailed, informative conversations (Barbour, 2018; Alsaawi, 2014).

However, there are challenges associated with focus groups. For example, while more free-flowing conversation amongst focus group members could uncover details that may have been missed, there is a risk that the topic of conversation veers away from the focus of discussion. This may be a result of a dominant voice or recurring theme beyond the scope of the research becoming the focus (Leung & Savithiri, 2009). The risk of this is loss of control for the moderator, which might result in the focus group not being suitable to include in the final analysis. Similarly, some dominant voices in the focus group may result in some focus group members’ thoughts being missed because of a lack of opportunity to contribute, anxiety

about contributing a new thought to the discussion or disagreeing with perceived preferences among the group (Smithson, 2000; Smithson & Diaz, 1996). Some people, particularly from traditionally marginalised or vulnerable groups, may not feel safe to contribute to the discussion in a group environment, or may feel uncomfortable with the idea of opening themselves up in front of others – especially if there are people in the group that they know outside of research participation (Sim & Waterfield, 2019). In addition, some people may find that they mask more in these environments to fit in or protect themselves in a potentially vulnerable discussion. While a focus group may be the ideal place for some people to participate in research, it can be a challenging or impossible place for others to engage and participate.

Another challenge with focus groups involves ethical issues around consent and anonymity (Sim & Waterfield, 2019). Unlike one-to-one interviews, where a conversation can be more controlled in content, a focus group involves several individuals who could potentially discuss topics that are distressing or harmful to others, and this cannot be predicted. Even with careful planning, the direction of the conversation could cause some participants to feel uncomfortable or uneasy, potentially resulting in the withdrawal of consent to participate. In an interview, it would be easier to bring the conversation to an end at the point where the participant expresses that they no longer wish to be involved (Ransome, 2013). When participating in a focus group, where participants are contributing to a conversation, it is more challenging to completely withdraw someone from that conversation without impacting the context of the other participants' responses.

As this research project involves organising focus groups with AuND people, it was important to be mindful of specific access needs that make traditional structures for focus groups inaccessible. Many AuND people experience difficulties with social communication, particularly with strangers and in unfamiliar environments (ICD-11, 2024; Jenkinson et al., 2020). Furthermore, some topics of conversation could cause upset or clashing sensory needs (such as someone needing to use sensory or visual stim to focus, while others might be sensitive to audio or visual stimuli). As part of the research design process, I participated in various autism research projects to observe the various barriers in place and adjustments that could be made to make research more accessible. I then discussed these approaches with focus group members at the beginning of the data collection process. This was an important part of ensuring that the research methods employed in this research were not only appropriate but accessible to the AuND community.



To make the process as accessible as possible, adaptations to traditional approaches as outlined above were made based on an understanding of the types of access requirements that should be met. Rather than running large focus groups (six to 12 people) and only in-person groups (which tend to focus on spoken communication), the focus groups were designed to meet the needs of AuND people. The size of focus groups was reduced to between three and six participants to ensure that there were not too many strangers involved in a conversation or too many people speaking, with the possibility of some voices being lost. Before the focus groups, a booklet was sent to potential participants with information on the research and what would be involved. This was intended to enable participants to feel more comfortable with what would happen and decide whether it was appropriate for them to take part or what additional adjustments they might need to participate. Rather than setting an expectation that all participants would need to take part in a room, or verbally, there were options to take part online, with opportunities to contribute in writing (either written responses handed to a moderator to read, with permission, or shared within a chat function). There were also planned breaks for anyone who needed to take respite in a quiet environment or recharge after the conversation.

Workshops are similar in function to focus groups as a participatory method. However, they are historically less prevalent in methodological literature when compared to other qualitative approaches (Caretta & Vacchelli, 2015). Like focus groups, workshops involve a facilitator or workshop lead organising and running a session with a group of people to find out about the group's opinion on a specific topic or project. Rikke Ørngreen and Karin Levinsen (2017) define a workshop as a group of people who “learn, acquire new knowledge, perform creative problem-solving, or innovate” concerning a specific issue in which the participants have a personal stake or expertise. In this research, the individuals consulted as part of both the workshops and focus groups were made up of the two core groups that the research was intended to serve: AuND adults and museum workers. They were designed to serve a pre-determined function and engage their participants on a topic related to the research purpose (Ørngreen & Levinsen, 2017). In addition, workshops are considered a reciprocal learning process for both the researcher and the group because of the cycle of discussion, feedback, and reflection that takes place for both parties (Caretta & Vacchelli, 2015 Moschitz & Home 2014). While focus groups tend to be more discussion-focused, workshops often have an independent component that enables the group to undertake an activity with others present (Chambers, 2002). In some instances, the activity can be a creative process or group task, while at other

times it can be a way of gathering and sharing reflections on a particular topic (Caretta & Vacchelli, 2015). Participants in the workshop should feel empowered to contribute their views and responses, with the researcher there to act as a moderator rather than directing the conversation (ibid). One challenge within workshops is expecting everyone in the room to agree on the topic, which contradicts the values of participatory research (Kapoor, 2002). Instead of focusing on reaching a shared consensus, in this project, the workshops were designed to be a forum for open discussion on the topic, with the researcher acting as an impartial moderator who would ask follow-up questions or seek further feedback from the group. In the context of this research project, the workshops blurred the line between focus group and workshop. Indeed, the workshops discussed in [Chapter 6](#) embody more aspects connected to a traditional focus group, such as gaining direct feedback on questions set out by the researcher. However, the individual feedback activities used and focus on generating discussion across large groups (approximately 20 participants per session) are closer methodologically to a workshop. While both methodologies aim to elicit discussion within a group setting, the level of involvement of the moderator, the type of activities undertaken as part of the session, and the level of power that the participants have all impact whether the approach is considered a workshop or focus group (Barbour, 2018). When the balance is right, a focus group can provide additional context and insight that a survey or interview may not be able to generate on its own. The benefits and challenges discussed concerning the focus groups therefore also apply to the workshops.

The success and value of the focus groups and workshops depend on the skills, understanding, and ability to construct a trusting relationship as a moderator and researcher.

### 3.4 Phase 1 – Focus Groups and Surveys

The first phase of this study focused on research questions 1 and 2, and can be divided into two specific steps. The first step in Phase 1 was to hold two focus groups, which were then used to test and adjust the surveys for AuND adults and later stages of the research. This section follows this structure and has been broken down into the following sub-sections: 1) focus group with AuND adults, 2a) surveys for AuND adults, and 2b) surveys for the museum workforce.

It was possible for members of the museum workforce who are also AuND (diagnosed or self-diagnosed) to choose which survey they wished to complete or select to complete both. This is in acknowledgement that AuND people work in the cultural heritage sector in a range

of distinct roles with valuable insights into how accessible their institutions are. Such respondents can offer valuable insights into both: a) their perspectives about the sector and provisions for AuND visitors at their institutions (museum workforce survey) and b) their experiences as AuND visitors to other institutions.

## 1) Focus Groups with AuND Adults

### i. Planning and Execution

Initial plans to start the research with a pilot survey for AuND adults were reshaped to allow the community to have greater involvement in the project and offer feedback on research aims and survey design by participating in two focus group sessions. These allowed the participants to reflect on the identified priorities and adapt the survey questions accordingly, ensuring they were accessible to AuND people.

Two focus groups were organised between May and July 2022, consisting of a total of seven AuND adults. Focus group participants were recruited from the UofG's Neurodiversity Network (which includes AuND staff and students) and one external PhD researcher from another Scottish university.

A "What to Expect from the Focus Group" booklet was designed to inform participants (Appendix [A](#)). While not required by the College of Arts ethics committee, which approved the methodology, this was influenced by my own experience participating in the Sensory Street research project (MacLennan, 2022). This provided a brief booklet with information, which was useful to have before and during the focus groups and acted as an informative model for the development of participatory practices utilised in this project. Information about the focus groups was shared with the Neurodiversity Network, the Scottish Autism Research Group (SARG) and the UofG Autism Journal Club. I had planned for a total of up to six focus group members (a total of up to 12 across the two groups), as it was important to keep the number of participants low. If there were more people interested in taking part in the focus groups than there was space available, I planned to a) create a "waiting list" in case anyone could no longer attend; b) organise an additional focus group if there was a demand for it, both from those interested in taking part and for further insight into specific topics; and c) ask if they would be interested in contributing at a future stage of the research. In the end, I conducted two focus groups and was able to receive valuable and insightful feedback that was sufficient to shape the overall research.

The focus groups took place on two different days and at contrasting times of day to accommodate several types of availability. The group sessions were held online using Zoom, which was chosen because of the accessibility and security features it offers, as focus groups took place during the COVID-19 pandemic in early 2022. Participants who completed their consent forms and secured a space at the sessions were sent the links to the Zoom session 48 hours before the session they were scheduled to attend. They were then sent the link again approximately two hours before the session with the option to notify if they were no longer able to attend or had any questions before the focus group. I started each Zoom meeting 15 minutes in advance to set up the PowerPoint slides, brief the volunteer co-moderator, check that the settings were correct, and allow participants who wished to join early to ask questions beforehand. Participants were informed in advance that the focus groups would be recorded to permit the opportunity to reflect on the discussion and what they would feel comfortable contributing. They were informed that their contribution would remain anonymous in the thesis or any related publications unless they had specified that they wished to be named.

Each focus group session ran for an hour and a half. In exchange for their time and feedback, each participant was sent a £15 voucher via email within five days of the focus group taking place. It was important to ensure that the participants were all compensated for their time and contributions to the project, as their input was important for the development of later stages in the research. This payment was in the form of a voucher, rather than a direct financial payment, because of the nature of compensation options available via the project's research funding and the relevant UofG regulations.

The sessions themselves were structured in two halves. The first half of the session included introductions, gave an overview of the research project (including aims, overarching research questions, and methodological approaches) and what the research was about, and allowed participants to offer feedback. Participants were able to communicate their views verbally and non-verbally, using the chat function. At the beginning of the session, housekeeping tasks were carried out, such as checking that everyone who was expected to attend had arrived and everyone was happy with being recorded, and a run-through of the rules as set out ahead of the session with the booklet, allowing an opportunity for questions before beginning the research overview. After this was completed, I explained that, at the end of each slide, I would pause and ask for thoughts on what was discussed and remind the group that they could comment in the chat or raise their hands if they wanted to ask any questions or give feedback as we went along.

There was a slide on each of the following headings:

- Research Aims
- Research Questions
- Literature Findings (so far)
- Methodology (explaining the three phases)

This first part of the focus groups, while primarily about familiarising the participants with the project itself, was treated as a sounding board for the overarching study. The participants were asked to share their opinions and suggestions for the direction of the research project, with the first section dedicated to gathering feedback on the above topics. This part was intended to last between 30 and 45 minutes, including a five-minute break. Participants were told at the beginning that they would be able to take comfort breaks whenever needed during the session. However, it was crucial to ensure there was a scheduled break to allow processing time before a change in activity and to offer the opportunity for anyone needing a break but perhaps finding it challenging to ask for one to do so without any anxiety about missing any of the discussion.

The second half of the session was about the survey distributed to them in advance to gain feedback. This elicited participants' views on survey questions (for example, whether the wording was clear and if it made sense to their understanding of the topic), the ordering of options in multiple-choice questions, their thoughts on certain questions (such as about gender and AuND identity), and whether there were any questions they would change or would like to see added. This section was more open-ended, although there were some questions presented in the "What to Expect" booklet (see [Appendix B](#)) that helped guide the discussion. The slide at the beginning of this section of the focus group included some written questions about what type of information I would find beneficial to receive feedback on. These questions were also posted into the Zoom chat so that everyone could see them when the shared screen was changed to show the survey. During this part of the focus group, each of the questions was presented one by one and discussed (for a better idea of clarity), with topics covered including whether there was anything unclear (change of word choice) and if the type of question (for example, Likert or open-ended) made sense, as well as whether there were any other questions that they would have expected to see.

The results of the focus groups had a significant impact on the re-design of the surveys for AuND participants (the results of which are presented in [Chapter 4](#)).

## ii. Sample Profile

Focus group participants had varying levels of experience and expertise in conducting or taking part in research, offering a wide range of useful feedback. Contributions varied from identifying terminology or word choice and layout changes to more significant changes, such as altering the structure of the survey itself.

There was also a variety of backgrounds and experiences among the two sets of focus group participants, which was represented in their feedback. The first focus group consisted of three individuals of varying ages, all female, with mixed cultural and ethnic backgrounds. Of those individuals, one was in academia, one had worked in occupational therapy, and one had participated in local groups and projects for people interested in museums. Their reasons for participating in the session varied: one was interested in the aims of this project as it aligned with projects they had been involved in previously; one was actively involved in projects like this to advocate for AuND people with co-occurring chronic illnesses; and the third took part because they were interested in conducting research using methods like the ones used in this study. Most of the responses reflected each participant's varied (and extensive) experience in participating in studies or projects of a similar nature. The different motivations for participating, alongside the openness in the responses and the variety of perspectives, offered an interesting insight into considerations that I had missed in the planning stages.

The second focus group consisted of four participants: three women and one man of different ages, all white, with three of the four from the UK. The participants included university students and staff, which was to be expected as the recruitment for this group was through two platforms at the UofG, and at the University of Edinburgh. Each participant provided different personal, professional, and cultural contributions to the discussion. They were interested in different areas (as they indicated when they signed up). One of the participants was a PhD researcher conducting qualitative research who had expressed interest in participating following my involvement in their work. Two of the participants had specific knowledge and interest in the research: one was an expert in statistics, while the other had worked on projects relating to neurodiversity. The final participant was an international student who was interested in inclusion and exclusion and stated that they had some experience visiting museums in the UK. As with the first session, knowing the context of why each participant was interested in participating and their general interests was beneficial and provided useful context

for the analysis, as it was often reflected in the types of observations, feedback, and recommendations made during the session.

Although only two focus groups were conducted at this stage of the research, the wide range of different experiences, expertise, and views proved not only informative but crucial in the development of the definitive version of the survey. When considering the range of different lived experiences and opinions on what would make the research more accessible to them on a personal level, there were very few contradictory findings from the sessions. Moreover, many of the points that Group 1 made were echoed in Group 2. To ensure that the views expressed by all the participants were addressed, to take accountability, and to demonstrate to participants that their contributions did indeed shape the next stage, I distributed the key actions taken following the focus groups to all participants for final feedback. Below is a summary of the main findings, followed by a summary of the key actions taken because of the focus groups.

### iii. Findings and Actions

A table was created with all the feedback from the focus groups – included anonymously – and the responses to this, such as immediate actions taken or changes to be considered in the longer term (Appendix [B](#)). While I attempted to address and incorporate all recommendations into the definitive version of the survey, some suggestions were not possible. The table indicated the key recommendations, insights, and observations, what the suggested changes were, whether they would be taken forward, and then how or why they were not taken forward.

This table was crucial for holding this project to account. As an autistic researcher, I am aware that a consistent criticism of autism studies and research into neurodivergence either does not involve AuND people or does not inform them of their impact. Furthermore, there must be a reliable paper trail of decisions taken at each stage of the project to ensure an appropriate level of insight from AuND individuals. This is to ensure that the research and findings are disseminated appropriately, AuND people can respond to any findings and be informed of how their contributions have shaped them (Sheely, 2018). In addition, having this level of accountability to each of the participants, as well as to supervisors, was intended to address potential power imbalances in the knowledge production process that such work involves (Wurm & Napier, 2017).

As a result of the focus groups, the following changes were implemented to the research questions, aims of the project, and survey questions of the research project, with specific outcomes recorded in Appendix [B](#).

## A. Research Questions

As a result of the focus groups, the original five research questions were simplified and refined. Participants unanimously proposed that questions 2 and 3 could be adapted to merge into one. The question that was identified as the lead question was number 5 and this was then combined with elements of question 1 to create a new question. Using the feedback, an updated version of the research questions was drafted and used.

The streamlining of the research questions became clearer following the focus group discussions and led to more focused research questions. One of the critiques of the questions as presented to the second focus group was that there seemed to be more emphasis on the museum workers and evaluation practices of what already existed than on how to make changes to make museums more accessible. As the impact on the museum sector is an important aspect of this research, it was important to reflect on what is currently available and what the barriers have been to progress, as well as the motivations for and barriers to visiting AuND people. Focusing the questions on 1) motivations and barriers to museum visiting for AuND people, 2) what museum professionals currently do for AuND people, as well as the barriers that have impacted this, enabling the balance to be redressed 3) what can be learned from working directly with AuND people to address the barriers and make visiting more accessible for a currently under-served audience group.

## B. Research Aims

The aims needed to be refined to reflect the changes made to the research questions. While the focus groups overall responded positively to the aims, with some expressing that they seemed clearer than the research questions so were useful to have alongside the questions, specific recommendations were made to simplify them to fit with the scope of the research more clearly. Using the feedback of the participants, and still corresponding to the research questions, the objectives were revised to those outlined at the beginning of the chapter.

Both focus groups quickly ruled out the initial third aim as it was a methodological approach rather than a key research objective. Feedback from the second focus group



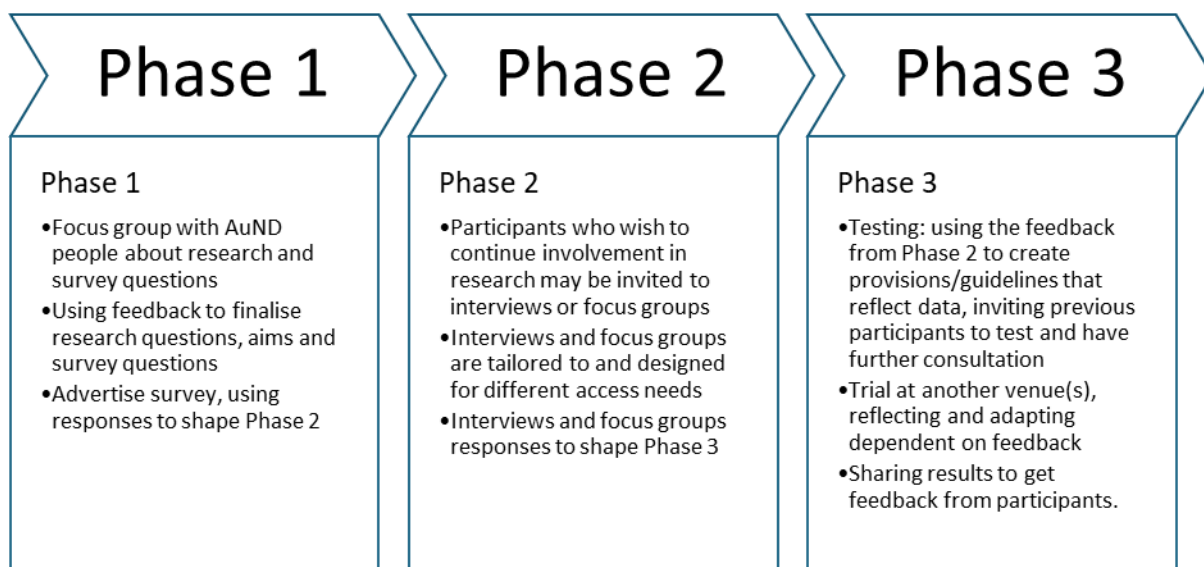
highlighting the need for more clarity about intended research outcomes that would allow for its impact to be measured led to one of the overarching aims being the creation of guidelines for the museum sector. The other aims were simplified and combined with changes to wording to reflect the language preferences of the focus groups – for example, moving away from using words such as “offer,” “strategies,” “audience”, and “AuND feedback” to language that is more engaging and focused on AuND people’s experiences and how they can contribute to this research.

Participants suggested that having the aims available alongside the research questions would be useful in all documents related to the project to allow for the rationale behind the research project and its methods to be more transparent. I decided to keep the aims and include them in future “What to Expect” booklets as part of the “Research Context” section. Furthermore, these aims were useful to undertake continual self-evaluation and reflection on whether the research was achieving the intended outcomes.

### C. Shaping of the Methodology – Making Accessible Diagrams

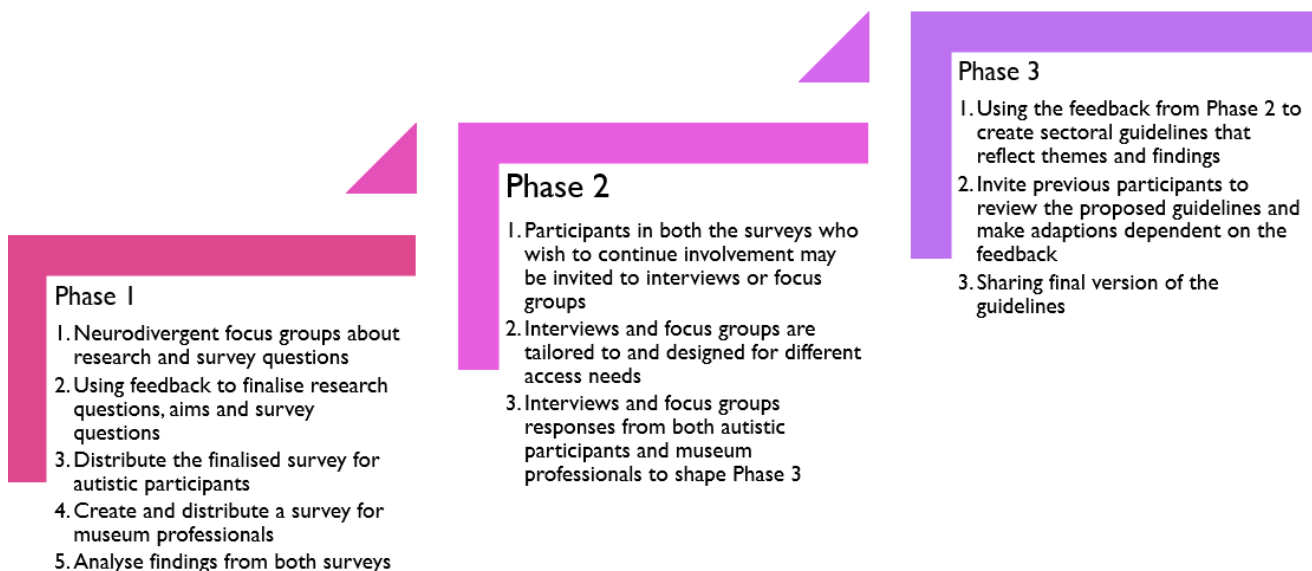
While the aim of these focus groups was not to make specific alterations to the methodology, it was important to communicate exactly what each of the research stages involved to demonstrate how the research questions and aims were being addressed. Feedback on the clarity of the verbal explanation of each stage as well as how this was visually presented in the slides would help to inform how best to present this information in future publications and presentations, as dissemination and open discussion of what the research involved were priorities for this type of research.

This was how the methodology was displayed in the first focus group:



*Figure 3-3 Original diagram of the proposed phases used in focus group 1.*

This is how the information was updated for the second focus group using the feedback from the first one:



*Figure 3-4 The second version of the methodology diagram was created using feedback from focus group 1.*

Using the feedback from both focus groups, I then created the following flow diagram to combine all the recommendations on how to present the information:



*Figure 3-5 The third version of the methodology diagram was created using feedback from both focus Groups 1 and 2. This version was used during the ITAKOM conference.*

The changes to the methodology element of the presentation may appear non-essential to the delivery of the research. However, as this is a community-focused project, it was essential to ensure that all the information that was shared with participants was as clear as the findings themselves. While the adjustments to the methodology were not related to the specific steps taken as set during the ethics application (Appendix A), it was evident from the focus groups that the information in writing did not give enough insight into what each stage of the research entailed. In addition, the first focus group stated that it was unclear what actions were taken for AuND people and for museum workers, which was potentially misleading. It did not explicitly state that the findings and approaches of the research were subject to continual reflection, analysis, and adaptation. One of the most consistent suggestions related to changing how the information was presented and colour coding it. It was clear that the information needed to be adjusted, but not completely altered, to take on the feedback but still work within a PowerPoint slide.

In addition, using the feedback from the first focus group, I re-wrote for the second one the sections where there was a lack of clarity or concerns over wording; one particular concern was the misleading impression that this stage was specifically for “students”, which I rephrased

to make clear that recruitment went beyond this audience to invite people from broader backgrounds. A statement at the end of each step highlighted the importance of analysis, as one of the key messages for people viewing this type of diagram was that reflection and continual adaptation were essential aspects of the methodology. The use of a flowchart – as suggested by the first group – was seconded as a logical way to present the information. Finally, both focus groups agreed that the more information was available in the diagram, the better for understanding the methodology.

The advice to separate the actions that related to AuND people from those associated with museum professionals was implemented to make clearer what each of these groups would be involved in and at what stage. The resulting flowchart was more detailed, which, while offering more details and minimising the risk of misunderstanding, significantly increased the likelihood of being overwhelming to follow. To test the updated flowchart, it was included in the poster presented at the It Takes All Kinds of Minds (ITAKOM) conference (2023), as this was an event with a high percentage of AuND delegates who could give useful feedback. The overall feedback from the ITAKOM conference was positive, with many delegates expressing their appreciation of the methodological approaches outlined in the flowchart and as part of the poster. There were no specific suggestions for changes during the poster presentation session in person or online via the conference APP, suggesting that the changes in the way the methodology was presented were effective.

## D. Survey Questions

The most challenging of the changes were to the survey questions. Although the feedback for the research questions, aims, and methodology was all consistent with no disagreement on the recommendations made, the same was not the case for the surveys. Where one focus group agreed on one view, the other often offered an opposing view. The clearest example of this was the recommendation of the first focus group to put the demographic questions at the end of the survey rather than at the beginning so that energy could be focused on the more important questions. Although half of the second focus group agreed with this, the other half expressed their preference to have the questions at the beginning as that is where they would expect to find them, with placing them at the end potentially resulting in them not being completed. A straightforward way to address this would have been to provide a question that asked respondents to choose whether they would prefer to answer these questions at the beginning or end of the survey, and for that answer to determine the order. However, this could risk the data

from these questions not being calculated together, instead being treated as distinct questions. A follow-up informal poll question on Twitter – which was open for four days and stated it was for AuND people – asked the same question. According to the 39 anonymous responses, 67% responded that they would prefer at the start, while 30% voted at the end (the other 3%, or one response, stated “other (please explain)”), but it was unclear whether they did respond. It was therefore decided that having the demographic questions at the start would be the preferable approach.

There was also a dispute over the inclusion of a question that asked about the diagnosis status of respondents. While some participants found this question positive as other research excludes self-diagnosed people based on not having a formal diagnosis, others felt that asking this question suggested that those who self-identified as AuND would be filtered out when the results were used. During this discussion, the rationale for the original decision to include this question was explained. I had concerns that, without including this option, people who self-identify because of inaccessible and long waiting lists for assessments would be deterred from participating, or risk their experiences being missed based on their diagnostic status. Furthermore, I hoped to demonstrate that – regardless of diagnostic status – the barriers and limitations to visiting AuND people can be experienced broadly beyond just those with a formal diagnosis, and therefore the findings could be beneficial for more people. While this explanation resulted in the first focus group agreeing that this question would therefore have a place in this research, the second focus group still felt that it was an unnecessary question that could ostracise some potential respondents. Both groups agreed that it would be useful to add a disclaimer stating that both individuals who were diagnosed formally and informally were welcome to take part.

Unsurprisingly, language, terminology, and inclusion were crucial to the discussion of the survey questions, especially when it came to how to discuss specific conditions. Initially, there was a question that asked respondents to select which option of a condition they identified as: 1) Autistic, 2) Neurodivergent, and 3) other sensory disorder/condition. The third option proved to be problematic, as the initial version used “disorder” to refer to the condition “Sensory Processing Disorder/SPD”. However, this does not reflect the preferences expressed through the social model of disability. In addition, using “sensory condition” could be misinterpreted as referring to conditions such as visual or hearing impairments rather than sensory processing. Furthermore, the other two options do not encapsulate what specific types of neurodiversity a person may have or could potentially exclude someone who does not use

either of those terms to describe themselves. As one of the participants in the first session explained, some people do not use the language that is currently preferred within the community, for example preferring to use person-first language or identifying as having Asperger's Syndrome despite this no longer being a recognised condition in the DSM.<sup>15</sup> This meant that some people might not respond to the survey as the language did not reflect their identity. However, the risk of incorporating all the different options in the list was that this could potentially alienate others who oppose the use of these terms or miss other terms (for example, Neurodivergent is an umbrella term under many distinct categories). One solution suggested during the second focus group was that the question asked be an open-ended one, asking the respondent to specifically write what they identify, meaning that their exact words and preferences would be captured without asking them to self-categorise based on limited options. Participants felt that this would be an effective way to ensure that all potential participants could participate and use their terms, rather than implying that they were not the focus of the research. Keeping the question open for participants to respond and including a disclaimer at the beginning and as part of the recruitment advertising that the survey was open for AuND people who self-identify or are formally diagnosed with different conditions under the neurodivergence umbrella should reduce the risk of excluding potential participants. While it was clear there was no way to ensure all language preferences and conditions were listed without the risk of missing any or causing concerns around the ethics and understanding of the politics of terminology, the open-question recommendation appeared the most logical.

Participants in both focus groups preferred open-ended and “tick all that apply” type of questions, with Likert scale questions recommended to be avoided. When asked about question types and the balance of the existing question types, the consensus was that there was a good balance between open-ended and option-selecting questions. There were no Likert questions in the first or second version of the survey, but, when asked if those would be useful, the response was that they could be more difficult to answer. The focus groups stated that they found questions that require them to rate or place a value on a statement – for instance, questions that ask for a ranking on whether they would agree with a particular statement –

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<sup>15</sup> Asperger's Syndrome (individuals with this condition sometimes refer to themselves as “Aspies”) has a complicated history. While it has always been considered a condition under the “Autism Spectrum Umbrella”, it was a sub-category often diagnosed when a person was not considered to have a learning disability or difficulty using spoken language and was often deemed to have average-to-above-average intelligence but shared other core autism traits such as difficulties with socialising, repetitive behaviours, and social communication difficulties that impact daily life. However, Hans Asperger (the Austrian paediatrician who studied and became the namesake of this particular diagnosis) was discovered to have a problematic connection to eugenics and the Nazi euthanasia programme during the 1940s (NAS, n.d.; Sheffer, 2018).

difficult to answer. This is because it can be difficult to determine which of the options on the scale are the most appropriate responses, potentially causing unnecessary stress or resulting in an answer that does not reflect their true feelings on a topic. This reflects the findings of Stacey and Cage (2022), whose research into questionnaires for AuND participants suggests that decision-making skills, and the way that AuND people process information, can impact how these questions are answered and the level of energy that it takes for the respondent. For these reasons, it was decided to avoid Likert scales and focus on multiple-choice or open-ended questions.

The open-ended questions as initially drafted only asked the question without providing any instructions or guidance for how to approach the answer. The first focus group, while pleased with the questions that were asked using this format, was concerned that the lack of word count or guidance could be intimidating for some, while others might write lengthy responses. The specific question discussed about this was “What does accessibility mean to you?”, which some felt could be perceived as too vague, if not focused on being about accessibility for AuND people, especially if respondents had co-occurring physical disabilities. It was felt that this question could result in a lengthy response from some, or others not writing much as they might be uncertain about what type of information to include. The first focus group therefore suggested setting a word limit of 100 to 250 words for this question and indicated that a suggested example (e.g., my sensory needs being met in public settings) could help respondents focus their responses. However, the second group felt that – while a word limit was useful to include – giving an example might make this a leading question. Consequently, there was a concern that an example could be considered coercive, directing respondents to answer how they felt the researcher would prefer rather than giving their honest answers. Although there was a concern that the question could result in broader answers that go beyond AuND-focused accessibility, the potential to guide respondents away from their views was too significant a risk. Further, the question intended to capture the respondent’s individual experience and views on accessibility, with disability, identity, and intersectional differences to be expected. Keeping this question non-specific offered the potential to provide greater insight into the experiences of AuND people with co-occurring medical conditions that were as (or more) impactful on their experiences of accessibility that should be included. The recommendation of setting the word count for the answer was taken on board, as was including the clarification that participants could answer in bullet points if preferred, to allow respondents to decide which way would be easier for them.

For the “tick all that apply” questions, there was also division about the number of options that should be available per question. While some participants stated that more options being available increased the likelihood that respondents’ views would be reflected without needing to use the “other” option to specify, others felt there was no such thing as too many options. For example, the question about “reasons for visiting” had the most options, and there were some overlaps as well as gaps perceived in the types of answers listed. Options such as “to visit the café” and “to visit the gift shop” could be simplified to “to visit facilities”. Furthermore, the options included did not incorporate more general options such as “nothing else to do”, “to get out of the rain or sun”, or “because I am on holiday”, which focus group participants stated as frequent reasons for visiting museums. Indeed, one of the participants felt that the options were more focused on specific reasons to attend, such as going to set events, while sometimes museum visiting is unplanned, and that the survey lacked options such as “to see a specific object that is an interest” or “to explore focused/intense/special interests”. It was therefore suggested that this question’s options be reflected upon, refined, and separated into different sections to make the list less daunting yet more representative of the diverse reasons for visiting.

When discussing the topics and key questions, the consensus was that the survey questions were appropriate and addressed the research questions and aims. However, one of the first focus group participants mentioned that the questions were focused more on the experiences of AuND people who do visit museums and existing visiting patterns, motivations, and barriers rather than reflecting on the potential or desired level of visiting. For example, the original survey asked, “How often did you visit museums before the Covid pandemic/in the last three years”, but answering how often a person *did* attend does not necessarily reflect how often a person *would want to* attend a museum if they could, or the reasons why these two answers might diverge. For example, a person may want to visit a museum but does not attend because their access needs may not be met. It was suggested that asking this question and following up by finding out why there may be a difference in response could give a greater insight into the demand for museum visiting for AuND people who are currently under-served, as well as informing the ways to address this. This was one of the most valuable recommendations offered by the focus groups on areas that were missing. The follow-up suggestion to ask AuND people about how museum visiting made them feel and how it could be improved formed the basis for the design of the focus groups and interviews at the second stage of the research.



The final changes to the survey were minor changes to the numbering and order of some of the questions, word changes to reflect the recommendations throughout the session, and updating the period from three to five years of museum visiting to ensure that no one skipped or mis-answered this question because of the limited timescale. Some of the recommendations and feedback around the confusing flow of questions were a consequence of the questions and options all being in one document and therefore harder to follow than when clicking through an online survey. The priority was thus to make all the major adjustments to the question wording, finalise the order, and determine which questions would be required as part of the survey before creating the digital version. To ensure that the recommendations were taken on board and test the functionality and clarity of the survey, the final draft was piloted and tested by some of the focus group participants who had expressed an interest in testing before it was officially launched. This final check stage aimed to address any final issues with the survey, allow for additional feedback from participants, and reduce the risk of errors being missed before the definitive version was officially launched.

## 2a and 2b) Surveys for AuND Adults and the Museum Workforce

This section explores how the survey for AuND adults (and the common aspects of the one for the museum workforce) were designed and the lessons learned from analysing the response rate and findings. The different options included in the one designed for the museum workforce are described in the following section.

### i. Survey Design

In the months following the pre-survey focus groups, feedback and recommendations were utilised to modify the surveys for AuND participants. The surveys (Appendix [C](#)) were designed specifically for AuND adults to answer online. The topics covered by the questions were:

- **Demographic information:** to gain a better understanding of who was responding to the survey, and to better understand the level of diversity in the representation. As research has traditionally reflected the dominance of formal AuND-related diagnoses being of white, often middle-class males, it was hoped that demographic information would help to monitor potential intersectional identities that can impact experiences (Grant & Kara, 2021; Cascio et al., 2020a & b).
- **Museum visiting habits:** questions about whether respondents visit museums, how often, and why they go or do not go. This was to better understand if there were any visiting patterns.
- **Accessibility:** questions about how accessible they perceive museums to be, to identify existing barriers, and to record their views on the needs of AuND people in museums.
- **Recommendations:** questions to find out what might help make museum visiting more appealing and/or to reduce barriers, as well as to determine whether AuND people would be interested in contributing to participatory and community projects in the field.

Once the themes of the questions were identified and the questions for both the AuND and the museum workforce surveys were re-drafted following the focus group feedback, the process of digitally creating the surveys was carried out.

Both surveys were created using Qualtrics, an online survey creation and analysis platform recommended by the UofG for research surveys. They were intended to be of similar length with some themes identical to ensure that they were consistent and could be compared. The two surveys aimed to capture the views and experiences of both AuND adults as visitors

or potential visitors to museums, as well as those of the museum workforce and their views on how accessible the institutions they were based at were for this audience.

The feedback from the AuND focus groups allowed me to adjust and refine both surveys as described in the previous section. To ensure a fair balance between open-ended questions, which allow the respondent the opportunity to share their own experiences in their own words, and the risk of too many open-ended questions resulting in disengagement, an effort was made to minimise open-ended questions. This was achieved by assessing questions and ensuring that the open-ended questions could not be converted to either multiple-choice ones or removed altogether. To reduce questionnaire exhaustion and respondent overwhelm, none of the open-ended questions were made mandatory and all were within a suggested maximum word count. All multiple-choice questions also included an open-text box response option. Furthermore, a box was included at the end of the survey for anyone who wanted to provide any last thoughts that they did not get the opportunity to add during the main body of the survey, or to give any follow-up feedback or thoughts they wished to share. This open-text box (which they could leave empty if they wished) proved particularly useful for follow-up thoughts, and the majority of fully completed responses included final reflections or feedback.

The greatest challenge was ensuring that the duration of the surveys was not too long, leading to potential participant drop-out. Both surveys had fewer than 50 questions, including the information sections (text boxes) such as the consent form and any introductions to sections resulting from Qualtrics's approach to measuring survey content. Most of the respondents would not see all these questions, as this number includes all the possible questions regardless of the options selected. For example, a museum worker who ticked that they had never run an event for AuND people would automatically skip all the questions asking about these events and be automatically moved to the next section relevant to them. Furthermore, other than the consent questions and those connected to eligibility to participate (for example, participants to the AuND adult survey needed to identify as AuND to be able to continue), all the other questions were optional. To ensure that all respondents were informed when they had missed answering a question, in case it was in error, a prompt would appear to check that the respondent had not missed a question accidentally to allow them to confirm that they were happy to progress without answering that question.

Qualtrics provides a tool as part of survey creation that determines the accessibility and usefulness of a survey. This measures the duration of the survey and provides an estimate of

how long a survey will take to complete. This estimated that the survey for AuND adults would take between 18 and 20 minutes, while the one for museum workers would take between 20 and 22 minutes. The latter was estimated to take longer, despite being similar in length but with fewer open-ended questions, because it had more blocks of text for respondents to read while completing it. These estimates did not reflect the actual average amount of time that respondents took to complete the AuND survey. The actual average completion time (in full) recorded for AuND adults was 10 to 15 minutes, with most participants appearing to have completed the survey in one effort. Meanwhile, the museum worker survey had a greater variation in the duration of completion time – some took only nine minutes to complete it in full, while others were recorded as taking over an hour. However, with the museum worker survey, this may be down to respondents opening the link to the survey and leaving it open – stopping to potentially complete other tasks as most were completed during regular office hours, suggesting it was completed during work, meaning that this was not reflective of actual time spent on the survey. This demonstrates that the estimate given by Qualtrics – while a useful guide – is not necessarily a reflection of the way these surveys were completed in practice. Those who completed it in one attempt had a higher completion rate and lower time spent on it than those who took some time away and returned. This suggests that, while having the option – and the reassurance – that a started survey could be returned to within a month, the completion rate fell for those who started with the intention to return to it than those who were able to commit the time to complete it in one go. Having insight tools into completion time was beneficial, particularly considering the substantial levels of detail recorded in some of the survey responses. However, an equally valuable insight was gained into those who did not complete the survey in full.

In addition to the duration of the survey statistics, the statistics for those who failed to complete the survey indicated that the highest drop-out rate was on the consent pages. This was understandable, as the consent pages were, despite considerable effort in their design, unavoidably heavy in content, jargon, and key information. For anyone who opened the survey expecting to start directly with the topic-based questions, being met instead with dense (but essential) consent information, might have increased the likelihood of leaving the survey. This may have been because they intended to return to it later, or because of the density of information appearing daunting. This poses a challenge for researchers, as having clear consent information available to ensure informed consent of participants and meet the requirements of ethical practices can be overwhelming for many individuals, particularly for individuals who

have difficulty reading or processing complex or detailed information. While overall the high number of respondents indicates that this did not have a significant impact on the AuND adults' survey response rate, the level of consent for cultural heritage workers – who may have been taking part with a level of hesitance as they would be discussing their workplace – could have made potential respondents even more hesitant. On reflection, a lesson to reduce participant drop-out for future surveys is to collaborate more closely with AuND people to develop Easy-Read<sup>16</sup> consent and participant information – as well as an Easy-Read version of the survey itself.

To protect against fraudulent responses and ensure survey reliability, steps were taken to minimise the risk of bot-generated data. Since the start of the PhD, and with the rise of AI and bots on the internet, there has been an increasing concern about research and data integrity (Griffin et al., 2021; Storozuk et al., 2020). To mitigate this risk, I took three key steps: did not offer any financial incentive for survey completion; employed Qualtrics's built-in bot detection software; and manually checked each response to identify and filter out any suspicious responses. During this process, the last two measures did not identify any responses created by bots. Qualtrics identified five responses as potentially having more than one response due to the respondents' IP address that the program registers; with this, I was able to check these duplicate records to filter through and moderate the responses. In these cases, it appeared that the respondents initially left the survey which they completed in their second attempt. As the analysis included only responses that were completed in full (by reaching and pressing the final consent button at the end of the survey), those first-attempt half-completed responses were not included in the final analysis.

Once both surveys were finalised and ready to be launched, they were promoted on social media and through specific online mailing lists.

### 3.5 Additional Characteristics of the Survey for the Museum Workforce

Alongside the survey for AuND participants, a second survey was created for the museum workforce, which ran from November 2022 to February 2023. This survey asked about the participants' museums, galleries, or other cultural heritage institutions to reflect on how

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<sup>16</sup> An easy-read version of a document is one that has been created using clear, jargon-free language to communicate a message in a way that is more accessible and easier to understand for diverse readers.

“autism-friendly” their organisations are currently, share what AuND-specific provisions they currently provide, and any future plans. They were also asked to reflect on their current strengths and areas for development that this research could support in addressing with its dissemination outputs. The main aim of the survey at this stage in the data collection was to identify patterns in what was available, barriers within their institutions for this audience that they were aware of, and barriers to their ability to address these – all topics previously highlighted as priorities by the museum sector at events such as the UK Museums Association’s inclusivity conferences – as well as to identify and address any gaps in knowledge or provisions.

Some feedback was requested from the sector regarding the most appropriate way to refer to museum workers. This is because of the historical tension between the term “museum professional” and what this means in the context of the organisational structure of cultural heritage institutions. While this research project started by referring to “cultural heritage professionals”, with greater insight into the debate around what makes someone a “professional” and where highly skilled volunteers might fit in this descriptor, it was only appropriate to seek feedback from the sector. This involved emailing museum workers and researchers, as well as asking on Twitter for insight. While this is not comparable to “community consultation” on the level of the pre-survey data collection consultation undertaken with AuND adults, it was sufficient when combined with survey testing. The feedback gathered from the high rate of responses to the first survey also ensured that the survey and its questions were acceptable to the sector.

### 3.6 Research Phase 2 – Workshops

In Phase 2 of the research, workshops were created to follow up on the Phase 1 themes and findings. These involved AuND adults and museum workers sharing feedback and further shaping the results from both surveys. The workshops were held at organised events addressed to AuND adults and museum workers, enabling workshop attendees to self-select whether to attend and participate in the session.

When Phase 2 was originally designed, it was intended that the focus groups and interviews would focus on finding out more about subjective experiences and views about museums, accessibility, and autism and would inform the third phase of the research. However, because of the significantly higher survey uptake by both AuND adults (466) and the museum

workforce (130), and the consequentially large amount of qualitative insight into these experiences and views from the open-ended survey questions (complementing the quantitative data), the plan for this shifted. Instead of focusing on “filling in gaps”, the initial plan for carrying out interviews and focus groups during Phase 2 shifted to organising workshops for collectively reflecting with participants on the findings of the surveys and receiving further feedback about a) analysis of the data, b) anything that they felt was missing, c) what might be useful to consider in response to the findings. Rather than being about seeking brand-new data to fill in gaps, the workshops therefore proved to be an opportunity to critically reflect on what was found during the first phase, ensuring that it was reflective of the experiences described and that any gaps in this data were identified and addressed. This section discusses the specific considerations that went into the design of the workshops for AuND participants, as well as for the museum workforce.

When considering the options, an opportunity to present a workshop at the Scottish Museum Federation’s (SMF) conference arose in May 2023. This led to the creation of a one-hour workshop that would both disseminate the findings from the surveys and seek direct feedback and insight from the attendees. The format, while similar to that of the original research-shaping pre-survey focus groups, this time invited attendees to respond to and ask questions about the findings and future steps of the research project. A key difference was that the workshops would be conducted in person (by that time, COVID-19 restrictions had eased), creating more opportunities for live responses and continued conversations following the completion of the official hour-long workshops, whereas the initial focus groups were both conducted online. Unlike the focus groups, it was determined that the workshops would not be recorded. This was to make the workshop space a place where attendees felt safe communicating their thoughts and experiences without fear that their words and experiences might be identifiable. This was important for AuND-identifying people disclosing individual experiences, some of whom might not be open about being neurodivergent, and museum workers who might worry about the impact of speaking about their organisations openly if their words could be traced back. As the purpose of the workshops was to create a space for attendees to provide honest feedback, particularly on whether the findings reflected their individual experiences, it was crucial to create an environment where all attendees felt safe to share freely. Anyone who desired to be identified could choose to sign their name in their written responses. However, the majority did not reveal their names. The first workshop for the museum workforce was used as a template for developing the subsequent AuND workshops, which ran

at the Autscope conference (August 2023), and the final museum worker workshop (held as part of the SMF-commissioned neurodiversity training session in October 2023). [Chapter 6](#) provides more detailed information about each of these workshops and presents their findings in depth.

The workshops were designed to be accessible for attendees with different communication style preferences. Attendees could choose to engage in verbal conversations, respond via the Mentimeter<sup>17</sup> questions or use the printed version of the questions if this were more accessible. If anyone was interested in taking part in this phase of the research but did not feel comfortable taking part in a group discussion or as part of the workshops, they were encouraged to get in contact directly via email or social media (Twitter/X account), to discuss the best way for them to take part. In the end, no one requested a one-on-one opportunity to participate in the research at this stage. Instead, four workshops were held: two with museum workers and two with AuND adults. Of the two AuND workshops, only one was formally included in the research findings,<sup>18</sup> which will be discussed in more detail in [Chapter 6](#).

As with previous stages of the project, access requirements were considered from initial recruitment and reflected on throughout the planning and running of the workshops. Information about what to expect at the workshops was provided in advance for each. More detailed information was made available for AuND-specific workshops, with a short research summary (Appendix [D](#)) produced for anyone who wished to access the key themes and findings, as well as the questions asked at the workshop. This could assist potential attendees or otherwise interested AuND people and inform their decision to take part or be informed about the project. Resources were created digitally and in physical formats on the day. It was important to me, as both an autistic person and researcher, to ensure that the findings of the research were not gatekept or that people who could not attend the workshops for whatever reason could still have access to key information and the opportunity to ask questions or share feedback outside the workshop environment. Contact details were therefore provided and I ensured that I was available and identifiable to anyone who desired to speak at any other time during the events.

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<sup>17</sup> Mentimeter is an interactive presentation tool that enables the presenter to ask the audience questions that they can respond to anonymously during the talk.

<sup>18</sup> The decision was made to have one formal session where participants were invited to consent and participate in the formal record of feedback (via the Mentimeter questions and printed surveys) and one where attendees could learn more about the project and contribute to discussions without the pressure or expectation of their views being used in the thesis.



Once all the workshops were completed, the Mentimeter and written feedback surveys were analysed, and notes made about the discussions in the room were re-visited. The feedback, responses, and follow-up questions were then used to examine the codes and themes identified from both surveys, as well as to examine the priorities for topics to include in the guidance toolkit. The findings from this stage will be incorporated into the planning and execution of the third and final phase of this study, the prototype development, testing, and guidance development phase.

### 3.6 Phase 3 – Sectoral Guidance

The findings from Phases 1 and 2 will be used to create a plan for sectoral guidance to make the cultural heritage sector more accessible. This phase of the project is intended to take place following the submission of the thesis, as the objectives outlined in the thesis were always intended to be a long-term project. I intend to facilitate community consultation with AuND-identifying museum workers to create a resource that will serve as a blueprint for enabling different types of cultural heritage organisations to evaluate their current practice, reflect on ways to make it more accessible and reflective of AuND needs and priorities, and provide some practical examples of ways to make the changes needed. I will utilise remaining research funding from the scholarship to compensate AuND-identifying museum workers' time.

The guidance toolkit will initially focus on the visitor experience. However, it is intended to be developed further to include guidance specifically for making cultural heritage a more accessible workplace for AuND people. The guidance toolkit will be disseminated in numerous ways, including through conferences, such as the MA's annual conference, or project-specific in-person or online events to meet different audiences. As one of the objectives of this research is to make its findings as accessible to as diverse an audience as possible, different channels of communication will be utilised.

While the original methodology was planned to include this stage as part of the PhD work and therefore in the final thesis, the reality was that it would not have been feasible for this work to be undertaken in an effective and meaningful way within the four years of funded research. It was decided that, rather than rushing to complete this work by the deadline of the thesis, it was more important to establish the firm foundation needed to undertake the work required to produce, refine, and disseminate useful sectoral guidance to meet the priorities of the communities it is designed to serve. The chapters that follow present the research stages between October 2020 and June 2024 and analyse the related findings, which will be used to create the guidance toolkit as a post-doctoral project.

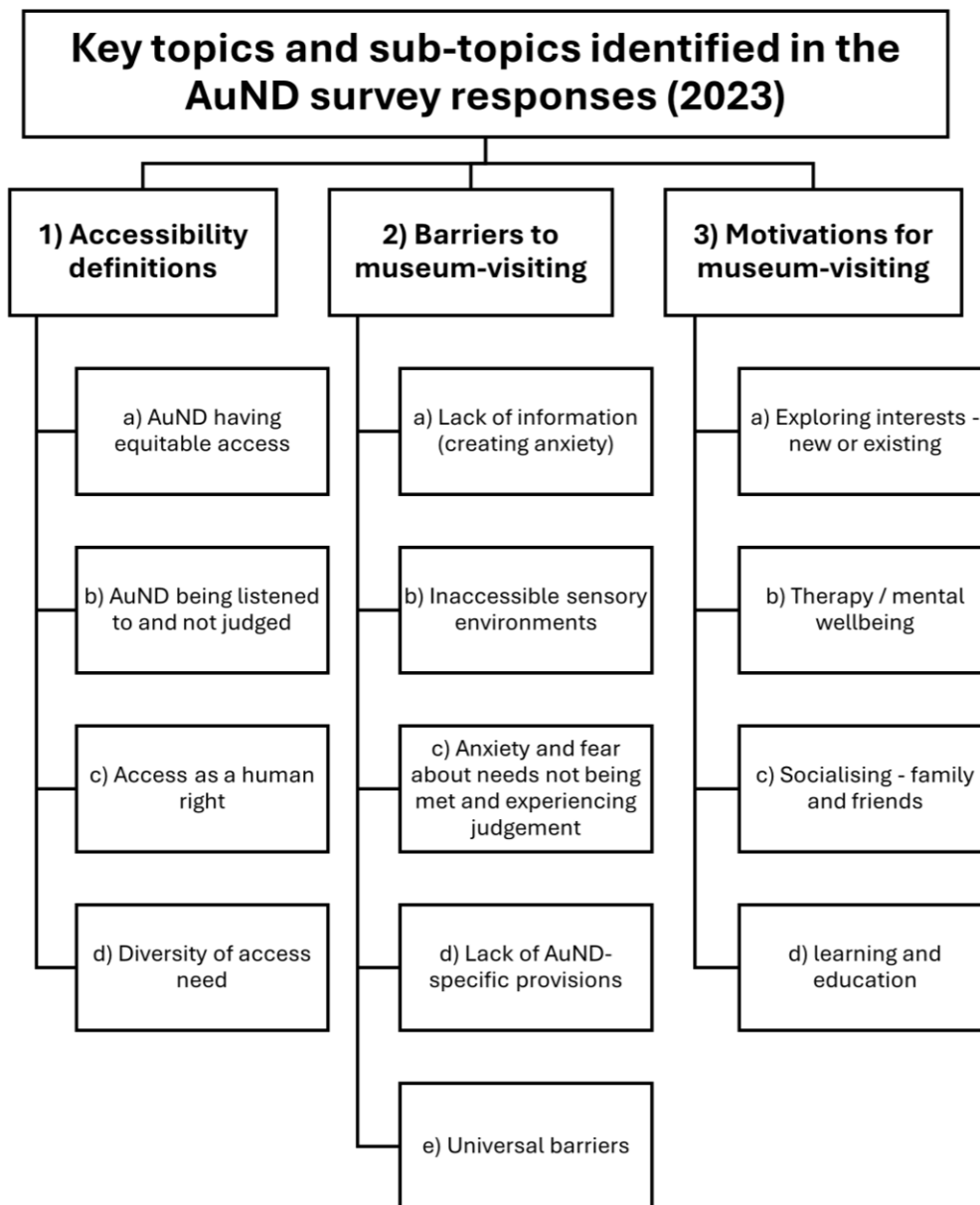
## Chapter 4 AuND Adult Visitors to Museums and Cultural Heritage Spaces: Accessibility, Barriers, and Motivations

*“No one can imagine another’s life well enough to develop services for them without involving them directly in that development.”*

Mark O’Neill 2008, p. 26.

Working with a specific group of people directly rather than assuming based on perceptions of needs is crucial to understanding access needs. As Mark O’Neill (2008) highlights, there is a growing recognition within the museum sector that to meet the needs of their audiences there must be direct consultation and involvement to address inaccessibility. This is especially important when engaging with groups who have been historically under-served or excluded from these spaces.

In this chapter, I examine the key themes (see thematic map of qualitative findings below) that emerged from the analysis of the data from the survey for AuND adults. Through Reflexive Thematic Analysis of the AuND survey responses (survey questions detailed in Appendix [C.1](#)), I identified the topics shown below, which I then quantified using Content Analysis techniques. The process of quantifying the codes identified assisted in confirming the topics identified during the initial analysis process. This methodological approach ensured that the topics accurately identified the most common responses among AuND adults. The topics that emerged from the thematic and content analysis naturally aligned with the original research questions, which was unsurprising given that the survey was developed based on input from the AuND focus groups. This alignment allowed me to organise the findings under topic categories that directly correspond to the research objectives.



*Figure 4-1 Topic map of AuND survey findings.*

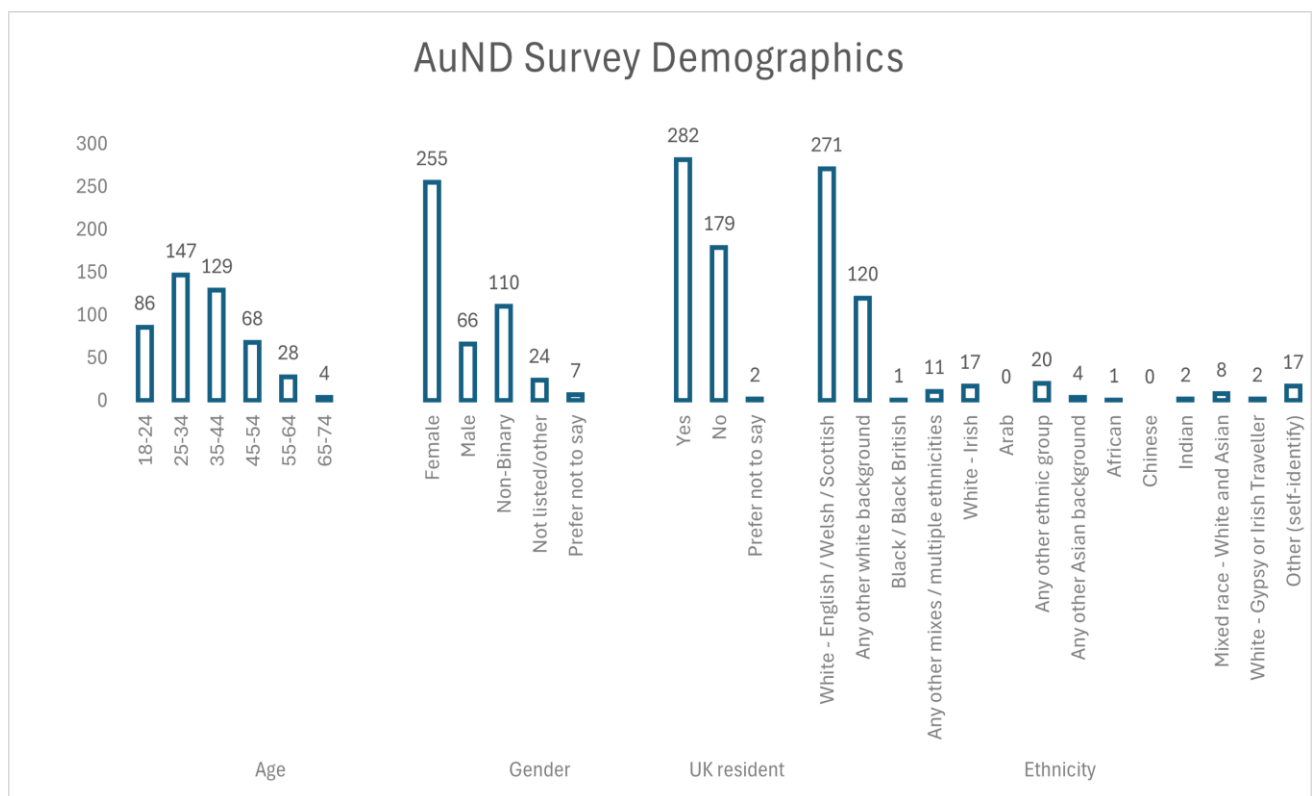
This chapter is broken up into three sections: the first explores the quantitative data collected, specifically the current and potential visiting patterns, while the second section presents an analysis of the qualitative data from the survey as gathered from the open-ended questions and “other” responses collected during the analysis process. Finally, the third section presents a discussion of the key themes and findings.

## 4.1 Quantitative Data

This section of the chapter focuses on the quantitative findings from the AuND survey, presenting the findings and an interpretation of potential meaning that can be drawn from the responses.

### 4.1.1 Demographics

Demographic data was collected to capture the diverse perspectives among survey respondents. The distribution of respondent demographic characteristics is shown in the following chart:



*Figure 4-2 Demographic characteristics of AuND survey respondents.*

This demographic data reveals a fairly broad age distribution, ranging from 18 to 73 years. The majority of the sample consisted of female respondents, followed by those identifying as non-binary. The predominance of UK-based participants reflects the survey's primary distribution through UK-focused social media groups. While respondents predominantly came from English-speaking countries (UK, Australia, and US), the sample also included participants from Europe, Africa, and South America. This geographic distribution suggests that the findings may be most applicable to English-speaking countries and Europe,

where the majority of the respondents reside. Further research would be valuable to explore these themes in other geographical contexts.

Beyond standard demographic questions, the survey explored respondents' preferred neurodiversity terminology for self-identification. This was an initial open-text entry which allowed respondents to write their preferred terminology, which was then automatically incorporated throughout subsequent questions. Responses to the self-identification question (n=461) ranged from single terms to multiple descriptors (such as "Autistic and Neurodivergent"). "Autistic" was the most common identifier (327), followed by "neurodivergent" (150) and "ADHD" (47). Less frequent responses included: "person with autism" (14), "person with ADHD" (9), ADHDeR (6), "Aspergers" (6), "dyslexia / dyslexic"(5), "On the spectrum" (5), "multiply neurodivergent" (4), "neurospicy" (4), and "neurodiverse" (2). The total count exceeds the number of respondents because many participants used multiple terms for self-identification, though single-word responses predominantly favoured "autistic" or "neurodivergent". These language preferences align with the AuND research discussed in the Terminology section of [Chapter 1](#), and validate the use of "AuND" throughout this project.

#### 4.1.2 Current Visiting Patterns

To understand the potential for museums to become more accessible to AuND adults, it was important to start by understanding the current patterns in visiting for this audience. The closure of museums during the COVID-19 pandemic impacted visiting experiences for all potential visitors, specifically around breaking visiting habits, changing existing ones, or leading to museums and cultural heritage institutions making changes that impact the visiting experience. This survey was intended to examine pre-COVID-19 visits and provide an indication of the impact that restrictions have had on returning visitors.

As a prerequisite for taking part, and to consider the impact of COVID-19 on museum visits for AuND visitors, respondents were required to confirm whether they had visited these settings within the last five years (from 2022 – i.e. approximately from 2017). If the answer were "yes" or "unsure", they would be able to continue with the survey, while a "no" answer would result in the survey ending. The large majority, as illustrated in the graph below, had visited a museum, gallery, or other cultural heritage setting within the last five years:

Q21 - Have you visited a museum, gallery or other cultural heritage site in the last 5 years?

463 Responses

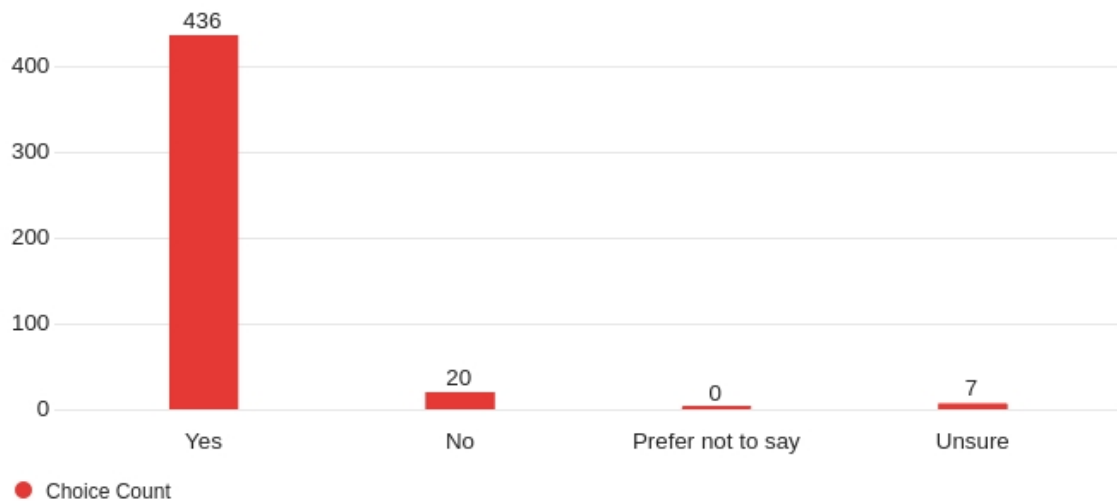
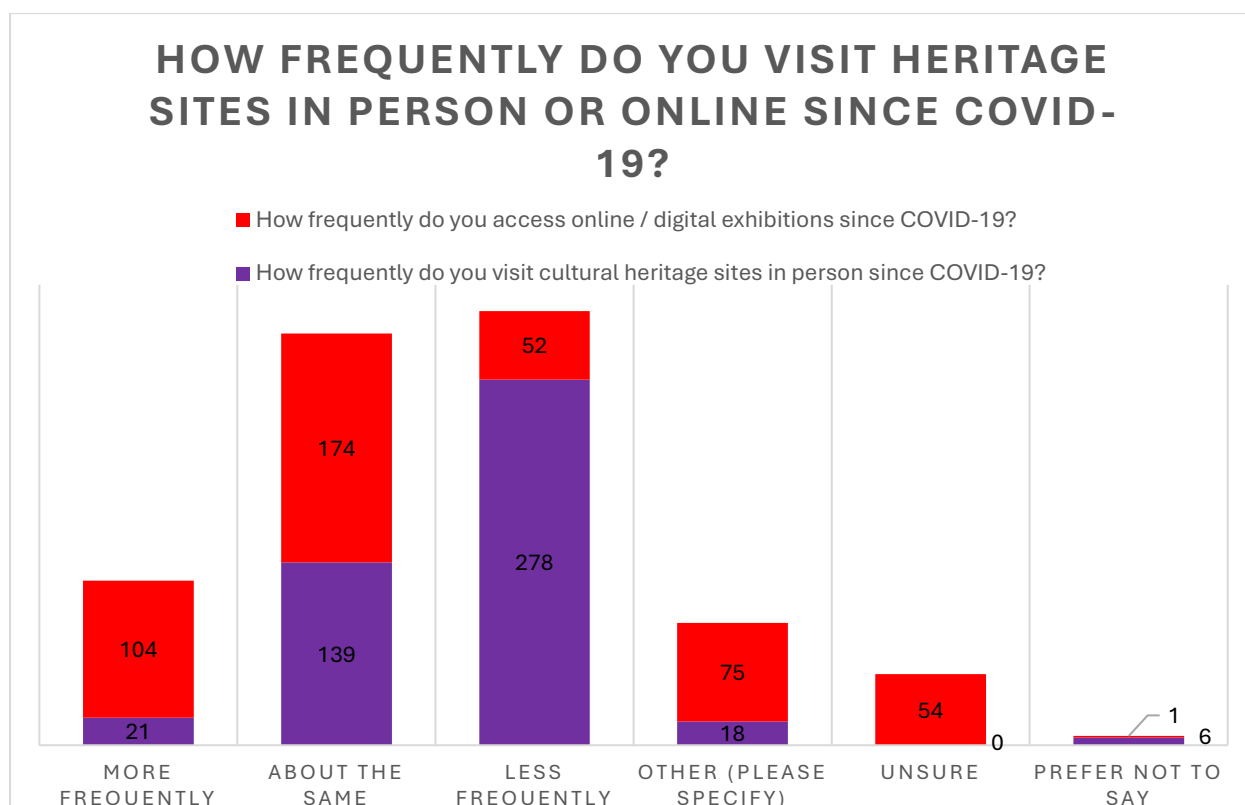


Figure 4-3 Bar chart of the frequency of museum visits in the last five years (2017–2022).

With this information, it was possible to deduce that the results from this question were derived from lived experiences of visiting. The survey asked about general visiting experiences before, during, and after the COVID-19 restrictions (c .2020–2022).

#### 4.1.3 Impact of COVID-19

As the project took place during the COVID-19 pandemic, it was important to identify the potential impact of these restrictions on museum-visiting when compared to their experiences before 2020. The graph below shows the self-reported impact of COVID-19 restrictions on visiting:



*Figure 4-4 Graph of the frequency of in-person visits to cultural heritage sites.*

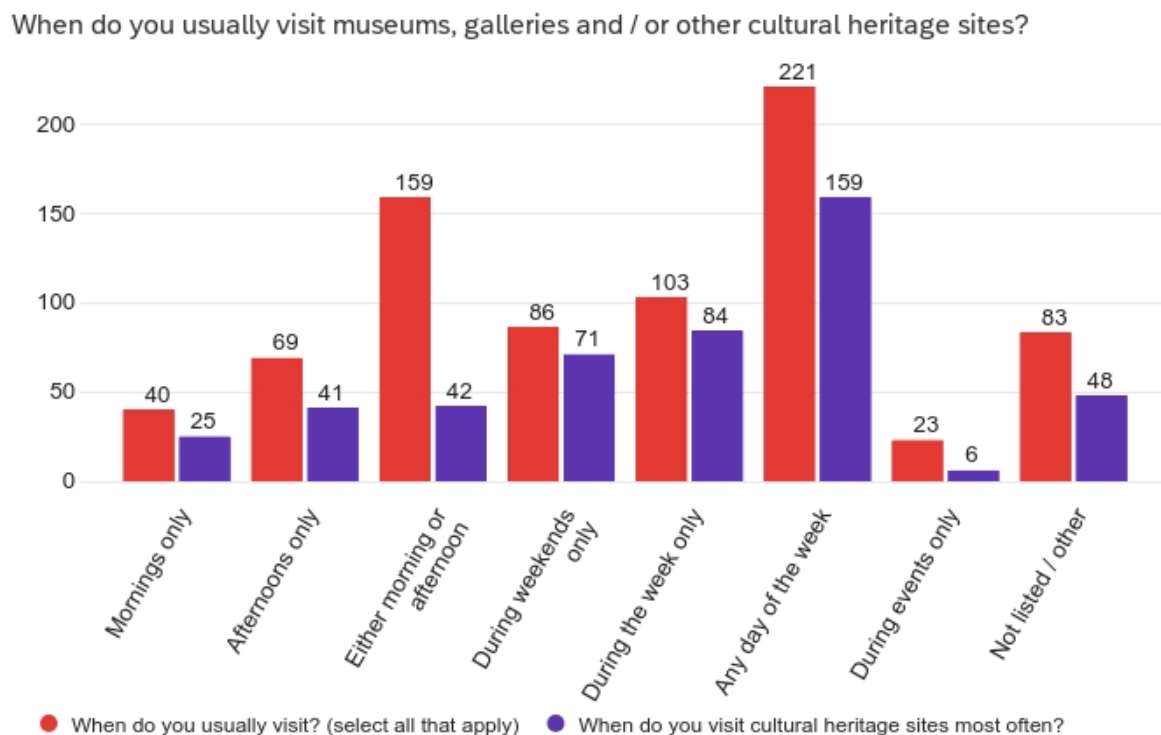
According to the graph, many respondents identified that they physically visited “less frequently” than before COVID-19, with the second option being “about the same”. When this is compared to the “current” visiting patterns, the “same” number of visits were not necessarily frequent. Some individuals responded that they attended more frequently, which was attributed to social distancing, set routes to attend, and required booking to keep numbers down appealing to some respondents. Meanwhile, the higher rate of “more frequently” for digital exhibitions reflected the shift that many cultural heritage institutions made to maintain engagement with their collections by creating – or more widely publicising – online ways to connect to collections. However, as noted in the “other” response, many of the respondents were unaware of online exhibitions in the first place.

#### 4.1.4 Days and Times of Visit

Most autism-friendly events currently organised by cultural heritage organisations tend to be run in the mornings, but I wanted to find out whether this reflected the visiting preferences of AuND adults. In the table below, which asked for the most common time of the day and period in the week for visiting, diverse preferences are apparent. The two highest responses were “any day of the week” and “either morning or afternoon”. Whilst respondents may have interpreted



“either morning or afternoon” differently, selecting this option suggests flexibility rather than a fixed preference for a specific time of day. Notably, one of the lowest responses was “mornings only”, which suggests that only holding events for AuND people in the morning may not be the best option. Eight respondents suggested evening visits in their “other” responses, the most frequent addition to the multiple-choice options. Other responses suggested that respondents “try to visit least busy times”, and some indicated that they use tools such as Google to check whether the museum is busy. Eighteen respondents indicated in their open-text responses stated that they prefer “less busy” times, with three people noting they specifically research visitor patterns before planning their visits. This suggests that environmental factors, particularly crowd levels, are more influential in timing decisions than specific hours of operation.



*Figure 4-5 Comparative bar chart for questions: “When do you usually visit museums, galleries and/or other cultural heritage sites?” and “When do you visit cultural heritage sites most often?”*

In the open-ended responses, some clarification was shared to explain why certain times or days worked better. The most common response links to sensory and anxiety barriers, with respondents expressing that they would choose to go during a time with “no crowds” and some specifically avoiding “school holidays” because of the higher number of people visiting –

barriers that will be discussed in the “barrier” section later in this chapter. Others stated that they would only go during days when their sensory needs were met. This was usually within relaxed opening hours. In addition, some stated that they would like to visit during relaxed or autism-friendly hours, but that mornings are not always the best time, especially if they are working, in education, or have childcare obligations. This suggests that, while many AuND individuals would be willing to visit at “any time”, they would not be able to visit if the museum environment does not meet their needs. Therefore, to improve accessibility for AuND audiences, museums should offer events across diverse time slots to better understand and accommodate their local community’ preferences. Museums should also apply insights from quieter visiting periods to enhance accessibility for AuND visitors throughout all opening hours.

#### 4.1.5 Who Do AuND People Visit With?

AuND respondents were asked to select “all that apply” when considering who they visit cultural heritage sites with. The table below shows that AuND adults most frequently visited “with family”, while solo visits (287 respondents) occurred only slightly more often than visits “with friends”, a difference of just nine responses. This shows that the majority of AuND people visit museums with other people.

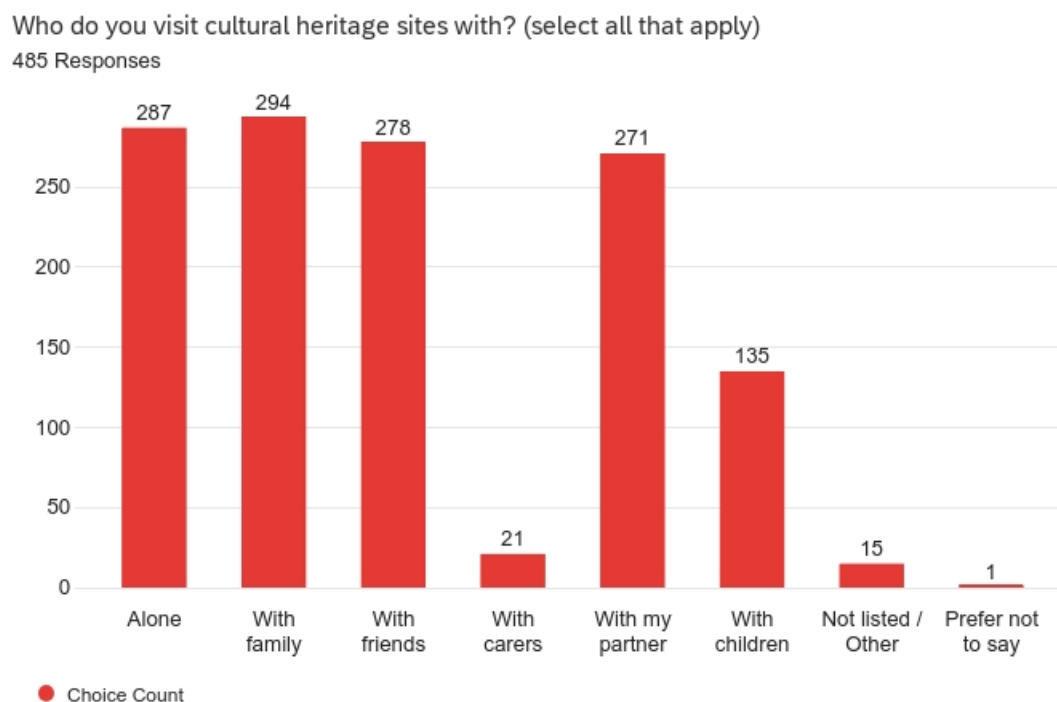


Figure 4-6 Bar chart for the question: “Who do you visit cultural heritage sites with?”

Most respondents chose options that involved socialising with others – such as family, friends, or a partner. As not having anyone to visit with was a potential barrier, one reason for visiting museums and other cultural heritage settings may be related to social connection or socialising.

#### 4.1.6 Potential Visiting Patterns

The graph below shows the findings from the two questions that reflect the current and potential visitor patterns. On the left is the bar graph for the question “How often do you currently visit?” and on the right is the graph for the question, “On average, how often would you want to visit if museums and cultural heritage sites were more accessible to you?” The same colour codes for the bars were used to compare the data. For the current visiting patterns, the clear leading response was “once every couple of months”, with over 150 of the respondents selecting this option. This was followed by “once every six months” and “less often than once a year”, respectively. This was reflected in the qualitative data, which indicated that many of the respondents either did not visit frequently enough to have a current visiting pattern or had limited access to visiting because of a variety of obstacles.

Q22 - How often do you normally visit museums, galleries and/or other cultural heritage sites in a year on average versus how often you would want to if museums were more accessible?  
487 Responses

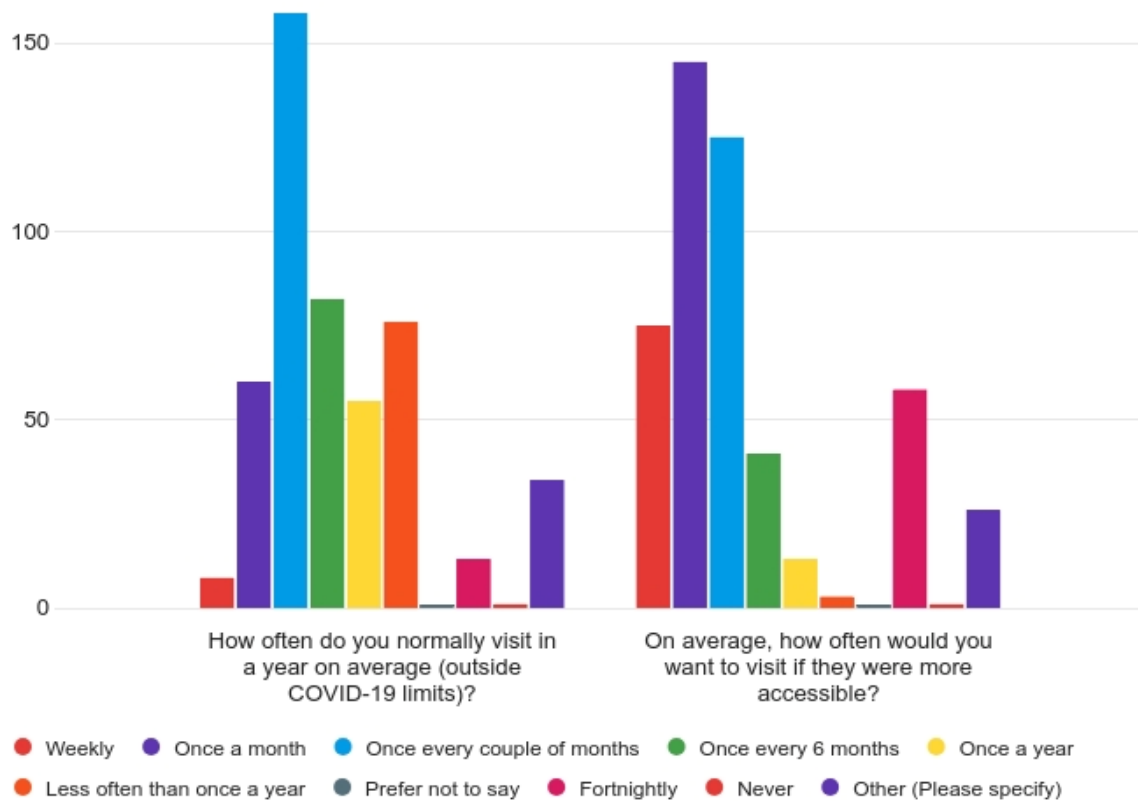


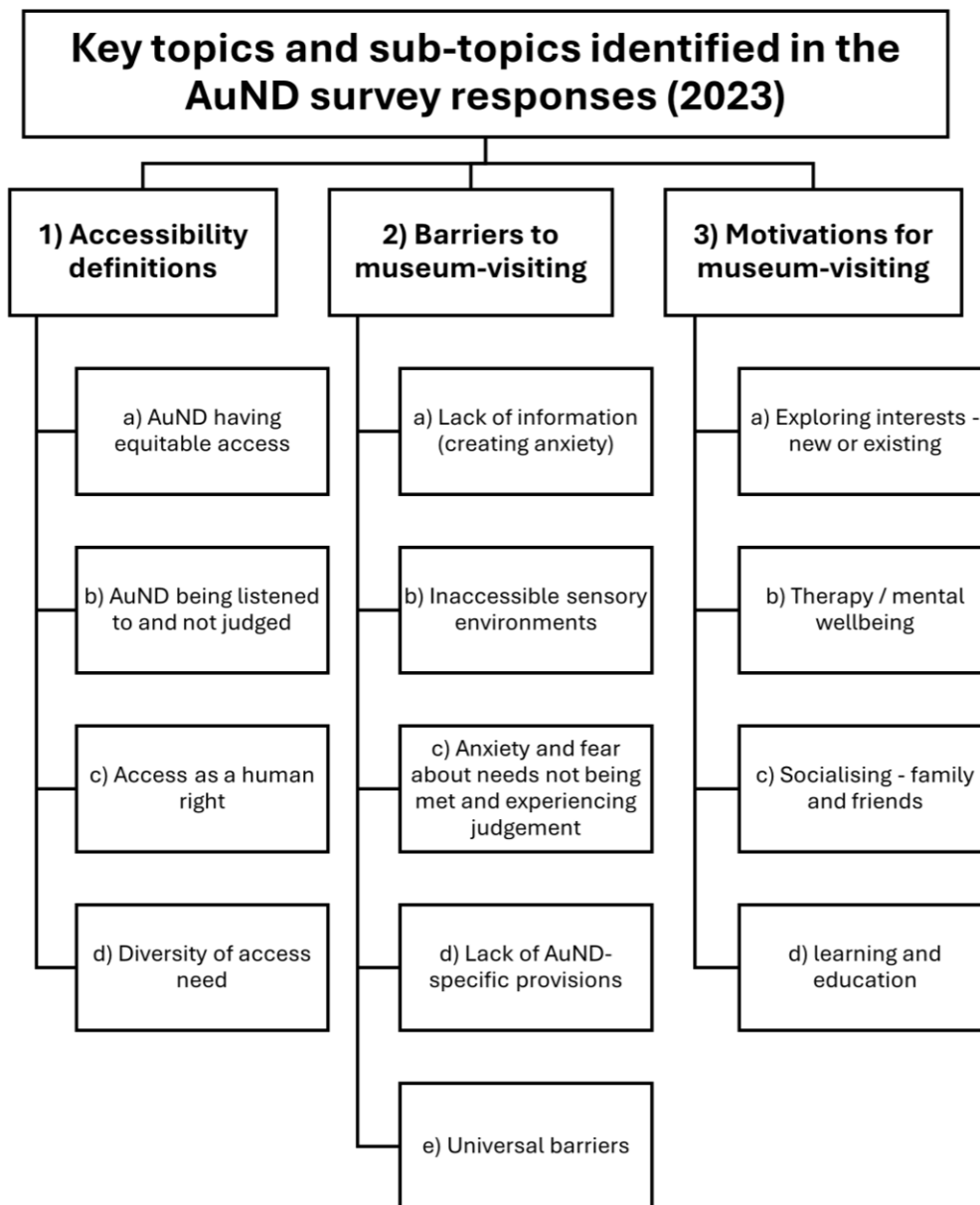
Figure 4-7 Comparative bar chart measuring current visiting pattern with how often respondents would “want to” visit if it were more accessible.

What is most remarkable about the graph on the right is how much more frequently the AuND respondents who completed the survey would want to go. The highest response was “once a month”, followed by “once every couple of months” and “weekly”. With the more scattered current visiting pattern, but typically towards the less frequent end of the scale, the response to the question on how often the respondents would want to go to museums is more concentrated at the end where visiting would be as frequent as “once a month” or more often, showing potential. This reveals, alongside the unusually high response rate to the survey, how many AuND adults are interested in museum visits or motivated to contribute to improving the experience for others within the neurodivergent community.

## 4.2 Qualitative Data

The qualitative data collected has been analysed using a reflexive thematic analysis approach, as indicated in the methodology chapter. This process involved an in-depth familiarisation with the data, coding (digitally and by hand: see Appendix [C](#)) the data based on common phrases and sentiments identified by an autistic researcher, breaking these codes down into larger topic and sub-topic categories based on the research questions the data referred to, then sub-categorising topics that fall within the wider research question-based themes (Braun & Clarke, 2023; Ibid, 2021). Once the key themes and sub-themes were identified, I worked to identify relevant quotes and provide an analysis that used research and lived experience to inform the findings in this chapter.

The qualitative survey responses were analysed using the Thematic Analysis approach outlined at the start of Chapter 4 to identify recurring patterns in the first instance, followed by Content Analysis to ensure that the key topics identified from the data reflect the most recurring topics from the respondents. All quotations from respondents in this, and further Findings chapters, are italicised to ensure they are identifiable. Below (figure 4.8) is the topic map introduced at the beginning of this chapter. The qualitative data will be explored using the topics discussed below:



*Figure 4-8 Topic Map of qualitative data from AuND surveys.*

#### 4.2.1 What is Accessibility?

The first open-ended question of the survey was about respondents’ understanding of accessibility. This question was asked to provide insight into what the respondent perceives accessibility – and, equally, inaccessibility – to be, from their perspective as neurodivergent individuals. It became clear while reading the responses that there was a wide range of interpretations for this question – while the majority reflected on what accessibility means to them in their everyday lives as AuND people, others considered a more general definition or reflected on difficulty in relating their own experiences to form a definition. The diagram below provides an insight into the most common topics in the responses to the question.

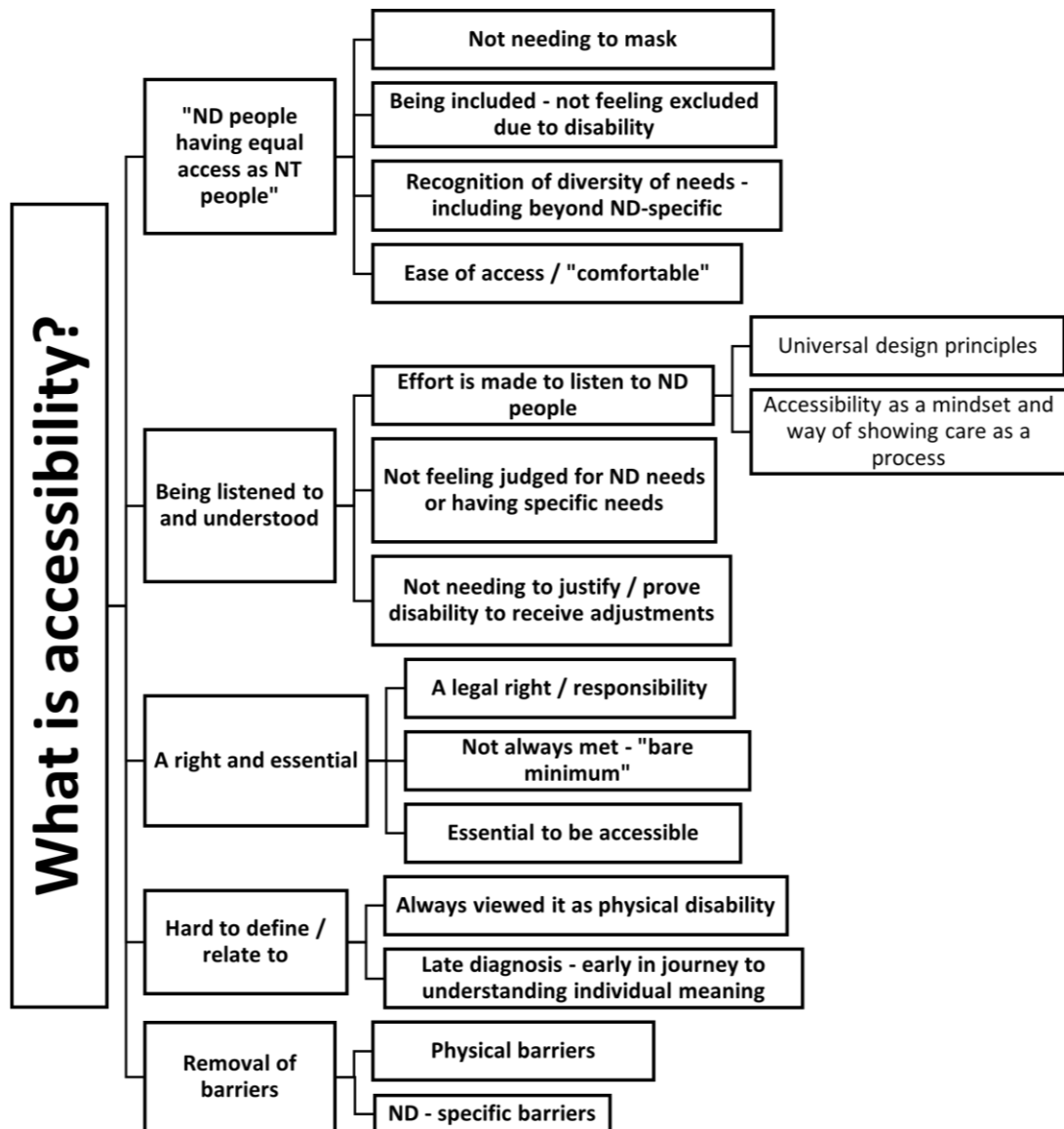


Figure 4-9 Detailed summary of “What is Accessibility?” topics and sub-topics.

### 4.2.2 Universal Definition

Some of the respondents offered more general definitions of what accessibility is or should be, not specific to their neurodivergence but to disabled people more broadly:

*“The world is not tailored to just abled people – it includes avenues for people of all abilities to participate and do things equally.”*

It was evident that experiences were the “*same*” or a “*similar level*” regardless of ability level. This notion of “*equal opportunity*” to participate or exist in a space “*regardless of their circumstances*” was a clear concept when describing what “accessibility” should be.

Other respondents related their definitions to more formal recognised definitions or signs of accessibility:

*“Under the social model of disability, accessibility happens when attention is paid to the removal of barriers to access services and buildings.”*

This approach to viewing accessibility was shared by others, who reflected on the ability to access a public space, service, or facility with “*little*” or “*no limitations*” compared to non-disabled individuals. Where those barriers may exist, there is a focus on how the provider can “*accommodate*”, be it ensuring step-free access to spaces or removing barriers that may be “*physical, environmental, or cognitive*” to create a “*level playing field*” for all who access the space or activity.

Fifteen respondents focused on the practical removal of barriers to create an accessible environment. They referred to these as both “physical” barriers and neurodivergent-specific barriers:

*“Removing barriers to engagement with something that most people do not have, and that sometimes do not even realise exists for others.”*

These respondents emphasised the importance of being able to access a space, service, or product without “barriers” that hinder them from using them. One noted that barriers not experienced by others are often overlooked, not because they are absent, but because they are less noticeable if they do not directly impact a person’s life. Some focused on general barriers, such as physical access-related issues around step-free access, while others focused on neurodivergent-specific barriers, including sensory issues, which will be discussed more in the



“Barriers” section. All these responses made clear the importance of removing barriers, whether visible or not, to enable more individuals to access the same opportunities as those who do not experience the same barriers.

Nevertheless, some respondents acknowledged that “accessibility” is about enhancing ease of access to a space, but that these approaches should not necessarily be about making something accessible to one person or group specifically (e.g. “*special adjustments*” but should be aimed at enhancing and establishing a general “standard” that is as accessible as possible for all individuals who access it.

While these definitions may be broad and applicable beyond the experience of AuND people, one respondent made clear that accessibility – and the act of being accessible – “*can be the difference between me being able to do something and not being able to do it*”, highlighting the importance of places such as museums enhancing their accessibility.

#### 4.2.3 “ND People Having Equal Access to NT People”

According to the 466 survey responses, the most common response to the question on “Accessibility” was to highlight that it should mean equal or equitable access to spaces for AuND people. Approximately 15% of respondents referred to society and the “world” being built for neurotypical people and not meeting neurodivergent needs:

*“As a neurodivergent, I have become so used to trying to navigate a neurotypical world that I do not know where to begin when thinking about what could make spaces more accessible to me.”*

*“Accessible places mean that I can go there for their intended purpose and have the opportunity to have the level of experience neurotypicals have in that place. An accessible place is one where I can feel safe regardless of autistic traits. An accessible place is one where I can unmask safely.”*

This emphasis on “equal” or “equitable” access to the “*same opportunities as anyone else*” was prevalent. For some, this meant reducing “undue barriers”, such as “flickering lights” that impact a space. For others, it was about being able to access a space that “*minimises my awareness of my diagnosis*” in settings shared with non-autistic or neurotypical people. One respondent stated that their ability to “*take part and enjoy things*” is connected to their autistic brain being “*taken into consideration*” so that their – and other autistic people’s – needs are

met. When this does not happen, some people feel “*disadvantaged*” as they often “*struggle in situations which for many are effortless*”. Indeed, the ability to access a space “*as easily as neurotypicals would*” was a common sentiment throughout the survey responses.

For some respondents, accessibility was measured by the ability to exist in a space without using extra energy:

*“It means making my life more bearable. The world is set up in a way that makes sometimes everyday things feel like I’ve climbed a mountain. Accessibility is relieving me and others of some of the social and physical stresses so that we can cope with an environment built against us.”*

*“Access should require no more investment in energy or effort than it is for anyone else in the community. Safety, autonomy, and dignity should be paramount considerations.”*

At least five respondents specifically focused on the importance of being able to “*enjoy*” the same things as neurotypical audiences without experiencing “*exhaustion*” because of the additional energy required to manage different social and sensory environments. This idea of equal energy expenditure comes from many AuND individuals needing to consider the impact of social interactions, new or large spaces, and the uncertainty that these experiences can bring, when making plans. Many neurodivergent people use more energy, or “*spoons*”, to visit a museum than a neurotypical person who is comfortable with being in these environments and does not need to mask, which can be a barrier to participation (Hansen, 2022; Pearson & Rees, 2021). This was evident in the responses, in which individuals stated that their ability to visit would depend on the number of “*spoons*” they had that day.

One of the most common ways that energy is used is in “*masking*”. Respondents highlighted the impact of the expectation to adapt to meet the expectations of others, “*masking*” their ability to take part or even their willingness to attend. An accessible space is, therefore, one where they do not feel as though they need, or are socially expected to, mask to be welcomed into a place:

*“Spaces where I do not feel pressure to act neurotypical; where alternative, or little communication, is accepted and I am not made out to be a burden, something to be ashamed of. Where you can wear*

*earplugs/sunglasses without being profiled (e.g. shoplifter) or made to feel awkward. Places where you can stim (hand flapping etc.) without being 'told off' or looked down upon."*

*"Not needing to 'perform' neurotypicality."*

Social and societal pressure to fit the “norm” and “perform” a way of being that is more widely accepted in society over being authentically neurodivergent was as much a means of defining what an accessible space could be as identifying a barrier. The focus on actions or accommodations that neurodivergent people often use in their day-to-day lives, such as “wearing sunglasses or earplugs” to be able to manage in challenging sensory environments, are often “othered” – as another respondent described it - or profiled as bad (or potentially indicating they are undertaking criminal activities such as “shoplifting”) show that many neurodivergent-specific behaviours can be demonised, forcing masking to exist in public spaces. Respondents often felt “forced” or “expected” to mask, so removing this expectation and ensuring that an environment without judgement of authentic neurodivergent behaviour would indicate accessibility and a “safe” environment.

Accessibility is also about feeling “welcome” and “included” in a space. Many respondents reflected on this, either by highlighting positive expectations for a space, or by highlighting experiences of feeling “excluded”, “unwelcome” or as though their presence or needs are a “burden” within the space:

*"It means social inclusion. Correct accessibility measures enable autistic people like myself equitable access to services that neurotypical people can use. Without facing a range of barriers."*

One respondent highlighted that acceptance of needs, rather than treating them as a “burden”, and willingness to accommodate diverse needs, can “also benefit wider society” because adjustments that benefit one group can benefit all – “ramps and elevators do not just benefit those in wheelchairs.” Three respondents emphasised the importance of not feeling like a “burden” or any form of shame for having specific needs or asking for assistance. In these instances, one respondent highlighted that “even an accessible space” can make you feel “unwelcome” if it does not consider a diverse range of needs in its accommodations.

Other frequently used words when defining accessibility related to feeling “comfortable” and “safe” rather than “uncomfortable” and in “pain”.

*“It means the freedom to have experiences in public space without accepting to pay for it with stress and pain or feelings of exclusion.”*

*“Something that is accessible to a neurodivergent person and makes them feel comfortable, able to participate, takes into account different needs and requirements.”*

The word “comfortable” was often used to demonstrate the impact of an accessible environment – as a facilitator for comfort – and as a marker of a welcoming and safe setting. A welcoming, comfortable space is one where neurodivergent people can “attend [and] experience with no or limited suffering”. Many of the respondents used words such as “suffering”, “distress”, “stress”, “confusion”, “pain”, and “hostile”, emphasising the need for museums (and public spaces generally) to create a “welcoming and non-threatening environment”. Many of the barriers experienced in a space can contribute to those feelings of pain and a sense of exclusion – as a lack of accommodations to make a space inclusive by design excludes people – and can impact the likelihood of the respondent spending time in a space.

Accessibility was recognised as a right, which one respondent described as “vital for a space to be considered inclusive”, while another described it as “vital and essential” to have reasonable adjustments met:

*“For me, accessibility is the right and the power to be in a place, [use an] object and use something without depending on anyone and without difficulties.”*

When those requirements are met, it can give an individual a “sense of power” in a situation that they may otherwise not have or feel if the space is not accessible. Accessibility is a right that many neurodivergent respondents felt was denied.

It is clear from the range of responses that this can mean an emphasis on physical disability, and measures to address neurodivergent needs are treated as “nice to haves” but are not currently legally required adjustments:

*“Accessibility means making reasonable adjustments that help me navigate the world more easily just as there is wheelchair accessibility (which took a lot of protesting for). I would like to be in a place where it isn’t viewed as unreasonable and is required by law.”*

*“Accessibility to me means that my access requirements are treated as “requirements” not “nice to haves” or “special help”. My requirements are as a result of an inaccessible environment/world/society – not as a result of me as an individual. Accessibility means nobody makes me feel bad or like a burden for asking for those requirements and in a perfect world I do not have to ask at all. Accessibility includes the built environment, the digital environment, and human communication.”*

The respondents showed an awareness that, while there is legislation that calls for physical adjustments to buildings to allow access, this typically does not include any guidance or legal requirement for environmental factors (such as the sensory scape of the space) to meet a specific standard. As one of the respondents acknowledged above, it has taken decades of protests by disabled people to obtain existing legal requirements, which is sometimes seen as the “bare minimum”, but this is not enough to achieve accessibility for every disabled person.

Finally, many respondents highlighted the importance of recognising the diversity of different people’s access requirements needing to be met to create an accessible space – both for neurodivergent people and other audiences who require accommodations for access:

*“Of equal access to all, regardless of marginalised/minority/less privileged state. Accessibility means that everyone, disabled or abled, neurodivergent or neurotypical, of all skin colours, sexualities, gender identities, social/economic class, etc., can equally access the place/situation being considered.”*

For respondents who focused on the intersection of accessibility and diversity, the priority was to achieve “social inclusion”, whether a person has visible or invisible disabilities, or other traditionally marginalised identities. According to one respondent, accessibility for her son “would be different as he’s ASD and my dad because he’s in a wheelchair”, demonstrating the importance of recognising diversity in individual definitions and needs. Some respondents shared their experiences to illustrate that differing access needs can exist within the same individual:

*“I have IBS and anxiety makes it worse, thus travelling can be a nightmare for me. ‘Access’ for me primarily means a smooth, predictable, and uninterrupted journey where bathrooms are readily*

*available, either en route or at my destination. I do not like proximity to people, so I am more comfortable with space around me. For instance, I would find a noisy and crowded café overbearing.”*

One of the strategies identified to manage these diverse needs was to plan for them from the conception of provision development or project planning. Some respondents either referred to “*universal design*”, measuring accessibility on whether “*universal design principles*” were successfully applied or described an approach that uses the principles to ensure that diverse needs are met. For example, the respondents emphasised the importance of “*choice*” and “*options*” to meet their specific access needs.

#### 4.2.4 Acceptance and Understanding

To create an accessible space for a wide range of different access needs, many respondents focused on acceptance, understanding, and efforts required to achieve this outcome:

*“Being accepted and having my needs met and understood and being respected by others.”*

*“Accessibility means that my strengths and weaknesses, and specific needs, will be understood.”*

The focus on needs being “*respected*” and “*understood*” was observed in several (approximately 20) of the responses as an important aspect of how they should be made to feel in a space. An example of this happening in practice commonly identified was an “*acceptance by staff*” of respondents’ “*communication*” and “*needs*” without expectations being placed on the respondent to change. Part of this “*respect*” and “*acceptance*” was about not making them feel like a “*burden*” when communicating their needs. Indeed, one respondent expressed the importance of feeling like their needs are listened to and actioned, not being told “*‘well, tough’ and ignore you*” and then left without support.

Many of the responses in this topic referred to “*effort*”, usually referring to staff or other individuals but also to other AuND individuals. The most explicit use of “*effort*” was by two respondents on the expectations of neurodivergent people, with one highlighting that there should be “*no more investment in energy or effort*” than for others, while another highlighted the importance of being mindful of the “*struggles*” that neurodivergent people can face, “*which for many are effortless*”. Many individuals identified a need for others to make the effort to “*listen*” to AuND people to better understand their needs and thus spread some of that “*effort*”

beyond themselves. Many respondents took the time to express what that effort would look like. This was often sensory-related (*“lights that are not harsh... in short, being able to be without a near meltdown”*), while others highlighted that staff would have *“a good awareness of possible communication and sensory differences and making reasonable adjustments, where possible, to meet those needs”*. Efforts being seen as *“adjustments”* or *“accommodations”* highlighted the importance of having needs directly addressed by implementing changes to help mitigate barriers and *“meet everyone’s needs”*. Knowing that neurodivergent needs have been *“considered in its design/implementation”* could reassure potential visitors that their needs will be met.

Another sub-topic was being actively involved and considered, with the provision of adjustments and options as a priority. Many respondents emphasised the importance of *“choice”* when developing accessibility, in recognition of the diversity of the needs that AuND people have. Seven respondents highlighted the importance of having *“options”* that they can choose from based on specific needs. Some specified that space *“is designed with multiple options for how to use it so that as many people as possible can do so”* and that these options should be in place to help *“anyone to be able to easily experience the same things in life.”*

Not feeling judged for being neurodivergent or having specific access needs was a crucial factor:

*“It means that I can physically, emotionally, and intellectually access buildings, information and activities or experiences without feeling discriminated against or made to feel unwelcome.”*

*“Space to enjoy myself and go at my own pace without judgement or getting overwhelmed.”*

To be able to exist in a space without feeling that neurodivergence was *“discriminated against”* or that their way of experiencing a space was being met with judgement was important. As with masking, there was a request that others do not *“berate”* neurodivergent people or *“make a big deal of how we are behaving”* when compared to other people in the space because it negatively impacts that sense of *“welcome”* and consequential ability to enjoy being present.

For some respondents, this judgement extended to include not being expected to *“justify”* or *“prove”* specific needs to access specific adjustments or resources:

*“Nothing physical but rather enough time, no crowds, quiet surroundings, possibility to ask questions, acceptance by staff even if they do not see my struggle, no need to justify myself all the time.”*

*“It means ability, comfort, understanding, and not having your personal life held against you as something bad.”*

Not being expected to justify needs or needing to “*jump through extra hoops*” to access adjustments was a clear priority. In addition, some respondents wanted to feel as though their needs had been “*considered without me having to request adjustments*” directly or being expected to provide “*lengthy reasoning and explanations*” for their needs to be met. When they do need to communicate specific needs, it was emphasised by one respondent that they did not want to be “*talked down to*” for expressing what they require. Needs should be “*taken seriously*” without requiring “*specific disclosure*” to be able to access adjustments.

Some felt that accessibility, and the act of becoming accessible, often comes down to mindset and attitude towards undertaking meaningful improvements. This can be understood as a “*long-term process*” where a space, service, or product provider goes beyond the minimum and actively embodies different qualities and aims:

*“It is collective care, belonging, welcome, acceptance, intimacy, relationships, and connection.”*

*“Accessibility is much more than offering a tone or an idiom, it is about [the] environment.”*

These intentional actions, based on value and care, as hoped for by respondents, illustrate a desire that those who undertake accessibility enhancements do so not only with good intentions or to meet a basic standard but to create accessibility driven by genuine compassion.

All these factors come down to respect and willingness to provide options that go beyond a “*one-size-fits-all*” model. They demonstrate commitment and genuine intention to improve AuND provision for those who often expressed that their needs were not considered:

*“Accessibility can be the difference between me being able to do something and not being able to do it. Some of the responsibility for making something accessible to me is mine (such as assessing a new*



*situation, familiarising myself with how to get there, taking someone with me if it's something I'll need support with, making sure I have enough low-demand time before and after etc.), but a significant amount falls to public, private, and third sector companies and organisations. These bodies must look at their provision from multiple perspectives (directly engaging with stakeholders) to maximise how accessible they are."*

*"Means making sure I can access space or activity fully and am treated with respect and as an equal while doing so."*

It demonstrates that AuND people recognise the importance of mutual effort, but there must be an assurance that meaningful energy and willingness to accommodate diverse needs are taken to create an inclusive and accessible experience.

#### 4.2.5 Hard to Define or Relate to

While most respondents identified factors that make a space accessible to them, or a definition that reflects their needs, it was apparent that some respondents found defining "accessibility" from a personal perspective challenging.

The most common responses came from respondents who had received a late diagnosis for their neurodivergence:

*"As someone only recently confirmed as neurodivergent, I still view accessibility in relation to \*myself\* to physical and sensory disabilities."*

*"To be honest, I'm not even sure because I was only diagnosed two years ago, and I feel like my whole life I've run in circles around everyone I know just trying to do basic things. The world was not supportive of my struggles or accessible. The result has been a life of utter hardship including homes, chronic illness, and poverty."*

One respondent, who was only diagnosed during the pandemic, identified that they are "still learning what accessibility means" to them personally because it is a new lens through which to understand themselves. They acknowledged it as a process of self-learning post-diagnosis, and they are beginning to recognise some ways that adjustments could be made. This

has meant that some neurodivergent people not only missed potential support but often did not recognise their need or right to access accommodations to make their lives more accessible.

Some late-diagnosed respondents explained that they had “*typically worn ableist blinkers*” and only understood accessibility to relate specifically to physical disabilities:

*“I do not really think about it, probably because it’s a word associated more with physical disabilities.”*

*“[Accessibility means] Very little, usually, because most providers do not think to be accessible to people like me. Accessibility is more than mandatory wheelchair ramps and closed captioning. It’s giving all disabled people equitable access.”*

The above quote indicates that some individuals may not have considered themselves as having a disability worthy of adjustments, as the typical representation or focus of accessibility has tended to be on physical accessibility.

Others felt that existing and adapting to live in a neurotypical world has resulted in them not being able to identify what they would need for a space to be accessible:

*“As a neurodivergent, I have become so used to trying to navigate a neurotypical world that I do not know where to begin when thinking about what could make spaces more accessible to me.”*

#### 4.2.6 Neurodivergent Needs and Barriers

Understanding the barriers that impact museum visiting for AuND people was one of the overarching research questions for this project. In the context of this research, a “barrier” is defined as any factor that can negatively impact or potentially prevent an AuND individual from being able to attend, participate, or otherwise access a cultural heritage institution. As part of the survey, AuND adults were asked directly about why they do not attend museums and cultural heritage settings as part of a multiple-choice question. The chart below shows the results of this question in the survey and the reasons for non-attendance.

Why do you not attend museums, galleries and / or cultural heritage (GLAM) sites? (Select all that apply)

476 Responses

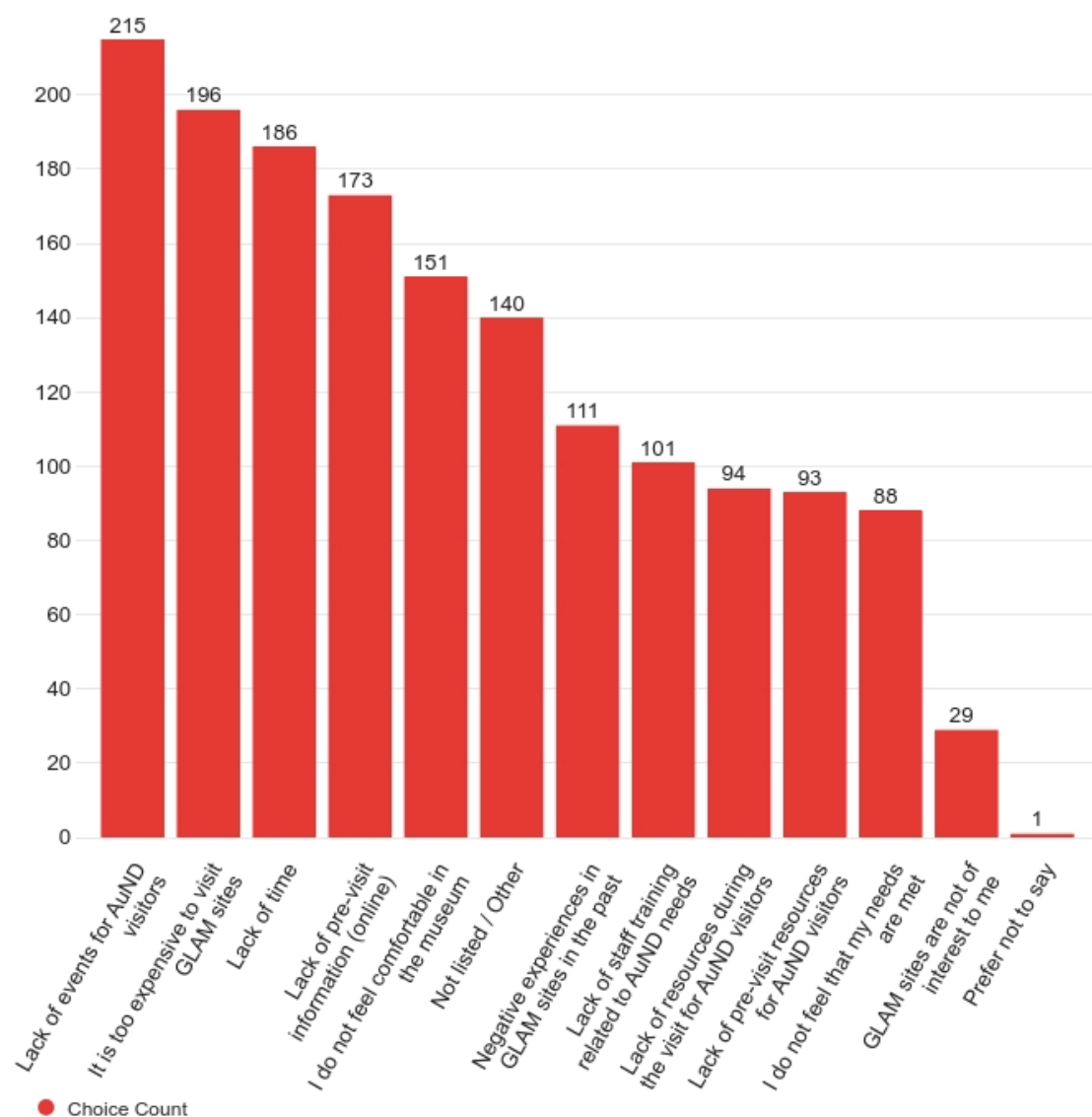


Figure 4-10 Results of AuND survey question on reasons for not visiting museums, galleries, and cultural heritage settings.

The majority of the 466 survey respondents answered the question. Respondents could select all the categories that applied and share other reasons not listed using an open-text “other” option.

While analysing the quantitative data from the multiple-choice options, clear barriers were selected by high numbers of respondents. These included:

- 1) lack of autistic/ND-specific events/resources
- 2) lack of information
- 3) not feeling welcome/feeling uncomfortable in museums
- 4) anxieties around lack of resources/staff or visitor understanding of neurodiversity and around the risk that needs will be unmet
- 5) general barriers that impact many different audience groups, such as expense.

From a surface-level analysis, this data suggests that AuND people benefit from having more neurodivergent-specific events, clear information, and efforts made by museums to make the environment more welcoming. However, this data is not the full picture, as will be explored in this section. From examining the “other” responses and the closed multiple-choice question on barriers, further insights emerged. For example, many of the respondents identify ways in which their needs could be met while highlighting the barriers that currently make it difficult to visit a cultural heritage organisation.

Below is a roadmap of the topics identified while examining the “other” responses to this set question. The responses received for this question were compared to some of the barrier-focused answers to the “What is accessibility?” question, as discussed previously. It is notable at this stage that many of the barriers identified connect to common neurodivergent traits and challenges – specifically concerning information processing, sensory needs, and co-occurring anxiety or other mental health conditions – that impact neurodivergent people in their day-to-day lives.

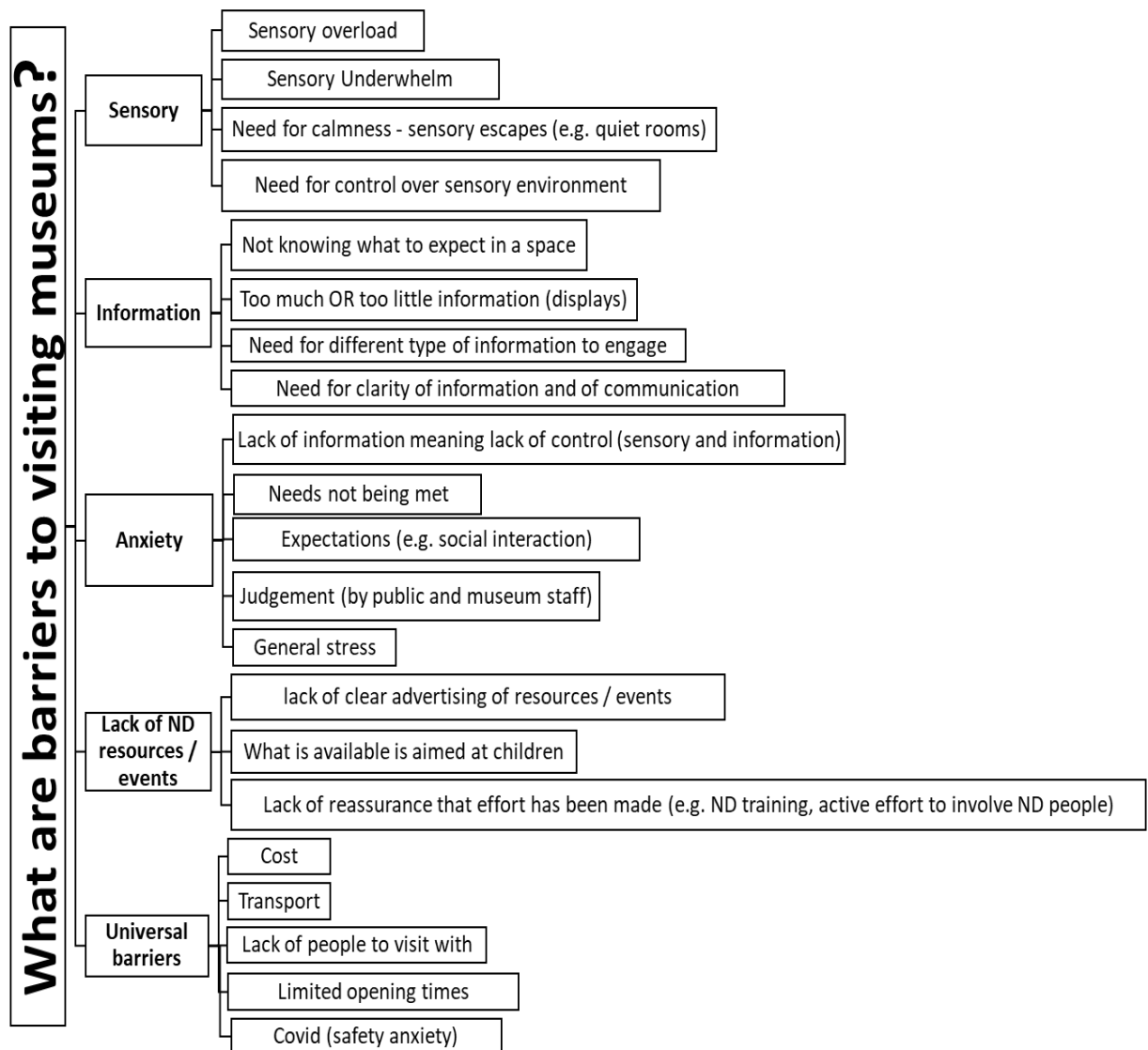


Figure 4-11 Detailed breakdown of “What are barriers to visiting museums?” – topics and sub-topics.

The following analysis and interpretation addresses the above topics, using these as a framework to better understand the most common barriers to museum visiting.

#### 4.2.6a Sensory

*“[Accessibility] means being able to exist in an environment that is palatable to me, where I will not go into sensory overload and need to leave. For example, a good type of accessibility to me would be a work environment where I am able to dim/adjust the lights, temperature and where I am able to be alone if I feel overwhelmed. Somewhere where I can access a quiet room and so on.”*

One of the most common types of responses related to the impact of the sensory environment on neurodivergent people and their ability to exist in specific spaces. In total, 157 responses related to sensory barriers were recorded across all the open-ended questions. Although none of the multiple-choice options on the survey directly referred to sensory needs, they frequently came up throughout the survey in open-ended responses. For example, responses to the “accessibility” definition question were based on the sensory environment being accessible and questions regarding potential barriers to visiting had responses centred upon the impact of sensory stimuli and how to address them to meet neurodivergent access needs. It became clear that sensory needs, and their impact if unmet, represent a common thread that runs through all aspects of neurodivergent people’s experiences.

The second highest section recording responses related to sensory needs included the question on why respondents do not attend museums. Most of these responses focused on the busy nature of the environment, anxiety about sensory overload, and uncertainty around whether there are any quiet spaces or spaces that would meet their sensory needs during a visit. In the following responses from AuND respondents, sensory triggers that can harm their visiting experience were mentioned:

*“Some places are designed like they’re arcades instead of museums. Too much sound, flashing lights, too many people not following sensical paths, thus people run into you/you have to pay too much attention to dodging.”*

*“Being able to exist and interact with the world in a way that the experience is not constantly abrasive.”*

*“Noise. Sounds. Screaming children. Other people’s headphones.”*

Some of the most common responses to hypersensitivity were attributed to the sound levels, lighting, and space needed to be able to safely move through an exhibition space. Throughout the responses – especially to the question about reasons for not attending museums – short phrases such as *“too much noise”*, *“too hot and busy”*, and *“too crowded”*, and general comments on lighting and brightness were common topics. Many described the noise – particularly if there are multiple multimedia or interactive displays playing videos with sound in an already busy space – with powerful language around the *“pain”*, feeling of *“my senses being assaulted”*, and feelings of *“overload”* or *“overwhelm”* to the point of not being able to stay within the space. Given the level of distress associated with sensory overwhelm across all the senses when in a cultural heritage setting, it is understandable that many neurodivergent people would avoid accessing museums, even if the subjects or themes of the galleries are connected to their specific interests.

While much of the focus on reasons for not attending were focused on environmental factors being unpredictable, uncontrolled, and overwhelming, others felt that there needed to be an awareness of sensory barriers and how these can vary:

*“True access for me is having control over my experience of a space. Knowing my own sensory needs and knowing what to expect would help me know what I’m getting into.”*

*“Selectable options giving greater ease to the individual. For example, silent sessions with dimmed lighting once or twice per week where sensory sensitive (or non-SS people) can CHOOSE to go.”*

*“I’d like to see more adjustable lighting and consideration given to sound in environments.”*

These responses demonstrate an awareness of the diversity of sensory needs and the importance of being able to offer options to meet those differing access requirements.

In the definition section, the term *“control”* was commonly used to refer to the ability to manage, choose, or create the sensory environment required to thrive rather than suffer. This referred to control of the sensory environment (such as granting the ability to adjust lighting, sound, or information levels within the museum) or being given information about the sensory environment that empowers neurodivergent people to be able to make decisions about what they need, or whether it is the right environment for them.

When sensory needs are not met, this can be a key cause of anxiety and stress for neurodivergent people:

*“This environment is thoughtful as to the sensory experience in multiple ways... the environment provides options/choices to allow me to engage in different ways, ideally without having to ‘claim’ disability to get access to those options.”*

*“Maybe put up a sensory warning [because] some on the Autism spectrum love bright light and loud noise and other people on the spectrum can’t stand loud noises.”*

The above quotes suggest that accessibility and barrier removal to meet sensory needs should be a more flexible approach, rather than a fixed one. As mentioned above, many neurodivergent people have differing sensory profiles and needs, with some people benefiting from a sensory environment with “multiple ways” to engage based on preference. While many find specific aspects of the museum environment “overwhelming” or “painful” because of their sensory sensitivities, others seek out stimulation and engagement through more interactive displays. Despite some respondents disapproving of the “arcade”-like gallery spaces with multimedia displays, others indicated that these are a reason for visiting museums. One respondent requested a “low-arousal” environment as a default state during a visit, a clear opposite to the “arcade” that some feel museums can become with their multimedia and busy spaces, to minimise the risk of being overloaded.

The absence of a space to retreat to if the sensory environment in the main gallery and visitor spaces is too overwhelming was a common obstacle:

*“Have panic rooms where people who are over-stimulated can go and have a breather. With the choice of limited lighting. Do not berate us directly and make a big deal of how we are behaving.”*

*“Quiet spaces for people to go if need be. No television/screens in said quiet spaces. Also, having spaces where people can be loud and express themselves. No judgement for tics or stimming.”*

While many respondents identified quiet spaces as useful facilities for neurodivergent people who need them to help manage their internal sensory systems, others identified the need for general quiet spaces throughout museums – containing seating or space to sit in a



wheelchair – if a closed-off space is not needed or available. For example, one respondent stated that they needed “enough quiet corners, nooks, rooms, hallways to take a break” from the sensory experience and information on display across displays, while another specified that they would want “*a more quiet space where you can withdraw for some time and go back into the main exhibit hall*” following recovery. A couple of respondents requested a “*sensory room*”<sup>19</sup>, where neurodivergent people would be able to go to stim (sometimes physical stims, at other times vocal stims), unmask or self-regulate without judgement or to regain a sense of “*dignity*” if they have reached a point of sensory overload.

#### 4.2.6.b Anxiety and Stress Related to Visiting

*“Accessibility means the ability to exist in a place without extreme anxiety, physical pain, embarrassment, stigma, and sensory overload. The place must also be safe and easy/safe to go to.”*

Anxiety, stress, and overwhelm caused by inaccessible environments were frequently referred to as leading factors when it came to decisions not to attend museums. Some respondents shared that they were anxious about their needs not being met:

*“Accessibility to me means somewhere I can access easily and feel comfortable in doing so, without suffering negative impacts on my mental wellbeing. It means somewhere without unnecessary barriers (physical or psychological). It should not be somewhere that causes me difficulty, distress, or discomfort.”*

*“[Accessibility is] about being able to access/participate/enjoy in the same things as neurotypical people, without the extra levels of stress/struggle that comes from people not having considered what an environment might be like for an autistic/neurodiverse person. Effort has been made to make it a more comfortable inclusive environment for everyone.”*

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<sup>19</sup> “Sensory rooms” are specially designed environments that provide controlled positive sensory stimulation. These spaces typically feature adjustable lighting (often dimmed or turned off), sensory elements such as fairy lights or water tubes, comfortable seating, and sensory toys. They are increasingly implemented in schools, museums and healthcare settings. For discussion on their application in mental healthcare contexts, see Wigglesworth & Farnworth (2016).

As indicated in the quotes above, emphasis was placed on removing the “*extra levels of stress/struggle*” that AuND people can face, which can lead to “*suffering*” and not feeling that their needs have been “*considered*” as well as negatively impacting their mental wellbeing.

Not knowing what to expect from a venue can be a significant source of anxiety for AuND people (NAS, 2023; Jenkinson et al., 2020). Many of the responses indicated that there are AuND people who would not visit if there was no information available before a visit about the museum and the visitor experience:

*“The access needs I have related to autism mostly centre around the ability to predict stimuli and expectations... So, a clear explanation of the event or location, including any strong sensory input (bright/strange lighting, loud/sudden noises, strong smells) as well as confirming social expectations as applicable.”*

*“... It reduces anxiety, knowing in advance that our needs will be met without fuss or embarrassment.”*

The two quotes above demonstrate the importance that information about an environment can have in reducing anxiety by conveying what to anticipate in a way that is “*accessible and transparent*” to enable planning.

#### 4.2.6c Communication, Expectation-setting, and Information (Processing)

*“Accessibility for me starts before I begin a journey. I like to be able to see inside the place I am going. Learn the layout, where the exit and quiet areas are and the loos and lifts. I like to know what the rules are and opening times and costs and so on.”*

Communication and information processing are shared challenges that AuND people experience in their day-to-day lives and are essential diagnostic characteristics for autism specifically (DSM-5). In addition to the processing of sensory needs and emotions or causes of anxiety, processing information that has been communicated, whether verbally or in writing, is a common aspect of processing that can be challenging for neurodivergent people (Miller et al., 2014). Many of the responses throughout the survey emphasised the significant importance that information, in its many forms, has on whether a museum is accessible or inaccessible.

A frequent topic that came up – particularly concerning pre-visit and in-person visiting – was that lack of information resulted in decisions not to attend a museum:

*“[accessibility means] I can find this way easily, without having to dig through multiple layers of [the] website. If I need to email someone to make this happen, this fact (and the email address) is clearly indicated, and the email is answered within 1-2 days.”*

*“Accessibility in terms of public services or websites means clear layout, precise language.”*

Identifying what to expect ahead of visiting was a common method to make museum-visiting accessible. One respondent stated that an accessible place provides “*comprehensive information*” that can assist in identifying both visible and invisible barriers to inform their trip. One of the most cited aspects was a preference to have information about more popular times or busier areas. For example, some respondents emphasised that they would only want to visit “*when it’s less busy*” and that having information “*like a map and lots of details online*” can help with planning to visit at a time that suits their needs. This reflects the responses about preferred times for visiting, where open-ended responses indicated that they would be willing to go any time that was not too busy.

A few respondents stated that having some form of “map” available online would enable them to plan a route ahead of their trip. A resource such as a map would enable neurodivergent visitors to familiarise themselves with potential places to visit, while being able to identify and avoid areas that may be overwhelming or less interesting. Another respondent focused on the importance of having “*good quality photographs*” of inside the museum available on the website as “*they provide clear expectations about the ‘flavour’ of the building*”, meaning that someone who has not visited before can visualise and plan their visit.

Many called for essential information to be communicated in a range of diverse ways, sometimes across different formats, to make it as accessible to different people’s needs as possible:

*“No huge info dumps/pieces of information to read – ideally a separate handout so people can choose to read/take their time.”*

*“Detailed and intelligently written text as too much is normally dumbed down.”*

*“Short summaries/explanations/descriptions.”*

*“[Accessibility is] having information presented to me in more than one format – i.e. not just written down on a card.”*

Some of the responses were focused on the amount of information available upon entering a museum, and others were more concerned with the availability of information within physical spaces. While some indicated that they wanted more information, often with “specialised” terminology if it was an object or display connected to a focused interest, others explicitly stated that they wished there was less information in the form of “short summaries”. According to the quotes set out here, some viewed less information as “dumbing down” while others viewed too much information as too much detail to process. The diverse viewpoints and preferred ways to engage with information demonstrate that this is a crucial area to consider when constructing future information.

AuND adults, like all people, have preferred ways to communicate and receive information. There was a focus on having access to information in a range of formats, designed to meet different accessibility needs, as well as different information style preferences that would empower neurodivergent people to take control of their (potential) visit:

*“Accessibility means options. It means being offered multiple ways to take in information.”*

*“Written descriptions in both plain text and braille, sign language interpreters available.”*

*“‘Accessibility’ is accommodation to people with a varied set of capabilities, disabilities, requirements, desires, and general wants. It is the option of a dark theme, the option of plaintext, it’s clearly conveying information, it’s asking if someone wants to do something in person or online (text or voice) ... It’s easy-to-access information.”*

Throughout the responses, there were several different suggestions for meeting diverse processing requirements and preferences. These included creating audio guides that visitors could control from their phones, videos with subtitles accessible online, QR codes and handouts with more detailed information for anyone interested in receiving higher levels of detail, and focusing on improving signage and signposting within the space to improve the visitor journey. Digital interactives, allowing visitors to engage in information in a more immersive way, also

divided the respondents as some found these essential, while others found them distracting. As every potential visitor to a space has individual learning and information processing needs, museums must be aware of how they currently communicate information and how they could expand this to meet differing preferences.

As well as information on objects, exhibitions, and programming, many of the respondents highlighted the importance of signage within the physical space to facilitate navigation during a visit:

*“Easy to get to, easy to enter, easy to navigate.”*

*“Basic help that isn’t spoken or needed to be asked for (e.g. socialising with a member of staff). This can be helpful things such as signage, a leaflet or audio announcements. Pre-warning before entering a space with [a] booming noise, harsh lighting, etc. (what I would call a sensory nightmare) ... Offering of other forms of communication that aren’t immediate or in front of a crowd (like emailing, ‘hanging behind afterwards’).”*

A common theme when considering information is how it can alleviate anxiety by preparing AuND visitors to be able to navigate the physical building. One of the respondents stated that accessibility meant that there were “*clear signs*” that not only highlighted where physical facilities such as toilets are located but also regulated, for example, whether photography is allowed in the space or not. Some respondents stated that part of the information that they would like from museums when preparing to visit and whilst in the space is not only a clear indication of what route they should take, but also “*what is expected*” from them as visitors.

While pre-visit information can encourage neurodivergent adults to visit museums, inaccurate information can be a barrier to visiting. Some AuND respondents stated that they would benefit from museums and cultural heritage settings being transparent and honest about all aspects of their accessibility, even if this is to highlight that some aspects are not accessible.

One example of this was:

*“When something is not accessible to all or a particular group, I think the most accessible thing they [museums] can do is clearly state why it is not accessible and that they are working on it rather than lying/not stating it.”*

This quote illustrates the frustration that can be felt when a business or organisation fails to communicate key information that would inform a future visit, with the perceived “lying” about or hiding of accessibility information negatively impacting sentiment towards and trust in institutions.

#### 4.2.6.d Neurodivergent-specific Planning and Resources

*“[Accessibility is] to be welcomed without barriers. Not to be confused with ‘to be tolerated at specific times when you won’t inconvenience the neurotypicals’.”*

A theme tying together the barriers, motivations, and patterns of visiting together is a focus on the importance of the development of events and resources specifically for AuND adults. Figure 4-9 shows that the highest response to the question of why AuND adults do not visit museums was a “lack of events for autistic/neurodivergent” adults. In the literature review, while there has been an increase in events and resources in recent years, most current provisions for autistic visitors to museums tend to be for young children. Some respondents did highlight that part of the reason they would prefer to have set times for AuND visitors is connected to the noise and unexpectedness of other visitors, particularly children:

*“Areas which are expected to be quiet (free of small children, phones on vibrate, etc.) for those who get overwhelmed by loud noises easily. Exhibits specifically for children and exhibits which specifically prohibit children (some of us cannot handle children).”*

*“There are always too many people inside of museums, and I cannot be around children because they give me horrible sensory overload and frequently breach my personal space.”*

For some respondents, this was a barrier, as they preferred the idea of having “quiet” or “relaxed” opening times for neurodivergent audiences and they are often advertised to families with young children.

This feeling of museums prioritising children was noted by some of the respondents, who explained why this was a barrier to them:

*“Lots of activities are aimed at children, not adults so do not feel comfortable attending.”*

*“Museums are usually family-oriented which means there are always loud parents and children present. The interactives are aimed towards children and do not meet my adult interest in the topic, and I find it really difficult to be around children because of how loud and disruptive they are, and how much space they take up.”*

The impact of this, as demonstrated by the quotes presented here, is that it does not feel like these events and spaces are available or accessible for AuND people.

#### 4.2.7 Access Panels and AuND Community Involvement

*“More than token gestures such as quiet hours first thing in the day. It’s about being safe.”*

As part of the survey, I wanted to understand how AuND adults felt about being involved in decisions to make museums more accessible. One of the questions asked was whether the respondent would participate in an access panel, where they could share their views to shape access at a museum.

If a museum, gallery or cultural heritage site had an accessibility panel or other method of including you in developing their accessibility, would you join?

476 Responses

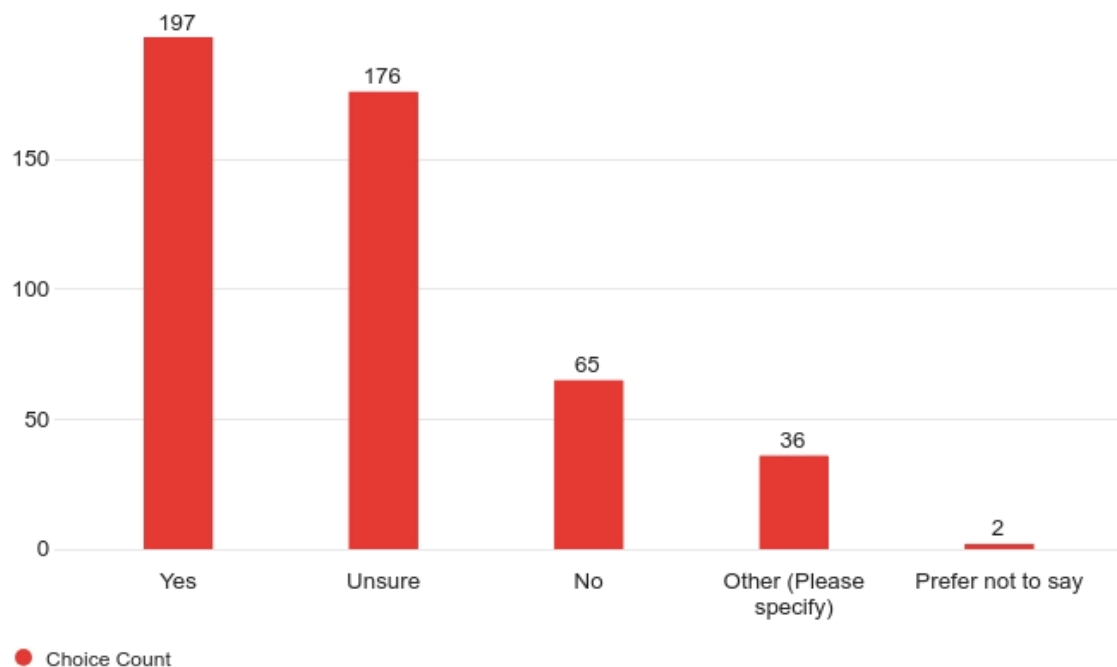


Figure 4-12 Graph showing respondent willingness to participate in a cultural heritage accessibility panel.

The responses to this multiple-choice question showed that there was an interest in being involved in decision-making, but a high number responded “unsure” or “other”. Respondents who opted to explain their answer highlighted that they would potentially be interested in taking part in an access panel, but only if it was not tokenistic:

*“Somewhere that genuinely takes the needs of autistic people into account and makes somewhere pleasant to visit rather than lip service.”*



*“I do not want to be tokenised, and BIPoC people should also have the space and audience to express their needs as well instead of just focusing on white neurodivergent experiences.”*

*“Depends [on] if I am interested in that site & believe it will really make a difference. Or if I’m reasonably paid for participating.”*

*“Yes [to taking part in an access panel] if it was genuine and not ‘box ticking’.”*

These quotes demonstrate that anxieties about needs not being taken seriously, and inclusion being some form of “*tick-box exercise*” or conducted with good intentions could prevent even engaged AuND people from participating in the consultation. Concerns about whether an organisation had “*genuine*” intentions or interest in improving rather than simply paying “*lip service*” were evident. Some stated that they were “*not sure*” for reasons related to “*payment*” for their services or insights, and others stated that it would depend on the organisation and their relationship to it.

#### 4.2.8 Universal Barriers

In addition to accessibility requirements specific to neurodivergent audiences, some responses highlighted that many AuND people are impacted by more commonly identified barriers to museum visits. Many of these obstacles are a result of geographical location, funding, and lack of provisions to meet the ever-changing needs of a society that is constantly changing in its structure and expectations. It is important to note that, while these are barriers that impact a broad range of (potential) audiences, for many AuND people these barriers are compounded because of their existence alongside specific access needs and barriers. For example, the impact of high rates of un(der)employment of AuND people, due to barriers related to entering or maintaining steady employment (such as inaccessible interviews and discrimination in the workplace), alongside other barriers can further reduce their ability to visit museums.

One of the most commonly identified general barriers was connected to access transportation to enable AuND people to visit the museum:

*“Lack of a car park, meaning I have to cope with public transport, which can be too much as well as the visit.”*

*“They’re difficult to get to as I do not have easy access to public transport (I live in a rural area).”*

The remoteness of cultural heritage organisations, and the difficulty of travelling by public transport or parking close to a venue, were identified in 67 responses to the survey. Some respondents stated that they had “*travel anxiety*”, which makes journeys to museums out of the question. This aligns with Lade’s (2010) findings that rural museum locations coupled with transportation barriers and travel costs can deter visitation, despite interest in museum experiences.

The cost of visiting a museum is also a significant barrier:

*“Sometimes it is too expensive.”*

*“It may be too far (expense, and the worry of the journey) and also it’s too expensive because I do not have a good income.”*

Some of the respondents shared that their anxiety about paying money to visit a museum, then feeling overwhelmed and needing to leave, was a barrier to even visiting, as they did not have the disposable income to risk losing money on an experience they could not access. This aligns with research on economic barriers to cultural participation. Kirchberg (1998) identified entrance fees as a significant deterrent to museum visiting, while later studies (e.g. Kluge-Pinsker & Stauffer, 2021) confirm that financial considerations substantially influence access to cultural heritage institutions.

One barrier often connected to transport and expense was not having anyone who would accompany them to a museum:

*“No one will take me.”*

The “*lack of a social network*” or support to visit identified by respondents indicates the importance of support or company when considering visiting.

The limited opening hours of many museums was another factor that had an impact on museum visiting. Some felt that museums were simply “*not open late enough*” for them to be able to visit, while others specified that they were “*inconvenient*” because of their work commitments.

### 4.2.8 Motivations for Museum-visiting

One of the purposes of this research was to examine the main reasons for AuND adults visiting museums. Throughout the survey, most of the respondents indicated that they had a positive attitude towards museums, either in terms of current visits or what they perceive as a potentially enjoyable experience if their access needs were met. In response to the question (Q27), which asked “Why do you go to museums?”, many suggested that a range of distinct factors motivate AuND people to visit cultural heritage organisations.

According to the 463 AuND people who responded to this question, it was positive that most respondents selected more than one reason for visiting museums, suggesting a general interest in museum visiting.

Below is a graph showing the most to least popular choices selected by the respondents:

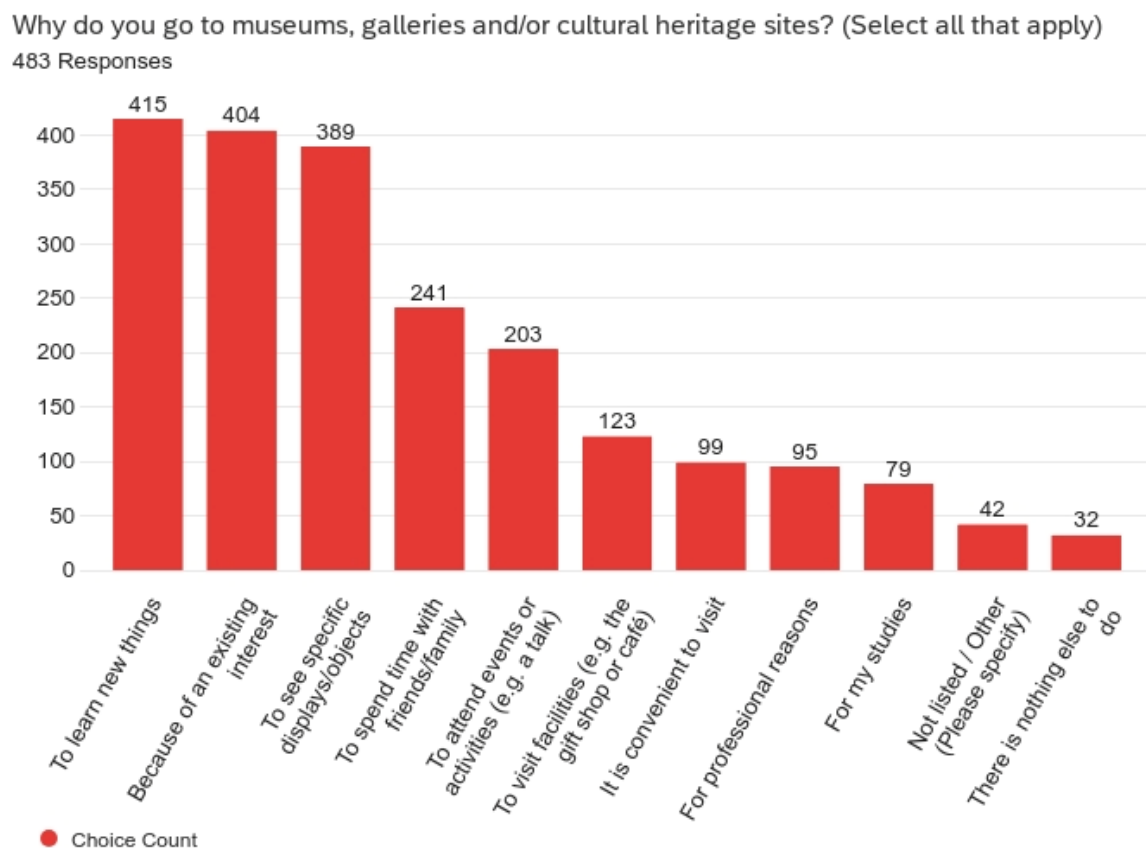


Figure 4-13 Bar chart for the question “Why do you go to museums, galleries and/or cultural heritage sites?”

One of the first significant findings from this question is that “*interest*” in what is on display is a leading motivation for AuND people. The top three responses were as follows: 1) to learn new things (for myself and/or others); 2) because of an existing interest/looking for a new interest; and 3) to see specific displays/objects. These three responses are all connected to respondents’ interest in learning and developing an interest, whether existing or new.

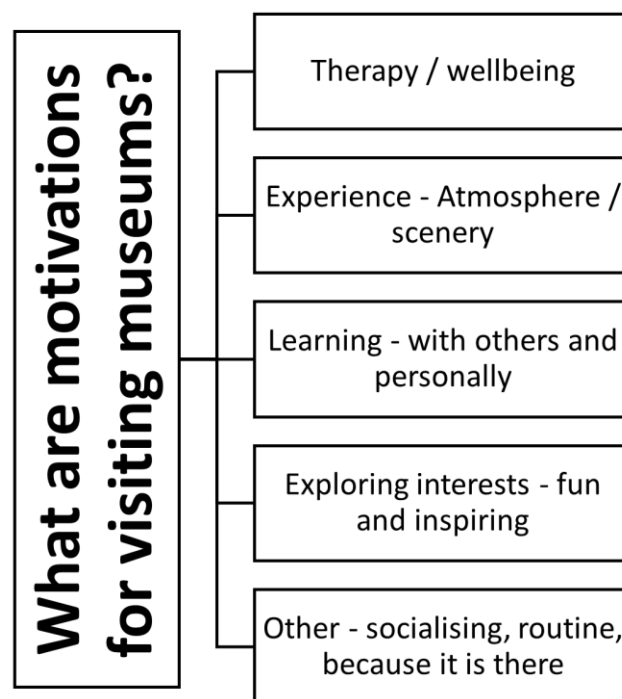
The second highest category of answers was connected to socialising and visiting with others. 241 people, half of all the respondents to this question, selected that one of the reasons they go to museums is to spend time with friends and family, suggesting that museums are regarded as suitable venues to facilitate safe socialising. This reflects the finding that some neurodivergent people do not visit museums because they have no one to go with. In the open-ended “other” section, some responses indicated that museums were places where AuND parents liked to take their children – either as part of home education or to share their interests with them – and with partners or friends.

The last topic identified in the multiple-choice element of the question was visiting out of necessity or practicality. This element can be broken down into the following responses: 1) to visit facilities; 2) it is convenient (e.g. to get out of the weather); 3) for professional reasons; 4) for my studies; and 5) there is nothing else to do. These categories suggest that not all visitors visit as a form of recreation. Several of the respondents stated that they worked in museums, and therefore were in their institution or visiting others as part of their roles, while others stated that they study courses that require visiting. Notably, these choices were significantly lower in their selection than those related to the experience of visiting to see specific objects, cultivate their interests or socialise with friends and family. Only 31 respondents out of the 363 people who responded to this question indicated that a reason for their visit was because there was “*nothing else to do*”, suggesting that the majority of AuND people who visit museums do so in a more active manner than those who view it as a way to pass time.

#### 4.2.8.a “[I visit museums] to be surrounded by beauty and peace” – Additional Motivations for Visiting

Alongside the multiple-choice responses, the question about why respondents visit museums had a variety of “other” responses. Some of these qualitative responses further explained their rationale for selecting the options they did in the multiple-choice, while others used this space to include personal reasons that they felt were not covered in the options given as part of the

survey. Below is a thematic roadmap, which shows the most common topics that emerged in the open-ended responses to this question:



*Figure 4-14 Closer breakdown of “What are motivations for visiting museums?” – key topics that emerged.*

A variety of responses emerged to the “other” option for this question. These ranged from seeking peaceful spaces to explore artwork to visiting being a form of “therapy” for some respondents. These themes can be divided into 1) mental wellbeing; 2) socialising; 3) work; 4) the environment; 5) routine; and 6) it is a place to develop own and other interests.

#### 4.2.8b Therapy and Mental Wellbeing

*“To claw back some inner peace.”*

The most common reason identified in the open-ended responses was to focus on the impact that being in a museum can have on individual mental health and a sense of calmness. While

one person stated that visiting a museum can help “*reset my mental health*”, another stated that they found being in a museum space “*calming and uplifting*”. Responses such as these, with six responses relating to museums being a safe space to improve mental health or feel peace, demonstrate the potential for these institutions to be a form of sanctuary for some AuND people. One of the most striking responses was simply “*for therapy*”, identifying that museum spaces can have a therapeutic impact on some AuND visitors. For some of the respondents, this may be related to the environment and opportunities available within museums, particularly if they are perceived to be “*calming and uplifting*” as well as a space for “*quiet activity*”.

#### 4.2.8.c Exploring Existing and New Interests

According to the quantitative responses, interests (existing or new) can be significant motivators for AuND visitors. Around half of the 58 open-text responses that included motivations for visiting were related to museums being places to learn and explore interests individually or socially:

*“To feel something new or interesting.”*

The quotes presented here demonstrate the connection between visiting museums and gaining – or facilitating the exchange of – information on a topic of interest. Respondents suggested that these interests may pre-exist and be the reason for visiting specific museums, or be new interests that a neurodivergent individual and whoever they are visiting with wish to discover. One respondent stated that they have “*planned vacations just to visit a museum with a specific exhibit*” while others were more likely to visit spaces where they could discover a new interest that inspires them. This demonstrates the variability in the level of interest held by AuND visitors, but the common theme is “*inspiration*” in an environment that can facilitate exploration.

#### 4.2.8.d Connection and Socialising with Other People

In addition to having the opportunity to explore interests as an individual, the second most common reason for visiting museums for AuND people was social connection. Respondents valued museums as spaces to connect with other people, specifically friends and family, both living and deceased loved ones, through the memories that exhibits can evoke. This social motivation was closely tied to exploring interests, as many respondents reported satisfaction in sharing their interests and discussing exhibits with companions.

*“To feel part of humanity.”*

These connections can be with other individuals, such as friends and family, and for several reasons. First, museums can be places to pursue both formal and informal learning or work obligations. Some respondents were AuND parents who take their children to museums to either home-educate them or as an informal way to help *“encourage my kid to develop his passions and interests”*.

In some instances, the connection can cross the line from accessing and connecting with an interest to that object enabling a person to feel a connection to deceased relatives:

*“To be inspired and fascinated & it is something that makes me feel connected with deceased parents.”*

The above quote about feeling *“connected with deceased parents”* reflects the power of objects and displays on potential visitors by evoking emotions and connections (mental, social, and intellectual) between what is on display and the visitors’ personal lives.

For other respondents, museums were seen as places where they could engage in socialising by sharing information or interest in what is displayed. For example, one respondent shared that they like to *“Share information I’ve learned about specific things with my friends and to get inspiration.”* Information sharing (sometimes referred to as *“info-dumping”* in the neurodivergent community) can be a way that a neurodivergent person can feel at ease when communicating with others, revealed through responses about displays being topics of interest. One of the respondents stated that they enjoyed visiting because it means a positive alternative space to visit as an adult to a bar, which is often associated with adult socialising.

#### 4.2.8.e Learning, Education, Work

In addition to citing the education and learning potential of visiting museums as reasons for going, some AuND people identified themselves as museum workers, without directly explaining what led them to pursue work in this field – potentially a combination of their interests and skills related to research or simply the enjoyment of being in a space that meets their environmental needs (e.g. quieter spaces that enable them to pursue their interests). These responses tended not to explain what it was that led them to the museum sector as a workplace or topic of study.

#### 4.2.8.f Experience of the Atmosphere and Scenery

The final reason is “*because it is a nice place to be*”. Some neurodivergent respondents to the survey stated that they visit because they enjoy being in the museum environment. One of the respondents highlighted that they visited because of “*the comfort of routine exhibition routes*”, enabling them to navigate around the space when they are not feeling over-stimulated. Some liked the “*atmosphere*” in museums, and how they are encouraged to be “*curious*” in their spaces, while others went because it was a place they could go when they had “*time to spare*” and did not wish to stay “*at home*”. Some respondents stated that museums are places that they might not necessarily choose to visit every day, but where they can have positive experiences while visiting when they do go.



## 4.3 Discussion

This survey was the first of this research project to ask AuND people directly about their views on accessibility to museum visiting, focusing on better understanding their experiences within cultural heritage settings. It did not require proof of diagnosis and was not limited to specific neurodivergent sub-types or geographic areas (as long as a respondent was aged over 18 and could read and respond in English). Using a reflexive thematic analysis to approach the qualitative data to the 466 full responses received and relating these to the quantitative data from the multiple-choice questions, it was possible to identify several key topics. This section examines the findings and what they suggest about the museum-visiting experiences of AuND adults.

As an autistic researcher, the most recurrent topics that emerged from the survey responses were not entirely surprising. Most of the responses related to common diagnostic traits – or anecdotally shared characteristics, as often discussed in both online and in-person neurodivergent-majority spaces – regardless of their specified form of neurodivergence. These included the importance of sensory environments, communication (styles and amounts), interests, social experiences, and information to plan visits. Not all the pre-set multiple-choice options included specific traits – for example, “sensory” was not an option in the “Barriers” question but was the most common response in the open-ended “other” section – which demonstrates the level of importance placed on these neurodivergence characteristics when considering overall visiting experience to museums.

### 4.3.1 Accessibility Definition

One of the ways that this survey aimed to assess what made a museum neurodivergent accessible was to ask the respondents what “accessibility” meant to them. The diversity of responses reflected the range of experiences, attitudes, and understandings of accessibility – and often inaccessibility – for individuals. Some respondents found it more challenging than others to reflect on or connect to the term “accessibility”, often as a result of where they were in their diagnostic journey (with more recently diagnosed respondents identifying the difficulty they had in connecting to the term as they are still processing what their diagnosis means to them). In addition, others specifically referred to it as a term often associated with physical disability, resulting in some self-reflecting on the lens that they use when thinking about access and disability categories. Societal understandings of and attitudes towards disabled people tend to vary from apparent lack of awareness (potentially because of the under-representation of

disabled people in employment, education, and workplaces) to directly excluding disabled people from conversations, even when the conversation is about the disabled person themselves (Scope, 2018). It is possible that a lack of understanding of the diversity of disability, and the different access needs that disabled people experience based on their situations, could be influenced by historic hierarchal understandings of disability. Furthermore, a person's attitude and understanding are likely to have been shaped in childhood, therefore if they have not had exposure to a disability or been educated about it then this impacts attitudes in adulthood (Babik & Gardner, 2018).

However, many of the respondents did share nuanced and personal responses to this question. According to AuND adults, "accessibility" means that neurodivergent individuals can comfortably exist and participate in the same spaces as neurotypical individuals. Many AuND respondents expressed that they were repeatedly neglected, misunderstood, and dismissed and made to feel unwelcome in a space. This reflects the findings of other researchers from, for example, studies of the anxiety or minority stress experienced by autistic people who have felt that their neurodivergent needs are treated as "less valid" than those of neurotypical others (Botha & Frost, 2020; Pearson & Rose, 2017). This was not a surprise, given the pathologisation and stigmatisation of neurodivergent adults discussed in the literature review and the common discussion of feelings of alienation and being misunderstood within the neurodivergent community (Seers & Hogg, 2023; Fusar-Poli et al., 2022; Hull & Mandy, 2017; Robertson et al., 2018; Bargiela et al., 2016). Crane et al. (2019) demonstrated that the high levels of stigma often experienced by young autistic adults, combined with barriers to accessing mental health support and not feeling listened to, contributes to their disproportionately high rate of mental health problems. This pattern extends into adulthood, with Level and Geurts (2016) documenting high prevalence rates of co-occurring mental health conditions among autistic adults. Research has further documented the psychological effects of social stigma and negative attitudes on autistic people (Han et al., 2022). These anxieties about being judged, excluded, or expected to mask to attend museums demonstrate a lack of trust in perceived neurotypical organisations to create an environment they felt was inclusive without forced medical disclosure. This is an issue commonly found in other disability studies (Holt, 2012; Robinson, 2010; Kanuha, 1999).

Another topic that emerged from the responses was that neurodivergent people were not just critical of the lack of accessibility but also actively shared advice or positive examples of accessibility in practice. Feeling listened to, respected, and understood were ways of

establishing trust and demonstrating a commitment to accessibility. This preference for a more individual-focused approach over a “*one-size-fits-all*” approach can be seen in recommendations for a more universal or inclusive design approach in autism research, as well as in the museum sector. In utilising a universal design or inclusive design approach, whereby museums plan for different access needs from the beginning of any project and include the community as part of the process, different potential options can be provided for engagement and participation by pre-planning accommodations (Milton et al., 2016; Steinfeld & Maisel, 2012). Several individuals expressed anxiety and uncertainty regarding the accessibility of cultural heritage environments, particularly whether their needs would be understood. Organisations could address this issue by providing a range of options for support and seeking out insights from neurodivergent individuals about what they need to actively participate in visits. This could boost the confidence of AuND adults in cultural heritage organisations.

In reflecting on what “accessibility” is in theory and practice, incorporating both what accessibility means personally and more generally, the AuND survey responses demonstrated that many of the barriers that create inaccessibility are connected to lack of action, negative attitudes, and lack of understanding and could be addressed by taking meaningful actions. Taking steps to listen to AuND people, identify common barriers, and respond with changes, means that museums have the potential to build trust with neurodivergent members of the community.

#### 4.3.2 Barriers to Museum-visiting

One of the research objectives was to identify common barriers to AuND people visiting museums. This survey actively asked its respondents about the barriers that they experienced using a multiple-choice question with an optional open-ended response for any barriers that were missing. While the list was developed by a neurodivergent researcher and received feedback from two neurodivergent focus groups and individual feedback from other AuND people before the final survey was published, it was clear that some significant barriers were not completely covered by the options available.

The most notable response related to sensory environments. Reflections on the potential of a sensory environment in limiting the accessibility of a place were common in both the “accessibility” definition and the “barriers” question, highlighting the significance placed on the sensory experience of AuND people. This reflects the findings in other research, such as the work of Keren MacLennan et al. (2021, 2022) during the Sensory Street project, which

similarly documented the negative impact of sensory environments on autistic individuals through focus group analysis.<sup>20</sup> Given the level of distress associated with sensory overwhelm across all the senses when in a cultural heritage setting, it is understandable that many neurodivergent people avoid accessing museums, even if the subjects or themes of the galleries are connected to their specific interests. Meanwhile, other respondents expressed the opposite – they felt that museums did not engage their senses enough for them to choose to visit. The diversity of sensory needs and their potential to vary not only from person to person but within the same individual dependent on a variety of factors demonstrated the importance of enabling neurodivergent people to know what to expect in a space to allow them to take control of their experiences (Docherty et al, 2022; MacLennan, 2022). Providing sensory information, which can inform a decision on whether a visit would be appropriate or to avoid certain areas, gives AuND people the ability to make informed decisions that are suitable for them. Furthermore, museums that can offer advertised times and spaces where specific sensory environments can be adjusted – for example, with lower light or noise levels – can enable neurodivergent people to enter a space they previously may not have considered because of concerns about becoming overwhelmed or experiencing sensory pain.

Most of the barriers highlighted in the survey responses were reflective of difficulties that are commonly noted by AuND people in research relating to the diagnostic traits that exist across the differing neurotypes (Rutherford & Johnston, 2023; Pellicano & den Houting, 2022; Miller et al., 2016). One example of an overlapping barrier and difficulty relates to how information is communicated, ranging from not having enough information (for instance, no pre-visit information) to providing too much information (for example, labels and interpretation). Lack of pre-visit information was a common factor identified in the “barriers” question. This reflects findings from the Museum and Heritage Access Surveys (2018 and 2022), which demonstrated that pre-visit information was deemed a crucial requirement for the majority of disabled people who took part in the research, yet 19% of UK museums and heritage sites still lack information on their websites to aid with trip planning. Among those organisations that provide information, this tends to be limited or hard to find. This suggests that neurodivergent individuals are not the only potential audience who would benefit from

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<sup>20</sup> Another example of research on the impact of the physical and sensory environment on autistic people is Dargue et al.’s 2022 systematic review, which reported on the negative impact that the sensory environment (e.g. lighting and noise) can have on autistic people. Their analysis also identified effective environmental modifications that can enhance accessibility and comfort for autistic people.

having pre-visit information, while the lack of sufficient information is a significant barrier for most disabled people.

It is noteworthy that these findings reveal barriers identified by AuND people – including cost, transportation limitations, and lack of social companions—parallel those experienced by broader audiences. However, as this survey targeted AuND people who had visited museums within the previous 5 years, a knowledge gap remains regarding non-visitors, whose experiences could illuminate additional barriers to visiting. As discussed by Kluge-Pinsker and Stauffer (2021), it is important to consider broader cultural and socio-economic factors, such as not feeling welcome or represented within museums and not growing up with museum visiting as a family tradition. This suggests two conclusions: firstly, that AuND people experience many of the same barriers as other audiences, but with additional challenges that compound their difficulty in accessing museums. Secondly, that more research into non-visiting patterns among AuND people is needed to better understand the obstacles that deter museum visits.

To address issues with information during a visit, many recommended presenting it in different formats – with varying levels of detail or social interaction required – allowing people with different communication needs or preferences diverse ways to access information. This demonstrates the importance of having multiple formats to meet different access requirements and address a variety of barriers. For example, anxiety could be reduced by providing all the information necessary to make a potential visitor more comfortable. Furthermore, more accurately identifying what AuND-specific resources or events are available could help potential visitors who require specific adjustments or events to identify what is available that might suit their needs. Providing all this information could be a way for museums to demonstrate to AuND people that their needs have been considered and that they have tried to understand specific needs and adjust accordingly. In providing information to make a visit more straightforward for neurodivergent people, museums could create a sound foundation to build up confidence in potential neurodivergent visitors and continue enhancing their spaces to meet more needs and build motivation for future re-visiting.

#### 4.3.3 Motivations for Museum-visiting

Despite these barriers, the survey revealed that the majority of respondents either actively visited museums or expressed interest in visiting if museum were made more accessible. With most respondents selecting multiple reasons for why they visit museums, it was clear that some

motivations were connected to a desire to socialise with others in a space that facilitated access to existing or potentially new interests. Furthermore, respondents highlighted the potential to visit museums as a way to aid self-care or potential self-improvement, as a space with the potential to enhance mental wellbeing and a sense of connection (to the self, others, history and interests), and as an environment to learn in that is calming – a positive indication that museums can be accessible and beneficial spaces for neurodivergent people.

The most common response was to explore interests. This finding does not come as a surprise, as a trait commonly associated with AuND people is their passionate and focused interests, which can significantly vary in type of topic (Grove & Hoekstra, 2018). Some neurodivergent people may have a narrow, quite specialist, topic or interest in which they become fully engrossed, while others may have a broader collection of strong interests that they find pleasure in pursuing. In the autistic community, the positive feelings an AuND person feels when able to pursue their interests can be described as “*autistic joy*,” and being in an environment where they are encouraged to be inquisitive, or access materials related to said interest could have a positive impact on their wellbeing. This suggests that cultural institutions, with their many displays, could attract neurodivergent people to explore such interests, potentially enabling them to become frequent visitors in spaces that facilitate access and give opportunities for immersion in collections that spark neurodivergent joy.

The second highest category was socialising with others. This was remarkable and surprising, as it is contrary to historic assumptions that autistic people prefer their own company over socialising. In the past, neurodivergent individuals – specifically autistic people – have been stereotyped as solitary or preferring their own company (Davis & Crompton, 2021). Research has since demonstrated that this misrepresentation of autistic people as preferring to be alone is not always true and potentially damaging, especially as there is increasing evidence about the positive impact of neurodivergent-to-neurodivergent social interactions on wellbeing (Crompton et al., 2020). This is because others may assume that neurodivergent individuals need less social contact than other people, which can lead to isolation.

It may be that museums and cultural heritage settings are places where meaningful conversations and socialising are focused on what is on display, and this is a positive experience for everyone involved. Shifts in the focus of interaction can move away from individual conversation towards a shared experience of immersion in exploring a space, discussing

objects, and learning as a more appealing way for some neurodivergent people to socialise. With museums typically offering own-pace opportunities to explore, it could be that museum visiting is a low-pressure way for some neurodivergent people to build relationships with others. Interest in attending specific events and activities suggests a specific social motivation for event attendance, meaning that museums represent useful spaces to facilitate new and existing social networks for AuND people as part of their events programming. Once again, the focus on having people to visit museums with is a common factor that impacts museum visiting for AuND, suggesting that any adjustments made to make museums accessible to neurodivergent needs could result in drawing in broader audience groups incorporating those who accompany AuND visitors.

The importance of space and providing an environment that is soothing and potentially benefits mental health cannot be overlooked. With high levels of neurodivergent people experiencing lower levels of mental wellbeing than neurotypical people, and higher rates of co-occurring diagnoses of conditions such as anxiety and depression, it is significant that neurodivergent people can have easy access to museums and use them to improve their wellbeing (Benevides et al., 2020; Lai et al., 2019). Many museums are striving to be institutions that can enhance the mental wellbeing of their visitors and local communities (such as Chatterjee & Noble, 2013). To achieve this, they must be aware of the elevated levels of anxiety that AuND people may experience and work to develop experiences that can help improve neurodivergent mental wellbeing. They must demonstrate their commitment to supporting the needs of local communities by tailoring what they offer to a variety of individual needs. With neurodivergent respondents highlighting the levels of discomfort, stress, anxiety, and feelings of exclusion when an environment is not accessible versus the sense of welcome, comfort, and sense of belonging they feel when their needs have been considered, efforts to improve the general accessibility within a space could have a positive impact on mental wellbeing for neurodivergent visitors.

The lowest response to reasons for visiting cultural heritage organisations was to options related to necessity or passive attendance: for example, needing to visit because of work or volunteering in a museum, or required attendance as part of their education. Passive attendance – for example, only visiting to use facilities such as bathrooms or because there was “nothing else to do” – was limited in the survey responses. This suggested that, for those who do choose to go to museums, this results from a genuine desire or interest to be in cultural spaces. It is significant that the AuND people who participated in the survey – regardless of

their views on the barriers within a space – had a genuine interest in visiting. This is confirmed by the high response to the survey, with many responses highlighting the importance that participants placed on making museums accessible so that they can visit.

There are numerous reasons for visiting museums for AuND adults. The survey captured recurring topics – connecting to friends/family, cultivating existing or forming new interests, and enjoyment of being in gallery settings – all of which demonstrate potential motivations for visiting. A positive observation of the common motivations shows the potential of museums that address their barriers to become not only the source of a neurodivergent person's interests but also a sanctuary and social hub.

#### 4.3.4 Current and Potential Museum-visiting

It was hoped that the data from this survey would be informative about the current motivations of AuND respondents to visit museums versus how often they would want to visit museums if they worked to enhance their accessibility for AuND audiences. With museums focusing on projects or audiences that they deem priorities because of their potential to boost overall audience attendance, I felt that this data would help museums understand the impact of prioritising AuND people's needs on this audience's attendance at their institutions.

The current pattern of responses shows that there was not a current dominant pattern. Instead, respondents stated that they went during times when they felt that their access needs would be met. Typically, this meant during quieter times, but these times often coincided with work or other obligations. There were no strong preferences for times of the day or days of the week, suggesting that most neurodivergent respondents were open to the idea of attending when they could. Open-text responses highlighted a preference for evening times, despite museums typically being closed during these times. Others stated that morning events do not usually work because of other commitments or because they need to rest. This suggests that museums may benefit from directly contacting local AuND groups to discover preferences in their community.

It is important to examine how the visiting patterns identified in the AuND survey compare with more general visitor research. However, most UK visitor research is limited in scope — it typically focuses on either specific institutions (for example, large organisations like The British Museum who are members of the Association of Leading Visitor Attractions or are DCMS-sponsored), or reports aggregate total visitor numbers rather than include the breakdown of audience type or the times of the day that visits most commonly occur (see



ALVA, 2023 for an example)<sup>21</sup>. This indicates that insights into the day-to-day patterns of visitors are either not recorded or reported in an accessible way. Another factor to consider, as identified by Sara Selwood (2018), is that these visitor numbers tend to count the overall number of visits to a museum, rather than the number of visitors who return or are one-off – which means many museums are unable to measure the exact number of visitors to understand if their programming is successfully resulting in visitors returning or attracting new visitors. Consequently, it is not possible to directly compare the visiting patterns of AuND respondents to this study with those of general visitors, other than to note that the DCMS (2024) have identified that visiting can fluctuate depending on whether there are school holidays or temporary exhibitions (which can result in higher visiting numbers) or when there is refurbishment (which can result in lower numbers due to closures either of areas or the whole institution). However, existing research offers some insight into what affects visitors' preferences. For example, Morris Hargreaves McIntyre (2020) analysed factors influencing visits to DCMS-sponsored museums. Their research found that visitors are drawn to museums as social places where they can spend time with others, value easy access to facilities and services within the space, and prioritise feeling welcomed by museum staff (ibid). These preferences align closely with AuND respondents' vision of an accessible museum —one where they feel welcomed, can easily access space and facilities, and can share meaningful experiences with friends and family. However, as discussed, many barriers to museum access cut across different demographic groups— from practical obstacles like transportation and admission costs to social and cultural factors like socio-economic background (for example, see Whitaker, 2018). The limited availability of comparable data on visiting patterns and visitor preferences highlights the need for more research examining both the shared experiences and unique challenges faced by AuND-identifying visitors compared to other community groups.

The “potential” visit pattern if museums were more accessible was one of the most meaningful results from the survey. With current frequency results less frequent than “once every 6 months” on average, the “potential” was the opposite, with the highest response “once a month”. These findings reflect the significant levels of motivation observed when considering reasons for visiting, as well as the respondents' willingness to participate in the survey and identify what would improve their experiences.

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<sup>21</sup> Only one paper could be found that discussed time preferences by Gao and Yu (2024), which looked at online reviews of museums from the Jiangxi Province of China. Their use of keyword and content analysis revealed that “afternoon” was the most commonly referred to time of the day when visitors reviewed their visits between April 2020 and May 2023.

While we cannot say with certainty that enhancing accessibility in museums for neurodivergent audiences is enough to increase visiting numbers, particularly to the level identified in the survey, it does demonstrate the potential to do so over time. With a potentially motivated neurodivergent audience that would benefit from museums making active and meaningful efforts to enhance their accessibility by working with ND adults, cultural heritage institutions and AuND people could benefit equally.

# Chapter 5 Understanding Current and Potential Provisions for AuND Visitors: Museum Worker Motivations, Barriers, and Development Areas

In addition to understanding the requirements of neurodivergent adults in making a museum experience accessible to their needs, it was crucial to understand the museum sector's current provisions and plans. This is because there is a variety of reasons why barriers exist within museums and these have been challenging to locate or address for museum workers. Directly asking museum workers to reflect upon their own organisations' current or future work – as well as what positively or negatively impacts these projects and provisions – helps to better understand why decisions are made. This research can provide insight into the types of sectoral guidance or support that would be beneficial in enabling cultural heritage organisations to become more neurodivergent accessible. This chapter focuses on the findings from the second survey of this project, which sought to gain insight from museum workers who have worked in the cultural heritage sector – both as paid and unpaid workers – about what they currently provide for AuND audiences.

## 5.1 Survey Overview

The survey (see Appendix [C.2](#) for the full survey) was launched online in November 2022 and ran until February 2023. It received 130 full responses from a diverse group of respondents, which will be discussed in the quantitative section of this chapter. It was open to anyone aged over 18 who had worked within a museum (or other GLAM organisation) within the last five years as an employee or volunteer and could read/write in English. There were no geographical restrictions, and neurodivergent workers who had taken part in the AuND survey from a visitors' perspective were also welcome to participate in this survey. This enabled those individuals to share more about their experiences as museum workers. Following the consent and demographic questions, the survey clarified its dual focus: understanding both the respondents' individual work roles and their organisation's broader efforts to improve accessibility for AuND people.<sup>22</sup> While most questions focused on institutional practices,

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<sup>22</sup> Under the section: "INFORMATION ABOUT YOUR WORK, THE ORGANISATION AND THEIR PROVISION FOR AUTISTIC / NEURODIVERGENT VISITORS", the survey stated: The following section

question 10.3 (Appendix [C.2](#)) specifically asked what provisions “you” personally use to develop accessibility— a framing that may have posed challenges for respondents not directly involved in their organisation’s accessibility initiatives.

The questions were designed to complement those from the AuND survey, such as the question on the definition of “accessibility” and the question on whether the respondent identified as neurodivergent. This was to determine any similarities or differences in understanding of accessibility and neurodiversity between these two groups. It was also important to identify barriers that impact the practical implementation of adjustments for neurodivergent audiences and to identify those that impact potential museum visits. This chapter is split into similar sub-sections as found in [Chapter 4](#): 1) Quantitative data, looking at the demographics of those who took part, 2) Qualitative data, exploring the common topics that have emerged throughout the survey and 3) Discussion, interpreting what the data and topics mean about making museums more accessible for AuND people – whether visitors or workers. These topics address research questions 2 and 3:

- 2) What do museums currently offer autistic and neurodivergent visitors, and what are the barriers museums face when addressing their accessibility issues?
- 3) How can museums learn from autistic and neurodivergent adults to adapt their practices to become more engaging and accessible to this audience?

Throughout this chapter, comparisons are made between the data and findings of the AuND survey where appropriate. In addition, some of the quantitative questions are examined based on the respondent’s neurotype identity (i.e. whether they self-identify as AuND or not) to determine whether this affects attitudes or experiences within the sector. This is intended to reflect on the importance of examining the views and experiences of AuND adults throughout the research and ensure that they are incorporated into future practice across the sector.

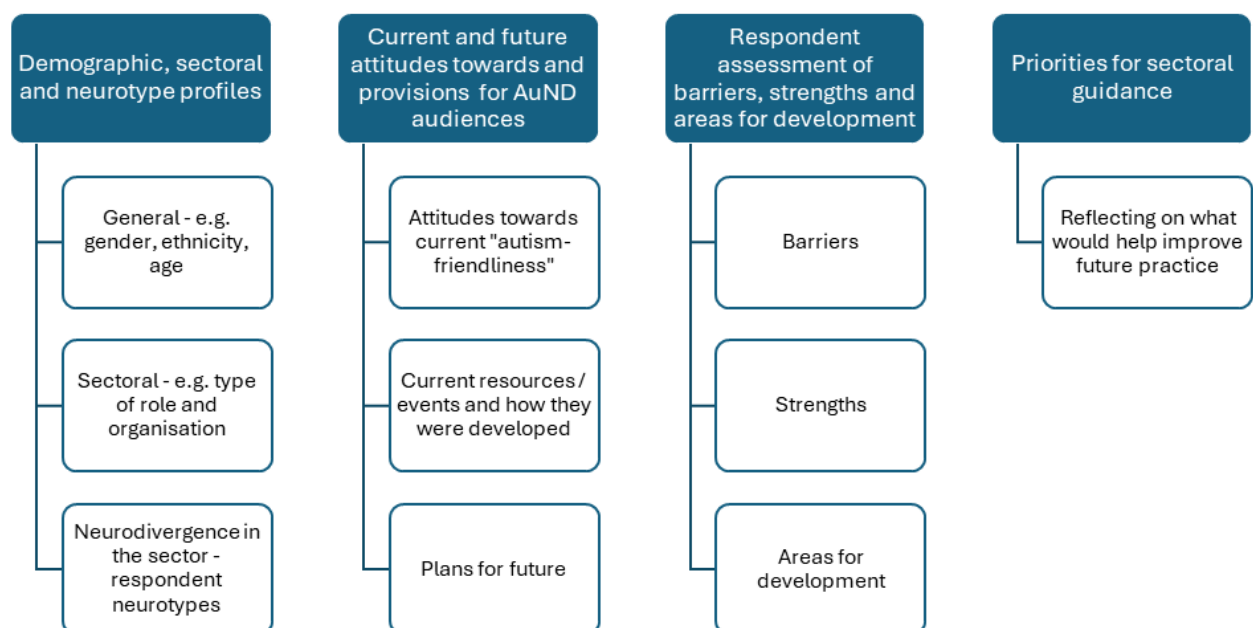
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shall ask questions about you, the organisation you work / volunteer for and what they offer for autistic / neurodivergent visitors. All contributions made will be used to inform understandings of what is available in museums, galleries or other cultural heritage organisations in Scotland currently, and to develop guidelines and approaches to enhance accessibility for this audience.”

## 5.2 Quantitative Data

This section explores the quantitative data collected from the survey responses. To meet the needs of the museum workers, this survey was intended to include closed questions with the option for respondents to provide more specific details in open boxes. This decision was made following the development of the survey, using informal advice from supervisors and other museum workers regarding the likelihood of respondent drop-out resulting from too many open-ended questions. The surveys collected confirmed this, showing a higher rate of respondents skipping open-ended questions, with completion dropping from an average of 95% for closed-type questions to an average of 50% for open-ended questions.

The quantitative data has been organised thematically based on the type of information gathered in the questions into the following categories:



*Figure 5-1 Thematic map of the quantitative data.*

Before exploring the themes identified in the survey, it is crucial to understand the demographics of the respondents.

### 5.2.1 Demographics, Sectorial Profile, and Neurotype of Respondents

The respondents were asked to complete basic demographic information questions at the beginning of the survey. This was to identify who took part in the survey and whether any groups were under-represented. In addition, it was useful to gain insight into any differences present depending on demographic representation. The below diagram shows the 130 respondents' answers to common demographic questions regarding their age, gender, ethnicity, and geographical residency.

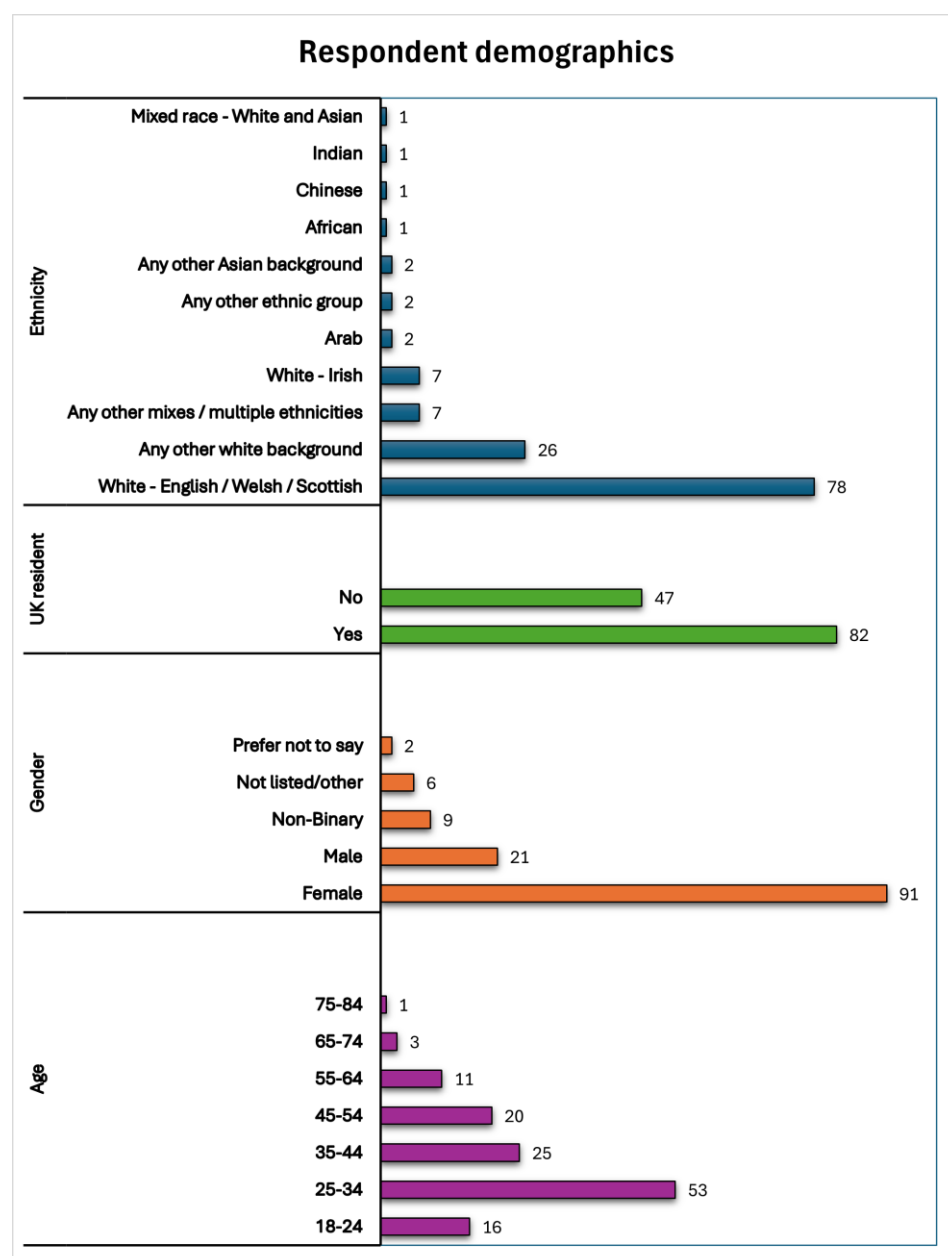


Figure 5-2 Diagram of respondent demographics, measured by number of responses.

The above diagram demonstrates that the survey was completed by a sample that is reflective of the cultural heritage sector within the areas where most respondents took part. The distribution of ages and gender identity of the respondents was reflective of the workforce in the UK and USA, where many of the respondents were from (Statista, 2021; Arts Council England, 2020; Sweeney et al., 2022). Perhaps surprisingly, the number of respondents identifying as “non-binary” in this survey was approximately 7%, while the ACE (2020) report’s percentage was under 3% (<1% of permanent staff). This slightly higher representation in the present survey could be connected to the proportion of AuND-identifying respondents that took part and increasing societal awareness of non-binary people since the ACE survey was undertaken in 2019/2020 (Warrier et al., 2020). Moreover, some respondents may have felt more comfortable disclosing personal details about gender in an independent survey than they might in an organisation or sector-wide one.

The lack of diversity in both ethnicity and geographical residency of the respondents is evident. This reflects the limited range of the survey because it is only available in English and shared on UK- and USA-based platforms. However, it may reflect a wider issue within the sector. According to ACE’s (2021) survey,<sup>23</sup> this is reflective of the workforce in England, where 51% of staff identified as “white”, 6% as “white other” and only 14% as “BAME (Black, Asian and Minority Ethnic)”. This echoes the findings of the Art Fund’s (2022) Curatorial Diversity report, which found few ethnic diversity workforce initiatives in the UK’s arts and heritage sector – particularly in comparison to the growing investment in diversifying the workforce in the USA – and only 2.7% of GLAM sector workers in the UK as a whole coming from ethnic minority backgrounds (Francis, 2018). Meanwhile, in the US, there appears to be an ongoing demographic shift with a slight increase in staff and 40% of new hires being people who identify as “Hispanic, Asian, and those who are Two or More Races” (Sweeney, et al. 2022). This suggests that the survey findings may reflect the current gap in ethnicity in the UK museum workforce. However, this could be based on data from before COVID-19 and not a reflection of the current workforce in the UK and internationally. The survey data must therefore be reflected upon with these gaps in mind.

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<sup>23</sup> In 2020, the 2019/2020 statistics were: 47% identified as “white”, 6%, as “white other”, and only 11% as “Black Minority Ethnicity”. This shift in 2021 shows that fewer “not known” responses were recorded and more people who identify as “white” or “Black, Asian and Ethnically Diverse” (as per 2021’s language change from BME). This slight increase appears to be reflective of post-COVID-19, and is possibly positively impacted by wider societal calls for greater inclusion and ethnic diversity within the sector. For example, the MA launched its “Museums and Anti-Racism” campaign (n.d., post-2021).

### 5.2.1.a Sectoral Profile

This survey asked whether respondents had been employed in the cultural heritage sector in the last five years at the time of taking part. These five years were chosen to ensure that the responses were from individuals who had recent experience in the sector that covered pre-COVID-19 times and the period of restrictions. Any individuals who had not been employed within the sector within five years, either in a paid or unpaid capacity, would exit the survey as they did not meet the minimum criteria to complete it.

### 5.2.1.b Organisation and Role Type

The respondents were asked questions about their organisation and role type to better understand how representative the sample was of the sector. As the survey could be conducted anonymously, this question was not mandatory, and respondents could choose to provide fewer specific answers. Instead of responding with their exact organisation name and role title, they were advised that they could instead write the organisation type – such as a large national or small local museum or art gallery – to protect their identity.

A range of diverse types of organisations were represented. Although some respondents chose to name their organisation directly, others chose to be referred to by type. Most respondents used the term “*museum*” to describe their organisation. In some instances, this may be because this is a word in the title, while others used it alongside a descriptive phrase – for example, “*small local*”, “*history*” and “*independent*” museums. Others stated that they worked in a “*gallery*” or “*heritage*” organisation. Finally, some respondents answered that they worked in a “*library*” as one respondent was a worker at the National Library of Scotland, demonstrating that diverse types of organisations within the GLAM sector were represented in the survey.

Respondents were invited to share their role, or role type, in their organisation. As the table below indicates, the respondents came from a diverse range of departments and levels of authority within their organisation (e.g. volunteers and directors).



ORGANISATION TYPE	NUMBER OF RESPONDENTS
MUSEUM (LARGE, NATIONAL OR UNSPECIFIED TYPE)	62
MUSEUM (SMALL / INDEPENDENT)	19
UNIVERSITY MUSEUM	5
GALLERY	13
SCIENCE CENTRE	3
HERITAGE CENTRE OR ORGANISATION (UNSPECIFIED)	6
HISTORIC BUILDING OR NATIONAL PARK	7
LIBRARY / ARCHIVE	1
CHILDREN'S MUSEUM	3

ROLE TYPE	NUMBER OF RESPONDENTS
DIRECTOR, CEO TRUSTEE OR MANAGEMENT POSITION	25
CURATORIAL (E.G. CURATOR)	23
LEARNING AND ENGAGEMENT	37
MARKETING, FUNDRAISING AND HR	7
COLLECTIONS (E.G. COLLECTIONS MANAGEMENT AND RESEARCH)	9
FRONT OF HOUSE, TOUR GUIDES AND RETAIL	18
VOLUNTEER AND / OR INTERN	12
ARCHIVIST / LIBRARIAN	3
CONSULTANT / FREELANCE (ACCESS SPECIALIST)	2

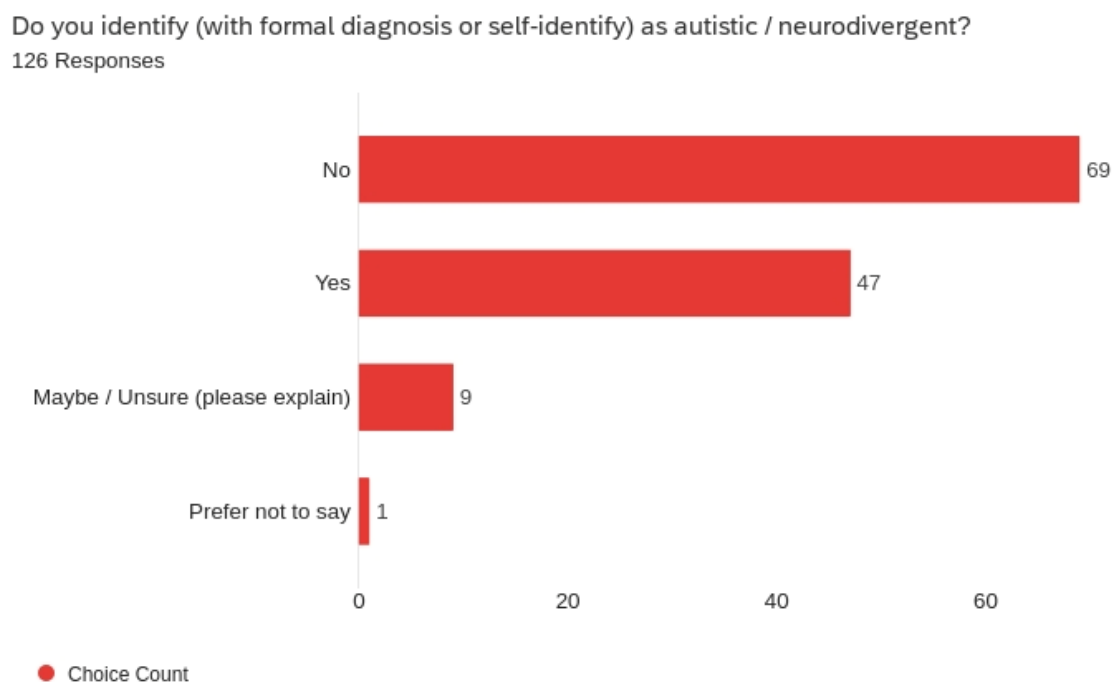
*Figure 5-3 Table of organisation types and role types represented by the 123 respondents who responded to this optional question.*

A wide range of job positions are apparent within the sector. Volunteers, paid staff, and public-facing and decision-making positions were all represented in the sample of responses.

While the total number of respondents is not representative of the extensive range of museum workers internationally, the range of roles covered among respondents offers an insight into different organisation types and perceptions dependent on status or role within institutions.

### 5.2.1.c Neurodivergence and Attitudes Towards Autism Accessibility Among Respondents

The respondents were asked whether they identified as neurodivergent. In contrast to the AuND survey, where it was a requirement that all respondents identified as neurodivergent, this was entirely optional. This question was included to understand whether the respondents were coming from a place of personal experience or motivation – for example, to improve the experience of other neurodivergent people like themselves – and potentially more knowledgeable of the subject.



*Figure 5-4 Diagram of how many respondents identified as autistic/neurodivergent.*

Of the 126 people who responded to this question, 47 responded “yes” and nine responded “maybe/unsure”. This is disproportionately higher than would have been expected when considering the lower levels of neurodivergent conditions diagnosed in adults compared

to children as reported in the UK.<sup>24</sup> On the one hand, this could be impacted by my involvement in AuND online communities, thus resulting in more AuND people working in the sector accessing the survey. On the other hand, it is worth considering that there are certain sectors – including academia and computing (see British Interactive Media Association, 2019) – where it is believed that there may be higher rates of AuND people working than in other sectors.<sup>25</sup> In a report by Freeman and Morris (2020) examining the impact of COVID-19 on employment in the Digital Culture Media and Sports (DCMS) sector, approximately 20% of the creative workforce self-reported as AuND. According to the Arts Council England (ACE, 2020)’s annual survey (2018-2019), approximately 7% of the workforce was known to be “disabled”, 58% “not disabled”, 29% “unknown”, and 7% “prefer[ed] not to say”. ACE’s 2021 EDI data report showed that among the total workforce, 7% identified as “disabled”, 56% as “non-disabled”, 31% preferred not to say, and 5% were “not known. The high number of “unknown” and “prefer not to say” responses suggests that disclosure issues may impact our understanding of how many people working in arts and cultural organisations, such as museums, may be disabled. Furthermore, the number of disabled people in the workforce remaining 7% in both the 2018 and 2021 reports suggests that there may not be support or initiatives that are successfully recruiting and retaining disabled people in the workforce. Whilst it is unclear how many of the 7% disabled workers identified in the ACE reports were AuND people, Catherine Bouckley (2022) suggests that the low numbers of AuND people in employment in general can be attributed to the labour market typically privileging neurotypical ideas of working. In particular, expectations relating to communicating and networking being set by neuroconforming people, can result in AuND people feeling excluded from the workforce.

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<sup>24</sup> Recent research has been carried out by University College London (UCL) and partners into the current number of adults diagnosed as autistic in the UK vs the potential adults who are not diagnosed for a number of reasons (e.g. changing diagnostic criteria, lack of access to assessment, past lack of understanding of autism, and different presentation) to estimate the potential total of autistic people living (diagnosed and undiagnosed) in England. The researchers used a population-based cohort study of existing primary care data in England to estimate that there may be between 435,700 and 1,197,300 adults aged 50+ in England who are autistic but undiagnosed (O’Nions et al., 2023). The NAS (n.d.) estimate that there could be around 700,000 autistic children and adults living in the UK. Both estimates are substantially higher than the commonly quoted 100,000 in government publications, demonstrating that this is an area where further research and better diagnostic services are crucial to better understand the true prevalence of autism and other ND conditions.

<sup>25</sup> This belief is one commonly shared within neurodivergent communities but is challenging to prove in a quantifiable way because of issues with lack of access to a formal diagnosis, as discussed in footnote two, and the fears of many people about the risk of experiencing discrimination in the workplace if they are open about their disability. One way of evidencing the presence of a high number of neurodivergent people is the increase in “Neurodiversity Networks” for colleagues to find peer support and advice. For example, the UofG has its own Neurodiversity Network. The mere existence and demand for such spaces demonstrate that there is a substantial presence within at least the institution where this research has been undertaken.

### 5.2.1.d Preferences for Language when Referring to Neurodivergence

The survey aimed to determine what language the museum workers who responded “yes” to being neurodivergent preferred to use when referring to themselves. In total, 53 respondents, out of 130 who participated in the survey, responded to this question. The highest response was “*neurodivergent*”, with 32 individuals responding either “*neurodivergent*” on its own or clarifying specific diagnoses. The second highest was “*autistic*”, with 16 people using identity-first language and three respondents preferring “*person with autism*”. 13 of the respondents identified as having “*ADHD*”, while three stated that they had a “*Sensory Processing Disorder*” and two identified as having co-diagnoses of dyslexia (one with ADHD and the other respondent as autistic). One respondent expressed that they had four co-occurring conditions. Most respondents to this question identified as having two or more distinct diagnoses or neurodivergent identities. This reflects our growing understanding that high numbers of neurodivergent people – particularly autistic people – have co-occurring conditions (WHO, 2023b; NICE, 2017).

More responses in this survey indicated a lack of certainty of a specific “*label*” or “*preference*”, instead indicating the AuND characteristics they related to. These tended to be connected to “sensory” processing, while others suggested discomfort at labelling without a formal diagnosis. This suggests that some people may have taken part who could be AuND but are not aware of this (because of wider issues surrounding societal understanding) or do not feel comfortable with self-identifying without a diagnosis. In addition, while some respondents relate to many characteristics associated with neurodivergence, they may not always feel that they relate to these strongly enough or in a way that impacts their day-to-day lives enough to identify themselves as having a specific disability.

### 5.2.2 Current and Future Attitudes Towards and Provisions for AuND Audiences

In this section, visualisations of the data from the quantitative questions will be analysed and interpreted using cross-sectional data about the respondents. While the visualisations will present the data gathered from all respondents, regardless of the respondent’s neurotype or confidence level, this section explores this data concerning the respondents’ identity as AuND or not to measure for differences in viewpoints dependent on whether the person is neurodivergent. Further, some of the themes reflect on how “autism-friendly”<sup>26</sup> the respondents

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<sup>26</sup> The term “autism-friendly” was used as this is a recognisable and commonly used term within the museum and wider cultural heritage sector. Often it is used as a ‘catch-all’ for anyone with sensory needs.

viewed their organisation to understand which factors might impact their measurement of accessibility. Below is an example of the type of cross-section of respondents that will inform the analysis:

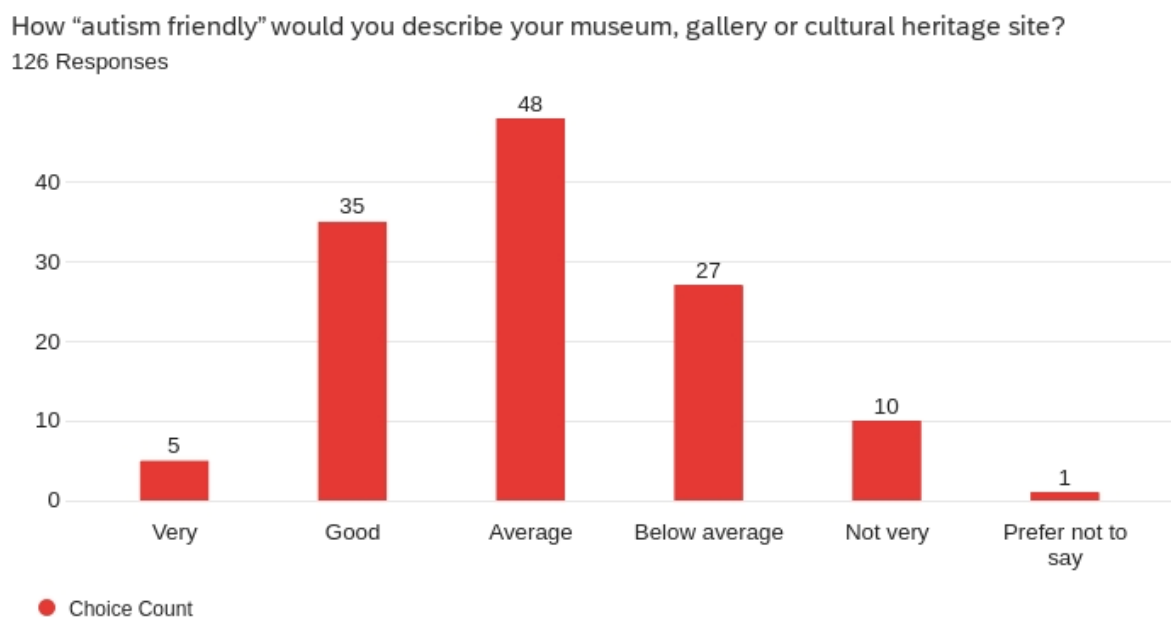
		Q6.1: How “autism friendly” would you describe your museum, gallery or cultural heritage site?						
		Total	Very	Good	Average	Below average	Not very	Prefer not to say
Q4.5: Do you identify (with formal diagnosis or self-identify) as autistic / neurodivergent?	Total Count (All)	126.0	5.0	35.0	48.0	27.0	10.0	1.0
	Yes	47.0	2.0	10.0	19.0	11.0	4.0	1.0
		37.3%	40.0%	28.6%	39.6%	40.7%	40.0%	100.0%
	Maybe / Unsure (please explain)	9.0	0.0	3.0	5.0	1.0	0.0	0.0
		7.1%	0.0%	8.6%	10.4%	3.7%	0.0%	0.0%
	No	69.0	3.0	22.0	24.0	15.0	5.0	0.0
		54.8%	60.0%	62.9%	50.0%	55.6%	50.0%	0.0%
	Prefer not to say	1.0	0.0	0.0	0.0	0.0	1.0	0.0
		0.8%	0.0%	0.0%	0.0%	0.0%	10.0%	0.0%

*Figure 5-5 Cross-examination of the potential connection between respondents’ neurotype identity and confidence in their organisation’s “autism friendliness”.*

Notably, when discussing the percentages of responses to each question by neurotype or attitude towards their organisation’s “autism friendliness”, differences often emerged. For example, when discussing the percentage of AuND-identifying respondents’ responses to a question, the percentage comes from the 47 respondents who identified as AuND in the survey rather than the 69 respondents who stated that they were not AuND. These percentages are contrasted to determine whether their response could be connected to the respondent’s confidence or neurotype.

### 5.2.2a Attitudes Towards Accessibility for Autistic Audiences in Respondents' Organisations

The respondents were asked to consider and rank how “autism-friendly” they perceived their organisation to be. While this research is for AuND adults, the survey acknowledged that most of what is already available tends to be labelled as “autism-friendly” and this is therefore a more recognisable term for museum workers who may have less experience or understanding of neurodiversity.



*Figure 5-6 Diagram showing how “autism-friendly” respondents described their organisation as, from “not very” to “very” autism-friendly.*

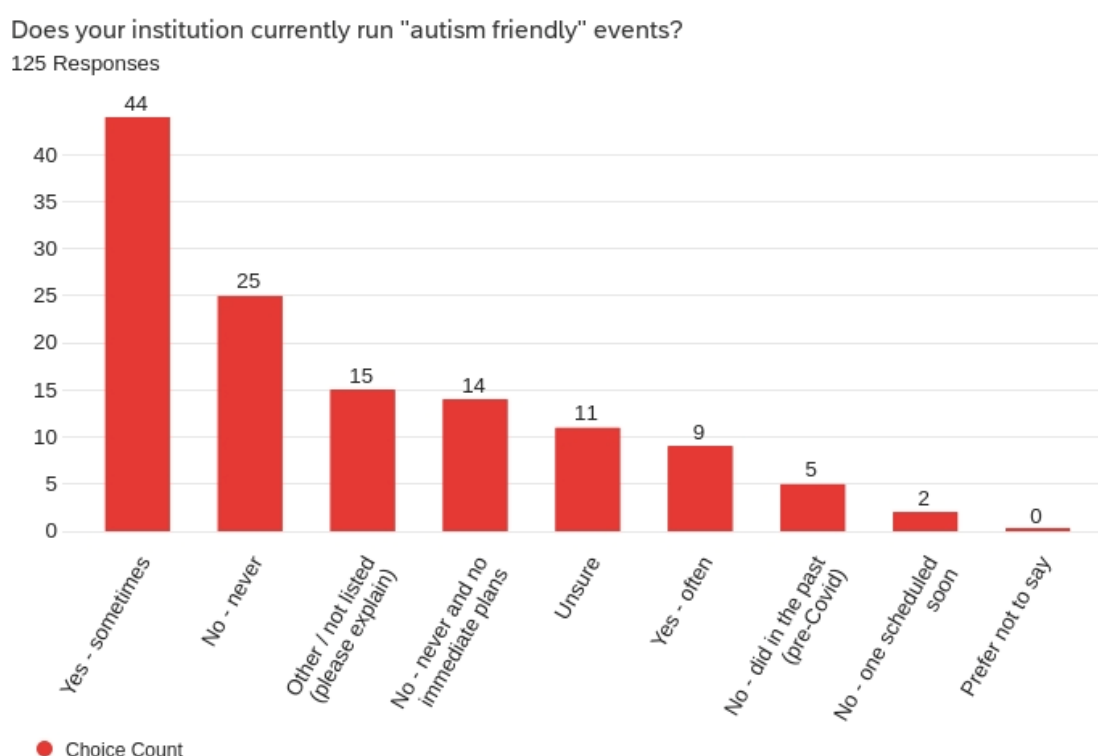
While the above diagram demonstrates that the majority (38% of all respondents) felt that their organisation was “average”, there was a slight disagreement in whether it was deemed above or below average dependent on whether the respondent identified as AuND. When examining the data using the lens of diagnosis, it was found that AuND respondents were more likely to respond with “below average” (23% of 47) or “not very” (9%) than those who were not AuND-identifying. For those who did not identify as AuND, 35% felt that they were “average” with 32% (of 69 respondents) stating that their organisation was “good” and 4% stating that they were “very good” respectively (this percentage was the same for AuND respondents). That is not to say that all the respondents who did not identify as AuND felt that their autism friendliness was above average. 22% felt it was “below average” and 7% felt that they were “not very” friendly. This suggests that people who identified as AuND were more

likely to rate their organisation’s autism friendliness as “average and below” when compared to those who did not identify as AuND.

The respondents were asked questions about what they currently offer to their visitors. These questions were designed to understand what was available to AuND visitors, and explore whether having specific provisions impacted their attitudes towards their organisation’s “autism friendliness”.

### 5.2.2b Events

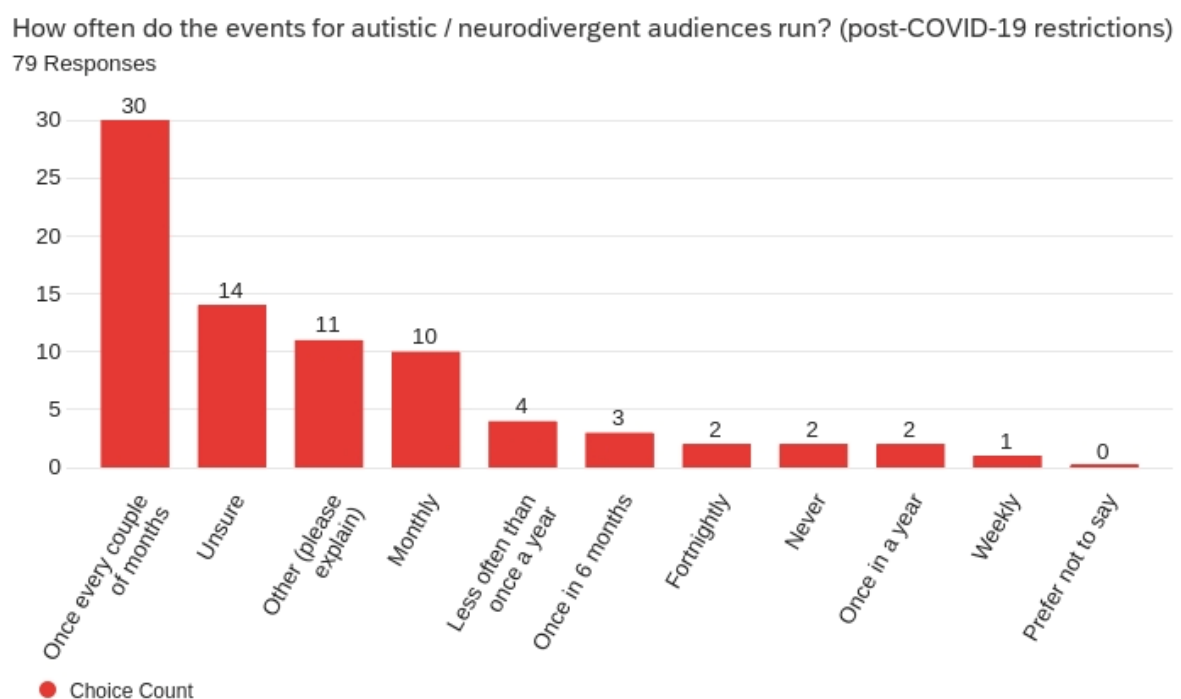
The first question asked about the availability of audience-specific events. Of the 130 respondents to the survey, only five did not respond to the question on whether their organisation currently hosts “autism-friendly” events. The diagrams below summarise the data on whether the respondents’ organisations offer events and resources for AuND visitors:



*Figure 5-7 Diagram showing whether respondents’ organisations currently offer any “autism-friendly” events.*

The highest response from all the respondents on average was “yes – sometimes” for both AuND and non-AuND-identifying respondents, with the second highest average response “no – never”. Comparison of the overall results of the autism friendliness rankings revealed

that there was not necessarily a correlation between those who ranked their organisation above average. Indeed, of those who ranked their museum “very” autism-friendly, 40% had never run events and had no plans to. This is compared to those who identified themselves as being “average” (19%) or “below average” (31%). It is notable that those who responded that they were “average” or below were more likely on average to organise events “sometimes” with 51% of those who ranked their organisation as “average”, 27% “below average”, and 39% “not very autism-friendly” respondents, respectively. This suggests that there is not a relationship between respondents’ neurotype and the ranking of their accessibility and availability of events at their organisation.



*Figure 5-8 Diagram showing the current frequency of events for AuND audiences at the respondents’ organisations.*

Asked about the frequency of the events for AuND audiences, while 30 of the 79 respondents to the question ran their events frequently, most respondents were either “unsure” or aware that it was not frequent.

Reflecting on the times the events were conducted, the majority of respondents to this question (48/68) selected that their events were conducted in the mornings, which is reflective of the findings discussed already in the literature review. A further 18 respondents selected “afternoons”, 15 selected “other”, and seven selected “evenings”. The majority of events for



autistic people, as well as those who would benefit from a “quiet hour”, are usually early in the morning. For instance, supermarkets such as Morrisons offer a “quiet hour” on Saturday mornings between 9am and 10am (Morrisons, 2018) and the Riverside Museum (Glasgow) offers theirs between 10am and 11am once a month on Fridays (Glasgow Life, 2024).

The final AuND event-related question asked respondents about their target audience age range. In contrast to the “time of the day” question, this question received 399 responses from 66 respondents, suggesting that most respondents conducted events or activities for a variety of age groups. The graphs demonstrate that many respondents who ran events aimed them at children. This is not surprising, as most events that are typically scheduled by museums often focus on family sessions for young people. Most organisations represented in this survey therefore arguably cater for AuND people under the age of 25, with fewer targeting adult or older adult audiences.

Comparison: What age ranges do your AuND events cater to?  
66 Responses

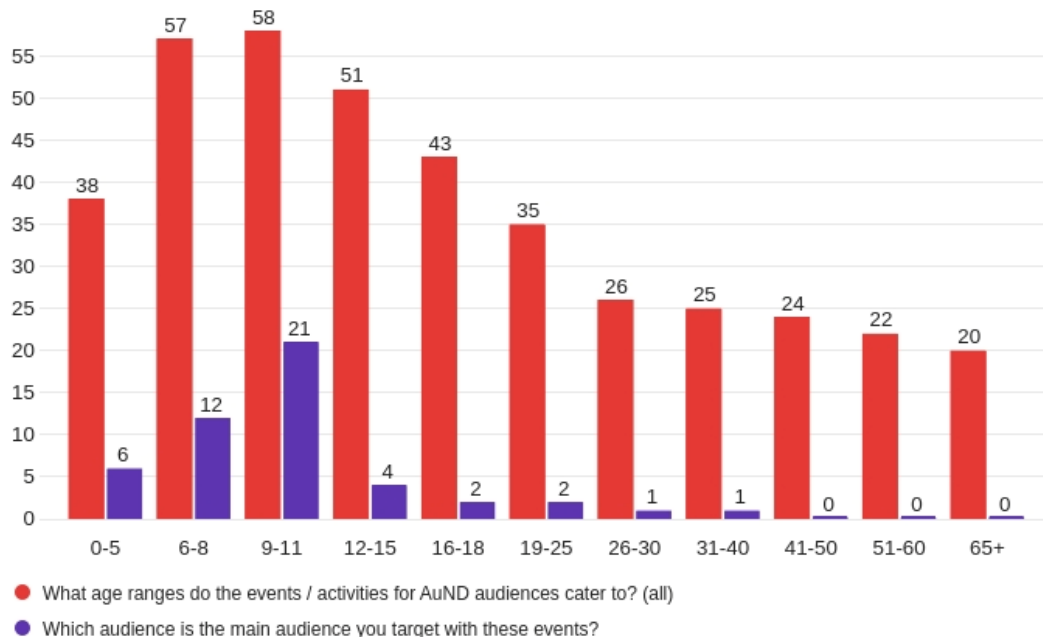


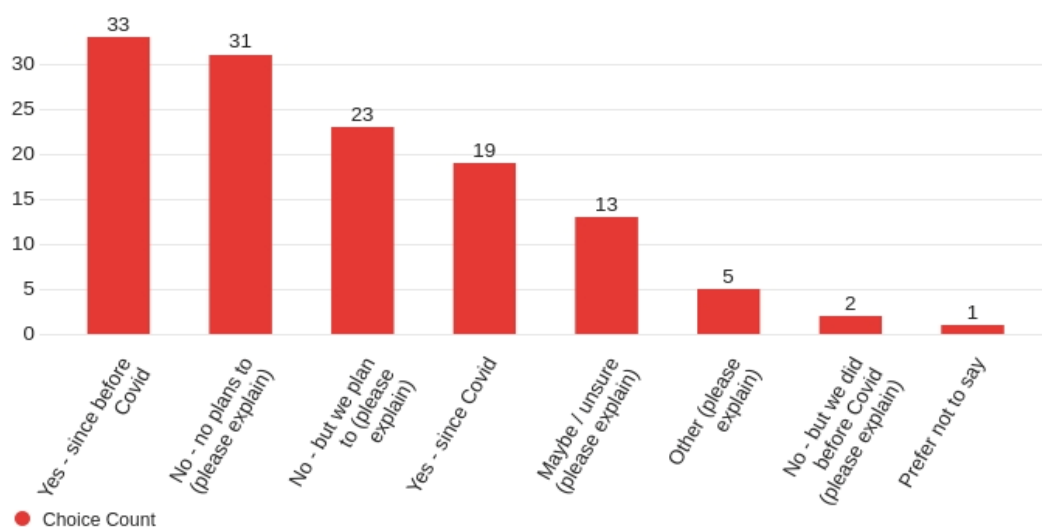
Figure 5-9 Diagram showing all the age ranges for which AuND-specific programming and resources are developed.

### 5.2.2.c Resources

The respondents were then asked to consider whether they provide specific resources for AuND visitors:

Does your institution currently have any autism resources (such as sensory maps, information packs, sensory backpacks)?

127 Responses



*Figure 5-10 Chart showing whether respondents' organisations currently have autism-specific resources available.*

The diagram above shows that most respondents either currently had resources available (41% of 127 respondents) or did not have any resources, with no plans to offer any (25% of 127 respondents). For those who expanded on why they had “no plans” to develop autism resources, the most common responses were:

- lack of funding
- staff and volunteers who worked on these projects left
- not a priority for management/trustees
- unsure what would be required in these resources.

Examining these responses with the data on autism friendliness outlined, there is a correlation between resource availability and confidence. According to those who responded that they were “very” autism-friendly, 80% of respondents had resources available pre-COVID-19 and 20% had resources following COVID-19. People who responded “good” had a similar pattern, with 46% having resources pre-COVID-19 and 17% following COVID-19.

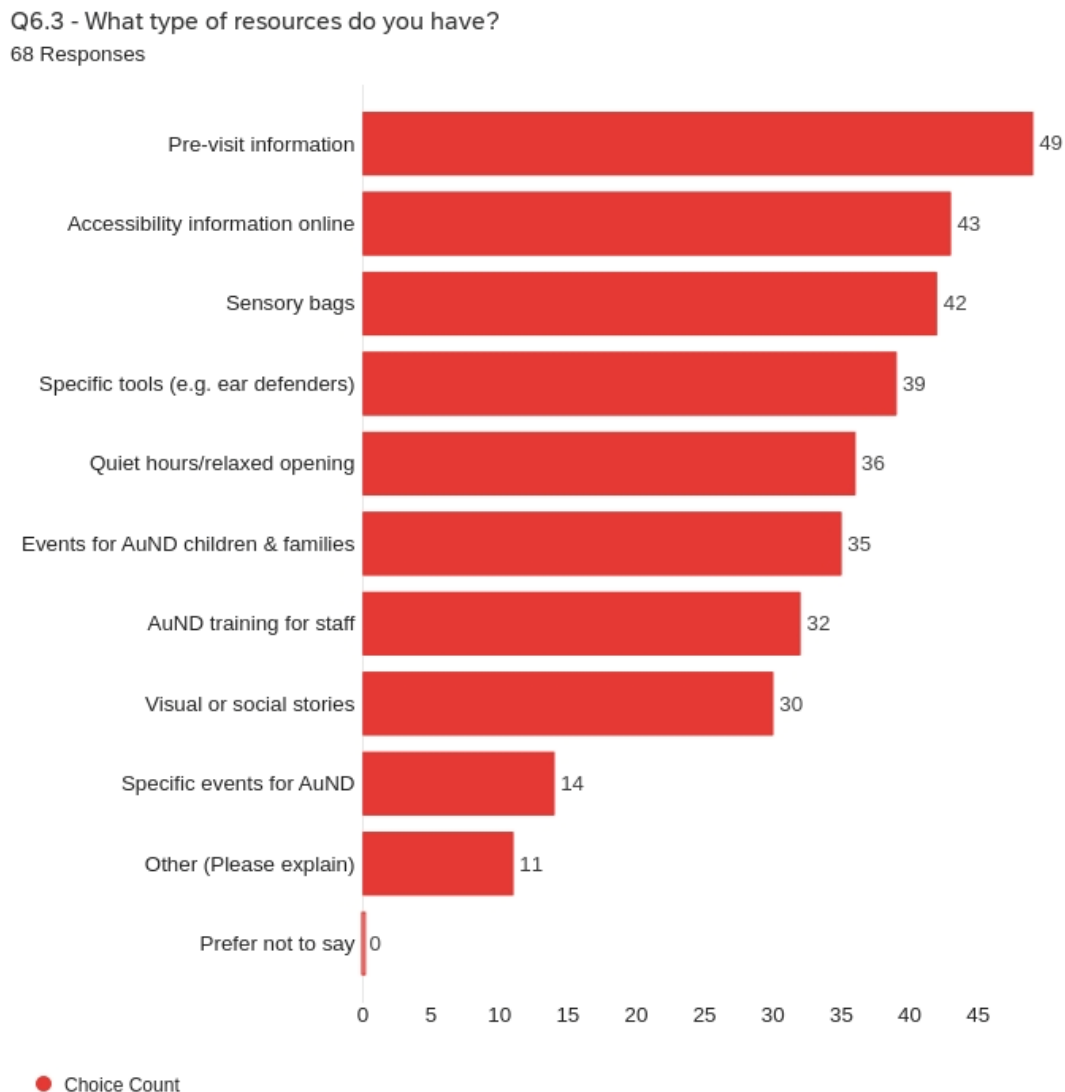
This is compared to those who responded “average” and below, where the highest category for each of these categories was “no – with no plans to”, with 26 individuals across these three categories selecting this option. Notably, a greater percentage of those who responded that their current autism friendliness is “below average” were more likely to have no resources but have plans to develop this. For example, 19% of those who rated themselves as “average” and 37% of those who rated themselves as “below average” were planning to address the gap.

Of those who expanded on their “unsure” answer, the most common reasons for their lack of certainty were:

- a) staff (including the respondent) who were responsible have left
- b) no designated resources specifically designed for autistic visitors
- c) lack of certainty about what is available since COVID-19 restrictions were introduced
- d) general uncertainty about whether what may be available is suitable for ND people.

### 5.2.2.d Overall Availability of Provisions for Neurodivergent Audiences

The respondents were asked to select what kind of provisions they offered to AuND audiences. Of those who responded that they provided “autism-friendly” resources for their audiences, 68 selected all the resource types they offer from a multiple-choice list:



*Figure 5-11 Chart showing what respondents identify as resources available at their organisation.*

According to the diagram above, most respondents selected more than one resource type from the list – from the 68 respondents who answered this question, a total of 331 total options were selected. The most common resource type was “information”, whether in the form of a pre-visit resource or information on their website. While the results were fairly consistent

on average, they did show that the organisations of respondents who were not AuND-identifying were more likely to offer sensory bags (41% of 68 respondents) and specific events for neurodivergent children (32%) than those who identified as AuND (23% of the 47 AuND-identifying respondents' organisations offered sensory bags and 19% offered events for neurodivergent children).

### 5.2.2.e Resource Development

As shown in the diagram below, the museum workers identified multiple sources of information when developing their current resources. Most respondents indicated that they use research into what other museums offer as the most common approach:

What resources did you use to develop your current provisions for AuND audiences? Please select all that apply.

70 Responses

Field	Choice Count
Researching other museum's resources (e.g. online research)	16% 33
Consultants (neurodivergent / autistic)	12% 25
Online blogs by professionals (e.g. Autism in Museums)	12% 25
Autism training (not museum / GLAM sector specific)	11% 23
Sector training (e.g. autism awareness training run within GLAM sector)	11% 23
Unsure	10% 21
Consultants (not neurodivergent / autistic)	10% 20
Online blogs by people with lived experience (e.g. neurodivergent or autistic people)	9% 18
Other (please explain)	8% 17
Case studies from the GLAM sector	2% 5
Prefer not to say	0% 0
Total	210

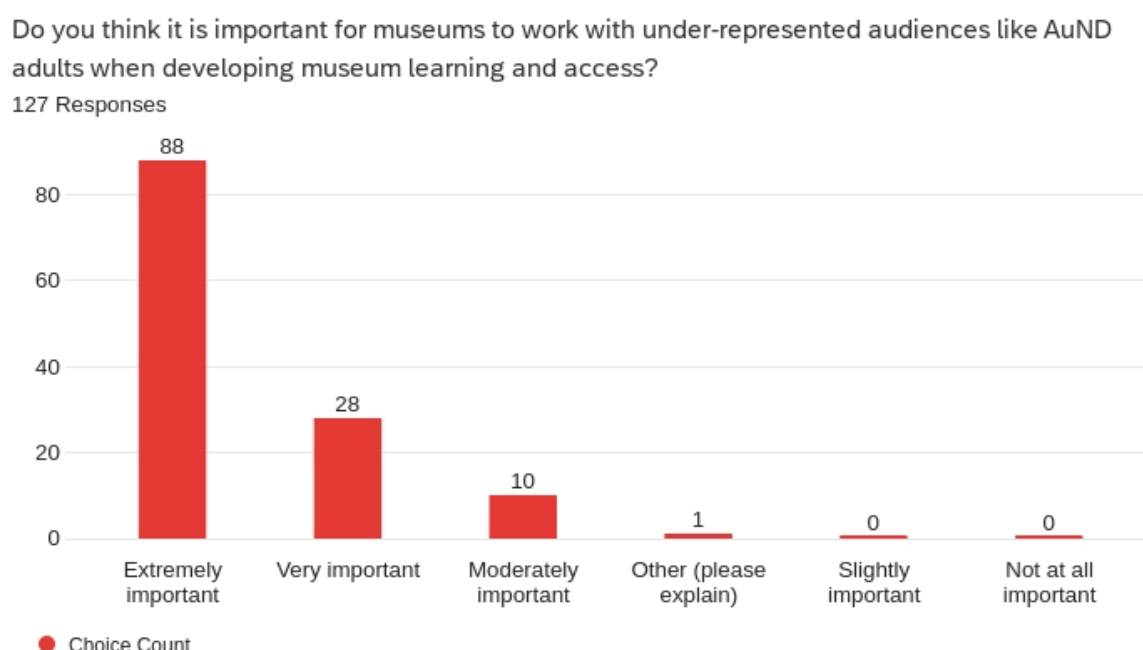
*Figure 5-12 Diagram showing what resources the respondents/their organisations used to develop resources for AuND visitors.*

Dividing the data into AuND and non-AuND-identifying categories revealed some neurotype-specific patterns. Non-AuND-identifying respondents were more likely to research what other museums offer (33%) and read online blogs (for example, Morris, 2017) by sector professionals such as Autism in Museums (26%). Notably, AuND respondents were more likely

to respond that they were “unsure” (21%) compared to 13% of non-AuND-identifying respondents.

### 5.2.3 Importance and Current Practice of Working Directly with AuND People

The respondents were asked to rank how important it is for museums to work directly with AuND audiences, and then to consider whether their organisations have undertaken this work:

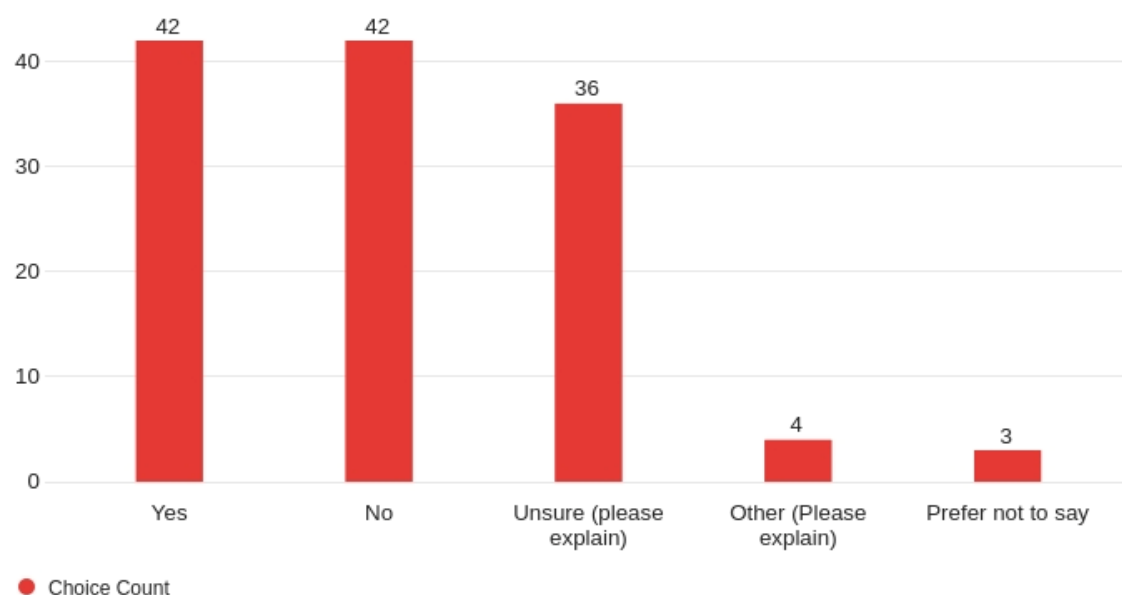


*Figure 5-13 Diagram demonstrating the level of importance that respondents place on the involvement of under-represented audiences (such as autistic/neurodivergent adults) when developing resources.*

According to the diagram above, most respondents (70% of the respondents) ranked it “extremely important” and 22% ranked it “very important”. Among the respondents who identified as AuND, 85% responded “extremely” and 13% responded “very” important. Compared to those who did not identify as AuND, 61% ranked working with AuND people as “extremely important” and 28% as “very important”. This indicates that, while the statistics are similar, AuND-identifying people ranked it more important to involve AuND people in developments than non-AuND-identifying people. However, was the level of importance of the direct involvement of AuND people in projects reflected in current practice within the respondents’ organisations?

Has your institution worked directly with AuND people before (e.g. access panel)?

127 Responses



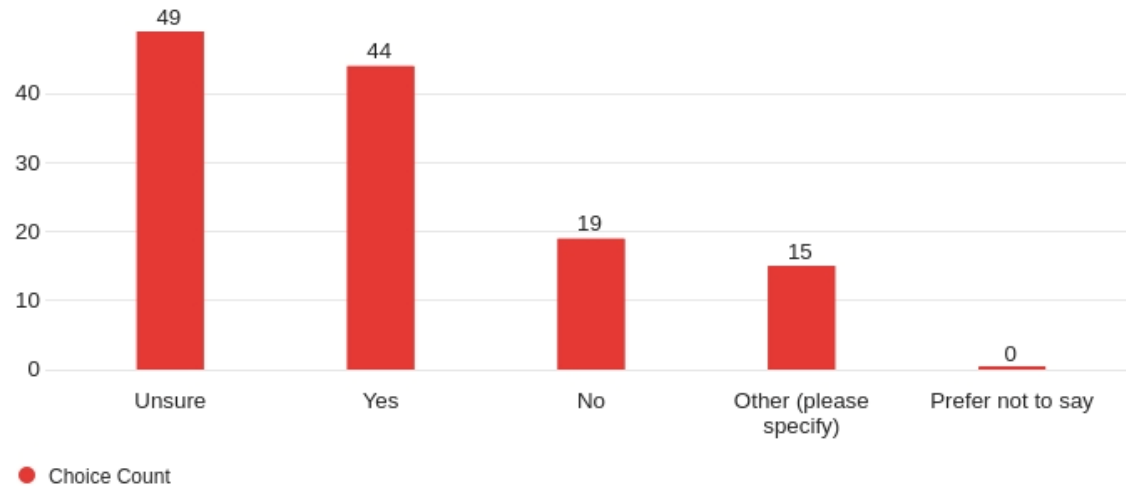
*Figure 5-14 Diagram showing how many respondents/respondent organisations have worked directly with autistic/neurodivergent people before.*

As the diagram above shows, there is nearly an equal split between the “yes”, “no”, and “unsure” categories for all respondents. Using the neurotype lens to analyse the data revealed that the percentage of respondents who responded “yes” is the same for both AuND and non-AuND-identifying respondents – 32%. However, AuND people were more likely to respond that they were “unsure” with 34% of respondents choosing this option (and either “yes” or “no” categories) when compared to 25% of non-AuND-identifying respondents. The highest response for non-AuND-identifying respondents, with 36%, was “no”.

## 5.2.4 Future Plans

Does your institution have upcoming plans to enhance its resources and visitor experience for autistic / neurodivergent visitors?

127 Responses



*Figure 5-15 Diagram showing whether respondents' organisations have current or upcoming plans to enhance what they offer for autistic/neurodivergent visitors.*

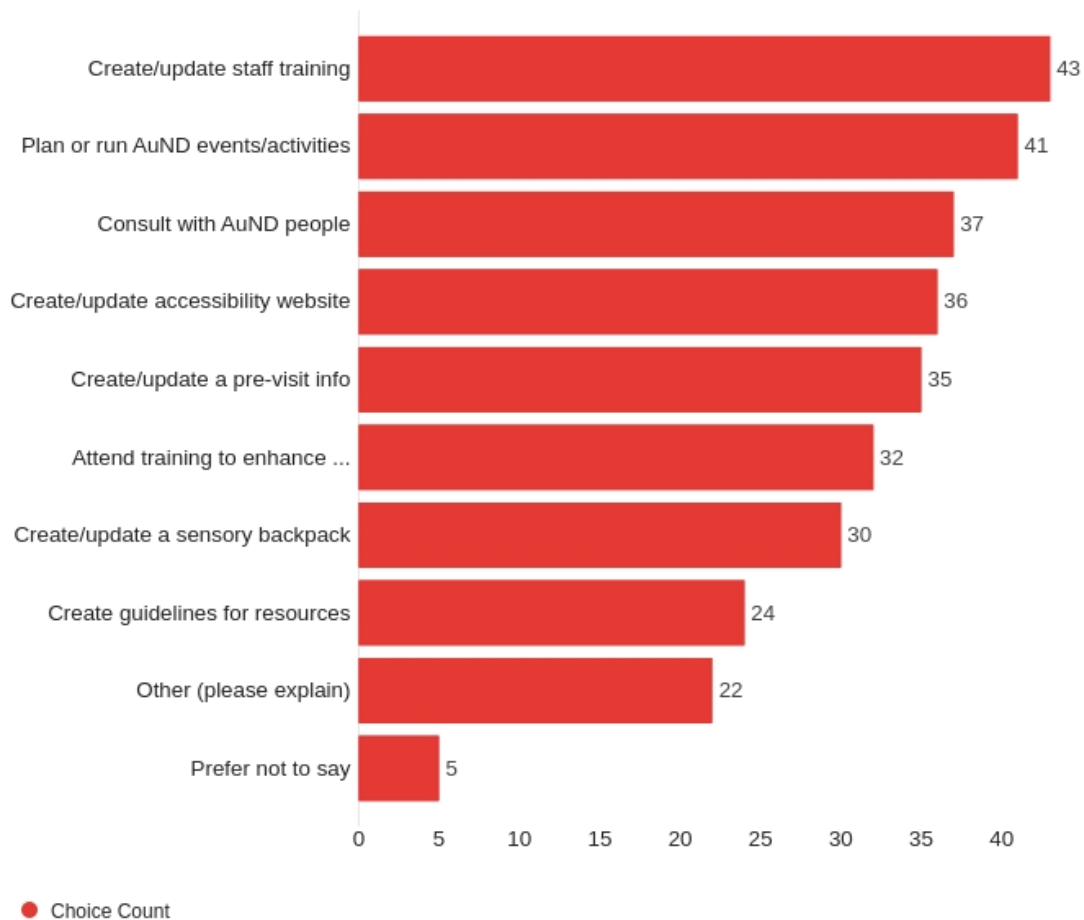
In addition to examining what is currently available for AuND audiences at the respondents' organisations, this survey asked whether they had plans to develop what is (or is not currently) available. The highest response, with 39% of all (127) respondents, was that they were "unsure", with 35% of respondents stating "yes" as the second highest response. When examining the data about the respondents' confidence levels and neurotype, certain patterns emerged. First, the highest "unsure" response rate came from those respondents who identified as AuND (47% of 47 respondents). In those organisations, AuND-identifying respondents are unaware or not involved in any plans to improve accessibility (therefore not including internal expertise by experience), or indicated that it is not a priority in their organisation. In contrast, those who did not identify as AuND were more likely to respond "yes" to having plans with 44% of 69 respondents stating this. When comparing this data to those who ranked their organisation as either "above" or "below" average, those who ranked their organisation as average or below were more likely to select "unsure" (40% of respondents who ranked their organisation as "average", 48% of those who identified it as "below average" and 30% of those who ranked it as "not very" autism-friendly). Those who stated that their organisation was "very" or "good" on the autism friendliness scale selected "yes" more often than "no" (e.g. 54% of the 35 respondents who said "yes" compared to 29% that said "average" and 26% that



said they were “below average”). This suggests that, while most respondents were unsure about plans, those who had higher confidence in their organisations’ autism friendliness were more likely to have plans than those respondents who viewed their organisation as “average” or below – approximately 67% of all (126) the respondents to this survey of those who completed it in full.

#### What does your institution plan to do for AuND audiences?

94 Responses



*Figure 5-16 Diagram of plans to enhance provisions for autistic/neurodivergent audiences.*

The diagram above shows that most respondents who responded “yes” to having plans were prioritising their training, planning to run more events, and consulting directly with AuND people.

## 5.2.5 Barriers, Strengths, and Areas for Development

To better understand what the cultural heritage sector needs to become more accessible to AuND people, it was important to establish existing strengths and areas for development within the sector. This section focuses on some of the most common responses to understand the impact that barriers, strengths, and areas for development can have on the sector's ability to become more neurodivergent accessible.

### 5.2.5a Barriers to Becoming More Accessible for AuND Audiences

The respondents had the option to select all the barriers that applied to their organisation, with a total of 385 responses by 119 respondents. This indicates that the average respondent selected three barriers that impact their organisation's ability to be more accessible for AuND visitors.

What is the main barrier that impacts AuND-specific resource development?

119 Responses

Field	Choice Count
Lack of funding / budget	42.02% 50
Other priorities (please explain)	13.45% 16
Lack of expertise for this audience	12.61% 15
Lack of staff training	10.92% 13
Other (please explain)	10.08% 12
Lack of space	3.36% 4
Lack of confidence	2.52% 3
Too time consuming	2.52% 3
Lack of facilities	2.52% 3
Prefer not to say	0.00% 0
Total	119

*Figure 5-17 Diagram of the main reasons identified by respondents for a lack of autistic/neurodivergent-specific resource development at their organisation.*

According to the diagram above, the three barriers identified by the 119 respondents who answered this question were “lack of funding” (70%), “lack of staff training” (60%), and “lack of expertise for this audience” (48% of all respondents).

When comparing the responses dependent on respondents' identified neurotype, the three barriers identified were consistent with each other. AuND-identifying respondents were slightly more likely to select "lack of confidence" (26% of 47 respondents) when compared to non-AuND respondents (20% of 69 respondents). This suggests that there may be some obstacles related to confidence in AuND respondents that impact the provision of resources for neurodivergent audiences compared to non-AuND-identified respondents.

### 5.2.5b Sectoral Strengths

Respondents were asked to consider their organisations' strengths in putting in place accessibility to AuND audiences. This was intended to assist in identifying areas that could be useful to prioritise when drafting guidance, as well as allowing respondents to reflect on what they felt was positive about their organisations regarding AuND audiences. The table below shows the respondents' views on their organisations' strengths:

What do you think are your institution's accessibility strengths in relation to AuND audiences?	
125 Responses	
Field	Choice Count
Awareness and understanding of access needs	24% 65
Seeking audience feedback about autism / neurodiversity access / provisions	11% 29
Resource development	11% 28
Event planning	11% 28
Training (providing autism / neurodiversity awareness training for staff)	10% 27
Unsure (please explain)	9% 24
Understanding priorities of autistic / neurodivergent visitors	9% 24
Working with autistic / neurodivergent people (e.g. access panels / consultation)	8% 21
Other (please explain)	5% 14
Prefer not to say	2% 6
Total	266

*Figure 5-18 Diagram showing what the respondents identified as their organisations' strengths in catering to autistic/neurodivergent audiences.*

In total, 125 respondents answered this question with 266 total answers, suggesting that respondents selected an average of two or more strengths each. While the response ranking was

consistent whether the respondent identified as AuND or not, it is notable that AuND-identifying respondents were more likely to rank their “event planning” higher than non-AuND-identifying respondents who – in turn – were more likely to rank their “resource development” as a strength. This suggests that, when considering ways to enhance the provisions for AuND audiences, collaboration between those who do and do not identify as AuND in the sector based on their strengths could help to address current gaps.

Notably, 38 responses were either “unsure” or “other”. The most common response to this open-ended option was to highlight that the respondent could not identify a specific strength. For instance, one responded, “I don’t think we have any strengths”, while another responded, “None at the moment”. Others responded that they were unsure of what their organisation had done and therefore did not feel confident to identify a strength. One of the respondents reflected that they “will now speak with the institution to find out what is more widely in place and adapt it for [the] gallery” following this question.

The lowest-rated pre-determined category with 21 responses was “working with autistic/neurodivergent people (e.g. access panels)”. Although respondents felt they had a good understanding, resource development and ability to seek audience feedback, this did not necessarily involve AuND people, or they did not feel confident in their abilities to undertake consultation.

#### 5.2.5.c Areas for Development

The survey examined the areas that respondents felt they could develop. In total, 121 respondents answered this question with 374 total responses recorded. As with the previous question respondents could select as many categories as they felt applied to them and their organisations. This indicates that, of those who answered this question, they identified an average of three areas they believed their organisation could develop to enhance its accessibility. The diagram below shows the areas identified:

### What do you think are your organisation's areas for development in accessibility?

121 Responses

Field	Choice Count
Understanding priorities from autistic / neurodivergent visitors	20% 73
Resource development	18% 69
Training (autism / neurodiversity awareness and understanding)	18% 67
How to work with autistic / neurodivergent audiences	17% 64
Event planning	17% 62
Specific training gaps (please explain)	4% 15
Specific gaps in knowledge / understanding (please explain)	4% 15
Other (please explain)	2% 7
Prefer not to say	1% 2
Total	374

*Figure 5-19 Diagram showing the most identified areas for development.*

The respondents who indicated that there were “specific knowledge gaps” and “specific training gaps” (both 15 respondents) were asked to share their opinions on what they believed these gaps were. Some respondents felt that there was a general lack of awareness and thus a need for “communication training”, while another respondent felt there needed to be training on “diversity and variety of needs in community”. One respondent stated that there was a need for training for trustees and decision-makers to improve their understanding of the need for audience-specific resources. The final response was simply “I don’t know what I don’t know”, highlighting the reality that many people may be aware of gaps or areas for development. However, without lived experience or related AuND expertise, it is difficult to identify these without support from individuals with a greater understanding.

It is noteworthy that, when examining this data through the lens of the respondents’ identified neurotypes, there were some variations in what were identified as areas of development. AuND-identifying respondents were more likely to identify “resource development” (68% of 47 respondents) when compared to non-AuND-identifying respondents (45% of 69 respondents). Most of the percentages in the two groups were similar, with an average of 5% variance between their responses. The consistently highly selected responses were “understanding priorities from autistic/neurodivergent visitors” and “training”. This

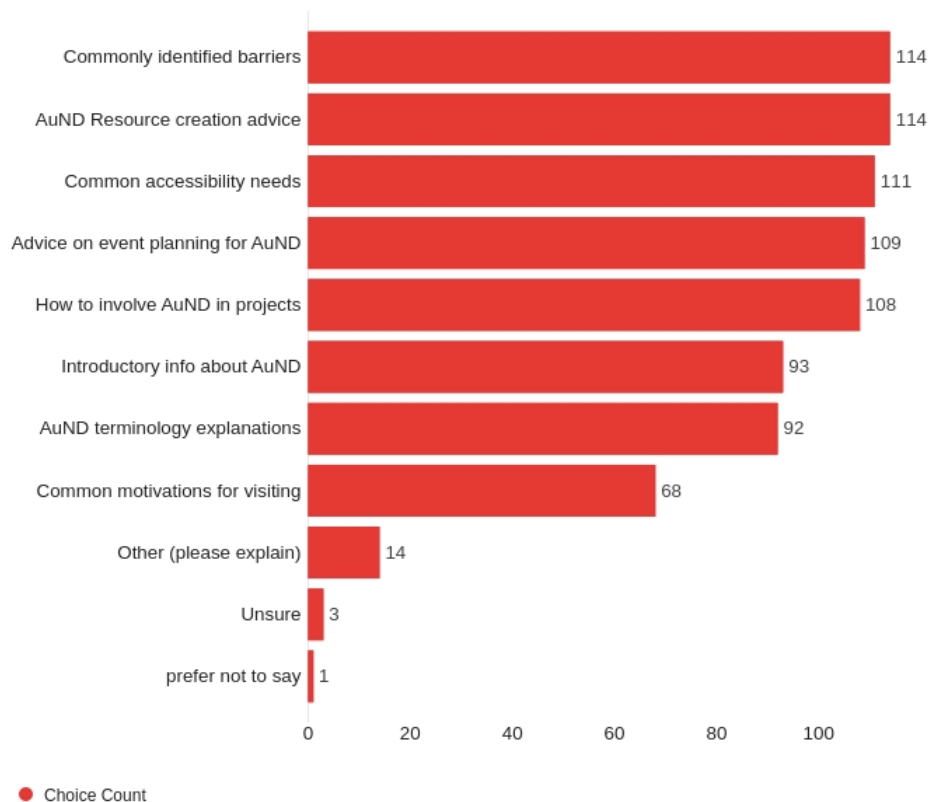
indicates that, regardless of respondents' neurotypes, most respondents believe that there is a need to improve their (and their organisation's) understanding of neurodivergence.

When comparing the responses about areas for development to the above strengths, some of the categories identified as top strengths – for example, “training”, “event planning”, and “resource development” – were identified as areas for development. It is worth noting the significantly higher number of responses to the “areas for development”, with some categories receiving double the number of responses to the “strengths”. This suggests that respondents identified that, while there are areas currently perceived as strengths, they believed that there was a need for improvement.

### 5.2.6 Guidance Toolkit

As one of the main objectives of this project is to identify the needs of both AuND adults and the museum workforce to create sectoral guidance, it made sense to ask museum workers directly what they felt would be beneficial for inclusion in a guidance toolkit.

If a guidance toolkit was made to help museums become more accessible for AuND audiences, what type of information would be useful to include in it?  
126 Responses



*Figure 5-20 Diagram showing the respondents' priorities for a sectoral guidance toolkit.*

Most respondents, 126 in total, selected multiple options. This question received 827 responses, higher than any other question in the survey, and demonstrated the usefulness of guidance on several topics. The joint highest responses, each with 114 responses, were “commonly identified barriers to neurodivergent visitors” and “suggestions for how to create resources”. These responses suggest that the participants were aware of a range of different barriers to museum visiting for AuND adults but would benefit from having these explicitly outlined. This may be because they want to ensure that their understanding of potential barriers reflects those identified by AuND people. It may be possible that they can use the findings to

provide evidence to management or funders to advocate for greater funding, new projects, or staff to address the barriers.

Examining the responses by respondent neurotype revealed some differences in what should be prioritised for guidance. In addition, respondents who identified as AuND were more likely to prioritise understanding “commonly identified barriers” (94% of 47 respondents) than non-AuND-identifying respondents (88% of 69 respondents). Non-AuND-identifying respondents were also less likely to select “introductory information” than AuND-identifying respondents (70% of non-AuND vs 81% of AuND). However, while a similar percentage of respondents (85% of both AuND and non-AuND-identifying) selected “ways to involve AuND people” as an area where they would like guidance, this was the second highest ranked option for non-AuND respondents but the fifth for AuND-identifying respondents. This may be because this type of information is less of a priority for AuND respondents who belong to the group that the guidance is intended to benefit.

There were 68 “other” responses to this question. Of these responses, the most common suggestions that came through in the open-ended answers included:

- a) Potential partnership options – e.g., groups or organisations to assist or offer encouragement
- b) Explanations of why it is important to work with AuND people
- c) Ways to include “existing AuND staff members in the process (should they want to be involved)”
- d) Marketing methods/activities – how to reach (potential) audiences
- e) Safeguarding and best practice case studies
- f) “Information about issues that are important to the autistic community (as this informs decisions about which organisations are suitable to work with)” – this may be about highlighting organisations that autistic people speak out against, such as Autism Speaks, as well as matters that are prioritised (societal focus – e.g. mental health and wellbeing identified as priorities for research and also areas to improve quality of life).
- g) Needs specific to AuND adults



- h) Guidance for HR (Human Resources) and employers on how to recruit and support AuND workers
- i) Emphasising the importance of payment of AuND people for their time – “if they are asked for input and expertise in creating resources for a site like they would for any other contractor”.

These responses suggest that respondents would find it beneficial to have information on a variety of specific, usually practical, or financial topics to enhance their abilities. Many respondents were focused on partnerships, marketing, and funding. These were topics that produced concerns about how to make events or resources available, and to reach the AuND people they are intended to be for. The final two in the list, which focus on neurodivergent people in the museum workforce, demonstrated an awareness that there may be a considerable number of AuND people in – or interested in joining – the museum workforce who may not have the support and adjustments they need to thrive. This highlights a wider issue regarding the importance of the accessibility of the sector to all individuals who enter their spaces, whether visitors or workers.

## 5.3 Qualitative Data

### 5.3.1 Section Overview

This section of the chapter explores the themes of the more open-ended responses and how these relate to the quantitative data as analysed above.

### 5.3.2 Themes

The responses to the museum worker survey were analysed using the same reflexive thematic analysis approach as the AuND survey responses. This process involved systematically identifying and coding the data – working question by question – to identify, categorise, and sub-categorise the themes (Braun & Clarke, 2023). The most prominent themes that emerged from this survey are identified in the thematic roadmap (below) and these findings will be discussed using the identified themes in the following section:

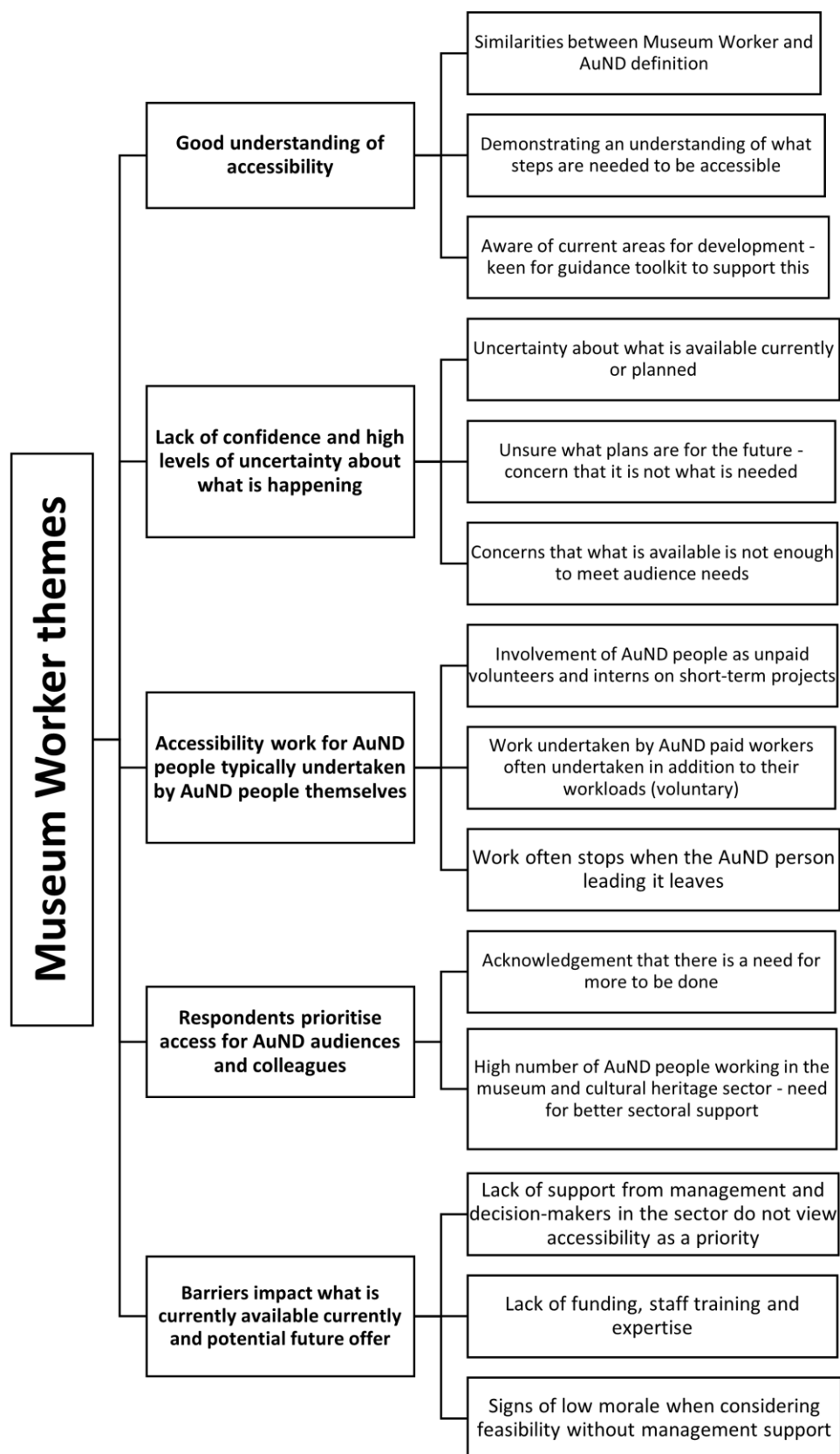


Figure 5-21 Thematic map of qualitative themes and codes.

### 5.3.3 Good Awareness of Accessibility and What it Means to be “Accessible”

The first recognisable theme was that the respondents had a good awareness and understanding of accessibility. There are several potential reasons for this elevated level of understanding. First, as the survey reflects a self-selected sample of museum workers, it is possible that those who chose to participate did so as they are already engaged or interested in improving accessibility. A second potential reason, as demonstrated in the higher-than-expected number of respondents identifying as AuND, is that those who chose to participate had a good understanding from their lived experience. As in the AuND survey, the museum worker respondents were asked to share their definitions of “accessibility” based on their understanding of what it means to be accessible. Many words that were commonly used when defining what “being accessible” means were similar to those identified by AuND people. These included “choice”, “equity”, “opportunity”, “comfortable”, “understanding”, “accommodations”, “diverse”, “welcoming”, and “communication”.

Much like the AuND respondents, museum workers expressed that they felt an accessible museum was welcoming and comfortable for all its visitors, regardless of who they were and what access needs they might have:

*“Creating a space that provides equal opportunity for ALL visitors to engage.”*

*“Being accessible means creating a space where everyone feels welcome. It means creating a safe space where all people feel comfortable being their authentic selves. Accessibility means ensuring that all people... can fully enjoy visiting a museum.”*

Some definitions align with more commonly accepted understandings of what accessibility is, as well as explanations regarding the experience of neurodivergent-identifying people. The responses from the museum worker survey typically overlapped with those identified by AuND adults in the visitor-focused survey. The general feeling was that it was the museum’s responsibility to create a welcoming, engaging, and inclusive space for all its visitors.

Emphasis was placed on equal or equitable access for all people, regardless of their background or disability:

*“Providing equitable access to everyone no matter their ability, background or socio-economic status.”*

It was clear that the museum workers felt that everyone – regardless of their background or whether they were AuND – deserved the same level of access to space as anyone else.

Another category that came through incorporated responses that indicated that, for accessibility to be possible, “*meaningful effort*” must be expended:

*“Flexibility, consultation, and willing to change.”*

*“Being accessible means making efforts to be barrier-free in terms of facilities, collections, and technology.”*

Some respondents stated that accessibility was an “*intentional effort*” to “*remove barriers*” for “*all audiences*” by providing a choice of adjustments. There was a feeling that museum workers must be aware of and provide choices in accommodations to achieve that welcoming environment and “*barrier-free*” experience. This would involve examining the specific needs of their AuND audience, as well as all other audience types.

A noticeable addition to the definitions was the desire for accessibility to be considered for *all* AuND people who use a space, not just visitors:

*“[being accessible] to my museum – access for people with visible disabilities. To me – access to all, including staff.”*

*“Being able to be present and interact with an entire site, interpretation and collections in a way that is meaningful to individuals who visit, volunteer, and work there.”*

Some of the respondents shared what accessibility meant to them from the perspective of being neurodivergent themselves. In these responses, they stated that they would also want to experience personally what they would like to see delivered for others. For example, one respondent said that an accessible environment is one where they feel “*comfortable to talk about my special interests*”. Another respondent shared that – because they were only diagnosed in their thirties – they are “*not used to having my needs accommodated*” and have had to manage using their own coping mechanisms. This suggests that museums and cultural

heritage organisations must not only be mindful of but also include the needs of their AuND-identifying workers, which might otherwise be overlooked. Such work is beginning to happen with the Neurodiverse Museum network (TNM). The network intends to improve the experiences of AuND people as both visitors and members of the workforce by centring lived experience to advocate for improved working conditions. While there are currently no specific support pathways or resources available aimed at improving the experiences of AuND workers within the museum sector (TNM, 2022), the creation of the network and the responses to this survey suggest a demand for greater understanding and support in cultural heritage settings.

Some respondents indicated that they had also taken part in the AuND survey from a visitor perspective. This high representation of neurodivergent people in the sample may explain the overlap in definitions and views of what it means to be accessible across the surveys. The survey did not ask respondents if they had any other form of disability or identity that could impact their individual experiences of accessibility. It is therefore uncertain whether some individuals answered this question through the lens of another form of disability, whether or not they identify as AuND. What was clear was that many of the respondents to this question had a good understanding of what “being accessible” means, whether it came from the lived experience of being or supporting someone with specific access needs or from a wider source (such as training or online resources).

#### 5.3.4 Lack of Confidence in What is Available

A recurring theme throughout the responses was how “unsure” respondents were about what their institution offered to its audiences. Regardless of whether they were asked a question about pre-, during, or post-COVID-19 restrictions, a consistently high percentage of respondents were uncertain about what their organisation had to offer for neurodivergent audiences. This included resources, events, and knowledge of how they were developed. Interestingly, similar uncertainty about what was available expressed in the AuND survey for visitors also emerged in the museum workers’ survey.

The diagram below uses data from the quantitative survey questions to demonstrate the consistent use of the “unsure” options in multiple-choice questions:

Question	Total responses	Responses answered "unsure" / "maybe"	Percent "unsure"
Do you identify as autistic/neurodivergent?	126	9	7%
Does your institution currently have any autism resources?	127	13	10%
Does your institution currently run "autism friendly" events?	125	11	9%
How often do the events for AuND audiences run?	79	14	18%
How has COVID-19 impacted accessibility for AuND audiences at your organization? (select all that apply)	173	17	10% (13% of all respondents)
Has your institution worked directly with AuND people before?	127	36	28%
What resources did you use to develop your current provisions for AuND visitors? (select all that apply)	210	21	10% (16% of all respondents)
Does your institution have upcoming plans to enhance its resources for AuND visitors?	127	49	38%
What does your institution plan to do for AuND visitors? (select all that apply)	305	12	4% (10% respondents)
If a guidance toolkit was made to help the sector to become more accessible to AuND visitors, what information would be useful? (select all that apply)	827	3	0.36 % (2% of all respondents)
What do you think are your institution's strengths in relation to AuND visitors? (select all that apply)	266	27	10% (21% of all respondents)
What do you think are your institution's areas for development? (select all that apply)	374	N/A	–

Figure 5-22 Table charting the percentage of "unsure" responses to various survey questions.

The table above shows that approximately 10% or more of respondents were typically uncertain about what their organisations have previously created, offered, or planned to provide for AuND audiences. The most significant factor was that 38% of respondents were unaware of any plans their organisations currently have to enhance or create provisions for AuND audiences. Two of the respondents stated that staff training had taken place, but that they were "unsure" of any other form of event or resource. One respondent stated that they "*developed backpacks for autistic children, not sure if they [the backpacks] were implemented once I left during COVID-19*", while another ND-identifying respondent highlighted that they were "*spearheading the neurodivergent programming and partnerships*" but that this too ended when they left. This suggests that some of the respondents who had been responsible for the

work have since found no clear indication of who is continuing their work for AuND audiences, or are aware that the work has stopped completely after they left the organisation. Some respondents also stated that they are employed in roles not connected to this type of work, meaning that their understanding of what is going on is limited to when “*they hold sporadic events*” advertised to the public.

The issue of uncertainty was explored through other questions. For example, 28% of respondents were unsure about whether their organisations had worked with AuND people in the past. When explaining why they were unsure, common reasons given were:

- a) Respondent started a new role at this organisation recently so was unaware of past projects (“*I’m relatively new to my museum (1.5 years) so I’m unsure if this type of work was done before I started.*”)
- b) Not involved in the department where such work is usually undertaken (“*not in my department (digital/online)*” and “*I am not involved in planning or production process.*”)
- c) Information is not communicated between departments (“*I am not privy to such information.*”)
- d) The organisation has an access panel, but it is unclear whether there are AuND people on it (“*We have had an access panel. I don’t think it had anyone neurodivergent sitting on it, but I can’t remember now.*”)

Uncertainty about what respondents’ organisations offer and their level of community involvement has an impact on confidence in their offer. 21% of respondents stated that they were “unsure” of their organisation’s accessibility strengths, even with multiple choices to select from. Given that most respondents (60%) chose to describe their organisation’s “autism-friendly” level as “average” or below, a connection could exist between a feeling of uncertainty and low confidence in their ability to identify strengths. In the “accessibility” definition question, the respondents showed a good understanding of what it means to be accessible. It may therefore be the case that their understanding and assessment of their organisation has contributed to their concerns that it may not meet the needs of some visitors.

18% of respondents were uncertain about the frequency of events that their institution holds. Some responded that they are “*sporadic*” and another noted that they are “*not sure*” if a regular group that visits their museum is planned by the group or the museum itself. Elevated levels of uncertainty about what is currently available – regardless of what was available in the



past or may be planned in the future – suggests issues surrounding communication within organisations, potentially between different departments.

This level of uncertainty suggests that it may be related to several issues within the sector. The most significant one may be connected to communication. In the AuND survey and the Heritage Access Surveys (2018 and 2022), a gap exists in information available online or easily accessible for audiences to find. Museum workers' lack of understanding about what was available, when they came from a range of different departments and levels of responsibility, indicates that this issue begins within cultural heritage organisations themselves. There was a particular gap in knowledge for front of house respondents, who felt under-informed and under-supported (e.g. identifying gaps in training) and respondents who worked in roles less connected with audience experience, such as collections. This suggests that efforts need to be made to include more workers from different departments in projects, planning, and distributing resources.

Uncertainty about what is available negatively impacts the experiences of audiences. Indeed, how can potential visitors be aware of what is available to them if the museum workers themselves are not aware of what is happening within their institutions? If respondents are not aware of what is available, this can increase their anxiety about what they can offer to visitors. This could validate potential visitors' concerns about their needs not being met (as reported in the AuND survey) and suggests that, if the museum workforce were to improve their internal communication about what is currently or planned to be available in the future, this could help to reduce the likelihood of uncertainty amongst workers and AuND visitors.

### 5.3.5 AuND-led Awareness and Projects Within Organisations

From the responses, it became clear that many respondents believed that AuND people developed the resources and events that were or had historically been available, including paid staff, volunteers (sometimes on placement), and AuND people who were part of a particular project that blurred the distinction between paid workers and volunteers. Some of these projects were commissioned – for instance, projects where autistic interns were brought in for a project – while others were started and completed by individuals working within the organisation already because of their personal motivation. When analysing the responses regarding the direct involvement of AuND people, it became evident that some projects were undertaken by AuND people. These were projects started by the respondents themselves or colleagues, who had varying levels of support from colleagues or managers. That AuND people led the

provision development and execution themselves, from conception of an idea to delivery, often unpaid, demonstrates a reliance on community members to create the change and accessibility they wish to see.

The most common response to questions 10.1 and 10.2 about working with AuND people as part of projects was that the respondents themselves – or others in their team – were neurodivergent:

*“A good majority of the staff that work there are actually neurodiverse.”*

*“Employing autistic and neurodivergent people and asking for their opinion.”*

They therefore had experience of working with neurodivergent people as colleagues or identified themselves as AuND colleagues who had been involved in projects. This is not surprising, given the high number of respondents who identified as AuND. Some respondents stated that there may be more AuND volunteers or paid workers at their organisation who they are unaware of, as not everyone would disclose this information.

Respondents indicated that many of the accessibility projects would end after an AuND person or team had moved on. This was often because of career progression or the end of a funded project:

*“I am an autistic person, but I also coordinate all of the SEND programming in my museum. As a result, I find that my opinion as someone with lived experience is valued by my colleagues when I coordinate events... the biggest challenge I have found since coming into this role is a lack of training for FOH staff and volunteers. This is also something I am hoping to change but that entirely depends on budgets.”*

*“We have a full team of unpaid interns that are neurodivergent that come and work with us in our various departments.”*

This reflects a wider issue of funding and staff retention within the sector, with a loss of designated individuals(s) undertaking the work and a strained workforce without the resources or confidence to deliver work previously undertaken. The museum sector, like many other sectors, has experienced prominent levels of redundancies and shrinking workforces over

the last 14 years (Statista, 2021). A further rise in redundancies has taken place since the COVID-19 pandemic (Adams, 2021; Statista, 2022). This has been exacerbated by the museum sector's reliance on project funding to create temporary roles, worsened by the impact of COVID-19 on the economy for many years. This indicates that the issue of under-staffing in the sector is likely to be ongoing. The MA published a report in 2021 (Statista, 2021), which highlighted that 4,100 redundancies were made in the UK alone that year, with this number continuing to rise and the impact of the cost-of-living crisis still being felt at the time of completing this thesis.<sup>27</sup>

Not all museum workers leave because of redundancy or the end of short-term contracts. Some leave as a result of a lack of incentives, such as job insecurity, low salary, and lack of progression opportunities. Poor working conditions can lead to workers leaving not just their organisations but the sector entirely (Dragouni & McCarthy, 2021). This indicates a need for future work to be evaluated to identify measures to be taken to ensure that the work is not lost at the end of a project or a staff member's time in an organisation. Moreover, with the challenges presented by short-term funding reducing what is possible, greater consideration must be made of ways to support long-term projects and make them sustainable following the end of funding periods.

There was a sense of frustration that progress to make organisations neurodivergent accessible only occurred when AuND workers themselves were responsible, often in addition to their usual workload, or as volunteers:

*“As an autistic former employee/contractor and employee, I have been asked to give feedback and design sensory-friendly interpretive materials and make recommendations, but my advice was not followed up as it required budgets, and they were not able to pay me for my expertise.”*

One respondent specifically acknowledged that there are a lot of AuND people in the workforce in different departments and numerous role types, but there is often a lack of awareness of this from others. One respondent stated that there “*could definitely be more effort put in*” to support neurodivergent colleagues. A rift is apparent between those AuND respondents who felt supported and that their work was encouraged, and those who felt the

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<sup>27</sup> The MA created a “redundancy tracker” on their website, where they updated a map with data on redundancies. As of October 2023 this tracker is no longer live.

opposite. One specified that their organisation did not hire or involve disabled or neurodivergent people and anyone who may have been neurodivergent *“never really talked about it”*.

The most common external involvement was with local groups of AuND people or charities who provide groups and support to organisations seeking to enhance their accessibility. Two examples were *“worked with an autistic-led charity”* and *“school groups”*. How the respondents worked with these groups differed: some of the respondents identified ways that AuND people had been involved in survey design or *“activity planning”*, while other respondents specified that they partnered with local groups or autism organisations that provide *“job training for people on the autistic spectrum”*. However, notably, not all planned projects, such as collaborative training, went ahead as intended. Other respondents stated that their involvement with AuND people was based on existing relationships with local community groups who are recurring visitors. One respondent stated that they had *“really good links with the autism community and organise visits to the site regularly”* but did not specify any more details about the nature of their direct work and how they may involve this community in their work. However, in other responses, some organisations have actively sought out autistic or *“accessibility consultants”* to provide direct feedback. One respondent stated that they had held a *“consultation event for autistic people to come and give us feedback on the museum”* to determine how to make the space more accessible. This suggests that, in the case of direct participation of AuND people in projects, the level of involvement varies from organisations, groups, or individuals being invited to provide formal feedback to simply having a good relationship with local groups who enjoy visiting the space.

Of those respondents who specified the types of groups they worked with, the majority with ties to local organisations tended to work with schools or AuND people who are still in some form of education:

*“We held a special tour for students from a school for those with educational issue[s].”*

As suggested in the findings relating to the age demographics that specific events are aimed at, it is unsurprising that some responses highlighted that their experiences of the direct involvement of AuND people were school groups in the form of *“childhood programmes”* and events *“catered usually to children with neurodivergent needs”*. One respondent expressed that their experience was specifically working with school groups and that all their *“activities are*

*highly accessible*” to neurodivergent people. Another respondent specified that their workplace “*usually work[s] with special need[s] groups – especially children*”, with no mention of any other age groups or explanation of *how* they have worked with children. This suggests that some respondents may have interpreted this question as one about whether they have provided specific activities or outreach activities rather than a question on “working directly” with AuND people as part of a project.

Overall, this suggests that the majority of work that has been undertaken to enhance accessibility for AuND people has either 1) been undertaken by AuND people themselves, often voluntarily, with no guarantee of it lasting after they leave the organisation or 2) has been undertaken with stakeholders who may not be AuND themselves, such as professionals who work with AuND people, or based on indirect observations. Notably, some respondents felt that there was no involvement of AuND people in their organisation, with one AuND-identifying respondent highlighting that they did not feel there are currently many projects in the sector that work directly with AuND people in meaningful ways.

### 5.3.6 Barriers Connected to Funding and Prioritisation

The survey responses showed that, just as there are barriers to AuND visitors accessing museums, barriers also exist for museums with the ability to make their spaces accessible to neurodivergent needs:

*“Inaccessible and complex museum infrastructure mak[e] creating access incredibly complex and frustrating.”*

As this quote illustrates, a sense of frustration is apparent among many of the respondents, several of whom feel that their prioritisation of accessibility is not shared by others in their organisation more widely. In addition to the data previously discussed (see 6.1.4), many respondents provided information about the barriers that impact what they can provide as an organisation. The primary factors identified were: 1) Lack of funding, 2) Other priorities, 3) Lack of capacity and training and 4) Staffing, with no specific person responsible for undertaking the work, it does not happen.

The most common barrier was financial. With a lack of funding and investment into projects, some respondents felt that managers or decision-makers did not prioritise accessibility because of perceived low levels of financial benefit:

*“Focus is more on making money than being accessible, which is VERY not ideal.”*

*“Museums report on numbers – number of attendees etc, rather than impact. My school program for neurodivergent kids was time-intensive (for me) without bi[g]numbers in the ‘output’ column. I was under pressure to ‘prove’ the value of this program.”*

Given the impact of decreased investment into organisations such as museums – particularly during periods of recession, cost-of-living crises, and de-prioritisation of cultural heritage – and with increased pressure on museums to prioritise organisation-generated profit (Morse & Munro, 2018), it is unsurprising that there are funding gaps.

It is notable that, while AuND accessibility may not be a priority, this does not mean that some museums are not prioritising accessibility more widely:

*“Current priorities are directed by funding, and current focus is currently on making [the] museum more physically accessible by adding a more accessible lift.”*

*“Basic site accessibility (trails, ADA compliance) are prioritised.”*

*“The higher-ups mostly do the bare minimum for accessibility in general.”*

These quotes suggest that, for some organisations, one barrier to prioritising the needs of AuND visitors could be that the institution has not yet met other key accessibility requirements. For example, some are prioritising physical access because their institutions do not meet legal standards.

Respondents believed that those responsible for deciding what to spend funds on were not aware of the needs of visitors, the demand for resources, and the experience of AuND audiences. As a result of this lack of awareness, they do view it as a priority:

*“Neurodivergent people had not been identified as a priority audience.”*

*“Lack of trustee support.”*

It is therefore not surprising that there is dissatisfaction around needs not being met and “no support from leadership” for visitors, never mind neurodivergent workers. With museums

needing to prioritise investing in projects with financial incentives, by, for example, bringing in more audiences, they set priorities based on potential income generation. This means that work conducted with an unambiguous evidence base (such as examples of successful practice), is considered less lucrative and is missed. This is challenging for museum workers who prioritise visitor experience and wish to prioritise inclusivity for both their visitors and colleagues.

If there is a “*lack of awareness*” and understanding of the needs of AuND people, then this also contributes to the gap in resource development:

*“Lack of interest knowledge or policy.”*

*“I do know that as a visitor guide, I have had no training around disability.”*

Many respondents felt this regardless of their roles or neurotype. Lack of understanding (despite the desire to receive training) resulted in a lack of confidence and uncertainty among audience-facing respondents. Moreover, others felt that a lack of training for decision-makers who are responsible for funding allocation contributes to the cycle of de-prioritisation of accessibility projects and a lack of support for future projects. Some of the respondents believed that, if all museum workers received training, this could help to build confidence and demonstrate why investing in resources is necessary. The majority believed that involving under-represented groups, such as AuND people, was essential but that there was a gap in confidence in how to work with these groups. This suggests that, with evidence of the potential benefits of investing in supporting AuND audiences, guidance on how to work with traditionally under-served groups and reassurance about potential impact for all audiences could help address funding and confidence barriers.

Issues around “*lack of capacity*” and staff being able to undertake work because they are “under-staffed” have had an impact on the feasibility and prioritisation of AuND audiences:

*“Many competing priorities for programming – insufficient time to focus on this specific aspect of audience need. It is recognised that there is a need to do more.”*

*“The work always seems to be ‘someone else’s’ to do, and so raising it as a priority is hard.”*

Moreover, lack of a clear delegation of work – often because there are not enough staff – can cause projects related to accessibility to slip. Many respondents used phrases to describe being “*so short-staffed*” and the impact of this on running even the more “*basic functions*” of their organisation daily. Some noted that this issue worsened because of delays caused by COVID-19, such as changes in the workforce. However, a lack of prioritisation from management means that projects are not scheduled. Another respondent stated that there were “*not enough permanent staff*” to operate a consistent schedule of events, while other respondents simply stated that this type of work falls outside their remit.

### 5.3.7 Desire to Improve What is Available for AuND Visitors and Colleagues

One of the most reassuring aspects from the analysis of the survey responses was a desire in those who responded to improve their organisations’ offer for AuND people. Most respondents identified multiple areas for development and priorities for guidance, indicating an understanding of what could be done to improve their accessibility. However, the barriers – particularly the lack of resources and confidence – impeded their work. Throughout the responses, particularly by those who identified as neurodivergent, there appeared to be frustration and feeling that not enough had been done, or that what had been done had not been adequately supported to keep it going. There was a sense from the responses that sufficient support and guidance would lead to more progress being achieved.

Many respondents to the survey (95%) identified working directly with AuND and other traditionally under-represented audiences as “very important” or “important”. Key reasons identified included:

A sense of duty – or legal/social responsibility – as a public-facing organisation to work with specific groups to ensure their needs are met:

*“Museums, I feel, have a duty to be accessible to everyone regardless of age or ability.”*

*“Museums are there to serve the public. So, they have an obligation to reflect the public.”*



Recognition also exists that projects undertaken without people who have direct lived experience often miss the nuances of access needs:

*“When a museum is run by people who aren’t neurodivergent, they often have no idea of how the museum is experience[d] differently by people who are. The only way to understand the needs and experiences of neurodivergent people is to include them in the development process.”*

*“You can’t truly represent a person without involving them.”*

The realisation of projects that involve or cater to the needs of families with AuND children often does not translate into the experiences or needs of AuND adults. Furthermore, those experiences vary widely from individual to individual, and recognition is important that a range of experiences or viewpoints are heard:

*“Often parents/families of autistic children are the only ones consulted, this is a valuable perspective, but it should not be valued over the lived experience of actually autistic people or neurodivergent people when developing museum learning and engagement for these groups.”*

*“Even though every autistic person is different, and we all have different struggles, nobody can understand us the way we understand each other. So often non-autistic people (even well-meaning) will just be infantilising or dismissive of our values as human beings.”*

Another point made by respondents is that access considerations in response to AuND-specific needs can have a positive impact on the experiences of all visitors to an organisation:

*“Different people have different needs, and it is important to include as many voices as possible in the conversation towards becoming fully accessible and inclusive.”*

*“Issues of neurodivergence are especially relevant for ALL users because measures put in place could help a range of other museum users also.”*

This acknowledgement of the benefits of direct involvement of AuND people in the accessibility of their organisations – both for AuND audiences and more generally for all

visitors – shows that the respondents are interested in improving the accessibility of their institutions.

It is also important to highlight that the motivation to improve what is available to enhance accessibility goes beyond visitors. Throughout the survey, an acknowledgement emerged that a high percentage of neurodivergent individuals may be employed in the cultural heritage workforce and others want to join but have faced numerous obstacles to entering the sector. For example, one respondent stated, “*A good majority of the staff that work there are actually neurodiverse.*” Meanwhile, another said that their organisation “*have several staff in the museum who are autistic, and they create our autism-friendly resources*”.

In addition, in answering the question about what the respondents’ organisations utilised to develop current resources, six of 18 respondents who answered “other” specifically referred to the “*lived experience*” of colleagues as a key factor. This is unsurprising, given that most AuND respondents to the survey were motivated museum visitors who faced numerous obstacles that impacted their ability to benefit from and access cultural heritage settings. This awareness, coupled with requests for guidance on how to improve accessibility for the workforce, from recruitment to in-situ support, suggests a commitment that goes beyond visitor experience and indicates a need for improved working conditions. These could be possible with better accommodations for the cultural heritage workforce. Furthermore, another aspect of an organisation that is truly sensitive and responsive to the accessibility issues of its visitors involves taking the initiative in addressing its workforce. This requires a culture change within the sector, particularly for management, to view accessibility as intrinsically connected to better experiences for all who access organisations.

## 5.4 Discussion

This survey, while smaller in reach than the AuND survey, gave an interesting insight into both the perceived strengths and areas for development that exist within the museum and cultural heritage sector concerning accessibility – both broadly and neurodivergent-specific. Among those who responded to the survey were a variety of different organisation types and roles (both paid and unpaid). A gap in respondents who identified as a non-white ethnicity was notable, and some of the respondents who took part may have worked in the same organisations as other respondents because of their ability to respond anonymously. A further remarkable point was the high percentage of respondents who took part in the survey who identified as neurodivergent – or suggested uncertainty about whether they may be neurodivergent – suggesting that many respondents may have been driven to take part because of a personal motivation to improve accessibility for fellow neurodivergent people. This survey showed a wide range of different perspectives and could have reached more respondents had it been advertised more broadly and for as long as the AuND survey.

### 5.4.1 Demographics

The profile of those who participated in the survey is important to the findings. As discussed, a higher-than-expected number of AuND-identifying museum workers participated in the survey. There are potential reasons for this. First, my position as a neurodivergent researcher, independent from their organisations and producing guidance to improve the sector may have resulted in some people taking part and disclosing who may not have felt comfortable responding to this type of research otherwise. Second, this survey may have directly appealed to AuND-identifying people due to the potential of it benefitting them as workers and visitors.

The impact of the elevated level of participation from AuND museum workers cannot be overlooked. The participants who took part are engaged in – and often leading – their organisational provisions for neurodivergent visitors because of their understanding and personal motivations. This may have contributed to the higher-than-expected understanding of accessibility and attitudes towards organisational provisions for AuND visitors, and could explain the high number of respondents who felt that management did not prioritise the work. This paints a picture – alongside the data indicating that the work towards creating a neurodivergent accessible environment is often led by AuND staff and volunteers directly – that the sector either does not undertake the work needed to become more accessible because of lack of prioritisation, or because it is dependent on the community to take on the lion's share

of the work. This discovery reflects experiences shared with me by museum workers at conferences, TNM meetings, and in general conversation (both in-person and online) when people are interested in addressing their accessibility issues. Often, museum workers who identified as neurodivergent discussed the (internalised) pressure that they feel to develop their organisations' accessibility. They stated that not being supported by the wider team or management negatively impacts their morale. This is not surprising given that disabled people themselves have led much of the disability movement's work to make society more accessible. The consequence of this is that many AuND people, often facing obstacles outside their work, face additional pressure to create the accessibility provisions they require as employees.

It is also necessary to consider who was missing from the survey. One of the challenges that all researchers face is engaging those who do not have an interest or motivation in the topic of research being investigated. It is therefore important to acknowledge that the survey has reached and been responded to by those who already have an awareness of the importance of the topic or a personal interest in or insight into neurodivergence and accessibility within the cultural heritage sector. As highlighted frequently in responses about the barriers and areas for development, there was a feeling by those who took part in the survey – as most respondents were public-facing workers – that management and sector leaders did not prioritise the need for funding, training, and development of access provisions. Although people from management positions were among the respondents, they were already engaged, usually for one of the reasons above. While the sector has seen a growing recognition of the need for developing accessibility – for example, in 2023 the MA (UK) launched its first-ever Anti-Ableism journal and focused on accessibility as a main topic for its conference in the same year – this demonstrates that the focus is still in its infancy when compared to other priorities in the sector.

It was fascinating to examine these findings after the AuND survey responses. First, most AuND-identifying respondents suggested that a substantial portion of the workforce in museums may identify as neurodivergent but may not openly disclose this in their workplace. This is not surprising, given that the work of many areas within this sector has the potential to engage AuND people's strengths and interests, as discussed in the motivations for visiting museums in [Chapter 4](#). Furthermore, the type of work in museums often aligns with common neurodivergent traits – for example, the ability to work in a space constantly in touch with either physical objects or interpretation and research related to topics of interest. Another factor to acknowledge is the impact of research being shared in cultural heritage-specific spaces and

in AuND-reaching communities with which I have engaged. Despite this survey being specifically shared in sector-specific mailing lists and groups, AuND museum workers may have found out about this project during other dissemination or participation opportunities and may otherwise have not engaged. While this research, and this survey alone, is not enough to make generalised claims about the percentage of neurodivergent people working or volunteering in the sector – it is enough to suggest a need for future research to be undertaken to better understand the workforce and needs of its neurodivergent members and extend accessibility beyond visitor experience. Furthermore, it is important to consider the position of researchers and examine whether they identify within the groups they are researching and how this can impact trust. In this instance, some people may have identified me as someone that they can trust because of my association with the AuND community. In addition, as I am someone who actively participated in wider community networks, this may have encouraged some respondents who otherwise may not have engaged or felt safe to disclose that they are neurodivergent in this survey.

#### 5.4.2 Strengths and Awareness of the Need for Improving Accessibility

It was also reassuring to discover that there was a good understanding of accessibility, as well as a desire to enhance adjustments to improve the visitor experience. A correlation may exist between the high percentage of respondents identifying as neurodivergent and this almost shared definition of “accessibility” but the general view that accessibility should be about creating equitable experiences for everyone reflects the views of the majority of AuND respondents.

In examining all the respondents’ reflections on their strengths and their priorities for guidance, a desire was evident to improve understandings of neurodiversity, regardless of respondent neurotype. Despite the respondents’ high ranking of themselves for “understanding” as a strength, identifying it as an area to develop showed that they recognised that, as our societal understanding of neurodiversity increases, ongoing training must be put in place.

The survey concluded that the respondents not only valued the involvement of AuND people in developing resources, but they also wanted to actively involve AuND people in future projects. The majority (90%) viewed working with neurodivergent people to be “very” or “extremely” important, and 86% of all respondents preferred the guidance toolkit to include information about how to involve neurodivergent people in developing resources. This is very

promising, but also not surprising given the trends towards more participatory practice within the museum sector (see literature review – an additional example is the MA in the UK offering a “Participatory Practice” training module). However, as with other aspects of the field, while the involvement of neurodivergent people is a priority for the respondents of this survey, the majority were unsure whether their organisation had undertaken any work that directly involved neurodivergent people. While this is a promising sign for the future of developing accessibility for neurodivergent people in the sector, this therefore depends entirely on its workers being able to undertake the work involved and overcoming existing barriers.

### 5.4.3 Common Barriers, Anxieties, and Areas for Development

A crucial finding from this survey was that there must be an investment (of time, energy, and compassion) for AuND visitors and also a greater focus on how to improve the accessibility of the sector for museum workers. While there are no research studies or data profiles that offer exact numbers of AuND people in the sector, this survey – alongside the founding of TNM – demonstrates the growing sectoral recognition that more needs to be done to support AuND across all aspects of the sector.

Some work is already being undertaken to enhance general accessibility within the UK. The CfC project provides fellowships to disabled, deaf, and neurodivergent individuals who have had difficulty accessing work in the sector. However, these opportunities continue to be limited. Moreover, some people who complete apprenticeship-type roles find themselves unemployed and face similar difficulties in accessing employment after their time in these posts’ ends. Neurodivergent people, specifically autistic people, have the highest rate of unemployment amongst different disability categories – often because of disabling recruitment processes, inability to make reasonable adjustments within the post, social pressures, and co-occurring health conditions – and would therefore benefit from greater support at all stages of their career. This research demonstrates that further work must be undertaken within the sector, as well as across different sectors, to address inequality in employment and ensure that workers experience the same level of care and consideration extended to visitors.

Levels of dissatisfaction, anxiety, and lack of knowledge about what organisations offered and general lack of confidence (or potentially pride) in what was currently available – particularly when compared to respondents’ motivations and understandings – highlighted a current disconnect between intentions and execution within the sector. Unsurprisingly, many respondents pointed to management when considering the shortcomings, or perceived lack of

consideration, of what is available in organisations. Given how many respondents to the survey showed discontent at the lack of prioritisation of accessibility, whether for AuND people or other under-represented groups not deemed likely to generate additional income, it is understandable that this impacts current and future access work.

Communication issues, particularly within institutions, regarding what is available, suggest that part of the reason for gaps in information for potential visitors (as highlighted in the barriers set out in [Chapter 4](#)) is that this is lacking internally in the sector. As an autistic museum visitor, researcher, and museum worker, I can see that this is a significant issue that impacts everyone, whether part of an internal workforce or external visitors. This is a problem that must be addressed to tackle the gaps in provisions and confidence issues and was particularly evident when asking respondents to reflect on what they currently have available and what their organisations have planned. Surprisingly, the least sure group of respondents on average were those who identified as AuND. This suggests that the organisations they work with may not actively engage AuND workers in their projects. It is important to note that employers may not be aware of all employees (whether paid or unpaid) and their neurodivergent identity, as this is dependent on comfort or safety in disclosing.

It is also noteworthy that not all AuND people want to be drivers of accessibility and change in their organisation. The open-ended question about the involvement of neurodivergent people in project development revealed that most of the work in the sector to enhance accessibility for AuND audiences has been led by neurodivergent people on a voluntary or short-term basis. Often, for those who were employed, it was not the primary function of their job and was undertaken in addition to their job because of a personal motivation to do that job. While some AuND individuals may be motivated to lead in creating and implementing the accessibility provisions they wish to see, this is often at a personal cost. Unsurprisingly, for many AuND individuals who must advocate for their rights, there is only so much energy to invest in projects where they may not feel widely supported or prioritised. From a personal point of view, which is shared by other AuND people (museum workers or otherwise), advocacy for better standards of access can often feel exhausting, underappreciated, or outright unwelcome. This is before considering the potential risk of “rocking the boat” by challenging inaccessibility or asking for investment in a person’s work relationship with colleagues or the perceived risk of inviting discrimination. As with all disability activism, while it has typically been led by disabled people advocating for change, it has often taken a long time for voices to be heard and action undertaken. It has relied on non-disabled powerholders to recognise the

need for change. This demonstrates the importance of not relying on all AuND or disabled people to carry all the weight of responsibility to create crucial accessibility changes. This must be shared across all individuals if a more equitable society is to be created.

The findings from this survey demonstrate that, while most respondents viewed the inclusion of AuND adults in provision development as a priority, it was felt that the sector has not yet managed to overcome obstacles to achieve this. The motivations presented among the respondents to improve the sector, as well as their understanding of not only what could be developed but what would be beneficial on their path, are not enough to result in meaningful change.



# Chapter 6 AuND and Museum Workers' Workshops: Community Consultation for Understanding Accessibility Priorities

One of the key objectives of this research project is to create sectoral guidance informed directly by the experiences and needs of AuND adults. Furthermore, the aim is for this guidance to be relevant and beneficial to museum workers. As presented in Chapters 4 and 5, several AuND adults and museum workers engaged in the data collection for this study. The feedback was collected directly from AuND adults and museum workers. This was to ensure that the research findings and subsequent recommendations were consistent with AuND adults' and museum workers' priorities and needs. This chapter examines the feedback from the consultation workshops conducted and discusses the implications for the next steps of this research.

## 6.1 Overview of Consultation

As outlined in the Methodology chapter, this research has involved various consultation stages and participatory involvement for AuND adults and museum workers. The initial consultation process involved two workshops for AuND adults to develop the methodology, research questions/aims, and survey questions. The recommendations and preferences expressed by both groups, as well as further feedback-gathering before the launch of the surveys, were essential in shaping the research. The significance of these focus groups was discussed in the Methodology chapter ([Chapter 3](#)), and the table of feedback and actions is available in the appendices ([Appendix B](#)).

The second consultation took place after both surveys were analysed and their findings summarised. As a result of the high volume of data from the surveys, I decided that holding consultation workshops was the most reasonable approach for discussing the findings. This involved organising two workshops with AuND adults held as part of the Autscope conference (August 2023) and two workshops as part of two SMF events (a 2023 conference and a neurodiversity training afternoon) with museum workers (May and October 2023). With each iteration of the workshop, I had the opportunity to reflect on the previous session and use the participants' feedback to ensure that the information was clear and the format accessible. This

followed the good practice guidelines for creating an effective workshop (Sufi et al., 2018; McInerny, 2016).

The next section provides an overview of how the workshops were organised, their context, and the profile of participants, before presenting the key themes and findings that emerged from the various consultation workshops.

## 6.2 Workshop Planning and Delivery Plan

The workshops each included approximately two weeks of planning and communication between the host organisation and the researcher. They were designed using my experience of attending workshops, focus groups, and practice-based research activities to create an engaging structure (McInerny, 2016). Both of the SMF workshops lasted approximately one hour, while the Autscope workshops lasted 1.5 hours. This was shorter than the recommended two- to three-hour average, incorporating various stages of involvement (Pavelin et al., 2014). However, this was the most appropriate duration of time for the workshops, as they were part of larger events and were affected by external schedules. As it was not clear whether the workshop attendees had previously participated in the research, or if they were fully aware of the research background, it was important to include information about the research questions and methodology. This lasted five minutes and led to an overview of the research findings. These were divided into “AuND” and “Museum Worker” sections with specific questions asked before transitioning to the next topic. This was intended to keep the topic fresh for the attendees. I also informed attendees that they could ask questions throughout the workshop rather than wait for designated times, resulting in some of the findings being discussed before the “formal” section where it was scheduled.

## 6.3 Workshop Overviews

This section outlines the three key workshops from Phase 3 of the research. Two workshops were formally held with museum workers, including one formal workshop with AuND-identifying adults with a further informal workshop also held for AuND adults. The workshops did not have an attendance screening before the sessions. This is not typically recommended for workshops as there is an expectation of some form of background check to ensure a mixture of perspectives (Pavelin et al., 2014). However, they took place during events where it was assumed that attendees met the criteria of being AuND adults or museum workers. The

attendees were asked to answer questions regarding the research findings and the future direction of the research, particularly the creation of a guidance toolkit. The questions are available in the appendices (Appendix [D](#)).

### 6.3.1 Museum Workers Workshop– Session One (SMF1)

The first workshop was held in May 2023 with museum workers at the SMF. This session, which lasted an hour, focused on presenting an overview of the research development process and noteworthy results from both surveys. I first presented a summary of the research and its findings for 25 to 30 minutes before inviting attendees to participate in the interactive feedback section of the workshop. Attendees were invited to share their thoughts in response to guided questions about the findings, specifically relating to what was present in, and what they believed may be missing from, the findings. In total, 20 people responded using the Mentimeter and printed forms. The responses to the prepared questions, as well as other questions raised by the attendees, were collected using Mentimeter. This enabled Mentimeter respondents the opportunity to contribute their thoughts or feedback anonymously. Participants were informed that, if they preferred, they could respond to the question in the room verbally and that these contributions would not be recorded using any technology. In general, the participants in this workshop contributed openly in both written and verbal ways throughout the session.

### 6.3.2 Museum Workers Workshop – Session Two (SMF2)

The second workshop with museum workers was held in October 2023. Like the first session, it was run for the SMF alongside an introductory “neurodiversity training” talk and practical activity exploring the host venue (Scottish Fire Brigade Heritage Museum, Edinburgh). In total, nine people participated in the workshop, with one PhD researcher and one individual interested in cultural heritage in attendance, along with current museum workers. Participants were informed in advance that the event would be a workshop that contributed to the research, and then the opportunity on the day to opt out of participating in the practical workshop component. All attendees completed the consent form (Appendix [A](#)) and chose to take part in the workshops by completing the accompanying surveys. The workshop was intended to utilise the same questions and Mentimeter format used in the previous session, with verbal contributions where preferred. However, the venue’s Wi-Fi was not functioning on the day. Instead, I had to run an offline version of the presentation – which I had prepared in case I encountered any such issues on the day – and print-out versions of the same questions to be completed instead. To provide the participants with the same opportunity to converse, share

feedback, and ask questions, there was still time involved in a group discussion. Many of the ideas that participants shared as part of the wider group discussion were also included in the surveys they completed. To ensure that participants had the same opportunity to contribute their thoughts anonymously, they were advised that they did not need to include their names in the printed responses. The written responses of seven of the participants were included in the analysis, with the responses of the PhD researcher and interested member of the public excluded because they had not worked within the museum sector in the last five years.

### 6.3.3 AuND Workshop – Sessions One and Two (Autscape)

While attending the Autscape conference in August 2023, I signed up to conduct a workshop as part of the “attendee-led” programme. This enabled me to be flexible in how I conducted the session as the only criteria was that the workshop fit within the programme based on space availability. I utilised the same Mentimeter presentation and questions as in the museum worker workshop – with slight modifications for clarity of language – to ensure consistency across the diverse groups. Information about the workshop was published in the programme in advance and was available in the information room from the beginning of the conference. As part of any information published in advance (such as on a conference’s website and in emails to attendees), the purpose of the workshops and accompanying participant information, consent forms, and workshop outline were made available (Appendix [A](#)). Contact information was provided in advance and on the day. This approach was influenced by my involvement in the Sensory Street project created by Keren MacLennan et al. (2022), where all participants were sent information about their participation in advance for their online focus groups. As I had attended the Autscape conference before, I could communicate with other returning delegates and flag who I was for anyone who had questions before the session.

The session ran for an hour and a half in total, allowing participants to hear the presentation, ask questions, and respond to requests for feedback. Unlike in the museum workers’ workshops, participants were able to ask questions throughout the session, rather than wait until specific points in the workshop. This was decided as I knew from previous AuND events that this was common practice at Autscape, and I am aware that some attendees may have found it more beneficial to ask questions when they arrived. Consequently, the Mentimeter presentation was not viewed in full, as the topics of those slides and questions had already been discussed. Of the 20 people in the room, with some people coming and going

throughout the session, 13 people participated in the Mentimeter or paper version of the questions and others contributed verbally as part of the discussion.

As the workshop occurred at the same time as one of the key formal programme events, and to ensure that everyone had the opportunity to hear about the research, I decided to organise a second session the following day. While the initial session was a formal feedback-gathering workshop that took place in the afternoon, the second workshop was designed to be less formal. It took place the following morning during a period with few programme clashes. This session had a total attendance of 15 people with some attendees coming and going due to the informal nature of this workshop. It was intended from the beginning that this second session would be a place where attendees could listen to the findings without any expectation of contributing. However, this workshop was also a place for anyone who wanted to give feedback or ask questions off-the-record, or who simply could not attend the first workshop because of programme conflict. Instead of using the Mentimeter version of the presentation for this workshop, I used the shorter PowerPoint version. For both workshops, attendees were informed that they could ask questions at any point in the presentation, and could come and go as often as necessary (which is a policy at Autscope). Both workshops were well attended, with minimal session drop-outs.

It is important to note that all the workshops were conducted in conference environments or alongside other training. While the participants in the workshops chose to attend the sessions and were informed ahead of each workshop that their feedback contributed to the research, their attendance was not necessarily based on interest in the workshop alone.

Overall, all workshops were well attended and were intended to follow a similar – if not identical – structure to maximise the consistency of data captured across the diverse groups. Although, understandably, the direction of discussion differed in each workshop as a result of group dynamics, common themes and feedback emerged. In the next section, I explore these themes and examine how I interpret each workshop from the perspective of an autistic researcher and accessibility practitioner.

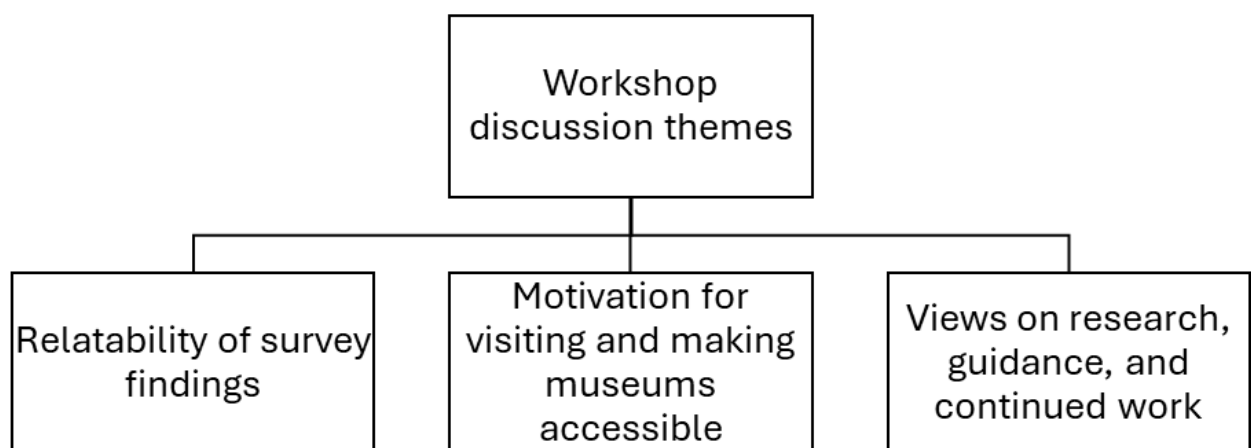
## 6.4 Findings

The findings discussed in this chapter are presented in two ways: first, an analysis of each of the recorded responses, identifying themes that exist across the three workshops and that are more specific to AuND or museum worker groups and, second, with a focus on the findings from the written responses to the researcher's recollection of the wider discussions that occurred in the room. The written responses collected through MentiMeter and from the printed questionnaires distributed at each workshop were compiled into an Excel spreadsheet. Content analysis was then applied to identify and quantify trends and themes across all responses. The quantitative data was then compared with the researcher's written notes recorded following each workshop, which documented the discussion topics that emerged in each session.

Notably, the written responses discussed below were reflected in the discussions that took place in the room. Consequently, while the verbal contributions were not recorded, the MentiMeter and printed surveys provide a glimpse into the talking points from each workshop.

### 6.4.1.a Analysis of Feedback

Below is a thematic roadmap of the key themes identified in the data:



*Figure 6-1 Thematic map of workshop findings.*

### 6.4.1.b Relatability of Survey Findings

At the AuND workshop, attendees were asked whether the findings reflected their lived experience as visitors, while museum workers were asked whether they reflected their experience as workers in the sector. The table below shows responses to the question about the relatability of the identified barriers to the attendees' own lived experiences:

<b>Do the common barriers identified reflect your experience or expectations?:</b>	<b>Sum of Session</b>
Yes (partly)	8
(blank)	1
Yes (fully)	1
<b>Grand Total</b>	<b>10</b>

*Table 6-2 Table of responses to “Do the common barriers identified reflect your experience or expectations?”, AuND workshop.*

The below table shows that most of the attendees agreed that the most common reasons for visiting museums reflected their own experiences or expectations:

<b>Do the common reasons for visiting identified reflect your experience or expectations?:</b>	<b>Sum of Session</b>
Yes (partly)	5
(blank)	2
Yes (fully)	4
Not sure	1
<b>Grand Total</b>	<b>12</b>

*Table 6-1 Table of responses to “Do the common reasons for visiting identified reflect your experience or expectations?”, AuND workshop.*

Attendees at both the AuND and museum worker workshops were also asked to reflect on their expectations for the survey for which they may not have had lived experience. The museum workers were asked if the findings from the AuND survey met their expectations while the AuND attendees were asked about their expectations for the museum worker experience. According to the chart below, most attendees at both SMF workshops responded that it “partly” met their expectations. However, some stated that they did not come into the workshop with set expectations:

Were the neurodivergent adults survey findings what you were expecting?	Sum of session
Yes (partly)	13
Yes (fully)	7
I did not have specific expectations	6
No	0
<b>Grand Total</b>	<b>26</b>

Table 6-2 Table of responses to “Were the neurodivergent adult survey findings what you were expecting?” (SMF1&2).

These findings demonstrate that most workshop attendees observed that the themes identified from the surveys reflected at least a part of their experience or exceeded their expectations of the results. This was reflected in the discussions within the room, where topics such as the sensory experience of AuND people were a key element, particularly in the AuND and SMF1 workshops.

## 6.4.2 Attendees’ Reflections on Findings

Attendees were also asked to reflect on potential “surprises” from the identified themes of the findings. The responses that they contributed to this question demonstrated a difference in question interpretation across the three sessions.

Some findings were either surprising or evoked a memory of an experience. The following sections examine the factors that did not arise from the survey findings and, in some cases, the impact that information had.

### 6.4.2.a AuND Workshop

At the AuND workshop at Autscope, participants were asked to consider what may have been missing from the list of barriers identified in the surveys. The responses to this question focused on specific events, resources, and spaces. For events, two of the attendees commented on the need for specific events for AuND people. A third attendee expressed that these hours should not just be in the mornings:

*“Museums [need] to embrace neurodivergent friendly periods within core hours, i.e. weekend 10–4pm. This might also help the general visiting population who might also benefit.”*



These responses regarding event timings suggest that AuND adults may benefit from having diverse access times. Museums and cultural heritage organisations should therefore consider varying opening times and events for this group of people.

Another theme related to events and experiences in the museum environment was the impact of “*too much*” happening at one time. Attendees expressed their appreciation for the impact of an overwhelming, busy space on their ability to process and enjoy being present in the environment. Some attendees focused on events, highlighting a need for “*structured events*” to help them organise their visit because, as another attendee mentioned, there can be “*too much on at one time*”, which can cause them to become overwhelmed. The “*clash of different activities*”, as another attendee described it, created by “*noisy or distracting interactive exhibits close to audio-visual presentations*” without “*separation*” could make attending museums incredibly challenging. Many of the attendees believed that the solution to these issues was often related to planning exhibitions with distinct areas for different interactive elements and the option of quieter areas to decompress. The impact of the sensory environment was, as in the surveys, a crucial topic for discussion at the workshop – specifically, when considering the barriers to museums and what attendees would want museum workers to be aware of when planning future exhibitions and events.

The discussion was also focused on the availability of information in various formats. In the recorded responses, one attendee stated that information at the museum must be easier to understand (i.e. “*not always written*”), while another simply stated that they wanted to “*make museum information more clear*”. Attendees discussed the impact of information that was too difficult to read and understand on their ability to attend (or stay in) the museum. As per the survey findings, the importance of having information available in an accessible location within the venue and online was preferred. One of the key recommendations was to have information available in different formats. For example, while some preferred written information, others preferred photographs of areas, or the availability of a member of staff to answer questions or guide them.

Another common code was connected to the availability of a quiet space and consideration of sound pollution in various areas of the building. This occurred in the written and verbal feedback when considering the impact of the sensory environment of a museum on the ability to enjoy being in the space. One of the respondents stated that they would like museums to introduce “*designated quiet hours*”, while another stated that the “*clash of different*

*activities, i.e. noisy or distracting interactive exhibits close to audio-visual presentations – no separation*” would help improve the sensory environment. These comments reflected the discussion in the room about the impact of unexpected loud noises and conflicting sounds on attendees’ likelihood of experiencing sensory overload and needing to leave the building. As some of the attendees used words like “*calm*”, “*quiet*”, and “*space*” to describe what a museum means to them, it can be interpreted that spaces that are the opposite can create a barrier to their ability to attend the space.

#### 6.4.2.b Museum Workers

The responses to the question asking for feedback on any gaps or unexpected findings from the survey differed in key themes across the two workshops. The SMF workshops were held at events pre-organised by the organisation, and the context of each of these events impacted the types of responses received by attendees. For SMF1, the workshop was at a conference and focused on sharing research findings to gain feedback. The attendees at this workshop specifically focused on the findings related to AuND people having both hyper- and hypo-sensitive sensory needs – as most had only been aware of hyper-sensitivity responses to sensory stimuli before the workshop. The second SMF workshop was held as part of sectoral training<sup>28</sup>, which began with an introduction to neurodiversity information session before the findings workshop, so this theme did not come as a surprise. This shows the significant impact of awareness training on attendees’ understanding and expectations of the research findings. This section explores the key findings of each of the workshops individually.

For SMF1, the museum worker attendees discussed the need for consultation on the types of events that they offer for AuND adults. For example, attendees reflected on the findings of the times that the events are typically held and the tendency for them to be specifically targeted at children. A key factor mentioned was the high motivation and visiting patterns identified by AuND people, which some attendees observed could help to create a case for more support and investment by their organisation for this audience. One attendee described the findings as a “*foundation for change*”, which they could use as part of funding applications to address current barriers. Some attendees were concerned that their organisation was not “*doing enough*”, while others expressed concern about “*limited space*” to make facilities such as quiet space happen. While many attendees were unsurprised by the barriers to accessibility

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<sup>28</sup> This training was delivered by the researcher, at the request of the SMF following positive feedback about the findings and insights from the workshop I had delivered at the conference held earlier the same year (May 2023).

developments, some indicated that *“it was upsetting to see management who don’t care to address these problems.”*

Comparable topics that emerged in SMF1 were also present in SMF2. This was an interesting coincidence, as the question asking attendees what could be done to enable the museum sector to improve its accessibility was intended to be left open for attendees to write their responses independently. While attendees of SMF1 could potentially see and replicate others’ responses on the presentation screen during the workshop<sup>29</sup>, rather than write their own responses, this was not possible in the second workshop. SMF2 attendees who wanted to contribute to the findings were required to share handwritten responses and could not view other responses. Attendees at SMF2 were also not informed of the feedback from SMF1, meaning that any overlapping responses were organic and in response to the presentation held on the day. Significantly, these groups responded similarly to the questions during different sessions, suggesting that the findings discussed from the surveys have a more precise application than anticipated.

The most common “surprise” for the attendees at the SMF2 session, as five of the seven respondents stated, was the significant level of motivation to visit museums from AuND adults. In these responses, one attendee stated they were *“happy to see the engagement and want to visit from neurodivergent people is there – to me this validates that work [is] needing to be done”*, while another said it was *“not surprising, really interesting to hear why people visit”*. One of the attendees specified that they were surprised about the “social” motivation, relating to the AuND survey respondents highlighting the impact of museums as a place to socialise. This attendee wondered whether this was a common motivation for all potential AuND visitors. Another respondent mentioned that they were also surprised about the *“high percentage of [the] workforce identifying as neurodivergent”*. These responses reflected the discussion on the day, which focused on the potential of research demonstrating visitor motivation and reasons for visiting to influence the development of future projects. In addition, the attendees discussed the high percentage of AuND-identifying respondents to the museum worker survey as this is difficult to record within organisations because of lack of disclosure. As in SMF1, attendees of SMF2 reflected on the potential of data like this, alongside a toolkit, in encouraging organisations to undertake work and providing *“proof for funding applications”* to make the work possible.

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<sup>29</sup> Due to the use of Mentimeter, which updates the presentation on the screen in real time.

In contrast to SMF1, where the diversity of sensory needs in AuND people was a common topic, this was not the case in SMF2. It is important to note the impact of providing introductory neurodiversity training before the workshop. This consisted of an hour of introducing terminology, the origin of it as a concept, and common traits experienced across the spectrum of neurodivergence on SMF2's attendees' understandings of key themes that would come up in the workshop when compared to SMF1. In the first workshop, 28% (five of 18) of attendees stated that they did not have expectations for the AuND survey results, compared to only one attendee at SMF2. This could be because, compared to SMF2, fewer people came to SMF1 with a background understanding of the diversity of AuND people's experiences, or because attendees were coming in with an open mind as to what the results would include. This suggests that, if more workshops were conducted with museum workers, providing introductory training or information sessions could help shape their understanding and reduce their anxiety.

Both sessions had AuND-identified individuals who recollected their experiences as museum workers and AuND people. These attendees disclosed their AuND identity either verbally in the room or independently before or after the session. For instance, one SMF1 attendee responded to this question with *"As a neurodivergent museum worker, nothing was particularly surprising to me!"* This meant that the discussion often drew from the personal experiences of openly AuND attendees about what resonated with their lived experience of the topic from visitor and worker perspectives. The decision not to record the workshops resulted in these demonstrations not being formally documented but enabled the individuals to feel comfortable sharing their views in the room.

### 6.4.3 Motivation for Visiting and Making Museums Accessible

Another theme that resonated across all workshops was the desire to either visit museums (AuND) or to make them neurodivergent accessible (SMF1 and SMF2). It was evident from the discussion in the room and the written feedback that the attendees were motivated by the topic of the workshop they attended. As they were self-selecting to attend the session, either as an option during a conference programme or as part of a training afternoon, most of the attendees openly shared that they had chosen to attend the workshop because of an interest in the research topic. Most AuND attendees at the Autscope workshop stated that they attended because they were keen museum visitors (or had been in the past). The AuND-identifying museum workers who attended SMF1 or SMF2 stated that they wanted to hear about the

research findings because of their connection as a neurodivergent person or because they were leading their organisation's accessibility efforts. For non-AuND-identifying museum workers, the motivation to attend the session varied from "professional" (attendees acknowledging a gap in their knowledge or undertaking accessibility work) to "personal" because of a connection (family or friend) with an AuND person who they were motivated to understand better. This suggests that the attendees of all workshops had a personal or professional motive, which led to them choosing to attend the workshop.

### 6.4.3.a Museum Workers

The museum workers attending both SMF1 and SMF2 demonstrated that they were becoming more “*optimistic*” about accessibility for AuND people by the end of the workshops. This was measured by asking the attendees to reflect on “how [they] currently feel about accessibility for neurodivergent people in your organisations?” and then asking them at the end “In a word, how do you feel about the future of accessibility for neurodivergent audiences after this workshop?” The first question was asked before the presentation of findings had taken place and was intended to capture their initial thoughts before hearing this and how they felt after the workshop. These questions were selected to help understand and measure the attendees’ confidence before and after the workshop to identify whether it impacted how they felt about a) their organisation’s accessibility now and b) their organisation’s potential to improve future accessibility. Questions about confidence at the beginning and end of a workshop can help to assess the prior knowledge and impact (Sufi et al., 2018).

When discussing how the attendees currently felt about their organisations’ existing accessibility for AuND people, there were two distinct groups – first, participants who felt uneasy about what was available. For these attendees, terms such as “*disappointed*”, “*alone*”, “*lacking*”, “*currently poor*”, “*patchy*”, and “*inconsistent*” came up across both workshops. This reflected the themes of the museum worker survey findings around discontent with or uncertainty about what was available. The second group was made up of attendees who felt that their organisations were starting to make progress. For the six attendees across both workshops who responded positively to this question, their responses tended to focus on “*good intention*”, “*making progress*”, “*small steps forward*”, “*getting better*”, and positive words such as “*passionate*” and “*curious*”. For this group of attendees, there was an acknowledgement that their organisations had already begun to work on improving accessibility and were therefore keen to improve what they were doing. This suggests that, regardless of how they felt about their organisations’ current accessibility, the participants attended the workshops because they identified a need to improve the organisations’ accessibility. This implies that all attendees were motivated to attend the session to learn from the findings and implement them in their practice.

By the end of the workshops, attendees were more motivated and enthusiastic when considering future accessibility. The most frequently used words to describe how the attendees felt after the sessions were “*hopeful*” (nine responses) and “*optimistic*” (four responses). Other words or phrases that reflected the above sentiment included: “*change is coming*”, “*motivated*”,

*“inspired”, “encouraged”, and “positive.”* Others expressed that they were *“keen to learn more”, “more equipped”,* and saw the future of accessibility for AuND people as *“heading in the right direction”*. These responses could be related to the conversation within the room, where attendees expressed that the steps they could take to make their organisations more accessible were not necessarily as challenging as they had previously believed before attending this workshop. Additionally, attendees at both sessions identified the significant role that working together within the sector can play in enhancing confidence and improving practice.

#### 6.4.3.b AuND Adults

The initial question for attendees to answer was, “What words do you think of when you hear the word ‘museum’?” This question was asked to gain insight into the attendees’ perceptions or views of what a museum is. All 13 attendees who participated in the written record of the workshop contributed their words, which could be organised into the themes “literal/theoretical”, “environmental”, and “motivation”. The first theme related to words that were literal features of a museum, such as *“exhibit”, “display”, “collection”, and “objects”*. The second theme described museum spaces and any feelings associated with them, such as *“calm”, “quiet”, “space”, and “reflection”*. The final theme was related to words that could be interpreted as motivation-related, such as: *“interesting”, “fascination”, “fun”, “educational”, and “cultural.”* These words can be interpreted as a connection to the individual’s experience or interpretation of what a museum is or should be. Attendees’ responses indicated that they expect certain features from a museum – that it is a building with displays of objects available for visitors on several topics. In addition, their responses asserted that these structures must hold objects or information that are of interest to visitors and give them the opportunity and space to reflect on them. These participants’ views of museums reflect those discussed in the Literature Review and those identified in the MA’s (2013) report on public perceptions of museums. This is particularly evident in two key areas: the widespread understanding of museums as custodians whose primary role is safeguarding objects, and the enduring image of museums as traditionally “quiet” spaces (e.g. Bennett, 1995). The responses to this question mirror the key associations identified in the Museums Association’s 2013 report, where terms like “educational” and “interesting” emerged as dominant descriptors when participants were asked about their immediate associations with museums (p. 11). The words *“fun”* and *“interesting”* in the workshop participants’ responses reflect the direction that museums are seeking to pursue (i.e. away from being perceived as a solely “educational” space towards one where there is more active engagement). This reflects a broader strategic effort by many

cultural organisations to improve their relationship with their audience and compete effectively with other leisure venues (Rodney, 2019; Coffee, 2008). These responses suggest that attendees had a good understanding and experience of visiting cultural heritage institutions that they could summarise in just a few words. They also suggest that the perceptions of museums by AuND people are reflective of wider audience perceptions of this type of organisation.

Autscape attendees were presented with these motivations for visiting museums elicited from survey responses ([Chapter 4](#)) and asked whether these reflected their own experiences. Of the 11 attendees who participated using Mentimeter, 10 responded to the question that asked them to rate whether it reflected their own experiences, ranging from, “No (not at all)” to “Yes (fully)”, with “not sure” available for anyone who needed it. In total, four responded “Yes (fully)”, five responded “Yes (partly)” and one responded that they were not sure, indicating that the findings did meet their expectations or reflect their own experience. When asked to consider whether they had any other reasons for attending museums, responses included: “*for work*”, “*for fun*”, “*to hyper-fixate on special interests*”, “*taste of locality*”, and “*sensory experience/spiritual experience*”. These responses were discussed in the room as they came up in the survey findings as minor but still present topics, demonstrating that each attendee had their own motivations for visiting museums. Some may result from work-related commitments, as one respondent stated that they were an architect and another was a consultant who had shared feedback with organisations. Others, meanwhile, mentioned that they visited for pleasure.

It was not surprising that attendees discussed the importance of exploring their interests in motivating them to visit. Some attendees shared anecdotes about visiting specific museums solely to visit a temporary exhibition or a single object of interest in the space. One example was an attendee who specifically visited the NMS before the refurbishment to see the koi fish. Others expressed an interest in specific “*sensory experiences*”, ranging from wanting to be in a space perceived as “*quiet*” or having the opportunity to interact with objects of interest. This indicates that, while most attendees identified with the survey findings presented at the workshop, more motivations for visiting museums were uncovered as part of the conversation within the workshop.

AuND attendees were also asked to share their thoughts on the research. In total, six attendees wrote responses to this question, representing half of the total attendees who participated in the Mentimeter and written responses. The responses were: “*very much needed*”,



*“hopefully will be helpful to get more people to be able to access museums”, “it’s well structured”, “valuable, ethical, important”, “very interesting research”, and “thank you – keep going”*. These responses suggest that the attendees found the research to be of interest and importance. This sentiment was reflected in the discussion within the room, particularly when considering the impact that both positive and negative experiences of museum visiting can have on the likelihood of future museum visiting. Attendees thus arguably valued research that they believed to be *“ethical”* and potentially beneficial. This is a crucial point to reflect on, given the elevated levels of anxiety and questioning of the ethics, methodologies, community priorities, and potential impact on neurodivergent people of research into AuND people (Realpe et al., 2023; Jones, 2022). The decision to participate in research is significant as it requires the individual to make an informed decision about whether it is appropriate to them and of interest.

#### 6.4.4 Views on Research, Sectoral Guidance, and Continued Work

The initial development of this research project was intended to lead to the creation of practical guidance or support for the museum sector to enhance its accessibility for AuND people. A key aspect of the workshop discussion was what form the guidance information should take. This was an important discussion to ensure that the final output would be effective and informative about the findings so that museum workers could utilise these as part of their work. The initial methodology and intended output of the research was a guidance “toolkit” or “booklet” containing evidence-based information from the lived experience of AuND individuals who participated in the project, to include useful practice examples and research that would be developed using AuND-led feedback. This technique of creating a toolkit can be seen within and beyond the museum sector to communicate complex information in a concise, carefully curated manner. For example, other toolkits include “Ethical Museum” (Collections Trust, 2020), “New Museums” (MGS, n.d.), and audience-specific toolkits such as those for “Early Years” audiences (Museum of London Docklands, n.d.). However, as my supervisor (ME) has stated, there could be concern about having too many toolkits in the sector already, potentially reducing the likelihood of museum workers accessing another one. To understand the preferences of museum workers, both the survey and workshops asked participants to consider whether they would find a toolkit or guidance booklet beneficial.

The written responses and discussion at both SMF workshops showed that the answer to whether a guidance toolkit would be useful was a unanimous “yes”, with the majority stating that it would be “extremely useful”. Combining the responses from both SMF1 and SMF2, 72% of attendees answered, “extremely useful”, and 28% answered, “very useful”. This reflects the findings of [Chapter 5](#), which revealed that many respondents also responded with the highest level of certainty regarding the usefulness of a guidance toolkit. The conversation then shifted to what guidance would be beneficial and what concerns could be addressed in the toolkit.

Barriers to undertaking accessibility projects for neurodivergent individuals were found to exist across both workshop groups. For SMF1, it was evident that most of the attendees’ biggest concerns related to “*getting it wrong*” and “*not doing enough*”. Another attendee shared a fear that they were “*not doing enough to make [AuND people] feel safe and comfortable in the museum environment*”, a theme that also occurred in the museum worker survey when considering what an “accessible” museum looked like. This occurred in the written and verbal

responses, where attendees shared that they feared taking the time to develop an event or resource that might receive a limited or poor response from AuND people.

These themes were echoed in SMF2. Themes that occurred more in SMF2 included *“lack of support”* from people in decision-making positions, concerns about *“pushback around segregating/separate people through specific events”* and the impact of (lack of) understanding from staff, volunteers, and other visitors that can feel beyond their control. As with SMF1, concerns about how to plan, advertise, and execute events or resources for AuND people were often a barrier to progress. There were concerns about venue limitations, changing accessibility (*“We have a quiet room, but it is not just a quiet room and gets closed for other purposes”*), and providing training to all workers to ensure a shared understanding of neurodiversity.

It was clear from these anecdotes that the attendees at both workshops were empathetic to the needs of AuND audiences, but that they failed to provide meaningful support in the form of events or resources. For example, one attendee stated they were concerned about *“inviting in an audience and then not catering to them adequately”*, while another shared anxiety about *“not being able to satisfy all needs”*. The recurring themes from the Mentimeter responses related to difficulty in reaching this audience group (*“how to get the word out”*), staff understanding (*“staff are not fully aware of the range of neurodivergence and tend to focus on the stereotypical autistic child”*), and ensuring that diverse needs are considered (*“anxieties about excluding someone due to the diversity of neurodivergent people”*). It was clear from the discussion and written responses that anticipated barriers – such as limited budget and worker capacity – and lack of confidence to undertake the work were factors that limited progress. Attendees of SMF2 also discussed their anxieties about lacking *“adequate funding, resource [and] time”* to undertake this work, alongside the reliance on AuND people to do this (*“stop putting pressure on ND staff to make it happen!”*).

Attendees of SMF1 suggested a guidance toolkit that provided information about how to organise events, develop resources, and meaningfully involve AuND people in their development would be beneficial. They stated that this would help them to develop their confidence and provide evidence to support them in advocating for this work to be held in their organisation. Some attendees highlighted that, in addition to having a toolkit, they would benefit from having *“specific training”*, an *“online space”* for sharing good practice examples, and some form of *“working group or forum”* that would enable *“knowledge sharing and training between museums”*. SMF2 attendees also responded positively to the idea of having a

guidance toolkit and other knowledge exchange platforms for “*sharing good practice with buy-in from ND people (rather than boasting about sensory backpacks)*” – suggesting an interest in information or practice that is AuND-centred rather than examples of existing practice. SMF attendees suggested that they would like to see a form of “*network*” or “*neurodiversity champion*” programme to help develop practice in a manner that was sector-wide, not localised to their organisation. As in SMF1, attendees at SMF2 suggested that it would be helpful to promote and “*celebrate*” best practices in a way that was kept up-to-date. This focus on collaborative development across the sector is crucial, as it demonstrates that the participants were aware that the work they do was not – and should not – be treated in isolation. By collaborating to share good examples of practice and to create neurodiverse networks in their organisations or signpost to TNM’s network and resources, they could collectively improve the experiences of both AuND visitors and workers.

The benefit of this research was explored in all the workshops, but particularly in the first Autscope and SMF workshops. While museum worker attendees focused on the types of information they would find beneficial in a guidance toolkit, AuND attendees shared what they would want to see and what they would want museum workers to know about their needs. For Autscope attendees, there was an interest in participating in projects to enhance museum and cultural heritage institutions’ accessibility. However, as reported in the survey, the projects needed not to be viewed as “*tokenistic*”, ensuring that significant impact, as well as compensation for participating, was clear.

For SMF1 and SMF2, an interest was apparent in working with AuND people to develop what they have available. However, there was a hesitation to undertake this work without a good foundation of knowledge about what it would take to meaningfully engage and ensure the access needs of AuND people were met. These discussions suggested an openness to undertaking projects to develop access that involved AuND people if there was support, which a guidance toolkit and workshops on participating in participatory practice with AuND people could enable.

## 6.5 Discussion

The creation of a participatory research methodology that puts AuND people first was a priority from the beginning of this research project to ensure it was engaging, accessible, and met the objectives of neurodivergent people (Fletcher-Watson et al., 2019; Nicolaidis et al., 2019). The initial focus groups helped to inform the design of the workshops, which were initially intended to be focused on identifying the themes collectively, instead of presenting them and seeking feedback. However, because of the higher-than-expected response rate for both AuND and museum worker surveys, it did not seem appropriate to expect a focus group to go through all the data in the way I had initially hoped as a result of how time-consuming this process would be. Instead, it was necessary to undertake the six stages of thematic analysis to identify recurring themes and summarise them before consulting with AuND and museum workers, as presented in Chapters 4 and 5. Despite this synthesising process, the amount of information was still significant, and the form for the participatory consultation would need to be developed. When the opportunity to present a workshop was established at the SMF in 2023, this provided me with a format to tailor an interactive presentation with workshop discussion points that would last an hour. This enabled me to develop a workshop that I could reuse and modify for the Autscope conference and SMF training day. For each of these sessions, while the content and the questions asked would remain the same, the phrasing would be updated to reflect the suggestions from previous workshops. This was the same reflexive practice used during the initial focus groups (see [Chapter 3](#)) and was openly discussed during the workshops. The workshops, like all aspects of the methodology, were designed to meet the needs and perspectives of AuND people and museum workers. This discussion focuses on the workshops both as a process and in terms of their impact on the next stages of the research.

### 6.5.1 Workshop Delivery

All three formal workshops and one informal workshop were well received, with a consistent commitment from attendees throughout the sessions. The decision to allow attendees to ask questions or interject with their thoughts throughout the workshop, rather than waiting until designated times to ask for feedback, had both a positive and negative impact. The feedback and questions that came up were relevant to the topic being discussed but frequently involved information I had planned to discuss later, which enabled me to identify and adapt the order of information for the next workshop. Enabling attendees to interject also allowed them to communicate what they were uncertain about or to ask any questions they had during the

relevant time, so the point was not lost by the time a feedback period was reached. This was beneficial in ensuring that I was able to hear, and respond to, attendee input promptly. Nonetheless, the impact of stopping the presentation to address attendee input sometimes impeded the flow of the discussion, which meant the potential loss of some information intended to be discussed. For the Autscope workshop, which had the highest amount of feedback and attendance of all the workshops, the interjections resulted in the full presentation not being completed in the manner intended. The Mentimeter questions in the last half of the workshop were not answered, despite the topics of the questions being discussed throughout the session. Consequently, if running these workshops again in the future, I would continue to enable attendees to converse when relevant, but I would also plan for a longer session (two to three hours, in line with Pavelin et al.'s (2014) recommendation for workshop length. I would also consider organising a recording in advance for workshops where the discussion may be the main source of insight, as was the case with the Autscope conference workshops. Overall, I would say that the format and ability for the attendees to contribute or ask questions throughout the session enabled a far richer conversation and helped to create an open environment for sharing experiences.

Care was taken to ensure that all attendees were informed in advance about what to expect from the workshop and that it contributed to research findings. As an autistic researcher and attendee at the conference, I was acutely aware of the importance of complete transparency about the workshop's intention and providing information and options for taking part, following attending a session at the Autscope conference the previous year that was not transparent. The outcome of that event was the creation of uncertainty and distrust, as we attendees were not informed that the workshop was contributing to research and the use of the information. What we were providing was unclear, leading to participants withdrawing. In reflecting on this experience and positive experiences as part of the Sensory Street project, I spent additional time providing information in as many formats and locations to access it as possible. The outcome was evident as the sessions had good attendance and there were no questions about the workshop format during the session.

### 6.5.2 Self-selection and Motivation

It is important to recognise that the workshops also had people who actively *chose not to attend* museums, despite the majority of attendees being people who already attended or are interested in making them more accessible. One powerful memory from the Autscope workshop was an

interaction with a person who approached the door and inquired about the workshop. Upon being told that it was a workshop about making museums accessible for AuND people, the person stepped back and said, “*I don’t like to visit museums, so this session isn’t for me.*” This statement resonated strongly as [contrary to this person’s perspective] the workshop was very much intended *for them* to have a space to share *why* they do not like to visit and *what could* make museums more appealing in the future. Similarly, when discussing who was present at both SMF workshops, most of the attendees mentioned that they were from front of house, learning, and engagement roles as well as incorporating volunteers. The *missing* attendees were those in decision-making positions, specifically directors or department heads, or those employed in departments not traditionally associated with audiences, such as collections. As with the Autscope workshop, the crucial factor of *choice* and the prioritisation (or deprioritisation) of accessibility for the SMF workshops highlighted the issue raised in [Chapter 5](#) about the lack of interest in this area from people in decision-making or cross-departmental positions. It is therefore important to consider that these workshops – while being met with motivated and pro-research participants – cannot be regarded as a reflection of all AuND or museum worker experiences, especially when people who are more critical of museums (Autscope) or who do view this audience’s needs to be a priority (museum workers) are absent from the discussion.

This interest-motivated attendance became evident in the discussion at each of the workshops. At the Autscope workshop, attendees expressed an interest in visiting museums, often sharing personal anecdotes from visits that had gone well or sharing why they like to visit cultural heritage organisations. At SMF1, some attendees stated that they attended the workshop because they were interested in improving their organisation’s practice or were currently undertaking projects to make their museums more neurodivergent accessible. For SMF2, attendance was a result of attendees’ desire to learn more about neurodiversity and create accessible experiences for AuND visitors, as was the theme of the training afternoon they attended. This shows that most attendees self-selected their attendance because of some existing interest in the topic.

While both AuND and SMF workshops explored barriers that impact the accessibility of cultural heritage venues – both from a visitor and worker perspective – the focus tended to be on what could help to overcome these barriers. Autscope attendees often shared about the barriers to their visit – particularly focusing on the sensory environment and attitudinal barriers

presented by others in the vicinity – and suggestions for addressing them. This reflected the approaches to answering the barrier question in the survey ([see Chapter 5](#)).

SMF1 and SMF2 attendees cited anxieties about the willingness of management to make changes. However, they asserted that research-based evidence that demonstrated the motivation of AuND people to visit and the benefits of undertaking accessibility work could motivate change in their organisations.

### 6.5.3 Workshop Engagement

Throughout the workshops, interest was clear from both the AuND and the museum worker groups in seeing cultural heritage organisations become more accessible. All the workshops were well-attended events, with an important level of engagement in both listening and contributing to conversations about what was currently experienced within the sector (both from the visitor and worker perspective) and what could enhance it in the future. The focus of all the workshops was on how to increase confidence, for both AuND visitors who have experienced negative museum experiences and for museum workers who feel that their current provisions are inadequate, and to encourage experience sharing. It was evident that those who attended the sessions had a genuine desire to see museums become more accessible and an interest in learning more about this research project.

Participation in each of the workshop sessions demonstrated the importance of creating a space to discuss the research findings directly with the groups that the research is intended to serve. The willingness of each attendee to engage in listening and offering feedback, often providing personal information to illustrate their point, suggests that they considered the research worthwhile to contribute to. In addition, creating a forum for shared discussion, and actively exploring how their inputs would be reflected in further refining the survey findings and the guidance toolkit, enabled open discussions to take place.

### 6.5.4 Challenges

While these workshops demonstrate a useful method of meaningful engagement and dissemination, they were not without challenges. Difficulties with the technology impacted some attendees' abilities to engage fully with the interactive components of the sessions. Whether that difficulty came from the actual technology not working (such as Wi-Fi issues at a venue or device incompatibility) or from attendees not feeling confident using interactive presentations, the use of technology created barriers to some areas of participation. However,



as the sessions were designed to be open spaces for discussion, there were other ways to take part: in writing, verbally, or by communicating after the session itself. This demonstrated the importance of not relying solely on one way of capturing insight into a topic and providing options. As indicated in the original focus groups about designing the research and both surveys, the workshops confirmed that a willingness to offer options for how to participate is essential to help alleviate potential barriers to taking part.

The workshops also further highlighted the importance of working to identify ways of engaging the not currently engaged. A larger challenge in this research project overall, especially in the workshops, was reaching people for insights into why they do not attend museums as visitors or museum workers who do not view making their institutions accessible for neurodivergent audiences as important. The attendees at the workshops were all people who were already engaged or interested in the research and its potential benefits. Attendees were often open about why they chose to attend, often related to *wanting* to visit more or having an existing *interest* in improving what is available for visitors. With conflicting sessions running when the workshop was held at a conference or the requirement to book in to specifically attend neurodiversity training, it was expected that this would mean that the attendees would have some form of invested interest or personal connection to the topic already. This was confirmed when one potential attendee did not come through the door as the workshop “*wasn’t for me*” as someone who did not go to museums. This challenge of “engaging the unengaged” is a significant barrier throughout participatory research projects, as the question of *how* you can start these conversations can be hard to address. Ideally, a step that could be taken to further develop this research would be to specifically focus on the experiences of AuND-identifying people who do not already attend or have an interest in visiting cultural heritage organisations specifically to better understand their reasons.

### 6.5.5 Next Steps

The findings from the workshops discussed in this chapter were used to reflect on the themes discussed in both Chapter 4 and Chapter 5. The initial themes identified were extensive, detailed, and often overlapping with sub-themes. Using the feedback, questions, and follow-up discussions from each of the workshops, I was able to re-examine the survey findings and themes to further develop them into the chapters of this thesis.

In addition to the impact that the workshops had on the thesis, these also influenced the direction of future output plans for the research. As discussed, many of the attendees viewed

the project findings and the idea of a guidance toolkit as “extremely useful” for the sector. Some of the SMF1 and 2 attendees shared insights into what type of information or format would be beneficial for them and their organisations. For the AuND attendees at the Autscope workshop, suggestions about what they would want museum workers to know and advice for enhancing cultural heritage institutions were also discussed. The ideas discussed during the workshops will be incorporated into the development of the guidance toolkit once the thesis is submitted.

As a recurring theme in both the museum worker survey and workshops was the presence of AuND people in the sector, it is intended that new workshops will be organised for AuND-identifying museum workers to finalise the guidance toolkit after the thesis is submitted. Invites will be issued to the AuND people and museum workers from all the surveys, workshops, and focus groups involved in this thesis to contribute to the development of the guidance toolkit. This will then be tested and developed with AuND-identifying museum workers to ensure its effectiveness. The guidance toolkit will ideally be viewed as a live document – not a static tick-box list – with community-developed insights that will be updated following feedback and will be adaptive to the needs of different organisations.

The workshops provided an opportunity to explore the experiences and viewpoints of its AuND-identified and museum worker attendees. While fewer voices could be heard via workshops when compared to the surveys, the ability to discuss the research findings to further refine them and ensure they are reflective of the intended groups they were designed to serve is beneficial to the development of this research. Having the opportunity to explore the themes that emerged in the surveys and to gain expertise by experience enabled a greater understanding of the findings. In many ways, the personal experience shared during the workshops – as well as less formal conversations with AuND people and museum workers throughout the analysis period – contributed to the findings. While a small number of attendees attended the workshops, the high level of participation and meaningful contributions from those present underscored the values of creating opportunities for active engagement. This helped ensure that the definitive version of the findings was based on the needs and priorities of the AuND people and museum workers that the research was designed to address.

## Chapter 7 Conclusion

Throughout this research project, the needs and priorities of AuND people have been at the forefront of every interaction and decision made. From the project's conception as a response to the inaccessibility and lack of direct involvement of AuND people in cultural heritage organisations, it intended to reflect on the priorities of the community it aimed to serve. For this reason, the project expanded from being solely about autistic people's experiences as visitors to being about neurodivergent people as visitors, and was also informed by AuND museum workers. At each stage of the project, the access needs of AuND people shaped the approaches taken, which meant offering different ways for anyone interested in participating or engaging in the study. Disseminating the research in several ways, whether at participant recruitment or findings-sharing stages, was a significant factor, which contributed to the high engagement this project received. Indeed, more than 1,000 AuND and museum workers contributed to the research over the four years of the project. In addition, there was an elevated level of enquiry or informal discussions with AuND people, museum workers, and other researchers about the project and what it means to them in an individual capacity. This engagement, direct and indirect, contributed to this project's direction and findings.

This elevated level of involvement has provided rich insight into a diverse range of experiences and needs. However, because of the diversity of experiences and needs of neurodivergent people, I do not believe it is responsible to claim that any findings can be representative of all AuND people, especially when voices traditionally absent from research and under-represented as museum visitors are likely still under-represented in this research. While this research cannot, and does not, claim to have all the answers to what AuND people need to access the cultural heritage sector, whether as visitors or workers, it certainly can contribute to further steps that could benefit this historically under-represented community and under-researched museum audience.

This concluding chapter is arranged as follows. Sections 7.1 to 7.3 summarise the key findings in response to the research questions outlined in the Methodology chapter, drawing from Chapters 4 to 6. The following section examines the limitations of the study, before discussing its novel contributions. The chapter concludes with final reflections on the research conducted, and its significance and implications for the future.

## 7.1 What are the Motivations for and Barriers to Museum Visiting for AuND Adults?

It was evident from the level of engagement of this research that a considerable number of AuND people are motivated by or interested in cultural heritage organisations, either as visitors or workers. This is revealed in the high number of neurodivergent adults who self-selected to take part in the research and contribute their perspectives, either as people who already visit or would be interested in visiting with better accessibility. AuND people provided insights into what it is that they find appealing about museums and cultural heritage environments as part of the focus groups, surveys, and workshops. The AuND survey revealed that motivations for visiting were related to the respondents' interest in the collections or display and their desire to explore existing and new interests. Moreover, some people associate the museum environment with mental health benefits and socialising with others. From the museum worker's perspective, it was equally unsurprising that the factors that appealed to neurodivergent visitors often contributed to their reasons for seeking employment in the field. These themes about AuND adults' interest in cultural heritage sites were also evident in the workshops, where museum workers and AuND adults shared personal observations about their positive experiences in these environments.

However, the findings showed that it was not enough to be motivated to visit museums. According to the AuND survey, many barriers make it difficult for respondents to visit a cultural heritage organisation. Although the sensory environment could be *enabling* for some AuND people, the majority identified this as *disabling* when it did not meet their individual needs. For example, many indicated that the presence of clashing interactive displays, echoey acoustics, and the busy nature of a space could result in sensory overload, while others found overly quiet spaces underwhelming. Lack of confidence in museum workers' and other visitors' understanding neurodivergent needs, fear of being judged, and uncertainty about the availability of resources specific to AuND people's needs meant that many respondents avoided visiting museums. For some AuND adults, these attitudes towards museums were the consequence of previous negative experiences. When combined with a lack of easily accessible and transparent information, this resulted in many assuming that a cultural heritage organisation that they might otherwise have wished to visit was not worth risking organising a visit to. This suggested that, even if AuND people were interested in spending time in a cultural heritage organisation, uncertainty about whether their access needs had been considered or addressed was enough to reduce the likelihood of them visiting.

This research found that, while most potential audiences are impacted by barriers related to cost, transport, and lack of time, AuND people have additional obstacles compounding the inaccessibility of museum visiting. Nonetheless, most AuND people who participated in the research expressed that they would still be interested in visiting cultural heritage organisations, with some already recurring visitors, if steps were taken to address the barriers. Interestingly, many stated that acts initiating change or identifying and then addressing common issues were enough to start building their confidence that they would be accepted and their needs considered.

A crucial takeaway from this research, as well as the identification of barriers to visiting for the AuND people who took part in this project, was their willingness to suggest potential solutions to address these barriers. Some examples of the solutions recommended, which will inform the development of the guidance toolkit, are based on the availability of information in different formats. While many found the lack of accessible information a barrier, they identified creating different versions of the information (e.g. easy-read formats, audio versions, and booklets available online and on-site) to help address this. Addressing the lack of understanding about neurodiversity and the diverse experiences of neurodivergent adults by providing AuND-led training or collaborating with this group in the development of resources and events (e.g. as an access panel) could also be useful, as could self-awareness and consideration that other AuND people may not wish to share their access needs or benefit from the same adjustments. This showed AuND people's empathy for other people (regardless of their neurotype) and willingness to make recommendations that would help their community and shape advice and practices for the cultural heritage sector. This demonstrates why participatory practices and community consultation are necessary if society is to truly develop its accessibility.

While one of the barriers to progress identified by museum workers was fear of doing the wrong thing, the AuND people who took part in this research demonstrated that there is no such thing as "full accessibility". This meant that many believed that willingness to listen, make changes, and take steps to address recurring barriers was motivation enough for them to visit the organisation. For this to happen, it was clear that museum workers should be transparent about the accessibility of their organisation, considering what they currently offer and exploring ways to build better relationships with AuND people in their local communities.

## 7.2 What do Museums Currently Offer AuND Visitors, and What are the Perceived Barriers Museums Face When Addressing Their Accessibility Issues?

The museum workers who took part in this research confirmed that most resources and events that exist for this audience are aimed specifically at autistic young people, take place on an ad hoc basis, and typically involve “quiet” or “relaxed” morning sessions. Among the cultural heritage organisations that provided AuND-specific resources, the majority tended to provide sensory backpacks, pre-visit information booklets, or quiet room spaces. Some respondents indicated that the COVID-19 restrictions impacted what was offered, with some being stopped or started during this period. It was clear that many respondents, whether working for an organisation offering AuND-specific resources or not, identified that they could do more to become more neurodivergent accessible. Furthermore, a desire existed to develop ways to improve their work with AuND people as a community group, audience, and/or colleagues.

Museum workers, some of whom identified as AuND themselves, expressed concerns about a lack of understanding and support when recruiting, employing, and retaining AuND staff. Some felt that there was not enough guidance or adjustments in place to make the work environment accessible and that there was a lack of understanding, which impacted experiences of entering and staying in the museum workforce. When planning or organising for AuND audiences, many museum workers felt that they did not have the support of their organisation or specific decision-makers. This resulted in many individuals undertaking accessibility work in addition to their usual workload, on a voluntary or ad hoc basis.

This reliance on workers, either paid or unpaid, to undertake this work beyond their roles or on a temporary basis suggests organisations do not prioritise accessibility projects. According to many of the respondents, this work is often led by AuND people themselves, or workers who have a close connection to AuND people (e.g. family, friends) and therefore additional reliance is placed on them as experts. However, it is noteworthy that many respondents’ express anxiety and lack of confidence about areas they may not be as informed about. For example, museum worker respondents to the survey and in the workshops expressed fear about what they do not know and the potential negative impact of “*getting something wrong*” on their organisation. Between the lack of prioritisation, support, cost (time and financial cost), and lack of confidence within the sector, it is not surprising that many museum workers feel limited in what they can do for AuND people.

While this research originally focused on the needs of AuND people as (potential) visitors to cultural heritage organisations, it became apparent from the findings and the engagement work with the workforce that more research needed to be undertaken inside the sector itself. While there are barriers for AuND visitors and museum workers, these can be compounded for neurodivergent people who wish to work in the field. Indeed, while this research began to reveal barriers to employment within the field, it only scraped the surface of a larger issue. Furthermore, more research into the barriers to working in the cultural heritage sector is essential to ensure that neuro-affirming practices are embedded for everyone.

### 7.3 How Can Museums Learn From AuND Adults to Adapt Their Practices to Become More Engaging and Accessible to this Audience?

This project, both in its methodology and its findings, demonstrates the crucial role that participatory practices can play in addressing inaccessibility. Involving AuND people at various stages of this research and adapting methodological approaches in response to the community's needs and preferences has resulted in processes tailored to AuND preferences and rich insights. This reflexive process revealed that, in taking the lead from the community the research was designed to serve and acting on the feedback received, engagement and accessibility should improve. Consequently, if museums employed this methodological approach and core strategy to design community-based projects, they would engage with and encourage more AuND people to spend time in these spaces.

In this study, it was clear that the use of diverse approaches in practice and provisions was crucial to fostering greater accessibility. For many AuND respondents, having choices and options enabled them to decide what would make their experience more tailored to their needs. The availability of information in different formats and styles is one example of meeting various information-processing needs. While some AuND people benefitted from the pre-visit information booklets most commonly available, others indicated that they would benefit from easy-read, video, or audio versions of this material. The content of the information is likely the same, but variation in how it is presented can make the difference between someone being able to access, understand, and utilise it or not. By working with a diverse group of AuND people, museum workers become more likely to identify and address different access needs. However, this requires a willingness to consult with and respond to this audience's needs.

A recurring theme throughout the research was the willingness of AuND people and all museum workers to provide insight into what they or the AuND people in their lives need to

take part in research and attend cultural heritage organisations. The research also aimed to highlight areas where they would like to see improvements within the sector. This research will contribute to addressing such improvements. As discussed in Chapter 4, most AuND respondents identified the barriers that impacted their ability to visit museums and shared some of the ways that they believed these obstacles could be tackled. Often, these recommendations were made with the caveat that “this may help some people, but not everyone”, demonstrating an understanding of the diversity of needs within the AuND community. Most recommendations come down to the involvement of AuND people, either as trainers or consultants, in the development of resources or events. Most of the suggestions incorporate being open to engaging in accessibility work as a participatory and iterative process, where museum workers reflect on and adapt the project, using feedback.

One key takeaway from this research relates to involving a diverse range of people who can contribute insights into multiple perspectives and lived experiences. As demonstrated by this research, there is no one answer to how to make the museum experience more neurodivergent accessible. Although many people may indeed wish that a “one-size-fits-all” approach is feasible and that this thesis could provide the perfect checklist to make this happen, the reality is that this is simply impossible. Neurodiversity, as defined in the introduction chapter, is a term coined to encapsulate the natural variations that exist from person to person because of differences that exist in the brain. Just as there are variations in the brain that mean society is neurodiverse, there are also differences in everyone’s needs irrespective of neurotype. This shows that museums and society need to be aware of and responsive to diverse needs. The only way to achieve this is to be open to learning directly from AuND people to better understand and address a diverse range of access needs.

Notably, if cultural heritage organisations adapt their practices to be more engaging and accessible to AuND audiences, this will likely have the same effect on other visitor groups. Not only would considering adaptations and resources be beneficial for multiple audiences, rather than exclusively AuND ones, but these approaches would also be useful for developing other participatory and community practices. For example, by replicating the participatory practices developed for this project and adapting them for different under-represented audiences, museum workers can work to make their organisations more inclusive for various current or potential audience groups. While this research project specifically focuses on what can be learned from working with AuND people to identify and address barriers to visiting museums, the methodologies and principles that have emerged from this research can therefore



benefit all audiences and research and cultural heritage projects involving under-represented groups.

## 7.4 Limitations

It was clear while analysing the data that, while I hoped to capture a diverse range of neurodivergent individuals' voices, this was not necessarily achieved in terms of cultural diversity. While I was delighted to have had such a high response rate overall, meaning that there was a large or significant amount of data to analyse, and that recognition of diversity was a theme in the "accessibility definition" question, the demographics were lacking in diversity. One gap in the survey was responses by non-white respondents. Although this is an issue common in autism research generally, it illustrates the risk of absence of representation in relation to the potential gap in considerations that would be beneficial for non-white neurodivergent people. This is an issue not directly discussed in the responses but which could be gathered when considering the importance of intersectionality as a theme. Damian Milton, in his studies of participatory practices in research (2022, 2019), has highlighted that this lack of representation of autistic people, particularly those that belong to other marginalised groups, remains absent or under-represented in research. While this research aimed to address the current disparity in representation and involvement in developing and delivering changes with a meaningful impact on AuND people, further work can be done to reach more segments within the neurodivergent community. This shows the need to directly reach out to under-represented sub-groups within the neurodivergent community to ensure that a diversity of experiences and access needs are collected and recognised.

The change in methodology from interviews and focus groups to workshops was not without its restrictions. For example, the original plan would have involved more direct involvement of AuND people in the thematic analysis process and the creation of more individual insight into topics or topics identified. However, survey responses vastly exceeded expectations in both volume and quality, with the majority of respondents providing detailed and valuable qualitative responses. This made it impractical to ask individuals in interviews or focus groups to review all the responses received, while the rich qualitative data obtained from the survey largely eliminated the need for follow-up interviews. Instead, a workshop format was selected as the most appropriate for that stage of the project. That said, it became clear throughout the workshop process that an hour to an hour and a half was not enough time to go through all aspects of the research in detail. For future research, I would suggest having either

longer scheduled sessions with breaks or a series of short workshops that cover different topics from the findings to allow enough time for dissemination and discussion.

Some may view the decision not to record the workshops to be a limitation to the study because of the inability to re-watch and validate the conclusions drawn. This decision was made to create a safe environment for individuals sharing experiences and potentially disclosing information (such as AuND identities) with which they may not have been comfortable if recorded. Additionally, as these workshops were at conference events, it felt inappropriate and unrealistic to request attendees' consent to be recorded. For future research, I would aim to have a mixture of workshops where some could be recorded (with permissions obtained in advance) and other workshops with written records (such as questionnaires or Mentimeter quizzes) to provide options for how to take part and have contributions recorded.

It is also important to recognise that, while this research has identified different barriers that exist for AuND people as visitors, the potential solutions that emerged may not address issues of accessibility for all audiences. Making a space or resource accessible for one audience group can sometimes inadvertently create barriers for others, presenting a key challenge in accessibility planning. For example, the assumed solution that “quiet hours” make a museum accessible for autistic audiences fails to consider that some visitors would prefer the freedom to make sounds and be vocal. This creates challenges even within a single community, as addressing one specific need may conflict with contrasting needs that coexist within the same space. The AuND survey and wider accessibility work demonstrate that there is no such thing as a “one-size-fits-all” approach to accessibility, nor is it possible to be fully accessible. These reflections can prove frustrating, or more problematically, serve as justification by cultural organisations not to undertake accessibility work. However, the findings of this research consistently and clearly emphasise the appreciation of having different options for engagement – be it different types of events or ways of presenting and disseminating information – which offer tangible evidence of the organisation's commitment to inclusive practices. Many respondents to the AuND survey acknowledged that there are diverse access requirements within the neurodivergent community, or emphasised that some adjustments may not be as beneficial for all audiences. However, some expressed that suggestions, such as those about having more information, could be beneficial to multiple audiences. Therefore, the perceived impossibility of achieving complete accessibility should not be interpreted as a constraining factor, but rather should serve as an impetus for continuous improvement through the implementation of increasingly inclusive practices.

## 7.5 Novel Contribution

This interdisciplinary research project was one of the first of its kind that centred on the experience of neurodivergent adults as visitors and workers in the cultural heritage sector. The Literature Review revealed a notable convergence in the evolution of both Museum Studies and Neurodiversity research. Despite their historically distinct disciplinary trajectories, both fields have been shifting towards participatory methodologies. This synchronicity presented an opportunity for this project to synthesise insights from both domains to address the understudied intersection of cultural heritage accessibility and autistic and neurodivergent adult engagement. This thesis has benefitted from high engagement at various stages largely because of my unique position as a researcher. As a neurodivergent person who identifies as both an autism and cultural heritage researcher, and who actively participates in the neurodivergent museum worker and neurodivergent research communities, I brought valuable lived experience to the project. From the initial design to the dissemination of the research, neurodivergent people and museum workers have actively participated or shown interest in the project, and the feedback received throughout the research enabled a reflexive approach to be taken at all stages. This means that all aspects of the research, from the planning to the final write-up of the thesis, have been informed by the communities it is designed to serve.

The research findings are valuable in their own right but also identify avenues for further investigation. From the AuND visitors' perspective, the survey and workshops demonstrate that this community is under-served by museums. However, AuND participants expressed increased motivation to visit if museums made efforts to improve accessibility, even if not all their access needs could be fully met. Common barriers were identified across the data, such as the impact of the sensory environment and information availability, which existed regardless of the specific condition a respondent identified. This suggests that museums should focus on identifying a range of barriers and their varied manifestations, rather than catering to a single neurotype. The goal should be to provide diverse options that can accommodate all visitors. For example, making information available in different formats offers all visitors the opportunity to choose how they access it to best meet their needs. Crucially, it indicates that – if museums met the needs of AuND people – this group would be more likely to visit more often. This thesis suggests that more work can be done to understand what neurodivergent people need to enable them to access cultural heritage organisations and begin to answer this question using the findings from the research respondents.

In addition, the museum worker survey demonstrated a strong interest in undertaking more accessibility-focused work for AuND audiences. However, respondents identified several barriers that hinder their ability to pursue this work effectively. The leading barrier is the impact of uninformed decision-makers on de-prioritising accessibility work. Lack of understanding about neurodiversity within the workforce impacts both AuND visitors and museum workers. The survey, alongside personal anecdotes from museum workers encountered throughout the project, suggests that many AuND people are working (or trying to work) in the sector who do not receive adequate support. This research therefore identified a need for greater support for visitors accessing institutions and internal cultural shifts to ensure that workers in the sector are supported. These shifts are crucial to ensure that museum workers are both adequately supported when they are neurodivergent themselves but also in their efforts to serve diverse and particularly AuND audiences. Addressing both external visitor needs and internal museum worker challenges is essential for creating truly inclusive and accessible environments within the sector.

Throughout the period of conducting this research, from initial conceptualisation in 2019 to the writing of this thesis, there has been a significant paucity of research examining AuND individual's experiences of visiting cultural heritage sites. As explored in the Literature Review, most of the existing research on neurodivergent accessibility predominantly focuses on autism-specific considerations, rather than encompassing the broader spectrum of neurodivergent experiences. *Autism in Museums* by Claire Madge (n.d.) is the leading UK-based blog which led her to opportunities to contribute to projects to make museums "autism-friendly", including the V&A and British Museum in London, which have shaped the UK museum sector's understanding of autism-inclusive practices (Madge, 2020). Despite the proliferation of autism-focused initiatives across UK museums<sup>30</sup>, significant gaps persist in cultural heritage research and practice. These gaps are particularly evident in three key areas: AuND adults' engagement with cultural heritage; consideration of broader neurodivergent experiences; and the implementation of participatory methodologies and consultation practices. The formation of The Neurodivergent Museum (TNM) in 2022, concurrent with this research, marked a pivotal shift in the UK sector's recognition of neurodivergent experiences as both visitors and workers in the sector. The rise in visibility of work has catalysed a significant shift in sectoral discourse, elevating neurodivergence from a specialised topic at small,

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<sup>30</sup> Examples of such projects include Dawnosaurs at the Natural History Museum (London), Relaxed Sessions at the Museum of Liverpool, and Quiet Openings at Glasgow Museums.

accessibility-specific conferences (such as the MA's "All Inclusive" conference on accessibility) to warranting dedicated sessions at mainstream events, as evidenced by its inclusion in the 2024's "The Joy of Museums" annual MA conference in Leeds. This shift towards neurodivergence and diverse sensory experiences being included at leading sectoral events, alongside the increase of funding for related initiatives and research<sup>31</sup> suggest that museums are becoming more accessible for neurodivergent visitors and sectoral workers. This transformation, coupled with the rise of neurodivergent-led initiatives and research projects, aligns with a key finding from this study's museum workforce survey: meaningful institutional change often requires leadership from within the communities such changes aim to serve. This research, therefore, advances an emerging field that had previously relied predominantly on the replication of existing models. It does so through two significant novel contributions: establishing an empirical foundation through systematic community consultation, and enhancing sectoral understanding of the imperative for direct neurodivergent participation to influence institutional change.

In recent years, there has been an increase in research and understanding about what neurodivergent people need to participate and thrive in specific public environments beyond the cultural heritage sector. As discussed in the Literature Review, work by researchers as part of the Sensory Street project (MacLennan et al., 2022) and ADI (Doherty et al., 2023 & 2022) has been conducted to better understand the needs of AuND people in specific environments and the barriers that can prevent access. The resulting SPACE Framework and Sensory Street Principles projects overlapped in some of their findings – such as the need to consider sensory needs, for acceptance, predictability and understanding – and in their recommendations for how environments or workspaces can become more accessible for neurodivergent people. This research identified similar barriers and needs to those identified in the Sensory Street Principles and SPACE Framework, identifying parallel requirements across domains. These commonalities encompass the need for clear information, the cultivation of non-judgemental environments, and consideration of diverse needs without requiring validation – which suggests the universality of these requirements across varied environments and contexts. This further demonstrates the need for a greater evidence base regarding the requirements for an environment to be accessible for AuND people, reinforcing Manning et al.'s imperative for enhanced consideration of sensory environmental factors. Although some of the findings from

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<sup>31</sup> For example, DCMS and Wolfson Museums and Galleries Improvement Fund (2022-24) and the funding of the Sensational Museum Project (2024).

this research can be identified as similar to other frameworks, there is arguably strength in numbers and the common threads that link these projects. Qualitative research has historically been critiqued for not being replicable, however, the overlaps and commonalities found across these projects counter this argument by suggesting that there can be similar patterns identified across different contexts when exploring the core needs and barriers of a specific community group.

This research has sought to address the gap in research within the museum sector by directly consulting AuND people about their experiences of visiting cultural organisations and their needs for best supporting these visits. While the decade prior to this study witnessed the development of some AuND-related resources and projects, the majority documented empirical evidence supporting their approaches. Instead, what existed tended to be the result of replication of what others in the sector were doing. This research aimed to catalyse a shift in sectoral practice from replicative approaches towards a more meaningful evidence-based participatory model, showcasing the rich insights of community consultation in advancing accessibility. The study's findings revealed that there are potentially large numbers of AuND people either working in museums or seeking to enter the workforce in the sector, coupled with a demonstrable commitment among museum workers to learn more to improve organisational practices for both visitors and employees. These key findings show the need for more participatory and community-led work to ensure accessibility for neurodiversity is considered within all areas of the cultural heritage sector.

## 7.6 Future Directions

Further research is needed to better understand the needs of AuND people, particularly museum workers. This thesis investigated a previously unexplored research topic using participatory and academic methods. Further research is needed to better understand which findings may be generalisable and which areas remain unexplored. In particular, studies should focus on countries where English is not the first language and those involving AuND individuals who are not current visitors of cultural heritage organisations. Another direction for future research could involve focusing on specific barriers or motivations, such as the sensory environment and the influence of focused interests, in the decision to visit and the quality of the museum visit, to gain greater insights into these experiences.

The findings of this research highlight common barriers and potential solutions, as recommended by AuND people. These insights will inform the development of a guidance

toolkit, which will include advice on environmental adaptations and considerations that will make the space more accessible for people with sensory needs. It will include information about neurodiversity, including advice on different ways of presenting information that is accessible for people with diverse processing styles. Crucially, it will provide information on how to meaningfully involve AuND people in the development of events and resources. Future work to enhance accessibility for AuND people must be inclusive and enabling of diverse access needs. This is an area that will be developed as the sector and research continues to actively collaborate with this group.

This research project serves as a foundation for future studies on enhancing accessibility in public spaces, particularly cultural heritage sites, for AuND people. Thus, the thesis provides a methodological framework that can guide subsequent investigations in this field. Additionally, the findings from this research will inform a future guidance toolkit aiming to make the sector more accessible for AuND visitors. The present study primarily focused on the experiences of AuND people as visitors. However, it also revealed a need for greater understanding and support of AuND workers within the sector. More research is needed to understand the extent of involvement and employment of AuND people within the sector, the level and impact that the burden of responsibility for undertaking accessibility work can have on these workers, and how to best support neurodivergent workers going forward. This will inform future research, which should focus on deepening our understanding of neurodivergent workers' experiences and how to make the cultural heritage sector more accessible for AuND workers.

## 7.7 Concluding Reflections

As an autistic researcher, this project was originally conceived and driven by both academic and personal motivations, born out of first-hand experiences with the lack of accessibility provisions in the museum sector. From conception to the final submission of this project, I have been fully aware of my positionality and its potential impact on the research being conducted. Conflicting attitudes exist towards neurodivergent researchers researching their community. On one hand, stigmatisation, and the belief that AuND people are more likely to be biased, can undermine the level of authority and credibility granted to us by colleagues who do not identify as neurodivergent. On the other hand, neurodivergent researchers undertaking research within their community can have better insights into the needs and priorities of the people the research is designed to serve. Furthermore, openly neurodivergent researchers have often spearheaded participatory and community-driven research practices. My position as an autistic researcher with a multi-disciplinary background has positively influenced this research by fostering an openness to interdisciplinary methods. This diverse approach has enriched the study, allowing for a more nuanced and comprehensive exploration of accessibility issues within the museum sector and highlighting the value of integrating different perspectives and methodologies. As I have been able to build trust within the community that I belong to, I have been hyper-aware of the importance of accurately representing the participants in this research. This personal connection motivated me to undertake research that is accessible and has the potential to have a meaningful impact on the AuND community. I have aimed to include as many perspectives as possible, demonstrating diversity in experiences, preferences, and recommendations within the community. In reflecting on these findings, both personally and in the discussion, I have sought to combine the community's insights with my interpretation of their implications for the museum sector. This approach ensures that the research amplifies the voices of neurodivergent individuals and provides meaningful, actionable recommendations for creating more inclusive and accessible cultural institutions.

This thesis began with the phrase “I did not go to museums as a child”, which may be an unconventional opening for an academic study. However, the decision to begin the thesis with this line was inspired by a discussion during the Autscope workshop that centred on motivations for visiting museums. An attendee at that workshop stated that I must be a person who has always visited museums and when I responded that this was not the case and that I had only started visiting museums in my late teenage years, their response was: “*You should*



*open with that.*” Although this may have been viewed as a casual remark to many people, I followed precisely what they recommended as part of my practice and commitment to the AuND community. This personal reflection not only set the tone for the thesis but also underscored the deeply rooted, personal nature of the research, highlighting how lived experiences can shape academic inquiry and advocacy. That participant recognised the significance of my shared experience as a fellow non-visitor to museums when I was growing up, seeing this as crucial to the project’s perspective. This observation sparked further discussions that day, which ultimately informed the research findings. These conversations emphasised the importance of relatability and the value of autistic-led practice, highlighting how shared experiences can deepen understanding and authenticity in research focused on accessibility and inclusion. One of the greatest risks in research is when the researcher loses sight of who the research is for. From the start, this project was designed with a dual focus: to serve the AuND community and to support museum workers, rather than strictly adhering to conventional research norms. This thesis therefore concludes by urging researchers, museum workers, and any other readers to reflect on who their research or work is intended to serve. It calls for a conscious effort to ensure that the voices of those impacted are heard and that they actively inform the projects undertaken. The future of autism, neurodiversity, and museum research should be participatory, aiming to foster cultural changes that make society more inclusive and accessible for everyone.

## 8 Appendices

### A. Ethics, Participant Information and Consent Forms

Information related to the ethics application, ethics approval letter, participant information sheet, and consent forms used for the focus groups/workshops are available via [Linktree](#).

## B. Focus Groups

### B.1 “What to Expect” Booklet for Focus Groups

#### **Autism in Museums: Focus Group Information**

Thank you for your interest in participating in this research project. This information pack shall offer an overview of the project and what to expect from the focus group.

#### **Contents:**

4. Information about the project
5. Objectives of the focus group
6. People involved in the focus groups
7. Focus group plan
8. Example code of conduct
9. Focus group possible questions
10. Using Zoom

If any of the information is unclear, or you have any specific access requirements, feedback or questions about this research or focus group then please contact a member of the research team.

#### **1. Information About the Project**

This research project investigates how museums can become autism accessible. In recent years, with the increase in autistic people being diagnosed across the world and an increasing focus within the cultural heritage sector to become more inclusive in their accessibility provision, it is clear that increasing accessibility for autistic visitors is a natural next step in museum development. However, to date, the focus on making museums “autism-friendly” in professional practice and related literature has tended to focus on children and not included autistic people in the planning or evaluation stages. Led by an autistic researcher, this project is about including autistic people in research that could result in sectoral change.

## **2. Objectives of the Focus Group**

1. To discuss the aims and research questions of the project to check that they are clear and reflect the priorities of autistic and neurodivergent people.
2. To discuss the types of questions that could be used in a survey and future focus groups for autistic and neurodivergent people to make sure that they are clear or if they should be adapted.
3. To find out if the questions are what participants would expect for the research.
4. To gather feedback from the focus group that can be used to shape the survey and interview questions used as the research progresses.

## **3. People Involved in the Focus Group**

The focus groups will consist of up to six participants who are all autistic or neurodivergent. The focus groups will be led by Aimee, who will explain the project and ask questions, while another researcher (Joy) will monitor the chat and take notes. Aimee will introduce Joy at the beginning of the session.

Participants in the study will be invited to participate via the University of Glasgow Neurodiversity Network, the Scottish Autism Research Group, by email or via invite by social media. Please do not share the invite to the session. Numbers have been kept low to ensure the session is accessible and to give everyone an opportunity to participate in discussions.

## **4. Focus Group Plan**

1. Introduction of group members
  - a. Aimee will introduce herself and her fellow researcher.
  - b. Group members will be asked to introduce themselves (optional) – name and where you are from and/or interests. You can choose to do this via the chat.
2. Introduction to the group
  - a. We will discuss the purpose of the group and our objectives.
  - b. Aimee will remind you that you can leave if you want to at any time or take a break and then come back later.
  - c. We will discuss the timings/structure of the session and what to expect. We expect the group to last approximately one hour to an hour and a half (discussion dependent).
3. Rules of the group
  - a. Aimee will read out some possible rules of the group (these are outlined below).
  - b. At this point we can discuss any of these rules and agree any additional rules based on how we want to work and what we agree is appropriate.
4. Discussion 1: the aims and questions of the research
  - a. Aimee will give a short presentation about the research project. This will outline the research aims and objectives, research questions, and methodology proposed.

- b. We will discuss the presentation. Possible questions for this section are outlined below.  
We will be focusing on the clarity of the research and ask for all feedback, positive and constructive, about this.

5. Discussion 2: the survey questions

- a. Ahead of the focus groups, a document with questions that have been proposed for the first survey will be distributed. We will be discussing these.
- b. We will discuss the types of questions that have been used, such as Likert scales, to gather feedback on accessibility.
- c. We will discuss specific questions that are proposed – for example, about the inclusion of “self-identify” as an option when disclosing.
- d. We will discuss whether any of the questions may need adapting – for example, inclusion of more options or simplification of language.
- e. There will be an opportunity to discuss anything we think may be missing or needs changed, as well as anything we think works well or could be developed.

6. Wrap up

- a. Before the focus group ends, a summary of some of the few findings from the focus group will be discussed to check if there is anything else anyone would like to add.
- b. There will be an opportunity to ask more questions about the research.
- c. Information will be given about how to be involved as the research progresses.

## **5. Example Code of Conduct (Group Rules)**

1. To ensure everyone gets a chance to speak, we will ask you to:
  - a. Mute your microphones until it is your turn. This will reduce unnecessary background noise.
  - b. Indicate when you wish to speak by raising a “virtual hand” or by waving your hand or alerting in the text chat. Aimee will let you know when you can come on and speak.
  - c. If Aimee feels like the conversation is going off-topic, or that others need to convey their opinions, then she may move on to another person/topic. She will let you know if she is going to do this.
2. There is no requirement to be visible on video if you do not feel comfortable. However, we will ask you to verify who you are to make sure you are present. After this point you can use the chat function to communicate in the group if you prefer.
3. If you want to say something in response to someone, please raise a “virtual hand” or type in the chat sidebar until it is your turn to speak. We can also read out any questions or comments for you if you would prefer not to speak.
4. Do not send private messages to anyone other than the hosts of the group. This is so we are aware of all conversations that are happening.
5. This is a positive online space. If the session is becoming negative or distressing, the hosts will step in.
6. Please keep your phone on silent throughout the session to avoid any noises.
7. Make sure that there is nothing in your background that you do not want to be seen by others. You can choose to blur your background or use a virtual background.
8. Please feel free to mute the session and take a break from main chat discussion if you need. Please message the host privately to let them know.
9. This is a safe space. Members may speak about their own experiences so please do not share sensitive information that others may disclose in the session.
10. Everyone experiences the world differently. It is okay to have differences, and differing opinions will be treated respectfully. Please respect other people’s opinions and how they identify.
11. Please do not swear or use rude language. If you do or say something inappropriate on video, audio, or chat, we will remove you from the session and reach out to you individually.
12. Please do not forward on any invites to the session. Only people who have applied and been accepted will be admitted.

## **6. Focus Group Possible Questions**

These questions are examples of what Aimee will ask during the focus groups. If any are unclear, please send Aimee an email in advance or contact her during the focus group. Some questions may change based on the discussion, but the aims and objectives of the questions and discussion will remain the same.

1. Are the research questions and aims clear? (are they what you expected them to be?)
2. Do the research questions and aims reflect what you would want from this project?
3. Does the methodology make sense to you?
4. Do you think it is the right level of involvement of autistic and neurodivergent people (should there be more or less?)
5. Does the question make sense to you when you read it?
6. If not, how do you read it, and how might we change it
7. Are there any questions you really like? Why?
8. Are there any questions you really don't like? Why?
9. Are there any questions you would like to see?
10. Do you think these questions will help answer the ones this research is aiming to answer?

## **7. Using Zoom**

For this research project we aim to use Zoom for the hosting of the virtual focus groups. This platform is similar to Microsoft Teams, and allows for video and chat function.

We have chosen to use Zoom for our virtual focus groups and interviews as we are able to record the session and save it securely to the University's OneDrive system, accessible only by the researchers. The transcription function of Zoom will be used to assist in the capturing of the discussion.

When the focus group time has been set, and you have returned your consent form to participate, Aimee will send out an invitation to join the Zoom meeting. This will be via email and the invitation can then be added to your email calendars.

When it is time to join the meeting, click on the link in the email, which will allow you to join the meeting either online or through the desktop app. If you have the Zoom app already it should open Zoom automatically. If you do not have a Zoom account, you should have the option to set one up or to add your name and join as a guest. We would recommend having an account ready for ease of access on the day.

 **Please wait for the host to start this meeting.**

**Start: 1:00 PM**

When you join the call, you may go into a virtual waiting room. We will let you into the call when it is ready to begin. If you join late or are not admitted, please email Aimee, who can make sure you are added to the call.



The bar above shows the buttons you will see in a Zoom meeting. For participants, the Mute, Stop Video, Chat, Reactions, and End buttons will be usable. Other buttons will not be available for participants.



## B.2 Summary of Focus Groups' Feedback, Recommendations and Actions Taken

Survey Questions	Action	Feedback/Rationale	Response
<b>Word Choice</b> – updating the wording to reflect changes made to aims and research questions.	Yes	For consistency, wording and language choice needs to be updated to reflect other feedback. Specific examples will be discussed below.	Questions to be checked and updated.
<b>Question Types</b> – not Likert, happy with a mix of “tick all that apply” and open questions.	Yes	When I asked about thoughts around the types of questions used, and whether Likert questions would be useful/accessible, the consensus was that Likert questions can be hard to answer.  Feedback was that the balance of open to “tick all that apply” questions was right.	No Likert questions have been added, and the existing open and tick all that apply questions have remained in an updated form (based on other feedback).
<b>Numbering (Clarity)</b> – in the version of the survey submitted, there were numbering inconsistencies, and it was hard to follow.	Yes	There were numbering errors to the documents submitted. This was because of changes in questions (particularly evident in the second session).	The question numbering will be corrected in time for creating the survey using the platform it will be hosted from.
<b>Terminology</b> – ensuring it is using a Social Model approach, e.g. replacing “disorder” with “condition”.	Yes	The term “disorder” came up when referring to “sensory processing disorder”.	Language will be updated to ensure that medical model/“disorder”-type language is not in the final versions.
<b>Question Order (Demographics)</b>	No	Some participants suggested having the demographic questions at the end of the survey,	As a follow-up to this, as there was a clear divide between the

		<p>while others preferred keeping them at the beginning.</p> <p>The argument for the end was that it meant respondents focused on important questions. The argument for having them at the beginning is that it is what was expected and can be used as a warm-up.</p>	<p>different participants on what would be preferable, I posted an informal question on Twitter to ask for views on where the demographic questions should be.</p> <p>Of the 39 people who responded, 67% chose “at the start” while 31% chose “at the end”. As a result, I have opted to put demographic questions at the start.</p>
<b>Add ethnicity question to other demographic questions.</b>	<b>Yes</b>	<p>Some participants suggested that capturing ethnicity data would be an interesting and useful insight into visiting patterns, especially as autistic and neurodivergent ethnic minorities are often more marginalised and under-represented in autism research.</p> <p>Other participants expressed concern that this is “data for data’s sake” and questioned the relevance of asking this.</p>	<p>To gain greater insight into visiting patterns for autistic and neurodivergent people with intersectional identities that have traditionally been marginalised or under-served by museums, it makes sense to add this question into the demographic questions.</p>
<b>Make demographic questions open for own response rather than having categories.</b>	<b>Yes (for some)</b>	<p>By keeping certain questions open (e.g. “how old are you?”), participants are enabled to describe/label/answer in their own words, rather than having answers prescribed to them.</p>	<p>These questions will be followed by small text boxes that will be programmed to allow participants to answer in their own way.</p>

<b>Include neurodivergent in the question wording rather than just focusing on autistic.</b>	<b>Yes</b>	Participants discussed the importance of not specifically referring to autistic people in a question, as it makes people who are neurodivergent less likely to answer. This may be because they feel the question is not aimed at them.	The survey will be open to autistic and neurodivergent people and the question wording updated to reflect this.
<b>Have options for different language preferences – have a disclaimer explaining decisions.</b>	<b>Yes</b>	<p>One participant explained that there are neurodivergent (or those who refer to themselves as a “person with autism” or “Asperger’s Syndrome”) who do not identify with autistic as a term, and they therefore may not answer the survey on the basis that it is “not for them”.</p> <p>Others suggested having a clear inclusion disclaimer that states that the survey is for all these groups and allowing people to write how they identify.</p>	<p>The survey will ask whether the respondent “identifies as autistic/neurodivergent” before asking participants to specify in their own words what condition they identify with (e.g. being autistic/a person with autism, neurodivergent etc.)</p> <p>The survey will also have a disclaimer acknowledging different language preferences.</p>
<b>Include self-diagnosed, and instead of asking to specify, ask “do you identify as autistic/neurodivergent/a person with autism?” with yes or no options, then ask for the person to specify.</b>	<b>Yes</b>	<p>There were mixed views on asking people if they “self-identify” or are “formally diagnosed” directly.</p> <p>While some people expressed that it was positive that self-identity was recognised and included in a clear way, others</p>	The question has been re-written to ask people to answer yes or no to the question of whether they are/identify as “autistic/a person with autism/Asperger’s Syndrome,

		<p>shared concerns that it was a way of “filtering out” self-diagnosis.</p> <p>It was suggested that a disclaimer at the beginning is instead used that specifies that self-identity is considered valid and is welcome as part of this research.</p>	<p>Neurodivergent” then asks them to specify.</p> <p>A disclaimer indicating that the survey is open to self and formally diagnosed people will be included in advertising.</p>
<b>A sensory condition could be read as meaning deafness or visually impaired, instead of focusing on a sensory processing condition.</b>	<b>Yes</b>	To avoid any confusion or lack of clarity around the intention of this question (to capture data from people who have a sensory processing condition) it is important to ensure that “processing” is added to the question.	The question will be updated so that it is clearer.
<b>Ensure it is clear which questions are optional or required.</b>	<b>Yes</b>	The document shared with participants does not indicate which questions are required and which ones are optional.	The final survey will be programmed so that the required questions (consent ones) have stars next to them, and all other questions will be optional. However they will “nudge” the respondent if a question is not answered in case it is an error.
<b>Including a word limit for open-ended questions.</b>	<b>Yes</b>	Some participants expressed that, while they like open-ended questions, not having a word limit as a guide can make the box more daunting to complete.	A word count, for example 100–250 words maximum, will be included in open questions.

<b>Including examples of types of answer for the open questions.</b>	<b>No</b>	Some participants suggested that having examples of the types of answers expected would be useful to help guide the respondents in their own answers. Others expressed concerns that this is too leading, arguing that including examples could result in people answering how they think they are expected to, rather than honestly.	To limit the risk of potentially influencing or guiding respondents to answer in a particular way, there will be no suggestions listed. Instead, respondents are encouraged to email if they have any questions, or something is unclear.
<b>Simplify the list for “tick all that apply” but ensure that there is still a range of different types of answers that can be selected.</b>	<b>Yes</b>	Both focus groups were happy with having a range of “tick all that apply” options but there were concerns about having too many and not enough variety.	The options will be assessed and reduced to limit the risk of being overwhelming, while maintaining a variety of option types. An “other” option with space to add own response will be added.
<b>Some of the options are too specific, and do not include options such as “I visit to get out of the rain.”</b>	<b>Yes</b>	While this question focuses on motivations related to the museum based on what they offer, it does not capture the experiences of people who may visit for convenience rather than out of direct interest.	The options were refined to ensure a reasonable number of options that cover a range of different reasons.
<b>Include questions that ask how often a person wants/would like to visit a museum.</b>	<b>Yes</b>	One participant expressed that the question “how often do you visit?”, while useful for identifying existing patterns of who <i>does</i> go, does not capture how often someone may actually	I have added in a question to ask “how often” a person would want to visit if it were more accessible to them.

		want to attend a museum event or visit.	
<b>Increase the length of time of museum visit reflection from three to five years</b>	<b>Yes</b>	Participants suggested that five years would make more sense, as this allows two years of potential museum visiting before the pandemic began.	I agreed that five years made the most sense, and the question has been updated.
<b>Focus on motivations for visiting, as well as the barriers that prevent visiting.</b>	<b>Yes</b>	Some participants felt that there was a gap in questions about the motivations in visiting museums, and why people may want to attend but be unable to.	Including questions asking about motivations and interests when considering visiting a museum will be included in the survey and Phase 2 interviews/focus groups.
<b>How does museum visiting make you feel? What can make museum visiting better? – suggestions of other questions to consider.</b>	<b>Yes</b>	Alongside the suggestion about capturing the motivations for attending museums, one of the participants shared about an evaluation form they had received from Glasgow Women's Library that they felt was useful.	The survey asks what museums can do to make museum visiting better. Questions about how the museum makes a person feel will be saved for focus groups/interviews.

## C. Survey – Survey design, Analysis and Coding of Qualitative Responses

### C.1 AuND Survey

# Neurodivergent Museum Visiting Survey

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#### Start of Block: Research Information

#### Q1 Welcome!

Thank you for your interest in this research. You are being invited to participate in a research study titled “Autism in Museums: Co-Creation Strategies for Making Museums Autism Accessible”. This study is being run by Aimee Fletcher from the College of Arts, School of Humanities (Information Studies) at the University of Glasgow. This survey is estimated to take **approximately 15 to 20 minutes** to complete, and can be saved and returned to within 1 month of starting it. **What is this study about?**

This project investigates how museums can become accessible to autistic and neurodivergent people. In recent years, with the increase in autistic people being diagnosed across the world and an increasing focus within the cultural heritage sector to become more inclusive in their accessibility provision, it is clear that increasing accessibility for neurodivergent and autistic visitors is a natural next step in museum development. However, to date, the focus on making museums “autism-friendly” in professional practice and related literature has tended to focus on children and not included autistic people in the planning or evaluation stages. Led by an autistic researcher, this project is about including autistic and neurodivergent people in research that could result in sectoral change. More information about the study can be found in the Participant Information. **Who can take part?**

To take part in this survey, you must be: Aged 18 and over Identify as autistic, and/or neurodivergent (e.g. having one or more of the following: Autism, ADHD, Dyspraxia, Dyslexia. If you are unsure, please contact Aimee Fletcher (a.fletcher.1@research.gla.ac.uk)) Be able to read and respond in English.

#### **What will happen if I take part?**

If you would like to take part in this research, you will be asked questions about:

Demographic questions, such as your age, gender, ethnic identity and whether you live in the UK or elsewhere. These questions are being asked as it helps to understand who is answering the survey, and to make sure it is as inclusive and diverse in representation as possible. It will ask you whether you identify as autistic and/or neurodivergent, and what language you prefer. This is also to help understand who is answering the survey, and to ensure the language used is correct. It will ask you about your museum, gallery or cultural heritage site visiting patterns during and outside of COVID-19 restriction times. Questions about motivations and barriers to visiting museums, galleries or cultural heritage sites, and what might help to make them more accessible to you.

Whether you would be interested in being involved at a later stage of the research. For example, taking part in an interview, focus group or museum visit adjusted to your access needs.

Information about the storage and use of the data gathered during this study, including the use of the findings, can be found in detail in the Participant Information. **Next steps if I would like to take part?**

If you are interested in taking part, please download a copy of the Participant Information sheet here,

read it carefully and retain it for your records before starting the survey. If you have any questions, please email me at [a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk) or my Lead Supervisor, Professor Maria Economou at [maria.economou@glasgow.ac.uk](mailto:maria.economou@glasgow.ac.uk). To start the survey, press the blue arrow at the bottom right of this page. **What if I start the survey, but cannot complete it in one go?** This survey is on Qualtrics, which automatically saves your answers and allows you to return to the survey up to 1 month after starting to complete it.

Uncompleted surveys will remain open for one month after starting. If the survey is incomplete after this time, the researchers will assume that you have withdrawn consent. Should you wish to withdraw your data after completion and submission, please contact Aimee Fletcher ([a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk)) for instructions. **Can I Withdraw from the survey?** Your participation is entirely voluntary, and you can withdraw at any time. You are free to omit any question that you do not wish to answer. **Who has reviewed this research?** Ethical approval for this project has been granted by the College of Arts Research Ethics Committee on 21/12/2021. If you have any questions about the ethical approval of this research project, please contact the University of Glasgow, College of Arts Research Ethics Committee ([arts-ethics@glasgow.ac.uk](mailto:arts-ethics@glasgow.ac.uk)). Thank you again for your interest in this research, please do not hesitate to get in touch if you have any questions. Aimee Fletcher ([a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk))

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Page Break



## End of Block: Research Information

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### Start of Block: Consent

**Q2 Consent** Before starting this survey, it is important that you take the time to read the Participant Information Sheet accessible using the embedded link. If you have any issues accessing the information, or if you have any questions about the study, then please email the researcher Aimee Fletcher, using [a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk). The Consent Form questions below include a question about your preference to be named, anonymised (removal of identifiable information, e.g. "Participant 1") or have a pseudonym (fake name). This refers specifically to the interviews, focus groups or museum visits if you wish to remain involved in this research after the survey. The survey itself does not ask your name and all the answers provided will be gathered and analysed together and any potentially identifying details removed to protect participants' rights to anonymity. The following questions are about Consent. Once these are completed, the survey will begin.

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#### **Q3 I am aged 18 and over**

- ☐ I agree (1)
- ☐ I do not agree (2)

#### **Q4 I have read and understood the Project Information Sheet and have had the opportunity to ask questions about the research and my participation ([a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk)).**

- ☐ I agree (1)
- ☐ I do not agree (2)

#### **Q5 I voluntarily agree to take part in this research project.**

- ☐ I agree (1)
- ☐ I do not agree (2)
- 

#### **Q6 I agree for the data collected by the researcher and/or produced by me during the research activities (hereafter called my data) to be used to inform the project's findings**

- ☐ I agree (1)
- ☐ I do not agree (4)

**Q56 I agree for the data collected by the researcher and/or produced by me during the research activities (hereafter called my data) to be used to inform the project's publicity (e.g. being presented at conferences)**

☐ I agree (1)

☐ I do not agree (2)

**Q7 The procedures regarding confidentiality (e.g. use of names, pseudonyms, anonymisation of data) have been clearly explained to me in the Information Sheet. Unless otherwise specified, participation in this survey will be anonymous.**

☐ I agree (1)

☐ I do not agree (2)

---

**Q8 I understand that my data is of long-term value for academic research and will be retained in secure storage of the university for a period of minimum ten years, starting 2022, under the conditions of anonymity I define below. Please note: *The survey itself will be anonymous, however if you wish to participate in future stages of the research (such as interviews and focus groups), and wish to be named or use a pseudonym, then please select the option relevant to you.***

☐ I agree, to be anonymous (e.g. Participant 1) (1)

☐ I agree, to use a pseudonym (a fake/alternative name) (2)

☐ I agree, to be named directly (3)

☐ I do not agree (4)

---

**Q9 I have the choice to leave any question unanswered. I may withdraw at any time and without explanation. I may withdraw my data within two months of supplying it before it is anonymised or until April 2024 if cited by name (interviews and focus group-specific).**

☐ I agree (1)

☐ I do not agree (4)

Page Break

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*Display This Question:*

*If I am aged 18 and over = I do not agree*

*Or I have read and understood the Project Information Sheet and have had the opportunity to ask ques... = I do not agree*

*Or I voluntarily agree to take part in this research project. = I do not agree*

*Or I agree for the data collected by the researcher and/or produced by me during the research activi... = I do not agree*

*Or The procedures regarding confidentiality (e.g. use of names, pseudonyms, anonymisation of data) h... = I do not agree*

*Or I understand that my data is of long-term value for academic research and will be retained in sec... = I do not agree*

*Or I have the choice to leave any question unanswered. I may withdraw at any time and without explan... = I do not agree*

Q57

Thank you for starting this survey! Unfortunately, you can proceed no further as you did not provide your full informed consent to participate.

If this was not intentional, please feel free to restart the survey. Otherwise, thank you very much for your participation and if you have any concerns or questions, you can get in touch with me at [a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk)

*Skip To: End of Survey If Thank you for starting this survey! Unfortunately, you can proceed no further as you did not prov... Displayed*

**End of Block: Consent**

**Start of Block: Are you autistic/neurodivergent?**

*Display This Question:*

*If I have the choice to leave any question unanswered. I may withdraw at any time and without explan... = I agree*

**Q10 This research survey is about collecting the experiences of people who identify as autistic/neurodivergent. I am aware that some people have preferences for specific terminology and language within the neurodiversity community that some people may not agree with. This research is for anyone who identifies as:**      Autistic      a person with autism      having Asperger's Syndrome      being neurodivergent (e.g. dyslexic, dyspraxic, ADHD. If you are unsure whether you can take part, please email [a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk))      having a sensory processing condition.

**Q11 Do you identify (with formal diagnosis or self-identify) as any of the above?**

☐ Yes (1)

☐ No (2)

☐ Unsure (if you would like to explain, please use the box) (3)

☐ Prefer not to say (4)

*Skip To: End of Survey If Do you identify (with formal diagnosis or self-identify) as any of the above? = No*



**Q12 How do you prefer to be referred to as? (e.g. autistic, person with autism, neurodivergent)**

Page Break

End of Block: Are you autistic/neurodivergent?

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Start of Block: Demographics

**Q13 The following questions are about demographic information. They are intended to help identify potential patterns, themes and gaps. You do not have to respond to these questions, however it would be helpful to assist in ensuring this survey reaches as many people and is as inclusive as possible.**



**Q14 How many years old are you?** *Type your answer in numbers (if you prefer not to say, please leave this question blank)*

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**Q15 To which gender identity do you most identify?**

☐ Male (1)

☐ Female (2)

☐ Non-binary (3)

☐ Intersex (6)

☐ Prefer not to say (4)

☐ Not listed / Other (Please specify) (5)

---

**Q16 What is your ethnic group?** *Please select the ethnicity which best reflects you. These categories were created using the Scottish Census as a guide.*

☐ White - English / Welsh / Scottish / Northern Irish / British (2)

☐ White - Irish (3)

☐ White - Gypsy or Irish Traveller (4)

☐ Any other White background, write in (5)

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☐ Mixed race - White and Black Caribbean (7)

☐ Mixed Race - White and Black African (8)

☐ Mixed Race - White and Asian (9)

☐ Any other Mixes /multiple ethnic background, write in (10)

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☐ Asian / Asian British (11)

☐ Indian (12)

☐ Pakistani (13)

☐ Bangladeshi (14)

☐ Chinese (15)

☐ Any other Asian background, write in (16)

---

☐ Black / Black British (17)

☐ African (18)

☐ Caribbean (19)

☐ Any other Black / African / Caribbean background, write in (20)

---

- ☐ Other ethnic group (21)
- ☐ Arab (22)
- ☐ Any other ethnic group, write in (23)
- 

**Q17 Do you live in the UK?**

- ☐ Yes (1)
- ☐ No (2)
- ☐ Prefer not to say (3)
- 

*Display This Question:*

*If Do you live in the UK? = Yes*



**Q18 Where in the UK do you live?**

- ☐ Scotland (1)
- ☐ England (2)
- ☐ Wales (3)
- ☐ Northern Ireland (4)
- ☐ Prefer not to say (6)
- 

*Display This Question:*

*If Do you live in the UK? = No*

**Q19 Which country do you live in?**

▼ United States (1) ... Zimbabwe (249)

Page Break

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End of Block: Demographics

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Start of Block: Accessibility

**Q20 What does “accessibility” mean to you as a(n)  $\S\{Q12/ChoiceTextEntryValue\}$  person? (max 200 words)**

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Page Break

End of Block: Accessibility

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Start of Block: Visiting pattern questions

**Q21 Have you visited a museum, gallery or other cultural heritage site in the last 5 years?**

- ☐ Yes (1)
- ☐ No (2)
- ☐ Unsure (4)
- ☐ Prefer not to say (3)





**Q22 How often do you normally visit museums, galleries and/or other cultural heritage sites in a year on average (apart from the times when access was limited due to COVID-19)?**

- ☐ Weekly (1)
- ☐ Fortnightly (8)
- ☐ Once a month (2)
- ☐ Once every couple of months (3)
- ☐ Once every 6 months (4)
- ☐ Once a year (5)
- ☐ Less often than once a year (6)
- ☐ Never (9)
- ☐ Other (Please specify) (10) \_\_\_\_\_
- ☐ Prefer not to say (7)



**Q23 On average, how often would you want to visit museums, galleries and/or other cultural heritage sites if they were more accessible?**

- ☐ Weekly (2)
- ☐ Fortnightly (3)
- ☐ Once a month (4)
- ☐ Once every couple of months (5)
- ☐ Once every 6 months (6)
- ☐ Once a year (7)
- ☐ Less often than once a year (1)
- ☐ Never (9)
- ☐ Other (Please specify) (10) \_\_\_\_\_
- ☐ Prefer not to say (8)

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Page Break



Q24 Who do you visit cultural heritage sites with? (*select all that apply*)

☐

Alone (1)

☐

With family (2)

☐

With friends (3)

☐

With carers (4)

☐

With my partner (5)

☐

With children (6)

☐

Not listed / Other (7) \_\_\_\_\_

☐

Prefer not to say (8)



**Q25 When do you usually visit museums, galleries and/or other cultural heritage sites? (select all that apply)**

- ☐ Mornings only (1)
- ☐ Afternoons only (2)
- ☐ Either morning or afternoon (3)
- ☐ During weekends only (4)
- ☐ During the week only (5)
- ☐ Any day of the week (6)
- ☐ During events only (7)
- ☐ Not listed / other (8) \_\_\_\_\_
- ☐ Prefer not to say (9)

---

*Carry Forward Selected Choices from "When do you usually visit museums, galleries and/or other cultural heritage sites? (select all that apply)"*



**Q26 When do you visit cultural heritage sites most often?** *(Select only one)*

- ☐ Mornings only (1)
- ☐ Afternoons only (2)
- ☐ Either morning or afternoon (3)
- ☐ During weekends only (4)
- ☐ During the week only (5)
- ☐ Any day of the week (6)
- ☐ During events only (7)
- ☐ Not listed / other (8) \_\_\_\_\_
- ☐ Prefer not to say (9)

*Skip To: Q27 If Condition: Prefer not to say Is Selected. Skip To: Why do you go to museums, galleries a....*

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Page Break

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**Q27 Why do you go to museums, galleries and/or cultural heritage sites? (*Select all that apply*)**

- ☐ To spend time with friends/family (5)
  - ☐ To see specific displays/objects (1)
  - ☐ To attend events or activities (such as a talk or art session) (2)
  - ☐ To visit facilities (e.g. the gift shop or café) (3)
  - ☐ Because of an existing interest / passion (6)
  - ☐ To learn new things (for myself or my family) (10)
  - ☐ For professional reasons (11)
  - ☐ For my studies (12)
  - ☐ It is convenient to visit (e.g to get away from the weather) (13)
  - ☐ There is nothing else to do (14)
  - ☐ Not listed / Other (Please specify) (15)
- 

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*Carry Forward Selected Choices from "Why do you go to museums, galleries and/or cultural heritage sites? (Select all that apply)"*



**Q28 Which is the most important reason for visiting museums, galleries or cultural heritage sites? (Select only *one*)**

- ☐ To spend time with friends/family (1)
- ☐ To see specific displays/objects (2)
- ☐ To attend events or activities (such as a talk or art session) (3)
- ☐ To visit facilities (e.g. the gift shop or café) (4)
- ☐ Because of an existing interest / passion (5)
- ☐ To learn new things (for myself or my family) (6)
- ☐ For professional reasons (7)
- ☐ For my studies (8)
- ☐ It is convenient to visit (e.g to get away from the weather) (9)
- ☐ There is nothing else to do (10)
- ☐ Not listed / Other (Please specify) (11)

\_\_\_\_\_

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Page Break



**Q29 Why do you not attend museums, galleries and / or cultural heritage sites? (*Select all that apply*)**

☐

Lack of pre-visit information (online) (2)

☐

Lack of pre-visit resources for autistic / neurodivergent visitors (such as story booklets) (3)

☐

Lack of resources during the visit for autistic / neurodivergent visitors (such as sensory backpacks) (4)

☐

Lack of events for autistic / neurodivergent visitors (including quiet hours / relaxed openings) (5)

☐

Lack of staff training related to autistic / neurodivergent needs (1)

☐

Lack of time (15)

☐

Museums, galleries or heritage sites are not of interest to me (7)

☐

I do not feel that my needs are met (8)

☐

I do not feel comfortable in the museum (9)

☐

It is too expensive to visit museums, galleries or cultural heritage sites (11)

☐

I have had negative experiences in museums, galleries or cultural heritage sites in the past (12)

☐

Not listed / Other (Please specify) (13)

☐

Prefer not to say (14)



Carry Forward Selected Choices from "Why do you not attend museums, galleries and / or cultural heritage sites? (Select all that apply)"



**Q30 What is the main reason for not attending museum, galleries or heritage sites? (Select only one)**

- ☐ Lack of pre-visit information (online) (1)
- ☐ Lack of pre-visit resources for autistic / neurodivergent visitors (such as story booklets) (2)
- ☐ Lack of resources during the visit for autistic / neurodivergent visitors (such as sensory backpacks) (3)
- ☐ Lack of events for autistic / neurodivergent visitors (including quiet hours / relaxed openings) (4)
- ☐ Lack of staff training related to autistic / neurodivergent needs (5)
- ☐ Lack of time (6)
- ☐ Museums, galleries or heritage sites are not of interest to me (7)
- ☐ I do not feel that my needs are met (8)
- ☐ I do not feel comfortable in the museum (9)
- ☐ It is too expensive to visit museums, galleries or cultural heritage sites (10)
- ☐ I have had negative experiences in museums, galleries or cultural heritage sites in the past (11)
- ☐ Not listed / Other (Please specify) (12)  
\_\_\_\_\_
- ☐ Prefer not to say (13)

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Page Break

**Q31 If a museum, gallery or cultural heritage site had an accessibility panel or other method of including you in developing their accessibility, would you join?**

- ☐ Yes (4)
- ☐ No (5)
- ☐ Unsure (6)
- ☐ Other (Please specify) (8) \_\_\_\_\_
- ☐ Prefer not to say (7)
- 

**Q32 What advice would you give a museum, gallery or cultural heritage site in order to be more accessible to neurodivergent audiences? (max 100 words)**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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Page Break \_\_\_\_\_

**Q33 The next 2 questions are about the impact of COVID-19 on how you visit museums**

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**Q34 How frequently do you visit cultural heritage sites in person since COVID-19?**

- ☐ Less frequently (9)
- ☐ About the same (10)
- ☐ More frequently (11)
- ☐ Unsure (12)
- ☐ Other (Please specify) (8) \_\_\_\_\_
- ☐ Prefer not to say (13)
- 

**Q35 How frequently do you access online / digital exhibitions since COVID-19?**

- ☐ Less frequently (8)
- ☐ About the same (9)
- ☐ More Frequently (10)
- ☐ Unsure (11)
- ☐ Other (Please specify) (13) \_\_\_\_\_
- ☐ Prefer not to say (12)
- 

Page Break

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**End of Block: Visiting pattern questions**

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**Start of Block: Communication**

**Q36 If you have any final thoughts, suggestions or feedback that you have not had the opportunity to share, then please do use this box. (Max 200 words)**

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Page Break

**Q37 Would you be interested in hearing more about this research project and the findings?**

☐ Yes (1)

☐ No (2)

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**Q38 Would you be interested in being involved in further research during this project (such as a taking part in an interview, focus group or museum visit and feedback session?)**

☐ Yes (1)

☐ No (2)

---



**Q39 Thank you for your interest. Please confirm the email you wish to be contacted at. If you do not wish to be contacted, please leave this box blank.**

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**End of Block: Communication**

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**Start of Block: Final Consent**

**Q40 By clicking the ‘right arrow’ button below, you are consenting to participate in this study, as it is described in the participant information sheet, which you can download here - Participant Information Sheet. If you did not yet download and keep a copy of this document for your records, we recommend you do that now. If you have any follow-up questions, please do email Aimee Fletcher (a.fletcher.1@research.gla.ac.uk), who is happy to answer any queries. Thank you very much for taking the time to respond to this survey.**

**End of Block: Final Consent**

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**Start of Block: Block 8**

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# Museum Workforce Survey - Final Draft

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### Start of Block: Welcome/information

**Q1.1 Welcome!** Thank you for your interest in this research. You are being invited to participate in a PhD research study titled “Autism in Museums: Co-Creation Strategies for Making Museums Autism Accessible”. This study is being carried out by Aimee Fletcher from the College of Arts, Information Studies at the University of Glasgow. The College of Arts Ethics Committee approved this research project in December 2021. **What is this study about?** This PhD thesis investigates how museums can become accessible to autistic and neurodivergent people. In recent years, with the increase in autistic people being diagnosed across the world and an increasing focus within the cultural heritage sector to become more inclusive in their accessibility provision, it is clear that increasing accessibility for neurodivergent and autistic visitors is a natural next step in museum development. However, to date, the focus on making museums “autism-friendly” in professional practice and related literature has tended to be on children and not included autistic people in the planning or evaluation stages. Led by an autistic researcher, this project is about including autistic and neurodivergent people in research that could result in sectoral change. More information about the study can be found in Participant Information. **Who can take part?** To take part in this survey, you must be:

Aged 18 and over  
Someone who works in a museum currently or within the last 5 years (paid and/or voluntary)

Able to read and write in English If you are an autistic/neurodivergent person who also works / volunteers in a museum, you are welcome to complete this survey as well as the one for autistic / neurodivergent visitors. **What will happen if I take part?** If you would like to take part in this research, you will be asked questions about: Your demographic profile - such as your age, gender, ethnic identity and whether you live in the UK or elsewhere. These questions are being asked to understand who is answering the survey, and to make sure it is as inclusive and diverse in representation as possible. a) What your museum, gallery or cultural heritage site currently offers for autistic and neurodivergent audiences, b) what gaps there are in current provisions and c) what it plans to offer autistic and neurodivergent people in the future Strengths and areas for development in making your museum more accessible for autistic and neurodivergent audiences

What may be useful to include in guidelines for the sector to enhance accessibility.

Whether you would be interested in being involved at a later stage of the research. For example, taking part in an interview or focus group adjusted to your access needs. Information about the storage and use of the data gathered during this study, including the use of the findings, can be found in detail in Participant Information. **I would like to take part** If you are interested in taking part, please download a copy of the Participant Information sheet here and retain this for your records before starting the survey. If you have any questions, please email me

at [a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk) or my Supervisor, Professor Maria Economou

at [maria.economou@glasgow.ac.uk](mailto:maria.economou@glasgow.ac.uk). **Who has reviewed this research?** Ethical clearance for this project has been granted by the College of Arts Research Ethics Committee on 21/12/2021. If you have any questions about the ethical approval of this research project, please contact the University of Glasgow, College of Arts Research Ethics Committee ([arts-ethics@glasgow.ac.uk](mailto:arts-ethics@glasgow.ac.uk)) **Can I**

**Withdraw?** Your participation is entirely voluntary, and you can withdraw at any time. You are free

to omit any question that you do not wish to answer. Thank you again for your interest in this research, please do not hesitate to get in touch if you have any questions.

---

Page Break

## End of Block: Welcome/information

---

### Start of Block: Consent

**Q2.1 Consent** Before starting this survey, it is important that you take the time to read the Participant Information Sheet accessible using the embedded link. If you have any issues accessing the information, or if you have any questions about the study, then please email the researcher Aimee Fletcher, using [a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk). The survey itself does not ask your name and all the answers provided will be gathered and analysed together and any potentially identifying details removed to protect participants' rights to anonymity, unless specifically requesting to be named as part of the Consent questions below. Once you have completed these questions, the survey will start.

---

### Q2.2 I am aged 18 and over

- ☐ I agree (1)
- ☐ I do not agree (2)
- 

**Q2.3 I have read and understood the Project Information Sheet and have had the opportunity to ask questions about the research and my participation ([a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk)).**

- ☐ I agree (1)
- ☐ I do not agree (2)
- 

**Q2.4 I voluntarily agree to take part in this research project.**

- ☐ I agree (1)
- ☐ I do not agree (2)
-



**Q2.5 I agree for the data collected by the researcher and/or produced by me during the research activities (hereafter called my data) to be used to inform the project's findings and their dissemination (e.g. at conference presentations).**

☐ I agree (1)

☐ I do not agree (4)

**Q2.6 The procedures regarding **anonymity** (e.g. use of names, pseudonyms, anonymisation of data) have been clearly explained to me in the Information Sheet.**

☐ I agree (1)

☐ I do not agree (2)

---

**Q2.7 I understand that my data is of long-term value for academic research and will be retained in secure storage of the university for a period of minimum ten years, starting from 2022.**

☐ I agree (1)

☐ I do not agree (2)

**Q2.8 Please specify the condition of anonymity for the use of your data.**

☐ I would like to be anonymous (e.g. Participant 1) (1)

☐ I would like for you to use a pseudonym for me (a fake/alternative name) (2)

☐ I would like to be named (please specify here) (3)

---

**Q2.9 I have the choice to leave any question unanswered. I may withdraw at any time and without explanation. I may withdraw my data within two months of supplying it.**

☐ I agree (1)

☐ I do not agree (4)

Page Break

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*Display This Question:*

*If I am aged 18 and over = I do not agree*

*Or I have read and understood the Project Information Sheet and have had the opportunity to ask ques... = I do not agree*

*Or I voluntarily agree to take part in this research project. = I do not agree*

*Or I agree for the data collected by the researcher and/or produced by me during the research activi... = I do not agree*

*Or I understand that my data is of long-term value for academic research and will be retained in sec... = I do not agree*

*Or I have the choice to leave any question unanswered. I may withdraw at any time and without explan... = I do not agree*

Q2.10

Thank you for starting this survey! Unfortunately, you can proceed no further as you did not provide your full informed consent to participate.

If this was not intentional, please feel free to go back and amend your choices in the consent questions to start the survey. Otherwise, thank you very much for your participation and if you have any concerns or questions, you can get in touch with me at [a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk)

*Skip To: End of Survey If Thank you for starting this survey! Unfortunately, you can proceed no further as you did not prov... Displayed*

**End of Block: Consent**

**Start of Block: Demographics**

**Q3.1 DEMOGRAPHIC INFORMATION** The following questions are about demographic information. They are intended to help identify potential patterns, themes and gaps. You do not have to respond to these questions, however answering them will help ensure that the survey is as inclusive as possible.

---

**Q3.2 In which age group do you belong?** *Please select one.*

- ☐ 18 - 24 (13)
- ☐ 25 - 34 (14)
- ☐ 35 - 44 (15)
- ☐ 45 - 54 (16)
- ☐ 55 - 64 (17)
- ☐ 65 - 74 (18)
- ☐ 75 - 84 (19)
- ☐ 85 or older (20)
- ☐ Prefer not to say (12)



**Q3.3 To which gender identity do you most identify?**

- ☐ Male (1)
  - ☐ Female (2)
  - ☐ Non-binary (3)
  - ☐ Prefer not to say (4)
  - ☐ Not listed / Other (Please specify) (5)
-

**Q3.4 What is your ethnic group?** *Please select the ethnicity which best reflects you. These categories were created using the Scottish Census as a guide.*

☐ White - English / Welsh / Scottish / Northern Irish / British (2)

☐ White - Irish (3)

☐ White - Gypsy or Irish Traveller (4)

☐ Any other White background, please write in (5)

---

☐ Mixed race - White and Black Caribbean (7)

☐ Mixed Race - White and Black African (8)

☐ Mixed Race - White and Asian (9)

☐ Any other Mixes /multiple ethnic background, please write in (10)

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☐ Asian / Asian British (11)

☐ Indian (12)

☐ Pakistani (13)

☐ Bangladeshi (14)

☐ Chinese (15)

☐ Any other Asian background, please write in (16)

---

☐ Black / Black British (17)

☐ African (18)

☐ Caribbean (19)

☐ Any other Black / African / Caribbean background, please write in (20)

---

- ☐ Other ethnic group (21)
- ☐ Arab (22)
- ☐ Any other ethnic group, please write in (23)
- 

**Q3.5 Do you live in the UK?**

- ☐ Yes (1)
- ☐ No (2)
- ☐ Prefer not to say (3)
- 

*Display This Question:*

*If Do you live in the UK? = Yes*



**Q3.6 Where in the UK do you live?**

- ☐ Scotland (1)
- ☐ England (2)
- ☐ Wales (3)
- ☐ Northern Ireland (4)
- ☐ Prefer not to say (6)
- 

*Display This Question:*

*If Do you live in the UK? = No*

**Q3.7 Which country do you live in?**

▼ United States (1) ... Zimbabwe (249)

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Page Break

## End of Block: Demographics

---

## Start of Block: Organisational question

**Q4.1 INFORMATION ABOUT YOUR WORK, THE ORGANISATION AND THEIR PROVISION FOR AUTISTIC / NEURODIVERGENT VISITORS** The following section shall ask questions **about you**, the organisation you work / volunteer for and what they offer for autistic / neurodivergent visitors. All contributions made will be used to inform understandings of what is available in museums, galleries or other cultural heritage organisations in Scotland currently, and to develop guidelines and approaches to enhance accessibility for this audience. **Please note:** organisations **will not be contacted** regarding your contributions, but some information could make you identifiable. If you have any concerns about being recognised or having details used, please contact Aimee Fletcher, who is happy to discuss and ensure identifiable details are redacted from any publications.

**Q4.2 Do you currently (or within the last 5 years) work or volunteer in a museum, gallery or cultural heritage sector?**

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not sure (please explain) (3) \_\_\_\_\_

*Skip To: End of Survey If Do you currently (or within the last 5 years) work or volunteer in a museum, gallery or cultural... = No*

---

**Q4.3 In which cultural heritage organisation do you work (e.g. museum, gallery or cultural heritage institution)?** *If preferred, you can state the type (e.g. National, small art gallery etc.).*

\_\_\_\_\_

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**Q4.4 What is your job role in the organisation?** *Please note: You do not need to hold a specific role in Museums, Galleries or other Cultural Organisations. E.g. Education Manager, Volunteer, Collections Officer. You can use this space to explain if there are specific tasks related to accessibility that you have undertaken in your role(s), if you wish.*

\_\_\_\_\_

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Page Break

**Q4.5 Do you identify (with formal diagnosis or self-identify) as autistic / neurodivergent?** *If you are unsure, or would like to learn more about the terminology of neurodiversity, more information can be found by the University of Glasgow's Neurodiversity Network. If you are unsure, you are welcome to email me (Aimee Fletcher at [a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk))*

☐ Yes (1)

☐ Maybe / Unsure (please explain) (2)

---

☐ No (3)

☐ Prefer not to say (4)

---

Page Break

Display This Question:

*If Do you identify (with formal diagnosis or self-identify) as autistic / neurodivergent?If you are... = Yes*  
*Or Do you identify (with formal diagnosis or self-identify) as autistic / neurodivergent?If you are... =*  
*Maybe / Unsure (please explain)*

**Q4.6 How do you prefer to be referred to as?** For example: Autistic a person with autism having Asperger's Syndrome being neurodivergent (e.g. dyslexic, dyspraxic, ADHD. If you are unsure whether you can take part, please email [a.fletcher.1@research.gla.ac.uk](mailto:a.fletcher.1@research.gla.ac.uk)) having a sensory processing condition. *Please note, this is not an exhaustive list of conditions considered neurodivergent, please add your preference.*

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**End of Block: Organisational question**

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**Start of Block: What does accessibility mean to you?**

**Q5.1 What does “being accessible” mean to you as a museum worker? (max 200 words)**

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Page Break



## End of Block: What does accessibility mean to you?

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### Start of Block: Accessibility

*Display This Question:*

*If Do you identify (with formal diagnosis or self-identify) as autistic / neurodivergent?If you are... = Yes*

*Or Do you identify (with formal diagnosis or self-identify) as autistic / neurodivergent?If you are... =  
Maybe / Unsure (please explain)*

*Or Do you identify (with formal diagnosis or self-identify) as autistic / neurodivergent?If you are... = No*

*Or Do you identify (with formal diagnosis or self-identify) as autistic / neurodivergent?If you are... =  
Prefer not to say*

### Q6.1 How “autism friendly” would you describe your museum, gallery or cultural heritage site?

- ☐ Very (1)
- ☐ Good (2)
- ☐ Average (3)
- ☐ Below average (4)
- ☐ Not very (5)
- ☐ Prefer not to say (6)

---

Page Break

**Q6.2 Does your institution currently have any autism resources (such as sensory maps, information packs, sensory backpacks)?**

☐ Yes - since Covid (8)

☐ Yes - since before Covid (15)

☐ Maybe / unsure (please explain) (9)

---

☐ No - no plans to (please explain) (10)

---

☐ No - but we did before Covid (please explain) (11)

---

☐ No - but we plan to (please explain) (12)

---

☐ Other (please explain) (13) \_\_\_\_\_

☐ Prefer not to say (14)

---

*Display This Question:*

*If Does your institution currently have any autism resources (such as sensory maps, information pack... = Yes - since Covid*

*Or Does your institution currently have any autism resources (such as sensory maps, information pack... = Yes - since before Covid*

*Or Does your institution currently have any autism resources (such as sensory maps, information pack... = Maybe / unsure (please explain)*

*Or Does your institution currently have any autism resources (such as sensory maps, information pack... = Other (please explain)*

**Q6.3 What type of resources do you have?** *Please select all that apply.*

- ☐ Sensory bags (1)
  - ☐ Pre-visit information (2)
  - ☐ Visual or social stories (3)
  - ☐ Specific tools (e.g. ear defenders) (4)
  - ☐ Quiet hours/relaxed opening (5)
  - ☐ Specific events for families with autistic / neurodivergent children (6)
  - ☐ Specific events for autistic / neurodivergent adults (7)
  - ☐ Autism / neurodivergence training for staff (8)
  - ☐ Accessibility information online (including contact details) (9)
  - ☐ Other (Please explain) (10)
- 
- ☐ Prefer not to say (11)

*Display This Question:*

*If Does your institution currently have any autism resources (such as sensory maps, information pack... =  
No - but we did before Covid (please explain)*

**Q6.4 What type of resources did you have?** *Please select all that apply.*

- ☐ Sensory bags (1)
  - ☐ Pre-visit information (2)
  - ☐ Visual or social stories (3)
  - ☐ Specific tools (e.g. ear defenders) (4)
  - ☐ Quiet hours/relaxed opening (5)
  - ☐ Specific events for families with autistic / neurodivergent children (6)
  - ☐ Specific events for autistic / neurodivergent adults (7)
  - ☐ Autism / neurodivergence training for staff (8)
  - ☐ Accessibility information online (including contact details) (9)
  - ☐ Other (Please explain) (10)
- 
- ☐ Prefer not to say (11)

**Q6.5 Does your institution currently run "autism friendly" events?**

- ☐ Yes - often (8)
- ☐ Yes - sometimes (9)
- ☐ No - never (12)
- ☐ No - never and no immediate plans (16)
- ☐ No - one scheduled soon (10)
- ☐ No - did in the past (pre-Covid) (11)
- ☐ Unsure (13)
- ☐ Other / not listed (please explain) (14)
- 
- ☐ Prefer not to say (15)

**End of Block: Accessibility**

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**Start of Block: If yes to question 8**

*Display This Question:*

*If Does your institution currently run "autism friendly" events? = Yes - often*

*Or Does your institution currently run "autism friendly" events? = Yes - sometimes*

*Or Does your institution currently run "autism friendly" events? = Unsure*

*Or Does your institution currently run "autism friendly" events? = Other / not listed (please explain)*

**Q7.1 How often do the events for autistic / neurodivergent audiences run?** *Please reflect on since the Coronavirus restrictions have lifted (for example, the last year).*

- ☐ Weekly (1)
- ☐ Fortnightly (11)
- ☐ Monthly (2)
- ☐ Once every couple of months (3)
- ☐ Once in 6 months (4)
- ☐ Once in a year (5)
- ☐ Less often than once a year (6)
- ☐ Never (7)
- ☐ Unsure (8)
- ☐ Other (please explain) (9) \_\_\_\_\_
- ☐ Prefer not to say (10)

---

*Display This Question:*

*If Does your institution currently run "autism friendly" events? = Yes - often*

*Or Does your institution currently run "autism friendly" events? = Yes - sometimes*

*Or Does your institution currently run "autism friendly" events? = Other / not listed (please explain)*

**Q7.2 What time in the day do you run your sessions, on average?** *Please select all that apply.*

☐

Mornings (1)

☐

Afternoons (2)

☐

Evenings (3)

☐

Other (please explain) (4)

---

☐

Prefer not to say (5)

---

Page Break

---

*Display This Question:*

*If Does your institution currently run "autism friendly" events? = Yes - often*

*Or Does your institution currently run "autism friendly" events? = Yes - sometimes*

*Or Does your institution currently run "autism friendly" events? = Unsure*

*Or Does your institution currently run "autism friendly" events? = Other / not listed (please explain)*

**Q7.3 What age ranges do the events / activities for autistic / neurodivergent audiences cater to?**

*Please select all the age ranges that are relevant to what you offer currently.*

- ☐ 0-5 (1)
- ☐ 6-8 (2)
- ☐ 9-11 (3)
- ☐ 12-15 (4)
- ☐ 16-18 (5)
- ☐ 19-25 (6)
- ☐ 26-30 (7)
- ☐ 31-40 (8)
- ☐ 41-50 (9)
- ☐ 51-60 (10)
- ☐ 65+ (11)

---

Page Break



Display This Question:

*If Does your institution currently run "autism friendly" events? = Yes - often*

*Or Does your institution currently run "autism friendly" events? = Yes - sometimes*

*Carry Forward Selected Choices from "What age ranges do the events / activities for autistic / neurodivergent audiences cater to? Please select all the age ranges that are relevant to what you offer currently."*

X→

**Q7.4 Which audience is the main audience you target with these events?** *Please select one.*

- ☐ 0-5 (1)
- ☐ 6-8 (2)
- ☐ 9-11 (3)
- ☐ 12-15 (4)
- ☐ 16-18 (5)
- ☐ 19-25 (6)
- ☐ 26-30 (7)
- ☐ 31-40 (8)
- ☐ 41-50 (9)
- ☐ 51-60 (10)
- ☐ 65+ (11)

**End of Block: If yes to question 8**

---

**Start of Block: Current provisions**

Page Break

---

**Q8.1 What barriers might have impacted your ability to provide audience-specific resources for autistic / neurodivergent visitors?** *Please select all that apply.*

- ☐ Lack of funding / budget (1)
  - ☐ Lack of staff training (2)
  - ☐ Lack of expertise for this audience (3)
  - ☐ Lack of facilities (4)
  - ☐ Lack of space (5)
  - ☐ Too time consuming (6)
  - ☐ Lack of confidence (7)
  - ☐ Other priorities (please explain) (8)
- 
- ☐ Other (please explain) (9)
- 
- ☐ Prefer not to say (10)

*Skip To: End of Block If What barriers might have impacted your ability to provide audience-specific resources for autisti... = Prefer not to say*

Page Break

*Carry Forward Selected Choices from "What barriers might have impacted your ability to provide audience-specific resources for autistic / neurodivergent visitors? Please select all that apply."*



Q8.2 What is the main reason?

- ☐ Lack of funding / budget (1)
- ☐ Lack of staff training (2)
- ☐ Lack of expertise for this audience (3)
- ☐ Lack of facilities (4)
- ☐ Lack of space (5)
- ☐ Too time consuming (6)
- ☐ Lack of confidence (7)
- ☐ Other priorities (please explain) (8)  
\_\_\_\_\_
- ☐ Other (please explain) (9) \_\_\_\_\_
- ☐ Prefer not to say (10)

---

Page Break

**End of Block: Current provisions**

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**Start of Block: Covid provisions**

**Q9.1 How has Covid-19 impacted accessibility provision for autistic / neurodivergent audiences at your museum / cultural organisation?** *Please select all that apply.*

☐

No change (please explain) (1)

---

☐

Fewer or no in person events (2)

☐

More events online (3)

☐

Creation of new resources / events (please explain) (4)

---

☐

Lack of access to physical museum (5)

☐

Loss of access to physical resources (for example, sensory backpacks) (6)

☐

More access to physical resources (for example, sensory backpacks) (7)

☐

Unsure (please explain) (8)

---

☐

Other (please explain) (9)

---

☐

Prefer not to say (10)

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Page Break

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## End of Block: Covid provisions

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### Start of Block: Working with neurodivergent people

**Q10.1 Has your institution worked directly with autistic / neurodivergent people before (e.g. access panel)?**

- ☐ Yes (4)
- ☐ No (5)
- ☐ Unsure (please explain) (6) \_\_\_\_\_
- ☐ Other (Please explain) (7) \_\_\_\_\_
- ☐ Prefer not to say (8)

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Page Break

*Display This Question:*

*If Has your institution worked directly with autistic / neurodivergent people before (e.g. access pa... = Yes*  
*Or Has your institution worked directly with autistic / neurodivergent people before (e.g. access pa... =*  
*Unsure (please explain)*

**Q10.2 Please can you share more about your experience / project working directly with autistic / neurodivergent people? (max 200 words)**

\_\_\_\_\_

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Page Break

Display This Question:

*If Does your institution currently have any autism resources (such as sensory maps, information pack... = Yes - since Covid*

*Or Does your institution currently have any autism resources (such as sensory maps, information pack... = Yes - since before Covid*

*Or Does your institution currently have any autism resources (such as sensory maps, information pack... = Maybe / unsure (please explain)*

*Or Does your institution currently have any autism resources (such as sensory maps, information pack... = Other (please explain)*

**Q10.3 What resources did you use to develop your current provisions for autistic and neurodivergent visitors?** *Please select all that apply.*

- ☐ Online blogs by professionals (e.g. Autism in Museums) (4)
  - ☐ Online blogs by people with lived experience (e.g. neurodivergent or autistic people) (14)
  - ☐ Researching other museum's resources (e.g. online research) (5)
  - ☐ Consultants (not neurodivergent / autistic) (6)
  - ☐ Consultants (neurodivergent / autistic) (7)
  - ☐ Sector training (e.g. autism awareness training run within GLAM sector) (8)
  - ☐ Autism training (not museum / GLAM sector specific) (9)
  - ☐ Case studies from the GLAM sector (10)
  - ☐ Other (please explain) (11)
- 
- ☐ Unsure (12)
  - ☐ Prefer not to say (13)

Page Break

**Q10.4 Do you think it is important for museums to work with under-represented audiences like autistic / neurodivergent adults when developing museum learning and access?**

- ☐ Not at all important (1)
- ☐ Slightly important (2)
- ☐ Moderately important (3)
- ☐ Very important (4)
- ☐ Extremely important (5)
- ☐ Other (please explain) (6) \_\_\_\_\_
- ☐ Prefer not to say (7)

---

**Q10.5 Please explain your answer**

\_\_\_\_\_

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Page Break

**End of Block: Working with neurodivergent people**

---

**Start of Block: Future plans**

**Q11.1 Does your institution have upcoming plans to enhance its resources and visitor experience for autistic / neurodivergent visitors?**

- ☐ Yes (8)
- ☐ No (9)
- ☐ Unsure (10)
- ☐ Other (please specify) (11) \_\_\_\_\_
- ☐ Prefer not to say (12)

---

Page Break



Display This Question:

If Does your institution have upcoming plans to enhance its resources and visitor experience for aut... =  
Yes

Or Does your institution have upcoming plans to enhance its resources and visitor experience for aut... =  
Unsure

Or Does your institution have upcoming plans to enhance its resources and visitor experience for aut... =  
Other (please specify)

**Q11.2 What does your institution plan to do for autistic / neurodivergent visitors?** Please select all that apply.

- ☐ Create or update a pre-visit information booklet (4)
- ☐ Create or update a sensory backpack (5)
- ☐ Create or update staff awareness training (6)
- ☐ Create or update guidelines for developing future resources (7)
- ☐ Create or update accessibility website (online and on-site) (8)
- ☐ Attend training to enhance understanding (e.g. sector-led or neurodivergent-led) (9)
- ☐ Consult with neurodivergent and autistic people (10)
- ☐ Plan or run events or activities for autistic and neurodivergent people (11)
- ☐ Other (please explain) (12)  
\_\_\_\_\_
- ☐ Prefer not to say (13)

-----  
Page Break

**Q11.3 If a guidance toolkit was made to help museums become more accessible for autistic / neurodivergent visitors, what type of information would be useful to include in it? Please select all that apply.**

- ☐ Autism / neurodiversity terminology explanations (9)
- ☐ Introductory information about autism / neurodiversity (10)
- ☐ Suggestions for how to create resources for autistic / neurodivergent visitors (11)
- ☐ Guidelines on what to prioritise in event / activity design for autistic / neurodivergent visitors (12)
- ☐ Commonly identified barriers to neurodivergent visitors (13)
- ☐ Commonly identified reasons for visiting (14)
- ☐ Commonly identified accessibility needs (15)
- ☐ Ways to involve autistic / neurodivergent people in the museum's work (e.g. panels / consultation) (17)
- ☐ Unsure (18)
- ☐ Other (please explain) (19)  
\_\_\_\_\_
- ☐ prefer not to say (20)

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Page Break

**Q11.4 What do you think are your institution's accessibility strengths in relation to autistic / neurodivergent visitors?** *Please select all that apply.*

- ☐ Event planning (4)
  - ☐ Resource development (5)
  - ☐ Understanding priorities of autistic / neurodivergent visitors (6)
  - ☐ Awareness and understanding of access needs (7)
  - ☐ Working with autistic / neurodivergent people (e.g. access panels / consultation) (8)
  - ☐ Training (providing autism / neurodiversity awareness training for staff) (9)
  - ☐ Seeking audience feedback about autism / neurodiversity access / provisions (10)
  - ☐ Unsure (please explain) (11)

---
  - ☐ Other (please explain) (12)

---
  - ☐ Prefer not to say (13)
-

**Q11.5 What do you think are your organisation's areas for development in accessibility?**

*Please select all that apply.*

- ☐ Event planning (1)
- ☐ Resource development (2)
- ☐ Understanding priorities from autistic / neurodivergent visitors (3)
- ☐ Training (autism / neurodiversity awareness and understanding) (4)
- ☐ How to work with autistic / neurodivergent audiences (5)
- ☐ Specific gaps in knowledge / understanding (please explain) (6)

---
- ☐ Specific training gaps (please explain) (7)

---
- ☐ Other (please explain) (8)
- ☐ Prefer not to say (9)

-----  
Page Break

**End of Block: Future plans**

**Start of Block: Communication**

**Q12.1 If you have any final thoughts, suggestions or feedback that you have not had the opportunity to share, then you can put these in the box below. (Max 200 words)**

\_\_\_\_\_  
Page Break

**Q12.2 COMMUNICATION** This final section is about future communication about this research. If you would be interested in finding out more about the research (for example, findings or ways to take part in future focus groups or interviews) please select "yes" to the relevant option to you and provide an email when prompted.

---

**Q12.3** Would you like to be kept updated about key steps and findings of this research?

☐ Yes (4)

☐ No (5)

---

**Q12.4** Would you like to be contacted about opportunities to contribute further to this research in the future (e.g. interviews or focus groups)?

☐ Yes (4)

☐ No (5)

---

*Display This Question:*

*If Would you like to be kept updated about key steps and findings of this research? = Yes*

*Or Would you like to be contacted about opportunities to contribute further to this research in the... = Yes*

**Q12.5** Enter the email you wish to be contacted at:

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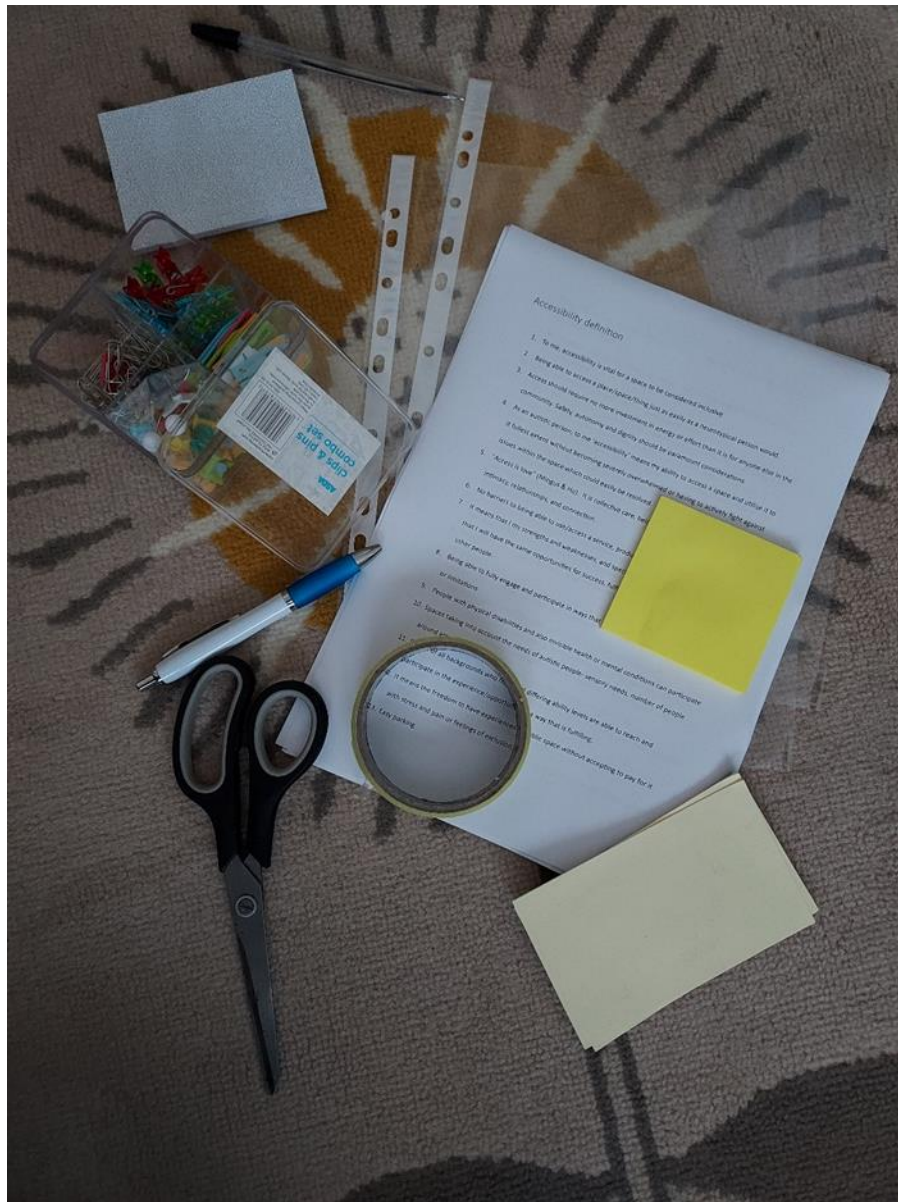
Page Break

**Q12.6** By clicking the 'Next arrow (pointing to the right)' button below, you are consenting to participate in this study, as it is described in the Participant Information Sheet.

**End of Block: Communication**

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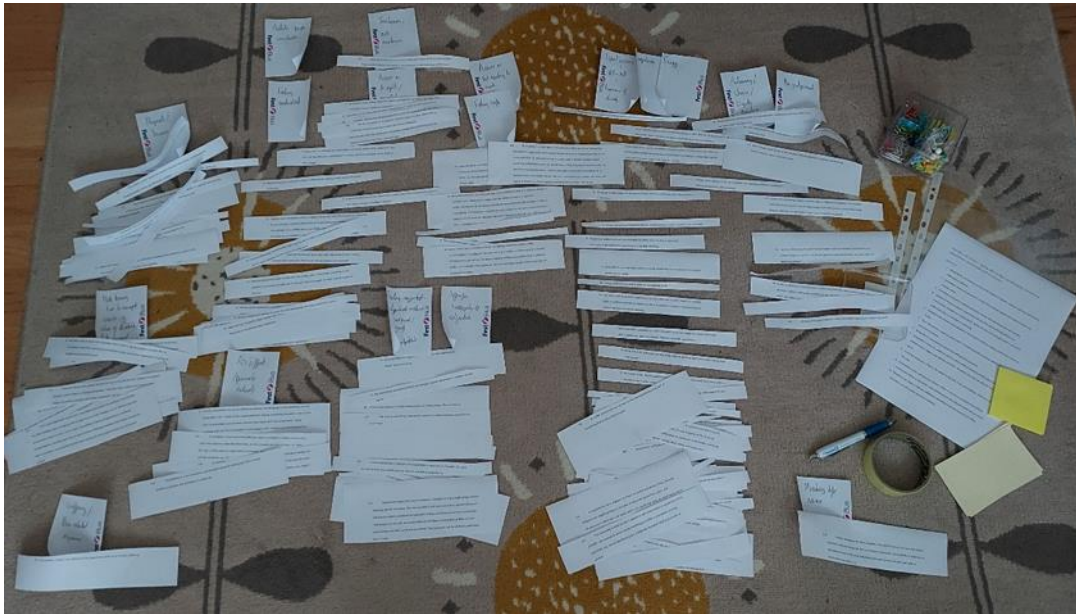
### C.3a Preparation for hand-coding the qualitative responses to the AuND survey



*Figure 8-1 Step 1: materials for qualitative data coding gathered.*

*Step 1: After pulling the qualitative data from the 466 responses into broad themes, I prepared to hand-code them to delve deeper into the codes and themes. This image shows the tools for analysis of the quotes from the survey on A4 paper, using scissors, different coloured post-it notes, a box of paperclips and page markers, a pen, and poly-pockets to put the paper in.*

### C.3b Sorting the Qualitative Data into Broad Themes with Sub-codes



*Figure 8-2 Step 2: cut quotes grouped into themes and codes.*

*Step 2: All the quotes are cut and laid across a carpet grouped into themes and sub-codes with post-it notes as theme markers.*



### C.3c Thematic Groupings of Hand-coded Qualitative Data

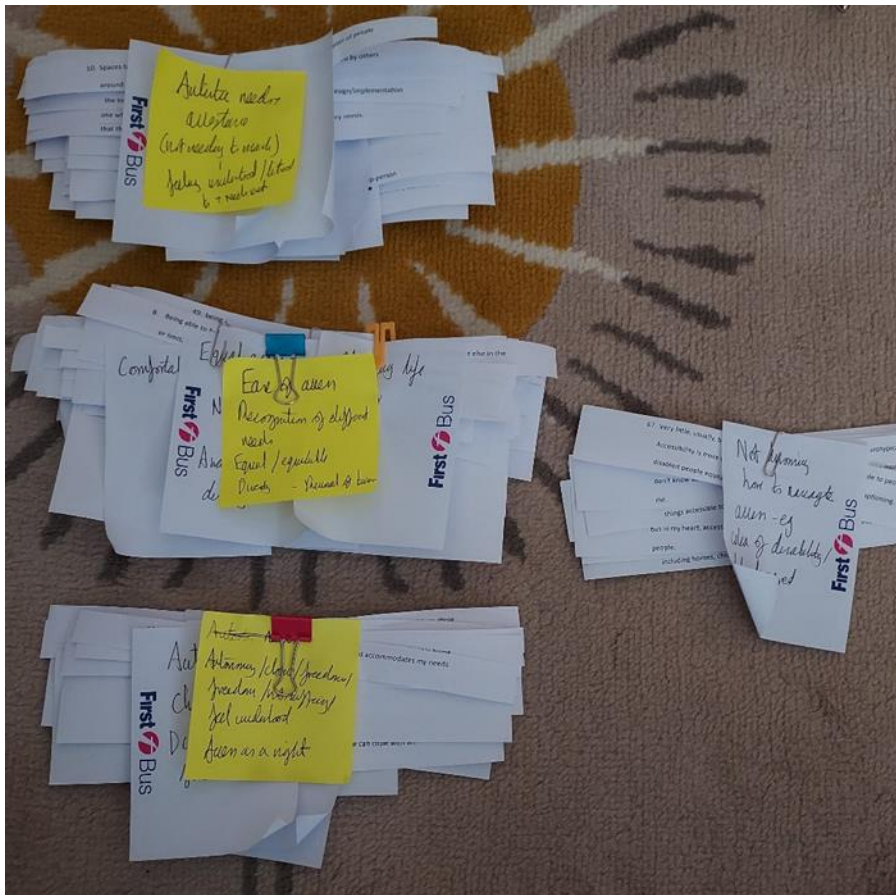


Figure 8-3 Step 3: qualitative response grouping.

Step 3: All quotes are organised into bundles, held together by coloured page markers, and then piled in three themes. Each bundle has a white post-it note with the related theme, with the yellow post-it notes identifying the broader themes. The bundle at the top of the picture includes quotes on “audience needs”, “not needing to ask [for adjustments]”, “feeling understood”, and “having needs met”, while the middle one includes “ease of access”, “recognition of different needs”, “equality and equitability”, and “personal barriers”, and the middle right one shows less-represented but relevant codes: “not knowing how to navigate/identify access needs” and “ideas of disability”. Finally, the bottom one has “autonomy/choice/freedom”, “feeling understood”, and “access as a right”.



## D. Workshops

### D.1 Scottish Museum Federation Workshop Questions

1. How do you currently feel about accessibility for neurodivergent audiences in your organisation? (please write up to three words)
2. Did the museum workforce findings align with your experiences? (please tick/circle)

Yes (fully)      Yes (partly)      No      Not sure

3. Were the neurodivergent adult survey findings what you were expecting? (please tick / circle)

Yes – Fully    Yes – Partly    No    I did not have specific expectations    Not Sure

4. What are your thoughts about the findings – are there any surprises?
5. What are your biggest concerns when organising events or resources for ND audiences?  
Consider what would be useful in guidance.
6. Would a guidance toolkit, created with lived and professional experience, be useful to you?

Not Useful    Somewhat Useful    Slightly Useful    Very Useful    Extremely Useful    Not Sure

7. How can we work together to support the sector to become more accessible?
8. In a word, how do you feel about the future of accessibility for neurodivergent audiences after this workshop?

## D.2 Autscope Workshop Questions

1. Practice – what word(s) do you think of when you hear the word “museum”? (please write up to three words)
2. Do you have any thoughts about the research overview? (please share)
3. Do the common barriers identified reflect your experience or expectations? (please tick/circle)

Yes (fully)      Yes (partly)      No      Not sure

4. What are your thoughts on these barriers? E. g. is anything missing?
5. Do the common reasons for visiting identified reflect your own experience or expectations? (please tick/circle)

Yes – Fully      Yes – Partly      No      I did not have specific expectations      Not Sure

6. What are your thoughts – are there any other reasons for visiting?
7. Do you think the advice identified in the findings reflects what you would like museums to know to improve ND visiting experiences?

Yes – Fully      Yes – Partly      No      I did not have specific expectations      Not Sure

8. Do you have any advice or information that you want to share with museums to improve accessibility?
9. If museums made an effort to improve their accessibility for ND audiences, would you be more likely to visit a museum? (please tick/circle)

Yes      Yes (but only if ND adults consulted)      No      Unsure

10. What do you think should be prioritised in a guidance toolkit?
11. Do you have any final thoughts about the research and/or findings you would like to share?

## D.3 Research Summary Handout for Workshops and Enquiries about Findings

### **Findings from the PhD research on accessibility in museums for autistic and neurodivergent adults**

#### **What is this document?**

The information in this document is intended to share some of the key findings of the surveys for autistic and neurodivergent adults (survey 1), and the museum workers (survey 2).

#### **How the data has been analysed?**

The findings have been analysed using a reflexive thematic analysis approach by an autistic researcher. To ensure that full consent was obtained, only surveys that were completed in their entirety (from start to finish) as recorded by Qualtrics were analysed, although question skipping was allowed if preferred. This meant that there were 466 fully completed surveys from autistic and neurodivergent adults (of 700 total recorded responses) and 130 fully completed surveys by museum workers.

#### **The process of the analysis was (for both surveys):**

1. Reading all responses of fully completed surveys from start to finish – making notes of observations.
2. Creating visualisations (charts, graphs, and word clouds) to view the trends in response to multiple-choice type questions and identify the most commonly recurring words that came up.
3. Creating documents using the top-level themes identified during stages 1 and 2 – then going through all the responses to match responses to the themes – all anonymised.
4. Once all the quotes were organised into the documents, I went through them to identify sub-themes that came up to identify recurring experiences, suggestions, or feedback.
5. Writing analysis combining the themes, quotes from the survey respondents, and researcher observations – for chapters and to share with neurodivergent adults and museum workers for feedback.

#### **Autistic and neurodivergent adults survey findings:**

466 full responses were received and analysed. There was a diverse age range (completed by people aged 18 to 73, with 35 as the average age), diverse gender representation, and international responses (the majority came from the UK and the US, with responses from other

parts of the world in fewer numbers). There is an under-representation of non-white participants, which is a significant gap in the findings.

**1) Barriers to visiting museums:**

- a. **Sensory environment** – causing overload (or is underwhelming), lack of quiet spaces to retreat to if needed, lack of information about the sensory environment to plan.
- b. **Lack of events/resources specifically for autistic and neurodivergent adults** – events not advertised or specifically for children, not running at times that are accessible.

**2) Lack of available information** – information is not available ahead of or during the visit, information available is not up-to-date or hard to find, interpretation information as either too much or not enough.

- a. **Anxiety about visiting** – connected to lack of information, concerns about needs not being met, not feeling comfortable or welcome in the museum.
- b. **Common barriers** – lack of time (museums open at times that do not work), cost of visit, lack of transport/parking, no one to go with, the environment is too busy, and concerns about COVID.

**3) Motivations/reasons for visiting:**

- a. **Motivated by interest** – it may be an exhibition/display that is on a topic that is an existing interest or they may be looking to find a new interest. It is a place to learn and explore interests.
- b. **Socialising with others** – it may be a place that can facilitate socialising with friends and family: a place to share interests or a social spot that does not require drinking.
- c. **Learning (formal and informal)** – it may be a place to go to learn more about specific topics or find something new. Somewhere that parents can take children to share interests and learn together, sometimes as part of home education.
- d. **For work or studies** – some respondents either worked in roles or studied courses that required them to visit.
- e. **For mental wellbeing and connections** – some respondents identified museum environments as positive for their wellbeing and connection to the world.

- f. **For convenience** – to attend specific facilities (e.g. café, gift shop, or bathroom), to get out of weather conditions, as something to do on a holiday, or because there is nothing else to do.

#### 4) **Common types of advice or adaptations recommended:**

- a. **Develop and provide information in different formats** – e.g. having audio guides, video, easy-read and detailed versions of information. Make sure that information online is up-to-date and easy to access.
- b. **Sensory environment adjustments** – create a low-arousal environment by reducing the level of light, noise, and crowdedness in a space. Offer information in advance to allow for preparation to visit. Be aware that some people are sensory seeking, so ensure there are options available.
- c. **Facilities** – having a designated quiet room space that is clearly advertised and available. Ensure there are seating areas throughout to allow for quiet contemplation and decompression. Allow food from outside for specific dietary needs. Ensure everything has clear signage.
- d. **Training and understanding** – ensure all staff receive training by neurodivergent adults, and factor in the needs of neurodivergent people into any planning. Highlight intersectionality and diversity of needs.
- e. **Events and resource development** – to develop events and resources specifically for neurodivergent adults, ideally including neurodivergent adults in their development. Listen and adapt to feedback and design with a diversity of needs in mind to offer a variety of options for individual needs.

#### **Museum workers survey findings:**

130 full responses were recorded for this survey. There was a diverse age range, representation of different roles levels of responsibility, and gender. 37% responded that they identified as neurodivergent (with a further 8% unsure). There was a gap in that few non-white participants took part.

This section will include the key themes as identified in survey 2. It will consider the most commonly identified:

- 1) Good understanding of accessibility, but low confidence in their organisation's accessibility.

- 2) High level of uncertainty about what is being done across the sector and within organisations.
- 3) Motivation to make museums accessible for autistic and neurodivergent adults, but barriers to making this happen including:
  - a. **Funding** – lack of funding and investment.
  - b. **Lack of staff/volunteers** – to run and keep events and resources up-to-date.
  - c. **Lack of facilities** – not having space to provide a quiet room.
  - d. **Lack of support from management** – a concern that it is not viewed as a priority by management compared to other audiences.
  - e. **Lack of training and knowledge** – concerns that there is not enough training and support to ensure ND awareness and understanding are up-to-date.
  - f. **Anxiety about getting things wrong** – this concern stretches from direct consultation/involvement of ND people in development to anxieties about not being informed enough to undertake the work needed to improve.
- 4) What were identified as priorities in a guidance toolkit for the museum sector:
  - a. **Commonly identified barriers to visiting** – to help understand what to prioritise when improving accessibility.
  - b. **How to create/plan events and resources for ND audiences** – guidance on what to prioritise when creating events and resources.
  - c. **How to involve ND people in planning** – guidance on how to meaningfully involve neurodivergent people in developing resources and events.
  - d. **Information and training on neurodiversity** – to help improve general understanding of neurodiversity, preferred terminology, and resources.
  - e. **Common reasons for museum visiting** – to help ensure that adjustments are made to help facilitate neurodivergent people and create resources and events informed by interests and preferences.
  - f. **Other** – marketing (how to make sure ND people find out about what is being done), partnerships (how to make and maintain partnerships with the ND community and other organisations), guidance on supporting ND colleagues, and guidance specifically on supporting ND adults to have positive visiting experiences.

**Any other thoughts, suggestions, or questions that you may have about the research and its findings are encouraged!**

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