

Neurodivergence and Inclusivity in Cultural Institutions: A Review of Theories and Best Practices

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Abstract

Whereas there has been increased attention paid to accommodations for neurodiverse populations in education and the workplace, the way cultural institutions—including museums, art galleries and other public collections are able to support such an audience remains understudied. The educational support afforded by law for children with autism spectrum disorders (ASD) is prescriptive and includes Individualized Education Plans (IEPs) with educators trained in providing identified intervention strategies. At the same time, there have been no such agreed upon strategies to support the same population in public educational spaces, especially later in life as adults, who often go undiagnosed. This study seeks to reconsider the role of cultural institutions in serving the neurodiverse population beyond childhood and provide practical strategies to address their needs. Through programs that include staff training and programming that goes beyond "sensory days," institutions can ensure that the educational opportunities afforded by their collections can support greater inclusivity and diversity.

Keywords

Neurodiversity, Museums, Art Galleries, Cultural Institutions, Autism Spectrum Disorders (ASD), Autism, Accessibility

1. Introduction

The American Alliance of Museum (AAM) has commissioned research into the state of inclusivity efforts among institutions and the attitudes of museum goers and the public at large (2020). In developing strategies, including primers for museum professionals to use, AAM has attempted to address efforts for greater

diversity, equity, accessibility, and inclusion (DEAI). Such strategies attempt to expand museum-going audiences beyond the largely white and affluent, and present perspectives and experiences representative of society at large. At the same time, as these DEAI efforts gain support and are celebrated within museums and collections, the appeal for incorporating neurodiverse support is lacking the same momentum. In fact, strategies provided in primers do not even touch upon neurodiversity as a consideration (AAM, 2020).

Cultural institutions have a mandate to serve the public and strive to create environments which are accommodating, engaging and supportive for those in their community. While strides have been made towards inclusivity with regards to race, ethnicity, religion, culture, gender, and physical disability, there is still a portion of the population overlooked (Andermann & Arnold-de Simine, 2012; Pohawpatchoko, Colwell, Powell, & Lassos, 2017; Ariese & Wróblewska, 2022). According to the Centers for Disease Control and Prevention (CDC), 1 in 44 children are diagnosed with autism spectrum disorders (ASD), making the population one of the largest among those with disabilities and resulting in a large portion of the public being underserved (2022). Moreover, there is a lack of available statistics for those who may have or go undiagnosed with ASD beyond adolescence, especially in adults, which further illustrates the fact that the research on how to support adults with similar disabilities has yet to come to receive appropriate attention (Lai, Lin, & Ameis, 2022; Wigham, Ingham, Le Couteur, Wilson, Ensum, & Parr, 2022). This population may be larger than anticipated due to "camouflaging" or "masking" as a learned behavior in adults with ASD (McDonald et al., 2022). The behaviors and strategies associated with camouflaging, as the term suggests, mask the visible symptoms of ASD, especially in social contexts, in order to appear "non-autistic" (McQuaid, Lee, & Wallace, 2022). The practice makes later diagnosis even more difficult, especially if individuals do not exhibit co-occurring intellectual disability (de Broize, Evans, Whitehouse, Wray, Eapen, & Urbanowicz, 2022). Therefore, the potential audience served by museums and cultural institutions likely has an even larger portion that requires additional considerations for accessibility.

Museums have a unique opportunity to create environments which are friendly for those on the spectrum and promote the importance of inclusive access to education for all in their community. In order to better support this museum-going group, professionals in cultural institutions need to be educated on the features of ASD and their symptoms. An individual with autism spectrum disorder is classified as having neurodevelopmental difficulties, which may include autism, ADHD, ADD and dyslexia as the most common co-occurring diagnoses (CDC, 2022). Given the range of intellectual and social abilities exhibited by the population, the diagnosis is referenced using the term spectrum disabilities given the range on which they may manifest. Neurodiversity was first coined by sociologist Judy Slinger, who advocated for looking at the category, not as something that needed correcting, but as a "state of nature to be respected, an analytical tool for examining social issues, and an argument for the conservation and facilitation of human diversity" (Deakin, 2022). Regardless, there are physiological considerations for those with ASD when designing experiences, such as exhibitions. For instance, those who self-identify or are diagnosed may find museums challenging environments to adapt to with changing intensity of lighting, unexpected audio, and crowded and/or confusing environments (Nisticò, Faggioli, Tedesco, Giordano, Priori, Gambini, & Demartini, 2022). These sensory sensitivities not only deter neurodiverse individuals, but their families due to the physiological discomfort, and resulting social behaviors, such experiences cause. With recent studies revealing that 44% - 52% of those diagnosed with autism have learning difficulties, once they overcome the difficulty of simply adapting to their environments, understanding the information presented is an additional hurdle (Madge, 2021; Giri, Aylott, Giri, Ferguson-Wormley, & Evans, 2022; Mammarella, Cardillo, & Semrud-Clikeman, 2022).

In order to expand the research on how best to support neurodiverse audiences for museums, art galleries and other public collections, this study seeks to provide a review of the literature on the theories and best practices through the present. In this review, practical strategies will be presented for professionals to address a range of considerations when it comes to serving a neurodiverse audience. Recommendations include guides specific to the audience that encourage individual exploration, sensory sensitivity materials, and specially curated audio guides.

2. Literature Review

2.1. Children's Museums

Early efforts to support audiences with autism spectrum disorders focused on children (Hladik, Meyer, Allen, Bonnici, Froelke, Romaniak, & Ausderau, 2022). Children's museums have long been studied as ideal institutions for informal learning in children under the age of 10 years. These organizations provide children with an open environment in which interaction is possible with each other and a wide variety of learning materials and subject matters (Jeffery-Clay, 1998). The manner in which learning is accomplished is also ideal for the discussion at hand since children's museums are designed to support hands-on, open-ended, and sensory rich activities and learning, which can support a variety of learning styles in participants. With such potential for a wide range of learners, children with ASD may still be prevented from visiting such museums due to sensory considerations, such as large crowds, unfamiliar lights, smells, and sounds, as well as staff that are untrained in facilitating learning for the group (Hladik & Ausderau, 2022). Growing awareness of the needs of the ASD population has led many institutions to develop strategies that include special hours, sensory kits, accessibility events, and staff disability awareness training to improve the experience (Jenson, Lee, Day, Hughes, Maroushek, & Roberts, 2022; Fletcher, Wiskera, Wilbur, & Garcia, 2022).

2.2. Staff Training Programs

While children's museums offered the first proving ground for these techniques, cultural institutions in the United Kingdom began expanding them into regular programming for adult populations, as well. One of the first practices implemented aligned with that designed for school-age audiences, and that is extensive staff training programs (Theriault & Ljungren, 2022). This includes efforts of autism awareness and "empathy training for staff [which] not only enables them to better help children with ASD but improves interaction experiences with all patrons" (National Autistic Society, 2022). By being proactive in how to respond to groups that need accommodations, public facing positions such as docents and visitor services staff can anticipate issues and how to assist parents within the facilities. Simply reaching out to The Autism Society or local communities' support to ask advice or assistance opens the door to building trust and proves that an institution wishes to take part in the discussion (Kotowski & Zybert (eds.), 2020). Training staff to both recognize and interact with neurodiverse individuals includes becoming familiar with possible physical attributes (such as limited eye control, use of stemming techniques such a physically self-soothing through rocking and repetitive gestures) and being aware of their difficulty understanding non-direct language (Sheply & McGinnis, 2020). Some institutions have also enlisted the assistance of local universities for hiring staff already trained in extensive accessibility knowledge when the ability of funds for on-site training is not possible. The modern museum communities' altruistic inclinations do include the availably of training materials shared online to lead by example (Kennedy, 2006; Restrepo-Harner, Marsico, & Kerr, 2021; Ghadim & Daugherty (eds.), 2021).

2.3. Sensory Maps

Along with preemptive preparation for guests with staff training, another effective support for visitors with ASD is the creation and dissemination of visual stories or sensory maps that may be viewed before arrival. Sometimes referred to a "social stories" (which is a term trademarked by Carol Gray in 1991), visual stories or sensory maps refer to the overarching "descriptions of a particular situation, event or activity, which include specific information about what to expect in that situation and why" (Gray, 1998: p. 168). By removing the unknowns of a new place, individuals can preemptively seek comprehensive pre-planning to reduce anxiety, which not only benefits the individual but reduces stress for the entire visiting family. Maps may be downloaded onto devices or printed prior to a visit, such as the Sensory Friendly Map of the Metropolitan Museum of Art

(https://www.metmuseum.org/-/media/files/events/programs/progs-for-visitorswith-disabilities/sensory-friendly-map.pdf). These sensory maps highlight possible crowded areas and/or identify more congested times, galleries which are particularly bright or dim, or instances where there is a dramatic shift in lighting also aid in this effort. Short videos showing the space or a visual story which illustrates all important information such as stairs, lifts, bathrooms, parking, and exits are also valuable tools.

For many, the use of virtual galleries to prepare visitors for the space before visiting the museum not only informs people of possible individualized areas of concerns, but also allows for identifying smaller galleries which are more likely to feel cramped for those with difficulty processing spatial issues (Kotler & Kotler, 2007). Some institutions like the British Museum have gone a step further and included additional information such identifying areas with strong smells, the appearance of entrance and exits, common attire for uniformed staff and listing possible activities taking place in the museum to allow the ability to opt out of large event days

(https://www.britishmuseum.org/sites/default/files/2019-11/British-Museum-Se nsory-Map-PDF-Download.pdf). Even understanding which exhibitions shops have placed at the end is helpful as some individuals find these occurrences difficult to navigate unprepared. According to The Euan's Guide to Access Survey 2017, "95% of respondents sought disabled access information about a venue prior to visiting for the first time" with 85% of that being done through the site's website (Madge, 2021; Euan's Guide, n.d.). Being conscious of this demand allows for valuable peace of mind for those affected, along with the comfort of their families, making the visit more likely and successful.

2.4. Sensory Days

Unfortunately, the most common attempt at inclusivity in museums for ASD currently centers around sensory days. These include early open events and/or special extended hours to help minimize crowds and create a more relaxed experience (Fletcher et al., 2022). With a focus on calmer environments, theses can include sensory hours where lights are dimmed and reduced noises for those with sensitivity to sound levels and reverberation--including shutting off hand dryers in the restrooms, reducing volume of interactive features or stopping audio that is triggered by movement. At the same time, there is growing criticism for these "token" autism inclusion days which tend to coincide around April 2, which is World Autism Awareness Day (Matson & Boisjoli, 2009). Considering the origins of the day beginning in 2007 were centered around well-intentioned parents and medical professionals who chose to align activities around "cures" and "combat" messaging, instead of feeling included in the space, the restriction or invitation to be allowed in off-hours reversely encourages seclusion. This coupled with the outdated use of the puzzle piece symbols to reference ASD efforts is emblematic of something being missing, i.e. their ability to function "normally." These shifts in choice of language and associations can be difficult for institutions to navigate if they are not already active in these discussions with their autistic communities (Praslova, 2022).

2.5. Identification Matters

In recent studies, neurodiverse adults' preferences include the use of identi-

ty-first language vs the previous use of person first and disability second (person with autism) (Vivanti, 2020; Botha, Hanlon, & Williams, 2021). The change in identifying language coincides with other marginalized communities wishing to reclaim their identity (Fraser, 2022; Williams, Foulser, & Tillman, 2022). Another instance is the selection of the infinity or butterfly instead and in the color of gold, multicolor, red, or tan (Praslova, 2022). These colors are favored over the use of blue, which is associated with the "light it blue" fundraising campaign for a cure and perpetuates the stereotype that autism is four time more common in boys than in girls, leading to less female diagnoses (CDC, 2022). Some research suggests that the issue with current museum ASD efforts is their origin being specifically created for children, from the perspective of neurotypical or "allistic" (non-autistic) parents. As a result, "the resulting activity is exclusionary and extremely limited. It has a focus on quiet hours, segregated activity, and provision which is other than the normal museum delivery" (Reilly, 2022). The use of time specific events is also counterintuitive to museums' free-choice informal learning experience. Removing times slots would instead help the stress of feeling rushed and allow the benefit of processing the experience in neurodiverse visitor's own time. While providing special sensory hours is important, it should not be the first step towards sensory inclusion. The goal of a positive museum program should be inclusion within regular operations and limited time events should be considered as a secondary add-on (Hladik et al., 2022).

3. Recommendations

The next step beyond exclusive events is more integrated programming inside the collections. After staff have been trained, they are better able to greet and anticipate the needs of ASD individuals visiting their collections. For those with social anxiety issues, stopping at the information center may be too overly welcoming and those visitors miss out on knowing about additional assistance, such as accessing audio guides or printed materials. Individuals must first feel comfortable enough in the environment to approach a front desk to learn about available tools to assist with their visitor experiences, which has been born out in other populations (Li & Ma, 2022; Sullivan-Baca, Babicz, Choudhury, & Miller, 2022). These available materials to support their comfort levels can include:

- **Checklists** to encourage highlights and independent exploration activities. This can include the use of Scavenger hunts over traditional lengthy tours as ASD individual tend to prefer zoning in on specific information;
- Sensory backpacks including items such as headphones (known as ear defenders in the UK), weighted lap pads and sensory toys (fidget devices, dark or colored lens/glasses, flashlights, magnifying glasses);
- Additional instructional material which clearer word choices, possibly including picture exchange communication systems (PECS) symbols materials. Clear identification of what is ok to touch, identification of off limit areas or identification of how to recognize which areas are not meant to be touched.

Acknowledgment of some unwritten museum rules like what is allowed to be touch;

• Audio guides have an added benefit of helping those with visual impairment and those with learning difficulties such as Dyslexia.

As those on the spectrum experience the world in different ways, it is important to know "some seek out sensory stimulus, whilst others avoid it" (Madge, 2021). Dedicated quiet spaces or sensory rooms are essential to allow regulation from overstimulating environments. Regulation areas create an environment of quiet with the reduction of unnecessary visual or auditory distractions and allows for a more inviting learning environment (Johnson, 2022). By design, museum spaces are often open floor plan in which sounds can echo and light can be magnified through windows combined with florescent lighting. Areas with minimal stimuli are valuable not only for reducing anxiety in ASD children and their parents, but for adults who have sensory issues but do not self-identify with being on the spectrum (Eckersley, Vos, Szymańska-Matusiewicz, Głowacka-Grajper, Wawrzyniak, Mears, & Davenport, 2022). For institutions with limited space, small museums have found success in adding the option of outdoor areas with portable tents outfitted with cushions, shaded lighting and the forementioned sensory materials. For those with smell sensitivity and/or sites where the regular café has ventilation issues, pop-up outdoor picnic areas allow those who find the noises and smell of cafes too overwhelming (Gurian, 2001).

Lastly, creating exhibits that are easy to follow and incorporate minimally invasive interactive experiences allow ASD visitors the opportunity to experience the exciting, but not overwhelming benefits of visiting collections. Directions with clear choices of options to see and using signage with visual cues on to what to do in facilities by including tape arrow or "stop and go" signs, allow for easier direction through exhibits. Lighting needs to be considered for direct placement only on items instead of in the viewer's direct sight line and be conscious of limiting changes in intensity of lights. Proper ventilation to minimize smells and using music at a volume where the environment is of a calming nature are also important considerations for ASD inclusivity. Limiting the use verbose, indirect and/or academic language and minimizing extended written blocks is more manageable for those who have difficulty concentrating and paying attention over long periods of time. Offering fidget and sensory toys helps neurodiverse individuals stay grounded and assists with focus during tour visits but are only effective if visitors know that they are available, and staffs are trained to understand why these tools are important (Eichenlaub, 2022).

Cultural institutions are becoming more conscious of their capacity to create truly inclusive and inspiring environments, but there is plenty of work still to be done (Shaindlin, 2020). Though well intentioned, the idea of being segregated to a specific time and day alienates those from being included within neurotypical society. Those who are incorporating greater emotional support in their sensory days with activities such as art and music therapists, are leading the way to helping mental wellness within the museum walls. Cultural institutions reflect

the communities they serve and by just going through this process of creating greater awareness, empathy and understanding in their staff, they are also creating a better staff culture by valuing other's perspectives (Richardson & Kletchka, 2022).

One recommendation gaining traction is the opportunity for exclusive curator access and having individualized staff at core educational stations. This allows the opportunity for individuals to ask questions in a small, localized environment, which not only helps those with social, learning and communication issues, but creates a space where people who find themselves situationally mute or nonverbal can be included in the educational experience. American institutions should consider incorporating the United Kingdom sunflower lanyard schemes which allows families with disabilities access out of a que and individualized assistance. The option to wear a familiar ASD symbol helps identified those who may need more assistance, but unable to voice the self-advocacy to do so.

As museums acknowledge the need to implement strategies to help those interact with collections in a more emotional and mentally comforting experience, the use of virtual galleries is a key area to help people familiarize themselves with cultural facilities. While many universities are expanding their Virtual Reality and 3D mapping technologies, there is an untapped education partnership to help museums virtually share their spaces and connect to the local student population. Reaching out to local community groups is a necessary step to allow ASD voices to be heard, and even collaborate in a way where both partners can benefit. Universities can also assist with helping to train staff and present new perspectives with the quickly changing social media culture. Having inclusive spaces with sensory tools aids is only effective if staffs understand how to use them properly and are educated to help identify those they could serve.

4. Conclusion

Simply supporting or teaming up with those who are doing the work to support ASD understanding helps build trust within the community which can lead to positive visitor experience and increase community attendance. The shift to inclusion and diversity has altered the overall view of disabilities from something to be fixed, into another unique perspective available to be shared. Yet there is still a disparity in exhibitions which reflect autistic experience through their own talents and expressive capabilities. Institution recommendations moving forward include the integration of autistic voices. This includes encouraging employee volunteers before hiring outside speakers in public, overhauling outdated exhibits by the integration of interactive audio and visual displays and enlisting the help of ASD communities' support. Lastly, by including works by those with disabilities, collections can create an inclusive environment which is rich in understanding and acceptance. Museums' integration of neurodiverse voices can amplify the strength and vibrance of autistic culture and help shift societal views on autism toward positivity.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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