

“BUT YOU DON’T LOOK LIKE MY AUTISTIC CHILD”  
ACCOMMODATING THE WIDELY IGNORED NEEDS OF AUTISTIC ADULTS  
AT HISTORIC SITES

by

MADELEINE MARKLE

(Under the Direction of Katie Marages)

ABSTRACT

It is widely assumed by the public that autism is a disability that mainly impacts children. This is not true. The Center for Disease Control estimates that over 2% of the American adult population is autistic. Historically, autism advocacy has prioritized the needs of autistic children and their caregivers. As a result, the needs of autistic adults have been largely ignored and even suppressed. Most historic sites do not provide adequate access to autistic people, despite a federal mandate to do so. Those that do, center the needs of autistic children and their families over adults. A child-focused accessibility approach at historic sites fails to address a population that accounts for more than 168 million people. Historic sites must begin to respond to the growing demand for autistic access as autistic adults become more visible in society, and more aware of their right to accessible space.

INDEX WORDS: Historic preservation, Historic site, Accessibility, Autism, Autistic adults, Disability, Universal design, Accessible design.

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## DEDICATION

This thesis is dedicated to Mary Katherine Keller, my favorite autistic person, who permanently altered the course of my life by pointing out my own autistic traits.

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## CHAPTER 1

### INTRODUCTION

#### Purpose of the Study

In the spring of 2023, I visited the Nathaniel Russell House with my graduate school cohort. I am obsessed with the historic built environment and am enrolled in a graduate program in historic preservation. On paper, I am the perfect audience for a historic site tour. Or, I should be. My experience at the Nathaniel Russell House was unpleasant. The rooms were too crowded, and I was anxious that someone would accidentally bump into me. No one had told me how long the tour would be or which rooms we would enter. I felt unsure as to where in the cramped rooms I should stand. Was I too close to the antique furniture? I couldn't parse if the guide was asking rhetorical or literal questions, so I resigned myself to saying nothing the entire tour. Most of the time, I couldn't make out what the guide was saying at all because of my auditory processing issues. I felt like I would be trapped in historic house museum purgatory indefinitely. I left the tour feeling incredibly frustrated. If I truly love historic houses, shouldn't I enjoy visiting them?

After the trip, I took some time to reflect on why I disliked my visit. It is well known that historic sites can be boring, pretentious, and completely disconnected from the concerns of modern people. For me, however, I found that my personal problems with historic sites are all connected to my autism. I find the social expectations around historic sites mystifying. I despise not knowing what will happen next on the tour, and the small spaces packed with people make me want to scream. I have embarked on a journey to discover how historic sites can improve the experience of autistic adults like myself. If I, a historic preservation student, am struggling to enjoy myself at historic sites, it stands to reason that other autistic people are struggling too.

Many of the accommodations that I would appreciate at historic sites improve the experience of many different visitors, not just those with autism. Accommodating autistic visitors has the potential to improve the experience of those who have other disabilities, language barriers, younger people, the elderly, and even your hypothetical average person who is having an off day and might want some respite from the overwhelm of the modern world. Caring about autistic people and the struggles they face allows us to recognize the ways in which we all could use accommodations from time to time. Acknowledging the needs of disabled historic site visitors has the potential to open up a broader conversation about how historic sites can be improved for all people.

Historic sites rarely take steps to accommodate autistic visitors in a meaningful way, and when they do, the needs of autistic children are prioritized at the expense of autistic adults. Research into adult autism is relatively new, and in many cases, adult autism is an invisible disability. Autistic adults are not given the same support that is given to autistic children. There is little information available to preservationists on how to accommodate autistic adults. The limited information that does exist is tainted by decades of misinformation. Preservationists fear that autistic access could threaten the historic fabric of sites or create an unnecessary financial burden, but I have found that these fears are mostly baseless. Autistic access tools rarely require a physical intervention and do not need to be costly. As autistic adults become more visible in society, it will become increasingly important that preservationists consider how this audience can be made more comfortable at historic sites. In my work I aim to identify the perceived challenges faced by historic sites when accommodating adult autistic visitors and propose solutions. My hope is that these solutions can enhance the historic site experience for everyone in some way, not just autistic people.

## Disability and Accessibility

The concept of disability is broad and encompasses many identities. As of 2021, 13% of Americans identified as disabled.<sup>1</sup> The Center for Disease Control defines disability as “Any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).”<sup>2</sup>

Disability has existed as long as humans have existed. There is archaeological evidence that physically and cognitively disabled people were part of everyday life in ancient times.<sup>3</sup> Disability scholars have identified passages of ancient Hebrew, Greek, and Roman texts that acknowledge the existence of cognitively disabled people.<sup>4</sup> During the 19th and 20th century there was a marked effort by public officials to remove disabled people from public life. Disabled people were institutionalized, forcibly sterilized, and banned from immigrating to the United States.<sup>5</sup> These practices continued well into the 20th century. As late as the 1970s, many U.S. states, including Georgia, still had sterilization laws on the books.<sup>6</sup>

The modern disability movement in the 1990s began to change the way that society engaged with disabled identities. Modern-day disability advocates promote the social model of disability, which proposes that the limitations on disabled people result not from the bodies and

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<sup>1</sup> Rebecca Leppert and Katherine Schaeffer, “8 Facts about Americans with Disabilities,” Pew Research Center, July 24, 2023

<sup>2</sup> CDC.gov. “Disability and Health Overview,” n.d. [https://www.cdc.gov/disability-and-health/about/index.html#:~:text=A%20disability%20is%20a%20condition,around%20them%20\(participation%20restrictions\).](https://www.cdc.gov/disability-and-health/about/index.html#:~:text=A%20disability%20is%20a%20condition,around%20them%20(participation%20restrictions).)

<sup>3</sup> Debby Sneed, “The Architecture of Access: Ramps at Ancient Greek Healing Sanctuaries.” *Antiquity* 94, no. 376 (July 21, 2020): 1015–29. <https://doi.org/10.15184/aqy.2020.123>.

<sup>4</sup> Edgar Kellenberger, 2011. *The Protection of the Simple-minded- People With an Intellectual Disability in the Bible and in Other Sources*. Theological Publishing House Zurich.

<sup>5</sup> Douglas Baynton, *Defectives in the Land: Disability and Immigration in the Age of Eugenics* *Journal of Social History* 51, no. 4 (2018): 1117–19. <https://www.jstor.org/stable/26804121>.

<sup>6</sup> Elizabeth Hargrett, "Eugenics in Georgia." *New Georgia Encyclopedia*, last modified Aug 21, 2019. <https://www.georgiaencyclopedia.org/articles/government-politics/eugenics-in-georgia/>

minds of disabled people but from the design of a physical and social environment that favors a normative ideal. The modern disability movement has also taken steps to acknowledge ableism and disability justice. Ableism is the systemic prejudices that reinforce the commonly held belief that disabled people are inferior to able-bodied people. Disability justice is an access approach that prioritizes the needs of disabled people who have intersecting marginalized identities. This includes disabled people who are also people of color, gender minorities, LGBTQ, or low income.

The social model of disability was developed as a critique of the medical model of disability. The medical model frames disability as a problem that resides within the individual. The medical model is rooted in Darwinism and the study of human development. It assumes that there exists one natural, normative human body. The normative body is able-bodied, white, middle class, male, heterosexual, and cisgender. All other bodies are held up against the normative ideal, and any deviation from the norm is viewed as the moral failing of the individual who possesses the non-normative body. Any deviation from the “norm” can be classified as a pathology under the medical model. The medical model seeks to remediate the “flaws” of the non-normative body through medical intervention, therapy, and education. The field of human development has encouraged parents and doctors to search for the signs of the non-normative body in children and to intervene as soon as possible.

The idea of the non-normative body begins to fall apart when we consider how it only exists in relationship to a constructed ideal. The normative body is not natural at all. It is a socially created falsehood that is artificially constructed and exists to uphold existing systems of power. The normative body is a set of developmental averages blended with cultural ideals. It says little about objective scientific truth, but it does reveal what our society values and fears.<sup>7</sup>

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<sup>7</sup> McGuire, *War on Autism*, 2016. <https://doi.org/10.3998/mpub.7784427>.

The social model views disability as a condition that arises not from the individual, but from the physical environments and social structures that we all live within. The social model recognizes that most bodies are not like that of the constructed ideal, and that the category of non-normative only exists if we continue to artificially create the category of “normal” for the benefit of a select group of people. The social model of disability promotes fighting for accommodations for disabled people, instead of treatments for disabled people.<sup>8</sup> Under the social model there are no bodies that fail to measure up, there are only systems that have failed to accommodate more than one type of body.

Disabled people first gained basic legal recognition in the United States in 1990 when Congress passed the Americans with Disabilities Act (ADA). Under the ADA all “areas of public life,” whether or not they are federally owned or funded, must be made accessible.<sup>9</sup> This includes physical and programmatic access.<sup>10</sup> The disability advocacy movement has seen significant growth over the last thirty years, but there is still much work to be done. The ableist attitudes of the 18th and 19th centuries still influence how our culture views disability. For example, as of January of 2022, 31 states and Washington D.C. still allow the forcible sterilization of disabled people.<sup>11</sup>

To understand the ADA, we must first investigate what accessibility means. Tanya Titchkosky defines access as “a way people have of relating to the ways they are embodied as

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<sup>8</sup> Allison Carey, Pamela Block, and Richard K. Scotch. "Sometimes allies: Parent-led disability organizations and social movements." *Disability Studies Quarterly* 39, no. 1 (2019).

<sup>9</sup> Americans with Disabilities Act of 1989, Public Law 336, U.S. Statutes at Large 104 (1990): 327-378

<sup>10</sup> Nicole Belolan, “Disability History.” *The Inclusive Historian’s Handbook*. January 3, 2014. Accessed January 7, 2025. <https://inclusivehistorian.com/disability-history/>.

<sup>11</sup> Autistic Women and Nonbinary Network. 2022. “Forced Sterilization Laws in Each State and Territory.” *National Women’s Law Center*.

beings in the particular places they find themselves.”<sup>12</sup> Embodiment in this context refers to how our physical being interacts with physical space and the social environment. All people require physical, social, sensory, and cognitive access to space to be the most fulfilled version of themselves. Access is how we are enabled or limited by physical and social environments. Accessibility is the act of enabling an environment's participants to be as fully embodied as possible in a particular space.

The ADA defines a disabled person as “a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.”<sup>13</sup> Historically, disabled people have not been allowed to be fully embodied in space because the physical and social environment is designed for able-bodied people. In 1990, Congress found that disabled people had been kept out of public spaces and private businesses because they were not given reasonable accommodations that would allow them to use the space in the same way as an able-bodied person.

Under the ADA, private and public spaces must allow the participation of all people regardless of physical or cognitive ability. The participation that is afforded to disabled people must be equal and not separate from the participation that is afforded to able-bodied people and must take place in the most integrated setting possible. This means that reasonable accommodations must be made for disabled people so that they may access space in a way that is equal to how their able-bodied counterparts access space. A failure to provide such reasonable

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<sup>12</sup> Tanya Titchkosky, *The Question of Access: Disability, Space, Meaning*, 2011. <http://ci.nii.ac.jp/ncid/BB08107814>.

<sup>13</sup> ADA.gov. “Guide to Disability Rights Laws,” December 19, 2024. <https://www.ada.gov/resources/disability-rights-guide>.

accommodations is considered discrimination. In a legal context, “reasonable” means rational, ordinary and appropriate.<sup>14</sup> What qualifies as rational, ordinary, and appropriate is subjective.

The ADA says discrimination can look like “a criteria for participation that screens out disabled individuals or failure to make reasonable modifications to policies, practices, and procedures.” It also includes “a failure to remove architectural barriers, and communication barriers that are structural in nature, in existing facilities, and transportation barriers in existing vehicles and rail passenger cars used by an establishment for transporting individuals.”<sup>15</sup>

Is autistic access a protected right under the ADA? In practice, not fully. The ADA primarily concerns physical access and largely ignores cognitive access and sensory access. Clouse and Wood-Nartker claim “(ADA) guidelines have not addressed the needs of people with mental, emotional, and/or developmental disabilities.”<sup>16</sup> There is no agreed-upon legal definition of autism or what presentations of autism are considered a disability.<sup>17</sup> The DSM-5 manual, a diagnostic tool published by the American Psychiatric Association, is not considered legal material, but it may be used as supporting material in legal cases. The DSM-5 is a set of guidelines that are up for interpretation, not a cut-and-dry set of rules. Who qualifies as autistic is up to individual psychological practitioners, not the DSM-5.<sup>18</sup> Therefore, it is unclear which autistic people have protections under the ADA. Presumably, diagnosed autistic individuals

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<sup>14</sup> LII / Legal Information Institute. “Reasonable,” n.d. <https://www.law.cornell.edu/wex/reasonable>.

<sup>15</sup> Americans with Disabilities Act of 1990.

<sup>16</sup> Joslin R. Clouse, Jeanneane Wood-Nartker, and Franklyn A. Rice. “Designing Beyond the Americans With Disabilities Act (ADA): Creating an Autism-Friendly Vocational Center.” *HERD Health Environments Research & Design Journal* 13, no. 3 (December 30, 2019): 215–29. <https://doi.org/10.1177/1937586719888502>.

<sup>17</sup> Julie Fogt, David N Miller, and Perry A Zirkel. 2003. “Defining Autism: Professional Best Practices and Published Case Law.” *Journal of School Psychology* 41 (3): 201–16. [https://doi.org/10.1016/s0022-4405\(03\)00045-1](https://doi.org/10.1016/s0022-4405(03)00045-1).

<sup>18</sup> Fogt, Miller and Zirkel, *Defining Autism*.

would have protections, but not every autistic person has an autism diagnosis. Autism has historically been underdiagnosed in people who do not present as white and male.<sup>19</sup>

Autistic access can be skirted at historic properties because it is not an easily definable or identifiable physical disability. The ADA would say that reasonable accommodations should be made for those with a mental disability, but who gets to decide what a “reasonable” accommodation is? As we have established, what is “reasonable” is subjective. Another issue is that some people do not consider certain presentations of autism a disability at all, which can limit autistic people's access to resources, funding, and legal protections.

In 2000, Simon Baron-Cohen argued that “high-functioning autism” (today, classified as ASD-1), is a difference, not a disability, and that autism is only a disability when a person is “low-functioning.”<sup>20</sup> Baron-Cohen ignores that there is no clear way to decide who is a “low-functioning” autistic person. He also forgets that many “high-functioning” autistic people self-identify as disabled regardless of what he personally thinks. Today, the autistic community largely rejects functioning labels altogether. According to the social model of disability, disability results from a world that is designed for a normative ideal, not from the body or mind of the disabled person. Baron-Cohen agrees that the social world is a barrier to autistic people, but says that a person with ASD-1 would not be disabled if the social world were different. However, we do not live in Baron-Cohen’s hypothetical world where the environment is designed with autistic people in mind.

Baron-Cohen's insistence against the disability label leads me to suspect that he has fallen into the trap of trying to distance disabled people from their disability in order to protect them

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<sup>19</sup> Bethany Driver, and Verity Chester. "The presentation, recognition and diagnosis of autism in women and girls." *Advances in Autism* 7, no. 3 (2021): 194-207.

<sup>20</sup> Simon Baron-Cohen, “Is Asperger Syndrome/High-Functioning Autism Necessarily a Disability?” *Development and Psychopathology* 12, no. 3 (2000): 489–500. <https://doi.org/10.1017/S0954579400003126>.

from stigma. The problem with ignoring disability is that it doesn't reduce stigma, it ingrains it. I, and many other 'high-functioning' autistic people are not afraid to identify with the disability label because we do not view disability as a failing. To me, disability is a morally neutral label that helps describe my relationship to my environment. If we jump through hoops to avoid calling people disabled, then we are admitting that we view disability as a personal failing.

The reality of life for most autistic people is that the world is designed in a way that limits their ability to be fully embodied. Autism should be accepted as a disability because a person with autism does not have a mind that matches what the broader culture would identify as normative. The physical and social environment of American life is not designed to accommodate autistic minds, therefore autistic people are disabled by an environment that is not for them. I would argue that autism is a disability when we take the social model into account, but I also respect the choice of individual autistic people who do not identify with the disability label since this is a very personal subject. When people like Baron-Cohen insist that autism is not a disability, they risk further distancing autistic people from resources and legal recourse (such as ADA protections) as well as increasing stigma against all disabled people.

### Historic Site Accessibility

The clause in the ADA that deals with architectural discrimination has had a major impact on how public and private buildings have been built and retrofitted since 1990. The mandate to accommodate disabled people through inclusive architecture includes some historic sites. "Historic site" refers to a historic landscape, or a specific plot of land that has historic buildings, structures, or objects on it. "Historic property" refers to any historic site, district, building, structure, or object. The terms "historic site" and "historic property" are used

interchangeably when used colloquially. In this thesis, the term “historic site” will be used to encompass historic landscapes, buildings, and districts that are open to the public and have an interpretive plan. When I use the term “site” it may be assumed that I am referring to a historic site. Under Title III of the ADA, accessibility for disabled populations at historic sites is legally considered a protected civil right.<sup>21</sup> Federal, state, or local government historic designation is not what makes a historic site bound to follow the ADA. The deciding factor is not designation or government funding, it is whether the site is open to the public. A private historic home, used as a residence, does not need to meet the ADA’s accessible design guidelines, but a private historic home that is open for events and tours does.

In 1993, the National Parks Service (NPS) published Preservation Brief 32, *Making Historic Properties Accessible*,<sup>22</sup> to address preservationist’s questions about the ADA.<sup>23</sup> The NPS recommended a three-step approach to creating accessibility at historic sites. First, the historic significance of the site and its character-defining features must be identified. Second, one must determine the site’s current level of accessibility and the required level of accessibility under ADA. Thirdly, one can evaluate accessibility options within a preservation context. Accessibility options should be considered within the context of the Secretary of the Interior's Standards for the Treatment of Historic Properties, a set of guidelines and standards that the NPS developed to guide responsible preservation.<sup>24</sup> Projects seeking out federally funded tax credits must follow the standards in order to access funding. Otherwise, the guidelines are used more informally by preservationists and are treated as best practices, not as law.

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<sup>21</sup> Heather Pressman, 2023. *An Accessible Past: Making Historic Sites Accessible*. Rowman & Littlefield. 8.

<sup>22</sup> Thomas C Jester, 1993. *Making Historic Properties Accessible*.

<sup>23</sup> Pressman, *An Accessible*, 7.

<sup>24</sup> Jester, *Making Historic Properties Accessible*.

Heather Pressman, in her 2023 book, *An Accessible Past: Making Historic Sites Accessible*, proposes historic properties use a process similar to the NPS three-step process applied to historic sites to plan and implement accessible solutions. Historic sites should carry out a review of historical significance, conduct an accessibility audit, and then create a transition plan.<sup>25</sup>

Historic sites are not spared from ADA requirements, but certain exceptions can be made when physical access threatens a site's character-defining features. Most historic sites do not qualify for an exception. For a historic site to qualify for an exception, it must be listed on the National Register of Historic Places or be eligible for listing.<sup>26</sup> Barrier removal at eligible historic sites must be undertaken if it can be done "without too much difficulty or expense."<sup>27</sup> Many historic sites have considered alternatives to physical access when alterations to the property would damage a character defining feature. For example, virtual access to a physical space is a way historic sites can provide access to disabled visitors.

### What is Autism?

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that impacts about one in sixty-eight people.<sup>28</sup> This common disorder is characterized by a person's atypical cognitive pathways that may result in cognitive and physical delays. Most autistic people experience social and sensory difficulties to varying degrees.<sup>29</sup> The term "autism" appeared in

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<sup>25</sup> Pressman, *An Accessible*, 23.

<sup>26</sup> Pressman, *An Accessible*, 24.

<sup>27</sup> Pressman, *An Accessible*, 16.

<sup>28</sup> J. Nieman, (2019). "Autism Spectrum Disorder (ASD): Designing Empowering Environments for Sensitive People." *The journal of aging and social change* 9(2).

<sup>29</sup>Nieman, *Autism Spectrum*.

the 1910s and was used to describe a person who lacks social reciprocity and lives alone.<sup>30</sup> In the 1940s, Leo Kanner used the term “autism” to refer to socially different children.<sup>31</sup> The term “Aspergers” was later coined by Hans Asperger, who noticed similar social issues in young boys.<sup>32</sup> Aspergers was considered a separate diagnosis from autism until the 2010s. Since the DSM-5 was published in 2013, it has been considered a part of the broader autism spectrum.<sup>33</sup> The DSM-5 is a diagnostic manual used by psychiatric practitioners. It is the modern manual of guidelines for the diagnosis of psychiatric disorders, but it does not encompass every disorder, nor is it a substitute for practitioner discretion. The DSM-5 only deals with diagnostic criteria that are clearly measurable which limits its practical applicability. It is updated every few years to reflect changes to the field of psychiatry.

Differences in sensory processing and social behavior are common in autistic people. Autistic people will often communicate differently than their non-autistic peers in both their verbal communication and their body language. Autistic people generally respond better to language that is literal and straightforward. They also have been observed to take on a more straightforward tone compared to their non-autistic peers. These communication differences can lead to misunderstanding and unnecessary stress. In this thesis I gave particular attention to using a straightforward tone and uncomplicated language to meet the communicative and social needs of autistic people.

The autistic brain will process sensory input differently than an allistic brain. An autistic person may be hyper-sensitive, hypo-sensitive, or both. Common examples of hypersensitivity are an aversion to loud noises, bright lights, certain textures, tastes, and physical touch.

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<sup>30</sup> E. A. Zaky, (2017). "Autism Spectrum Disorder (ASD); The Past, The Present, and The Future." *Journal of Child & Adolescent Behavior* 5(3).

<sup>31</sup>Zaky, *Autism Spectrum Disorder (ASD)*.

<sup>32</sup> Zaky, *Autism Spectrum Disorder (ASD)*.

<sup>33</sup> Zaky, *Autism Spectrum Disorder (ASD)*.

Hypo-sensitivity, a lesser-known symptom of autism, is a decreased sensitivity to inputs. This can look like the inverse of hypersensitivity (e.g., not noticing loud noises, strong odors, or bright lights). Hypo-sensitivity can also present as a lack of attunement to the processes going on inside the body, like hunger cues and temperature sensing.

Because of these sensitivities, or lack thereof, an autistic person may present as sensory avoiding at times and sensory seeking at others. Autism is not simply an aversion to sensory input; it is a completely different way of interpreting sensory inputs. When we talk about the needs of autistic people, we must keep in mind that autistic people will need less stimulation in some situations and extra stimulation in others.

In *Disability Discourse*, Judy Singer writes of autistic people, "How do you include people who may need the benefits of inclusion but cannot bear the physical and emotional presence of it?"<sup>34</sup> This is the situation that many autistic people find themselves in, longing for social connection and involvement in public life but trapped in a world that is not designed for their unique social and sensory needs.

### Autism in Adults

Between 1998 and 2018, there was a 787% increase in autism diagnoses in the United Kingdom.<sup>35</sup> There is less data about rises in autism in the United States, but it is expected that this trend is not limited to the United Kingdom. Researchers in the United Kingdom have dedicated more time to studying the rise in autism than American researchers at this point in time. The demographics that saw the greatest rise in diagnosis were adults, gender minorities,

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<sup>34</sup> Judy Singer, (1999). *Disability Discourse*.

<sup>35</sup> Ginny Russle, Sal Stapley, Tamsin Newlove-Delgado, Andrew Salmon, Rhianna White, Fiona Warren, Anita Pearson, and Tamsin Ford. "Time Trends in Autism Diagnosis Over 20 Years: A UK Population-based Cohort Study." *Journal of Child Psychology and Psychiatry* 63, no. 6 (August 19, 2021): 674–82. <https://doi.org/10.1111/jcpp.13505>.

and those with perceived lower support needs.<sup>36</sup> The rise in adult diagnosis results from the broadening of the definition of autism, and a greater understanding of how autism can present in those who are not children. After the DSM was revised in 2015, a larger group of people fell under the ASD umbrella. Doctors Meng-Chuan Lai and Simon Baron-Cohen refer to this group of people as the “lost generation of adults with autism spectrum conditions.”<sup>37</sup> They define this lost generation as “people who were previously excluded from a diagnosis of classic autism.” “Classic autism” is what Kanner and Asperger would have defined as autism; a condition that only impacts young boys.

Before 1980, there was no research on how to identify autism in adults. From 1940 to 1980, autism research focused solely on identifying autism in children, and treating autistic children.<sup>38</sup> Diagnosis in adults can be challenging because many autistic adults learn to “mask” their autism over time. They develop social strategies that allow them to present “normally” due to the intense social pressure to fit in. For example, they may script out entire conversations before a social interaction, or use prepared stock phrases. Many autistic people will learn over time how to make eye contact and mimic the facial expressions and demeanor of the people around them to gain social acceptance. An autistic person who has adopted masking strategies can pass as allistic. Masking has allowed many autistic people to survive in a world that would otherwise exclude them, but it has also caused their invisibility. High-masking autistic individuals may still need support but are unable to access it if society views them as “weird” allistic people rather than autistic people.

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<sup>36</sup> Russell et al., *Time Trends*.

<sup>37</sup> Meng-Chuan Lai, and Simon Baron-Cohen. “Identifying the lost generation of adults with autism spectrum conditions.” *The Lancet* 2, no. 11 (November 2015).

<sup>38</sup> Baron-Cohen and Lai, *Identifying the Lost*.

Autism has a high comorbidity with other psychiatric and physical disorders that appear in adolescence and adulthood: 50% of autistic people have anxiety, 50% have depression, 30% have obsessive compulsive disorder, and 40% have attention deficit disorder.<sup>39</sup> This further complicates the issue of diagnosis. Many autistic teens and adults will be misdiagnosed with another disorder that is not the underlying cause of their mental and physical health challenges.<sup>40</sup> Because of the lack of research around autistic adults, masking strategies, and misdiagnosis, specialists frequently fail to identify autism in adults, hence the “lost generation.”

Rates of autism in adults are rising, but this is not because more people are becoming autistic. It is because more people are becoming aware that they were autistic the entire time. Masking behaviors can become so automatic to how an autistic person functions that their autism is not only hidden from others but also to themselves. Many adults who received an autism diagnosis later in life report that they did not suspect they were autistic because they did not identify with the stereotypical descriptions of autism.

### Language

The words that we choose to describe disabled people change frequently and are not always agreed upon. Many people within the disabled community disagree on what language is appropriate to use. The autism community is no exception. Some autistic people dislike the term Aspergers because of Hans Asperger's connections to the Nazi Party.<sup>41</sup> The term “high-functioning autistic” is equally as outdated because autism is no longer viewed as a spectrum of symptoms, from mild to severe, but as a cluster of symptoms that can appear in

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<sup>39</sup> Baron-Cohen and Lai, *Identifying the Lost*.

<sup>40</sup> Baron-Cohen and Lai, *Identifying the Lost*.

<sup>41</sup> H. Czech, (2018). "Hans Asperger, National Socialism, and “race hygiene” in Nazi-era Vienna." *CzechMolecularAutism* 9.

different combinations. However, it is important to note that there is no official consensus among autistic individuals regarding the most appropriate terms.<sup>42</sup> A 2020 study asked autistic people what terms they found the most and least offensive. The term “autistic” was voted both the most and least offensive label.<sup>43</sup>

The concept of neurodiversity was created by autistic scholar Judy Singer in the 1990s. According to Singer’s theory of neurodiversity, there are many ways the brain can be arranged and function. A neurodivergent person has a brain that operates in a way that is outside what most people would consider standard. Neurodivergent is an umbrella term that encompasses those with autism, attention deficit disorder, dyslexia, tourettes, bipolar disorder and epilepsy.<sup>44</sup>

Allistic is a label that refers to a non-autistic person. The term originates in a 2003 satire piece written by Andrew Main titled *Allism: An Introduction to a Little-Known Condition*.<sup>45</sup> When autistic people are described as neurodivergent, and non-autistic people are described as neurotypical, it frames autistic people as the deviant group. The word “typical” is nested within the label “neurotypical.” This implies that non-autistic people are normal, while autistic people are an aberration. Main created the term allistic to show non-autistic people that one could just as easily frame neurotypical behavior as the abnormality. These days the term allistic is used by the autistic community unironically.<sup>46</sup> When one uses the terms autistic and allistic, it does not place

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<sup>42</sup> Patrick Dwyer (2022). "Stigma, Incommensurability, or Both? Pathology-First, Person- First, and Identity-First Language and the Challenges of Discourse in Divided Autism Communities." *Journal of Developmental & Behavioral Pediatrics*.

<sup>43</sup> Czech, *Hans Asperger*.

<sup>44</sup> McGuire, *War on Autism*, 59.

<sup>45</sup> Andrew Main, 2003. “Allism: An Introduction to a Little Known Condition.” Fysh.Org. January 30, 2003. Accessed October 26, 2024. [https://www.fysh.org/%7Ezefram/allism/allism\\_intro.txt](https://www.fysh.org/%7Ezefram/allism/allism_intro.txt).

<sup>46</sup> Ruth Monk, Andrew J.O. Whitehouse, and Hannah Waddington. 2022. “The Use of Language in Autism Research.” *Trends in Neurosciences* 45 (11): 791–93.

one group above the other. It simply acknowledges that different neurotypes exist, without labeling one as normal and the other as abnormal.<sup>47</sup>

When dealing with any group of disabled people, it is important to establish whether or not to use Person First Language (PFL). When using PFL, one would refer to a disabled autistic person as a “person with autism.” PFL was developed as a way of separating a person from their disability. This was theorized to reduce stigma. Today, some view PFL as having the opposite effect. Separating a person from their disability can have the unintended consequence of stigmatizing the disability itself, which further stigmatizes the disabled person. Autistic people don't need to be separated from their autistic identity because autism is not shameful. Autism is a part of a person's personhood and should be included as an integral part of their identity.<sup>48</sup> Identity First Language (IFL) advocates promote the use of phrases like “autistic person” or “autistic individual.”<sup>49</sup>

At this moment, support for IFL is higher among autistic people.<sup>50</sup> A 2022 study showed that IFL is preferred by autistic people over PFL.<sup>51</sup> How we view autism and neurodevelopmental differences can further inform what language is the most respectful and empowering. It is important to note that not all disability communities have come to the same conclusion on the PFL v. IFL debate. While the autistic community may generally prefer IFL, this does not mean that other disability communities prefer IFL.

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<sup>47</sup> Monk, Whitehouse, and Waddington, *The Use of Language*, 792.

<sup>48</sup> Devon Price, *Unmasking Autism: The Power of Embracing Our Hidden Neurodiversity*. Monoray, 2022.

<sup>49</sup> Patrick Dwyer (2022). "Stigma, Incommensurability, or Both? Pathology-First, Person- First, and Identity-First Language and the Challenges of Discourse in Divided Autism Communities."

<sup>50</sup> Dwyer, *Stigma, Incommensurability, or Both?*

<sup>51</sup> Monk, Whitehouse, and Waddington, *The Use of Language*, 792.

In light of the recent PFL versus IFL debate, and the preference for the term autism over Aspergers, I will be using IFL, and be referring to people with autism as autistic. I will use the word allistic to refer to non-autistic people, to avoid implying that autism is an abnormality.

### History of Autism Advocacy

To understand autism accessibility at historic sites, one must first understand the history of autism advocacy. The narrative around autism has always been one of contradictions and tensions—nature versus nurture, parents' rights versus autistic self-determination, and pathology versus acceptance.

The first tension is that of nature versus nurture. In the 1930s, psychologists Kanner and Asperger assumed that autism was an innate disease, brought about by natural causes.<sup>52</sup> Post World War Two, the naturalization theory fell out of favor because of the philosophy's connections to Nazi eugenics propaganda. After the fall of Nazi Germany, psychologists attempted to distance themselves from Asperger and Kanner by casting autism as a mental disorder caused by insufficient nurturing in early childhood. Thus, the blame for autism was placed on mothers.

The term “refrigerator mother,” popularized during the 1950s, describes an archetypal cold matriarch who does not connect with their child in infancy. The expression originated from the informal, unscientific, observations of Dr. Bruno Bettelheim.<sup>53</sup> The “nurture” theory did not reflect the realities of autistic people and their families, but it did reflect the dominant social messaging in a post-war United States. After a decade of unprecedented women's independence during the war, more scrutiny was placed on mothers to bring women back into the private

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<sup>52</sup> McGuire, *War on Autism*, 41.

<sup>53</sup> McGuire, *War on Autism*, 39.

sphere. Mothers were expected to be the ever-attentive watchers of their children, and doctors became the watchers of the mothers. Any perceived abnormality in childhood was blamed on the mother's supposed carelessness, neglectfulness, or even maliciousness.<sup>54</sup> This narrative continued until the 1960s when mothers began to respond to these baseless claims.

In the 60s and 70s, a confluence of movements brought about the second major tension in the autism narrative- pathology versus acceptance. Mothers of autistic children were fed up with the accusation that their parenting was to blame for their children's developmental disabilities. The women's liberation movement motivated mothers to advocate for themselves and their children. In 1962, the organization known today as the National Autistic Society was formed by a group of desperate parents trying to escape unfounded accusations of child abuse.<sup>55</sup> Autism Society, an American organization that still exists today, was founded in 1965 by parents of autistic children.<sup>56</sup>

To move the blame away from themselves, parents shifted the blame to the pathologies of their children. This was done through the medicalization of autism and a focus on external causes existing outside the home. The rise of awareness around environmental toxins in the 1970s led some parental advocates to believe that pollutants or vaccines caused autism. This narrative was not founded on credible research and has since been thoroughly debunked, but the debunking mattered little to some desperate parents.<sup>57</sup> The toxin narrative was too emotionally compelling! An environmental cause allowed parents to feel absolved of the guilt that they had been carrying. The characterization of autism as a disease with biomedical causes implied that autism could be

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<sup>54</sup> McGuire, *War on Autism*, 38.

<sup>55</sup> McGuire, *War on Autism*, 42.

<sup>56</sup> Camilo, "Who We Are | Autism Society." Autism Society, September 30, 2024. <https://autismsociety.org/who-we-are/>.

<sup>57</sup> Michael Davidson, 2017. "Vaccination as a Cause of Autism—Myths and Controversies." *Dialogues in Clinical Neuroscience* 19 (4): 403–7. doi:10.31887/DCNS.2017.19.4/mdavidson.

cured and, more importantly, prevented. In “War on Autism,” Anne McGuire describes the attitude that parents adopted about their children’s neurotype. “Autism was represented as a grueling cost. A life-draining epidemic. A dangerous threat. A biological problem necessitating a biological solution. An illness that needed to be stopped, cured, fixed, eliminated... Autism is not ‘someone’ it is ‘something’.” The parent is not the threat. The Autism is.<sup>58</sup>

Ivar Lovaas, a founder of Autism Society, created another advocacy group called “Defeat Autism Now.” This name exemplifies the rhetoric that surrounded autism. Autism was not just a disease to be cured; it was an enemy to be defeated.<sup>59</sup> Lovaas pioneered Applied Behavioral Analysis (ABA), a controversial behaviorist treatment for autistic children. ABA is a Pavolian system of punishments administered when an autistic person engages in behavior that is seen as deviant, such as hand flapping, info-dumping, or verbal stimming. When the autistic person conforms to the expectation of the therapist, they are rewarded.<sup>60</sup> ABA teaches autistic people, parents, and educators that autistic behaviors are shameful and disruptive.

In the 1990s and 2000s, pathologizing rhetoric and support for ABA would continue under groups like Autism Speaks.<sup>61</sup> In 2009 Autism Speaks released the film “I Am Autism.” In the film, autism is personified as a villainous intruder into a family’s formerly idyllic life. “Autism” says, “I am autism. I’m visible in your children, but if I can help it, I am invisible to you until it’s too late. I know where you live... I hover around all of you... if you’re happily married, I will make sure that your marriage fails. Your money will fall into my hands, and I will bankrupt you for my own self-gain. I don’t sleep, so I make sure you don’t either. I will make it

<sup>58</sup> McGuire, *War on Autism*, 38.

<sup>59</sup> Cassandra Crossman, 2021. “Good Autistic Advocacy Organizations Vs. Bad Autism ‘Charities.’” In *The Loop About Neurodiversity*. April 26, 2021. <https://intheloopaboutneurodiversity.wordpress.com/2019/11/28/good-autistic-advocacy-organizations-vs-bad-autism-charities/>.

<sup>60</sup> McGuire, *War on Autism*, 45.

<sup>61</sup> McGuire, *War on Autism*, 45.

virtually impossible for your family to easily attend a temple, birthday party, or public park without a struggle, without embarrassment, without pain. You have no cure for me. Your scientists don't have the resources, and I relish their desperation. I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness. I will fight to take away your hope. I will plot to rob you of your children and your dreams... I am still winning, and you are scared. And you should be. I am autism. You ignored me. That was a mistake."<sup>62</sup>

This framing of autism separates the disorder from the person. The child is not themselves if they are afflicted with autism because the autism is controlling them. The autistic child is a falsehood. The real child, the *normal* child, is still in there somewhere and can be "saved" by intervention. But what if autism isn't a disease? What if it isn't the enemy? What if autism is a neurological difference that is morally neutral? What if autism is not separate from the person? Maybe some people are just autistic and not "afflicted" by autism. There is indeed no cure for autism, but maybe there doesn't need to be.

It is important to note that some parents have resisted the biomedical model of autism and focused their advocacy on acquiring accommodations for their children rather than curing them.<sup>63</sup> However, these parents do not negate the decades of dangerous rhetoric perpetuated by formalized institutions that characterize autistic people as pitiful at best and possessed by evil forces at worst.

This leads us to the third tension of the autism advocacy movement. Up until recently, autism advocacy has been controlled by the parents of autistic children, not autistic people themselves. How can an advocacy movement represent a population without any meaningful

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<sup>62</sup> Autistic Self Advocacy Network "Horrible Autism Speaks 'I Am Autism' Ad Transcript." 2009. Autistic Self Advocacy Network. September 23, 2009. <https://autisticadvocacy.org/2009/09/horrific-autism-speaks-i-am-autism-ad-transcript/>.

<sup>63</sup> Mary Langan (2011) Parental voices and controversies in autism, *Disability & Society*, 26:2, 193-205, DOI: 10.1080/09687599.2011.544059

input from the population it purports to represent? In 2012 Jim Sinclair, an autistic self-advocate, published the pivotal essay “Don’t Mourn for Us.” In the essay, he explains what it feels like to have your identity pathologized by a group of people who claim to fight for you.

“Non-autistic people see autism as a great tragedy, and parents experience continuing disappointment and grief at all stages of the child's and family's life cycle. But this grief does not stem from the child's autism in itself. It is grief over the loss of the normal child the parents had hoped and expected to have... when parents say, I wish my child did not have autism, what they're really saying is, I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead... what we hear... (is) that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.”<sup>64</sup>

Sinclair has spoken about his advocacy experience. “...Autistic people organizing together, autistic people pursuing our own interests rather than furthering the interests of parents and professionals... were perceived as a threat.”<sup>65</sup> Autistic self-advocacy challenges the power of allistic people who control the mainstream autism conversation, and as a result it has received push back from traditional autism advocates. Autism self-advocates have had their competency questioned by allistic people who are uncomfortable with the shifting balance of power in the advocacy world. Many autism self-advocates turned to creating their own organizations because they were pushed out of traditional autism advocacy networks by allistic people.<sup>66</sup> The self-advocacy movement, led by people like Sinclair, has taken off over the last decade.

This movement prioritizes and is led by autistic adults. Instead of parents acting as a representative for their autistic children, autistic adults are given the power and self-determination to speak for themselves. The self-advocacy movement has brought more

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<sup>64</sup> Jim Sinclair, 2012. “Don’t Mourn for Us.” March 10.

<sup>65</sup> McGuire, *War on Autism*, 65.

<sup>66</sup> McGuire, *War on Autism*, 65.

attention to autistic adults as an important part of the disabled population. The rise in late diagnosis among gender minorities and people of color has also contributed to the recent awareness around autistic adults.<sup>67</sup> The contemporary autistic self-advocacy movement has adopted the social model of disability and disability justice as frameworks for understanding autism. The use of these frameworks has expanded many people's understanding of how autism can manifest in those with intersecting marginalized identities. As a result, marginalized people who wouldn't have been labeled autistic ten years ago are now being diagnosed as adults. As more adults receive an autism diagnosis, it is likely that the autistic self-advocacy movement will continue to grow.<sup>68</sup>

In the last decade, there has been a notable uptick in the number of conversations had about autistic disability programming at historic sites. However, these conversations often exclude autistic people. Autistic adults should be at the forefront of community engagement for preservation accessibility programming. Instead, the group with the loudest voice is still the parents and educators of autistic children.

### Research Question

Despite the rise in self-advocacy and autistic adult visibility over the past ten years, very little has changed at historic sites regarding autistic access. Historic sites are required to be accessible by law, but what that means beyond physical access is unclear. It is mostly up to historic sites in how they choose to accommodate autistic visitors, not the law. Most autistic access at historic sites is limited to autistic children. A child-focused accessibility approach fails to address a rapidly growing population of autistic adults. How can historic sites respond to the

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<sup>67</sup> Driver and Chester, *The Presentation*.

<sup>68</sup> McGuire, *War on Autism*, 63.

growing demand for autistic access as autistic adults become more visible in society, and more aware of their right to accessible space?

### Methodology

Before addressing parameters and methodology, some concessions need to be made. Firstly, the autistic adult population is not a monolithic group. This research cannot be generalized to every autistic person. Autistic people's needs can vary greatly depending on sex, gender identity, race, class, age, age of diagnosis, cognitive function, and upbringing. Every autistic person will have different needs at historic sites. However, this does not mean we should not try to make historic sites more accessible. As preservationists, we are responsible for accommodating autistic people at historic sites regardless of the perceived difficulties of serving a heterogeneous group. I hope this research can give preservationists at least a starting point.

I was diagnosed with autism, as an adult, in 2022. My personal experiences as an autistic person could color the outcome of my research. I hope that my personal experiences with autism will enhance the quality of the research rather than detract from it.

The field of neurodiversity studies is constantly being updated and improved. It is possible that this research could be outdated in a few years. The modern conception of autism as defined in the DSM-5 has only existed for ten years. There is limited research on how autism presents in individuals with a female gender identity, queer people, and people of color. It is likely that our understanding of autism will continue to change as autism research expands to include the experiences of historically marginalized groups.

Historic sites frequently change their accessibility programming. I have observed a high staff turnover rate at historic sites. This impacts accessibility programming. When new staff

come onto the scene, they bring their own unique take on programming and accommodations. The specific programs and accommodations that are discussed in this thesis may not necessarily reflect the reality of certain sites in even a couple years.

I will use specific historic sites as case studies to investigate how historic sites accommodate autistic adults. The identified sites are limited to historic sites that advertise their programming online and mention programming for autistic individuals or other developmental disabilities. I limited my search to sites within the United States because my preservation education is focused on the preservation practices and history of the United States specifically. I cannot speak as well to the preservation practices of other countries.

All sites are required by federal law to accommodate autistic visitors if those accommodations are asked for, therefore, it would not be helpful to look into *every* site that offers accommodations. Technically, every site offers accommodations. However, the quality of those accommodations are not guaranteed. My research is interested in sites that advertise their autism accommodations, are well known for their autism programming within the preservation or autistic community, and are clearly going beyond the vague legal mandate to accommodate autistic people.

I found case studies by using different search term combinations including “autism,” “accessibility,” “museum,” “historic museum,” “historic house museum,” “historic site,” “sensory,” and “disability.” I also referenced a database of disability programs in museums created by parent advocates.<sup>69</sup> I referenced the books *The Art of Access: A Practical Guide for Museum Accessibility* and *Programming for People with Special Needs: A Guide for Museums and Historic Sites* to identify historic sites that have notable accessibility programs. When

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<sup>69</sup> Map-project. “Museum Autism Programs Project: Listings of ASD Programs Across the US,” n.d. <https://www.museummapproject.com/>.

looking into sites, I paid special attention to what accommodations they offered, the year they began offering advertised accommodations, how their website markets accommodations, and what outside autism organizations they have affiliated themselves with.

I identified twenty sites that offer accommodations and programs for autistic visitors and actively advertise these accommodations. Out of these twenty sites, three of them were chosen as primary case studies. My main case studies are organizations that manage historic sites and historic house museums, and offer three or more accommodations to autistic adults. To see a full spreadsheet of the sites I looked into and the accommodations they advertise, see Appendix B. My chosen primary case studies are as follows: Historic Hudson Valley, Mount Vernon, and The Henry Ford Museum. I interviewed staff members at these sites who manage accessibility programs.

The Mount Vernon Estate is a historic site in Mount Vernon, Virginia, that includes the mansion and tomb of George Washington. Mount Vernon began offering sensory-friendly programming in 2018. The Estate offers social stories and sensory mornings a couple times in the fall. The Estate's sensory programming is managed by the lead specialist for family learning, Maddie Sisson. Sisson inherited this series of programming a little over a year and a half ago. Her background is in history and museum education. Sisson says that the Estate's goal is to make the history of Mount Vernon accessible to all audiences. "We want the (autistic) population to know that they are welcome here." she says.<sup>70</sup>

The Henry Ford Museum manages a historic site, house museum, and traditional museum, in Dearborn, Michigan. The Henry Ford site consists of the Museum of American Innovation, Greenfield Village, and the Ford Dearborn Truck Plant. Greenfield Village is a

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<sup>70</sup> Maddie Sisson (Lead Specialist in Family Learning at Mount Vernon Estate) in discussion with the author, October 2024.

historic site that consists of 80 historic structures that are divided into seven themed “historic districts.” The Henry Ford began offering accommodations to autistic visitors when a staff member with an autistic son suggested that the site do more to reach autistic audiences. In 2000, the site hosted their first event with the Autism Society of Michigan. The event was a train themed “Day Out with Thomas.”<sup>71</sup> The site worked with the Autism Alliance of Michigan to offer safety training for staff. A limited number of sensory events were offered until 2015. In 2015, Caroline Branden was brought on as full-time accessibility manager. In 2016, Branden published a paper in the University of Michigan's Museum Studies Programs series “Working Papers in Museum Studies” titled *Welcoming All Visitors: Museums, Accessibility, and Visitors with Disabilities*. Branden created the Michigan Alliance for Cultural Accessibility (MACA) in 2016. The MACA is a group of museum professionals who want to improve access for disabled people in Michigan’s cultural institutions. In 2020, a grant from the Institute of Museum and Library Science expanded Henry Ford’s accessibility services. After Branden took over the position as accessibility manager, Henry Ford’s autism programming increased significantly. Now, the site hosts three to four sensory events per year, and has begun to serve autistic adults specifically.

Historic Hudson Valley (HHV) is a collection of historic sites and historic house museums that are all managed under one historic trust. The sites are all within the Hudson River Valley. Last year, the organization began implementing accommodations for autistic visitors under Nicole Wallace, Director of Education. Wallace was a founder of the Bronx Children’s Museum and brings her experience in disability programming to HHV. Over the last year and a

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<sup>71</sup> “A Brief History of Sensory-Friendly Programming at the Henry Ford -- the Henry Ford Blog - Blog - the Henry Ford,” January 15, 2021. <https://www.thehenryford.org/explore/blog/a-brief-history-of-sensory-friendly-programming-at-the-henry-ford/>.

half, HHV has introduced sensory backpacks and social narratives into their sites. Wallace estimates that autistic people make up the largest portion of disabled visitors at HHV sites.

In addition to the three primary case studies, I conducted an email survey of thirteen other historic sites to gather more information about how autism accessibility is being handled at smaller sites. I conducted informal interviews with disability professionals who provide training to historic site staff. This information, in combination with historic site staff interviews, gave me a well-rounded view of how autism accessibility is currently handled at historic sites of various scales. Interview questions and email correspondences are included in Appendix B.

### Thesis Organization

The introductory chapter of this thesis aims to give the reader a basic understanding of relevant background information. It introduced the basic concepts of disability, access, autism, autism advocacy, autism in adults, and explained a historic site's legal responsibility concerning access. Chapter 2 is a literature review and critique of past works that deal with autistic access at historic sites. In Chapter 3, I will analyze case studies, survey data, and informal interviews. The data collected will be analyzed using the frameworks introduced in Chapter 1 and Chapter 2. Chapter 4 will conclude the thesis with recommendations for preservationists regarding autistic access at historic sites.

## CHAPTER 2

### Literature Review

Since the mid-twentieth century, the definition of autism has steadily broadened to encompass more people.<sup>72</sup> The increase in autism diagnoses, particularly in adults, has led to an increased awareness of how our society can work to accommodate autistic people. Autistic people deserve and need to be included in public spaces, but their social and sensory differences pose a challenge to those who design and manage public space. This chapter aims to analyze the existing literature surrounding autistic access at historic sites, and to assess whether adults are included in the current literature.

The literature reviewed makes up the body of work that is often cited by preservationists and museum professionals as influential when they are creating accessibility programs at historic sites. The literature review will first focus on broader design literature, before narrowing down to museum studies literature, and then historic preservation literature. The chapter will conclude with a critique of common misconceptions perpetuated by the current literature.

### Design Literature

The bulk of research surrounding autistic space has been conducted in design fields. It is important to understand design literature because it provides a foundation for museum studies and historic preservation literature. Before autistic access was being discussed in the museum world, it was being discussed in the design world. Design scholars have made important observations regarding how autistic people interact with their environment, and how public spaces can be improved to accommodate autistic needs. The findings from design literature are relevant to how we accommodate autistic people at museums and historic sites.

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<sup>72</sup>Zaky, *The Past, The Present*.

Dr. Guila Tola, Urban Planning and Architecture professor at the University of Sassari, Italy, states that autistic people are often denied the opportunity to engage in public city life because of sensory and social differences. According to Tola, autistic people could use increased visual support and less sensory overload. She concedes that making specific recommendations is difficult because of the varied nature of autism symptoms.<sup>73</sup>

Dr. Rachna Khare, professor of Planning and Architecture at the Birla Institute of Technology and former Georgia Tech doctoral research fellow, discusses creating effective educational environments for autistic people. Her work focuses on elementary school design.<sup>74</sup> Khare points out that most research regarding the creation of accessible space has focused on physical disability, not behavioral disability. She challenges future scholars to consider how environmental design can support the broadest range of disability, not just physical disability.<sup>75</sup>

From Tola and Khare's research, we can conclude that the sensory needs of autistic people are not being met in public spaces, partially because the accessibility conversation centers around physical disability and ignores cognitive disability. This mirrors the statements of Clouse and Wood-Nartker who discuss how the legal system has likewise failed to recognize the needs of cognitively disabled people.

In *Autism Spectrum Disorder (ASD): Designing Empowering Environments for Sensitive People*, Julia Niemen discusses two frameworks for designing accessible spaces for autistic people. She proposes that designers look to Sensory Integration Theory and Prospect Refuge

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<sup>73</sup> G. Tola, V. Talu, and J. Lindert. "Built Environment and Autism: Towards a Set of Spatial Requirements for Autism Friendly Cities." *European Journal of Public Health* 30, no. 5 (September 2020). <https://doi.org/10.1093/eurpub/ckaa165.1393>.

<sup>74</sup> Rachna Khare, and Abir Mullick. "Designing Inclusive Educational Spaces With Reference to Autism." *Proceedings of the Human Factors and Ergonomics Society Annual Meeting* 8, no. 53 (n.d.): 517–20. <https://doi.org/10.1177/154193120905300807>.

<sup>75</sup> Khare, Rachna, and Abir Mullick. "Incorporating the Behavioral Dimension in Designing Inclusive Learning Environment for Autism." *International Journal of Architectural Research* 3 (n.d.). <https://doi.org/10.26687/archnet-ijar.v3i3.189>.

Theory.<sup>76</sup> Sensory integration is the act through which a person uses sensory information to process and interact with their environment. Niemen suggests that building from low levels of stimulus to higher levels over time may help autistic individuals acclimate to their environment. Prospect Refuge Theory says that an autistic person will fare better in their environment if they have the opportunity to preview it beforehand and the option to escape when necessary. Niemen says that autistic people should be given the option to preview a space beforehand, and leave the space easily, and on their own terms.

Neimam also uses the Autism ASPECTSS Design Index in her work. The index consists of seven facets that contribute to a successful accessible space; acoustics, spatial sequencing, escape space, compartmentalization, transitions, sensory zoning, and safety. The acoustics of a space should be controlled. This includes limiting background noises, and giving the user control over the volume of intentional noises. The spatial layout of the space should reflect an obvious sort of logical progression, and have minimal distraction. The space should have an escape area with minimal noises and distraction. The space should be separated into compartments that each have a clearly defined function. Transition spaces should be used between compartments to acclimate the user to the next sensory zone. High stimuli should be grouped together, and low stimuli should be grouped together. A feeling of safety should be created by providing a straightforward plan, personal space, and clear sightlines.<sup>77</sup> These frameworks could be applied to the design of historic sites to make them more accessible for autistic people, and for others with sensory challenges.

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<sup>76</sup> Nieman, *Autism Spectrum Disorder*, 67–82.

<sup>77</sup> Nieman, *Autism Spectrum Disorder*, 67–82.

## Museum Studies Literature

Katie Stringer's *Programming for People with Special Needs: A Guide for Museums and Historic Sites*,<sup>78</sup> outlines accessibility best practices for museum professionals. The book references historic sites when mentioning historic site exceptions to ADA, but other than that, it makes little mention of the unique needs of historic sites.

Singer dedicates a chapter to sensitivity and awareness training. She points out that sometimes, the most daunting barrier to disabled populations in museums and historic sites is the limited knowledge of the staff. She advocates for the disability training of museum staff and for including disabled people in programming decisions. She recommends that museum professionals look to the Museum Access Consortium (MAC) for guidance on accessibility best practices. The MAC is an organization based in New York City, composed of museum professionals and disabled people. MAC members exchange museum accessibility information.

I did some research into the recommendations that have been promoted by MAC. In 2013, MAC held a workshop on the experiences of autistic adults in museums. A panel of autistic MAC members answered questions about their museum experiences. Many panelists mentioned the importance of training staff on autistic behaviors, effective wayfinding, and clear communication.<sup>79</sup> MAC has guidelines for autism-friendly programming published on its website. They recommend that staff involve autistic input in the planning stage as well as consulting precedents in other museums. Design recommendations include clear visual boundaries where the program is held, a quiet space, multi-sensory experiences, schedules, visual

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<sup>78</sup> Katie Stringer, *Programming for People with Special Needs: A Guide for Museums and Historic Sites*. United States: Rowman & Littlefield Publishers, 2014.

<sup>79</sup> "Adults on the Spectrum Share Their Museum Experiences - Museum, Arts and Culture Access Consortium." Uploaded by MacAccess, April 30, 2020. Accessed February 15, 2025. <https://macaccess.org/resources/audio-clips-adults-on-the-spectrum-share-their-museum-experiences/>.

prompts, repetition, social narratives, and guidelines for acceptable behavior. Some of the recommendations are clearly designed for children. For example, the document recommends that staff take cues from parents.

*The Art of Access: A Practical Guide for Museum Accessibility* by Heather Pressman and Danielle Shulz explores how museums can improve their accessibility for a wide range of disabled visitors.<sup>80</sup> The book uses examples from art museums, science museums, history museums, and historic sites. Universal Design (UD) is a guiding principle throughout the book. The term was coined in 1985 by Ronald Mace, a physically disabled designer. The motivating idea behind UD is that providing accessibility can benefit disabled and able-bodied populations alike.<sup>81</sup> There are seven tenets of UD; equitable use, flexibility, simplicity and intuitive use, perceptible information, tolerance for error, low physical effort, and size and space for use.<sup>82</sup>

According to UD accessible space should provide equitable use as opposed to segregated uses. The most accessible design solution can be used by every person, regardless of ability. Accessible design is flexible, and offers multiple options for users to choose from. The design should be the most simple, and intuitive to use. All important information about the design should be easy to interpret, regardless of the user's level of cognitive ability. There should be a tolerance for error, so if the design is used in an unconventional way, it will not pose a hazard to the user. All components of the design should use little physical effort to operate. All objects should be placed at heights that are accessible to all users.

These principles don't only help disabled people. Every person can benefit from UD in some way. A lowered counter can be helpful for a wheelchair user, but it can also help a child, or

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<sup>80</sup> Heather Pressman, and Danielle Schulz. *The Art of Access: A Practical Guide for Museum Accessibility*. Rowman & Littlefield, n.d.

<sup>81</sup> Pressman, *The Art of Access*, 56.

<sup>82</sup> Pressman, *The Art of Access*, 56.

a person who is shorter than average. A levered door knob can help a person with cerebral palsy, but it can also help an elderly person who has lost some of their fine motor skills. A wayfinding sign that uses pictures in addition to English words can help a cognitively disabled person. It can also help someone who does not speak English. All of these design solutions benefit multiple demographics of people, while at the same time, remaining usable by a person whose abilities are perceived as normative. As a result disabled people are not relegated to using different spaces than able-bodied people. UD aims to integrate disabled people into public life by making accessible design the default, not the exception.

*The Art of Access* has two chapters that are especially relevant to autistic accessibility- Chapter Six, Sensory Access, and Chapter Five, Cognitive Access. Pressman and Shulz emphasize that museums should always give visitors options. All sensory-disabled people have different needs, so the goal shouldn't be to design the perfect program for one person but to provide every person with the agency to choose how they experience (or don't experience) the program. For example, museums should not make tactile elements mandatory in the museum experience. All sensory experiences should be optional.<sup>83</sup>

They promote giving visitors information to help them prepare before the visit. Sometimes, the most helpful accommodation isn't a physical change to the design of the museum but better communication about what to expect in the museum. If a person has an aversion to loud noises, it would be helpful for them to know where loud noises in the museum are located. Other sensory information that is worth communicating includes bright lights, flashing lights, sudden noise, motion-activated noise, videos with loud music, buzzing light bulbs, uncontained scents, off-gassing materials, materials visitors must touch, and crowded galleries. Museums can also help visitors by communicating where quiet spaces are. A helpful

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<sup>83</sup> Pressman, *The Art of Access*, 77-91.

tool for communicating where sensory stimuli are located in a museum is a sensory map. A sensory map is a floor plan of the museum that shows areas where sensory stimuli are located. The practice of using sensory maps in art museums has become increasingly popular, but at this time, it is not currently a common practice at historic sites.<sup>84</sup>

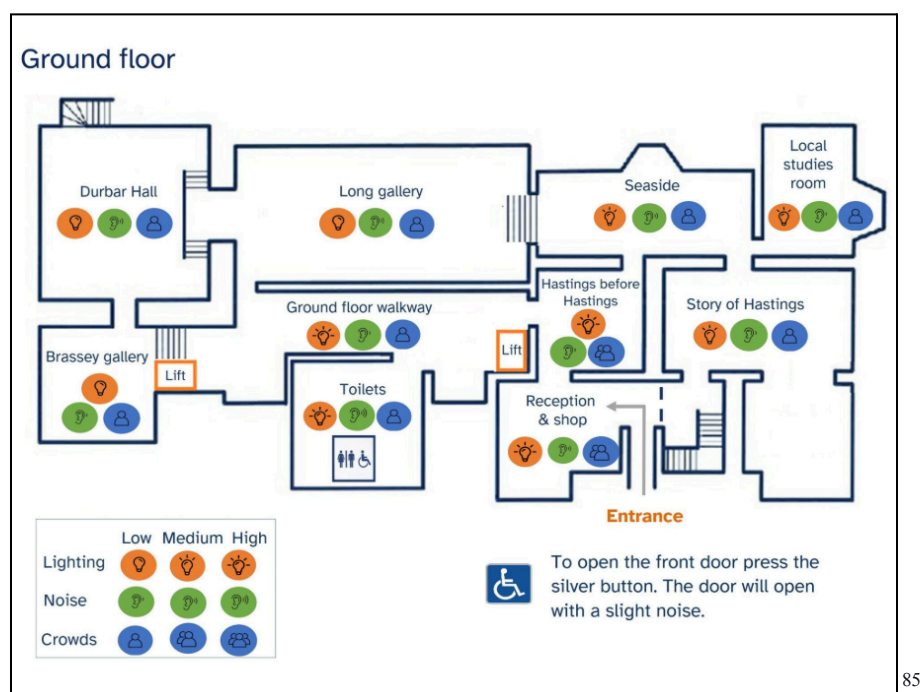


Figure 1. An example of a sensory map from the Hastings Museum.

The chapter on cognitive access has information that is relevant to the social needs of autistic visitors. Museums should never assume that a social rule or expectation is obvious. One of the most stressful parts of being autistic is trying to interpret implicit social rules. Museums run on social cues and implicit rules, which can be incredibly challenging to autistic visitors. Museums should always clearly outline rules and social expectations, no matter how obvious these rules may seem to an allistic visitor. If a visitor does not understand an unspoken rule, this

<sup>84</sup> Pressman, *The Art of Access*, 77-91.

<sup>85</sup> *Sensory Map of the Hastings Museum*. n.d. <https://www.Hmag.Org.Uk/Sensory-Map/>.

is never the visitor's fault. Historic sites are frequent offenders when it comes to unspoken rules. Not everyone knows innately which furniture they can sit on or how loudly to talk. If expectations are not outlined and “mistakes” are made, autistic visitors will start to associate historic sites with feelings of shame. Unfortunately, this experience is not unique to autistic visitors. In his book, *The Anarchist's Guide to Historic House Museums*, Franke Vagone shares his own experiences of being shamed alongside his daughter at a historic house museum for not following strict implicit rules.<sup>86</sup>

Chapter six gives ideas for how museums can better communicate relevant information to visitors. Signs are a museum's best cognitive access tool! Museums should aim to have signage that communicates directions, gender-neutral restrooms, visitor areas v. staff areas, quiet spaces, nursing rooms, the front desk ticket office, museum preservation practices, and rules.

Museums can use social narratives and visual schedules to communicate with their visitors better. A social narrative is a document that outlines the process of a museum visit. Social narratives give the visitor detailed information about where to park, how to get tickets, how long the visit will be, rules etc. Autistic people may feel more comfortable going to an unfamiliar place if they have as much information about the place as possible before arriving. Most social narratives are designed for children, but the language in a social narrative can be adapted for adults, too. A social narrative is not only helpful for autistic people but can also help people with PTSD, anxiety, or other developmental or cognitive disabilities.<sup>87</sup> Social narratives are a wonderful example of universal design. They inconvenience no one and have the potential to help a multitude of people, not just autistic people.

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<sup>86</sup> Franklin D. Vagone, and Deborah E. Ryan. *Anarchist's Guide to Historic House Museums*. Routledge, 2016.

<sup>87</sup> Pressman, *The Art of Access*, 61-75.

Somerset Place, Social Story


Abbreviated tour: Suckey Davis' House, Reconstructed Hospital, Laundry/Kitchen, Collins' House. Send an email or call the site to set up a time for this sensory friendly tour. [Somerset@ncdcr.gov](mailto:Somerset@ncdcr.gov) and 252-379-6020.

1. Arriving
2. Parking/walking
3. Visitor Center
4. A place of quiet/escape
5. Suckey/Hospital
6. Laundry/Kitchen
7. Collins Home
8. Back Home


We are going to an historic site called, Somerset Place. Historic sites can be a fun place to learn about people and see artifacts from a long time ago.

Somerset Place used to be a plantation (a really large farm) with thousands of acres of land. So, to get there we might have to drive for quite a while, because it's not near any big roadways.


When we arrive, we'll park in a parking lot where the big sign that says, Somerset Place State Historic Site, is. It's a fun little parking lot where you walk across a little foot bridge and follow a brick pathway to get to the visitor center. Did you know the brick walkway is rounded to prevent rainwater from forming large puddles? Pretty neat!



Inside there are two rooms downstairs. One room has furniture, beds, eating table, pots and pans, and other items that enslaved people used in their houses.



The other room has benches where we can sit down and listen to the tour guide tell us about the people who lived in this building.



There are also items similar to what the enslaved men and women made, and we can touch some of those things while the tour guide is talking. If we raise our hand, we can ask the tour guide questions. They'll be happy to answer any questions we have.

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Figure 2. An example of a social narrative from Somerset Place Historic Site. North Carolina Historic Sites Website. <https://historicsites.nc.gov/somerset-place-social-story/open>.

### Historic Site Literature

Preservationists often take guidance from the NPS when it comes to best practices. The NPS has published seven articles on accessibility in National Parks. *Preservation Brief 32* outlines how to make historic properties accessible under the ADA. Unfortunately, NPS guidance for accessibility is vague, and gives little thought to cognitive disability, much less autism. Public Historian, Perri Meldon, has expanded on the NPS best practices at NPS sites in her master's thesis, "*Interpreting Access: A History of Accessibility and Disability*

*Representations in the National Park Service.*"<sup>88</sup> She concludes, "That great need to diversify the parks and their interpretation of American disability history remains."

The late disability advocate, Ansel Luro, wrote about historic site accessibility in their article "*Engaging Children with Autism at Historic Sites: Developing an Audience-appropriate Curriculum.*"<sup>89</sup> Beyond Luro's work, little has been written about how the current autism accessibility literature can be applied to historic sites. Luro's work is limited in that it only concerns the education of children.

*An Accessible Past*, by Heather Pressman,<sup>90</sup> is the most recent research relevant to this thesis. Pressman, co-author of the book *The Art of Access*, wrote *An Accessible Past*, to specifically address historic sites. Pressman recommends that historic sites consider the sensory needs of their visitors, including those who have autism. The book features writing from other museum and historic site professionals.

Pressman showcases the writing of Sara Thompson, Museum Access Manager of the New York Transit Museum. The museum's "Subway Sleuths" program is lifted up as an example of successful autism programming. The New York Transit Museum implemented this program after realizing that their exhibits were attracting a large number of autistic visitors who had a special interest in trains. A special interest is an interest an autistic person engages with on a much deeper level than what is considered normative by allistic people. It is theorized that special interests may be related to autistic restrictive and repetitive behaviors. Trains are a stereotypical autistic special interest. You may already be familiar with the "train-loving autistic boy" trope. The Subway Sleuth Program is specially designed and facilitated by special

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<sup>88</sup> Perrie Meldon, "A History of Accessibility and Disability Representations in the National Park Service." MA Thesis, University of Massachusetts Amherst, 2019.

<sup>89</sup> Ansel Luro, "Engaging Children With Autism at Historic Sites: Developing an Audience-appropriate Curriculum." *Journal of Museum Education* 3, no. 41 (2015).

<sup>90</sup> Pressman, *An Accessible Past*.

education professionals, for autistic children. Spots within the program are limited, and applicants must go through a screening and application process. The application process includes an interview with an autism consultant and a trial run of sorts with other applicants at the museum. The program facilitators look for students who show a strong interest in trains, and are independent enough to travel with the group. The selected students get to come back to the museum to participate in games and activities that build communication and collaboration skills. The goal of the program is to teach the children important life skills while also giving them an opportunity to engage in their special interest.

The Subway Sleuth program is a favorite of museum professionals. Pressman is not the only scholar to take note of the program. It appears in almost every recent book about museum accessibility I have found. The program is carefully designed for autistic children in a way that is largely unprecedented. It is not surprising that the program has made such a stir in the museum community. However, it is notable that the most popular example of autism programming is a highly selective program for children that aims to help them build life skills. For being an accessibility program, Subway Sleuths is incredibly inaccessible for most autistic people. Not only do you have to be a child to participate, you have to be a very specific type of autistic child that can make it through an intensive interview and trial process. There is a disproportionate emphasis in the literature on programs that are designed for children and have a goal to help them “gain skills” which implies that autistic people lack the skills of their allistic peers.

Caroline Branden, who I had the privilege to interview, writes about autism programming at The Henry Ford in Chapter 8 of *An Accessible Past*. The Henry Ford offers exclusive access times to autistic visitors and hosts special events like sensory friendly movies. Branden mentions that the Henry Ford has developed a program for young adults. Autistic speakers come in and

talk to autistic young adults. A parent said of the program, “This is the first time that autism has been shown in a positive way with adult content. (The daughter) left feeling empowered and hopeful.”<sup>91</sup> This is the only mention in the literature I have seen that specifically mentions adult programming.

### Problems Within The Current Literature

The most common, and egregious problem within the current literature is the unspoken assumption that autistic people are mostly children. As a result, most of the available information about autism programming focus on the experiences of the parents of autistic children instead of highlighting the experiences of autistic people. This assumption is visible to some degree in every work I have encountered. Lurio exclusively writes about child programming.<sup>92</sup> Pressman primarily discusses children's programs like “Subway Sleuths.”<sup>93</sup> Similarly, Stringer’s examples of sensory accommodation revolve around children and students. She also references the Subway Sleuth Program. Singer writes about an autism awareness night for “families and children” in Philadelphia and quotes the writing of a parent who attended the event but does not address how the autistic participants themselves felt about the event. She also provides an example guide at the end of the book titled “Asperger's Syndrome: Strategies for Teaching Students With Special Needs.” The guide is clearly designed for addressing the needs of children, not the autistic population as a whole.<sup>94</sup>

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<sup>91</sup> Caroline Branden, “A Brief History of Sensory-Friendly Programming at the Henry Ford.” The Henry Ford Blog, January 15, 2021. <https://www.thehenryford.org/explore/blog/a-brief-history-of-sensory-friendly-programming-at-the-henry-ford/>.

<sup>92</sup> Lurio, *Engaging Children*.

<sup>93</sup> Pressman, *An Accessible Past*.

<sup>94</sup> Stringer, *Programming for People*.

*An Accessible Past* cites emails from a parent, not an autistic person to prove the success of the Henry Ford's autism programming. "Thank you for seeing our kids for who they are and for going to them where they are and for INCLUDING them in the Wonderful Henry Ford programming," says one parent. Another parent says "I can't adequately express just what a weight was lifted being in a place where the kids could be themselves! No getting embarrassed by meltdowns. Everyone knew what you were going through. I could literally cry, it was that lifegiving."<sup>95</sup> According to this parent, the Henry Ford Program is successful not only because it provided her child a place to be themselves but also because it saved her the embarrassment of having to deal with meltdowns. I am glad that this mother had such a positive experience, but as someone who was once an autistic child, I can't help but to feel hurt hearing this mother admit that she feels embarrassed by the behavior of her autistic child. Unfortunately, the narrative that autistic people are an embarrassment and burden to their caregivers is not uncommon. Branden, of The Henry Ford, is the only professional who explicitly tailors accommodations to adults but even when talking about adult programming, Branden cites the opinions of parents as proof of the program's success. Citing the feedback of parents infantilizes autistic adults. If an autistic adult enjoys a program, I would like to hear that from them in some way, not their allistic guardian.

In Chapter 16 of *An Accessible Past*, a theoretical autistic person is mentioned to exemplify why museums might use digital access tools. "Nine-year-old Joshua is interested in World War II and wants to visit a local exhibit about the war. Joshua has autism and needs to know what to expect when he is visiting so he feels comfortable."<sup>96</sup> The discussion of digital

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<sup>95</sup> *A Brief History*.

<sup>96</sup> Pressman, *An Accessible Past*, 220.

tools is helpful, but this example also perpetuates the idea that autistic people are mostly young boys.

To clarify, there is no issue with museums and historic sites providing services to autistic children and their families. These services have immense value to the children they serve. As a child, I would have greatly benefited from a space where I could have been around other autistic children in an environment that was designed with my needs in mind. However, there is an issue when museums and historic sites only create programs and accommodations for children, and prioritize the opinions of parents over actual autistic people. I have noticed when the same authors who write about autism write about physical disability, they don't use case studies that center children as often. It is assumed that a wheelchair user could be either a child or an adult. It is assumed that a deaf person could be either a child or an adult. It is assumed that a blind person could be either a child or an adult. So why is it almost always assumed that an autistic person is a child?

This assumption does not originate within the preservation or museum community. Rather, the preservation and museum studies literature reflects a deep-seated cultural attitude that most allistic people hold: that a person with autism is probably a child. In 2011, 95% of autism advocacy web pages used pictures of children on their home pages. 90% of autistic characters in fiction books were children. News outlets featured stories about autistic children four times more than stories about autistic adults.<sup>97</sup>

All disabled populations are in some way infantilized, especially those with a developmental or cognitive disability.<sup>98</sup> It is impossible to discuss the infantilization of disabled

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<sup>97</sup> Jennifer Stevenson, Beverly Harp, and Anne Morton. "Infantilizing Autism." *Disability Studies Quarterly* 3, no. 31 (2011).

<sup>98</sup> Robey, Kirschner, and Beckley. "Implicit Infantilizing Attitudes About Disability." *Journal of Developmental and Physical Disability*, 2006. <https://doi.org/10.1007/s10882-006-9027-3>.

people without acknowledging that in American culture, being an adult is directly tied to work and wealth. National Museum of American History curator Katherine Ott, says, “How disability is portrayed (or not portrayed) is directly related to core cultural values, including how achievement is defined, how wealth is generated and distributed.”<sup>99</sup> In a capitalist society, where one’s worth as an adult is measured by productivity, the disabled are automatically considered childish because of their perceived dependence on those who produce capital.

The infantilization of autistic people is further exacerbated by a specific interaction between parental advocacy, the news media landscape, and fictionalized works.<sup>100</sup> Autism advocates are more likely to represent autistic people as children because a sensationalized “think of the children” message is more likely to resonate with donors and policymakers. The news will then pick up on the work of parental advocates and further this message. The media landscape, which profits from sensationalism, benefits from a limited view of autism that is confined to either a sentimental tale about a persevering autist, or the dangers of a mysterious disease that is coming for *your* innocent child! Then, the message will infiltrate into fictionalized works, like books and TV. The average person’s initial introduction to autism will be a representation of an autistic child. This results in the widely accepted assumption that most autistic people are children, or child-like incompetent adults.

Some museum studies literature takes the harmful assumption that autistic people are children or at the very least, unrealized adults, even farther, and conclude that museums have a responsibility to therapize autistic visitors. In their article *Museums and Autistic Visitors: Accessibility and Inclusion*, Patel and Patel argue that because museums are living institutions obligated to serve the community, they have a responsibility to serve a diverse audience,

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<sup>99</sup> Katherine Ott. “Disability and the Practice of Public History: An Introduction.” *The Public Historian* 27, no. 2 (2005): 9–24. <https://www.jstor.org/stable/10.1525/tph.2005.27.2.9>.

<sup>100</sup> Stevenson, Harp, and Morton, *Infantilizing Autism*.

including those visitors with autism.<sup>101</sup> They emphasize how early intervention and therapies can mitigate communicative, sensory, and social deficits in autistic people. Patel and Patel conclude that museums can help autistic visitors by providing art therapy, touch-and-feel activities, and sensory rooms.

Patel and Patel conflate accessibility and inclusion with therapeutic intervention. Facilitating an art therapy session in a museum is not the same as creating accessibility. Patel and Patel assume that autistic people want museums to help them overcome their autistic behaviors in the form of therapeutic programming. But this is not the desire of autistic people; it is the desire of the families of autistic people. They state in their conclusion, “Visiting museums remains a stressful activity for families that have children with Autism Disorder Spectrum.”<sup>102</sup> but they do not address whether visiting museums is stressful for autistic people. It is assumed that museum curators have a responsibility to address autism at museums because autism is a problem that negatively impacts communities. There is little discussion on how curators can mitigate the harm that a museum environment might cause to autistic visitors. Throughout the article, autism is framed as a deficiency that needs to be overcome instead of a morally neutral neurological difference.

The current literature reflects an outdated concept that Anne McGuire, author of *War on Autism*, refers to as “the development of non-autism.” There is a misconception about what “good” autism advocacy looks like. This misconception stems from the parental advocacy movement. McGuire studied the messages of the most prolific autism advocacy groups and found that most groups advocate *against* autism, not for it. She points out that most advocacy groups advocate *for* something not *against* something. The expectation among mainstream

<sup>101</sup> Ambika Patel, and Drishti Patel. “Museums and Autistic Visitors: Accessibility and Inclusion.” *Heritage: Journal of Multidisciplinary Studies in Archaeology* 8, no. 1 (2020).

<sup>102</sup> Patel, and Patel, *Museums and Autistic Visitors*.

advocates is that the best way to advocate for autistic people is to help them return to a life of normalcy or non-autism. This means promoting therapies that seek to mitigate the “symptoms” of autism. Museum programs like Subway Sleuths that promote “building life skills” have adopted the language and goals of parental autism advocacy. “Building life skills” can be a gentle way of saying “therapy to help return your child to their natural, pre-autistic state.”

Some museum accessibility programs are guilty of platforming harmful organizations like Autism Speaks.<sup>103</sup> For example, in a recent MAC workshop, a speaker from the Intrepid Sea, Air, and Space Museum presented on the museum’s Parent Advisory Council. Parents on the council were recruited via Autism Speaks. Autism Speaks recommended specific parents to sit on the council.<sup>104</sup> The Autism Self Advocacy Network published a report in 2022 that reveals that less than 1% of the money generated by Autism Speaks goes towards services for autistic people. Most of Autism Speaks’ budget is spent on lobbying, research for a “cure” and “awareness campaigns.” Out of 26 Autism Speaks board members, only one is autistic.<sup>105</sup> Autism Speaks is the epitome of the normative parental and corporate advocacy that acts against the interests of autistic people. Most allistic people have limited exposure to autistic issues and are not aware that organizations like Autism Speaks do not represent autistic people. The Intrepid Air, Sea, and Space Museum’s deference to Autism Speaks is the natural consequence of our culture’s prioritization of parents’ needs over autistic needs.

The current literature leaves a gap in the research regarding quality writing on adult autistic accessibility. There are no established best practices for accommodating autistic adults at

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<sup>103</sup> Langan, *Parental Voices and Controversies*.

<sup>104</sup> MacAccess, *Workshop*.

<sup>105</sup> Autistic Self Advocacy Network. “Before You Donate to Autism Speaks, Consider the Facts,” March 31, 2022. Accessed February 15, 2025. <https://autisticadvocacy.org/2022/03/consider-the-facts-4/>.

historic sites. The recommendations that do exist disproportionately represent the experiences of autistic children and the parents of autistic children. Some of the literature is actively harmful to autistic people and references sources like Autism Speaks, or promotes the biomedical model of disability and seeks to therapize autistic individuals.

## CHAPTER 3

### Analysis

In my research, I have discovered that the historic preservation community frequently takes cues from the museum studies community when creating autism programming. There are a few well known examples of autism programming in museums that have influenced the way historic preservationists conceive of accessibility best practices. Many of these examples can be found in large east coast cities like New York or Washington D.C. The types of programs and accommodations that are available to autistic visitors at historic sites closely mirror those that are available at museums. Likewise, the training that is given to historic site staff is similar to that of museums. I have found that word of mouth is the most important means preservationists have of transmitting accessibility ideas. Some of the staff I have talked to at historic sites started their careers in the museum studies world and are now bringing their expertise to historic sites. The flow of ideas between the field of historic preservation and museum studies is one that happens naturally through community means, in addition to the formal exchange of ideas that is facilitated by academia.

Most preservationists have not considered what autistic access is. The programs I have observed as case studies only sometimes consider the specific needs of autistic adults. It is common for historic sites to only offer accommodations by request, which can prove problematic for a population who struggles with communication. It is common for autistic programming to center the needs of autistic children and the parents of autistic children. There is a clear connection between autism programming and local school systems. This partially explains the strong focus on child programming.

While there are real barriers to accommodating autistic adults at historic sites, many historic preservationists do not understand what these barriers are. Many preservation professionals assume the fabric of the historic site poses a major barrier to autistic access, but through my research I have found that this is rarely true. On the contrary, historic environments are more suitable for autistic visitors than modern environments.

### Influences

Historic sites get their information about autism accessibility from three main sources: other historic sites and museums and autism advocacy groups. Most historic site staff I spoke to reported getting their inspiration by word of mouth. Many historic sites look to other sites to inform their programming, and education directors at different sites talk to each other and discuss how they are accommodating visitors.

New York City is a commonly recognized focal point of accessibility interventions in the United States. I identified twenty sites that advertise their autism programming online. Ten of these sites are in New York City, or the surrounding Hudson River Valley Area. The New York area has a large concentration of autistic programming for a few reasons. Firstly, the Museum, Arts, and Culture Access Consortium (MAC), based in New York City, is a leader in museum and historic site accessibility. Secondly, the Historic House Trust of New York (HHT) was involved in the 2016 Lurio study that I discuss in Chapter 2. As a result, many of the HHT historic sites have participated in autistic access programs as part of the study. Lastly, New York City is home to some of the most influential museums in the country. The staff from these museums are in communication with the staff at the New York area historic sites. Some staff members have moved between museums and historic sites and have taken their accessibility

ideas with them. Nicole Wallace, for example, cites her time at the Bronx Children's Museum as influential on her current work at Historic Hudson Valley.

Even in areas that are geographically removed from New York City, preservationists at these sites still make reference to New York City museums as important precedents for their programs. For example, Caroline Branden from The Henry Ford Museum in Dearborn Michigan, took inspiration from the New York Transit Museum and the Brooklyn Children's Museum. Branden also modeled a local museum access consortium after the MAC.<sup>106</sup>

She also cited looking at the Michigan Science Center's sensory programs. The Michigan Science Center's programs are inspired by the Smithsonian's "Morning at the Museum" events. The Smithsonian's indirect influence on The Henry Ford exemplifies how access ideas spread. There are a select number of tastemaker museums in large cities like New York City or Washington D.C. who are known for their access programming. They are often the first examples that preservationists will look to when they are considering the design of their own programs.

Annual conferences and disability workshops, like the American Alliance of Museums (AAOM) conference and the American Association for State and Local History conference (AASLH), are much less influential. Wallace says that AASLH have their own disability training but that it focuses almost solely on physical access and does not discuss accommodation options for autistic visitors.<sup>107</sup>

Some historic sites look to autism advocacy groups for guidance on autism programming. Many autism advocacy groups have a history of promoting harmful ideas about autism that are rooted in the medical model of disability. I talked to Ms. Hernandez-Miller, from Hormel

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<sup>106</sup> Caroline Branden (The Henry Ford Accessibility Manager) in discussion with the author, October 2024.

<sup>107</sup> Nicole Wallace (Historic Hudson Valley Director of Education) in discussion with the author, October 2024.

Historic home. She compared the autism programming of Hormel to that of one of her influences, AuSM, the Autism Society of Minnesota.<sup>108</sup> AuSM is the Minnesota Branch of the American Autism Society, an organization that has a long history of promoting biomedical interventions that are tied to the outdated medical model of disability. The founders of Autism Society, Bernard Rimland and Ivan Lovass, suspected that autism was a disease caused by pollutants or vaccines. Lovass would go on to create Applied Behavioral Analysis Therapy (ABA).<sup>109</sup> Today, Autism Society includes the voices of autistic people in their messaging, but they still treat autism as a public health crisis on their website. They emphasize that an early diagnosis is critical.<sup>110</sup> Disability self-advocates identify emphasis on early diagnosis as a sign that an organization views autism as a pathology.

Many autism advocacy groups were founded by concerned parents, not autistic people, which could explain why they lean towards a medical model of disability, and focus their efforts on access and programming for children. Some autism advocacy groups, like Autism Society, provide historic sites with a child-focused perspective that promotes the medical model of disability. Resultantly, historic sites that consult autism advocacy groups uncritically, risk perpetuating harmful views. However, not all autism advocacy groups are created equal. While some still promote harmful, outdated views, others have taken steps to include the perspective of autistic people. This means that the advice historic sites get from autism advocacy groups can vary in terms of quality.

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<sup>108</sup> Danielle Hernandez-Miller (Hormel Historic Home Community Autism Resource Specialist) in discussion with the author, October 2024.

<sup>109</sup> Cassandra Crossman, “Good Autistic Advocacy Organizations Vs. Bad Autism ‘Charities.’” In *The Loop About Neurodiversity*, 2019. Accessed February 15, 2025. <https://intheloopaboutneurodiversity.wordpress.com/2019/11/28/good-autistic-advocacy-organizations-vs-bad-autism-charities/>.

<sup>110</sup> McGuire, *War on Autism*, 53.

Historic sites can consult autism societies without perpetuating harmful ideas if they make a concerted effort to diversify the perspectives they are taking into consideration. Mount Vernon is an example of a site that integrates input from multiple sources. As Sisson continues to develop Mount Vernon's sensory programming, she has been in contact with the local public school system, museum professionals, special needs teachers, specialists, and actual autistic people. The Estate also looks to other historic sites and museums as a source of programming inspiration.<sup>111</sup> The Autism Society of Northern Virginia trained the Mount Vernon staff, but their point of view is not the only one Mount Vernon considers. Historic sites that consider input outside of traditional advocacy groups are more likely to make informed decisions when it comes to autism programming and accommodations.

### Training

The quantity and quality of disability training offered to the staff at historic sites varies. In some cases, there is no disability training offered outside of random continuing education sessions. One historic site I contacted hadn't had disability training for staff in over a decade. Many historic sites do not have the time or money to dedicate to disability training, much less autism-specific training. Sometimes historic sites only have the resources to do a disability training with the staff members who are most likely to interact with disabled visitors, or will only do a training when the site is in the process of testing out a new access tool. Historic Hudson Valley employees are educated on the site's social stories and sensory backpacks for instance,

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<sup>111</sup> Maddie Sisson (Lead Specialist in Family Learning at Mount Vernon Estate) in discussion with the author, October 2024.

and education employees attend workshops that discuss disability topics such as terminology and ways to welcome disabled visitors. But there is no standard program for training all staff.<sup>112</sup>

In other cases, autism societies, disability advocacy groups, or special education teachers offer disability training to historic properties. Mount Vernon receives training from the Autism Society of Northern Virginia. At the Henry Ford, staff are trained by the Autism Alliance of Michigan. They are given information on how to recognize autistic traits, and how to communicate with autistic visitors. For large events, staff members are given tip sheets on how to interact with visitors.

### Programming

I have observed historic sites using three common models of accommodation for autistic visitors. Historic sites can choose to create a program for visitors, create preparation materials for visitors to consume prior to arriving at the site, or provide mitigation tools after visitors arrive at the site. The first model is what I call the programming model. I define a program as a discrete event, separate from normal historic site operations, that aims to provide entertainment, or education for autistic visitors and their families. A program can be sensory hours, quiet hours, a private tour, a touch tour, or another special event. Historic sites that use the programming model will host programs for autistic visitors, but may not have a plan for accommodating autistic visitors on a day-to-day basis.

Hormel Historic Home is an example of a historic site that uses a programming model. The House's mission is to honor the legacy of the Hormel family through education, hospitality, music, and community service through outreach programs. The Hormel education mission has

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<sup>112</sup> Nicole Wallace (Historic Hudson Valley Director of Education) in discussion with the author, October 2024.

resulted in the creation of Autism Friendly Austin, a city wide program that aims to support the local autism community through programming and community outreach.

Licensed special education professionals descend on Hormel every summer to facilitate summer camps for autistic children and young adults. The Little Learners Camp is designed for kindergarteners. Circle of Friends Day Camp is for 1st-5th graders. All Access Community Explorers is for 6th-12th graders. Camp Just For Me serves visitors who require one-on-one attention from ages 7-17. In addition to summer camps, Hormel hosts recreation nights for autistic children, teens, and young adults. There are also two music therapy groups that Hormel hosts, one for teens and one for adults over 18. Hormel hosts caregiver support groups, which are more informal. Hernandez-Miller has stated that Hormel's goal is to expand its programming to autistic adults, but they do not have the resources to do so at this time.<sup>113</sup>

Hormel's situation is unique because its autism programming is almost entirely separate from the historic home. The autism programs are held in a modern event space on the site. Autistic visitors can visit the historic portion of the home like any other visitor, but the house museum programming itself is not designed with autistic visitors in mind. The autism programming at Hormel is incidental. Autism Friendly Austin is essentially just using the Hormel event space and the Hormel funding to carry out a separate program.

Sensory events are the most common example of autism programming. The historic site staff I talked to, and the literature alike both put a great emphasis on sensory programming. The Henry Ford Museum reported that their sensory programs regularly garner the interest of 1,400 local families. Their 2024 Fall Sensory Program is expected to get over 900 attendants.<sup>114</sup> These

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<sup>113</sup> Danielle Hernandez-Miller (Hormel Historic Home Community Autism Resource Specialist) in discussion with the author, October 2024.

<sup>114</sup> Caroline Branden (The Henry Ford Accessibility Manager) in discussion with the author, October 2024.

events are hugely popular, and visitors return to them over and over again. Tickets are required for events and admission may be limited. The Henry Ford will sometimes host speakers to talk at autistic events who are autistic themselves. The Henry Ford has also hosted a collecting event where autistic visitors were encouraged to bring in their collections. Many autistic people are passionate about collecting certain items, especially if they are associated with a special interest. At the collecting event, the participants were not only allowed to talk about their special interest, they were actively encouraged to talk about their special interest.<sup>115</sup>

The programming model is useful because programs can be specially designed for autistic people. The staff at historic sites who use the program model are among some of the best trained. At Hormel for instance, the staff that facilitates the programs are special education professionals. Because programs are usually for autistic people exclusively, an autistic visitor may feel more at ease being around other autistic people. Special programs for autistic visitors have incredibly high attendance rates. There is a huge demand for autistic programming, and this demand is a great way for historic sites to draw in repeat visitors.

Undoubtedly, sensory programs offer something valuable to the autistic community. The high interest in Henry Ford programs proves this. But Henry Ford is a large, well known site with ample funding. Most historic sites do not have the same resources. If the conversation around autistic accessibility is focused solely on elaborate programs, less resourced sites may be left with the impression that expensive programs are the only way to accommodate autistic visitors, which is not true. When done properly, they are among some of the most successful examples of autism programming, but they are not the only option.

There are serious drawbacks to relying solely on programs. They are expensive and time consuming to put together. Programs are designed specifically for autistic visitors, therefore they

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<sup>115</sup> Branden, *A Brief History*.

are usually not attended by allistic visitors, unless they are the family of an autistic person. As a result, they reach a limited audience. Autistic visitors usually need to register for programs beforehand. In the case of the New York Transit Museum, visitors must go through a competitive screening and application process. Historic sites that use the programming model, like Hormel Historic Home, do not have other accommodations for autistic visitors available on a daily basis. Some historic sites will schedule autistic programs a couple times throughout the year, but others only host an autism program once. I have found that in most cases, regularly scheduled autism programming is uncommon. Regularly scheduled programming for autistic adults is almost unheard of.

Programs can require a large amount of planning in advance for the autistic visitor. A registration process can be burdensome for a person who already struggles with executive functioning. Some programs have a cap on how many visitors can register. This means that not everyone who wants to attend a limited program can. The programming model does not follow the principles of universal design. Having programs only during certain times may give off the impression that autistic visitors are only welcome at the site on certain days. If autistic people only feel comfortable at a site during special events they are effectively being segregated from their allistic peers. Some autistic people do not want to go to a special event, they want to participate in the historic site experience during normal hours, with a variety of other people. Programs are usually well attended by local autistic people, but are not helpful for out of town visitors who cannot schedule their visit around program dates. The program model requires more effort on behalf of historic site staff than other models of accommodation. Special programs may require historic site staff to work outside of normal site hours, or undergo special training to prepare for the event.

### Preparation and Mitigation Style Accommodations

The preparation and mitigation model aims to prepare visitors for the sensory and social inputs they may encounter at the site. It relies on a series of small, inexpensive interventions. The main goal of this model is to give the visitor as much information as possible before they arrive at the site, and to accommodate their sensory needs when they arrive at the site. All of these accommodations fit within the normal operations of the historic site and do not require a separate program or interpretation. Historic sites that use the preparation and mitigation model provide social narratives to inform autistic visitors about the social and sensory experiences they could encounter during their visit. Oftentimes, this information is published on the historic site's webpage. Once the visitor arrives at the site, there will be ample signage to communicate important information to the visitor. The John Brown House Museum, in Providence Rhode Island, uses the preparation and mitigation model. There is a social narrative and a visitor checklist published on the webpage, and once a visitor arrives at the site, there is easy to understand interpretive signage.<sup>116</sup> For more information on easy-read interpretive text, see the resources in the appendix.

Mitigation tools aim to help autistic visitors self-soothe if they become overstimulated or understimulated while at the site. A historic site that utilizes mitigation tools may provide earplugs, fidget toys, or quiet spaces. The Gamble House, in Pasadena, California, provides tactile touring kits for autistic visitors to help them self-soothe during their visit. Historic Hudson Valley also employs preparation and mitigation techniques. Sensory backpacks are located behind the site's front desk, and social narratives are available by request. The use of sensory backpacks is a mitigation approach, and the use of social narratives is a preparation approach.

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<sup>116</sup> The Rhode Island Historical Society. "Accessibility," n.d. <https://www.rihs.org/visit/accessibility-a/>.

The preparation and mitigation model of accommodation can be beneficial for a couple of reasons. First, these interventions are relatively inexpensive, in terms of both time and money. A staff member can write a social narrative in a couple of hours, and it costs almost nothing to publish it to a website. A historic site doesn't even need to print physical copies for this tool to be effective. The preparation and mitigation model fits within the framework of universal design. Many people could benefit from a sensory map or social narrative. A person with attention deficit disorder, generalized anxiety, social anxiety, post-traumatic stress disorder, or an auditory processing disorder could also benefit from these accommodations. These tools are not only limited to autistic people, and they do not interfere with normal site operations. The preparation and mitigation model does not require preservationists to change anything about the historic fabric of the site. It only requires that preservationists communicate more effectively about the site experience, and provide unobtrusive accommodations once visitors are at the site. Preparation and mitigation style accommodations are available on a daily basis, and do not require scheduling in advance.

Most historic sites will use a combination of the models outlined above, but will lean more towards one or the other. Mount Vernon hosts sensory programs that are in line with the programming model, but also keeps social narratives and maps up to date on their website. The Henry Ford Museum is well known locally for their programming, but they also offer extensive visitor preparation information on their website. Out of the twenty historic sites, I identified 30% leaned more towards the programming model. 35% leaned towards the preparation and mitigation model. The other 35% used an equal combination of both models.

### Consideration for Adults

Consideration for adults is uncommon. I spoke with Nicole Belolan, a public historian, who specializes in the material culture of disability. Belolan works with historic sites to educate preservation professionals about disability history and site accessibility. “Most people don’t realize that there are neurodiverse adults. (They) don’t know what an accommodation for an autistic adult would be... They aren’t thinking about autistic adults as an audience,” she says. “People don’t know where to start. A lot of people don’t know what language to use surrounding disability. They may assume that neurodivergent people are unintelligent. Non-disabled people may wrongly assume neurodivergent people have more than one disability... Many people don’t even know the word neurodiverse, much less how to accommodate a neurodiverse audience.”<sup>117</sup>

There are multiple reasons why the preservation community is under informed when it comes to autistic adults. Firstly, autism programming at historic sites is more often than not connected to school systems. Nationally, about 14% of special education field trips are to historic sites.<sup>118</sup> About 70% of disabled students have a cognitive disability. 20% of those students are autistic.<sup>119</sup> Another 23% have an unspecified developmental delay, which may also fall under the broader autism umbrella.<sup>120</sup> In school systems that screen more thoroughly for developmental disability, like the New York City Public School District (NYSED), autism programming is more likely to exist at nearby historic sites. In 2021, NYSED had a 96% compliance rate with timely evaluations for disability screenings, which means that more students are getting screened for

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<sup>117</sup> Nicole Belolan (public history, material culture, & disability historian) in discussion with the author, October 2024.

<sup>118</sup> Stringer, *Programming for People*, 52.

<sup>119</sup> Stringer, *Programming for People* 53.

<sup>120</sup> Stringer, *Programming for People* 53.

disabilities, and then getting accommodations for those disabilities.<sup>121</sup> 19% of NYSED students have an individualized learning program (ILP). This is much higher than in other cities of comparable sizes. Los Angeles has a 12% rate of ILP enrollment. In Houston, it's 7%.<sup>122</sup> These special education program numbers can be used to accurately predict which state's historic sites have autism programming and accommodations. New York State has ten historic sites with autism programming. Texas, on the other hand, has zero, even in large cities like Houston and Dallas.<sup>123</sup>

Old Stone House (OSH) is an example of a site that has put significant effort into their autism programming for children, but has failed to address the needs of autistic adults. OSH's programming choices are influenced by the local school district. OSH is a property in New York that the Historic House Trust of New York (HHT) manages. In 2014, OSH teamed up with Spellbound Theatre to create a performance for autistic visitors.

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<sup>121</sup> NYSED Data Site. "Special Education Comparison," 2021.

<https://data.nysed.gov/specialed/?year=2021&instid=800000048663#EnrollmentandClassificationRate>.

<sup>122</sup> Fancsali, and Farley. "What Are the Contours of NYC's Special Education Landscape: Spotlight on NYC Schools." *Research Alliance for New York City Schools*, 2018.

<sup>123</sup> There are no historic sites in Texas that advertise programming for autistic visitors, or mention accommodations for autistic visitors on their website as of October, 2024.



Figure 3. Old Stone House’s Spellbound Theatre. Photograph courtesy of Amy Kelly.

The program was part of the larger HHT initiative to create accommodations and programming for autistic children in partnership with the Wagener Program for Children with Disabilities. The Devereux Foundation trained HHT staff and created programmatic materials for Spellbound Theatre’s performance. OSH does not stage performances with Spellbound Theatre today but offers other accommodations for autistic visitors. Maggie Webber, OSH Director of Education, says, “We offer visits by appointment outside of our open hours. We serve many students on the spectrum through our school programs. We ask visitors to indicate if they have special needs before their visit and adapt our programs through more direct language and explicit conversation. We allow students to move from our second-floor great room to our gallery space as needed. In addition, we have had children on the spectrum enrolled in our Garden Explorers

program. This program has a very small student-to-counselor ratio and is able to create accommodations for students who may need more individualized attention in order to function.”<sup>124</sup>

OSH is connected to a network of New York City schools and parent associations, like the Park Slope Parent Association. These connections help their programming for autistic children flourish. OSH does not currently offer accommodations that are aimed at autistic adults. Accommodations for adults are made when requested by the visitor. This leaves the responsibility of accommodation in the hands of the visitor. They must be prepared to know what they need and know how to ask for it. Keep in mind that knowing what you need and how to ask for it can be extremely difficult for a person with sensory processing and communicative difficulties.

OSH is doing much more for autistic visitors than the average historic site. They have a decade long history of accommodating autistic visitors and say they are prepared to adapt their child programming for autistic adults. However, there are no accommodations specifically for autistic adults. This is in part due to the nature of historic site programming at large. Much of historic site programming focuses on school groups, so naturally, there is more programming for autistic children than autistic adults. OSH has strong ties with the New York City Public School district and parent groups. Their programming reflects these connections.

OSH is not opposed to serving autistic adults by any means, but there are no financial or social incentives to serve autistic adults, like there is for serving autistic children. Creating a program for autistic adults has more barriers because parents and educators have less of an interest in autistic adults. OSH gets support and encouragement from parents and educators when

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<sup>124</sup> Maggie Webber, (Old Stone House Director of Education) in email correspondence with the author, October 2024.

creating programs for children, but when it comes to adults, there is no authority to guide them. Autistic adults who visit OSH must be prepared to fend for themselves.

Autistic adults are more likely to show up to a historic site with their own accommodations, or are unlikely to request accommodations from staff. Some autistic adults have already developed coping strategies to be comfortable in public space. Sisson and Hernandez both reported that in their experience, autistic adults are more likely to show up with the tools they need already on hand. Wallace also mentioned that adult groups tend to come with their own accommodations, like headphones or fidgets. Historic sites may feel less motivated to accommodate a population who is seemingly more than capable of taking care of themselves.

Shanna Kattari, professor of social work at the University of Michigan Ann Arbor, defines invisible disability as “someone who might not be assumed to be disabled at first meeting.”<sup>125</sup> This description fits many autistic people, especially autistic adults who may have spent their entire lives honing their allistic “mask.” When autistic people give off the impression at first meeting that they are allistic, they gain social acceptance, but lose access to accommodations that otherwise may have been offered to them. The autistic people who “look” autistic to allistic people are children, because the media has disproportionately represented autistic children. I suspect that the need for autistic accommodations at historic sites is much higher than preservationists may know because autism is sometimes an invisible disability. The amount of autistic people who are visiting historic sites could be much higher than what preservationists estimate if high masking autistic people are not disclosing their disability.

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<sup>125</sup> Kattari, Olzman, and Hanna. “You Look Fine!”: Ableist Experiences by People With Invisible Disabilities.” *Affilia: Journal of Women & Social Work* 4, no. 33 (2018): 477–92. <https://doi.org/10.1177/0886109918778073>.

Jennifer Michel, Tour and Education Director at Gamble House, says “I have not encountered an autistic adult visitor who has requested anything special.”<sup>126</sup> It is unlikely that autistic adults never visit Gamble House. Autistic adults, who visit Gamble House, are probably not asking for accommodations because they either have already developed coping skills to get through the visit, or they do not want to sacrifice social acceptance for the sake of accommodations.

As I have established in my literature review, the autism accessibility conversation is dominated by parents. Historically, parental groups have ignored or suppressed autistic opinion. The media landscape supports the incorrect assumption that most autistic people are children or childish. As a result, preservationists have an implicit bias that causes them to over-value parental feedback, or assume that parental feedback is a suitable stand-in for autistic feedback. Mount Vernon, The Henry Ford, Historic Hudson Valley, Hormel Historic Home, and all my email-survey respondents mentioned parental feedback when I asked how they solicit comment from the autistic community. Most sites referenced parental feedback before referencing autistic feedback, or only referenced parental feedback. Over valuing parental input creates a positive feedback loop that causes future programming to further center parents and children.

There are consequences to programming that focuses solely on autistic children. Just as allistic adults have different needs from allistic children, autistic adults have different needs from autistic children. Freeman Tilden, in his 1957 work *Interpreting our Heritage*, states, “Interpretation addressed to children... should follow a fundamentally different approach. To be at its best will require a separate program.”<sup>127</sup> Tilden’s work is the foundation of modern historic site programming in the United States. It is a commonly accepted preservation practice to create

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<sup>126</sup> Jennifer Michel, (Gamble House Tour and Education Director) in email correspondence with the author, October 2024.

<sup>127</sup> Freeman Tilden, *Interpreting Our Heritage*, 1957. <https://muse.jhu.edu/chapter/1723153/pdf>.

separate programs for children and adults, and has been since the 1950s. Then why is it the case that we lump autistic children and adults together? I theorize that preservationists feel okay putting autistic adults in programs for children because they subconsciously view autistic adults as a type of child. If preservationists truly respected autistic adults as individuals with a fully developed sense of self and agency, I believe that they would feel uncomfortable lumping them in with children, and would design their interpretation to separate adults and children as is standard for allistic visitors.

### The Unique Needs of Autistic Adults

Through my investigations, I learned of the ways autistic adult needs differ from that of autistic children. Accommodating autistic adults will require historic sites to use a different approach than their approach for autistic children. Treating autistic adults differently from their child counterparts is a form of basic respect, as well as a way to improve the historic site experience.

Most of the social stories and sensory maps that I found were designed for children. Somerset Place's social story says, "The room with chairs is where we'll be starting the guided tour. I can sit with the adults who brought me."<sup>128</sup> The author of this social story probably only expected children to use it. I have come across many examples of social stories that assume the reader is a child. Social stories work best when they use easy-read text so that a wide range of people can access them, but that does not mean that they need to talk down to the reader, or assume that the reader is a child. Social stories that assume the reader is a child exclude a huge

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<sup>128</sup> *An Example of a Social Narrative From Somerset Place Historic Site.*

demographic of people. Mount Vernon, on the other hand, has a social story online that uses easy-read text, but it does not make reference to the reader being a child.<sup>129</sup>

A common accommodation offered to autistic historic site visitors is sensory mornings. Sensory mornings are far more common than sensory evenings. Sensory mornings can be wonderful for a family with young children, since young children tend to be awake early anyways. However, adults may wish to sleep in later. Autistic adults, in particular, commonly suffer from Delayed Sleep Phase Disorder (DSPD). “Delayed Sleep Phase Disorder is defined as a condition characterized by significantly delayed sleep onset times compared to social norms, leading to difficulties in waking up early.”<sup>130</sup> A sensory morning is not accessible to an autistic adult with DSPD because they will not be awake, but a sensory evening could work.

Mount Vernon’s sensory programming serves mainly children, ages 3-18 years old. Sisson says, “In the past, these programs have been marketed for kids, but we are trying to fix that. We are going to have a sensory-friendly evening for adults.”<sup>131</sup> The idea of a sensory evening came from a special needs teacher who runs autistic programs for adults. This special needs teacher is autistic herself. Her input shows why it is important for autistic adults to have a say in autistic programming. Autistic adults have unique insights into the accommodations that work for them. It is especially important for historic preservationists to consult autistic adults since current museum best practices do not always reflect the desires of autistic adults.

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<sup>129</sup> “Let’s Explore the Historic Area: A social narrative for visiting the Historic Area.”

*Mtvernon.Org*, n.d.

<https://mtv-main-assets.mountvernon.org/files/resources/historic-area-social-narratives-preservation.pdf>.

<sup>130</sup> Ballester-Navarro, Pura, María José Martínez-Madrid, Auxiliadora Javaloyes-Sanchís, César Belda-Cantó, Victor Aguilar, Inda María-Del-Mar, Amanda Richdale, and Javier Muriel. “Interplay of Circadian Clock and Melatonin Pathway Gene Variants in Adults With Autism, Intellectual Disability and Sleep Problems.” *Research in Autism Spectrum Disorders*, no. 81 (December 28, 2020). <https://doi.org/10.1016/j.rasd.2020.101715>.

<sup>131</sup> Maddie Sisson (Mount Vernon Estate Lead Specialist in Family Learning Mount Vernon Estate) in discussion with the author, October 2024.

Nicole Wallace, at Historic Hudson Valley, reports that groups of adult autistic people are more likely to visit for shorter periods of time. Adults want to move on to the next room or building at their own pace. This is the most common way autistic adult tours differ from autistic child tours. Usually, children are with caregivers or educators and may be required to complete the tour at a predetermined pace.<sup>132</sup> Wallace's observations are supported by Prospect Refuge Theory which theorizes that autistic people fare better in environments that allow them more agency to preview and leave spaces as they please. According to Prospect Refuge Theory it is essential that autistic people are given the agency to navigate a space at their own pace. Children may need more guidance, but there is little reason to restrict the movements of autistic adults.

A common theme among historic sites is that they will provide accommodations if requested. Accommodations by request have the advantage of being tailored to the individual. But, the act of making a request can be particularly painful for autistic visitors, many of whom already struggle with communication. Unlike autistic children, autistic adults may not have a caregiver with them to advocate for their needs. Social interactions, in general for autistic adults, are draining and stressful. Self-advocacy is even more socially draining and anxiety-inducing. In a dialog with autistic adults facilitated by the MAC, autistic adult Svetlana Novozhenina speaks about hesitating to ask museum staff for assistance. "The person with autism, they will delay asking to the last moment. There is some anxiety about asking."<sup>133</sup> Asking for help can be stressful even for an allistic person! What good is accommodation by request if the person who needs accommodations cannot reasonably request them?

The accommodations-by-request model also assumes that autistic visitors will know what accommodations they will need before the visit. Unless the visitor has been to the site before, it

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<sup>132</sup> Nicole Wallace (Historic Hudson Valley Director of Education) in discussion with the author, October 2024.

<sup>133</sup> MacAccess, *Workshop*.

is unlikely that they will know exactly what accommodations they will need. This is another reason why visitor preparedness measures are so important. A set of ready-made accommodations takes the pressure off of the visitors to advocate for themselves.

These examples speak to how autistic children and autistic adults experience historic sites in fundamentally different ways that require different programming approaches from historic sites. Children and adults cannot be given a one size fits all approach.

### Methods of Soliciting Feedback

I have observed historic sites soliciting feedback after a program has been orchestrated or informally, while a program is occurring. At most sites, autistic people and their families have little input during the design process, but their feedback is welcome during or after events.

At Mount Vernon, an evaluation is sent out to all visitors after a sensory-friendly morning. During the program, the staff talks to parents to get their feedback. Sisson mentioned that the most important form of feedback that the Estate gets is in the form of accessibility questions that get sent to her via email. These inquiries give her an idea of what the accessibility needs of the local autistic population are.

At the Henry Ford, a survey is sent out after events take place. Earlier in the program design process, the organization conducted an advisory group who tested the programs. The advisory group consisted of parents, teachers, and a couple of autistic individuals. Branden says that some of the most valuable feedback they get is from the local families who attend the program. She says that she is close to the families, and that they talk regularly.

Historic Hudson Valley's autism programming is still in its early stages. They stated that outreach to the disability community is still a work in progress while they continue to develop the program.

At all sites the most valuable feedback is gathered during informal interactions, like casual conversations with visitors and impromptu emails, not formal surveys. The historic sites that have long lasting relationships with autistic people and their families are more likely to get helpful input. The Henry Ford and Mount Vernon get better feedback than Historic Hudson Valley sites because their programs have been around for longer, and they are better known in the community.

### The Historic Fabric of the Site

I have found no evidence that the historic fabric of sites poses a barrier to autistic access. In fact, I have found quite the opposite. The staff members I talked to offered me no reason to believe that the historic fabric impedes site programming. Historic fabric may limit physical access, but it does not innately limit cognitive access.

Accessibility coordinators and historic site directors reported that a smaller, more intimate environment was easier to control in terms of possible sensory inputs. When asked about the relationship between accommodations and the site's historic fabric, Webber gave a surprising answer. She says that the site's historic fabric improves the experience for autistic visitors and does not hinder the programming. “As a small historic site, we are able to provide individualized attention to visitors on the spectrum. Individualized attention and a lack of ambient noise and light that can make navigating a larger space difficult.”<sup>134</sup>

Webber views the compact nature of the Old Stone House as an asset. Unlike a large museum, a small historic home may be less overwhelming for autistic visitors. In a smaller environment, it's easier to control sensory inputs. Noises that would normally carry in a sparse

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<sup>134</sup> Maggie Webber, (Old Stone House Director of Education) in email correspondence with the author, October 2024.

modern museum are muffled by the textiles in historic buildings. Communicating wayfinding information can be easier in smaller, historic buildings. Smaller groups of visitors allow autistic guests to connect more with their guides for an individualized experience.

Historic buildings are consistently viewed positively by autistic visitors. Sisson reported that the historic house was a favorite location for autistic visitors, children, and adults alike. “I think, personally, that (the historic fabric) hasn’t impacted the program. We don’t have to change the mansion at all. We don’t need to.”<sup>135</sup> she said.

Brandon reports that the historic structures at Henry Ford support the creative theming of sensory events, and do not hinder cognitive or sensory access. “In Greenfield Village, we have many historic buildings. The buildings give us different themes to choose from. Sometimes too many buildings can be too much for an autism program, so we have to limit it to a couple of buildings.”<sup>136</sup> Branden does not see the historic fabric of the site as a barrier to autistic access. She sees it as a programming tool that enhances the experience, when done properly at an appropriate scale.

The Historic Hudson Valley recently completed an accessibility audit with an outside consultant, Westchester Living, at all of their historic sites. The consultants understood that the site's historic fabric could create limitations for physical access. The consulting firm identified ways that the historic fabric of the site impaired physical access, but they reported no instances of the historic fabric impairing sensory or cognitive access.

Historic Sites can be analyzed using the Autism ASPECTSS Design Index. Historic sites are suitable spaces for autistic people because they fit the index criteria for acoustics, spacial

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<sup>135</sup> Maddie Sisson (Lead Specialist in Family Learning at Mount Vernon Estate) in discussion with the author, October 2024.

<sup>136</sup> Caroline Branden (The Henry Ford Accessibility Manager) in discussion with the author, October 2024.

sequencing, compartmentalization, transitions, sensory zoning, and escape. Safety is the only point on the index that is not met. Historic buildings limit acoustics. The materials of a historic space do not let sound echo as easily as a modern space. Historic spaces do not have open floor plans. Closed layouts create a natural sequence of space. The spatial layout of historic buildings reflects a logical progression, where each room has a compartmentalized, defined function. A closed off floor plan creates a natural opportunity for preservationists to implement sensory zoning. Sensory stimuli can be easily clustered in different areas of a historic building, because historic buildings have many rooms, not one open space. It is much harder to meet these points on the index with an open floor plan. Historic buildings are generally smaller than modern buildings. Wayfinding is earlier in a smaller historic building than it is in a large, modern building. A historic house, for example, should be easier to navigate, than a four-story art museum. A smaller building also means an easier escape. Enclosed spaces might also create a sense of safety for some, but it does impede sightlines and reduce the amount of personal space a person have, which conflicts with an autistic person's need for safety.

Wallace from Historic Hudson Valley gave me some insight into how preservationists generally view the topic of accessibility. She says the attitude of many sites is “We’re a historic site; there's nothing we can do or change!”<sup>137</sup> Be wary when a preservationist claims that autism accessibility isn't a reasonable goal. Autism accessibility and preservation are not inherently at odds. It's all too common to hear preservationists protest that they can't change the character defining features of a site. To that, I say, then don't! Your site may already be naturally compatible with sensory access needs!

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<sup>137</sup> Nicole Wallace (Historic Hudson Valley Director of Education) in discussion with the author, October 2024.

Another common complaint is that accessibility measures are expensive. Nicole Belolan says there are cheap and easy measures that historic sites can take to improve autistic access. “They cost time, and not much more.”<sup>138</sup> The challenge to autistic access is not the static nature of a historic environment, or money. The real challenge is finding time. Social stories, sensory maps, and quiet hours are relatively inexpensive interventions that can positively impact the visitors who cannot bear the normal historic site experience. And best of all, these interventions do not change the site's historic fabric.

### The Real Barriers to Autistic Access

Many preservationists wrongly assume that the fabric of the historic site is the largest barrier to autistic access. I have found that this is not the case. The real barriers to access are as follows: The first real barrier is limitations on information technology. At Historic Hudson Valley (HHV) social narratives are available by request but are not published on the website. HHV does not currently have the information technology resources to publish social stories online. The social narratives were created relatively easily, but hosting them on a website is a challenge because the IT department does not have the time to upload them online. HHV has stated that they intend to make their social narratives available online at some point.<sup>139</sup>

The second real barrier is the expense of training all staff members. Training is a real expense, and is time consuming. In a disability training environment where some autism advocacy groups offer more credible information than others, it also may be difficult for a site to determine who is a trustworthy voice. Some historic sites have overcome the training barrier by

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<sup>138</sup> Nicole Belolan (Public history, material culture, & disability historian) in discussion with the author, October 2024.

<sup>139</sup> Nicole Wallace (Historic Hudson Valley Director of Education) in discussion with the author, October 2024.

only training the front line staff and education staff who are the most likely to come into contact with disabled visitors.

The third real barrier is the small scale of historic buildings. As I discussed in the last section, the small scale of historic buildings makes them largely compatible with autistic needs. This does not apply when we consider a feeling of safety. Neiman states that a feeling of safety should be created by providing personal space and clear sightlines. The fabric of historic buildings do not lend themselves to plentiful personal space and clear sightlines. Preservationists can mitigate a lack of personal space by limiting tours to small groups, and being cognizant of how many people are allowed into a small room at once. Maps can indicate to a visitor the layout of the historic building to help overcome the overwhelm that could come with a lack of clear sightlines.

I have repeatedly stated that accommodations for autistic people do not inherently require a change to a site's historic fabric. Sensory rooms are the exception. Sensory room installation requires sites to set aside physical space. Sensory rooms work well in large museums that already have extra space. I have not found an instance of a historic site installing a sensory room, and I would not recommend it. Sensory rooms are a large expense, that in my view are unnecessary when there are so many other ways to accommodate autistic audiences.

The main barrier to autistic access I have identified is the fear preservationists have of working with and for disabled populations. Many well intentioned people do not know where to start when it comes to approaching cognitive and developmental disability. There is limited information on how to approach autism at historic sites. Some preservationists are understandably afraid that if they try something new, they will get it wrong.

Sisson wisely said, “I have found that (the autistic) audience, in particular, is very understanding and forgiving. Everyone is so willing to give feedback. Showing that you are trying and want to help makes a big difference. I think from grad school, the rest of my cohort found (disability programming) intimidating because we didn't know how to do it. It's not covered regularly in grad school... The only way to do it is to try it.”<sup>140</sup>

I would encourage preservationists to remember that perfect is the enemy of good. When trying out new accommodation methods, it is likely you will get some things wrong, but the autistic community is not looking for perfection, they are looking for compassion, and effort. If you extend compassion to the autistic community, then they are more than willing to extend that compassion back to you.

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<sup>140</sup> Maddie Sisson (Lead Specialist in Family Learning at Mount Vernon Estate) in discussion with the author, October 2024.

## CHAPTER 4:

### Conclusion

Through my research I have concluded that historic sites do not often explicitly accommodate autistic adults. There are millions of autistic adults in the United States, but very few historic sites have programming that is designed for autistic adults. Accommodating autistic adults, and others with cognitive disabilities, at historic sites does not need to interfere with the fabric of the site. Historic sites are generally amenable to the small changes that have the potential to improve the autistic experience. Many historic preservationists are hesitant to accommodate adult autistic visitors because there is a lack of information on what accommodations would be helpful. Hopefully, this thesis can inform preservationists on the best practices for accommodating autistic adults at historic sites. My recommendations for historic sites who wish to accommodate adult autistic visitors are as follows:

Accommodating autistic visitors starts with training staff members who are the most likely to interact with visitors, including security staff. Autistic MAC members report that they feel stress interacting with museum staff members who do not recognize autistic behaviors in adults. Since most people imagine a child when they imagine an autistic person, they are not prepared to encounter an adult presenting with the symptoms of autism. An underinformed staff member may incorrectly assume that an autistic adult is behaving “abnormally” because they are mentally ill or abusing substances. Staff members who interact with guests should be prepared to recognize stimming behaviors, a lack of eye contact, and repetitive behaviors in adults. Staff should also know that many autistic adults, especially those who are high masking, may not disclose their autistic status.

Autism societies sometimes provide disability training to museum staff. But beware, not all autism organizations are created equal. Historic sites should look for organizations that promote autistic self-advocacy, and who employ autistic people. Online resources are also available, and are a cost effective option for historic sites with a limited budget. I recommend the online resources from the Autistic Self Advocacy Network website.<sup>141</sup> Digital resources that prioritize the needs of autistic people, and were created by autistic people, will be linked in the appendix.

Historic sites should have digital access tools like social narratives and sensory maps available online for visitors to access before they arrive at the site. Social stories and sensory maps are low cost accessibility options. If done in house, they only cost time. Social stories should include logistical information such as directions, parking considerations, ticketing, the length of tours, and the average number of guests per tour. The social story should show your guests the route of tours on a map, notate no touch areas, areas where food is or isn't allowed, and the location of restrooms. A social story is a good place to point out any unspoken social norms that are at work at your site. Social stories should also be used to communicate important sensory information about your site. Are there parts of your site that are loud, bright, smelly, or crowded? Also, note areas that have low levels of sensory input. If your site has the ability to invest money into a better researched social story and sensory map, consider reaching out to local autistic organizations that promote the voices of autistic self-advocates. Some may provide services such as a sensory audit, which can reveal site-specific sensory information.

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<sup>141</sup> Autistic Self Advocacy Network. "Autistic Self Advocacy Network," n.d. <https://autisticadvocacy.org/>.

Once social stories and sensory maps are created, be sure to provide printed copies at your historic site. Place them in a highly visible, easily accessible spot. It is not wise to limit these resources to visitors who disclose a disability or “look autistic”.

Many autistic adults would benefit from a quiet/sensory hours program. Consider opening your historic site outside of normal hours to accommodate autistic visitors. During quiet/sensory hours you can dim lights, reduce loud noises, reduce visitors in crowded spaces, and provide noise canceling headphones or earplugs. Quiet/sensory hours that occur in the evening are more accessible to autistic adults than morning hours. Repeat sensory hours once a month, or once a season on a predictable schedule. Sensory events that happen as a one-off contribute less value to your local autistic community.

Modified tours can be useful for accommodating autistic guests. There are many ways one can modify tours. The first way is to hold tours with a limited number of guests or private tours. Reduced sensory tours can look like a normal tour, but with lights dimmed, and reduced noise. A touch tour can include additional sensory elements such as objects that visitors can hold and touch. These additional tactile elements can be real or replica artifacts that relate to the site. Touch tours can also accommodate those with limited vision. If sensory tours interest you, I would recommend looking to The Henry Ford touch tours as a useful precedent. Modified tours can also combine elements from all three of these models.

When designing sensory hours, tours, or other autism friendly events, refer to the Autism ASPECTSS Design Index principles from Chapter 2. Historic sites should allow guests the option to easily leave a space if they feel uncomfortable. Be sure to highlight exits and let your guests know that they have no obligation to stay for the entire tour or event. Group areas of high sensory input together so they can be avoided completely if the visitor so chooses. If your event

involves sensory input, introduce it to guests slowly over time, and build from a low level of input to a higher level of input. Use the compact nature of a historic building to your advantage and create clear zones with definite functions. Use hallways, pantries or other small rooms as transitory zones between spaces with different functions or different levels of sensory input. The flow of the tour should use an easy to follow logical sequencing.

When creating programming, remember that autistic adults are coming to your site to experience the site not to learn how to communicate better or to reduce their autistic behaviors. When researching program precedents, you may come across examples of other sites that use autism accessibility programming to “teach life skills.” These programs are usually designed for children, and should not be replicated for autistic adults. Any attempt to therapize autistic adults is infantilization and is not within the scope of historic preservation. You should not try to “teach” autistic adult visitors for the same reason you would not try to teach allistic adult visitors. The point of historic site interpretation is to facilitate visitor learning through experiences, not to “teach important life skills” that are unrelated to the site. Keep educational content within the scope of the site’s interpretive plan and treat autistic adults like any other adult visitor.

Your programming does not need to be advertised for autistic people explicitly. Consider marketing your events as “sensory friendly” so that the widest range of visitors feel comfortable taking advantage of your accommodations. Visitors with other sensory, cognitive, and developmental disabilities can also benefit from sensory programming options. Remember, according to the principles of universal design, accommodations should be designed for the benefit of all people, not just for the benefit of one type of person.

Providing cognitive and sensory access is an iterative process. Don't be afraid to make a mistake or two. Solicit feedback through focus groups or surveys after testing out new strategies. Remember to talk to people while events are going on. These informal conversations often offer up much better insights than surveys that aren't asking the right questions. The best way to find out what works for your site and your local community is to test out an intervention, get feedback, and try again. When you engage in a feedback-driven iterative design process, you are building rapport with your local autistic community, which will serve to help the effectiveness of your interventions in the long run.

Don't be afraid to consult autistic people and ask them for feedback. Your local autistic community will most likely be thrilled that you tried out something new, even if it did not go to plan. When soliciting feedback make sure you are paying attention to the experiences of autistic people and not over representing the experiences of family members and educators. Autistic adults can be found by contacting autism self-advocacy groups or museum access groups. The Autism Self Advocacy Network, for example, has local chapters. If you have the means, consider paying autistic people for their feedback. This shows that you respect their time and value their expertise.

You are under no obligation to take all of these recommendations, or to implement them all at once. Start with what is easiest for your site to implement, and work your way up to more time-consuming and expensive accommodations and programs as you grow your confidence and secure more funding. The preservationists that I have interviewed all started small and grew their accessibility programming over the course of many years. Many autistic adults, myself included, can tolerate historic sites just fine without any accommodations. If you do nothing, it will not be the end of the world. But, if my guests were only tolerating my site, I would take that as a sign

that something needs to change. By listening to autistic people, and accommodating their needs without judgment, you have the opportunity to open up your historic site to a whole new audience who might have otherwise felt unwelcome. I look forward to seeing how you choose to make your historic site a gratifying experience for everyone.

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## APPENDIX A

Recommended Resources for Historic SitesUnderstanding Autism Self Advocacy

*Loud hands: Autistic people, speaking.* Washington, DC: Autistic Press, 2012.

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Understanding How Autism Presents in Adults

Bartmess, Elizabeth. *Knowing Why: Adult-Diagnosed Autistic People on Life and Autism*, 2018.

Accessible Programming and Event Planning Resources

“Holding Inclusive Events: A Guide to Accessible Event Planning.” *Autistic Self Advocacy*

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Research Based Design Resources

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## APPENDIX B

### Extended Methodology

#### Script for Email Survey Questions

1. What accommodations are available to autistic visitors on a day-to-day basis outside of special programming?
2. When did the site begin offering accommodations for autistic visitors?
3. What disability training is offered to the staff?
4. How does the site connect with the local disability community?
5. Question the specifics of site-specific programming (Ex. What does a private tour look like?)

#### Examples of Email Survey Exchanges

##### ***Gamble House, Pasadena CA***

***9.20.24***

Thank you for contacting us about touring for special needs visitors. I'm happy to answer any questions. We have a small kit of objects that we have pulled out for a very young visitor at the request of his mother. We use the same kit for adults with vision challenges. But I have not encountered an autistic adult visitor who has requested anything special. It will be interesting to get your perspective on what might interest adults.

##### ***The Old Stone House, NY***

***9.23.24***

*Does the Old Stone House still put on autism-friendly shows with Spellbound Theatre? If so, what makes these shows autism-friendly?*

In March 2015, OSH partnered with Spellbound Theatre to create a special series of performances for children and adults on the Autism spectrum. The resulting performance piece, *Under The Tree*, featured puppetry and animation and was participatory, so that if an audience member would stop to touch or interact with the performers we would alter the performance for them. These performances were held on weekend mornings, when OSH was closed to the public. A corner of our gallery space was adapted into a quiet space and included bean bag chairs, a soft foam floor, and tent walls to provide privacy and a quiet space.

In addition, OSH built a social story for visitors on the spectrum to help them manage anxiety about entering an unknown space.

Since 2015, Spellbound has undergone many changes and no longer performs at OSH. We continue to offer children's programming, but do not currently have the capacity to build more dedicated performances for children and adults on the autism spectrum.

We do continue to use the practical lessons learned from this process to help support visitors on the autism spectrum.

*What accommodations are generally available for autistic visitors?*

As a small historic site, we are able to provide individualized attention to visitors on the spectrum individualized attention and a lack of ambient noise and light that can make navigating a larger space difficult. We offer visits by appointment outside of our open hours.

We serve many students on the spectrum through our School Programs. We ask visitors to indicate if they have special needs before their visit and adapt our programs through more direct language and explicit conversation. We allow students to move retreat from our second- floor great room to our gallery space as needed. In addition, we have had children on the spectrum enrolled in our Garden Explorers program. This program has a very small student-to-counselor

ratio and is able to create accommodations for students who may need more individualized attention in order to function.

*Does the Old Stone House have accommodations for autistic adults?*

We are not currently offering any directed programming for adults on the autism spectrum. We make accommodations for visitors with special needs as requested.

*When did the Old Stone House first begin offering special programming for autistic visitors?*

We have been offering programming for visitors for many years, but I would say our 2014 work with the [Devereaux Foundation](#) enriched our understanding of visitors on the spectrum and how to serve them.

*What disability training is offered to the staff?*

We offer regular professional development meetings. Workshops and field trips to our staff on a wide range of topics, including serving individuals with special needs. We could use another group discussion about serving a community of neuro-diverse visitors, so thanks for the reminder!

*How does the Old Stone House connect with the local disability community?*

OSH is a very active community space and is utilized by a wide range of visitors. We partner with a series of schools and organizations including classroom teachers working in NYCDOE Special Education programs as well as Park Slope Parents and a variety of other organizations.

***Correspondence with Amy Kelly of Devereux***

***9.23.24***

Hi Maddy. Yes, I was directly involved with that (OSH Autism Programming). I did a disability awareness training and developed some tip sheets for the staff on how to assist families. I also wrote some short stories for the houses, so the kids could become aware of the environment ahead of time. I've attached a copy of them for your reference. (Please don't distribute for the public because they are proprietary between Devereux and NYHHT).

*Morris Jumel, NY*

*10.7.24*

Dear Maddy

Thank you for your inquiry regarding programming for autistic adults. We have various hands-on reproductions that allow for a more tactile experience, and we offer a tactile map of the Mansion for those with low-vision, as well as anyone on the spectrum. There is a 3-D virtual tour that can be viewed before arrival so that adults on the spectrum can anticipate what they will be seeing. We do not presently have a box of items with which to offer calming toys or a weighted vest, nor do we have a cool down room for lack of space. In the warmer months, a tour around the park is an opportunity for those on the spectrum to see the outside of the Mansion, and explore the garden.

Interview Questions for Primary Case Study Staff

1. Can you tell me about your background as it relates to working in a historic house museum?
  - a. How are you related to x site?
  - b. How long have you worked at x site?

- c. What is your role here?
2. What is your educational and professional background in?
3. Why do you offer accommodations to autistic visitors?
4. When did your site begin offering accommodations?
  - a. What was your goal in beginning to offer these accommodations?
5. What is the median age of a visitor to your site?
6. What age group is your programming tailored for?
7. What sources did you look to when developing accommodations and special programming?
  - a. What did your research process look like when you were developing your programming?
  - b. Where do your program ideas come from?
  - c. What precedents does your site look to when creating programming for autistic visitors?
8. Are you personally affiliated with any disability advocacy groups?
9. Is your org affiliated with disability advocacy
10. Are disabled people involved in program planning?
11. How do you fund your disability programming?
12. What disability training is available to your staff?
13. Walk me through the accommodations you offer.
  - a. Have you considered other types of accommodations? (Social stories, sensory mapping ect)
14. How did you settle on this specific program?

15. Has your site ever hosted a special program for autistic visitors?
16. If an autistic visitor was to visit your site on an average day, what accommodations would be available to them?
17. Does the historic fabric of your site limit your programming?
18. To access accommodations, do visitors need to make special requests in advance?
19. Is there an extra cost for requesting accommodations?
20. How do you solicit feedback on your programming?
21. What is something that people don't know about museum work that you think they should know?
22. Where do you see accessibility programming for autistic people going in the future?
23. What are your future goals?

HOUSE	ADDRESS	Social Story	Sensory Map	Quiet Hours	Private Tours	Special Programs	Website Notes	Affiliated Orgs.
NYC Tenement Museum	103 Orchard Street, New York, NY 10002				Yes		Private tours available on request, 2 weeks notice required	MAC
Lefferts Historic House	Prospect Park, near Ocean Avenue Brooklyn	Yes		Not officially, but quieter times are recommended on website		Yes	Website has accessibility page with social story	Involved in 2016 study for historic site ASD programming. Part of HHT. Devereux.
Bartow Pell	895 Shore Rd, Bronx, NY 10464					Yes, infrequently, as part of the HHT	Limited accessibility info on website	HHT, Devereux
Old Stone House	336 3rd St Brooklyn	Just for Spellbound Theatre				Spellbound Theatre		HHT, Devereux
Wyckoff House	5816 Clarendon Rd Brooklyn				Yes			HHT, Devereux
Morris-Jumel Mansion	65 Jumel Terrace Manhattan				Yes, upon request	"Touch History Family Workshop"		HHT, Devereux
Bowne House	37-01 Bowne Street Queens	Available upon request for school groups						
Hormel Historic Home	208 4th Ave. NW	Yes				Yes, MANY, for children and teens but not adults	Links to Autism Resources	Autism Society, Autism Speaks, Autism Society of Minnesota
Hunter House victorian museum	240 W Freemason St, Norfolk, VA 23510, USA						Nothing about access on website	
Henry Ford Museum	20900 Oakwood Boulevard, Dearborn, MI 48124-5029	Yes	Yes	Yes		Sensory days	Extensive offerings for ASD visitors are advertised on the website. Easy to find. Visitor prep materials easy to find.	Autism Alliance of Michigan
Molly Brown House, Denver	1340 Pennsylvania Street	Yes			Sensory friendly tours, and touch tours		Extensive accessibility page on the website.	
Weeden House Museum and Garden	300 Gates Avenue						No accessibility info on the website.	

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The John Brown House Museum, Rhode Island Historical Society	52 Power Street, Providence, RI 02906	Yes					Interpretive signage and checklist available online at Rhode Island Historical Society site	The Rhode Island Historical Society
Macculloch Hall Historical Museum	45 Macculloch Ave. Morristown, NJ 07960	Yes				Third Saturday sensory tours		MAC
James J. Hill House	240 Summit Avenue	Yes				Sensory friendly day (not repeating) by reservation only		
Mount Vernon	3200 Mount Vernon Memorial Highway Mount Vernon, Virginia 22121	Yes, 4 of them	Not a sensory map per se, but a sensory focused social story on web			Sensory Mornings	Upon arrival, guests will receive a sensory bag (while supplies last). Explore the Historic Area with a special self-guided tour. Explore the Mansion at your own pace. Visit the Discovery Cart for hands-on lesson about the production of textiles at Mount Vernon. A take-a-break room will be available from 8 a.m. to 9a.m.	
Gamble House	4 Westmoreland Place Pasadena, CA 91103				Yes		With advance notice, we are pleased to assemble a touring kit with tactile objects and visual aids. Please contact the Tour and Education Manager at <a href="mailto:jenniferm@gamblehouse.org">jenniferm@gamblehouse.org</a> or 626-793-7419 for more details.	
Kykuit	381 N Broadway, Sleepy Hollow, NY	Upon request					Sensory backpacks and social narratives are available upon request	National Trust and Historic Hudson Valley
Philipsburg Manor	381 N Broadway, Sleepy Hollow, NY	Upon request					Sensory backpacks and social narratives are available upon request	National Trust and Historic Hudson Valley
Washington Irving's Sunnyside	3 W Sunnyside Lane, Irvington, NY 10533	Upon request					Sensory backpacks and social narratives are available upon request	National Trust and Historic Hudson Valley
Conner Prairie	13400 Allisonville Road, Fishers, IN 46038		Yes	Yes			Quiet spots with sensory kits, weighted blankets, fidgets, lotion, children books.	Anthem Blue Shield sponsors the sensory kits