



“Nothing About Us, Without Us.”

Designing Sensory Inclusion

for Museum Visitors
with Autism Spectrum Disorder

Rachel Landress MEPD Thesis 2019

A thesis submitted to The University of the Arts in partial fulfillment of the requirements for the Master of Fine Arts degree.

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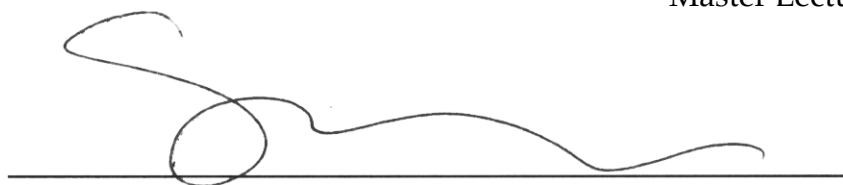


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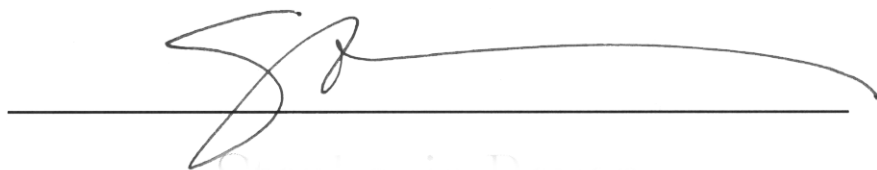
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Abstract

Questions asked at the beginning of this study: What steps can museums take to create a daily environment that is inclusive for autistic individuals with sensory issues? What changes should museums make to achieve this inclusion? This study introduces what Autism Spectrum Disorder is and the different aspects. While taking a look at how museums can become more inclusionary through many aspects, from staff training to design elements to community conversations. To give this thesis a more human voice, museum interviews and family with Autism Spectrum Disorder interviews were conducted, bringing to light the experiences and ways in which they can come together to create an inclusive museum for its community and visitors. The conclusion of this study gives a list of practices, needs and wants, and a visual poster of Inclusionary design.

Keywords: Autism Spectrum Disorder, sensory processing, autism and museum experiences, autism and the built environment, inclusionary design

Acknowledgement

I want to thank my family and friends for giving me support through these last few years. You all have supported me through thick and thin. To my family, who has given me a lifetime of love and experiences, to whom I dedicate and write this thesis. To the families like mine, who have gone through a lot with their own children, brothers, sisters, and loved ones, in hopes that my research will make its way to exhibit designers. To my cohort sisters, who have been a major force during this whole experience with so many laughs and beers. Lastly, to the families that shared their story and experience, you have made this thesis and the reason why inclusionary design is so important.

Dedicating this to my mother, Garret, Aunt Di, and Jamie, who has been a major part of my life and my story.

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Personal Statement

I have been around special needs people my entire life. Growing up, I did not understand that my cousin has an intellectual disability—delayed speech, a slight delay of fine motor skills—with the mentality of a young teenager. It was not until I turned thirteen years old when my little brother, Garret, was born, that I understood the things that can make us different. Garret was born with Down syndrome, a chromosome disorder that can manifest with a range of health, physical, and mental issues.

These diagnoses rocked our family, and yet we jumped into action by finding early intervention programs along with physical and speech therapy to work on having a “normal” life. We wanted everyday activities like going to the store, playing in the yard, attending school field trips, doing chores, participating in sports and getting grounded to happen with as little disruption as possible. Soon, we were attending the best intervention program three days a week, sometimes two to three hours at a time. This kind of schedule places a hardship on a family with a single working mother, but the family does what is needed for the children.

Both my mother and aunt had to figure out how to make our family lives as normal as possible, which can be difficult when there are other active children and limited support from outside the family. I remember my mom being so tired at times that there were weeks when we ate out every night—not an ideal situation, but it was the reality.

Just finding time to attend activities was hard, but if the event was one of importance or at a reasonable time and date, we would go. Those events were usually a family day with one of the advocacy groups in the area who arranged trips to places like the zoo or a science center that was either cheap or free. For my mom, she had to make sure she had enough energy or have me come with her; my little brother was a runner and would be off and gone any time he saw the opportunity. Either way, both my mother and aunt’s biggest concern for their children was to have a full life as much as possible to make them feel included despite their disorder.

Having a child with a serious genetic disorder or disability is always a hardship due to the many medical and/or behavioral issues that arise during their life; adding in additional children only heightens the stress of the parents. Even with all these factors, my family would not want it any other way. My brother and cousin are both some of the most fun, loving people one will ever meet. We see these things as small bumps in the road to a wonderful life worth living.

My life experiences have inspired me to think about designing exhibition spaces through a personal lens. I want to find a way to make experiences at museums and cultural institutions inclusionary and welcoming for families, contributing to their overall ease of everyday life.



Pictures of my family through the years.



Introduction

For my thesis, I will focus on the importance of creating sensory and inclusive exhibitions for visitors with Autism Spectrum Disorder (ASD) in children's, science, and natural science museums. I chose ASD due to the prevalence of the disorder and the wide range of attributes within the spectrum. One of the many challenges of the disorder is how the brain processes something as natural as touch or sound and how a person with ASD can react.¹ Though many with ASD have trouble with sensory processing, they are not the only ones, as many other disorders share this trait.² These are representational experiences for many families with special needs children.

Over the last half-century cases of ASD have continued to rise despite efforts to identify and address root causes.³ Accessibility efforts of public teaching spaces have not kept pace. Many museums have sensory-friendly days a few times a year for a limited number of hours, usually programmed through the education department. Having limited and sometimes non-frequent sensory-friendly days and times do not always fit into a child's schedule. Children with special needs, no matter what diagnosis, adhere to a mild to very strict schedule due to the need for structure and certainty.⁴ Those who have a strict schedule may become overwhelmed with an unknown event.⁵ **What steps can museums take to create a daily environment that is inclusive for autistic individuals with sensory issues? What changes should museums make to achieve this inclusion?**

Over the last decade, many researchers have studied causes and reactions for those on the

spectrum, including the many behavioral and social difficulties.⁶ Through personal interviews with museum staff conducted at the preliminary stage of this study, it appears that sensory friendly days are only offered three to four times a year for a few hours at a time. During these designated times, the museum will lower lights and sound and set up quiet spaces with pillows and rugs and add docents to assist the children with the activities.

In recent years, there have been a few architects pioneering the design of how to create buildings, classrooms, and environments for autistic users. With the use of these principles and museum exhibition design tools, museums might start to become more thoughtful about creating museums and new exhibitions in the future.

Autism Spectrum Disorder (ASD) is a complex neurological disorder defined by a wide range of characteristics of social, behavior, verbal, and sensory challenges. Symptoms of the disorder can be diagnosed as early as eighteen months old, though most are diagnosed between four to eight years old and affect daily function. The term “spectrum” is used to convey a wide range of symptoms and levels of behaviors.⁷ ASD is the number one growing developmental disorder in America with more than 3.5 million (1% of the population) Americans diagnosed.⁸ According to the Center for Disease Control (CDC), the number of diagnosed cases of autism has increased significantly with 1 in every 166 in America (2004) to 1 in every 59 (2018) by age 8, of which 1 in 36 are boys.⁹

Scientists have yet to identify the primary cause of ASD, but they have determined it might be a combination of environmental and genetic factors.¹¹ Genome mapping has identified the potential markers for the disorder, with the possible disruption of brain growth/ development at an early age.¹² The specific environmental factors have yet to be identified.¹³ Over the last two decades, there was a panic over the notion that autism was caused by vaccinations.¹⁴ This has been thoroughly disproven by the medical community that vaccinations do not cause ASD.¹⁵

Identified Prevalence of Autism Spectrum Disorder
ADDM Network 2000-2014 Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Combined Prevalence per 1,000 Children (Range Across ADDM Sites)	This is about 1 in X children...
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88
2010	2002	11	14.7 (5.7-21.9)	1 in 68
2012	2004	11	14.5 (8.2-24.6)	1 in 69
2014	2006	11	16.8 (13.1-29.3)	1 in 59

Table 1 From The Center for Disease Control¹⁰

Early indicators include:¹⁶

- Not responding to name
- Little to no babbling or pointing by 18 months, speech by 2 years
- Withdrawing from social situations
- Little to no eye contact
- Obsessive lining up of objects
- Intensity during activities
- Unusual reactions to touch, smell, sound

Once a child has been diagnosed with ASD, parents might have the opportunity to start the child in early intervention programs; working on speech, fine motor skills, social interactions, and physical therapy. There is no cure for the disorder; using therapy programs and social interactions can lessen the symptoms to a livable level, creating a “normal” life.¹⁷

“If you’ve met one person with autism, you’ve met one person with autism.” -Dr. Stephen Shore¹⁸

“This quote emphasizes that there is great diversity within the autism spectrum. While the commonalities of people on the autism spectrum include differences in communication, social interaction, sensory receptivity, and highly focused interests, it’s important to understand that the constellation of these characteristics blends together differently for each individual. This is why some on the spectrum are good at mathematics while other may be good in their arts, sports, or writing – just like the rest of humanity. Autism is an extension of the diversity found in the human gene pool.”¹⁹

The puzzle ribbon was adopted in 1999 as the universal sign of autism awareness. Although this image is a trademark of the Autism Society, the organization has granted use to other non-profit organizations in order to demonstrate unity and advance a universal mission as opposed to any individually held interests or promotion of a single organization.²⁰

www.autism-society.org

1. **Autism**- a complex neurological disorder defined by a wide range of characteristics of social, behavior, verbal, and sensory challenges.
2. **Developmental Disability**- a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.
3. **Intellectual Disability**- involves problems with general mental abilities that affect judgment, learning, and daily life activities.
4. **Physical Disability**- a limitation of a person's physical mobility, stamina, or function and can limit daily living and other bodily functions.
5. **Participatory Design**- strong collaboration between the intended users and the designer team by identifying their needs and strengths with the purpose of building interfaces that fit the special needs of users. In some cases, other stakeholders such as teachers or parents can share their thoughts and experiences.
6. **Sensory processing disorder**- the way in which the central nervous system of the body receives messages from the senses of the body and uses that information to act in an appropriate motor or behavioral responses. Sensory processing disorder (SPD, also known as sensory integration dysfunction) is a condition in which the sensory signals received by the central nervous system do not become organized into an appropriate response.²¹
7. **Haptic**-relating to the sense of touch, relating to the perception and manipulation of objects using the senses of touch and body awareness.
8. **Handlungsspielraum** – the conceptual creative space in which participants and designers collaborate, exploring unique pathways by balancing given structures and freedoms in order to creatively think about the design at hand.²²
9. **Universal Design**- design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability, or disability. An environment (or any building, product, or service in that environment) should be designed to meet the needs of all people who wish to use it.
10. **Social Story**- guides or tools to help prepare individuals with autism for social interaction and public events; in this case, a visit to a museum.
11. **Golden Ratio**-a common mathematical ratio found in nature that can be used to create pleasing, natural-looking compositions in your design work.²³
12. **Echolalia**- the uncontrollable repetition of words or noises.
13. **Want**- have a desire to possess or do (something); wish for.
14. **Need**- require (something) because it is essential or very important. Expressing necessity or obligation.
15. **Gobo**- a stencil that can be placed in theatrical lighting instruments or lighting source to create a pattern or effect on a surface.

16. **High function-** a term used to describe a person with a disability as how independently they can carry out day-to-day activities like eating, dressing, speech, etc.²⁴
17. **Low function-** a term used to describe a person with a disability that has multiple impairments in development and verbal skills that can affect day-to-day activity.²⁵
18. **Pre-visit guide-** a visual guide that visitors can view prior to a visit. The guide is usually a combination of images and descriptive words to show/describe the many aspects of the museum.
19. **Gross motor skills-** skills that refer to the larger muscular areas that are more generally broad like: walking; sitting; jumping.²⁶
20. **Fine motor skills-** skills that refer to dexterity and hand-eye coordination.²⁷

Rationale

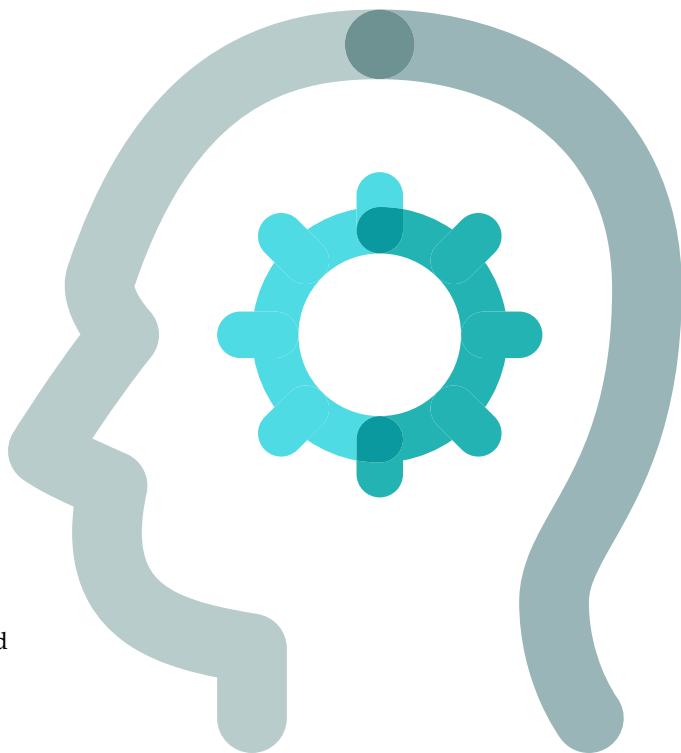
With the number of autism diagnoses on the rise, the number of programs for children with autism have been slow to be incorporated in museums and institutions. **With the current rate of 1 in 59 people on the spectrum in America, what can we do to fast-track the process to have an inclusive environment?**

Museums are educational and inclusive institutions for communities, especially children, to have a safe, fun, informal learning environment. Lisa Jo Rudy writes, “Unlike schools, museums have always operated on the assumption that visitors learn through all their senses. As a result, they have always designed their exhibits, programs, workshops, and classes to be interactive, multisensory, and open-ended.”²⁸ Any opportunity to give a child an open place to learn is a benefit to their health and socialization.

With intellectual disabilities, children can sometimes struggle within the classroom due to the different stimuli encountered such as: other people moving around, sounds, and layout of the space. Cultural institutions, like museums, provide an alternative learning environment to create more inquiry-based learning, integrating more optional school interactions. Many studies have shown the positive effects museums give children with autism—a free-choice learning experience that can become engaged through object-centered, inquiry behaviors. About 80% of surveys that were taken by families of children with intellectual abilities agreed that the museum experience enhances the use of their social and communication skills. These studies demonstrated learning in museums provided a promising solution, challenging the traditional education practice in

America’s educational system.²⁹

I have used the philosophy in the autistic community, “Nothing About Us Without Us”—a term which refers to the inclusion of people with disabilities being included in decision making about things that affect them—to ground and vocalize the needs, wants, and experiences of these individuals and families. This philosophy evolved out of the 1980s and 90s when the fight for the Americans with Disabilities Act (ADA) was ramping up.³⁰ This study is presented in the hopes of giving families and individuals the chance to feel encouraged to attend museums more frequently with the confidence that their needs for sensory and social sensitivities will be met.



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Background & Research

The first part of this investigation is empirical research, looking at what experts have found within the design field and the impact it has allowed. The second part is divided into two parts: interviews with institutions and interviews with families. It's important to not only see how the different kinds of museums create sensory friendly environments, but how the families experience those various institutions.

Top photos: Petros Giannakouris/AP PHOTO

Bottom left photo: sdtbw.wordpress.com/2013/06/14/from-nature-to-design-the-golden-ratio/

Bottom right photo: www.apexproject.com.in/golden-section-application-architecture-design/

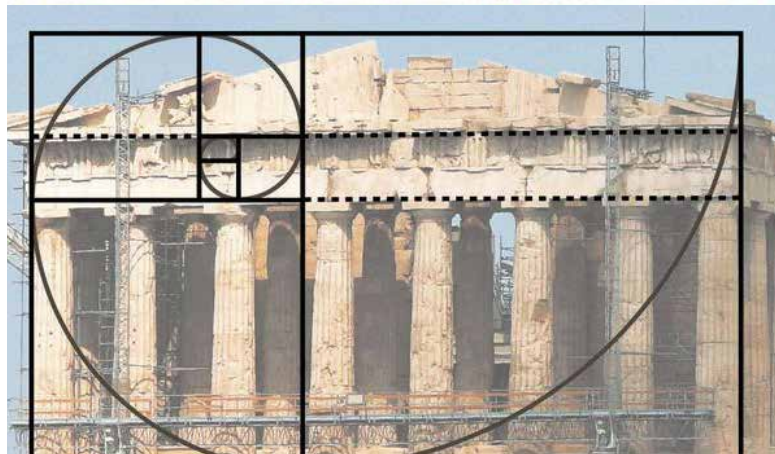
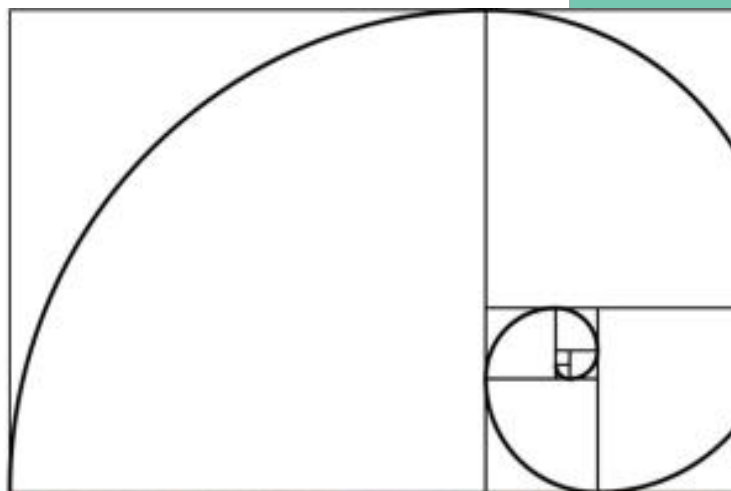
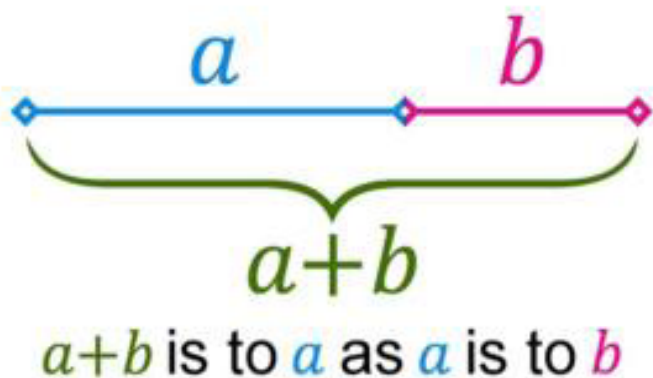


Architecture & Creating Space

Researchers have been exploring layouts and aesthetics of physical spaces and architecture for creating an appropriate environment for ASD. In the article “Autism and the Built Environment” authors Pilar Arnaiz Sánchez, Francisco Segado Vázquez, and Laureano Albaladeio Serrano write about the architecture of the space.³¹ One of the first things to think about is how to keep to the space calm and organized through the use of design and materials.³² The sense of calm and simplicity is not limited to the way in which the floorplans and divisions of the building have been designed, but also applies to the use of materials. Selecting a limited palette of materials, finishes, textures or colors, can achieve a sense of calm.³³ Reducing the background visual stimulation to a minimum allows caretakers and teachers to

introduce the precise degree of stimulation according to each child’s needs.³⁴

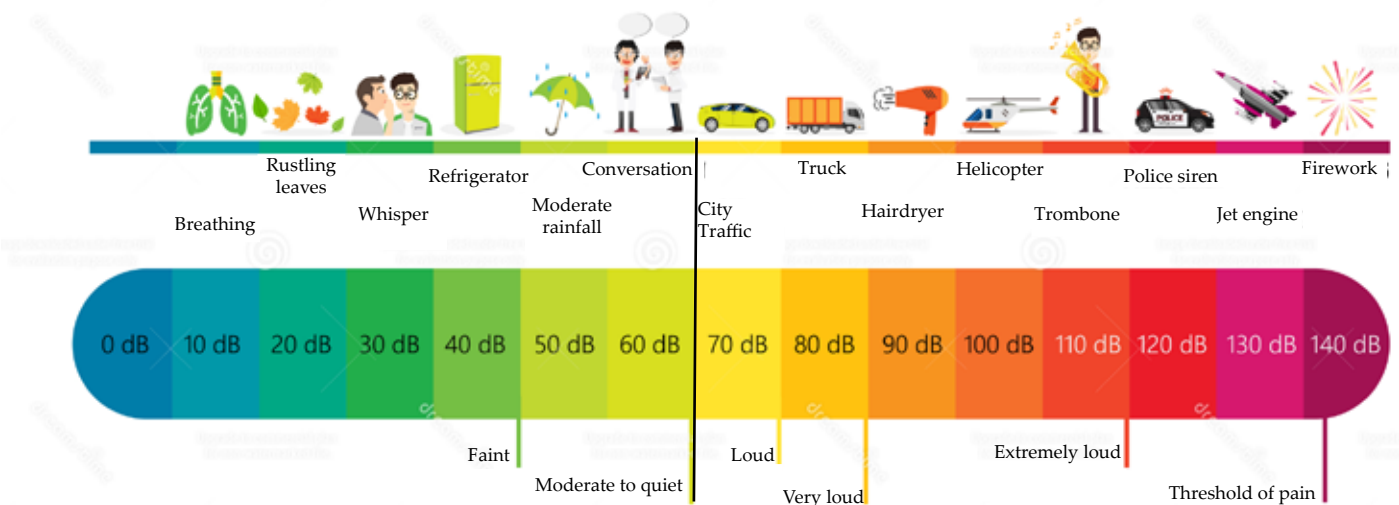
The Golden Ratio is a design tool that uses math to create a pleasing aesthetic to the eye—a pattern that has been found in nature for over 2,000 years.³⁵ Trying to create proportions using the Golden Ratio—a special number found by dividing a line into two parts so that the longer part divided by the smaller part is also equal to the whole length divided by the longer part—on buildings and spaces designed for people with autism allows for space to feel calm.³⁶ The 1:1.61 ratio allows for the natural looking and pleasing design within any project.³⁷



The second thing to consider is how the space feels and the visual noise that the different elements can create. Even natural light, with strategically placed windows, gives the space a more open and natural feel.³⁸ The authors state, “Light fixtures can be hidden from sight, thus achieving indirect and diffuse illumination. Specifically, this reminds us to avoid traditional fluorescent lamps, as people with ASD might be greatly sensitive to the flickering produced by them, even though other people will never notice it. A good option which the lighting industry offers us is the use of dimmers to control different illumination scenarios, each of which will generate a different ambiance.”³⁹

Sound can be hard for some to differentiate and can be overwhelming in a space that has too many sources, frequency, and decibels.⁴⁰ Considering the acoustics of the architecture and how the material can buffer sound allows for a smoother transition within the space.⁴¹

The last thing to think about is the logistics and configurations of the space. Individuals with autism need space for interactions with others and with objects.⁴² If the space is too crowded, then the person can become overwhelmed and might have negative responses. Allowing children to be confined in a single room with one entrance/ exit, but able to explore with supervision, enables them to experience interactions with others.⁴³



Suggested max volume is 70dB, but the pitch is the bigger concern.⁴⁴ Illustration 102089547 © Tuksaporn Rattanamuk - Dreamstime.com

The Autism ASPECTSS Design Index is an international design guideline to create built environments for individuals with autism.⁴⁵ This index consists of seven aspects to think about while design and creating space:

Acoustics: The acoustical environment needs to be controlled to minimize background noise, echo, and reverberation. The level of such acoustical control should vary according to the level of user-focus required within the space, as well as the skill level and severity of the autism of its users. For example, activities of higher focus should be allowed a higher level of acoustical control and be part of low-stimulus zones, described shortly. Requirements should also be made for different levels of acoustical control, so students can graduate from one level of acoustical control to the next, slowly moving towards a typical environment in order to avoid any overflow of noises into the next.

Spatial Sequencing: Based on the concept of benefit from the affinity of individuals with autism to routine and predictability it requires areas to be organized in a logical order and the typical scheduled use of such spaces. Spaces should flow as seamlessly as possible from one activity to the next through one-way circulation whenever possible, with minimal disruption and distraction, using Transition Zones.

Escape Space: These spaces provide a quiet sanctuary for users from the over-stimulation found in their environment. Such spaces may include a small partitioned area or crawl space in a quiet section of a room, or throughout a building. These spaces should provide a neutral sensory environment with minimal stimulation that can be customized by the user to provide the necessary sensory input.

Compartmentalization: Defining and limiting the sensory environment of each activity like organizing a classroom or even an entire building into compartments. Each compartment should include a single and clearly defined function and consequent sensory quality. The separation between these compartments can be as simple as furniture arrangement, a difference in flooring, a difference in level or even through variances in lighting. The sensory qualities of each space should be used to define its function and separate it from its surrounding compartment. When coupled with uniformity of activity, this will help provide sensory cues as to what is expected of the autistic user in each space, with minimal uncertainty.

Transitions: Presence of transition zones allowing the user to re-adjust their senses as they move from one level of stimulus to the next. Such zones can take on a variety of forms and may be anything from a distinct node that indicates a

shift, to a full sensory room that allows the sensory adjustment before transitioning from areas of high to low stimulus or vice versa.

Sensory Zoning: Spaces should be organized in accordance with autistic user's sensory quality, rather than typical functional zoning. This requires grouping spaces according to their stimulus level, into "high-stimulus" and "low-stimulus" with transition zones aiding the shift from one zone to the next.

Safety: Safety is even more of a concern for children with autism who may have an altered sense of their environment.⁴⁶

The creator of this index, Dr. Mostafa, stated that her main purpose to create this guideline for ASD design was "to free the child's sensory network of unnecessary traffic and sensory noise from the surrounding environment- and make those fleeting moments where they can communicate, respond, learn and interact, a little bit longer."⁴⁷ As the child grows up, the restrictions would lessen within spaces and grows along with their newly acquired skills, becoming a more round part of the community in a less controlled environment.

Designing for and with Visitors with ASD

Over the last few years, museums have started to partner with outside organizations to provide sensory friendly days for children and families on the spectrum. These events have historically been scheduled infrequently and in short time frames of two to three hours. These scheduled blocks of time are either in low peak or early hours to decrease the noise levels and the number of distractions throughout the museum, allowing for families to have a judgment-free experience. With the rise of awareness around accessibility, the use of light levels, simple signage, and lower audio levels have improved the sometimes-intense environment. The creation of pre-visit guides, which are usually available online, has been a tool that museums have started to use to help visitors with autism and their families to prepare for the otherwise unknown elements they might encounter at the museums; allowing them to know the space, program schedule, and front-line staff. Though these devices are a step in the right direction, the progress of these features has been slow to include those with intellectual disabilities.

During the last two decades, researchers have discovered that individuals with autism tend to be visual learners. Using different visual technologies such as computers, 3D models, and virtual reality, individuals can improve their language skills, cognitive functions, and social/communication skills.⁴⁸ Further, these technologies can help individuals with autism to control and predict their environment by providing exact visuals of the space and other features—think of Google Arts and

Culture.⁴⁹ Adapting visual technologies allows the media developer to integrate the use of participatory design with its visitors with autism, which allows for better accommodations for the group's needs within the museum community.⁵⁰

With the growing interest in digital media, the development of museum-based applications for individuals with autism needs to be considered. Researchers, Dimitra Magkafé and Nigel Newbutt explores the benefits of having individuals with ASD participate in the museum's visitor development and experiences.⁵¹ There is a strong evidence base that values the use of touchscreen devices in aiding children with autism, helping to improve multiple skills sets and opportunities.⁵² "Developing accessible digital products is thus of much wider significance, and in the case of children with autism, design access becomes an issue. Given that the heterogeneity of the spectrum is a barrier, researchers in this field need to consider ways of minimizing the challenges and designing more inclusive programs aligned with these needs."⁵³



Pre-visit guides—like these from the National Constitution Center in Philadelphia, PA—give visitors both a visual and verbal script of what to expect at the museum. A large blockade for individuals with autism is the unknown aspect of a location or activity.

NATIONAL CONSTITUTION CENTER

I am going to the National Constitution Center.

LOBBY

Many people will be in the lobby to see the exhibits
The lobby may be crowded.
I can go to the break room if I want to get away from the crowds.

WAITING

I might have to wait in line to get my ticket, to get to my seat in the theater, or to get into the bathroom.



TICKET OFFICE

The ticket office staff are friendly and helpful.
I will be given a wristband to wear to go into the museum. I will show the staff my wristband. I can wear the wristband on my wrist or just carry it with me.
The museum staff will help me find other exhibits in the museum. If I need help I can ask a museum staff member.

GOING TO THE NATIONAL CONSTITUTION CENTER

PRE-VISIT STORIES

NATIONAL CONSTITUTION CENTER



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STAFF MEMBERS

The staff members are friendly and helpful.
The staff members help me find other exhibits in the museum. If I need help I can ask a staff member who is wearing a red shirt.



BREAK ROOM

If I need to take a break from the museum, I can go to the quiet room to relax or do a calming activity.



MAIN GALLERY

There are many activities I can do throughout the space.
There may be times when it is too loud or too crowded.
I can go to the break room if I want to get away from the crowds.



SIGNERS' HALL

There are statues of people who signed the Constitution throughout the space.
I can slowly walk around the statues to explore them.
I can touch the statues.



I am going to see a show and listen to a speaker talk about American History.



If I need help, I can ask a museum staff member to help me find the theater.



I might have to wait in line to get into the theater and to get to my seat.



I will give my ticket to the usher in order to enter the theater.



SIDNEY
KIMMEL
THEATER

PRE-VISIT STORIES



When I get inside the theater, I can sit anywhere I like to see the show. To get to my seat, I will hold onto the hand rails as I walk on the stairs.



I can find a theater usher to help me up to the top row.



Images can even appear on the floor and around the top of the room.

CLAPPING

Permission of use from National Constitution Center.



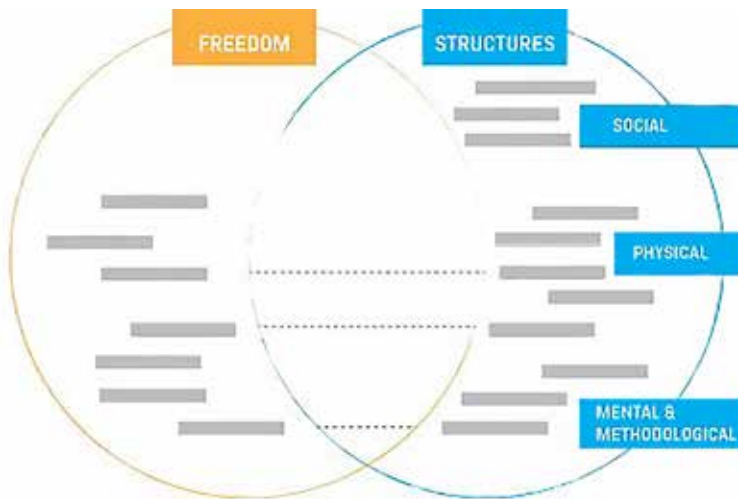
One of the primary factors outside the sensory issues is the lack of training on how to identify the needs of visitors with autism and their families. As the increase of sensory friendly days continue, museums are bringing in experts to train front line staff on identification and sensitivity training and awareness. Sensitivity training brings greater awareness and ability to communicate clearly with its visitors. The organizations that museums can sometimes partner with can be found within the community, while some organizations offer the country a wide variety of training. KultureCity (KC) has trained frontline staff across the country, across community spaces—from museums to big arenas. KC requires the institution to recertify each year after the initial training. However, some institutions do not need to leave their community to receive training. In Philadelphia, the group Philadelphia Autism Project gives a free 12-week training program that can be tailored to the individual institution. Although these programs are available, not all museums have used this resource. When I surveyed families about their experience in museums, almost all of the 87 respondents stated that they wanted to see all frontline staff have training on awareness—these respondents were mostly from the northeast and south regions of North America. With this sample size across half the United States, it shows that not enough people who work with the public have this sensitivity and awareness training.

In the article “Creating creative spaces for co-designing with autistic children: the concept of a ‘Handlungsspielraum’”, authors Julia Makhaeva, Christopher Frauenberger, and Katharina Spiel, have

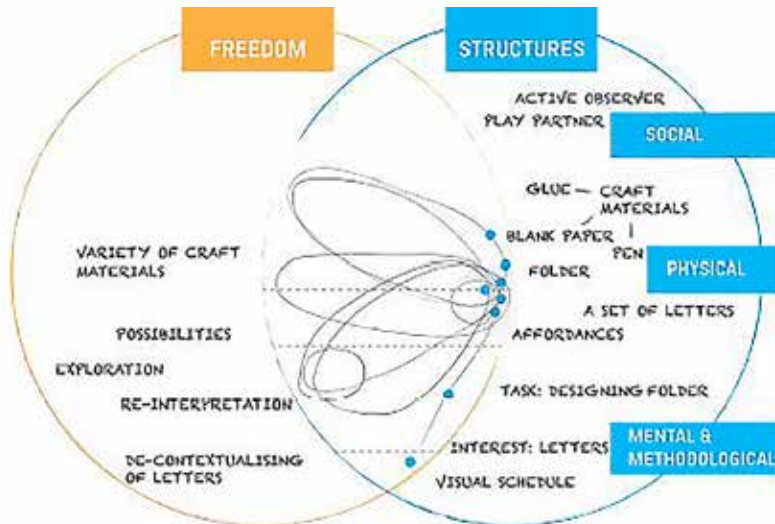
promoted the universal understanding that everyone is creative.⁵⁴ The use of participatory design and the German concept of Handlungsspielraum (HSR) allows for a more collaborative environment when producing a specific activity for a niche group of people.⁵⁵ “Many people with ASD are visual and pattern thinkers, typically with great attention to detail. Often, they show extraordinary skills, remarkable abilities and a passion for particular subject areas. According to the conception of creativity as an essential quality of everyone, autistic creativity is individual and subjective, as all children have talents and creative potentials in unique ways, but particularly for children on the autistic spectrum it is difficult to unfold their potential of creativity in environments shaped by and for non-autistic adults and children.”⁵⁶ The goal is to create a safe environment for children with autism to engage and motivate them to unlock their potential.⁵⁷ Ideally, the process follows three steps: planning co-designed spaces, conducting activities, and reflection. Researchers found that incorporating structure as a way to allow for creative freedom will often lend to a more engaging experience for children.⁵⁸

The format of HSR is broken down into two categories: structures and freedoms. These categories overlap and create cause and effect for creativity in activities for meaningful participation.⁵⁹ The overall intention is, “to create a structure aim to provide safe spaces in which participants feel comfortable, relaxed and stimulated. Spaces for creative freedom open possibilities for participants to contribute their own ideas.”⁶⁰

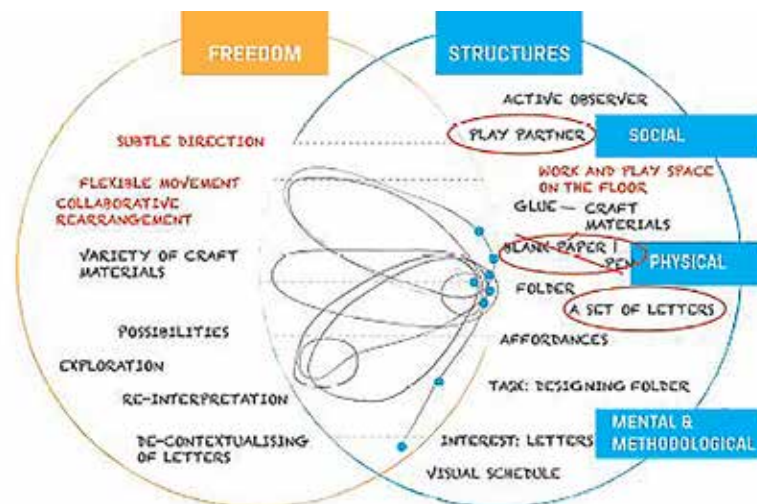
HSR diagram examples⁶¹



< This is the base format for Handlungsspielraum.



< Example of the Planning of Structures and Aspects of Freedom, and Concluding Exploration of HSR in an ideal session.



< Example of the Reflection on Co-Design Activities in an ideal session of HSR.

Diagrams from "Creating creative spaces for co-designing with autistic children: the concept of a 'Handlungsspielraum'"

In 2017, San Diego Natural History Museum (The Nat) spearheaded the SPECTRUM Project, partnering with 10 young adults with ASD in an effort to increase accessibility within the Balboa Park community.⁶² Over sixteen meetings, the young adults helped with the SPECTRUM project by going around the park and taking photographs and experiencing all the park has to offer. The young adults and museum staff came together to create very specific social stories. The museum staff gave a framework and structure to this growing project to give these young adults a pathway to build upon social and communication skills, self-esteem and confidence, and a place in society.⁶³ Additionally, the process was documented not only to fulfill requirements of the grants, but also for museums to show the impact of these accessibility measures. “The American Alliance of Museums describes inclusion work as an ‘ongoing effort;’ that is, inclusion requires thinking deeply about one’s practice, questioning, making subsequent adjustments, and then doing it again. Inclusion is an iterative learning process which arises from authentic interactions. Museum professionals must learn more about autistic people, especially considering the growing population of adults identified as autistic.”⁶⁴

As museum professionals, we constantly talk about evaluating visitors and the community for title testing, new exhibits, and programming. By asking visitors with autism or parents of children with autism to have a conversation with the design team and the museum, continues along this same line of thinking

and community engagement. Many of the participants for this thesis survey have expressed the want and the need to have these conversations between the two entities. One parent had this to say:

“they (museums) should work with the community and hear from the disability community. Too often, these decisions are made without even considering the voice and input of those living with the disabilities the museums are working to include. Museums need to put programs for people with disabilities FIRST. Also, disabilities are more than just physical. A lot of times I see museums focusing on accessible ramps and calling themselves an accessible space when in fact, there is nothing within the museum that was created to make their experience more enjoyable. Basically, I think museums need to do more, to hire a staff member who focuses solely on accessibility and is constantly working to educate themselves further.”

The disability community is crying out to be heard. They feel disenfranchised and unheard. By partnering together to create these experiences, all visitors will have a more inclusive experience in museums and cultural institutions.

Designing Details in the Space

The United Kingdom’s Home Office (a government department) created a set of guidelines that increase the idea and awareness of accessible service design. Their interest in this accessibility helps to increase the discussion of inclusion. These posters have spread the idea of inclusionary design across Europe and into North America. In the beginning, the team created four posters, including one for ASD. As these posters become more widespread around and outside of the UK, the team has added new posters for accessibility.

This poster gives some basic do’s and don’ts about designing and writing for people with autism in public spaces.⁶⁵ While this poster was intended for use within the autistic community, the principles can be applied to serve all kinds of people. These principles serve as a potential first step towards universal and inclusive design for all.

Poster designed and published by Home Office Digital, Data and Technology, UK.
Download this poster and the other posters in the series: accessibility.blog.gov.uk/2016/09/02/dos-and-donts-on-designing-for-accessibility

Designing for users on the autistic spectrum

Do...	Don't...
<p>use simple colours</p>	<p>use bright contrasting colours</p>
<p>write in plain English</p> <p>Do this.</p>	<p>use figures of speech and idioms</p>
<p>use simple sentences and bullets</p>	<p>create a wall of text</p>
<p>make buttons descriptive</p> <p>Attach files</p>	<p>make buttons vague and unpredictable</p> <p>Click here!</p>
<p>build simple and consistent layouts</p>	<p>build complex and cluttered layouts</p>

As designers, we think about what needs to go in the space, how things react to each other, and the story that it tells. Throughout the process, we look at spatial configuration, color, lighting, and material. Lighting is one of the most expensive and last-minute concerns within the space. Christopher Henry writes in his article “Designing for Autism: Lighting” that there is a limited amount of research in the effects of lighting among ASD and architecture—where there is research, there consists many conflicting reports.⁶⁶ With this type of research, architects are using anecdotal evidence and flawed research to make the best-educated guess they can make for a space. Although, Fletcher Thompson’s research has more profound evidence that natural space can cause those with ASD to become more distracted due to glare, intense light, contrast, and the outside view.⁶⁷ On the opposite side of the research, natural light and windows have been found to increase overall health and attention rates.⁶⁸ As the research on lighting effects on ASD tighten, the architecture field will have a better understanding of how to create a more ASD friendly space.⁶⁹ The progression of lighting design research in architecture can be a cross-disciplinary exploration into museums and can help exhibit designers think more deliberately when creating a new exhibit.

Very few studies have looked at how children with ASD react to different colors. Researchers have found that many people with ASD have a color obsession or aversion among the colors: red, pink, yellow, brown, green, and blue. Marine Grandgeorge and Nobuo Masataka study “Atypical Color Preference

in Children with Autism Spectrum Disorder” takes a look at how neuro-typical children and children with ASD react to color.⁷⁰ They conclude, “findings have led us to hypothesize that while the basic mechanism underlying perceptual categorization of colors would not differ between people with ASD and without ASD, the enhanced sensitivity to sensory stimulation, in general, that is characteristic of ASD would influence color perception exhibited by people with this disorder, and this would result in aversion to some specific colors that are usually favored by neurotypical people. The current study was designed to explore this possibility, using the same stimuli as those in the previous pioneering work, on the assumption that ASD children possess perceptual color categories equivalent to those in TD children.”⁷¹ Simple colors help create environments that provide a warm but not overstimulating atmosphere.⁷²



It has been suggested to used colors to create a sense of calm in the space⁷³

People with autism have been noted to have a greater sensitivity to sound.⁷⁴ Many sources have said that the sensitivity comes from the way the brain processes the stimuli either over or under stimulation.⁷⁵ Activities and digital media are a common part of the museum experience, as are people. Therefore, museums need to look at how the mix of the sources adds to the overall noise level of the space. We know that using basic noise reduction solutions like acoustic panels, material choices, sound levels, and point elated speakers and components can combat the problem.⁷⁶ Using noise canceling headphones and earplugs can help the individual lessen the stimuli without feeling overwhelmed. Providing signs that specify loud areas can help visitors decide whether they feel comfortable entering the space.



KultureCity gave Akron Zoo the tools for its visitors during their visit. The picture on the left shows a sign indicating the area is loud and might want to use headphones or to avoid the area. The picture on the right shows the items that can be found in the sensory bag that can be checked out free of charge.



^ Sean Ahlquist, University of Michigan

Ahlquist created a prototype of these structures and invited children. This play experience is to teach the whole body, not just the hands.

√ Gregory Wendt/Sean Ahlquist, University of Michigan



Social Sensory Architectures in “These Architectural Playscapes Provide Therapy for Children with Autism” have created a prototype of a therapeutic structure that is tension fabric over pliable tubes creating an immersive environment for autistic children.⁷⁷ “Responding to touch, sounds are triggered, and 2D imagery is projected onto the fabric’s surface, as if on a screen. This visually demonstrates the connection between motor skills and auditory and visual feedback, helping children with autism adjust the amounts of force appropriate to apply at a given movement—a common issue among those on the autism spectrum.”⁷⁸ The architects and collaborative researchers noticed through their prototyping that the structure was becoming more than something you interact with, instead, it has become an immersive structure that goes around the children using light, different materials, and 2-D projections. The architecture firm was able to connect motors skills to the sensory feedback of the children through these spirals and swirls.⁷⁹ The fabric tension was able to queue in the hard/softness of touch in using their visual and auditory senses, allowing children to actively connect multiple senses at once. When the use of these tunnels allows the children to crawl through them, the tension of the fabric can create a compression effect. Compression is one of the ways to ground people from autism when feeling overwhelmed.⁸⁰ These tunnels are also working on motor skills, a function that some children need extensive therapy.

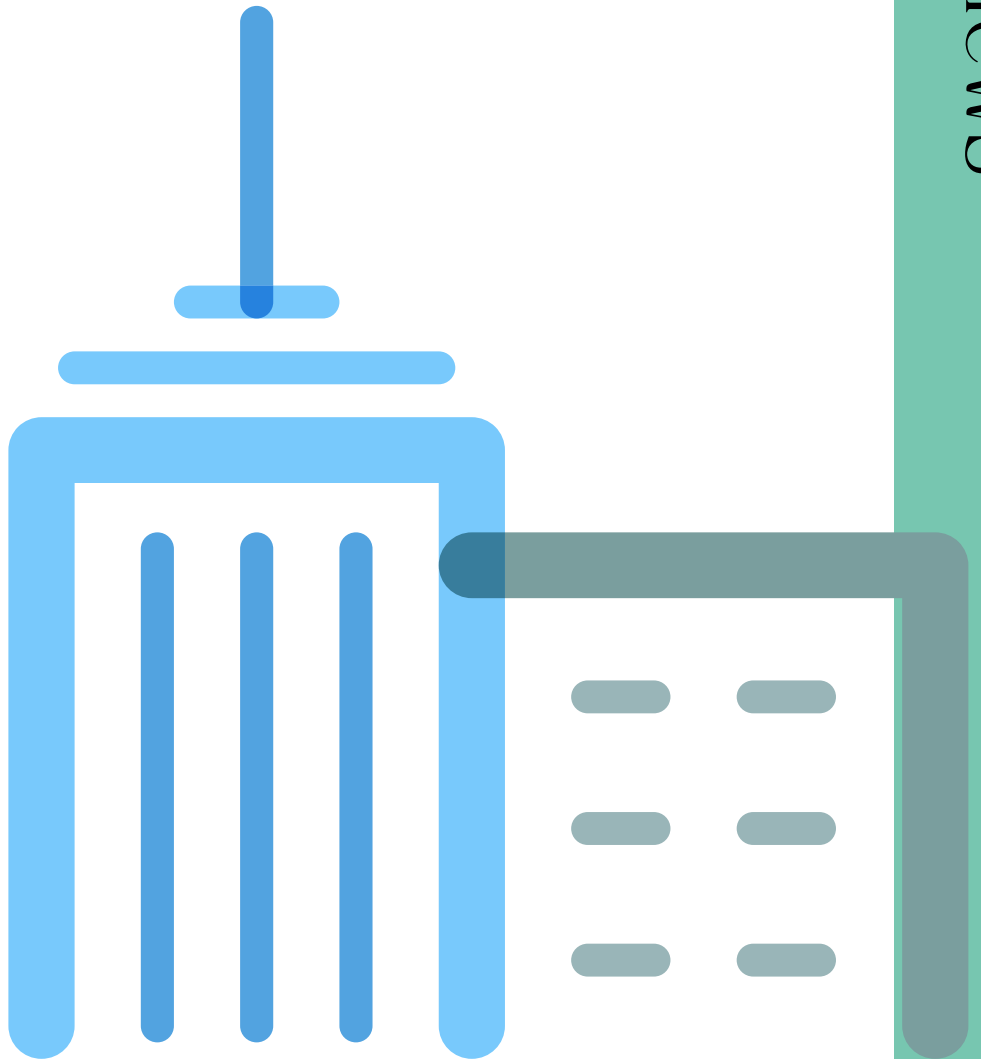
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Institution Interviews

With a topic like this one, I felt that I needed to see what different institutions were doing to provide sensory inclusion for their audiences. At the beginning of my research, I spoke with any institution that has sensory-friendly days. After some research, I started to narrow down the kind of institutions that cater more towards children and families.



McWane Science Center



Facade of the McWane Science Center. Photo Credit: McWane Science Center

I interviewed Lamar Smith, VP of Exhibitions, and Peggy Chewning, VP of Education, of the McWane Science Center in Birmingham, Alabama, because of the institution's collaboration with a startup non-profit, KultureCity (KC). KC is a Birmingham based organization that works with other institutions and attractions to become sensory-friendly through evaluation of space and staff training. The McWane Center has been taking certain steps to create a more inclusive environment with the help of KC, but they are working to move forward with more universal design of their spaces. It seems the collaboration with KultureCity is allowing more families to feel comfortable within the institution. McWane is also starting to increase the frequency of sensory-friendly days to give its visitors and the community it services, better access to this program.

A few months later, I met with Erik Lizée, Director of Exhibits of the McWane Center, to get a more in-depth look at the quiet rooms and the continuing direction of the institution's inclusionary design. KC approached the institution about how to incorporate sensory inclusion into its building. Mr. Lizée was the point person on the collaboration of

KC. The accessibility organization came into the museum to survey the space. They needed to identify loud areas and quiet areas to update the visitor map. KC also came in to create a quiet room for visitors to have a place in order to calm down or to take a moment to regroup. This room has an array of different tools to help individuals calm down including a compression chair, weighted bean bag, adjustable lights, and a touchable art. This room is used multiple times throughout the day and is located in a convenient location to the front desk for quick access.

As part of the KultureCity's certification, they train all of their staff in identifying need as well as expressing sensitivity to visitors with autism. This training must be recertified every year to keep its accreditation. They have also created bags that visitors can check out for free that includes noise-canceling headphones, a response card for non-verbal visitors, fidget spinners, and tinted glasses. These sensory bags are checked out every day and throughout the day. Many respondents of my survey mentioned the McWane Science Center as feeling as a more sensory friendly experience.

McWane Center is in the process of master planning its 180,000 square foot building—the first major overhaul since it opened its doors in 1998. As

forward, the exhibit team is looking at the different aspects of universal design—what’s good for one is good for all—with their recent feedback from visitor surveys and through their partnership with KultureCity. The design team has been looking at ways and materials to reduce noise bleed; ceiling treatments; reducing reflective surfaces; and updating light fixtures to LED and to place the light levels at an appropriate level depending on the exhibition. The hope is to create a more inclusive environment for the Birmingham community, making its visitors feel free to explore.



The Academy of Natural Sciences



Facade of the Academy of Natural Sciences. Photo Credit: Mike Servedio/ANS

I spoke with Mary Bailey, Interim Head of Public Experience, from The Academy of Natural Sciences of Drexel University in Philadelphia, PA. I had heard that The Academy was working towards a more inclusive experience and I had read a journal that discussed how dioramas in natural science museums are a wonderful learning tool for engaging children with autism in learning. After my interview with Mary, I realized that the institution is slowly working on becoming more inclusive. I also spoke briefly with The Academy's exhibit designer, Lauren Duguid. She told me that she was interested in creating more inclusive exhibits. A few years ago, Lauren designed a special exhibition on the topic of bioluminescence called "Glow: Living Lights". A woman emailed the museum after visiting asking about certain aspects of the design. Her daughter has autism and was extremely happy and content within the exhibit. Her mother wanted to see where she could find the lights that were used to create the underwater immersive area so she could buy for her daughter's room. The lights in the underwater area were a combination of water-effect gobos from above and a custom LED system that mimicked the smooth movement of deep-sea creatures. Lauren stated that

she felt extremely happy that her design could bring excitement to the girl.

A few months later, I observed the museum during one of its sensory—friendly days, or what they like to call Access to Science Initiative. The Academy opens its doors one hour early on a specific Saturday morning, giving families free admission and a quieter experience. From 9am to 11am, the museum has community partners come into the space to give assistance, knowledge, and sometimes therapy chickens to start a conversation with these individuals and families. The quiet room—located in the Dinosaur Hall—is available during all hours of operations; however, they are only publicized during the sensory days or when there are a large number of children. The room is kept simple with a large table in the middle of the room with a dozen or so chairs.

The Academy usually does not have themed sensory days—unlike some of the other programming—their mission for this program is to give these children and their families the same experience as if they would come in during a busy time. The hope is for these families to come back—maybe at a busier time—or even decide to become members. The success of the program comes from its staff;

staff, on board with the museum's initiative.

While observing during this sensory day, I noticed more than just families and children with autism were attending. There was one family with a child with an unknown disability—though she was unsteady on her feet and sometimes used a stroller to get around—she seemed to enjoy her time looking at all of the dioramas and I watched her parents show their daughter the videos on the two new interactive labels on the second floor. This family was able to enjoy their time interacting within the space at their own pace without the pressure of a packed museum. As I walked around, all the families were having a typical experience at the museum, there just happened to be fewer people than normal for a Saturday morning. Although there was no final visitor count for the event, there were numerous families that took advantage of having a quieter museum, giving every person a real museum experience.

The Academy of Natural Sciences' sensory days for 2019 will be on June 1st, July 14th, and August 25th.



National Constitution Center



Facade of National Constitution Center Photo Credit by M. Kennedy for Visit Philadelphia

The National Constitution Center (NCC) located in the Independence Mall of Philadelphia, PA, offers its visitors many accessible features to experience the museum's Freedom Rising show and its exhibition space. The museum offers: assisted devices, open captioning, large print and braille scripts of its exhibitions, interactives, and programming. Along with these amenities—all are free of charge. The NCC also offers sign language interpretation with advance reservations and free entrance for all personal care attendants.

In recent months, the National Constitution Center has been preparing to introduce sensory-friendly days for its visitors. They have partnered with Art-Reach, creating and advocating accessible opportunities through art within the Philadelphia area, to train all of their staff and with Roger Ideishi—an occupation therapist from Temple University, to survey the space and ensure a safe. As part of the sensory-friendly days, the museum will be providing additional programming and introducing a pre-visit guide and noise canceling headphones for visitors. The NCC had its initial sensory friendly day on March 24, 2019. Lights in the box office area were at a lower level which can create a calming effect within the space. Before

entering the auditorium for the show Freedom Rising, a sign explained what to expect during the performance. The only noticeable difference between performances were lower sounds levels and full lights. As the show began, an attendant introduced the show and told visitors that they should feel free to come and go as needed during the performance.

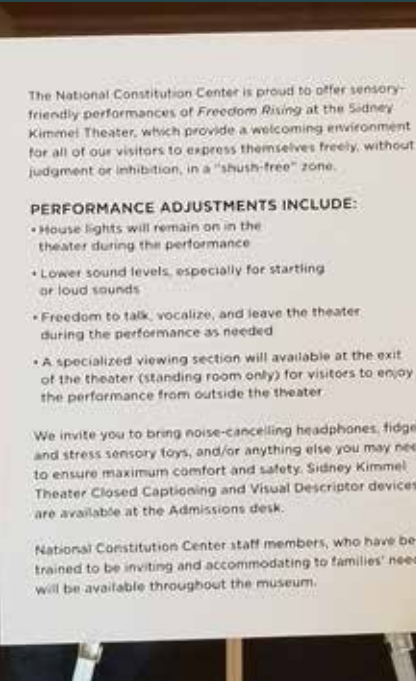
During the show, I noticed a family that had two teenage girls—one had ASD and the other had Down syndrome. Both girls had balloons to keep their hands busy throughout the show. The daughter with ASD was a bit talkative but was not overly distracting to others. As the big banners dropped down during the show, I watched the girls response to this sudden action. They didn't respond negatively and both seemed to be highly engaged throughout the entire show. After the show, visitors went up the stairs and into the main exhibit space. A volunteer explained how the exhibit is set up, how they could choose to start in either direction and how to engage with the various activities. Walking around the exhibition space, visitors noticed the artifact carts that were pulled out so they could get hands-on with the collection—people love being able to

touch and make a physical connection. While continuing to walk around the circle, the noise level is lower, giving a more calming environment.

The NCC set up four quiet rooms in the building. The “blue” room was set up at the entrance of Freedom Rising, its blue lights created a fun, yet calm environment. Along the tables, were different activities: coloring, small toys, and a few sensory play boxes. A second room was located in the “Living News” theater space in the main exhibit. This room allowed the visitors to have a convenient place to take a few minutes to calm down without having to leave the exhibit completely. The other rooms were also located on the second floor, allowing for multiple visitors/families to have space to take a breather from everything if needed.

Normally, a Sunday attendance during the spring is about 250 visitors. Today the attendance was 435 visitors.

The National Constitution Center’s sensory days for 2019 will be on June 23th, August 25th, and December 8th.



Other Institutions

As these three institutions give us an in-depth look at how some museums are moving to a more inclusionary experience; other institutions were also reviewed for this study with interviews conducted to explore how institutions handle inclusionary practices with a focus on children in their spaces.

As part of my research, I interviewed Aaron Goldblatt from Metcalf Architecture in Philadelphia, PA. At the beginning of our meeting, Aaron told me that while working on a new project with Reading Terminal Market, he came across a mother who brought her children with autism to the active market on an almost daily basis. When asked why, she stated that they took these trips during busy hours to help acclimate the children to the heavy activity and noise, helping to desensitize them to the sometimes-overwhelming environment. The mother believes that her children didn't need to be in a bubble and attacking the problem head-on would allow them to live more comfortably as adults.

A few years ago, Aaron Goldblatt and his museum team at Metcalf Architecture were elected to design fun, calming environments utilizing new environmental graphics and small play spaces throughout Children's Hospital of Philadelphia (CHOP). The hospital has strict regulations on installed materials due to certain sanitary obstacles within the design of spaces around the campus. When I asked Aaron what kind of requirements the hospital had regarding the design of the space and autism, the response was that they didn't really have much input for that disorder specifically. Rejections and approvals regarding design and materials happened on

a case by case basis throughout the project within the requirements of the hospital oversight committee.

The most important special designs were the different waiting areas on each floor of the hospital. Each pod had a different design and function; active, quiet, and digital pods. The quiet pods allowed the children to retreat from rooms, parents, etc., to have time to read, hide, or decompress during their time in the hospital. My takeaways from this interview were more anecdotal than from the CHOP project. Aaron's story about the woman with two autistic children really showed me how other parents – though just like mine – think it's best to take them to busy places and to have basic experiences with no need for "bubble wrap". In the CHOP project, the hospital was more concerned with germs and imagery than looking at creating sensory inclusion.

I talked with Katie Woelfel, Education Coordinator, at Please Touch Museum (PTM) in Philadelphia, PA. The Museum's audience is of the museum is children and it has a long-standing history in the Philadelphia community. With a new team at PTM, the Museum staff is re-evaluating what it means to be inclusive and how they can use universal design to create these new spaces. PTM holds sensory-friendly days several times throughout the year with about 500 visitors during those times—an indication of its great success. Please Touch Museum partners with multiple organizations from the community to have resources and tables during the events.

Currently, PTM offers a "Play Without Boundaries" Accessibility Event every other month.

Typically, they are on Sunday mornings from 9-11am, before the museum opens to the general public at 11 am. Attendance at these events has been steadily growing and survey data shows visitors are interested in another option for their accessibility events. In response, the Museum is excited to offer its first nighttime “Play Without Boundaries” (from 5 pm-7pm) this year. Typical Attendance for these days is around 500 visitors in total- around 250 children and 250 caregivers. For 2018, PTM had a total attendance of 4,457 pre-registered and 2,292 attended.

In my interview with Sandra Bonnici, Associate Director of Education, Diversity, and Inclusion, she specifically pointed out the work she and the Madison Children’s Museum in Madison, WI, are currently doing on sensory inclusion. She was recently on an Association of Science-Technology Centers (ASTC) panel about her work. Sandra and the team at MCM are pioneering ways to create a more inclusive institution through their partnerships within the community and their focus on a more universal design. They received a grant to continue this research shows which is having an impact on the way museums are looking at inclusion.

After speaking with Sandra, I was able to talk with MCM’s Director of Exhibits, Brenda Baker, about the approach the museum uses in creating new exhibits. In their new exhibit, *Zip, Zap, Zoom*, the color palette of the walls was changed from the original; the new colors are more muted, but fun and playful—two shades of green and a shade of blue—

creating softness in the space. The team also chose a softer font for signage, not wanting to create harsh visual lines among the many panels in an exhibition; word placement along the wall supported the use of sounding out words. The biggest part of the project was the technical and material use. The museum specifically chooses materials that can absorb sound—woods not metals, acoustic panels, carpeting, and fabric. These material choices help when thinking about how sound can fill a room and affect the visitors. In addition to thinking about sound, they also talked about how the room was being lit, adjusting to a softer, daylight glow.

One thing that became clear through these interviews was that children’s museums tend to be the most inclusive compared to museums that serve adults as their primary audience. Obviously, children grow up to be adults and sensory issues can change with age; but sometimes they do not simply go away. The following section highlights conversations with three parents with growing children with ASD. These family stories drive home the need for inclusionary spaces and design outside of children’s museums.

Family Interviews

With the philosophy “Nothing About Us Without Us”, I reached out to my contacts to interview individuals and families about their experiences in museums. These experiences and personal stories will help highlight the sensory concerns that visitors with autism have within museums and community spaces and influence our design choices for a more universal and participatory design.



Emily

Emily is a teenager who has autism. In 2018, Emily and her mother visited the Philadelphia Art Museum and the National Museum of American Jewish History in Philadelphia, PA. Visually looking at art was not enough to get Emily very involved in the museums and hearing a description of a display did not engage her because she is a much more hands-on type of learner. The family wished there were more interactive parts of the museum and more opportunities to use other senses rather than only sight—such as touch and sound.

For instance, in the art museum, there was a beautiful display with a carved wooden fireplace; but this did not interest Emily. Her mother read the description of the fireplace, but having a more hands-on experience would have been more beneficial to her learning process as a kinesthetic learner. Being able to touch artifacts or any hands-on activities allow the individual to have a greater connection to the object or subject matter. Museums have so much to offer, but for those that relate to the world in a more tactile or auditory way rather than purely by sight, having other means to explore the treasures inside would be a much more engaging experience.

Emily's parents want to find engaging exhibits that will be meaningful to Emily, but they also want her to feel comfortable, sometimes going to sensory friendly hours when needed. When Emily was young, her parents looked for quiet rooms and sensory areas. Now, they just try to make sure that she can have movement breaks every so often as opposed to just sitting still. If it is crowded around a particular exhibit and Emily is talking out loud (echolalia) they move away and return when it is less crowded. Her mother tries not to allow her to disturb others who may be engrossed in an exhibit.

Emily and her mother do not visit museums on a regular basis although it is something that they would like to do. When Emily was young, they visited the Discovery Museum in Cherry Hill on a weekly basis as it is very interactive. That museum is only for children, so it was great for Emily when she was younger. She has since grown out of that particular venue and would need a more adult-learning driven experience.

Sometimes Emily could “hear” a sound that her parents could not hear. When she was younger, Emily would cry and become very upset when they would go to certain places. The thought is that appliances or other machinery made a sound that only Emily hear—that may have been high pitched and irritating. Her mother came to this conclusion because a restaurant near them had the same effect. So, when they go out to museums or elsewhere, she always watches for how Emily reacts. She has noise canceling headphones in a backpack just in case Emily needs them. They always appreciate a quiet room to escape to if needed on the premises.

Emily does struggle with noise and light at times and wears her headphones when she is around a loud volume of noise—at movie theaters, pep rallies, fire drills, etc. Her parents keep a pair in each of their cars and she has a pair at school. They have not yet encountered a need to wear them at a museum. Emily is also sensitive to light and wears sunglasses when outdoors—though does not have problems with light indoors.

Ways to calm Emily are:

- Remove her from the sensory overload situation
- Massage her arms and back to calm her
- Tell her “just ____minutes more” and then count how many minutes were left. (to set her expectation)
- Have a favorite snack to give her
- Distract her in whatever way was handy

Pete & David

Pete is a 20-year-old man with autism, the youngest of four children with a twin brother, David.

Recently, Pete and his family attended the World War II Museum in New Orleans, LA, where he kept wandering off to look at other things and it was hard to redirect attention to the rest of the museum.

When he can participate in an activity that he can touch or interact with, Pete is able to focus and enjoy his experience more. When Pete was younger, he had many issues with noise that tend to accompany crowds, specifically in movie theaters.

One thing that really helped him calm down while at museums—sometimes attending McWane Science Center and Imax—were the many hands-on activities and the sensation of touch with the bed of nails and stingray touch tank. The family chooses to not attend the other major museum in the area—Birmingham Museum of Art—partially due to the lack of activities and other hands-on experiences. Pete tends to do better at museums when there are a variety of tangible experiences; it allows him to focus on a task and not wander off.

As Pete has gotten older, his sensory problems have gotten better through coping behaviors, school and camps, and by just growing up. One thing that he loves to do is go to theme parks and ride the rollercoasters; the scarier the better.



^ David left, Pete right, recent birthday

Ways to calm Pete are:

- Weighted Vest
- Using a hairbrush on his arm
- iPod
- Removing him from the situation
- Calm spaces that have hands-on activities

Some of these techniques are no longer needed and some have expanded. Even now, Pete is able to attend Auburn University football games—with an average game attendance of 86,000 to 87,000—and can sit through the games with no major problems. Pete does carry his iPod in with him to listen to music and will often take videos throughout the game. Pete's parents believe he does this as a way to help him process the different components of the environment, but generally behaves with no major outbursts.

As stated before, Pete has a twin brother, David. Though, David has no official diagnosis of autism, he does show some attributes of the disorder—

problems with noise and crowds, lack of eye contact—along with a language processing disorder, Dyslexia, Attention Deficit Disorder (ADD), and Attention Deficit Hyperactivity Disorder (ADHD). Compared to Pete, David does not have the same kind of sensory issues. David does have a higher sensitivity to noise when he is not the producer of the noise or when he is not expecting it. He does get easily agitated, but things like bike riding, music, and playing with Pete help calm him down.

David and his mom went to the Civil Rights Institute and Kelly Ingram Park nearby in Birmingham. The park has an audio tour that explains the significance of Birmingham's place in the Civil Rights Movement during the 1960s. David was able to enjoy both the museum and the park's experience through the use of interactivity and being able to experience it at his own pace.



^ Pete, recent photo

✓ David left, Pete right, 2008



Anna

Anna is a 22-year-old girl that has a unique factor in her life—she has a dual diagnosis of autism and Down syndrome (DS). This dual diagnosis is expected only to happen 16-19% of all of those with Down syndrome.⁸¹ Down Syndrome is diagnosed at birth and has a specific set of symptoms and characteristics that manifest with this disorder. Anna's mother—a

registered nurse—started noticing symptoms of ASD when she was two years old, but was not officially diagnosed until she turned six years old—girls are usually diagnosed later in life. Anna is the fourth child with three older brothers.

When Anna was younger, her mother took her to museums; able to contain her more since she was in a stroller. As an adult, Anna and her mother do not attend museums unless there is another companionable to assist and in hopes, the space is fairly empty. Anna is low functioning (mentally 18-24 months old) with low vision and gross motor skills. She has many issues with sensory sensitivity, is risk averse, and wary of crowds. She needs to do things at her own pace and may need to do things multiple times. When they do go to the McWane Center, Anna will wear her headphones and iPod to help with the noise and to keep her occupied while in line. If Anna



^ Recent picture of Anna and her mother, Kara.

is having a hard time with the stimulus of the space, they will use the quiet room or go to the admissions desk for a sensory bag.

Anna's mother also expressed the worry about looks and judgment that she has received in the past when Anna has a meltdown in public; causing the disturbance of others during an experience. It has happened before and is an unpleasant experience. When asked about going to the McWane Science Center during the sensory day, Anna's mother stated that it wasn't something she really thought about. She explained that it is hard to go somewhere when you are a caregiver for multiple people in the family; you go when you have time. Although, she did say that it is something that might be worth looking forward into.

Thesis Project

Methodology

I conducted a front-end evaluation in the form of an online survey with open-ended and multiple-choice questions. The online survey allowed a broad base of participants from across the country to participate. Having the survey administered via the internet allowed proper data collection while getting the most robust answers from visitors to the questions. I utilized Google Form and dispersed using social media, forums, and personal connections.

Evaluation Plan

Key Evaluation Questions:

- What more can museums do to create inclusivity for autistic visitors?
- How are museums currently satisfying the needs of the autistic community?
- What changes do autistic families and individuals want to see?

The administration of the survey took place from November 4, 2018, to January 14, 2019, with a total of 87 respondents—a total of 27 respondents with ASD and 60 respondents with other disorders. The sample sizes have been determined based on an ideal number of possible recipients to achieve enough data to accurately achieve a margin of error of 6.7-8%. I wanted to understand how individuals and families with autism feel museums can improve on their inclusion programming and design opportunities. A subgroup of other sensory processing disorders compared in the results are by individuals with other physical and/or intellectual disabilities help to solidify why having sensory inclusion should be part of the design process for new exhibitions.

Following the front-end survey, I selected three to four families and/or individuals with autism to conduct a one-on-one interview about their experience with autism and museums. These interviews will be conducted through in-person, phone interviews, or email at a set time and location agreed upon by myself and the interviewee. These selected interviews are to give an in-depth look at how families and individuals interact with museums.



Project Schedule

Tasks	October	November	December	January	February	March	April
Writing	X	X	X	X	X	X	
Interview with Institutions	X	X	X	X	X		
Evaluation		X	X	X			
Interview with families				X	X	X	
Draft 1					X		
Draft 2						X	
Defend							X

Findings & Recommendations

Most museums are nonprofits and rely on a combination of rotating income. As the ASD rate increases, the accessibility of these institutions needs to grow with it. Families rely on museums to not only educate their children, but also to help provide them with social and coping skills. Part of the solution is relatively low-cost, low-impact to museums.

Based on my findings here is a list of recommendations for Museums and cultural institutions:

- All staff should receive training in recognizing behaviors.
- Creating pre-visit guides of the program or space thereby making the unpredictable, more predictable.
- Provide quiet rooms or spaces allow the child and/or family to calm down if they are feeling overwhelmed in the moment.
- Have sensory-friendly days and times as part of their programming to give families a calmer experience and even help prepare them to come back during “normal” museum hours.
- Creating visitor maps that indict quiet rooms, loud spaces, and any other related amenities.
- Employing outside services and apply for grants and funding to grow the inclusionary design of an exhibit and museum.⁸²
- Conversations with the ASD community (families and individuals with ASD, Special Ed teachers, occupational therapists) when beginning the design process or new programming. These conversations give an insight to how these individuals and families interact within the space.
- Looking at how objects can be handled by the visitors. Touching objects or any hands-one activities allows for a better learning experience for all visitors.

The time frames for inclusionary design vary can either be a slow or quick process dependent on the many different variables like: time, money, experience, and so on. Many institutions like the Madison Children’s Museum and the San Diego Natural History Museum have received grant funding in recent years to progress and test different aspects of inclusionary in their respective institution. Funders and organizations like Institute of Museum and Library Services are dedicated to giving money to museums and libraries that serve and bring their community together.

We know that children’s museums tend to be a more inclusive space for its audience, but what about when they grow up? In our society, we tend to forget that people with disabilities do not stop having disabilities once they turn 18 years old. Many individuals still need special accommodations passed the adolescent stage in many aspects of everyday

life and museums are still a great place for fun learning beyond those ages. As part of this thesis, I conducted a survey about individuals and families with autism and their experiences in museums. The respondents were very honest and vocal about what they wanted and needed in order to be more accepted in museums while attending. Their frankness and honest opinions really helped me understand more deeply from the person-first perspective, which I feel is paramount when designing a welcoming and accessible spaces and experiences.

Needs	Wants
Staff trained on recognizing and awareness	To be a part of the process. To have a conversation during the design process when introducing inclusion into the space.
Noise reduction	More hands-on activities and objects to touch and handle for those with vision impairment.
Pre-visit guides	Better programming
Signs that give visitors a general sense of what to expect (quiet areas, loud areas). The biggest concern is the unknown.	More Sensory friendly hours and days

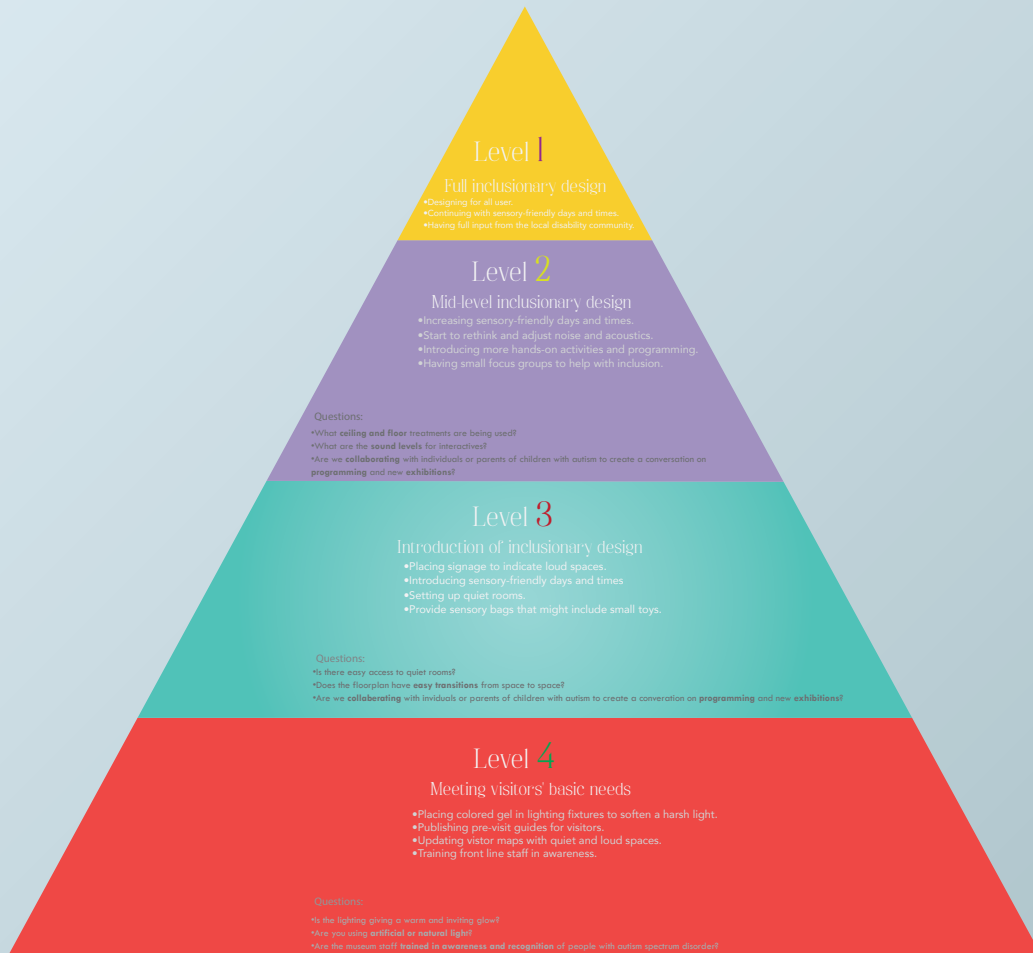
INCLUSIONARY DESIGN

This poster offers you a quick reference for creating new programs and exhibitions in museums. The questions asked are a reminder of the many different aspects of inclusionary design.

The triangle is based on Maslow's Hierarchy of Needs. Maslow's idea was the most basic needs of an individual needed to be met before obtaining the one above.

There are four levels that indicate how inclusive your museum is for your visitors. Level 4 means that you are meeting your visitors' most basic needs and level 1 means the museum is fully inclusive. In an ideal world, each level of inclusionary design builds upon the last until full inclusion is achieved. In actuality, an institution might be working on different items from each level depending on resources.

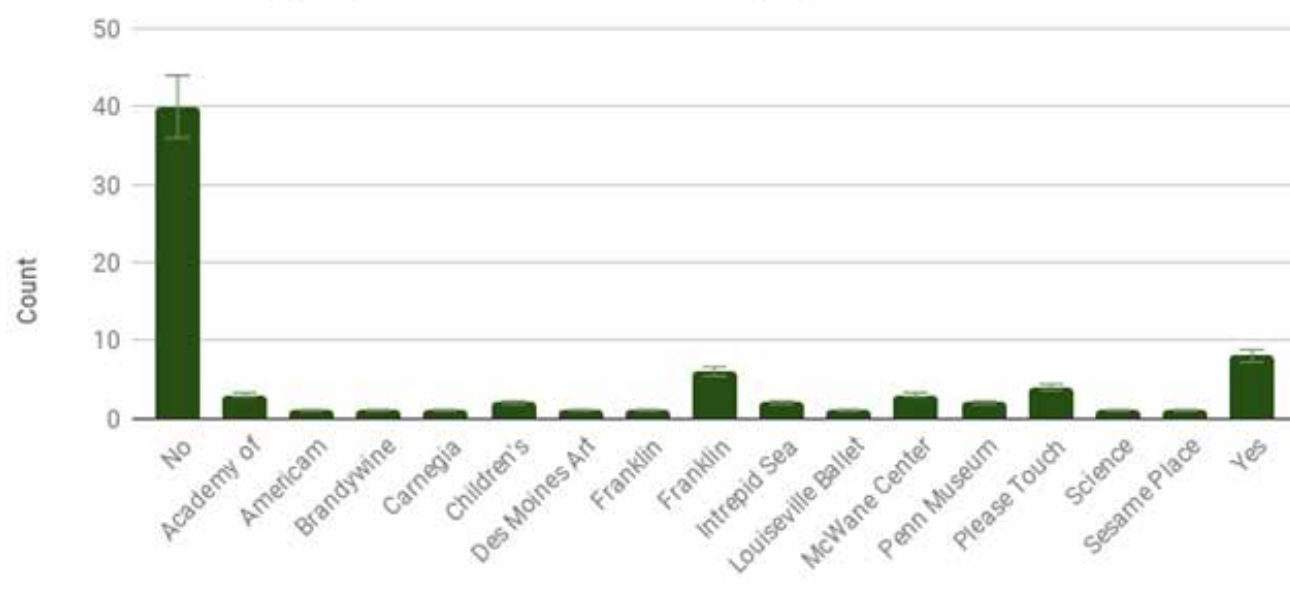
Needs	Wants
Staff trained on recognizing and awareness	To be a part of the process. To have a conversation during the design process when introducing inclusion into the space.
Noise reduction	More hands-on activities and objects to touch and handle for those with vision impairment.
Pre-visit guides	Better programming
Signs that give visitors a general sense of what to expect (quiet area, loud areas). Biggest concern is the unknown.	More sensory—friendly hours and days



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Generally, people were excited to see sensory inclusion being talked about for everyday exhibitions. The respondents had a lot to say about what more they wanted to see change and the things they liked already in place at museums. When asked if they knew of any museums that were accommodating to visitors with physical or intellectual disabilities, 52% of the respondents said no, they did not know of any museums they felt were inclusive to any extent. Others responded with a specific museum (15 named museums); however, those responses were under 9% each.

Do you know of any museums that have programs or facilities that accommodate people with intellectual or physical disabilities?

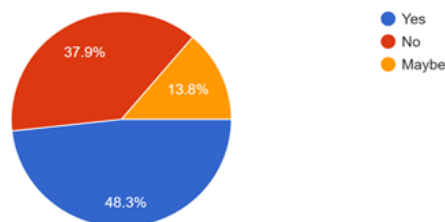


When asked about sensory stimuli problems 48.3% of the 87 respondents stated they or their family member have a sensory problem, whereas 13.8% respondents said they might have stimuli problems—this is very normal for ASD. Individuals with this sensitivity can react to the pain caused by over-stimulation by either acting out or withdrawing completely—most common among children and teens.⁸³

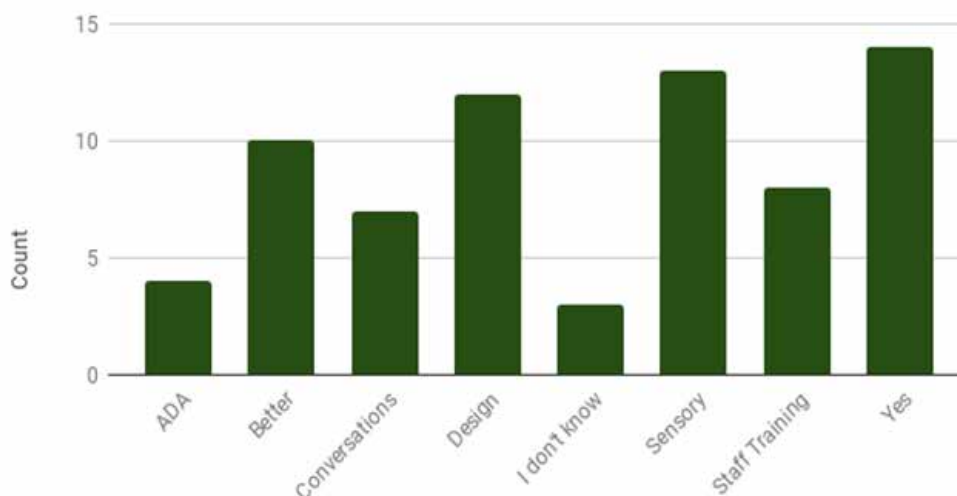
Respondents, in general, want to see inclusionary design happen in museums with an over yes answer of 19.8%, while 18.3% did directly state they wanted to see more sensory friendly days and times. Twelve respondents (16.9%) gave very specific design elements they wished to see changed (ie: noise reduction, quiet rooms, more touch activities, audio descriptions). Although many did want to see more overall inclusionary design within an exhibit, 11.2% want to see more front-line staff trained in awareness and 9.8% want to participate in a conversation with the museum about new programming and exhibits, some stating the tag line: *Nothing About Us, Without Us*.

Does anyone in your family have any problems with sensory stimuli (for instance light, sound, smell, touch)?

87 responses



What do you think museums should do to be more inclusive of people with disabilities?



Future

As museums and other institutions move towards a Universal Design concept, visitors will start to feel more comfortable within the space. Inclusionary design goes in tandem with Universal Design, adding the thought of more community input and working together as a single entity to strive for a common purpose: creating engaging environments for all of the museum's visitors. Cultural institutions need to progress with the communities that they serve. The need to become more inclusionary is a necessary factor to consider when the number of individuals with autism or any other disability is on the rise. Unless we listen to what that community is saying, we cannot strive to meet that goal or understand the why behind their voice, wants, and needs. The disability community is also telling us (museums) that they want to be heard and included in creating this inclusionary practice.

There is still much to learn about this disorder and generally more acceptance in our society. The best we can do is continue to learn and grow as much as we can, continuing through personal exploration and conversations within the community.

Going forward, this research needs to take a look at how schools and teachers are looking at how children with autism handle a learning space. What can we take away from a formal learning space and bring into museums? What new research is coming out about how architects are looking at school design? As exhibition designers, we can explore how spatial configuration, break up, and layout of the space might affect the attention span and compartmentalization of activities and experiences.

Currently, there are not many thorough studies on the different aspects of accommodating visitors who are sensory sensitivity or who have autism in museums. The more we know and understand the nuances of autism, the more we feel comfortable to have these conversations—to be as one—and work towards more inclusive experiences. When given the chance, the exhibition design team should start having conversations with parents of children with autism and other disabilities to have the communities input when designing new exhibitions. Starting to prototype a new design process that includes inclusionary design thinking will help the museum design teams create a space that is inclusive to all communities.



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Peggy Chowning, VP of Education. McWane Science Center. August 31, 2018. Interview via phone.

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Susan Peddy, Parent of Pete & David, March 12, 2019. Interview via phone.

Kara Bishop, Parent of Anna, March 22, 2019. Interview via phone.

Appendices

A. Survey Instrument

Sensory Inclusion in Museums

This survey's purpose is to look at museum audiences and new ways to change the way we think about sensory inclusion for those with a disability or limitation. The results of this survey will be included in my final thesis paper.

* Required

1. How often do you visit museums?

Mark only one oval.

- ☐ Less than once a year
☐ 1-2 times a year
☐ 2-5 times a year
☐ More than 5 times a year
☐ Never

2. Does anyone in your family have a known intellectual or physical disability? *

Mark only one oval.

- ☐ Down Syndrome
☐ Autism Spectrum Disorder
☐ Cerebral palsy
☐ Communication disability
☐ Socialization disability
☐ Other

3. Does anyone in your family have any problems with sensory stimuli (for instance light, sound, smell, touch)? *

Mark only one oval.

- ☐ Yes
☐ No
☐ Maybe

4. Do you know of any museums that have programs or facilities that accommodate people with intellectual or physical disabilities?

5. What do you think museums should do to be more inclusive of people with disabilities?

6. How strongly do you feel about seeing more sensory-friendly days in museums?

Mark only one oval.

1 2 3 4 5
Disagree ☐ ☐ ☐ ☐ ☐ Strongly Agree

7. How strongly do you feel about seeing more sensory-friendly hours in museums?

Mark only one oval.

1 2 3 4 5
Disagree ☐ ☐ ☐ ☐ ☐ Strongly Agree

8. How strongly do you feel about seeing more quiet rooms in museums?

Mark only one oval.

1 2 3 4 5
Disagree ☐ ☐ ☐ ☐ ☐ Strongly Agree

9. How strongly do you feel about seeing more frontline staff trained on disability awareness in museums?

Mark only one oval.

1 2 3 4 5
Disagree ☐ ☐ ☐ ☐ ☐ Strongly Agree

10. Which of these options for you feel would enhance the experience for your family?

Check all that apply.

- ☐ Pre-visit script of what to expect
☐ Signs of what to expect (loud areas, quiet areas, etc.)
☐ Sensory bags (includes: noise cancelling headphones, tinted glasses, fidget spinners, etc.)
☐ Other: _____

11. Please mark which family member has a disability.

Mark only one oval.

- ☐ Mother
☐ Father
☐ Brother
☐ Sister
☐ Son
☐ Daughter
☐ Aunt
☐ Uncle
☐ Other
☐ Me

12. Please tell me the age of your family member with a disability.

Mark only one oval.

- ☐ 0-1 years old
☐ 1-4 years old
☐ 4-10 years old
☐ 10-15 years old
☐ 15-20 years old
☐ 20+ years old

13. Zip code *

14. Please mark your age? *

Mark only one oval.

- ☐ Under 18
☐ 18-25
☐ 26-35
☐ 36-45
☐ 46-55
☐ 56-65
☐ 66-75
☐ 75+

15. I understand that the results of this survey will be used as part of thesis research and paper. *

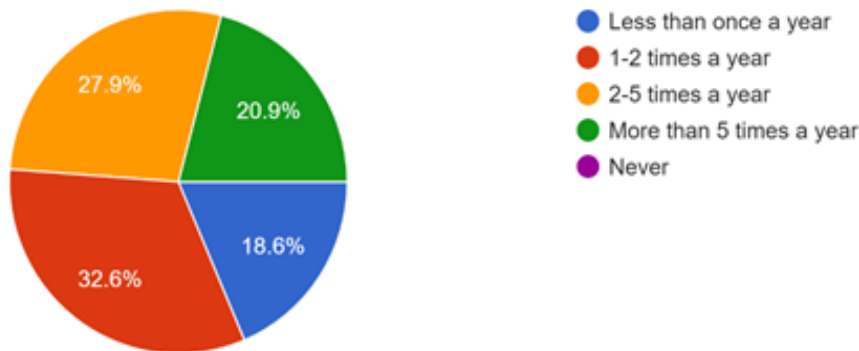
Check all that apply.

- ☐ Yes, I understand and give consent

B. Survey Responses

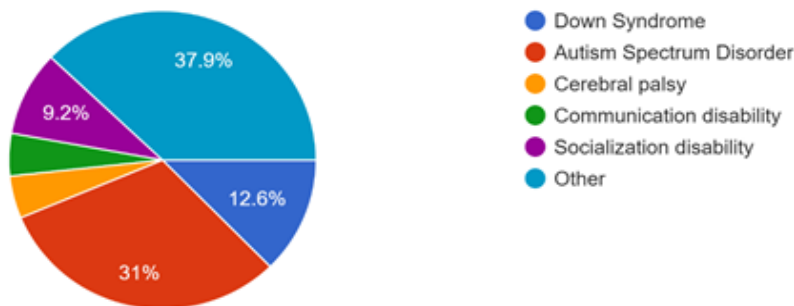
How often do you visit museums?

86 responses



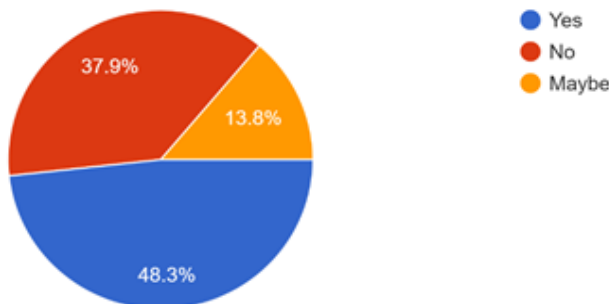
Does anyone in your family have a known intellectual or physical disability?

87 responses

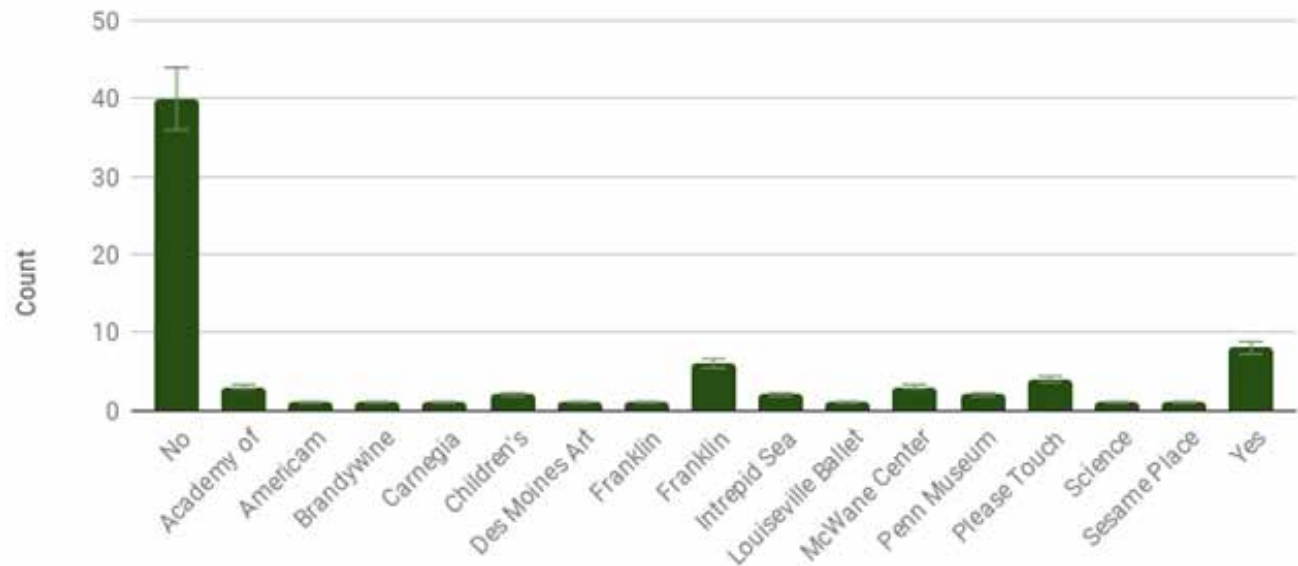


Does anyone in your family have any problems with sensory stimuli (for instance light, sound, smell, touch)?

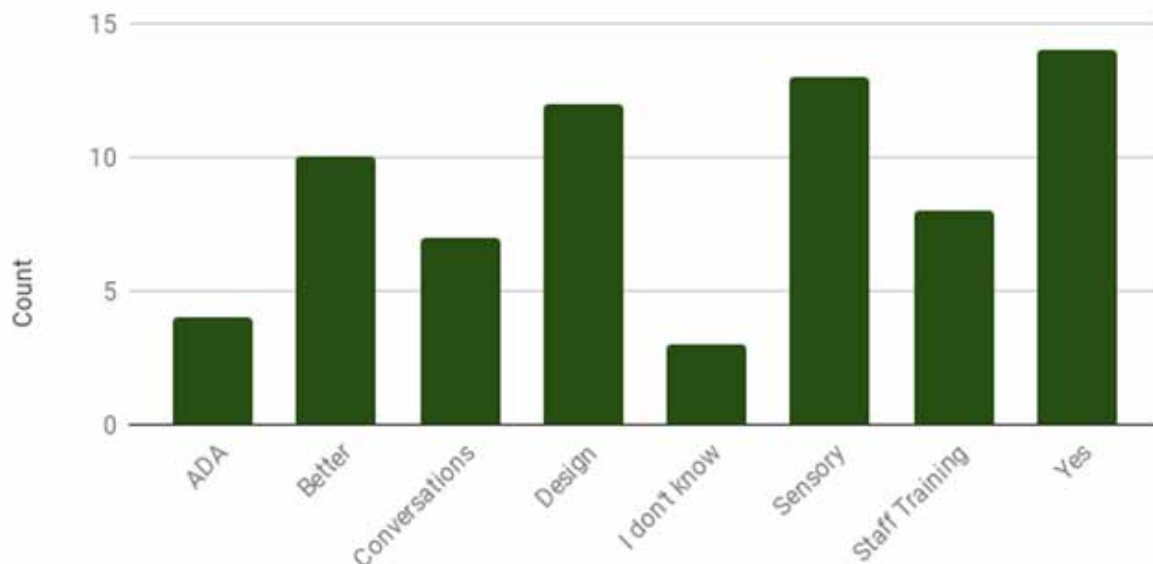
87 responses



Do you know of any museums that have programs or facilities that accommodate people with intellectual or physical disabilities?

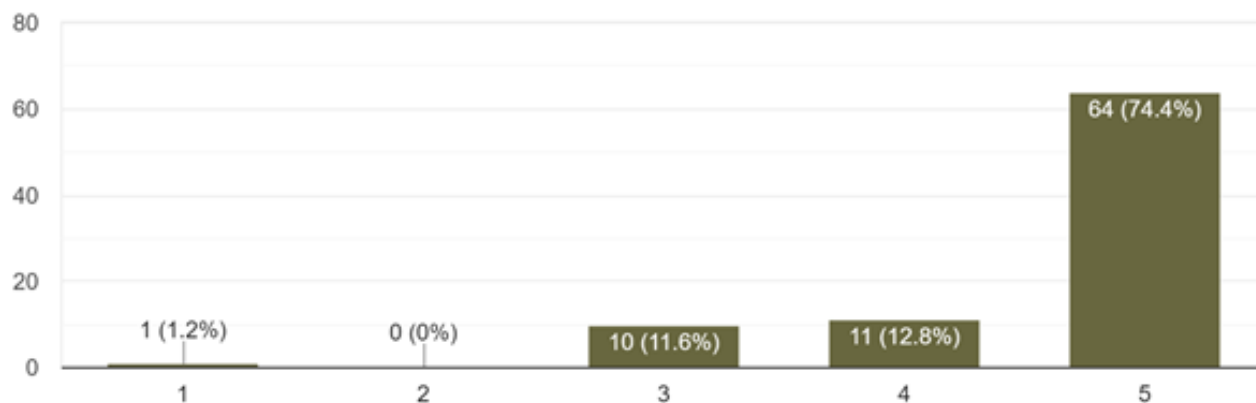


What do you think museums should do to be more inclusive of people with disabilities?



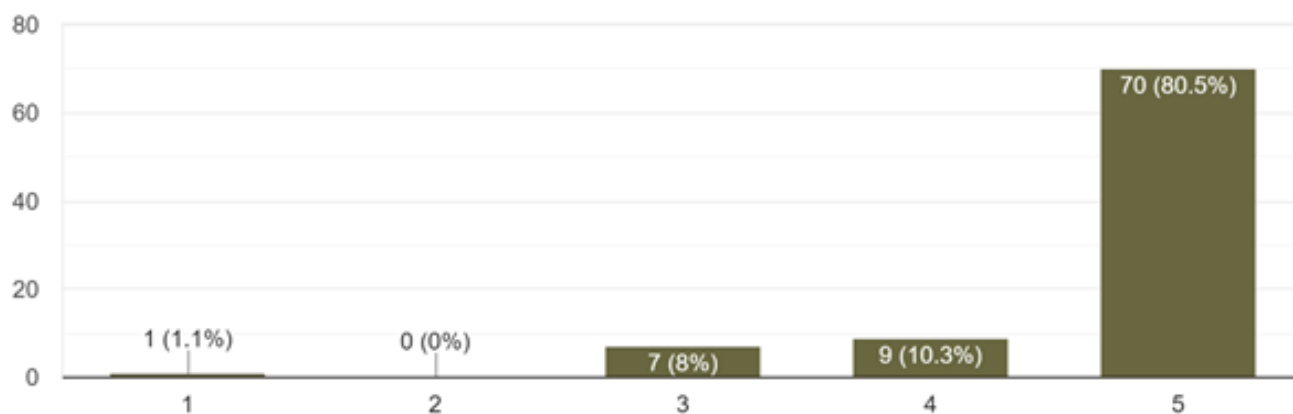
How strongly do you feel about seeing more sensory-friendly days in museums?

86 responses



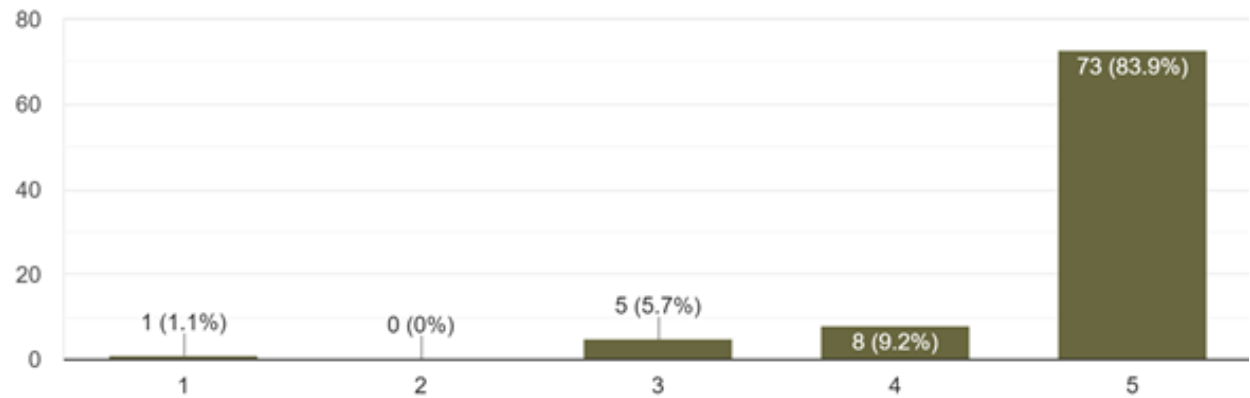
How strongly do you feel about seeing more sensory-friendly hours in museums?

87 responses



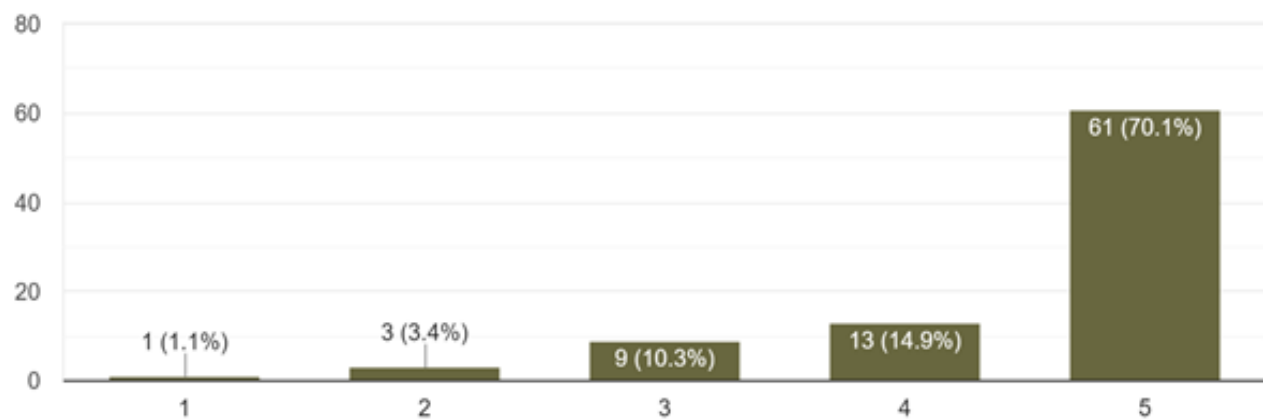
How strongly do you feel about seeing more frontline staff trained on disability awareness in museums?

87 responses

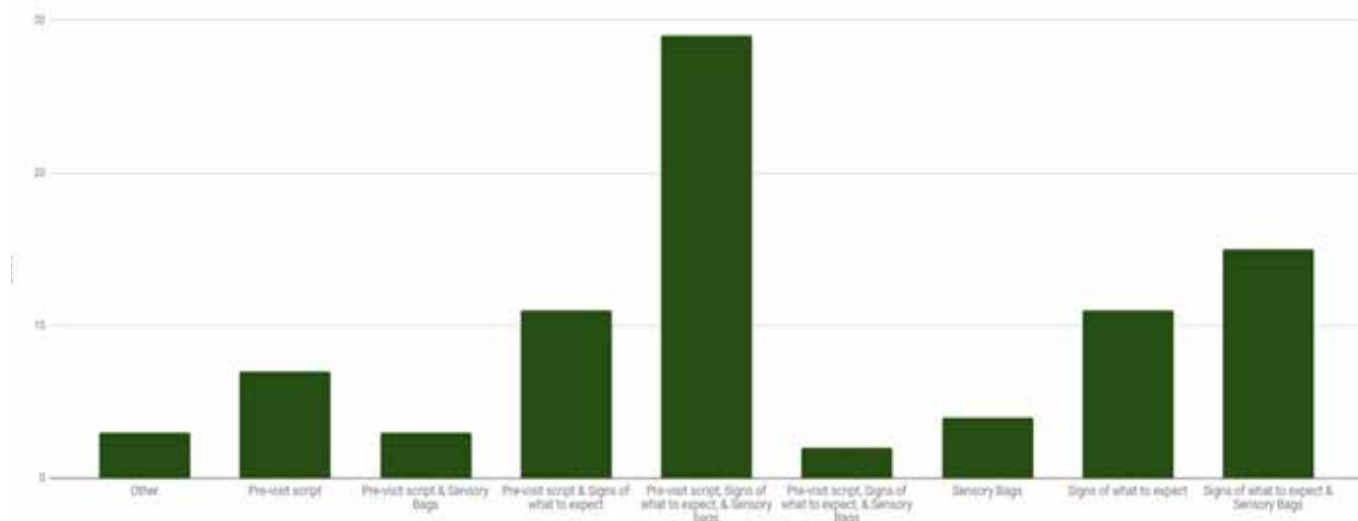


How strongly do you feel about seeing more quiet rooms in museums?

87 responses

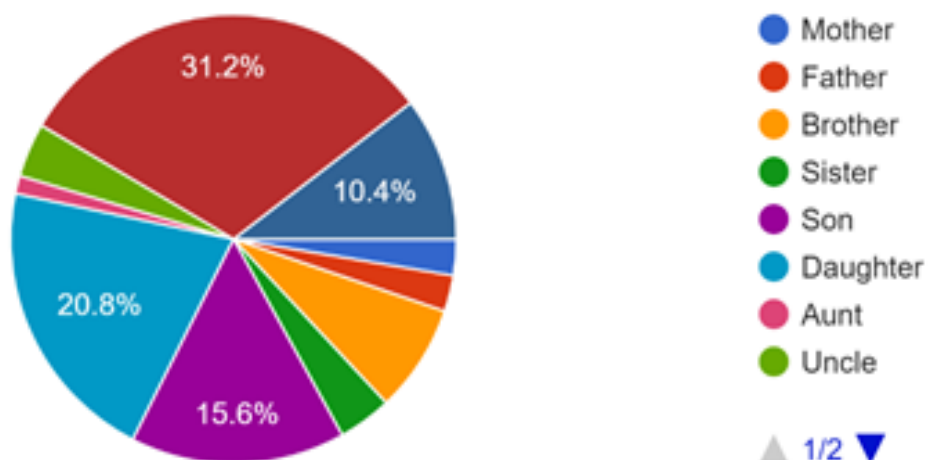


Which of these options for you feel would enhance the experience for your family?



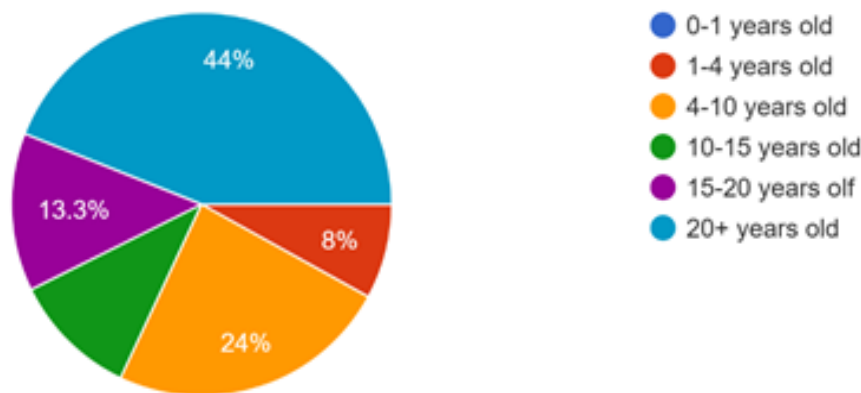
Please mark which family member has a disability.

77 responses



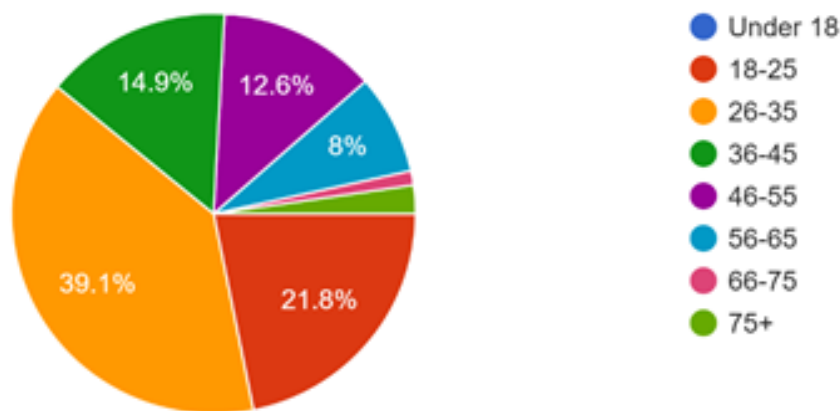
Please tell me the age of your family member with a disability.

75 responses



Please mark your age?

87 responses

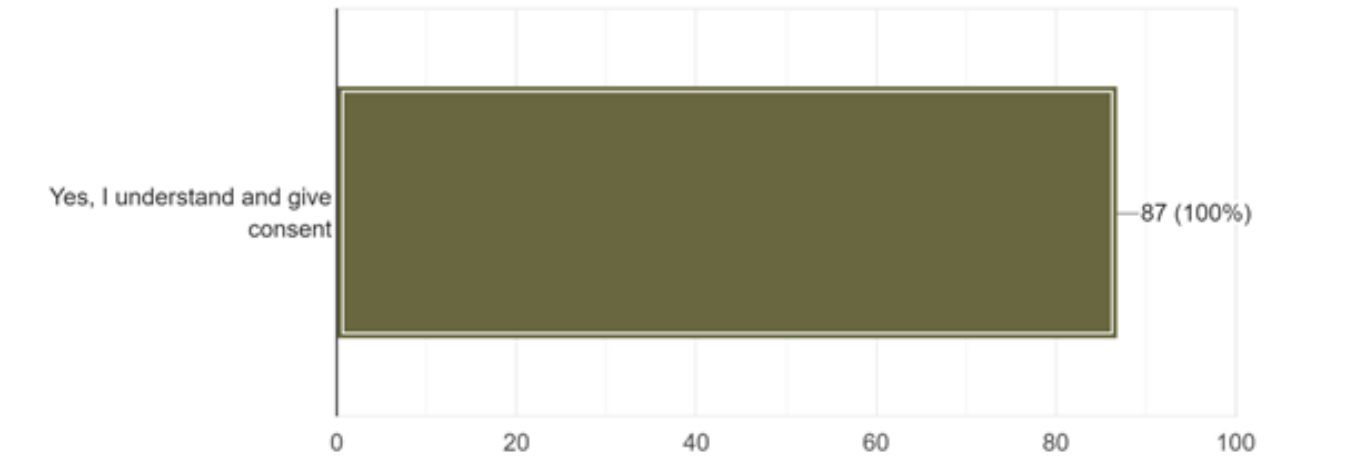


Zip Code

Input start distance	End distance	% of respondents
0	10	20%
10	25	16%
25	50	4%
50	100	0%
100	250	9%
250	and greater	33%
	outside U.S.	18%

I understand that the results of this survey will be used as part of thesis research and paper.

87 responses



C. Interviews

Lamar Smith, VP of Exhibitions and Peggy Chewning, VP of Education, McWane Science Center, Birmingham, Alabama

Responses are summarized

Q: How did KultureCity become involved with the institution?

A (summarized): KultureCity approached to come in to train staff, set up of a quiet room and zones, and introduce sensory bags. These bags include fidget spinner, communication cards, tinted glasses, and headphones. 80% of the staff was trained in identification and interactions with autistic visitors. Now, all new employees must go through training as part of the collaboration. Yearly recertification is required through the program.

Q: Based on recent evaluations, was there an indicator that the museum was lacking these visitors?

A (summarized): No. It wasn't until KultureCity came in did they realize that these special interest visitors did not feel welcomed unless it was a sensory day.

Q: How often are the sensory services used?

A (summarized): Sensory bags are checked out, free of charge, daily. The sensory room is used less frequently than the bags or quiet zone, but are very appreciated by the parents. The room can be used for 15-20 minutes at a times.

Q: Have you noticed a rise in attendance because of the partnership with KultureCity?

A (summarized): As far as they know, there has not seen an increase in attendance due to the partnership. Attendance is based on many things; the weather, time of year, new exhibits and IMAX movies, so it's hard to tell if there's been an increase in this population. They do know, based on social media and in talking with our guests, that parents of kids with sensory difficulties feel much more comfortable coming to the center, because of our association with KultureCity and the quiet areas provided.

Q: Is the institution planning on integrating more sensory elements into the museum?

A (summarized): The museum is currently working on a master plan for the redesign of the museum. At this point, the master plan is only 30% complete. Once the plan is at a more developed stage, the exhibit team will be discussing these elements for future exhibitions. In the meantime, the institution is in the process of starting all day sensory days once a month, including Imax.

Laura Westmoreland, Associate Educator, Brandywine Art Museum, Chadds Ford, PA

Responses are verbatim

Q: How often are your inclusion days?

A (verbatim): We currently offer special sensory-friendly programs on three Saturdays per year – once in early January (which ties into our holiday train exhibit), once in the spring, and then once in the summer or fall.

Q: Does the museum have quiet rooms or areas available for those who become overwhelmed?

A (verbatim): We do not have any permanent quiet areas set up, although in our social story (pdf, video to give a visual to the visitor so they know what to expect) we suggest that they visit a seating area in one of our lobbies if needed. We do set up a quiet area on our three sensory-friendly days.

Q: During your sensory days/ hours, does the museum change the environment in any way?

A (verbatim): We set up a quiet room that is equipped with a tent and another “hiding spot,” each filled with pillows, blankets, and fidget toys. We also put padding down on the floor in the quiet room and put out weighted lap pads, additional fidget toys, a tumbling pad, a sensory sack, books, drawing materials, theraputty, and we cover the fluorescent lights and add some gentle colorful projected light.

We open the museum early for these events, so they can access the galleries before general hours, and we set up three stations in our galleries. At each station, there is a docent, rugs on the floors, manipulatives that relate to the art, tactile objects, and other objects such as iPod with sounds, salt shakers with scents, and additional fidget toys. We set up our lecture room with two different art projects (that can be adapted for various needs), and we set up a welcome table in our lobby where we give maps, noise-canceling headphones, and fidgets to people who want them. In the lobby, we also set up a practice station in case a family wants to practice how close they should stand to a work of art.

Q: During non-inclusion days, are there any tools like tinted glasses, weighted blankets, or headphones available for guests?

A (verbatim): We have six sensory-friendly museum packs available to check out, and each includes fidgets, noise-canceling headphones, museum map, printed social story, gallery seek-and-finds, discussion questions, and a packet of community resource information.

Q: Is there a pre-visit guide of what to expect to lessen the unknown?

A (verbatim): Yes, we email these out to families who register for our Sensory-Friendly Saturdays, and we also have them available online for general visits, as well as printed versions in our sensory-friendly museum packs.

Q: For any new exhibitions going forward, will the museum look to include an assessment for daily inclusion (lighting, layout, etc.)?

A (verbatim): So far, this has not been discussed as a part of exhibition design.

Q: Have you and the institution done any surveying for these sensory days? If so, what were some big takeaways?

A (verbatim): Yes, we survey after each event. Participating families have been extremely satisfied with what we're doing. Surveys let us know that most people hear about our events through social media and online events calendars. When asked which aspects of the event are most helpful, staff/volunteer assistance is always ranked the highest, with fidgets and break areas following second.

Q: What is the attendance of these days?

A (verbatim): Our lowest event had 19 people at it, and our highest had 48. We average about 40.

Q: Are there any plans in the future to expand the program?

A (verbatim): Not with our current staffing level. We recognize that to expand this program we would need additional staff or to cut other programs.

Q: Is the front of house staff trained to identify autistic visitors and their needs? I know some institutions are starting to train their staff on how to interact with these visitors.

A (verbatim): Our manager of visitor services attended a disability etiquette training session that I held, but otherwise they have not been trained in autism. We have access to online training through an organization we are working with but have not required staff to take it. Brandywine is prioritizing some general customer service training first.

Katie Woelfel, Education Coordinator, Please Touch Museum, Philadelphia, PA

Responses are verbatim

Q: How often are your inclusion days?

A (verbatim): Currently we offer a Play Without Boundaries Accessibility Event every other month- so 6 times a year. Typically, they are on Sunday Mornings from 9-11am, before the museum opens to the general public at 11 am. We're excited this year to offer our first nighttime Play Without Boundaries from 5-7pm since our attendance at these events have been steadily growing and survey data showed visitors are interested in another option for our accessibility events.

Q: Does the museum have quiet rooms or areas available for those who become overwhelmed?

A (verbatim): Yes. The Museum has 5 pop up sensory friendly tents, that we offer to visitors who are looking for a quick break during typical museum hours. On our Play Without Boundaries days, we transform 2 meeting rooms 1 on the top floor, and 1 on the bottom floor into a quiet room where we showcase our accessibility resources (sensory toys, fidgets, weighted blankets, books, crayons etc.)

We are in the process of identifying and transforming areas in the museum to be permanent quiet rooms and are working with exhibits to discuss what space in the museum makes sense to be a permanent quiet room and what other structural/engineering changes would need to be made to make this dream daily quiet space a reality.

Q: During your sensory days/ hours, does the museum change the environment in any way?

A (verbatim): Yes, so a few years back we were evaluated by the Global Abilities Foundation- who identified areas of improvement in our institution to make our museum more accessible. Specifically, they did a walkthrough and identified structural changes (making ramps/ countertops ADA compliant etc.) and at the time they identified sounds/ lighting cues that could be considered overwhelming to our sensory friendly visitors. It has been some time, since we've had another evaluation done, we are in conversation with CHOP's CAR (Center for Autism Research) to have them do a walk through to update our museum environment- but currently our engineers go around and dim all lighting cues, and reduce the sound if it has the ability to be reduced or completely shut off all sound cues.

Q: During non-inclusion days, are there any tools like tinted glasses, weighted blankets, or headphones available for guests?

A (verbatim): Yes, at any time that you visit our museum all of our guests have access to our aforementioned accessibility bin which has weighted vests and snakes, glasses, sensory toys, fidgets, books, etc. a crash kit, and AAC (Alternative Augmentative Communication Device) Touch Screen. This bin lives at our front desk and all a visitor has to do is ask to see the kit to borrow any of our resources during their stay.

Q: Is there a pre-visit guide of what to expect to lessen the unknown?

A (verbatim): So most recently I wrote a Social Story for Thomas Explore The Rails, this has been promoted on our website and is also available at our front desk. For the whole museum, years ago somebody wrote a brief, and not an all-encompassing social story of the museum. We have not promoted it for a while now because it is very out of date with new staff changes, new exhibits, and new museum protocol. We are currently in the process of figuring out what makes the most sense for our visitors- should it be a long tedious document that goes through each exhibit? Should it be a series of short documents, one for each exhibit? Should we hire a videographer and try and do a video walkthrough of each of our spaces? These are just a few of the conversations PTM's Accessibility Working Group comprised of Museum Employee's and parents of Children with ASD are considering.

Q: For any new exhibitions going forward, will the museum look to include an assessment for daily inclusion (lighting, layout, etc.)?

A (verbatim): As mentioned earlier we are in conversation with CHOP's CAR to re-evaluate daily inclusion and sensory accommodations for our visitors. We also have a new director of exhibits; whose wife works at the AJ Drexel Center for Autism Research and so we are excited for the beginning of a collaboration with this institute to continue to make our museum accessible for all.

Q: Have you and the institution done any surveying for these sensory days? If so, what were some big takeaways?

A (verbatim): Yes, we are huge on our surveys- especially on PWB days. From our surveys we know 1.) that our visitors were interested in having a late-night event- which we are testing out on October 19th. We know that visitors are excited by our community partners that come and set up resource tables and drop in programming with visitors. These partnerships include:

- Art Ability- Bryn Mawr Rehab
- Dance Movement Therapy
- Floreo Virtual Reality
- PAWS for People
- CHOP
- AJ Drexel Autism Institute

We also know that coming to Please Touch, even on a sensory-friendly day, can be overwhelming for both child and caregiver and that while they are excited to engage with our resources- it is often not possible because they are running around with their child; so we are currently making an action plan for how to potentially offer visitors with pre-registration a takeaway goodie bag with the information of our community partners, or something like that.

Q: What is the attendance of these days?

A (verbatim): Typical Attendance is around 500 visitors in total- around 250 children and 250 caregivers. For FY18 we had a total attendance of 4,457 pre-registered and 2,292 attended.

Q: Are there any plans in the future to expand the program?

A (verbatim): As an institution we are in a year of assessment and maintenance- figuring out how to offer a 5 star experience for all of our visitors based on what we already offer, What this looks like for us right now is taking a step back, re-evaluating what teams before of us have done, accessing it, and testing new solutions and offerings across our entire museum.

We are eager for growth, and look forward to having the staff support to eventually offer things like a sensory map that identifies areas of the museum that might be overstimulating, a permanent quiet space, more community programming, and up to date museum-wide social story, ASL Storytime, more inclusive signage with play prompts that are friendly not only for kids who can't read by ESL grownups, and relaxed performances in our theatre space- just to name a few things we are considering.

Q: Is the front of house staff trained to identify autistic visitors and their needs? I know some institutions are starting to train their staff on how to interact with these visitors.

A (verbatim): We have had museum-wide general sensitivity training on how to handle families in crisis (as you can imagine there are a lot of child meltdowns at our museum) and we have been interviewing outside organizations to lead a training specifically on working with ASD children and families. It is in our working plan to have staff trained on this by the end of Quarter 2 (which would be March 2019).

Sandra Bonnici, Associate Director of Education, Diversity, and Inclusion, Madison Children's Museum, Madison, WI

Responses are summarized

Q: How often are your inclusion days?

A (summary): Last Monday of each month from 5 pm to 7 pm.

Q: Does the museum have quiet rooms or areas available for those who become overwhelmed?

A (summary): There is three designated space during SF time. There are no designated comfort areas during general hours, but the First Aid Room on the first floor is a good place to cool down. The Cozy Cottage can be used when it is unoccupied.

Q: During your sensory days/ hours, does the museum change the environment in any way?

A (summary): Yes. Hand dryers will be closed off and paper towels will be available in all bathrooms. They have learned the hand dryers are one of the biggest issues among Autist children due to the noise and pressure of the air. The Wilderrest, Cozy Cottage, and first floor First Aid room will be designated comfort rooms. The entire museum, except for the Log Cabin, will be open and all ages are welcome, including friends and family. The Wayback Machine exhibit and pinball machines will be turned off for the events, including all lights, sounds, and video. Fidgets, timers, headphones, and other sensory resources will be available for children and families to use in the museum. Simple signage designating quiet zones and sensory-seeking areas will be posted throughout the building. The Roman Candle Sparkler Café will not be open, but the café area will be available for eating if attendees wish to bring their own food. We request that families eat only in the café area, and only bring foods that are free of peanuts and tree nuts.

Our primary goal in making these changes is to create a welcoming, supportive, and fun environment for families to play and explore together. To assist the museum in meeting this goal, we welcome and encourage participants' feedback on every aspect of our sensory-friendly programming.

Q: During non-inclusion days, are there any tools like tinted glasses, weighted blankets, or headphones available for guests?

A (summary): Yes. Headphones, glasses, gloves, and a variety of small toys are available to visitors during general and SF times at the front desk.

Q: Is there a pre-visit guide of what to expect to lessen the unknown?

A (summary): Yes. MCM is in the process of creating short videos of each area to better understand what happens in each space. These videos will be in a child's voice and perspective.

Q: For any new exhibitions going forward, will the museum look to include an assessment for daily inclusion (lighting, layout, etc.)?

A (summary): MCM is in the process of master planning and will be looking at how to include a more universal design to its spaces. In the meantime, MCM has made some minor changes that can already create a daily impact. MCM has switched from white paper to pastel papers; changed to lighting to give it a pinkish hue, and has limited as much noise as possible.

Q: What is the process when considering lighting and layout for new exhibitions?

A (summary): You should talk more with our Director of Exhibits.

Q: Have you and the institution done any surveying for these sensory days? If so, what were some big takeaways?

A (summary): MCM is constantly doing an evaluation, it's part of a current grant. These evaluations have indicated several things that we can do better. We place the results in a "toolkit" that we distribute during some conferences and to other institutions that are improving their inclusions.

Q: What is the attendance of these days?

A (summary): Attendance is not counted during SF time. Some visitors are coming in to use the quiet time to prepare for general hours. They know that the unknown can be scary when you have Autism, allowing the children to come during these times makes the later experiences more enjoyable and less scary.

Q: Are there any plans in the future to expand the program?

A (summary): MCM is constantly evaluating the programs and spaces. MCM partners with occupational therapists to make changes based on the needs of the visitors, working for a more universal designed space.

Q: Is the front of house staff trained to identify autistic visitors and their needs? I know some institutions are starting to train their staff on how to interact with these visitors.

A (summary): Yes. Every front-line staff member is trained. If they recognized the signs of a possible meltdown, they can help the family find a quiet area to cool down in.

Mary Bailey, Interim Head of Public Engagement; Public Programs, The Academy of Natural Science, Philadelphia, PA

Responses are verbatim.

Q: How often are your inclusion days?

A (verbatim): Once a month, approximately every 2 months. In order to make it less overwhelming for guests we look at the full yearly calendar carefully, so we don't overlap with other accessibility events or parkway programs.

Q: Does the museum have quiet rooms or areas available for those who become overwhelmed?

A (verbatim): During the event, we reserve a room that is easily accessible for guests just off of Dinosaur Hall. The room is available until 2pm even though the event ends at 11. On other days, our staff will find spaces for guests who need a spot for a multitude of quiet activities: breast feeding, calming down, having a rest.

Q: During your sensory days/ hours, does the museum change the environment in any way?

A (verbatim): We will turn off the noisier interactives and allow guests to attend during a quieter time.

Q: During non-inclusion days, are there any tools like tinted glasses, weighted blankets, or headphones available for guests?

A (verbatim): We received a mini-grant this year to build accessibility kits that guests can borrow including fidget toys, blankets, etc. The prototypes will be available by the end of the fiscal year (June 2019) for us to pilot and hopefully fully incorporate.

Q: Is there a pre-visit guide of what to expect to lessen the unknown?

A (verbatim): Yes, all our pre-visit materials are available online, and we advertise them more during the inclusivity events.

Q: For any new exhibitions going forward, will the museum look to include an assessment for daily inclusion (lighting, layout, etc)? - Lauren has told me that she is hoping to look into incorporating some design aspects in the future.

A (verbatim): We already include best practices for accessibility in all exhibits, including requirements for walkways, sightlines, etc. For the next iteration of museum design, we would love to incorporate even more universal design thinking to create a welcoming and accessible experience for all guests.

Q: Have you and the institution done any surveying for these sensory days? If so, what were some big takeaways?

A (verbatim): We have not done formal surveying for this program, but informally, we found that the numbers are going up and guests seem very happy. The main takeaway is that this program is eliminating barriers for guests in a strong way that is evidenced by the attendance. The bigger the program gets, the more we realize that this is a necessary program that benefits guests in a real way.

Q: What is the attendance of these days?

A (verbatim): We cap attendance at 150 to make the best experience for guests. We hit capacity most of the time and our lowest attendance dates are around 80-100.

Q: Are there any plans in the future to expand the program?

A (verbatim): It recently underwent an expansion (from 2-3 times a year to semi-monthly, as well as the development of

the sensory-friendly kits) so we are going to see how it goes for at least a year.

Q: Is the front of house staff trained to identify autistic visitors and their needs? I know some institutions are starting to train their staff on how to interact with these visitors.

A (verbatim): Yes, we have been incorporating professional development and training for staff and volunteers for as long as I have been here (5 years) and we do refresher trainings periodically. We also offer information and toolkits for all staff, including behind the scenes staff, regarding working with all guests, including multi-generational groups, people with disability needs, etc.

Emily

Her mother sent me an email about two recent experiences to local museums in the Philadelphia area with a few follow up questions.

Emily has autism. This past year we visited the Art Museum and the Jewish Museum in Philly. Emily can move around the museum just fine as she has no physical limitations. However just visually looking at art was not enough to get Emily very involved. Just hearing a description of a display did not impart much information to her because she is a much more hands-on type of learner. We wished there were more interactive parts of the museum and more opportunities to use other senses rather than only sight such as touch and sound.

For instance, in the art museum, there was a beautiful display with a carved wooden fireplace. But it did not interest Emily. I read the description of the fireplace but it would have been wonderful if there was a piece of carved wood (not the original of course) that Emily could touch.

The day we visited the Jewish museum, there was a problem with the audio-visual system and the interactive display was not working. So it isn't totally fair for me to comment. But I think it would have been wonderful if there was music playing from each of the time periods that the museum presented (each floor represented a different time period.) Or maybe sounds from that time such as children playing. I believe the Jewish museum did have a few interactive areas such as a kitchen from the 1950s. Emily enjoyed that.

These museums have so much to offer but for those that relate to the world in a more tactile or auditory way rather than purely by sight, having other means to explore the treasures inside the museum would be a much more engaging experience.

Q: Do you choose which museum to go based on sensory issues, sensory friendly days, or just for the exhibits?

A (verbatim): It's a combination of both. We want to find engaging exhibits that will be meaningful to Emily. But we also want her to feel comfortable. When Emily was young, we looked for "quiet rooms" and sensory areas. (We used to go to AMC Sensory Friendly movies when Emily was young so she could sing or walk in the aisles during the movie.) But now we just try to make sure that she can have movement breaks every so often and not just sit still. If it is crowded around a particular exhibit and Emily is talking out loud (echolalia) we move away and return when it is less crowded. I try not to disturb others who may be contemplating an exhibit.

Q: Does Emily have any sensory issues with noise, color, and/ or light?

A (verbatim): Yes, noise and light are can be problematic at times. Emily wears noise canceling headphones when she is around a loud volume of noise. She wears them at movies, pep rallies, fire drills, etc. We keep a pair in each of our cars and there is one at school. So far we have not encountered a need to wear them at a museum. She is also sensitive to light and wears sunglasses when outdoors. This has not been an issue at museums.

Q: Are there any museums in the area that you and Emily attend on a regular or semi-regular basis and why? When Emily was younger, did she have any issues with crowds or sensory overload? If so, where there any ways to help her calm down?

A (verbatim): We do not visit museums on a regular basis although that sounds like fun. When Emily was young, we visited the Discovery Museum in Cherry Hill on a weekly basis. However, that museum is for children and it is very interactive.

Ways to calm Emily were:

- Remove her from the sensory overload situation
- Massage her arms and back to calm her
- Tell her “just ____ minutes more” and then count how many minutes were left. (to set her expectation)
- Have a favorite snack to give her
- Distract her in whatever way was handy

One last thing to mention. Sometimes Emily could “hear” a sound that we could not hear. We tried a few times to take her into Wendy’s (as a baby, toddler and at 5 or 6 years) and each time she cried and was very upset. My opinion is that the electronic fryers made a sound that only Emily heard that may have been high pitched and irritating. I came to this conclusion because a restaurant near us had the same effect and it also had deep fryers. So when we go out to museums and elsewhere, we always watch for how Emily reacts. I have her headphones in a backpack. We always appreciate a quiet room to escape to if needed on the premises.

D. Additional Graphs



Auditory Sensitivity Issues in Children with Autism

J. Kiely Law, MD, MPH^{1,2}; Eric Rubenstein, ScM³; Alison

¹Department of Medical Informatics, Kennedy Krieger Institute, Baltimore, MD, USA; ²Department of Pediatrics, Johns Hopkins University

Background

Sensory sensitivity issues are strongly associated with autism spectrum disorders (ASD). Research suggests 30-90% of people with ASD either over or under react to sensory stimuli. Auditory hypersensitivity is most common, affecting 30-50%, and is highly concerning due to the often unpredictable nature of the stimulation, and the potential to lead to avoidant or challenging behaviors.

Objective

To describe auditory hypersensitivity and hyposensitivity issues in children with ASD.

Methods

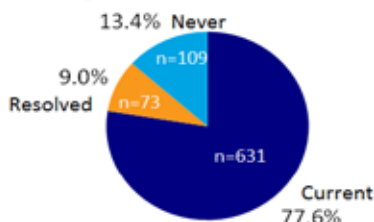
- ⇒ Parent participants in the Interactive Autism Network (IAN), a large, validated and verified autism research registry, were invited to complete the Auditory Sensitivity and Child Safety Study during 2015.
- ⇒ Parents completed a survey about their children ages 2-17 years with ASD.
- ⇒ The survey asked about the child's past and current levels of auditory sensitivity, and how auditory sensitivity affects the child's behavior and impacts their family.

Results

- ⇒ Surveys completed for 814 children with ASD
- ⇒ Child characteristics:
 - ♦ 82.4% male
 - ♦ 87.5% non-Hispanic
 - ♦ 84.8% white
 - ♦ Age:
 - ◊ Median = 10.3 years
 - ◊ Interquartile Range (IQR) = 6.66 years

Results: HYPERsensitivity

Reported Rates



Child's Emotional State

(n=631 responses)

Stressed	77.7%
Irritable	61.3%
Scared	55.2%
Nervous	54.4%
Frustrated	43.9%
Annoyed	40.9%

Median age

- Onset: 2.0 years
- Resolution: 7.5 years
- Worst symptoms: 4.5 years

Child's Physical Response

(n=631 responses)

Covers ears	85.9%
Yells or screams	52.2%
Tries to run away	42.3%
Cries	36.3%
Tries to stop sound/noise	33.8%
Tries to hide	25.2%

Common Interventions

	USED BY	Very Satisfied	Somewhat Satisfied	Somewhat Unsatisfied	Very Unsatisfied
Warning/preparing child for trigger sounds	90.9%	13.5%	39.5%	9.3%	10.3%
Avoiding trigger sounds	89.8%	23.9%	34.1%	6.4%	4.2%
Taking quiet breaks	85.6%	31.0%	40.4%	4.1%	4.5%
Ear buds/standard headphones with music	57.6%	23.3%	31.1%	11.1%	12.2%
Ear muffs	50.3%	24.0%	27.4%	11.0%	19.2%
Ear plugs	44.8%	7.1%	17.4%	16.7%	45.0%

n=631 responses

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Law, J. K., Rubenstein, E., Marvin, A., Toroney, J., & Lipkin, P. H. (2016). Auditory sensitivity issues in children with autism spectrum disorders: Characteristics and burden. Pediatric Academic Societies Meeting; April 30-may 3, 2016, Baltimore, Maryland. Poster.
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Autism Spectrum Disorders: Characteristics and Burden

R. Marvin, PhD¹; Jaimie Toroney, MHS¹; Paul H. Lipkin, MD^{1,2}

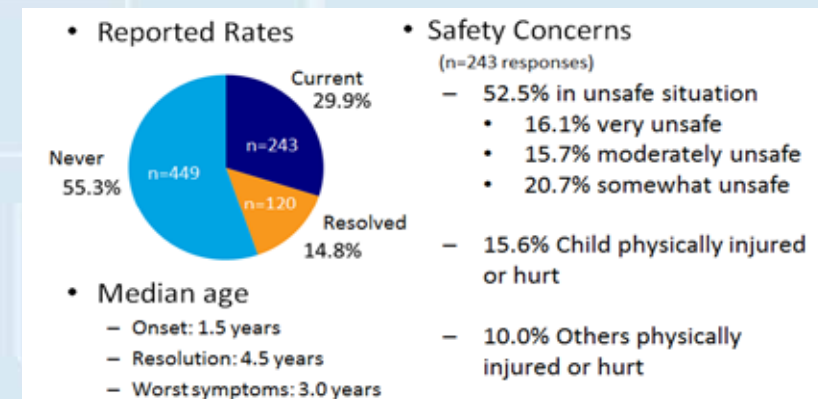
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Results: HYPERsensitivity (Continued)

- ⇒ **Higher ASD Severity:** Children with hypersensitivity experienced more severe ASD symptoms by SRS raw score: 111.6 vs. 99.3 ($p < .001$).
- ⇒ **Link with Seizure Disorders:** Children with hypersensitivity were more likely to have Epilepsy/Seizure Disorders: 11.3% vs. 7.3% ($\chi^2 < .001$ FET). 30% (18/60) reported seizures related to auditory triggers.
- ⇒ **Limits social participation ("always" or "frequently"):**
 - ♦ 31.1% Family activities
 - ♦ 29.8% School activities
 - ♦ 38.5% Community activities
- ⇒ **High burden:**
 - ♦ 63.4% of children have weekly episodes (26.0% daily)
 - ♦ 49.5% of parents reported moderate/extreme difficulty managing
- ⇒ **Safety concerns:**
 - ♦ 43.2% of children were reported to be in an unsafe situation (11.0% very unsafe; 10.7% moderately unsafe; 21.5% somewhat unsafe)
 - ♦ 18.2% of children were themselves physically injured
 - ♦ 28.1% of children physically injured others

Results: HYPOsensitivity



Conclusions

- ⇒ Auditory sensitivity occurs frequently among children with ASD.
- ⇒ Auditory sensitivity is associated with:
 - ♦ safety concerns,
 - ♦ challenging behaviors, and
 - ♦ loss of opportunities at home, in school, and in the community.
- ⇒ Auditory hypersensitivity is associated with more severe ASD symptoms.
- ⇒ Auditory hypersensitivity may be associated with seizure activity.
- ⇒ Improved understanding of auditory sensitivity may lead to improved treatments aimed at improving social participation, decreasing behavioral difficulties, decreasing family and community stressors, and decreasing child injury.



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DC/Emory University); Joseph Pillion, PhD (Audiology/KKI); Louis Hagopian, PhD (Behavioral Psychology/KKI).

Krieger Institute and the Simons Foundation. Visit the Interactive Autism Network at www.IANproject.org

Provide multiple means of Engagement

Affective Networks
The "WHY" of Learning



Provide multiple means of Representation

Recognition Networks
The "WHAT" of Learning



Provide multiple means of Action & Expression

Strategic Networks
The "HOW" of Learning



Access

Provide options for Recruiting Interest

- Optimize individual choice and autonomy
- Optimize relevance, value, and authenticity
- Minimize threats and distractions

Provide options for Perception

- Offer ways of customizing the display of information
- Offer alternatives for auditory information
- Offer alternatives for visual information

Provide options for Physical Action

- Vary the methods for response and navigation
- Optimize access to tools and assistive technologies

Build

Provide options for Sustaining Effort & Persistence

- Heighten salience of goals and objectives
- Vary demands and resources to optimize challenge
- Foster collaboration and community
- Increase mastery-oriented feedback

Provide options for Language & Symbols

- Clarify vocabulary and symbols
- Clarify syntax and structure
- Support decoding of text, mathematical notation, and symbols
- Promote understanding across languages
- Illustrate through multiple media

Provide options for Expression & Communication

- Use multiple media for communication
- Use multiple tools for construction and composition
- Build fluencies with graduated levels of support for practice and performance

Internalize

Provide options for Self Regulation

- Promote expectations and beliefs that optimize motivation
- Facilitate personal coping skills and strategies
- Develop self-assessment and reflection

Provide options for Comprehension

- Activate or supply background knowledge
- Highlight patterns, critical features, big ideas, and relationships
- Guide information processing and visualization
- Maximize transfer and generalization

Provide options for Executive Functions

- Guide appropriate goal-setting
- Support planning and strategy development
- Facilitate managing information and resources
- Enhance capacity for monitoring progress

Goal

Expert learners who are...

Purposeful & Motivated

Resourceful & Knowledgeable

Strategic & Goal-Directed

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