

# AUTISM MATTERS

MAKING GALLERIES AND MUSEUMS ASD/SPD FRIENDLY

BETH DAVIS-HOFBAUER



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## THE PROBLEM

Many children and adults with Autism Spectrum Disorder (ASD) and/or Sensory Processing Disorders (SPD) are unable to access numerous galleries and museums due to the lack of provision made when determining what constitutes making something “accessible”. As conservative estimates put those on the spectrum at 1% of the general population<sup>1</sup> there are a large number of people affected by this. So, what can be done to make galleries and museums more *ASD/SPD* friendly?

## ASD, SPD & THE PROBLEM WITH PUBLIC SPACES

What is *ASD*: *ASD* (used interchangeably with *ASC*) is a “lifelong developmental disability that affects how people perceive the world and interact with others” (*National Autistic Society*<sup>2</sup>). The term is applied to a wide range of conditions/ways of being, that share common behaviors and characteristics. These range from *Classic Autism* to those conditions often seen as less debilitating such as *Aspergers* and *PDA (Pathological Demand Avoidance)*. However, though some variants of *ASD* are seen as “less debilitating” than *Classic Autism*, it is widely accepted that all forms of *ASD* can be equally affecting for the autistic person<sup>3</sup> and have a detrimental effect on their life (though not in every case and largely due to societal pressures/barriers).

*ASD* is often co-morbid with other conditions that affect personality, behavior and the senses<sup>4</sup>. One of these is Sensory Processing Disorder<sup>5</sup> (*SPD*).

What is *SPD*: *Sensory Processing Disorder* is:

*“a condition in which the brain has trouble receiving and responding to information that comes in through the senses.....”*<sup>6</sup>

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<sup>1</sup> This figure is liable to be much higher due to the difficulty in diagnosing, the changing diagnostic criteria, the number of girls and women who are discounted from most statistics due to the difference in symptoms to males meaning diagnosis is often later in life, if at all. We also need to consider those suffering from other neurodevelopmental and neurodegenerative conditions that may contribute to a lack of access to really assess the true scale of this invisible barrier.

<sup>2</sup> “What is Autism?” <http://www.autism.org.uk/about/what-is/asd.aspx>

<sup>3</sup> Studies have shown that suicide ideation are nine times higher amongst adults with *Aspergers*

<sup>4</sup> These include ADHD, Hearing Impairment, Dyslexia, Dyspraxia, etc., in “Related Conditions”

<http://www.autism.org.uk/about/what-is/related-conditions.aspx>

<sup>5</sup> *Sensory Processing Disorder* is also co-morbid with other neurodevelopmental disorders

<sup>6</sup> <http://www.webmd.com/parenting/sensory-processing-disorder>

Those who experience *SPD* are either *hyper* or *hypo* sensitive to every stimulus; meaning that their ability to live a “normal” life, even without the added issues of a neurodevelopmental disorder, is greatly diminished. The symptoms of *SPD* are many and varied, one example of this is *Hyperacusis*. People with *Hyperacusis* are unable to tolerate every day sounds due to hypersensitivity to noise: merely the sound of others talking at a slightly raised volume can be painful and feel literally like “a nail being driven into the head” or “like sandpaper moving across the brain”<sup>7</sup>.

How does this affect their ability to experience art galleries or visit museums?

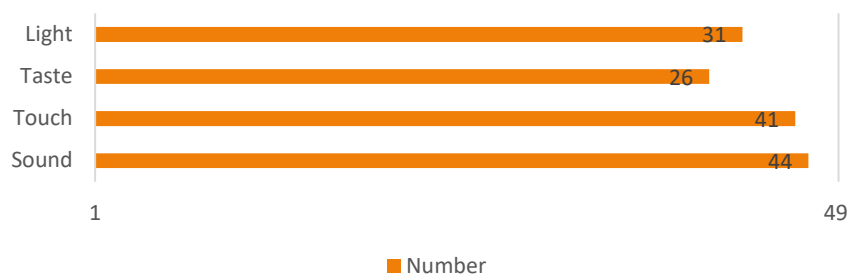
When people with *ASD* (and other neurodevelopmental disorders), and/or *SPD* are confronted with environments<sup>8</sup> which are loud, bright, busy, or with “too much information”<sup>9</sup>, they experience sensory<sup>10</sup> and information overload. This leads to an inability to take part in “normal” activities, including some creative activities or visiting places which are likely to induce panic or sensory “overload” (e.g art galleries), due to severe pain, distress and anxiety.

## WHAT CAN BE DONE?

In a bid to discover how museums and galleries can best meet the needs of people with neurodevelopmental disorders, including *ASD* and *SPD* and how these differ to the approaches currently taken by museums and galleries I surveyed 49 families of children with autism and autistic adults, and interviewed those who work with people who suffer from Profound and Multiple Learning Disabilities (*PMLD*) and autistic artists.

Most of those surveyed had, or had children with, problems with sound and touch. Parents of children with these issues employed various strategies and utilised sensory materials<sup>11</sup> such as chewing toys, weighted vests and ear defenders to help their children cope.

### Incidence of Sensory Issues



<sup>6</sup> <http://www.nhs.uk/conditions/hyperacusis/Pages/Introduction.aspx>

<sup>8</sup> This can also apply to taking part in activities that have a sensorial element to them (e.g. painting)

<sup>9</sup> See the National Autistic Society's *Too Much Information* campaign

<sup>10</sup> To gain a better understanding of Sensory Overload, the National Autistic Society have created a VR film at [https://youtu.be/DgDR\\_gYk\\_a8?t=28](https://youtu.be/DgDR_gYk_a8?t=28)

<sup>11</sup> 83% of our respondents had used sensory materials themselves or with their children. The most useful of these was found to be ear defenders which work by blocking majority of sound.

These sensory materials, and equally spaces which allow for sensory feedback (e.g. softplay areas and sensory rooms) have been almost universally positive for families with an autistic child<sup>12</sup> (including young people in their late teens). Thirty-Four of our respondents had visited a sensory room<sup>13</sup> (or had one in their house) and 80% of these found them to be beneficial.

So, what is a sensory room?

A Sensory Room<sup>14</sup> is a space where different sensory materials (including lighting effects, color, sounds, music, and scents) can be explored in a safe and contained environment. Their power lies in the fact that unlike many spaces they do not oppress the user but allow them to explore materials at their own pace. This ability to control the space allows the experience to become affecting in a positive way, rather than making the individual affected by sensory overload<sup>15</sup>.

## How Does This Apply to Art Galleries and Museums?

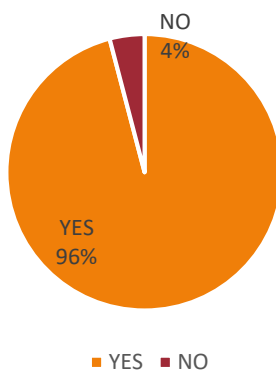
Through my interviews with autistic artists I discovered that attending galleries and private views is near impossible for those who experience sensory issues. They are negatively impacted by the shiny and reflective surfaces, the bright lighting, the noise, and the crowds. The result is sensory overload and so they either don't attend exhibitions and private views, or are

only able to spend a relatively short amount of time in them. This of course can have a negative impact on people's careers as they are less able to network and make connections with others. As Jon Adams says:

*[Galleries have the wrong idea about Autism]... mainly because people who are not autistic tell them what to do and not those with sensory issues. ....*

This is backed up by survey findings. Forty-Seven respondents believed that galleries and museums need to do more to become accessible for people with *ASD* and *SPD*. When asked what they wanted, most participants felt that reduced sound and calming noises would be most beneficial. With dimmed lights and separate sessions where materials used in different art works and displays could be interacted with along with the work itself, coming a close second.

### Do Galleries & Museums Need to do More to Become More Accessible to Those With ASD & SPD?



<sup>12</sup> 97.5% of those who had used sensory materials had found them to be beneficial.

<sup>13</sup> Most modern houses are too small to accommodate a sensory room and so experience of these was largely through the hiring of rooms in private and local authority spaces.

<sup>14</sup> Also known as Snozelen Room and originally created by two Dutch therapists in 1975, Jan Hulsegge and Ad Verheul

<sup>15</sup> We gained similar results when asking respondents about their experience of soft-play, with 58% of respondents visiting them regularly with their children and 59% of these believing they were beneficial, allowing children to explore sensory feedback in a “safe” way.

What is clear from the research is that there is a genuine need for our cultural spaces to become "autism friendly":

*Autism friendly means being aware of social engagement and environmental factors affecting people on the autism spectrum, with modifications to communication methods and physical space to better suit individual's unique and special needs.*

So, how can galleries and museums better serve those on the autistic spectrum and those with SPD<sup>16</sup>?

There are numerous ways that cultural institutions can easily accommodate those with ASD and SPD and become truly *Autism Friendly* rather than just paying lip-service to the idea of *Access for All*. These range from the expensive and which must be considered at a planning level and others which are relatively very low cost and which can be adopted and implemented very quickly. Some of the suggestions here have already been successfully implemented by theatres and cinemas offering *relaxed performances*.

## SOCIAL STORIES

By making social stories available before people visit your institution you can help mitigate a lot of the stress involved in such trips. This can be done by making interactive flash animations available on your site, simple photo stories, or downloadable PDF files. These very simply structured illustrated (with images or photos) stories are promoted by CAMHS services for young people with ASD and similar and have already been utilized by some theatres to great effect<sup>17</sup>.

Social stories should also be made available upon arrival at the gallery/museum so that those without a smart phone, or access to a printer can make use of them. These stories can be used for any activity where one would be helpful and so cultural organisations/institutions should provide them for individual activities and one off exhibitions as well as for the venue itself.

An example of a social story and guidance on how to create one are included in the Appendix.

## LOWER LEVEL LIGHTING

It became very apparent through the survey and subsequent discussions that lighting was a big issue for those with a sensory element to their ASD (the majority). The majority of autistic artists, other autists and parents of autists suggested they had a big issue with the brightness and types of lights used in most venues. This is often down to the use of fluorescent lighting in

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<sup>16</sup> And other neurodevelopmental disorders

<sup>17</sup> *The Mayflower* theatre in Southampton is an example of a theatre which has been offering these for a few years alongside their relaxed performance offer.

many locations and “sub-visible” flicker<sup>18</sup> that research has suggested those on the spectrum are more susceptible to, believed to contribute to migraines, eye-strain, headaches, and even repetitive behaviors, the “humming” noise of these lights (due to ballasts) has also been mentioned as a source of discomfort for *SPD* sufferers. There has been anecdotal evidence that although the research was conducted using older style, bar fluorescent lighting that modern CFLs have a similar effect.

Although lower levels of lighting where possible is the ideal (ideally 25-35 fc opposed to the traditional levels of 30-50 fc<sup>19</sup>), this is not always achievable for practical reasons. It is for this reason that when developing a new site, or looking at redeveloping a building it is important to consider how to maximise natural light sources whilst considering how glare, bright direct sunlight and outside distractions and crowds can affect those with sensory disorders. Sky lights have been used to great effect in a few spaces as these allow natural light but also minimise unwanted affects, as have high windows and filters or blinds to minimise glare. Further sources to support planning considerations are available in the Appendix.

In existing sites, there are numerous options where light quality is a vital consideration. Firstly, where possible there is mounting evidence to suggest that Fluorescent lighting should be replaced with LED panel lighting (rather than LED tubes which can still cause issues) as these do not cause flicker even when dimmed, however these should be positioned high up and in a manner, that they do not cause too many shadows or reflective glare (c.f Long, 2010).

If fluorescent lighting cannot be avoided, then using filters is a very cheap and simple way to reduce the flicker and glare associated with them. These are usually constructed out of heat resistant, flame retardant material and securely cover fluorescent panel lighting. If dealing with fluorescent tube lighting then coloured sleeves can be used, although these are not as effective as flat panel filters (please see appendix for further information).

## VISUAL AIDS

Through discussions following the research it became apparent that many on the more severe end of the spectrum, and families with *ASD* children, would benefit from visual aids accompanying exhibitions and displays. These can take the form of photos, or be based on PECS (Picture Exchange Communication System)<sup>20</sup> and should be used to encourage interaction with work, or to make it clear what is not to be touched.

They should be placed on displays or next to work telling people what to do. They should not be too complicated and words should be kept to a minimum. They can also be used to good effect in workshops alongside the use of social stories.

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<sup>18</sup> Cf. Research by Richard S Colman, et al 1976, "The Effects of Fluorescent and Incandescent Illumination upon Repetitive Behaviors in Autistic Children."

<sup>19</sup> Cf. Emily Ann Long, 2010 "Classroom Lighting Design for Students with Autism Spectrum Disorder"

<sup>20</sup> A Free Alternative to PECS is available at PICTO SELECT, please see Appendix for further details



Using PECS to inform ASD audiences how to interact with work/displays removes ambiguity and makes the gallery/museum experience a simpler one due to the problem those with ASD have in interpreting ambiguous situations.

Removing this barrier also makes it easier for families with autistic children to visit cultural institutions as fear of their children “doing something” often prevents engagement.

If running workshops, PECS can be used to create a visual schedule to remove ambiguity and enable greater participation among some groups.

## COMPUTER/TOUCH SCREENS FOR INFORMATION

The use of touchscreens to teach, inform and engage those with ASD is a rapidly growing area of study<sup>21</sup>. However, there is already a dearth of anecdotal evidence to support its validity, as a means of engagement, with most we spoke to using tablets with their children regularly.

Many museums are already employing the use of touchscreen information to great effect (a particularly good example is the Mary Rose Museum in Portsmouth) for all audiences. However, this method to relate information/educate audiences is particularly useful for those with ASD as it simplifies the process of acquiring information, enabling small pieces of information to be delivered at once. The power of the individual to control the flow of information and to be able to interact with that information (and be offered more chances to engage with the subject) is what makes it so powerful and far better for autistic audiences than the standard wall of words presented in most exhibitions.

If touchscreens are too exorbitant a cost then a cheaper option is using QR codes alongside traditional information so that those who are unable to engage with a wall of words, or a handout can control the information and choose whether to engage with it.

<sup>21</sup> Cf. Connie Kasari, et al 2014



## SUBTLE USE OF COLOUR

Many autistic adults questioned found the use of bright white paint in many galleries a problem for them, largely owing to its reflective and bright nature. Muted and soft neutral colours are better for those on the spectrum, so an off white such as magnolia is preferable if possible.

However, if bright white needs to be employed, the negative effects can be mitigated somewhat using light filters as discussed earlier.

## CHANCE TO EXPLORE MATERIALS

The survey, and subsequent discussions showed that many on the spectrum respond very well to interaction with sensory materials; this is strongly connected to the prevalence of *SPD* among those with *ASD*. By allowing individuals to engage with materials featured in an exhibition/ used in a piece of art, and explore them safely and at their own pace, museums and galleries are enabling broader audiences to meaningfully engage with the work.

How could this work in practice? A gallery could for example, have a panel next to works in oil (which of course you do not want people to touch) with oil paint quite thickly applied and using PECS and/or audible instruction advise people of their ability to interact with it. This could also take the form of a table exploring different materials used in works featuring in a show (in much the same way as some museums currently have sensory displays to engage children).

Separate sessions with artists where materials can be meaningfully engaged with, without expectation of creating a specific piece of “art” would also be beneficial.

## CHILL OUT OR SENSORY SPACES

A very real problem associated with *ASD* is sensory overload, which can, if not dealt with quickly, lead to meltdown. A meltdown can take many forms, from screaming and lashing out, to completely shutting down. The anguish that the threat of a meltdown causes family members and those with sensory problems related to *ASD* means that often spaces that may induce such overloaded emotions are avoided.

One way to combat this is to anticipate that visiting your establishment will inevitably be stressful and possibly provoke a response in someone with *ASD/SPD* and provide a safe space where a meltdown is acceptable. This can take the form of a chill-out area in a quiet space in your venue. This should be away from other distractions and people. If possible it should feature a sensory space (or be contained in a sensory space). These can be entire rooms given over to a sensory room or take the form of a dark den (these can be purchased so that they are large enough for an adult to stand up in). Inside the sensory space should be coloured lights of some form (fibre optics, rope lights, small light projectors etc. are all suitable), cushions or bean bags and other small sensory toys (these can be purchased widely from specialist shops).

The scope for these spaces is as large or as small as you can accommodate; even providing a separate seating area and weighted lap pad or vests will greatly help.



Source: <http://www.sensorydirect.com/sense/sensory-dens/black-sensory-pop-up-pod-light-up-toy-jar.html>



Source: <http://www.sensorydirect.com/lap-pad-fire-retardant-1kg.html>

## VOCAL GUIDES AND NOISE CANCELLING HEADPHONES

Sound was a big issue for many of those who took part in the research and thus was a big barrier to visiting museums, galleries and other cultural spaces and events. Although people can mitigate some of the problems by using ear defenders (these were the most used and effective sensory tool people mentioned during the research) their very use acts as a barrier to engaging with the work.

After discussing the results of the research with a smaller sample of respondents and asking how cultural spaces could best meet their needs; it became apparent that many on the low functioning end of the spectrum also had a problem with being presented with walls of words in galleries and museums (as previously discussed) and having to engage with this, and the work, and the unpleasant sensory affecting aspects of visiting such a space, and dealing with crowds etc. was a key factor in causing meltdowns and thus, avoidance of these spaces.

Respondents agreed that a positive way of resolving some of these issues would be to provide noise cancelling headphones to those with ASD and SPD and having these connected to MP3 players, or via Bluetooth with information about the exhibit available via a downloaded sound file. When information was not being shared, these could feature music so that users had reduced sensory overload from noises associated with being in such a venue. This is similar to audio descriptions already available in many museums, however the added feature of noise cancelling headphones will mean that a further barrier is removed.



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Video:

Autism TMI Virtual Reality Experience, The National Autistic Society, 2016 accessed at [https://www.youtube.com/watch?v=DgDR\\_gYk\\_a8](https://www.youtube.com/watch?v=DgDR_gYk_a8) on 18<sup>th</sup> November 2016

# APPENDIX

## SOCIAL STORIES

A couple of examples of social stories we created for Sticks Gallery, for both the space and the some of the workshops we have run in the past are included in this Appendix to see how they work in action.

As previously mentioned Social Stories are simple stories whose structure is based on the work of Carol Gray

They are usually simply illustrated with either PECS images or photographs and are used to convey a simple message; this could be where you are going, what you are going to do, or even to help with behavior and knowing how to act in a given situation.

There are numerous sources on the Internet to help in the construction of social stories some of which are listed here:

NAS: How to Write A Social Story: <http://www.autism.org.uk/about/strategies/social-stories-comic-strips/how-to-write.aspx>

Social Stories Tips and Sample: [http://challengingbehavior.fmhi.usf.edu/explore/pbs\\_docs/social\\_story\\_tips.pdf](http://challengingbehavior.fmhi.usf.edu/explore/pbs_docs/social_story_tips.pdf)

Carol Gray, Social Stories: <http://carolgraysocialstories.com/social-stories/>

Connectability, Free Social Story Creator: <http://connectability.ca/>

There are many more free and paid for resources on the Internet if you should need them, but these should give a simple starting place for creating simple social stories.

## SOURCES FOR DESIGN CONSIDERATIONS (when planning new space and redevelopment)

Designing for Autism: Lighting: <http://www.archdaily.com/177293/designing-for-autism-lighting>

Autism Friendly Design: <http://www.autism.org.uk/professionals/others/architects/autism-friendly-design.aspx>

Design for Autism: Spatial Considerations: <http://www.archdaily.com/179359/designing-for-autism-spatial-considerations>

Designing Buildings for Children With Autism: <http://www.citylab.com/design/2014/04/designing-buildings-children-autism/8960/>

Emily Long's work on lighting: <http://krex.k-state.edu/dspace/bitstream/handle/2097/6915/EmilyLong2010.pdf;jsessionid=B41FBAEEAC7113AA7E3763B806DB814E?sequence=3>

## Light Filters

Simple blue panel light filters can be purchased for below £20 from various retailers for 2

<http://www.cheapdisabilityaids.co.uk/fluorescent-light-filters-set-of-2-26165-p.asp>

other filters for tube lights can be bought at <http://www.covershield.co.uk/colourtubes.html>

## PECS

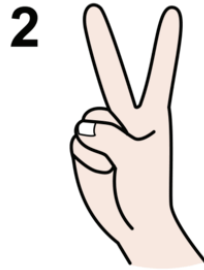
A free and very good alternative to PECS is PICTO-SELECTOR, this can be downloaded via <https://www.pictoselector.eu/>



# What is an Art Gallery?



An Art Gallery is a place you



visit

to

look



at

art.

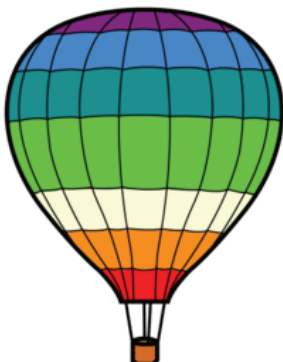


Art

is

painting,

sculpture,



installation,

drawing,

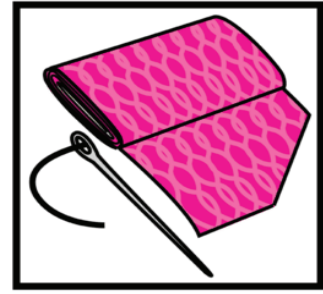
printing,



sound,



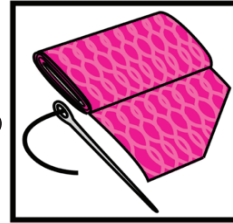
film,



textiles,



+



and sometimes more than one artform mixed together. This is mixed media.



OK

An Art Gallery can be scary.

It is ok

2



to be



scared.



If I



get scared

@

at

STICKS

sticks



art gallery



I



can sit



down



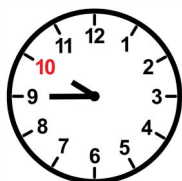
in the chill out



area until I feel happier.

# SEN WORKSHOPS AT STICKS

*On Saturday*



*at 10:45*



*I am going to*



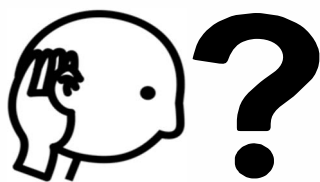
*Sticks Gallery*



*in Fareham*



*to do some creative activities.*



*I will need to listen and work with others*



*I will listen and try to join in.*

**OK**



*It is okay to be scared*



*New places, people and activities can be scary.*



*People are happy as long as I try!*