Supporting autistic flourishing at home and beyond:

Considering and meeting the sensory needs of autistic people in housing





National Development Team for Inclusion

office@ndti.org.uk

This project and report was co-produced with a group of people with lived experience and commissioned in 2020 from <u>NDTi</u> by the <u>Care and Health</u> <u>Improvement Programme</u>, which is jointly managed by the <u>Local Government Association (LGA)</u> and the <u>Association of Directors of Adult Services (ADASS)</u>.

© 2020 National Development for Inclusion www.ndti.org.uk

Contents

Contributors	5
Writers and editors	6
Images	7
Thanks	7
Foreword	9
Introduction	11
Building the Right Support	13
Housing	15
A note on language	17
Autism viewed as a sensory processing difference	18
Roundabout theory	19
The Eight Senses	20
Internal sensing systems	21
Shutdown and meltdown	24
Alexis' Story	26
External Senses	28
Sight	30
Lighting	30
Shadows	31
Colour	32
Storage	32
Sound	33
Building structure	35
Appliances, including heating	36
Alarms	38
Doors	38
Flooring	39
Outside noise	39
Smell	41
Household smells	41
Other people	42
Public spaces	42

Taste	44
Sight	44
Sound	44
Smell	44
Touch	45
Interoception	45
Proprioception	45
Touch	46
Textiles – including clothing	46
Sleep	46
Furniture	47
Hypermobility	48
Washing	48
Other things to consider	50
Shared spaces and communal living	50
Defined areas within the home	51
Interests and hobbies	52
Outside space	53
Pets	54
Security	54
Support	55
Self-management and self-regulation	57
Sensory environment checklist user guide	59
Sight	60
Sound	63
Smell and taste	68
Touch	70
Other considerations	72
Our approach	74
10 STEPS to creating a neurodiverse inclusive environment	75
Links, references and further reading	78

Contributors

Alexis Quinn

Autistic campaigner and activist, public speaker, author of Unbroken.

Angela Heeley

An autistic person with high sensitivity to sound, light, touch, and odour, a parent of an autistic individual, and a Chartered Architect with insight into construction matters and domestic design.

Anna Levermore

Anna is an autistic Expert by Experience working on Care Education and Treatment Reviews. She is a member of Bemix, a self-advocacy group in Kent.

Carly Jones MBE

Carly is an autistic woman and campaigner for the rights of autistic women and girls.

Conor Eldred-Earl

Conor is an autism advocate, public speaker and advisor. He is passionate about supporting meaningful autistic involvement in decisions affecting autistic people.

Cos Michael

Cos is an autistic speaker, trainer and consultant on autism and ageing. She led the NAS Autism and Ageing workstream and now delivers training and presents at conferences in the UK and abroad.

Dr Damian Milton

Damian is a Lecturer in Intellectual and Developmental Disabilities at the Tizard Centre, University of Kent, and a Project Leader of the National Autistic Taskforce.

Dr Ruth Moyse

Ruth has worked as a primary school teacher and is now a full-time doctoral researcher into the experiences of autistic girls at mainstream schools.

Emma Dalmayne

Autistic advocate and writer. Author of It's An Autism Thing I'll Help You Understand It. CEO Autistic Inclusive Meets, founding member of Autism Inclusivity Facebook group.

James

James has audio and visual sensitivity. He is a sensory seeker and enjoys running, climbing, mountain biking and swimming in the North Sea.

Karl Stephenson

Karl is an autistic Expert by Experience working on Care Education and Treatment Reviews. He supports businesses and healthcare providers to understand the sensory needs of autistic people.

Kelly-Anne Harmer

Kelly lives in London with her husband and one year old child. She is autistic and works in food science and development.

Marion McLaughlin

Marion is an autism campaigner and team member at Triple A's - an entirely autism led peer support charity for autistic people.

Rachel Cotton

Rachel is a founding member of Autistic Pride Reading.

Richard Maguire

Richard is a keen photographer. He is an author (I dream in Autism), an autistic trainer and mentor and the director of Autism Live.

Writers and editors

Ann Memmott

Ann is an autism trainer, advisor and mentor. She is the office manager of a busy surveying company. Ann is passionate about improving lives and services for autistic people.

Chris Memmott

Chris is an autism trainer, advisor and mentor. Chris works as an Expert by Experience on Care and Treatment Reviews and advises on sensory environments.

Dr Gemma Williams

Gemma is an autistic Early Career Researcher and ESRC Postdoctoral Research Fellow based at the University of Brighton, with research interests in autistic communication, loneliness, social justice and social policy.

Jill Corbyn

Jill was the autism development lead at NDTi. She established the autism team at NDTi and supported delivery of sensory environment checks in hospitals, advisory work for autistic people and peer support for autistic people and their families. She is now an NDTi Associate.

Images

Flow Observatorium

Flow Observatorium is a neurodivergent led hub that enables artists to connect, network and access opportunities. They aim to increase visibility, understanding and confidence of neurodivergent artists. Flow Observatorium was pleased to support connection and collaboration on this project, with Tom and Jon producing artwork that gives an additional autistic flavoured visual metaphoric contribution.

Jon Adams

Jon is both a contemporary Artist, advocate and researcher. He makes a variety of work in many differing media often referencing his autism, synaesthesia and dyslexia, all interwoven with history, science, time and his past experiences. He's shown in galleries such as Royal Academy, Tate Modern and been commissioned by many arts and science organisations including projects for Parliament, London 2012 and on stage. He advocates for the rights of Neurodivergent people to fully access the arts, funding, health care and relevant research.

T.E.Yates

"Unassuming, unusual and enigmatic, T.E. Yates is a multi-disciplinary artist of rare and disarming qualities that must be seen and heard to be believed." - Louis Barabbas

Yates produces detailed pencil drawings utilising a hybrid of graphite and charcoal. He is also a digital illustrator, multi-instrumentalist, singer-songwriter and award-nominated animator.

Thanks

Julia Avnon

Julia is an experienced psychologist who specialises in the assessment and intervention for neurodevelopmental conditions. Thanks to Julia for her support to the team and enthusiasm about the work we are doing.

Kate Linsky

Kate is the Programme Lead for Mental Health at NDTi. Thanks to Kate for being an early supporter of the team and helping make this work and our inclusive approach possible.

Professor Mark Brosnan, Dr. Chris Ashwin, Emma Collis

The Centre for Applied Autism Research (CAAR) at the University of Bath. Thanks to CAAR for sharing the STEPS framework (page 45 and appendix).

Sue Gale

Sue is the Assistant Director, Building the Right Support, Local Government Association. Thanks to Sue for supporting the development of this project.

Foreword

The last decades have revealed new understandings of autistic people and our lives. Originally seen as a series of disastrous behaviour problems to be fixed, new research and years of collaboration with autistic people of all kinds has changed almost everything society thought it knew about autism. We now know that autistic people are in every role in society, whether it is a volunteer at a charity, or as a front-line healthcare professional. Enabling autistic lives does not just mean improving care home settings but considering the environments for the vast majority of autistic people who live and work in everyday places. We are also more aware of the diversity of autistic people, and are locating far more who are older, female, part of the Black, Asian and Minority Ethnic communities, and part of the LGBTQ+ communities.

One of the most important findings is that most autistic people have significant sensory differences, compared to most non-autistic people. Autistic brains take in vast amounts of information from the world, and many have considerable strengths, including the ability to detect changes that others miss, great dedication and honesty, and a deep sense of social justice. We now know that autistic people use a different form of social communication, every bit as effective as that of others, thanks to the work of the DART team (http://dart.ed.ac.uk/research/nd-iq/reference). But, because so many have been placed in a world where they are overwhelmed by pattern, colour, sound, smell, texture and taste, those strengths have not had a chance to be shown. Instead, they are plunged into perpetual sensory crisis, leading to either a display of extreme behaviour – a meltdown, or to an extreme state of physical and communication withdrawal – a shutdown. If we add to this the misunderstandings from social communication with one another, it becomes easier to see how opportunities to improve autistic lives have been missed.

If we are serious about enabling thriving in autistic lives, we must be serious about the sensory needs of autistic people, in every setting. The benefits of this extend well beyond the autistic communities; what helps autistic people will often help everyone else as well.

The sections within the report guide teams on how to consider sight, sound, smell, and touch, when designing or commissioning spaces. There is discussion of the different internal and external senses, including that of balance and knowing where our bodies are. Also discussed, the perils of shared spaces, the joys of outdoor spaces and pets for some, and the importance of a personal space and somewhere for the person's key possessions and hobbies. Thought is also given for matters of security and creating a real sense of belonging. A useful checklist acts as a starting point for discussions and audits, building projects and housing searches.

It is our strong recommendation that this work is done with autistic teams whose sensory input is vital to achieve success, alongside team members such as Occupational Therapists with sensory training.

It is an honour and pleasure to read the personal accounts of so many autistic people within this report, which has been put together with great care by the team.

Together, we can bring about great change for countless autistic lives.

Ann Memmott

Introduction

Right from the start, from the time someone came up with the word 'autism,' the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced.

Donna Williams, (1996:14)

This report is informed by autistic experience and by what autism 'feels like from the inside'.

This report introduces autism viewed as a sensory processing difference. It outlines some of the different sensory challenges commonly caused by physical environments and offers adjustments that would better meet sensory need in housing.

Individual autistic experience and sensory perception vary enormously, so it can be difficult to generalise. This report provides information about sometimes conflicting individual experience (one person's pleasure is someone else's pain). However, the aim is to reduce the overall sensory input.

There is often a lack of understanding into why things are occurring. People are going to express their extreme distress and sensory overload. It just spirals and spirals until someone is in a severe crisis. Getting the sensory environment right can make a huge difference.

Damian

Autism is not well understood. As a result, collectively, autistic people are not well understood. As Beardon (2017:18) states, 'the very fact that there is more than one set of diagnostic criteria establishes the fact that we don't yet have any consensus in terms of how we collectively understand autism'.

The term autism was first used by Kanner in 1943 and was first listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1952. The diagnostic criteria continue to change but are still deficit based and focus on the external presentation and behaviour, rather than the individual experience.

Unsurprisingly, therefore, many housing development providers and support providers focus on autism as a behavioural disorder. Sometimes this means that people are managed rather than understood.

Beardon (2017) developed a principle to illustrate the importance of the sensory environment in understanding autistic experience. It is:

Autism + environment = outcome

He gives examples of how environments, including other people, noise and lighting, affect individual's ability to thrive. (It's an excellent book and highly recommended reading.)

If my sensory environment is right, it's blissful. It it's not right I feel stressed and it can provoke meltdown, anxiety and depression.

Fmma

This report may be considered as a reference point, rather than a document to be read and followed in its entirety. Everybody, autistic or not, has individual sensory profiles and needs. Every autistic person is an individual, with different dreams and interests and strengths and needs. It is likely that sections of this report will not be relevant to everyone.

This report provides some background information about the senses and autism. It then offers individual examples about how the physical environment can impact each of the external senses. At the end of the report, we include an autism environments checklist to support a practical application of the information we share.

The involvement of autistic people in reviewing and changing the sensory environment will support the identification of things that are not visible or audible to their neurotypical counterparts. We strongly encourage this wherever possible.

If I'm fighting sensory input I don't have processing space to deal with anything else. I can't filter it out. Sensory input really matters. Not being able to adapt an environment means that I have sensory input that increases my stress levels.

Marion

Building the Right Support

The Winterbourne View scandal in May 2011 led to a national response and a government commitment to 'Transform care' – to prevent further abuse from happening. It committed to ensuring that people with learning disabilities and autistic people are not 'placed in inappropriate care settings' but are instead enabled 'to lead fulfilling and safe lives in their communities'. (TC report 2012)

This report aims to support autistic people who are at risk of admission to hospitals, and those who have been part of the Transforming Care Programme, as well as their support providers, housing providers, commissioners, and families. We hope that the content will be relevant and of use to other people too.

Assuring Transformation data shows that over the course of the Transforming Care Programme the proportion of autistic people who are part of the programme has increased. This may be partly explained by low identification and reporting of autistic people, particularly in the early stages of the programme.

The number and proportion of adults and children with a learning disability in hospitals have decreased since the start of the Transforming Care Programme. The number of autistic adults (with and without a learning disability) has slightly decreased, but the number of autistic children (with and without a learning disability) has slightly increased.

96% of children and young people in mental health hospitals as part of this programme in September 2020 are autistic. Anecdotally, it is reported that around 60-70% of children and young people who are admitted to general adolescent units may be autistic, though many are undiagnosed. In October 2020 there were 1421 mental health beds for children and young people nationally.

Adults in hospital as part of transforming care

	Autism only	Learning disability and autism	Learning disability only
March 2015	370 (14%)	630 (23%)	1575 (58%)
September 2020	430 (23%)	505 (27%)	905 (49%)

Children and young people in hospital as part of transforming care

, , ,		•	
	Autism only	Learning	Learning
		disability and	disability only
		autism	
March 2017	155 (63%)	30 (11%)	55 (23%)
September 2020	170 (83%)	25 (12%)	10 (4%)

The average cost of an inpatient stay is £3500 per week, or £182,000 per year (NHS digital 2020). Hospitals are expensive and are particularly challenging sensory environments for autistic people. Getting it right in the community is often cheaper and leads to better outcomes for people.

Since the emergence of the diagnostic criteria in the 1940s our understanding of autism has shifted dramatically. However, some of our practice hasn't kept up with the learning and research. Much of it is rooted in approaches that focus on an external interpretation of behaviour, rather than an understanding of the internal or lived experience.

This paper aims to share information from a lived perspective to support improved understanding. We hope that the information, suggestions and links to further reading will be helpful to support change in practice. When sensory needs are understood and met, autistic people can thrive. We hope that this will support a change in practice that leads to better lives for people in communities and homes instead of hospitals.

A home needs to be a safe space you can relax and be comfortable in. After a day being at work and sensory overstimulated it's imperative for mental health to have a space that heals not exacerbates sensory overload, works for living in and thinks about the diversity of residents' access needs, safety, comfort and security.

Kelly

Many autistic people are living good, ordinary lives in communities rather than hospitals. Many of these successes are unseen and unrecognised.

Nobody measures why you're successful, they only measure the challenges.

Marion

This report shares the experience of the autistic contributors and makes suggestions about how to reduce sensory input at home. This report recognises the often-unseen challenges that people have identified and addressed themselves and shares the solutions that contributors have found work for them.

Their experience shows that it is possible to reduce sensory input while maintaining and increasing comfort and homeliness.

People design homes that are like a posh clinic. They think that autistic people need a home that you can clean with a j-cloth. I don't want that. I want a home that is calm and comfortable.

Cos

Housing

The most important thing about autistic housing is to note that it's a sanctuary from the outside world. Being outside means exposure to all sorts of sensory assault, especially in places shared with other people. Home needs to be the place where we can relax, unwind and work off that stress. Home also needs not to cause stress so it needs to be easily navigated, protection from sensory stimuli and where wanted, exposure to agreeable sensory stimuli. Home needs to aid those of us with significant issues in executive dysfunction and give us scope to be creative.

Rachel

International human rights law recognises everyone has a right to an adequate standard of living, including adequate housing. This includes security of tenure, accessibility and protection against threats to health. UN Habitats (2014:4) state that 'housing is not adequate if the specific needs of disadvantaged and marginalized groups are not taken into account'. For many autistic people, this means a consideration of the sensory environment.

The right home environment is essential to health and wellbeing, throughout life. Our homes are the cornerstones of our lives. Housing affects our wellbeing, risk of disease and demands on health and care services. We need warm, safe and secure homes to help us to lead healthy, independent lives and to recover from illness.

Public Health England (2018:1).

This report aims to provide information about how to consider and meet the sensory needs of autistic people in housing. Other publications (such as Building the Right Support and Building the Right Home) offer guidance on the role of local services and commissioners in understanding, planning, and meeting housing needs. They provide information about the range of housing models and finance options available.

The NHS Long Term Plan identifies autism as a priority area and commits to providing better diagnostic support and to reduce the number of admissions to inpatient units (NHSE).

We will only successfully prevent people with learning disabilities and/or autism and challenging behaviour needing to be admitted to inpatient settings, and discharge those currently in hospitals, if we can achieve a major expansion, and major improvement in quality, of community-based support services (including ... appropriate housing...).

The Bubb report (2014)

Housing needs to be tailored to meet the individual needs of autistic people. Many of the changes and adjustments that are highlighted in this report are not costly or challenging to implement. However, for many people, this will be a change in approach that understands autism as primarily a sensory processing difference rather than a behavioural disorder.

What makes a house a home? As well as considering buildings and houses, it is important to focus on the individual and their interests, personality and needs to transform the space into a home. In this report we consider some general themes and suggest questions to ask and encourage exploring with individuals what would work best for them.

Being out in the world is frequently exhausting, so being able to come home to a space that is relaxing and reviving is essential to me. The garden recharges me. I can sit there or do some weeding or planting, listen to the birds, read under the trees. The curves and softness of the plants are soothing. Having space to escape to in the house means, again, the ability to decompress as well as places to recharge. So, a low arousal environment is key for both.

Ruth

We hope that this report will support autistic people, their families and housing and support providers to realise their own ambitions and those that are set out by in the Bubb report and in the NHS long term plan – a comfortable home in the community that is built to last.

We require continuity. We don't want to be moving. Build in adjustments for ageing, consider the needs of older autistic people early. Not everyone will want or need all of the adjustments, but if they are built in they might be guietly appreciated.

Cos

A note on language

The DSM labels autism as 'Autism Spectrum Disorder' or 'ASD'. To meet the diagnostic criteria, it describes that people must have 'persistent deficits' in social communication and interaction as well as restricted, repetitive behaviour. (DSM-5)

The diagnostic criteria are based on a deficit rather than asset-based approach – an attitude that is reflected in research (Bottema-Beutel et al 2020).

In the diagnostic criteria everything is pathology, including strong and passionate interests. This casts a dark shadow over the concept of autism: not everything is a problem and seeing it that way is itself disadvantageous, even though there are some real extreme difficulties that must not be discounted.

Murray (2020:25)

Beardon (2017:18) suggests that the fact that there is still more than one set of diagnostic criteria establishes 'the fact that we don't yet have any consensus on how we collectively understand autism'. He highlights that there are no 'autistic behaviours' that are not also seen in the rest of the population.

Milton (2020) identifies that the term 'neurodiversity' originated in 1998 and is based on the concept of 'Biodiversity, and its broad argument that the more diversity within an ecosystem, the more resilient and sustainable it would be.' This is a marked contrast from the 'medical model of disability, which contrasts 'normal' development with that of 'abnormal', traditionally framed in terms of deficiency and dysfunction'.

In this paper we explain autism as a sensory processing difference rather than deficiency, dysfunction or disorder. Language influences how people understand and are understood. We encourage language and descriptions that provide a positive and accurate description, that values autistic experience and considers the strengths and benefits as well as the challenges that autistic people face. Language can move us towards an equal, diversity affirming and inclusive narrative.

We use identity first language - autistic person, rather than person with autism. This is the preference of most autistic people (Kenny et al 2015).

We support the right of all individuals to decide which language they prefer to describe themselves.

Autism viewed as a sensory processing difference

Understanding the sensing and perceptual world of autistic people is central to understanding autism.

Our five senses are how each of us understands everything that isn't us. Sight, sound, smell, taste, and touch are the five ways – the only five ways – that the universe can communicate with us. In this way, our senses define reality for each of us... What if you're receiving the same sensory information as everyone else, but your brain is working differently? Then your experience of the world around you will be radically different from everyone else's, maybe even painfully so. In that case, you would literally be living in an alternate reality – an alternate sensory reality.

Temple Grandin and Richard Panek (2014:70)

In this paper we share examples and further information about how autistic people experience physical and sensory inputs. It may be useful to support autistic people to explore their own sensory experiences.

Before I was diagnosed, I didn't always know what things were bothering me. I thought everyone had the same problems, but that they hid it well.

Cos

A number of people who contributed to this report said that they had to learn to identify their sensory needs, and that hearing the experience of other autistic people was one of the most positive and useful ways to do this.

Knowing that my sensory needs are understood and respected lowers my stress levels.

Marion

To support this understanding, it is helpful to understand the role of our internal and external senses.

Everyone has eight sensing systems, the first five being sight, hearing, smell, touch and taste. These five give us information about the world outside our bodies. We will examine these external senses in more detail as we consider the physical sensory environment in relation to housing.

Three internal sensing systems give us information from inside our bodies – our vestibular, proprioception and interoception systems. These are less well-known.

Roundabout theory

Although not all the external senses are equally affected by the physical environment, we consider them all – as they collectively add to the 'sensory load'. **Any** sensory input needs to be processed and can reduce the capacity to manage and process other things.

Chris Memmott explains this using 'roundabout theory'. He compares neurology to roads and suggests that neurotypical brains have more (medium size) A Roads. They are generalists and traffic moves easily in all areas.

Chris describes that rather than having 'A Roads' autistic brains are more likely to have some motorways and some country lanes, so traffic doesn't move evenly in all areas. It moves very fast to some parts of the brain, and very slowly to other parts.

Neurotypical brains divert sensory input – or traffic. It doesn't all have to be processed. Autistic brains are more likely to process all sensory input – and the 'traffic' jams.

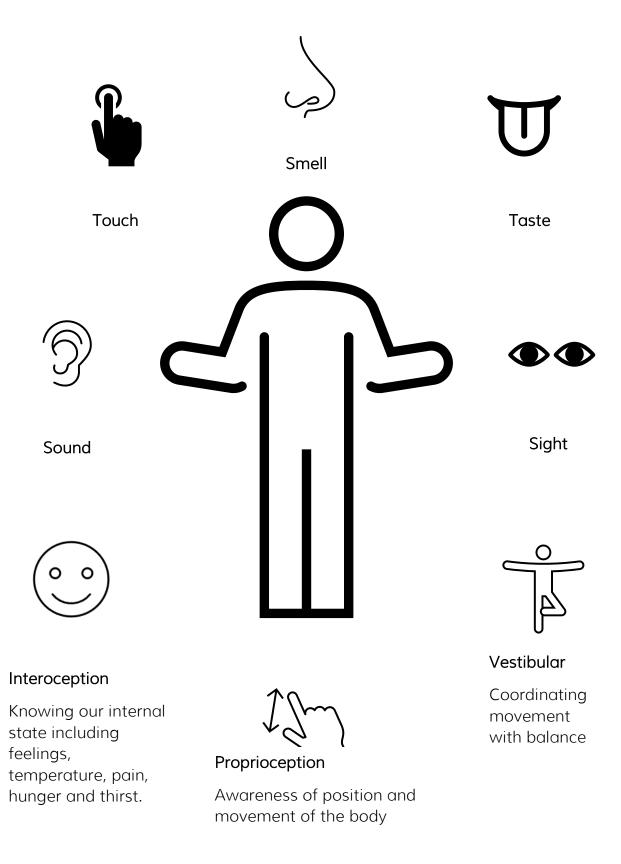
The more sensory input that is added, the more overwhelmed systems get and the longer the wait for processing. This can lead to delayed responses, and then to meltdown or shutdown.





The Eight Senses

We have five external senses and three internal senses. All must be processed at the same time and therefore add to the 'sensory load'.

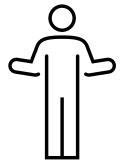


Internal sensing systems



Interoception

Knowing our internal state including feelings.



The

Proprioception

Awareness of position and movement of the body



Vestibular

Coordinating movement with balance

Our **vestibular** system gives us a sense of balance and orientation in space. It helps us coordinate movement with balance.

The vestibular sense has another important job: getting all the other sensing systems to work together to keep us calm and alert. This is the 'master sense', helping us develop self-regulation of our arousal level so we can adapt to the ups and downs of daily life.

Kranowitz (2016:19)

Proprioception is the awareness of the position and movement of the body. When it works well it tells us where we are in space, how our body is moving and how much pressure we need to use. When it is under-sensitive, people might find it hard to know where they are in space and to navigate obstacles or may stand very close to other people.

A clear, clutter-free environment with space to move between furniture can be helpful. Some people find it easier to enter spaces keeping their hand on the wall, in which case it may be helpful to have some walls free from furniture. Handrails can also help give a sense of depth and help to reassure those with vestibular and proprioceptive challenges. These considerations, supports and adaptations are particularly important as people get older.

Nobody thinks autistic people get old. Most of the research focuses on children, and the research that is about adults involves people up to 35

years old. The vestibular needs of autistic people are particularly relevant as we get older and our bones get weaker. This is especially true for post-menopausal women. We need good access, wide doorways that will accommodate walking frames, even flooring and handrails. It will benefit other people too if it's already built in.

Cos

Interoception is a sense that provides information about our internal state, including emotional states, or feelings such as fear, anger and joy; and physical sensations such as cold, pain, hunger and thirst.

Our bodies are designed to strive for homeostasis on an automatic, unconscious level as well as in a conscious, purposeful manner. For example, when faced with a situation that evokes fear, the interoceptive sensations set off a series of unconscious, automatic reactions, such as increased blood flow to the muscles, in preparation to attack or run.

Mahler (2017:10)

Some people experience interoceptive signals that are so strong, they are immediately overwhelmed and confused. Others experience dulled interoceptive signals that leave them unable to respond to emotions until they are present in excess.

It is very stressful and unsettling to be in a state of disequilibrium, and people may use a variety of responses to attempt to return to equilibrium.

Krakowitz (2016:30) asks readers to consider what life might be like when our sensing systems don't work well. She suggests that 'daily functioning is possible, but for people who struggle to learn, participate, or feel good in their daily doings, life can be frustrating, lonely, and even painful.'

Kranowitz identifies that the following abilities are all functions of an integrated sensing system.

- balance
- body awareness (knowing where your body parts are and how they move and interact)
- directionality, bilateral coordination (for example, clapping, catching a ball)
- fine motor control (eg using a knife and fork)
- gross motor control (eg running, getting dressed)
- Laterality moving either side of the body separately from the other
- Midline crossing using one hand, foot or eye across the imaginary line dividing two sides of the body (eg scratching an elbow)
- Motor planning organising and sequencing the steps of unfamiliar and complex body movement (eg taking a shower, roller skating)

- Visual-spatial awareness understanding where you are and how to move around in the environment
- Auditory-language skills understanding and responding to sounds and words

People who do not have integrated sensing systems are therefore likely to face additional challenges with some or all the areas identified above. They naturally impact how we engage with other people and the world around us.

No two autistic people have the same sensory profile, but most of the time our external senses are hyper-sensitive, and our internal senses are hypo-sensitive. This means that we are normally getting too much information from what is around us (sight, sound, smell, touch and taste) and not enough from within our bodies (balance, position and movement and processing feelings). We must deal with this imbalance. This takes effort and causes us to become sensorially and cognitively overloaded very quickly, with a lack of awareness of how we are being affected internally. This leads to overwhelming sensory and emotional overload.

An autistic person will be aware of what they are sensing to a very high degree. They must pay attention to everything they are aware of with no means of prioritising or lessening the intensity of a sensory input. We notice detail that most people miss, and we have to make sense of all these details before proceeding. We can develop ability to mask this in social interaction and appear to be OK with processing through life and interactions with people. However, this is just what it is, masking.

Masking comes at a price in overload, tiredness, difficulty moderating mood, difficulty concentrating and needing extended periods of rest and low stimulation environments to lower our sensory arousal and be able to process all that has happened and where we have been.

Autistic people have single attention and cognition. We focus on and process one thing at a time. Everything in our life needs to process in turn and in detail. But sensory environments impact multiple senses – auditory, visual, and olfactory stimulus hit us simultaneously. We aren't able to process them at the same time, creating a delayed response and sometimes leading to overload. A lot of our life is spent defending ourselves from sensory input and seeking sensory simplicity.

The sensory environment will impact us quickly and comprehensively having a large effect on our ability to function, relate to ourselves others and live our lives.

In general, the phrase Less is More is useful in understanding what works in the sensory world of an autistic person, also sensory comfort. What is comfortable will vary with every autistic person and the amount

of sensory pain we are in. Getting the sensory environment to be comfortable is key in the autistic life, if it is not, we are in pain and turmoil, then masking this until we can take no more.

Richard

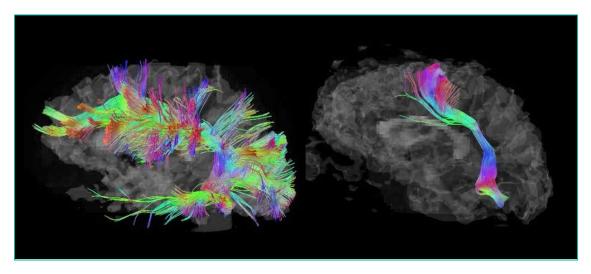
Shutdown and meltdown

As many autistic people process one thing at a time, sensory stimulation can stack up. As the brain's highways become congested, there are repercussions throughout the entire neural network. This can lead to headaches, nausea and the fight and flight response, this is what causes many meltdowns and shutdowns.

Sensory overload, to me, is exhausting, so living in a low arousal environment is an essential part of maintaining good mental health and emotional regulation for me. Part of the solution is feeling safe.

Ruth

Social situations demand involvement from the whole brain for many autistic people. The now famous scan of Temple Grandin's brain (left image) shows how many more neurons are fired when compared to a non-autistic person.



With social interaction you process every detail – including visual and verbal communication. It's multitasking at quite a high level.

Damian

When the sensory portion of the brain is overloaded, the surrounding portions can experience disruption. Verbal processing is one of these surroundings portions of the brain. It may result in overloaded autistic individuals going non-verbal and failing to process any verbal communication directed at them.

My sensory needs fluctuate. Sensory overload can disable me for a couple of days. I need to lie down in a dark space. I always used to think it was migraines.

Fmma

Meltdowns and shutdowns are often viewed as behaviours. In fact, meltdowns and shutdowns are subcortical processing responses – they are different presentations of biophysical overwhelm. The brain has gone into survival mode.

Too much sensory overload may result in systems shutdowns, in which the person loses some or all of his or her normal functioning.

Bogdashina (2016:103)

With a shutdown, the brain switches off the ability to think, talk and perhaps move at all. Sometimes this is interpreted as sulking, non-compliance, or rudeness.

Individuals with poor interoceptive awareness lack insight into their emotions and have limited information alerting them with the urge to act or the urge to use emotional regulation strategies. Not surprisingly, therefore, they often experience emotional regulation difficulties, including experiencing meltdowns, high anxiety, rigid and inflexible thinking, overwhelming emotions and reactions, resistance to change and poor problem solving.

Mahler (2017:21)

With a meltdown, this distress is expressed outwards. This may present as swearing, wild behaviour or running away. It is not aimed at getting something. In fact, giving the person something makes no difference. It is not a 'tantrum'. It is more akin to epilepsy (see Nicotera et al 2019).

It takes about an hour and a half to cool the brain down again and 'switch back on', given the right conditions. The right support and a calm sensory environment can enable this and reduce the need for restraint or other interventions.

Physical intervention during this time may lead to flight or fight responses being activated. Giving people time, space and a reassuring presence is often the most helpful response.

This video online illustrates how overwhelming sensory environments can be https://vimeo.com/52193530

Alexis' Story

I have massive sensory sensitivity. Especially to light and sound. My sensitivity fluctuates depending on how overloaded I am. If I'm not overloaded, then I can tolerate a lot more.

My understanding has really grown over time about this. I didn't always know or understand about my sensory sensitivity or how it impacts me. This meant that I didn't always know what I needed to do to help myself, or what others could do to support me. I naturally did some things to help me cope, like walking or pacing, but I didn't know how important they were until I was stopped from doing them.

Patterns are a real problem for me. I get absorbed by them – they take all my focus and it's really distressing. When I'm overloaded sound and visuals can become too intense. My ability to manage fluctuates depending on how overloaded I am. When I'm overloaded, I can't manage visual clutter, things on mantelpieces and walls, open fires, pattered carpets or clocks ticking. These are all things that would seem fine on a good day but become too much.

I grew up in a seaside town, so I've always been able to manage my sensory needs. I need to have space to walk and to exercise. I need space that's quiet to do this.

When my daughter was born, she added a lot of noise and chaos. Babies are unpredictable. I was doing OK but I became unwell when my brother died. It all became too much, and I needed support.

I asked for help from mental health services – my biggest mistake. I was admitted to hospital and really struggled with the sensory environment and with the lack of understanding about my autism. I couldn't tolerate the light and the noise and the lack of space to move away from other people. I didn't always have access to outside space and was restricted from walking and running – things that help me to destress.

I was discharged from hospital a number of times with no support and no understanding. I was discharged to my family home which has colourful and patterned carpets, cluttered walls and other patterns. It was too much, and I would flee, then the police would pick me up and I would be returned to hospital.

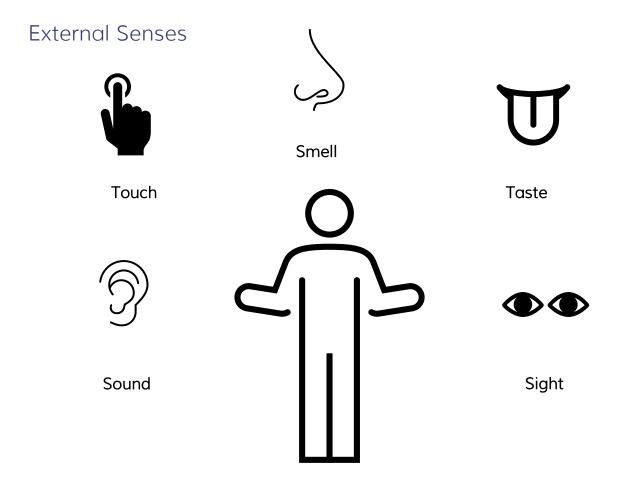
Now I realise that I need a low arousal space. I think that everyone who is autistic and discharged from hospital should have time in quiet countryside away from other people and other demands so they can decompress.

When I left hospital the last time and moved overseas, I had nothing on the walls. It was a very plain environment. Then over time, as I settled, I could

manage more, I added pictures to the walls. I was living on a beach and it was calm and quiet. If I hadn't had that environment I wouldn't have got well.

It's absolutely crucial to get this right for people.

I'm now back living in the UK with my family. The sensory respite I got from being in a calm and quiet environment made it possible for me to return to my family home. The patterns on the carpet are still the same. I'm not in the same difficult place that I was before, and there's always the sea to walk next to.



The external senses provide information about our physical environment. This information is then processed, telling us what this information means.

As Grandin and Panek (2014) write, if you receive the same sensory information as everyone else but your brain interprets it differently, then your experience of the world will be radically different from everyone else's. You would be living in an alternative sensory reality.

Though autistic people live in the same physical world and deal with the same 'raw material', their perceptual world turns out to be strikingly different from that of non-autistic people.

Bogdashina (2016:55)

Richard Maguire describes autistic people as being on a 'different operating system' than neurotypical people.

We consider each of these external senses in relation to the physical environment, so that we may bridge the perception gap and better understand and support autistic experience. Many contributors reported that their experience had not always been understood by others who might experience things differently.

Personally, it seems the effect of noise particularly and also light on my wellbeing is underestimated.

James

Sight

Our sight impacts our ability to process, interact and communicate with the world around us. Visual input is a key consideration for most of the people who contributed to the report – it was one of the most dominant senses.

Light and colour can provide stimulation and joy – for instance, stained glass can be used for small windows receiving direct sunlight.

Angela

Vision can support meaning, connection and self-expression.

Being aesthetically pleasing is also very important, I want to feel proud of my home and look forward to seeing it... a home is an expression of yourself and I like to think I'm far more than just a box.

Conor

Visual stimulation can be a source of comfort and joy and can also lead to sensory overwhelm. The good news about this is that there is a solution – or rather, a range of solutions.

Lighting

Natural light is very important to me.

Conor

Fluorescent lights are the most challenging light source for many autistic people. They give significant glare and flicker (Bogdashina, 2016), quickly leading to sensory overload. The preferred lighting sources for many autistic people, after natural light, are incandescent bulbs such as tungsten and halogen.

Fluorescent lights make me stutter. Flickering Christmas lights are a complete nightmare. I turn off lights in the evening and light candles. Instead of a central light I put on one or two lamps that I can adjust the shading of – and I can make sure they're not in my eyeline.

Cos

Some autistic people have very acute peripheral vision, some of whom may manage challenging visual stimuli by looking directly at things that are challenging – such as flickering lights.

It is possible to directly swap many fluorescent bulbs for better alternatives.

Where it is not possible to use incandescent bulbs, warm LEDs are preferable to fluorescent bulbs. Warm LEDs don't tend to cause pain but are more tiring for many people than incandescent bulbs because of the colour spectrum they

are on. It is worth noting that dimmable LEDs may flicker, causing a strobe like effect and may be best avoided.

It is impossible to filter out flickering lights.

Marion

Diffused lights that are covered with a shade rather than a visible bulb creates a gentler light that may be easier to tolerate. Where direct lighting is required, diffused alternatives such as lamps can provide flexibility and a more comfortable environment.

Two contributors to this report have installed smart bulbs that can be changed from a phone app, including changing the colour of the light emitted.

A home with variable lighting is a major factor for me, being so light sensitive, I can go into shutdown if exposed to too much artificial light. This renders me almost catatonic and unable to speak in a great deal of pain. I use a lot of small yellow lights and light bulbs. I also have in past had a room painted black to help with sensory overload. I need to have a neutral paint scheme with most things are now beige or white.

Carly

Clear windows with visibility outside and good natural light are both helpful – particularly in larger buildings where it can be difficult to maintain orientation.

It can also be important to be able to control and manage natural light, particularly in bedrooms.

Blackout blinds and curtains cuts down on the harsh streetlights coming in also reduces traffic noise and cold draughts.

Kelly

Several contributors to this report talked about a very specific sleep environment – some preferring partial lighting and others preferring total blackout, including covering blue lights emitted from alarm clocks and other sensors. (See sleep section on page 38 for more on this)

Shadows

Strong natural light and direct bulbs can cast significant shadows. Multiple light sources (such as spotlights or numerous bulbs) can create multiple shadows which can be disorientating.

Significant changes in light levels, particularly over thresholds and between rooms can make transitions more challenging. Consistent lighting between areas and glass panels in and surrounding doors can help make movement between spaces easier.

Colour

From a sensory perspective, 'less is more'. Bland, pastel and plain colours make for an easier sensory environment. Several paint manufacturers have a range of paints in colours designed to be calming. These can be used in combinations that still allow good contrast for those with visual impairment.

Clashing wallpaper can also induce nausea and headaches. Conversely - pleasing colours do wonders.

Rachel

Children and young people sometimes have a preference (or a perceived preference) for strong or bright colours. Where individuals express this preference, it might be helpful if they are limited to certain areas, removable and not in entrances or restricted spaces that other people also use.

Storage

Some autistic people process what they see literally, taking in every detail in every scene.

If the slightest detail is changed (e.g. a picture on the wall is not straight or a piece of furniture has been moved a few inches to the side), the whole scene ... is different, that is, unfamiliar. For them to recognise things, they must be exactly the same as they have already experienced.

Bogdashina (2016 p63)

Several contributors to this report specified that they like busy walls and visual stimulus – particularly where items were linked to their hobbies and interests or family life.

I like having a lot of visual input. I like busy walls.

Marion

Other people expressed a strong preference for a clear spaces and storage to keep items out of view.

Storage is very important. I get sensory overload by things being messy I can't relax it affects my mental health greatly. Storage space for things to be away visually is really helpful and helps having space to move around. It sounds silly but it seems to be overlooked in new built places. Wardrobes, storage cupboards for ironing boards, hoovers etc. Especially when you have children and need to keep things away from little fingers.

Kelly

As ever, it is important to personalise space and for individuals to lead on what works best for them. A calm and neutral 'canvas' that can be adapted and

added to may be a good starting point. It is often easier to add sensory stimulus than to take it away.			
Sound			
The most important element for me, and perhaps the hardest to get right, is for my home to be a quiet space.			

Ruth

Williams et al (2020) suggest that decreased sound tolerance shouldn't be viewed as a single condition but separated to distinguish 'hyperacusis (the perception of everyday sounds as excessively loud or painful), misophonia (an acquired aversive reaction to specific sounds), and phonophobia (a specific phobia of sound)'. This distinction may be helpful when considering and understanding individual circumstance and need.

Many autistic people experience hyperacusis – 'an unusual intolerance to ordinary environmental sounds' (Davies, 2019). This can mean an ability to detect noise from a distance out of the range of hearing of other people, such as outside noises like cars and aeroplanes. People may also be able to hear sounds from inside the building – such as voices or noises from other rooms, or water in pipes and electricity in the walls.

I have added more soundproofing around the windows (better silicon seals).

Conor

Many autistic people process one thing at a time and can't 'tune out' inputs. Every noise will continue to be heard, will be a distraction and will take 'bandwidth'. The detail of the auditory environment is vitally important to creating a comfortable and safe sensory environment.

Overload on an auditory level ... (is caused by) the number of simultaneous sound sources, the duration of these stimuli and the rate of the bombardment relative to process *capacity*.

Bogdashina (2016:101)

It is particularly important to involve autistic people in reviewing the auditory environment wherever possible, as they are physically able to hear things that are not within the range of those with a typical auditory function.

More than 20% of people who contributed to this report talked about being able to hear electricity in the walls, in plug sockets or items charging in different rooms.

I rented a flat and was kept awake by a humming electrical noise. It was a quiet new build flat, in a quiet environment. The noise was coming from inside the wall. After a while, I realised that on the other side of the wall, in the bathroom, I had an electric toothbrush plugged in. The noise of the electricity was keeping me awake at night.

Cos

As a child I thought it was normal to hear electric. I could even close my eyes and know which plug sockets were on and which were off. I could easily find the route of the buzzing by following the sound. I would have to turn off whatever the source was, not so bad if it's a lamp or a TV but if the buzzing was a heater, and autistic person would have to make the choice over a painful buzz or being warm?

Carly

It might be possible to reduce the noise of electrical items by turning them off. Other people use white noise machines, music (a sensory input but a chosen one), or noise cancelling headphones to manage this. Some people prefer to limit electrical appliances in some areas of their home, or to have an outside space such as a yurt or garden shed where it is possible to get sensory peace.

It is important to consider the way that noise can carry between rooms and walls, including from adjoining flats and houses. Several contributors told us that everyday noise from neighbours has been a challenge for them, particularly where buildings are joined. People told us that everyday noise can cause them distress but isn't always something that they felt able to either control or complain about. It's not that their neighbours were being unreasonably loud, but that everyday sounds had a disproportionately negative impact because of their auditory sensitivity.

Soundproofing between dwellings would really help. So many places I have lived you can hear everything next door and drives me crazy, soundproofing is really needed between dwellings and now technology is such that soundproofing can be very thin and not take up much space. Kelly

It is important to consider whether individuals want and are able to live with other people, and what adjustments might be needed to ensure that this is a positive experience. We further explore shared housing in a later section.

Building structure

Building materials affect how heat, sound and light access or move within and between spaces. For people with sensory sensitivity, getting the right type of build can make a significant difference to how sound moves within the building and to their long-term sensory comfort – or discomfort.

Housing is better [in my view] if <u>not</u> of lightweight construction, such as timber frame. This is bad for sound, and bad for the thermal flywheel. Traditional masonry construction is the better alternative, especially for autistic occupants. Thinking in terms of low energy design has parallel advantages with sound and heat sensitivity.

Angela

The structure and shape of a building can cause sound to echo in unpredictable ways, impacting an autistic person's sense of space. This can be made worse by hard surfaces such as walls, floors and ceilings.

Curved or slanting walls and ceilings can cause sound to echo in different directions and frequencies. Convex walls reflect sound away and concave walls focus sound. This might be difficult to detect for those without auditory or vestibular sensitivity, but can make it difficult for some autistic people to orientate themselves in the space.

If the curved wall is convex – encroaching into personal space, there would be the sense that some of my space is missing – and is behind the wall. In passageways and routes through buildings curved walls create confusion about the layout and what to expect and might increase anxiety through uncertainty. On balance I think they detract from a good sensory environment.

Angela

Appliances, including heating

Appliances and heating within the home, and those run by neighbours, can add significant background noise. Many heating, air conditioning and water systems hum, buzz and rumble. For people with auditory sensitivity, it can be impossible to block out this 'background noise'. This can be significantly disruptive at any time of day but may be particularly challenging for people at night or when trying to sleep.

In shared spaces it can be helpful to consider and agree in advance when noisy activities such as hoovering, and washing will take place. For people who need staff onsite and awake overnight, it may be helpful to consider where staff will be located, what they might be doing, and what noise disruption this may cause for anyone trying to sleep.

Our house was built in 1876, it is properly naturally lit being built decades before electric light. It uses lime mortar, lime plaster, brick and lots of wood meaning the acoustics are peaceful. We have not fitted central heating because it is noisy and would cause us distress, we are all autistic and have hyper-sensitive hearing. A house like this is heated room by room, compartment heating, so we manage temperature in rooms as needed. We do not like it too hot, so we live like Victorians in this respect, our house is a lot cooler than centrally heated houses and we wear extra clothes to keep warm. Our house is also draughty meaning the air is fresh and healthy, never stuffy. We get very few

coughs and colds as a result. I really do think the sensory environment worsened in the C20th and is continuing to worsen with modern design. Richard

Angela Heeley, an autistic architect comments that:

Fan ovens and washing machines – consideration is needed at the room layout planning stage. For instance, where a bedroom is adjacent to a kitchen the position of a fan-assisted oven might cause a stressful background noise.

Tumble Driers – the new ultra-low energy heat exchanger type of driers are a fantastic money-saving design, but have a drying time of over 3 hours (we've got one – it drones on and on, adding to the level of background noise), and so it's important to consider the position of the drier within the house, and incorporate external drying space.

Bathroom and kitchen and utility room extractor fans are a requirement of the Building Regs. These are a stressor due to the 'white noise' they generate. The Building Regulations <u>do not</u> require that they are wired to come on automatically with the light switch, although this is routinely the way they are installed. (Especially in internal bathrooms in hotel accommodation, and I have experience of having to use the bathroom in the dark to avoid this sound.). A separate switch should be provided.

Hot water cylinders which fill from a header tank are noisy, especially in multi-occupancy households. Mains pressure hot water, with or without a cylinder, is the preferred option.

Heating – fan heaters, fan-assisted heat-exchangers and fan-assisted radiators are best avoided due to the stressful 'white noise' sound, and also air movement which might be unwelcome. Underfloor heating or panel radiators are the best options.

Large low temperature radiators are a safer option than smaller higher temperature ones. Again, this works well with low temperature environmentally friendly heat systems such as ground or air source heat pumps. [I have a slow response to realising that I am touching something hot and so am at risk being burned by radiators]

I am particularly affected by the sound of metal curtain rails. These would be better in plastic or wood.

Kitchen cupboards and drawers should have quiet 'soft closing' mechanisms or be of 'old fashioned' heavy wood construction so that they are closed slowly.

Alarms

Alarms include burglar alarms, alarm clocks, washing machine and cooker alerts, fire alarms, car alarms, personal safety alarms, door alarms.

Alarms, by design, are alarming. They push many autistic people straight into shutdown, meltdown, fight or flight. This is a stress response.

The timer on the cooker is triggering. It's not just annoying. It climbs into your soul and pulls it out.

Emma

Generally, autistic brains don't habituate, so people will register a full alarm every time it sounds. Some autistic people are not able to tune noise out. This can cause people to be in a state of perpetual anxiety and distress. Sometimes this will show as meltdown, but many people will go into shutdown instead, so their distress is not as obvious. Some people will not show their distress until later due to processing delays.

Changing the sound for a gentler noise that would be less intrusive and distressing and alternative systems that vibrate rather than sound could be considered.

For many people, it can be useful to know when an alarm will go off and how long it will last, but it is important that any information shared is accurate. A review of how and when fire (and other) alarms are tested and what information is shared with people to prepare them for and support them with this.

Doors

Doors can be very noisy when opening and closing. For some autistic people, this can deliver frequent but unpredictable shocks.

In various shared accommodation I have lived in I've had problems with doors closing. In one house the doors were very heavy fire doors that would slam very easily. People would inevitably get angry at some point and slam their doors which I found very traumatic. I found it very difficult to relax and was in a state of constant vigilance. Small plastic bumpers are useful in stopping cupboards and doors slamming.

James

Minor adjustments, use of Velcro pads, door silencers, or kitchen cabinet door buffers could all reduce the audible impact of doors closing. In some areas, it might be possible to install overhead door closers to ensure that they shut but do not slam. However, door closers can pose a safety risk and are not appropriate for all areas.

Several of the autistic people who contributed to this report expressed preferences relating to the arrival of visitors and deliveries at the door. Where people are not able to verbally express a personal preference, it may be helpful to trial a number of different systems to see which is preferred.

I find knocking much more disturbing than the noise of a doorbell.

James

Kelly expressed a preference for a video phone with adjustable ringing volume.

I have a door entry phone which is very useful, however the ringer volume can't be adjusted and have auditory processing issues I can't always understand them, having a video entry phone would help to lip reading and also see whose there.

Kelly

Flooring

Flooring can significantly change the sensory environment in a room.

Soft furnishings help to muffle general sound and create a softer audio ambience to a space. There should be curtains and carpet and upholstered chairs.

Angela

Plain (un-patterned) neutral carpets tend to be favoured as they do not cause visual disturbance and they benefit the auditory environment by absorbing sound. Patterned carpets can add to the sensory load and are likely to be best avoided.

Hard surfaces can add to the echo and 'noisiness' of a room. When wipe-down surfaces are required, acoustic vinyl may be the best option for reducing ambient noise and creating a more comfortable environment.

Outside noise

External noise can have a significant impact on internal environments. This includes noise from roads, schools, playgrounds, shops, airplanes, trains and building work. It can also include noise from neighbours.

External noise isn't always consistent – it can vary at different times of the day and year. Some noise may be short term but have a significant impact. Other noise may add to the 'sensory load' but not be significantly challenging.

Many contributors to this report talked about particular types of noise being more problematic. Sometimes this relates to their predictability, but sometimes also to volume or pitch. Some people find road noise problematic, other people struggle with alarms, others knocking, or building work, others ambient

background noise from neighbours. Some people would be happy in a residential road by a school, other people would find this challenging.

It can be helpful to understand this before choosing a building location.

Building work is the worst – multiple types of noise, the volume, unpredictable noises and the relentlessness of not knowing when it was going to stop (or start). There was no escape – unless I left the house – which I really didn't want to do because I was exhausted and overwhelmed from the noise and not sleeping. Catch 22.

Ruth

Smell

Smell is pervasive – it is not possible to close our nostrils as we can close our eyes.

As many autistic people do not 'habituate', a smell will remain distinct and present, though neurotypical people might only notice a smell when they initially experience it, for example when entering a room.

Smell is not problematic for everyone that contributed to this report – but was a significant factor for some. It can be a positive experience as well as negative.

Certain smells can really help to calm and soothe me. On the contrary other smells can make me feel quite unwell. For some autistic people the sense of smell can be so strong that it feels like you are being force fed.

Carly

Marion described using Vicks vapour rub, body spray or roll-on scented aromatherapy to block out other smells. This can be applied under the nose or on the wrist and can be used to overpower other smells. It's worth noting that while this might be preferable to other unavoidable smells, it adds a sensory input – albeit one that can be chosen.

Household smells

People that we spoke who have sensitivity to smell to expressed strong views in relation to their preferred products.

I adore the smell of fresh laundry, clean smells but not too overpowering. It can take me ages to find the 'right' smells.

Carly

People told us that they tend to have a preference for certain types of smells (eg floral cleaning products), but that even their preferred products can still be difficult.

Suggestions for managing smells include:

- limiting use,
- managing the timing of use,
- trial and error with product types,
- consistency of use when preferred smells are identified,
- management between spaces (eg closing doors, having specific areas for cooking or drying laundry)
- use of alternate and preferred scents eg candles, essential oils, etc

People spoke about the challenges of managing smells within buildings and between spaces. Being able to close doors and reduce the transmission of smells between rooms can be helpful.

The smell and heat in a hospital or residential environment would be hugely problematic to me. I would want to be in a room far away from the kitchen, bathroom and dining rooms because of the smells.

Cos

One person observed that wet washing smells stronger than when it is dry and said that they dry their clothes outside whenever possible and do not dry clothes on radiators in their bedroom.

Sharing spaces such as bathrooms and kitchens can be challenging for some people with olfactory sensitivity. These spaces are often associated with scented products.

A shared bathroom with scented perfume and shampoo would be problematic.

Marion

Other people

People smell. We might smell of soap, of laundry detergent, of smoke, of food or drink, of perfume or aftershave, of deodorant, of body odour – and often a mix of a number of these.

When it is a familiar and comforting person and scent, this can be reassuring. When it is a new or different scent, if it is particularly strong, or unexpected, or at a time of sensory overload it might be additionally challenging.

Some of these personal smells can be difficult to reduce – others can be considered and managed.

Public spaces

Smell can affect how accessible different locations are for some people.

Bleach can be unbearable, swimming pools, public toilets and eating places that use a lot of bleach and chlorine for example can be inaccessible.

Carly

For people who are not sensitive to smells, this can be confusing – many locations do not have consistent smells and people may respond very differently on different days.

Smells can vary significantly and might be affected by when spaces were last cleaned, which products were used, who has been in the space recently, perfume or aftershave of other users, if food has been recently cooked or served, how busy the space is, whether the doors and windows are open, if the heating is on, ad infinitum.

This can also be true of communal spaces, where the individual may have reduced choice and control because the space is shared by other users.

Taste

This paper focuses on the physical sensory environment in housing. However, we know that taste (and texture) can be significantly challenging sensory inputs for some autistic people. We heard from some contributors that the right physical environment can support them to manage and enjoy food. We don't fully explore this sense but reference it in relation to the sensory environment.

We use all our internal and external senses when we eat. Reducing the sensory load by getting the physical environment right can make a significant difference to people's ability to eat and enjoy food. It is possible to reduce the sensory load at mealtimes by getting the environment right.

I need to be able to eat away from other people. This isn't all the time, but if they're eating smelly food, or making loud noises, or eating with their mouth open, it makes me feel quite ill.

Cos

When we consider the many ways that our senses are used at mealtimes, it is easy to understand how challenging this can be for autistic people with sensory sensitivity.

Sight

- Foods come in all shapes and sizes. They are colourful and dull. Sometimes spaces are well lit, sometimes they have natural light, sometimes there are dim lights or strong shadows.
- Natural light when possible, and a well-lit space with tungsten bulbs when needed. It can be helpful to consider the direction of light and where shadows fall. It can help for the plate to be well lit, but not too bright.

Sound

- Many dining spaces have solid floors, heavy, noisy furniture, solid walls and limited soft furnishings.
- Cutlery, plates, drinking glasses can all add noise.
- Crunching, chewing and swallowing are all activities that make noise and can be challenging for the person making them and/or if made by other people.
- Eating with other people can be additionally challenging they add an array of sensory input.

Smell

 Food can smell strongly. Smells from cooking, from other people eating, from other courses can all add to the sensory load.

Touch

- The tongue has many 'touch' sensory and will detect texture.
- Dining room furniture is often hard and uncomfortable.
- Cutlery can be cold and heavy and means that people might miss important sensory information about the texture of food. Some people find it easier or prefer to eat with their fingers instead of cutlery.
- Each food has a different texture and temperature and can be unpredictable.
- Presentation and separation of food types or textures may be important for some people.

Interoception

- Our internal system that tells us what we are feeling and if we are hungry or full
- It can take time for this sense to register, and it may be harder to 'hear' if the external senses are overwhelmed.

Proprioception

 We need to locate different parts of our bodies and move our hands and arms to our mouth to eat and drink. This takes effort and coordination that is additionally challenging for some autistic people (see earlier section on internal sensing systems).

The sensory 'load' that is added at mealtimes makes it particularly important that other sensory stimulus is reduced. This is why it is so important that people have choice and control over where they eat, if they eat with other people and that the physical environment doesn't make eating more challenging.

For many neurotypical people, mealtimes are seen as a social occasion and eating with other people is a positive and beneficial experience. However, this can add to the sensory load at a time when there is already a significant amount of sensory input. Many autistic people prefer to eat on their own.

Choice and control over what to eat is important. Fresh fruit and vegetables can be really hard – there's so much variation so it's difficult to know what something is going to taste like. It can be helpful to explore the variety of ways to get nutrients in. Smoothies can be good.

Marion

Touch

Our skin is the largest organ in the body. Hypertactility, an acute or heightened sensitivity to touch, is very common among the autistic population (Bogdashina 2016:84).

Others experience hypotactility, a reduced sensitivity to touch. 'Those with hypotactility seem not to feel pain, hot or cold temperatures... they are prone to self-injuries... they like pressure and tight clothes'. (Bogdashina 2016:85)

Temperature, texture and pressure (from touch as well as from atmospheric pressure) can all add to the sensory load. We experience a mix of these things all the time.

It can be helpful to use predictable materials that do not change temperature significantly.

Materials which need to be touched should be predictable – e.g. Handrails shouldn't shock with unexpected coldness (as is the case when they are made of metal).

Angela

Textiles – including clothing

For people who are hyper or hypo sensitive to touch, getting clothing right can make a significant difference to sensory management.

It may be useful to explore different materials and styles – softer cloth, looser or tighter fit, cutting out tags and buying seamless socks may all enable people to be more comfortable.

I have a sensitivity to material, so I don't like tough fabrics. Manmade fibres irritate me.

Karl

Consider the texture and weight of duvets, pillows and bedding, too.

Sleep

Sleep is a strong predictor of quality of life and has been related to cognitive and behavioral functioning. However, research has shown that most autistic people experience sleep problems throughout their life. The most common sleep problems include sleep onset delay, frequent night-time wakings and shorter total sleep time.

Pavlopoulou (2020)

The quality of the bedroom environment and specific requirements to aid sleep were mentioned by several contributors to this report. People mentioned a

range of things that affect the quality of their sleep including light sensitivity, external noise, smells, needing a distinct and defined sleep space that is free from other items, and the need for specific sheets.

As bedrooms are often the rooms people retreat to fully relax, extra care needs to be taken here to offer opportunities for a restorative sensory environment. For example, our bedroom includes heavy curtains to block out light and sound, my weighted blanket, my ear plugs etc. Again, care needs to be given to touch and colour of soft furnishings - for me this means soft cotton bed sheets, and smooth flooring.

Rachel

I have created a very heavy weight for a duvet. The added weight helps me sleep better. I've got a memory foam mattress which is comfy and quiet.

Karl

Pavlopolou's excellent research with autistic adolescent makes further suggestions about daytime and evening / bedtime activities and routines that are important for individuals and support good sleep.

Tiredness makes things worse.

Damian

Furniture

Soft furnishings and furniture can have a positive impact on the soundscape and on the comfort in the room. Most people have preferences about the shape, support, and colours of furniture they want in their home.

Leather sofas are a nightmare – they are noisy and very cold to sit on. The look, smell, texture, and sound of plastic furniture (imitation leather) would be really difficult for me. A fleecy blanket or throw can help me sit on something I don't like.

Marion

It's important to recognise that the impact of the unsuitable furniture can be significant for people with sensory sensitivity.

I like neutral tones in soft furnishings, paying care to how things feel too. When we moved in our living room had different patterned wallpapers and carpet, plus the carpet was really tickly. It would give me a headache whenever I went in. We've changed it so the room is largely shades of teal and white. Plus, we have a smooth rug underfoot in similar colours.

Rachel

Some people may find beanbags more supportive and comfortable than sofas.

Hypermobility

Hypermobility is an issue for many autistic people, though it often goes undiagnosed. When people experience hyper-mobility, they can't get comfortable. People's bodies don't support them properly, they are likely to fidget, be in a lot of discomfort, don't want to sit still and wake up exhausted. Good quality supportive furniture can be helpful for people with hyper-mobility. Assessments are critical to ensuring that people are well supported and understand how to look after themselves.

I have Ehlers Danlos syndrome which I know is comorbid with ASD and we live in a top floor flat, no lift and have a baby. After being out for a walk I'm already exhausted and in pain, having to walk 5 flights of stairs carrying my son is so painful. But also access for those who have wheelchairs, prams is needed. Also, many adults with ASD I know order shopping online due to sensory overload in shops, so many delivery companies won't bring shopping in if there's no lift, leaving you having to leave baby unattended and make several trips up and downstairs.

Kelly

Washing

Personal hygiene can be a particular barrier due to executive dysfunction and sensory issues. Therefore, particular attention needs to be paid to the type of shower head used, tap flow etc. This is different according to different needs - certainly an adjustable shower head for different flows can be useful. I personally feel claustrophobic in baths with glass screens, others loathe the feeling of dealing with a soggy shower curtain. All can be barriers to keeping clean.

Rachel

For people with tactile sensitivity, washing can be an overwhelming sensory experience.

Many autistic people find water (including/especially hot water) to be very soothing, and so a bath should be available, not just a shower.

Angela

Bathing can add significant and unpredictable sensory input. The temperate and pressure of water and the room and stages of changing and undress can all be differently uncomfortable sensory experiences. A comfortable physical environment can make this easier.

Bathroom floors – should warm to bare feet, achieved by using vinyl (or natural materials such as marmoleum), or ceramic tiles with underfloor heating (which could be electric, or part of a low-energy heat pump

system which would be an ideal use due to the lower temperature of hot water produced compared with a traditional boiler).

Angela

Some people may find baths easier than the 'needles of water' of a shower. Others may prefer a wet flannel to being submerged in 'human soup'.

I have increased the water pressure. Water pressure was a tactile reason, as well as one for hygiene- it just didn't feel right using a weak shower and more over it caused sensory irritation by having many different temperatures and sensations on my body at once- higher pressure meant better coverage and only one overall sensation to process.

Conor

Other things to consider

This section includes comments from contributors that don't fit neatly under one of the sensory headings but are important considerations.

Shared spaces and communal living

None of the people who contributed to this report spoke positively about shared housing or accommodation, beyond sharing with their immediate family – including partners, parents, grandparents and/or children.

Sensory wise shared accommodation made such a huge negative impact on my mental and physical health.

Carly

The main reasons for this were the limitations in choice and control for sensory stimulus, including unpredictable and uncomfortable sounds and smells, and challenges in shared spaces.

If I was living with other people again then good sound isolation in my bedroom would be important, so I could escape if needed.

James

Generally, people reflected on the challenges of everyday and ordinary activities that are not unreasonable but have a disproportionately negative impact on people with heightened sensory sensitivity. This included: other people having different schedules and arriving home late or having early alarms; different smells – including foods, cleaning products, perfumes, washing detergents; use of TVs, mobile phones or music; the noise of doors closing; washing machines, heating and other activities that may alter the physical environment or add to noise in the water pipes.

Shared spaces, including entrances, living rooms, kitchens, bathrooms, laundry rooms etc can also be anxiety-provoking.

I think one of the problems with communal spaces is that they can seem faceless, not seeming to belong to anyone, therefore at risk of not being cared about and then neglected. Which makes them a more anxiety-provoking place to be, a place where things may not work or people don't care what happens to them, or to the people in them. Fights, bullying, abuse. Like the playgrounds at school where I might shrink to the edges, or the canteen you can't enter unless you are with one of the 'right' people.

Just to add, the difficulties with communal spaces are, for me:

1. Do I feel like I belong in them?

- 2. Can I be in that environment without feeling overwhelmed from a sensory perspective (and from social interaction demands)?
- 3. Do I feel safe?

I guess, therefore, the way to make them safer is to engage the whole community in designing and caring for and 'owning' the communal areas.

Ruth

People also commented on the importance of being able to have private space other than a bedroom to relax in.

If there was a communal living area, I would find that tough. I'd prefer to live on my own. It would be very stressful to be around lots of people and not be able to find my own space. I would find it a very very very stressful experience feeling like I couldn't go and find a space to chill out. It would lead to mental shut down or trying to leave the area to find somewhere quiet.

Karl

This comment links to the following section, about the need for distinct areas for different activities and different times of day.

Defined areas within the home

Several contributors to this report talked about the importance of having defined and distinct areas within the home for different activities.

I need a defined living area and sleeping area I find it sensory overwhelming and affects my mental health if I don't have separated spaces. I know many Local Authority or rented places turn the living room into another bedroom meaning no space to study, watch TV, eat or workout that's separate from the sleeping room. It makes it hard to relax as you don't associate the space with sleep. It also makes the room smell of food.

Kelly

I have different areas of my house that are for specific purposes. I have a designated room for the day – my office, that has my books. When I've finished working, I move to my evening room.

Cos

People told us that it is important to be able to close doors between the different spaces. Open plan living may ease transitions for some people but may add to stress for other people.

We put doors in all the rooms - many rooms had no doors which was just awful.

Rachel

In larger buildings clear signs may be important to support people to comfortably access the space. Buildings can be disorientating, especially in bigger buildings, when different doors and corridors look similar, and when there is limited views outside that could support orientation.

Interests and hobbies

(A degree of passion) is so often seen as a negative – 'obsessive behaviour'. And yet the passionate interests of many autistic people should surely be celebrated. Definitions of challenging behaviour refer to levels of intensity, duration and frequency – all which can be found in some people's engagement with their subject of interest – but this cannot always be seen as a negative. Having a passionate interest in something can be amazing for the individual – and it has a massive contribution to make to the wider society. After all, advances in academic disciplines, among others, may well stem from autistic passion...

Beardon (2017:113/114)

For many people, the things that make a house a home are personal items. These may be linked to family and friends or to hobbies and interests.

It can be important to have safe, defined display and storage areas for personal collections and hobbies. This might be photographs, sports equipment, historical artefacts, toys, models, films, music, shoes, clothing or sports memorabilia, or anything else.

I have a fairly large collection of model railways. I have a display case in my bedroom. It's important for me to have space for them. Some people would say it's busy, but it works for me.

Karl

The authors of this report do not believe that it is appropriate to limit access to items connected to interests and hobbies (safety reasons not withstanding), or to use these as a punishment or reward.

A twitter poll conducted by Ann Memmott in October 2020 asked 'If someone took your most precious possession/collection, and made you pretend to be nonautistic to get it back for a few minutes a day, would you be: unbothered / a bit upset / very upset / traumatised?'

960 autistic people voted. The final results showed that over 70% of responders would be traumatised by this.

Unbothered (1.1%)

A bit upset (2.2%)

Very upset (25.3%)

Traumatised (71.4%)

*This was a twitter poll and was not formal research. Link to poll and comments: https://twitter.com/AnnMemmott/status/1322089326533087232

Outside space

Having a garden is so important, as therapy, for relaxation, as a small social space.

Ruth

The need for outside space was a common theme in the feedback received from contributors to the report. This included reference to having direct access to a garden, and also to other natural environments.

Many autistic people like to use their gardens for a variety of reasons - some enjoy gardening, some physical exercise, some trampolining etc. A garden is a useful way to enjoy being outside without having to come into contact with people outside the household. This is especially necessary when interaction with those outside the household can be distressing or unwelcome - thinking oy my own kids enjoying our trampoline in the garden after a day of being misunderstood at school.

However, neighbours can be tricky creatures in terms of not understanding that older children/adults find sensory regulation in trampoline bouncing and other noisy activities so it might be worth investing in high fencing, and trees. Shrubs etc to soak up a bit of noise. Of course Disability Discrimination acts do offer protection for this sort of thing but that's massively stressful. Sometimes equipment can be placed at the far reaches of gardens to also cut down on how noise reaches the neighbours.

Rachel

I also need access to nature and the outdoors- away from many people, pollution (not just cars/homes but also light and sound) and space to stretch out and just enjoy nature. For me this is essential.

Conor

I went through my photographs on Flikr to find images of sensory peace, what works for sensory comfort. On looking at them something struck me; they are mostly of old buildings lit with natural light, containing no artificial primary colours and with soft acoustics. The other photographs are of countryside, outside places, naturally lit with natural sounds. None of these photographs include modern artificial colour or design, no

artificial lighting and would have no modern sounds with the exception of aircraft flying overhead. All these places are places I choose to be and will travel a long way to get to. In all these places I am in sensory peace, becoming relaxed and want to stay.

Richard

Pets

Allowing pets, pets really help with sensory issues and meltdowns so many places don't allow them. Not just assistance dogs but other animals like cats or a rabbit.

Kelly

Security

Several contributors mentioned things that would help them to feel safe and secure at home. This may be particularly important for people who are living alone.

Security/ front desk stop cold callers/ people with untoward motives safety because my ASD (autism) means I struggle to understand others' motives having security/reception would make me feel safer.

Kelly

A big part of it is feeling safe/secure for me- so if it was an apartment complex being at the end of the corridor so people aren't constantly walking past and having building security/key carded doors would help greatly.

Conor

Support

This paper is primarily about changing the physical environment to reduce sensory load. But when it is needed, the quality of support impacts accessibility. A positive emotional engagement can make it more possible to deal with other things.

Kindness and warmth make a huge difference.

Richard

Predictability and consistency of support are both likely to be significant factors for autistic people.

Predictability is a huge part, but it's not everything – things can be predictably awful.

Damian

Changes to support teams – whether longer term because of staff changes, or short term because of illness – can be disruptive and add to the 'sensory load' as changes need to be processed.

It's natural that it takes time to build relationships and rapport. Everybody builds a range of relationships, with some stronger and more positive than others. This is true, too, for autistic people – particularly where people have limited choice or control and may be dependent on these individuals for support with daily activities.

Some people will ask who is working and when. People ask, sometimes repeatedly, because it matters to them. If maintained and accurate, a visual timetable may support people to process and predict who will be working with them, and when.

Professor Mark Brosnan from Bath University presented to an AT-Autism conference the framework they use to ensure that autistic students are positively supported. This approach might be useful to other people. Their work hasn't been published but is shared in the appendix.

It suggests consideration of the:

Sensory environment

Does the individual have a place to work where they feel comfortable?

Timely environment

Has appropriate time been allowed for tasks?

Explicit environment

Is everything required made explicit? Are some tasks based upon implicit understanding which draw upon social norms or typical expectations?

Predictable environment

How predictable is the environment? Is it possible to maximise predictability?

Social environment

Does the workplace have social occasions and is the individual keen / reluctant to participate? Are there essential social occasions? Can group activities be adjusted to enable the staff member / student to take part – e.g. issuing a clear invitation to a specific, time-bound event.

Self-management and self-regulation

The right sensory environment can support improved health and wellbeing. It can support people to self-manage and to have more energy and concentration for different aspects of life.

I feel my mentality has improved much now I'm living on my own and I'm able to rest in peace and quiet when I feel agitated which also allows me to be more outgoing when in social situations.

James

Many autistic people naturally develop ways of managing sensory overload. However, these natural strategies and techniques are sometimes discouraged by others. For example, many autistic people find eye contact painful or overwhelming and so look away from people who are speaking them so they can listen better. However, there is a neurotypical expectation that people need to be looking at each other to listen. This instruction from well-intended parents, teachers, colleagues and care givers can make it more difficult for autistic people to process what is being said.

From the time we are born, interoceptive signals alert us that our balance is off and motivate us to take action, to do something that will restore the balance... when we feel that our internal balance is off, we are motivated to act, to seek immediate relief from the discomfort caused by the imbalance.

Mahler (2017:42)

The following suggestions may be useful to people to reduce the sensory input and/or to support self-management, and to restore balance.

Hats and caps worn inside as well as outside can be useful to reduce the risk of sensory overload and glare from lights and to narrow the field of vision.

Sunglasses worn inside as well as outside can help to reduce the sensory impact of lights. Some people find tinted or coloured lenses to significantly improve their visual processing.

Noise cancelling headphones can be used to reduce the impact background noise.

Leaning on walls, crossing legs, weighted blankets, weighted backpacks can help produce more sensory input to help autistic people to get enough stimulation to their vestibular and proprioceptive systems. This can help balance and navigating obstacles.

Weighted blankets should be the right weight for the individual.

Choice and control over where to spend time. Many autistic people naturally gravitate to spaces that are more comfortable to be in - areas in room that are quiet, have less echo or better light.

Taking time out. The neurotypical norm is to have a constant and busy day. However, many autistic people work intensively for a period and then need down time between activities. Down time might look different to the neurotypical norm and may involve quiet time, physically resting or doing a favourite activity.

Stimming. Stimming, or self-stimulating, is the use of repetitive movements to communicate, calm and balance internal body-senses. Stimming might include flapping or rocking and can be useful to people to self-regulate.

Autistic people... 'describe repetitive behaviour as a refuge from sensory anxiety and try to develop ways of managing their stress... In the absence of sensory tranquillity and lacking intake that they can make sense of, people... provide themselves with a point of focus to shut out the overload, so that there is at least something that is within their control.' Caldwell, 2016

Stimming is sometimes discouraged by other people, making it more challenging for people to self-manage or requiring people to mask their management techniques. Caldwell notes that self-injury is often a response to sensory overload, so supporting people to manage sensory input and to process it in a non-harmful way might also mean that people find alternative ways of reducing and managing overload.

Swinging and bouncing. For people with a hypo-sensitive vestibular system, swinging or bouncing can offer calming and reassuring stimulus. This can be a great way for some people to self-regulate and return to a calm state. It might be helpful to consider how this could be safely supported.

Sensory environment checklist user guide

This checklist is intended to support improvements to the sensory environment.

Wherever possible, we encourage the involvement of autistic people in reviewing sensory environments. We believe that autistic people are uniquely qualified to review environments for themselves or for other autistic people as they live in an 'alternate sensory reality' (Grandin and Panek 2016) to the neurotypical population.

We offer some general suggestions that will help to reduce the sensory input. We hope that this will be helpful to lots of people. It can be used in shared houses as well as individual homes.

It is possible to use parts of this document but not others, depending on individual sensory needs. It is possible that not all parts will be relevant to everyone, please feel free to use the parts that are helpful.

We identify common sensory challenges as well as some suggested solutions. You might have other ideas for solutions too. It can be helpful to consider the issues identified at different times of day, and possibly also at different times of year.

It's useful to remember that sensory needs can change throughout life due to experience, or if one need is well met and catered for then other ones will become more apparent. The home should be thought of as a dynamic environment where things can be monitored and tweaked as necessary. Also, as a person ages their ability profile will change.

Rachel

We recommend considering all senses in every space – including entrances. Slow down, walk through, pause in each space, what do you notice?

We explain these elements in more detail in the report, please read this for further information. This checklist is intended as a practical summary to support those considering and reviewing environments. See also:

Simpson, S. (2016). Checklist for Autism-Friendly Environments. **National Institute for Health and Care Excellence** [online]. Available at: https://positiveaboutautism.co.uk/uploads/9/7/4/5/97454370/checklist for autism-friendly environments - september 2016.pdf

Triple A's Aberdeen. Guidance for Teachers Transitioning Autistic People. [online] One Stop Shop Aberdeen. [Viewed on 14th December 2020]. Available from: https://webspace.oss-aberdeen.co.uk/Guidance for Teachers2/

Sight

Challenging sensory stimuli	Suggested alternatives	Comment
Fluorescent lighting (flickers)	Tungsten (halogen, incandescent) or LED.	
Dimmable lighting (flickers)	Not dimmable.	
Direct lighting (uncovered bulbs)	Diffuse – using a shade. Or use lamps as an alternative source.	
No natural light	Getting the lighting right where there is no natural light is important. This space should have limited use.	
Windows obstructed (eg covered in non-transparent film)	Uncover windows where possible – even partial visibility helps.	
No covering for windows, or transparent curtains	Blackout blinds or curtains that can be fully controlled, particularly in bedrooms.	

	These can be fitted within the window or press studs or Velcro fastenings could be considered if needed.	
Significant light changes between rooms or areas.	Consider additional blinds, lighting or windows within doors to reduce the change in lighting levels.	
Strong shadows, moving shadows (eg from trees)	Additional lighting sources or diffused light can reduce shadows.	
Reflective surfaces eg flooring or walls	Consider a matt finish.	
Limited visibility between spaces	Increased visibility between spaces can ease transitions – transparent panels in doors.	
Bright colours	Swap for neutral, natural and pastel colours.	
Bright posters, murals and wall designs	Limit this in small spaces and entrances. Involve people in choosing the detail of design if desired.	
Patterns on floors, carpets and soft furnishings	Plain materials in neutral colours.	

Posters, postcards and inspirational quotes	Limit use of these unless the person indicates the prefer a busy visual environment. Ensure wording is accurate if interpreted literally.	
Cluttered environments	Store items in cupboards, clear surfaces, limit the amount of furniture in each room.	
Add your own		

Sound

Many neurotypical people can 'block out' noise, but some autistic people struggle to do this and hear every sound. Including things that might not be audible to others.

A decibel meter can be useful to support this work (now available as a phone app for those in need).

Challenging sensory stimuli	Suggested alternatives	Comment
Outside noise – traffic, schools, airplanes (consider different times of day)	An important consideration in location as there are limited options to reduce this noise. Double glazing or acoustic glass may help.	
Hard floors and walls, adds to noise (eg footsteps) and creates echo	Soft furnishings (carpets, curtains, furniture) absorb noise. Acoustic vinyl is often a better option than laminate where carpet isn't appropriate. Sound absorbing panels could also be considered.	
Curved and angled walls and ceilings – affects how sound moves in the space and can be disorientating for those with proprioceptive issues.	Straight walls and 'flat' ceilings. Soft furnishings and sound absorbing panels can reduce the impact of this where change is not possible.	

High ceilings	Where these are present soft furnishings and sound absorbing panels can help.	
Electrical buzzing	Can items be turned off or moved?	
Forced air, heating or air conditioning humming	Is it possible to control this? Can it be turned off? Can it be serviced to reduce the noise?	
Heating noises	Is it possible to control this? Servicing may reduce the noise volume.	
Fan heaters or fan assisted radiators	Swap for panel radiators or underfloor heating. Large low temperature radiators may be safer than smaller higher temperature alternatives.	
Water pipes including from toilets, appliances and pipes	Are they noisy in all areas or are there quieter spaces? Is it constant? Can it be controlled or managed? Limit use of spaces where it is particularly noisy.	
Washing machine and clothes dryer	Consider agreeing timings of use. Some people find this sound comforting and helpful to self- regulate.	

Dishwasher and other appliances	Consider position of this and timings of use.	
Cooking noises, including fan	May be more manageable if the person is involved and controlling this. Is it possible to close doors between spaces? Limit use if noise is more challenging than smells.	
Bathroom extractor fan	Connect to a separate switch so it doesn't automatically come on when the light is turned on.	
Hot water cylinders from a header tank	Mains pressure hot water is quieter	
Printer	Consider timings of use. Agree times and stick to this.	
Ticking clocks	Replace with clocks that don't tick.	
Noise from staff if present (including if waking night, sleep in, supporting, office space)	Do staff need to be in the person's space? Could assistive technology be used to support from a distance? Ensure they are aware of and minimise noise including TV, radio, typing, voices, keys jangling, radio	

	transmitter chatter, footsteps – particularly at night.	
Other residents or neighbours	This is often unpredictable, can't be controlled and can cause distress. Attached or shared properties won't be suitable for everyone.	
Wall and ceiling angles	Flat and straight walls are often preferred. Good lighting, sound absorbing panels and carpet can all help reduce the echo and improve orientation.	
Fire and other alarms (including testing)	Make the person aware that fire alarms is expected. Some people find noise less distressing if they can control when it goes off – can they run the test?	
Alarms from electrical appliances eg dishwasher, washing machine	Turn off where safe to do so.	
Noise of doors opening and closing (including kitchen cupboards)	Use of Velcro pads, door silencers, or kitchen cabinet door buffers, door arms, turn off electronic sensors that beep.	

Doorbell or knocking	A choice can be helpful. Clear instruction can direct people towards the resident's preference. A video bell is helpful for some people.	
Metal curtain rails	Wooden curtain rails are quieter.	
Add your own		

Smell and taste

As this document focuses on the sensory environment, we haven't given detail about taste. However, we recognise that this is an important sensory consideration for some people.

It's not possible to 'turn off' this sense (as you could close your eyes).

Challenging sensory stimuli	Suggested alternatives	Comment
Outside smells	This can be very difficult to control, so may be an important consideration when choosing location.	
Paint smells	Use low odour paint. Consider timing of use.	
Cleaning products – including air freshener, toilet cistern blocks, bleach, surface wipes, floor cleaner.	Use unscented. Involve the person in choosing the product where possible. Consistency may help. Many eco products are less smelly.	
Laundry powder and conditioners	This is often scented, though some unscented varieties are available. Choice and consistency may help. Involve the person in choosing the product where possible. Limit changes to products used.	
Washed clothing often smells stronger wet than when dry	Where will clothing be dried? Is there a separate area? Avoid drying clothes	

	in bedrooms, and where possible also avoid drying clothes in living areas.	
Household smells Consider how smells can be contained if areas are not separated.	Shut doors between rooms to limit smells drifting.	
People smells	Limit use of perfumes and aftershave. Consider personal smells including smoke	
Dining room / eating locations	Many autistic people prefer to eat alone. Are there choices for where to eat? Could there be?	
Add your own		

Touch

Challenging sensory stimuli	Suggested alternative	Comment
Carpets and rugs	Change or remove these if needed. Try swapping for calmer colours and different textures.	
Bedding – including low quality materials that can be 'scratchy'	Choice of bedding. Soft, quiet materials. Many people feel more comfortable with 100% cotton and a high thread count.	
Mattresses and pillows	Choice of pillows – including soft, quiet pillows. Avoid using plastic mattresses wherever possible – could a mattress protector work instead?	
Metal door handles (can shock with unexpected coldness)	Alternative materials including wood and plastic can be more predictable	
Shower or bath	A choice is helpful.	
Bathroom temperature	A predictable and consistent temperature can be helpful.	
Clothing	The material, style, fit and texture can all be important depending on personal preference and need.	

Leather or imitation leather (plastic) furniture	Both can be noisy and cold to touch. Fabric alternatives or a soft throw can improve this.	
Unsupportive furniture	Supportive furniture – OT input may be helpful.	
Add your own		

Other considerations

Challenging sensory stimuli	Suggested alternative	Comment
Shared living areas	living independently, private spaces.	
	Explicit agreement about	
	expectations in shared spaces.	
	Access to private spaces at any time.	
Open plan living and undefined areas	Defined areas for different purposes	
	and times of day.	
	Option to close doors between	
	different areas.	
	different dieds.	
No outside space	Access to outside space (preferably a	
	private garden but may also be a	
	nearby park, countryside or beach).	
No pets	Choice and control to have pets	
	where safe.	
No security, lots of passing people	Security – a front desk, reception	
	area or key carded doors.	
Changes to support team	Consistent and predictable support	
Changes to support team	team.	
Restricted access to items that	Access to items that support self-	
support self-management,	management, including noise	
discouragement from stimming		

	cancelling headphones, weighted blankets, fidget toys, sunglasses etc.	
Add your own		

Our approach

This paper was inspired by the needs identified by NDTi's Autism Team – Richard Maguire, Ann Memmott and Chris Memmott.

The team have been supporting sensory environment assessments of mental health hospitals. They also work as Experts by Experience in Care Education and Treatment Reviews. As part of this work, the team reported that sensory needs are rarely understood, and very rarely accommodated.

We wondered if the high number of admissions that we continue to see for autistic people (see Transforming Care stats on page 8) might be reduced if people lived in good sensory environments and realised that there is very little information available to support people to understand sensory needs in housing.

The content for the paper was coordinated by Jill Corbyn, Autism Development Lead at NDTI. Chris Memmott and Ann Memmott advised on content, approach, and involvement. Chris and Ann worked to ensure that:

- We asked the right things
- We asked in the right way
- We had the right support in place
 Over the three-week engagement period, a qualified psychologist with
 experience of working with autistic people was available for contributors
 to get support if needed.
- We share control and ownership of content with contributors, giving people final sign off so they can be confident that they are contributing to a paper that is positive about autistic people and accurately and fairly represents views that have been shared.
- We offer a range of ways that people can choose to contribute valuing different communication systems.
 People were invited to respond to questions in writing, verbally, by video, using photos, with drawings or in any communication system they chose.
- People are paid fairly for their time and contributions.

When we had written the content, we identified autistic artists to contribute to the paper. We were keen to use the opportunity to showcase autistic talent.



10 STEPS to creating a neurodiverse inclusive environment

Developed by the University of Bath, Centre for Applied Autism Research (CAAR)

Workplace adjustments (or 'reasonable adjustments') are adaptations or accommodations that are made to the workplace that enable a diverse range of people to work successfully. Workplace adjustments can focus on adapting the environment to ensure it is accessible and can also focus on supporting the individual. Whatever the focus, considering workplace adjustments with the individual is essential.

A. ADAPTING THE ENVIRONMENT

1. The sensory environment

Does the individual have a place to work where they feel comfortable? Are the ambient sounds, smells, and visuals tolerable? Is the lighting suitable? What about uncomfortable tactile stimuli? Has room layout been considered? Can ear defenders, computer screen filters or room dividers be used to create a more comfortable work environment? Do people working with them have information about what might be a problem – e.g. strong perfume – and do they understand why this matters?

2. The timely environment

Has appropriate time been allowed for tasks? Allowing time to reflect upon tasks and address them accordingly will maximise success. Are time scales realistic? Have they been discussed? Are there explicit procedures if tasks are finished early or require additional time? Are requests to do things quickly kept to a minimum with the option to opt out of having to respond rapidly?

3. The explicit environment

Is everything required made explicit? Are some tasks based upon implicit understanding which draw upon social norms or typical expectations? Is it clear which tasks should be prioritised over others? Avoid being patronising but checking that everything has been made explicit will reduce confusion later. Is there an explicit procedure for asking questions should they arise (e.g. a named person (a mentor) to ask in the first instance)?

4. The predictable environment

How predictable is the environment? Is it possible to maximise predictability? Uncertainty can be anxiety provoking and a predictable environment can help in reducing this and enable greater task focus. Can regular meetings be set up? Is it possible that meetings may have to be cancelled in the future? Are procedures clear for when expected events (such as meetings) are cancelled,

with a rationale for any alterations? Can resources and materials be sent in advance?

5. The social environment

Does the workplace have social occasions and is the individual keen / reluctant to participate? Are there essential social occasions? Can group activities be adjusted to enable the staff member / student to take part – e.g. issuing a clear invitation to a specific, time-bound event. Do staff in the workplace recognise that a reluctance to engage socially does not imply dislike or rudeness? Would the person benefit from having a traffic-light system (e.g. green, yellow or red post-it notes) to signal their willingness to interact and / or current stress level?

By thinking of 'Workplace Adjustment STEPS', you can consider the extent to which the environment is Sensory, Timely, Explicit, Predictable, and Social. Supporting the individual is on the next page.

B. SUPPORTING THE INDIVIDUAL

6. Disclosing diagnosis

Is the individual willing to disclose their diagnosis to colleagues, and if so, how would they like to manage this? Would people who work with the individual benefit from training, or an opportunity to ask questions? If so, can a trusted, independent person be brought in to orchestrate an open and friendly discussion? If the individual does disclose to their colleagues, are they also willing for those colleagues to share the information more widely, or is this privileged information? Using autism as an example, - if and when autism comes up in conversation, what language does the person prefer? (e.g., autistic person, Aspie, autistic, person with autism).

7. Project management

Does the person experience difficulties with planning, flexibility, sustained attention or inertia? What exacerbates these difficulties and how can they be minimised? Are there digital tools (e.g. time management apps, shared calendars) which can provide extra structure to the project? Is the individual's preferred planning system non-linear (e.g. mind maps, sketch notes) or linear (e.g. gantt chart, "to do" list) and can this be accommodated? Does the person prefer to be immersed in a specific topic or task, or to have a selection of different tasks / intermediate deadlines – and can this preference be built into the project work plan?

8. Communication styles

Does the person prefer literal, specific language? And if so, can their line manager / supervisor and colleagues be reminded to use this? Does the person prefer written communication, or face-to- face? Is Skype easier than a phone



call? Should colleagues be reminded to explain why they are offering a particular comment or piece of advice, as well as offering the comment? Does their line manager / supervisor / colleagues cultivate an atmosphere that enables them to ask for help if needed?

9. Well-being and work-life balance

Is the individual sleeping and eating well? Are meetings scheduled at times that suit their personal routine? Can they work from home or have more flexible working hours and breaks? Is the person known to relevant services including disability support or HR? Are they registered with a GP? Do they require disability leave to receive treatment or therapeutic support? Do they need support or advice from external services like Access to Work?

10. Trouble-shooting

Have you talked to the individual to discuss what is working well and what isn't? Are there coping strategies that they use in other settings that could be used or adapted here? Could tasks falling within the job role or course be altered? Or could work be shared between workers so each can play to their strengths? Work together to come up with new solutions to difficulties that haven't been solved, and address new difficulties should they arise.

These STEPS were based upon and adapted from the work of the Centre for Applied Autism Research (go.bath.ac.uk/caar), and Natalie Jenkins + Sue Fletcher-Watson (http://dart.ed.ac.uk/supportingautistic-people-in-he/).

Any comments/feedback? Please email CAAR@Bath.ac.uk

Links, references and further reading

Beardon, L., (2017). Autism and asperger syndrome in adults. Sheldon Press

Beardon, L., (2020). Avoiding anxiety in Autistic Children: a guide for autistic wellbeing. Sheldon Press

Bogdashina, O., (2016). Sensory Perceptual issues in autism and asperger's syndrome. Different sensory experiences – different perceptual worlds. Jessika Kingsley publishers

Bottema-Beutel, K., Kapp, S. K., Lester, J.N., Sasson, N.J. and Hand, B.N. (2020). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood* [online] 1-12. [Viewed 18th November 2020]. Available from: https://www.liebertpub.com/doi/pdf/10.1089/aut.2020.0014

British Institute of Human Rights., (2016). Learning Disability and Human Rights: A practitioner's guide [online]. The British Institute of Human Rights. Available from:

https://www.bihr.org.uk/Handlers/Download.ashx?IDMF=7a174e6e-f594-4fc0-a4bc-53ba5d1cfe0f (BIHR doc for people with a learning disability, but may also apply to some autistic people in supported environments)

Caldwell, P., (2013). The Anger Box: Sensory turmoil and pain in autism. Pavilion

Casanova, E., L., Baeza-Velasco, C., Buchanance, C., B. and Casanova, M., F. (2020). The Relationship between Autism and Ehlers-Danlos Syndromes/Hypermobility Spectrum Disorders. *Journal of Personalized Medicine* [online]. 10 (4), 260. [Viewed 3rd December 2020]. Available from: https://www.mdpi.com/2075-4426/10/4/260/htm

Centres for Disease Control and Prevention., (2019). Autism Spectrum Disorder (ASD) Diagnostic Criteria. [Viewed 18th November 2020] https://www.cdc.gov/ncbddd/autism/hcp-dsm.html

Davies, W.J., (2019). Autistic Listening, *University of Salford Manchester* [online]. Available from

https://usir.salford.ac.uk/id/eprint/56380/1/Davies Autistic Listening paper 201 9 v4.pdf

Department of Health, 2012. Transforming care: A national response to Winterbourne View Hospital [online]. Available from

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/a ttachment data/file/213215/final-report.pdf transforming care 2012

Grandin, T. and Panek. R., (2014). The autistic brain: exploring the strength of a different kind of mind. Rider Books

Great Britain. NHS. (2020). Mental Health Services Monthly Statistics Performance July, Provisional August 2020. NHS. Available from: https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-services-monthly-statistics

Jiron, M., (2012). Sensory Overload (Interacting with Autism Project [online]. Vimeo. Available from: https://vimeo.com/52193530

Kenny, L., Hattersley, C., Moline, B., Buckley, C., Povey, C. and Pellicano, E. (2015). Which terms should be used to describe autism? Perspective from the UK autism community. **Autism** [online]. 1-20. [Viewed 18th November 2020]. Available at: https://altogetherautism.org.nz/wp-content/uploads/2015/10/2015-Kenny-terms-to-describe-autism.pdf

Kranowitz, C.S., (2016). The Out-of-sync Child grows up. Coping with sensory processing disorder in the adolescent and young adult years. Tarcher Pedigree

Mahler, K., (2017). Interoception the eighth sensing system: practical solutions for improving self-regulation, self-awareness and social understanding. AAPC publishing

Milton (2020). Neurodiversity past and present - an introduction to the Neurodiversity Reader. In Milton, D. Ridout, S., Murray, D., Martin, N., Mills, R. (eds.) Neurodiversity Reader, Hove: Pavilion Publishing: 3-6

Memmott, A., (2016). Autism and Lighting in Buildings. **Ann Autism Blog.** [online]. Available from https://annsautism.blogspot.com/2016/09/autism-and-lighting-in-buildings.html

National Collaborating Centre for Mental Health Commissioned by the National Institute for Health and Clinical Excellence., (2012). Autism Recognition, referral, diagnosis and management of adults on the autism spectrum [online]. National Institute for Health and Clinical Excellence [Viewed 18th November 2020]. Available from

https://www.nice.org.uk/guidance/cg142/evidence/full-guideline-pdf-186587677

NHS (2019). The NHS Long Term Plan [online]. **NHS online**. Available from: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/

NHS (2020). Learning Disability and autism patient trends and change over time. [online] **NHS England**. [Viewed on 17th December 2020]. Available from https://www.england.nhs.uk/wp-content/uploads/2020/12/learning-disability-and-autism-patient-trends-and-change-over-time-sept-2020.pdf

Office of the United Nations High Commissioner for Human Rights. (2014). **The Right to Adequate Housing** [online]. UN Habitat. [viewed 29th November 2020]. Available from

https://www.ohchr.org/Documents/Publications/FS21_rev_1_Housing_en.pdf

Pavlopoulou, G. (2020). A Good Night's Sleep: Learning about sleep from autistic adolescents' personal accounts. *Frontiers in Psychology.* December 2020

Public Health England (2018). Improving health and care through the home: a national memorandum of understanding [online]. Public Health England website. [viewed 9th November 2020] Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/atachment data/file/691239/Health Housing MoU 18.pdf

Simpson, S. (2016). Checklist for Autism-Friendly Environments. **National Institute for Health and Care Excellence** [online]. Available at: https://positiveaboutautism.co.uk/uploads/9/7/4/5/97454370/checklist for autism-friendly environments -september 2016.pdf

Triple A's Aberdeen. Guidance for Teachers Transitioning Autistic People. [online] **One Stop Shop Aberdeen**. [Viewed on 14th December 2020]. Available from: https://webspace.oss-aberdeen.co.uk/Guidance for Teachers2/

Williams, D., (1996). Autism – An Inside-Out Approach: An innovative look at the mechanisms of 'autism' and its developmental 'cousins', Jessica Kingsley Publishers

Williams, Z.J., He, J.L., Casico, C.J. and Woynaroski, T.G. (2020). A review of decreased sound tolerance in Autism: definitions, Phenomenology, and potential mechanisms. **ResearchGate** [online]

https://www.researchgate.net/profile/Zachary Williams19/publication/3460838 21 A Review of Decreased Sound Tolerance in Autism Definitions Phenome nology and Potential Mechanisms/links/5fba9503458515b79762657c/A-Review-of-Decreased-Sound-Tolerance-in-Autism-Definitions-Phenomenology-and-Potential-Mechanisms.pdf?origin=publication_detail