"It's Not Rocket Science"

Considering and meeting the sensory needs of autistic children and young people in CAMHS inpatient services

National Development Team for Inclusion

This report was commissioned by National Quality Improvement Taskforce for children and young people's mental health inpatient services

In autumn 2019, a National Quality Improvement Taskforce was established to improve current specialist children and young people's inpatient mental health, autism and learning disability services in England.

The goal of the Taskforce is to make rapid improvements in care across five key areas: people, care management, quality assurance, environment (including technology) and restrictive practices. This report was commissioned from NDTi by the Taskforce in support of its work on inpatient environments.

www.ndti.org.uk

Cover artwork "A Functional Space" by Tomos Percy

Contents

Contributors

Contributors are aged between 16-25 and have experience of being in hospital on a CAMHS ward. Some people wanted to be identified by their first and last name and other people preferred to use their twitter tag, first name only or to use a pseudonym.

@AutisticPB
@AutisticPB's interests are SEND, OCD and autism research. They are an autism advocate and mental health activist.

Beth Gee
Beth enjoys writing poetry. She studies psychology and education.

Beth Watkins
Beth is an autistic activist who is very passionate about raising awareness of mental health and acceptance of autism within society. She is an expert by experience in the Hertfordshire CAMHS young people's council and is also a young commissioner for Hertfordshire County Council.

Bethany and Jeremy
Bethany is an amazing 20-year-old autistic woman who loves life. Her experiences of secure inpatient services highlighted the lack of support for her sensory needs and led to her experiencing ever increasing restrictive practices including seclusion and restraint. Her father Jeremy fought to get her needs properly assessed and understood. She now enjoys going for walks, caring for her pets and experimenting with new hairstyles and clothes.

Jeremy co-chairs the Parent Council of NHSE's Quality Improvement Taskforce for Children and Young People with Autism, Learning Disabilities and Mental Health, and has a variety of other roles with the NHS, CQC and DHSC challenging poor practice. You can find out more about Beth's journey on Twitter @JeremyH09406697

Caitlin Hire
Caitlin is an autism and mental health advocate. She is passionate about sharing her experience to support positive change. Caitlin has a number of wonderful pets, including hedgehogs, lizards and dogs.

Charli Clement
Charli is an autistic, dyspraxic and chronically ill activist who discusses her disabilities alongside mental health, asexuality, politics and education. She

works as an Expert by Experience for the NHS in the West Midlands as well as being a Politics & International Relations student.

Emily
Emily (@ItsEmilyKaty) is a 19-year-old autistic student, mental health activist and autism advocate. She is a member of Hertfordshire CAMHS Young People's Council, a Public Governor for HPFT, and a Trustee for the Autistic Girl's Network (@autisticgirls_).

Jamie
Jamie was sectioned in hospital for over 5 years and is now on a mission to make a difference and try to combat stigma that surrounds mental health and autism. He has produced various videos to help do this too. Jamie is currently also volunteering for the NHS as a steward at vaccination sites across the Southwest of England.

Rebecca
Rebecca is a 17-year-old young woman who was recently diagnosed with autism during a six-month hospitalisation for anorexia nervosa. She attends her school sixth form where she is studying for three A Levels and she particularly enjoys mathematics and politics. During her spare time, she plays the recorder and clarinet and enjoys drawing, reading and yoga.

Additional Contributors

Additional contributors fall outside the 16-25 age range, might not be autistic and/or don't have experience of CAMHS inpatient hospitals. They have all added valuable support and information to the report.

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Angela Watson, Principal Speech and Language Therapist, Inpatient CAMHS/Deputy SLT Manager at Parkview Clinic, Birmingham Women's & Children's NHS Foundation Trust. She shares a working good practice example of changes that have been made at Parkview.

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

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.

Rachel Winder
Rachel is a 42-year-old Autistic ADHD'r and full-time mother of two charismatic boys aged 3 and 7. The oldest child is also an Autistic ADHD'r. Rachel loves singing, signing and making TikTok content to increase the visibility and acceptance of the Autistic community under the name, @rachelosaurus.

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.

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Yasmin is the National Programme Lead for Learning Disability and Autism; Specialised Commissioning - NHS England and NHS Improvement. Yasmin worked with Bethany and Jeremy in her previous role with Midlands Specialised Commissioning and has been an early supporter of NDTi's autistic led reviews of sensory environments.

Writers and editors

Ann Memmott
Ann is an experienced autism trainer, advisor and mentor. Ann is passionate about improving lives and services for autistic people. Follow on twitter @AnnMemmott

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Jill supported the development of the autism team at NDTi, delivering sensory environment checks in hospitals, advisory work for autistic people and peer support for autistic people and their families. During the writing of this report, she received an autism diagnosis.

Kirsten Newton
Kirsten is an autistic advocate with experience of being an inpatient in a number of CAMHS units. She is keen to use her experience to increase awareness of the impact that sensory environments have on autistic people, and to support positive change. She currently doing A-Levels in chemistry, biology and psychology and plans to work in medicine.

Illustrators and artists

Sam Chown-Ahern
Sam Ahern is a visual artist. Her work has been shown online with the Barbican Young Visual Arts Group, at the Camden Arts Centre, Red Gallery (Shoreditch) and other venues. In 2018, Sam was one of the co-presenters alongside Georgia Harper and Anna Richardson of Channel 4's 'Are You Autistic?' She studied at Wimbledon College of Arts and lives and works in London.

Sam created the artwork in the main body of the report.

Tomos Percy
Tomos is 17 years old who was adopted by his family as a baby. He was diagnosed with ADHD at 7 and with autism at 9. Before his diagnosis he was excluded from my mainstream school and spent 4 years in a Pupil Referral Unit (PRU). Tomos understands that his autism diagnosis took so long to get because CAMHS assumed that his difficulties were all adoption/ trauma/ attachment related … they weren't and aren't. Tomos spent 10 years in special education before he returned to mainstream 6th form last year. He is studying art and maths.

Thanks

Dr Ruth Moyse and the girls and families who supported her work
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.

Ruth worked with autistic girls and their families, including Daisy*, whose quote is referenced in the title of this report.

*Pseudonym

Hearts and Minds
Hearts and Minds are a peer led charity and service for young people experiencing mental health difficulties. Thanks to Hearts and Minds for supporting us to hear from people https://heartsandminds.org.uk/

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.

Peter Flanagan
Peter is an Operational lead on the National CAMHS taskforce. He saw the value in the work of the writing team and experiences of autistic people who have been in hospital and supported this paper with interest and enthusiasm from our first meeting.

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 107 and appendix).

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Content warning: This report contains reference to hospitalisation, seclusion and segregation, restraint, sensory sensitivity, self-harm and suicide, and autistic voices not being heard.

Top ten recommendations

This report makes numerous recommendations to suggest how inpatient CAMHS sensory environments can be improved. We encourage everyone to read the full report and to apply as many as possible. Some are significant changes, but many are small things that will make a big difference. They are all listed at the back of the report. The ten recommendations identified on this page are at the top of the wish list.

These recommendations have been 'picked up' and 'built on' by the National Autism team at NHSEI. They are now the foundation of Sensory Friendly Wards.

1. Create a predictable environment. Let people know what to expect, who to expect and when. Offer accurate and timely information to create more certainty and support a feeling of safety.

2. Involve autistic people with relevant expertise in reviewing the sensory environment, in a meaningful way. Every location is different and will have different things that need to be prioritised. Autistic people have different sensory perceptions, so it's critical to involve people. Listen and take action. Continue to review. It can be beneficial to bring in external expertise, but it's also important to involve people using the space. Ask them what's working and what needs to change.

3. Ensure all staff have training from autistic experts and allies that understand autism and sensory needs. All staff includes the MDT, healthcare staff, the ward team, facilities staff, educators, cooks, cleaners, and agency staff. Each of these roles impacts on an autistic person's experience.

4. Assess everyone's sensory need on admission and consider how sensory need will be accommodated and supported in care plans. Support people to reduce problematic sensory inputs and manage these to support restraint reduction. As part of care planning, support people to do the things that help them to self-regulate, including repeated movement ("stimming"), access to hobbies and favourite possessions, quiet spaces, outdoor space, and access items such as noise cancelling headphones, caps, blankets etc.

5. Personalise risk management and decision making. Support people to have choice and control. Make decisions in relation to individuals, involving the person (and their family, as appropriate) wherever possible. Avoid blanket bans (decisions or bans that affect everyone, rather than being decided on an individual basis).

6. Swap alarms for 'silent' alarms. This will significantly reduce noise and escalation on the ward and reduce the frequency of distress caused by alarms for those with auditory sensitivity. Staff need to be alerted – silent alarms will support this to happen without causing distress to other people.

7. Reduce noise and echo. Ensure there is quiet space and outdoor space that people can access at any time. Soft furnishings, gently closing doors, carpet, sound absorbing panels and acoustic vinyl can all help. Consider background noise too (including roads, heating and cooling systems, extractor fans, voices, keys, TVs/radio etc). Ensure there is an actually quiet space and outdoor spaces people can access at any time.

8. Consider the impact of lighting and support user control. Hypersensitivity to lighting can be painful. High quality bulbs and component parts can reduce potential flicker and noise (which can be more likely if lights are dimmable). Ensure that lights can be turned off easily, that low level lighting is available, and that lights are warm yellow and diffused (shaded).

9. Consider the impact of smells. This includes smells from people, food, cleaning products, and laundry products. Neutralise smells wherever possible (closing doors, using unscented products, supporting people to 'mask' smells with preferred scents, or to use preferred products).

10. Consider the impact of touch and texture. Hypo and hyper sensitivities might mean that people may be more, or less, sensitive to physical contact. This needs consideration in relation to potential physical restraint (best avoided), food, shower / bath / personal care and textures of materials including bedding, furniture, clothes and towels.

Rating Factory by Tomos Percy

Introduction

> "Small changes that can easily be made to accommodate autism really do add up and can transform a young person's experience of being in hospital. It really can make all the difference."
> Beth W

This report is informed by autistic experience and by what autism 'feels like from the inside' and is based on the experiences of children and young people who have experienced Child and Adolescent Mental Health Services (CAMHS) inpatient environments.

> "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)

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 in a Child and Adolescent Mental Health Service (CAMHS) inpatient environment.

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'.

> "Staff need more education ... on autism, including education about how autistic girls can present less stereotypically, and their needs are often shrugged off because they don't 'appear' autistic. Being overwhelmed from being on the unit exacerbated my mental state and mental distress so I was probably there for longer than I would have been there otherwise."
> Emily

The term autism was first used by Sukhareva in 1925 (Zeldovich 2018), and later by Kanner in 1943. It 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.

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 is an excellent book and highly recommended reading.)

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 inpatient services. Some of the 'background' information text is shared with another report – 'Appropriate Environments for Autistic People: Considering and Meeting Sensory Need in Housing' – but all of the comments in this report are from young people and relate to inpatient services. The recommendations and detail of the report is tailored to these environments.

Not only is it good practice to make accommodations that will support positive outcomes for autistic people, but it is also a legal requirement under the Equality Act 2010. All healthcare providers have a duty to make reasonable adjustments, including adjustments to the environment.

Hospitals are difficult places for lots of people, and can be particularly harmful for autistic people, with additional sensory sensitivity and misunderstanding of autistic communication and culture. It's unlikely that autistic people will thrive in hospital – but the recommendations in this report will help people to better tolerate the challenging environment.

The CQC report into restraint, seclusion and segregation (2020:12) found that 'people were not having their needs met. Environments they were living in were not adapted to their sensory needs and they were not being offered support to communicate. Some providers were not making reasonable adjustments legally required under the Equality Act 2010.'

> " Inpatient environments are not right for most people – but it's especially bad if you're autistic."
> Charli

The CQC report goes on to say 'Being placed in an inappropriate environment can be damaging and creates a pattern of distress, restraint and seclusion, which often cannot be broken. In many cases, we found that the impact of the environment on people, such as the noise, heating and lights of the wards, had not been considered. In many cases staff did not understand people's individual needs and the distress that being in the wrong environment could cause, particularly for people with sensory needs. This could lead to people expressing their distress in a way that others find challenging, leading to staff resorting to using restrictive practices.' (CQC 2020:13)

Recommendations included in this report will support providers in anticipating reasonable adjustments that may be required. They are highlighted throughout the report and summarised at the end. We believe that understanding and meeting sensory need will reduce distress caused and reduce the use of restrictive practices. It will support providers to ‘advance equality’ for people they are serving. This report focuses on recommendations that will neutralise the sensory environment. Some people are sensory seeking and will benefit from more sensory input. It is as necessary as ever to tailor support and personal spaces to meet individual need.

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.

> “Some autistic people’s needs will conflict with each other. For example, some autistic people may need the TV playing to calm down, as it can help to focus on specific sounds. But for others this may cause more stress depending on their mental state. Additionally, some autistic people may need to stim to feel relaxed and comfortable, or it may be involuntary when they are stressed, but noises they make (e.g. verbal stims), could really stress another autistic person out. I think the key here is space.”
> Emily

The report set out with the focus to look at physical and built environments and to identify practical changes that could be recommended. However, the scope has expanded to include culture and approach. This is because the people we spoke to told us that other people are the most unpredictable elements in any environment. Where other people are warm, receptive, reflective, and seeking to work with and understand, the overall sensory environment is much more tolerable. The young people we spoke to told us that staff understanding, attitude and approach is the most important factor in getting CAMHS inpatient sensory environments right. A positive culture will help make a poor environment manageable, and a negative culture will make a good environment unmanageable.

The report has also expanded to include a chapter on community and crisis support, as improvements here could support admission avoidance. As the National Institute for Health Research (NIHR) literature review into the experience of children and young people cared for in mental health, learning disability and autism inpatient settings notes, the experience of inpatient care extends to the activities around it, including pre-admission and discharge arrangements. The clinical example later in this report shares examples of how practice can be changed to better support this.

Buildings need 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 condition.

At the end of the report, we include a recommendations 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, audible or otherwise detectable to their neurotypical counterparts. We strongly encourage this wherever possible.

Summary: Introduction

At the end of every section we include a summary of the main points.

This report is based in autistic experience and what autism 'feels like from the inside'. We spoke to autistic young people who have had experience of Child and Adolescent Mental Health Services (CAMHS) inpatient environments.

Autism is viewed as a sensory processing difference, and healthcare providers have a legal duty to adjust the environment to accommodate autistic people.

This report makes recommendations for changes that providers of CAMHS inpatient services can make to improve the sensory environment.

As well as talking about changes to buildings, autistic young people we spoke to told us that staff approach is important. We listened to them and included information about this in the report too.

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 2021).

> "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.

The term 'neurodiversity' originated in 1998 and was coined by Judy Singer. Milton (2020) identifies that it 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 refer to autism as a sensory processing difference rather than deficiency, dysfunction, or disorder. The exception to this is in a contribution from a clinician (pages 61-66) who determined that descriptions of clinical services should not be altered. This service is making a significant positive contribution and supports an understanding of how sensory needs are being considered in practice.

Language influences how people understand and are understood. We believe in a more positive and accurate description, one that values autistic experience and considers the strengths and benefits as well as the challenges that autistic people face. It moves 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; Gernsbacher 2017; Botha, Hanlon and Williams 2021; Bury, Jellett, Spoor and Hedley 2020).

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

We don't use functioning terms as we believe they are unhelpful and can be misunderstood. As Beardon (2020:11) states: 'to be told your child is 'high-functioning' might insinuate that she doesn't have any support issues at all; to be told your child is 'low-functioning' might be unjustified and unfair … the same person might function brilliantly in one environment and be completely 'at sea' in another'. Research by Alvares, Bebbington et al (2020) support this, finding 'that 'high functioning autism' is an inaccurate clinical descriptor when based solely on intelligence quotient demarcations and this term should be abandoned in research and clinical practice'.

Summary: A note on language

Language influences how people understand and are understood.

We use identity first language – autistic people, rather than people with autism.

We don't use functioning labels such as 'low functioning'.

There is one section, written by a clinician, on pages 61-66 that refers to ASD. We avoid this term in other parts of the paper, referring instead to autism and autistic people.

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.

> "One hospital I was in did a Sensory Integration Assessment. They SaLT (Speech and Language Therapist) explained things to me. She explained what was going on in my head. She was so amazing. It helped me to know how to look after myself."
> Caitlin

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.

Recommendation: The sharing of information with peers is something that services can support.

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 interoceptive systems. These are less well-known.

> "I believe that achieving the correct sensory environment is essential when trying to treat autistic people with mental health problems. When this is not addressed autistic people are less likely to respond or engage with treatment as they are preoccupied with sensory imperfections. Also,

> when the sensory environment is incorrect, this can exacerbate the mental illness symptoms either directly or indirectly when increased anxiety causes autistic rituals to become more severe."
> Rebecca

Roundabout theory

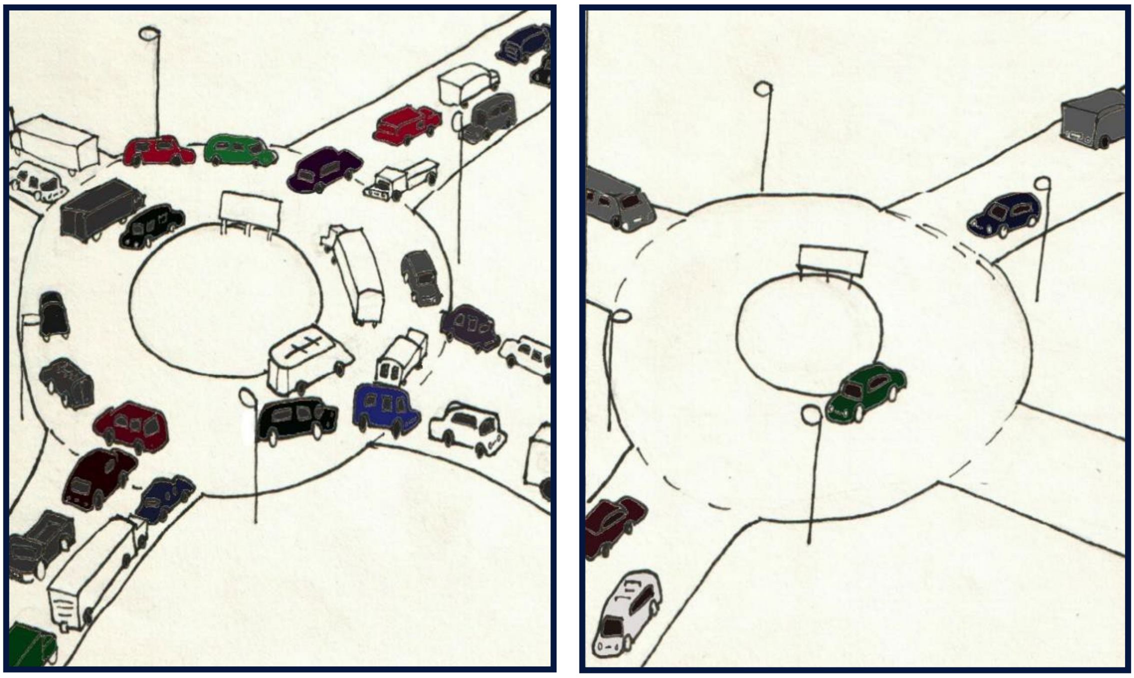
Although not all the external senses are equally affected by the physical environment, we consider them all – as they collectively add to the 'sensory load'. Any sensory input needs to be processed and can reduce the capacity to manage and process other things.

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.



Summary: Autism viewed as a sensory processing difference

We have five external senses: touch, sight, hearing, taste and smell.

We have three internal senses that give us information from inside our bodies.

Autism is viewed as a sensory processing difference. Information from all of the senses can become overwhelming and can take more time to process. This can cause meltdown or shutdown.

Neurotypical brains often divert information from the senses, so they don't have to process as much information.

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.

This report aims to provide insight to hospital teams supporting autistic people in Child and Adolescent Mental Health Service (CAMHS) in inpatient services. We expect that the content will be relevant and of use to other people too.

In October 2020, there were 1421 CAMHS beds nationally. 724 of these are on general adolescent units. In addition, there were 32 specialist learning disability beds on general adolescent units, 7 learning disability beds on low secure units, and 17 learning disability beds on medium secure units. There are currently no specialist CAMHS beds for autistic people.

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 the Transforming Care Programme in September 2020 are autistic. In October 2020 there were 1421 mental health beds for children and young people (not all of those young people are part of the 'Transforming Care' programme). Anecdotally, it is reported that 60-70% of young people admitted may be autistic, though many remain undiagnosed.

Recommendation: Screen all inpatients for sensory needs and autism, and assess those who pass a screening threshold.

	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%)

Adults in hospital, as part of Transforming Care

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

Children and young people in hospital, as part of Transforming Care

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. We have heard from the people who contributed to this paper that they would have been better able to engage in therapy and would have been ready for discharge sooner if the sensory environment had been better.

Since the emergence of the diagnostic criteria in the 1950s our understanding of autism has shifted dramatically. However, some areas of practice haven'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.

The next chapter about crisis support includes reference to how challenges and delays with diagnosis mean that some children and young people are not eligible for services and support that could have supported them to stay well and avoid hospital admission.

This paper aims to share information from a lived perspective to support improved understanding. 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 support for autistic children and young people in hospital, enabling a quicker return to their homes and communities.

> "To have my needs met as an autistic person would have transformed my experience in hospital. The sensory input added to my emotional dysregulation. I couldn't engage with all the therapy on offer because of the added distress. Small changes would have made a big difference."
> Emily

Summary: Building the right support

In October 2020, there were 1421 CAMHS beds nationally. There are no specialist autism CAMHS beds.

The number of people with a learning disability in mental health hospitals is falling. The number of autistic people in mental health hospitals is rising.

The young people who contributed to this report told us that they would have been better able to engage in therapy and would have been ready for discharge sooner if the sensory environment had been better.

Diagnosis and community and crisis support

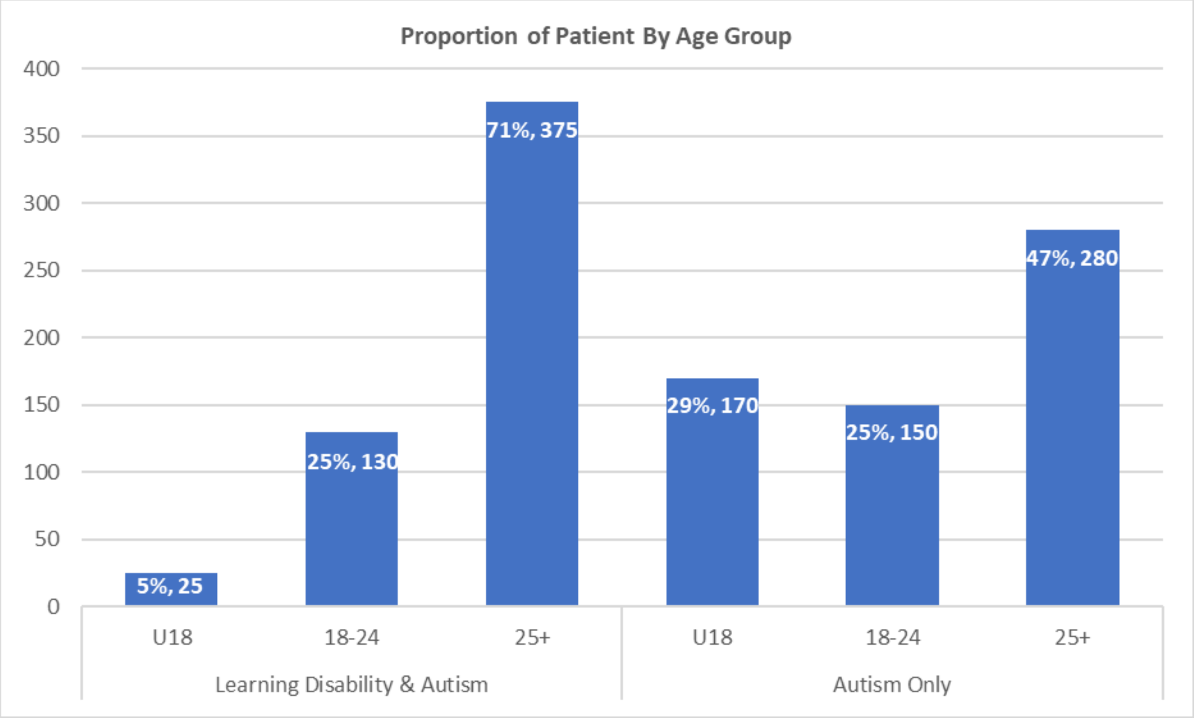
This chapter has recommendations that are applicable to those working with autistic children and young people in the community. This may include community teams, educators, and commissioners. Recommendations that are not targeted at inpatient providers are clearly marked. However, many of the education recommendations will also be of interest to educators working in CAMHS hospitals. Good support in all locations, joined up working and a consistent approach is important to ensuring good outcomes for individuals.

> 'People often ended up in hospital because they did not have the right support, early on, in the community at the time they and their families needed it. This was particularly the case for people we saw who were diagnosed as autistic.' CQC (2020:8)

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).

> "I was very lucky that when I was in hospital, I had a lot of therapeutic input. It was a good circuit breaker, but I shouldn't have been in that environment. Overall, the trauma from the inpatient stay wasn't worth it, even with the all the therapy I had."
> Charli

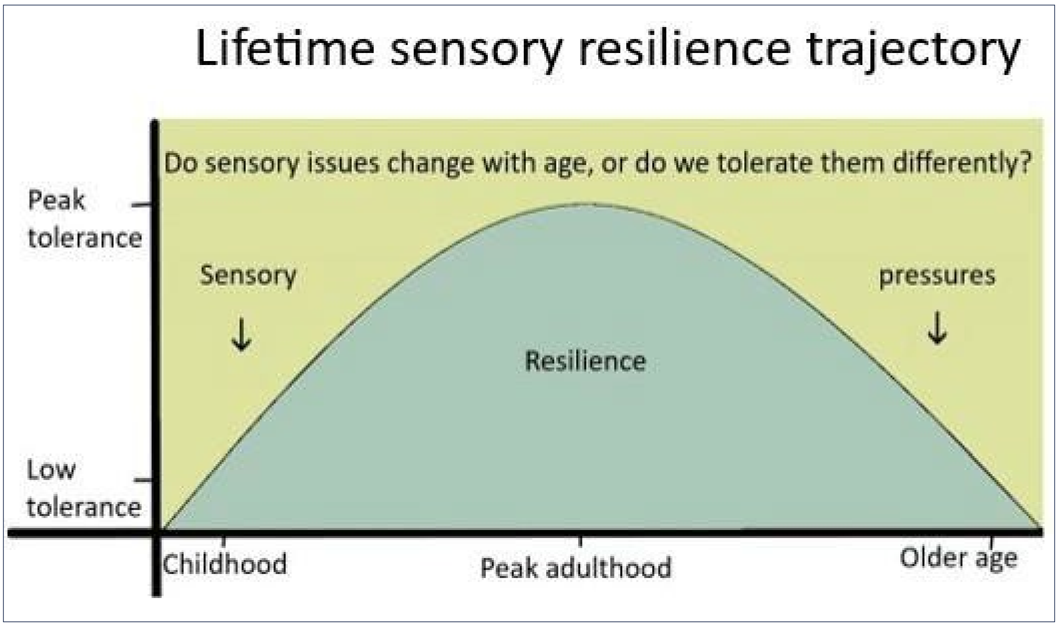
The graph below, with data from Assuring Transformation 2020, shows that 29% of autistic patients are under 18, and 54% are under 25.



Cos Michael (unpublished) theorises that autistic sensory tolerance changes with age, with most autistic people having low tolerance in childhood and in older age. Cos plots this in a bell curve (see below) and questions whether sensory issues change with age, or if people tolerate them differently. Reasons for low tolerance of sensory issues in childhood are likely to be due to inexperience and lack of learned responses. Therefore, they may include:

- Fight or flight response to sensory bombardment
- Lack of learned experience of sensory input
- Undeveloped resilience, due to childhood
- Lack of learned defences, due to childhood
- Limited autonomy over environmental choices

Cos elaborates that 'My theory is that all children respond as children, so the major difference is not autistic deficit, but a higher level of sensory pain, leading to a more extreme response, until age, experience and learned control / masking, kicks in. Which is why if you pinch a non-autistic child hard, they will react with pain. An autistic child is more likely to feel the same level of pain from a lesser pinch, as their sensory pain input is set at a lower threshold. As they grow older and gain life experience, all children learn to moderate their response – the key word is resilience, which is a learned response. Resilience is built during all childhood and diminishes in ageing in all people – irrespective of neurodivergence. The problem autistic people have is the difference in sensory input.'



The National CAMHS benchmarking report 19/20 indicates that:

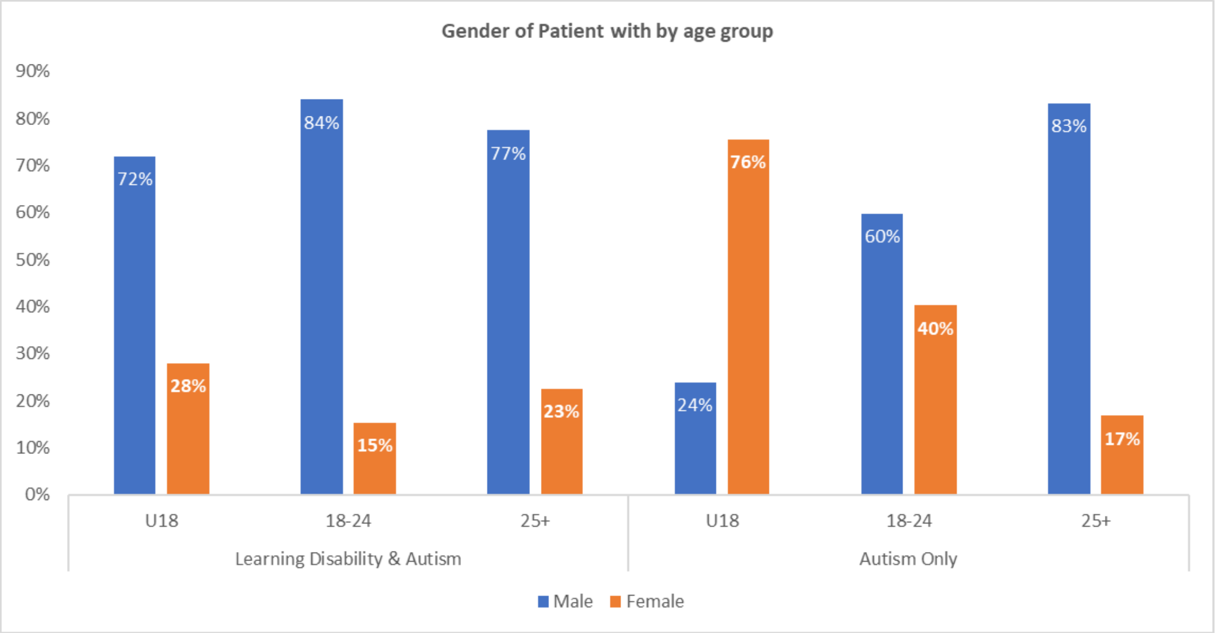
- The overall community CAMHS caseload is 54% male and 46% female
- The autism community caseloads are 70% male and 30% female
- All CAMHS admissions are 27% male and 72% female*

*Alternative data from CAMHS performance data identifies 69% of admissions as female, 24% as male and 7% as unknown or indeterminate.

George (2016:140) found that 33% of autistic people and born female did not identify with that gender, compared to 13% of neurotypical people; for those born male 22% of autistic people and 7% of neurotypical people did not identify with that gender.

Recommendation: Data collection and recording and services need to consider a range of gender identities for everyone, and particularly for the autistic population they support.

Graph below is informed from Assuring Transformation data September 2020 and are rounded to the nearest 5.



This data highlights the low numbers of autistic girls accessing community support and the much higher proportion of girls (including autistic girls – and particularly autistic girls under 18 year old) that are reaching crisis and requiring hospital admission. This suggests that more work is required to identify females in need of additional support earlier. The learning and recommendations in the following pages may be beneficial to community services seeking to change their approach and provide earlier support to autistic girls.

Recommendation for community colleagues: Different 'flags', or identifiers may be required to ensure that people who need support are not missed.

Recommendation for community colleagues: Community teams and schools may also benefit from training and development support to ensure that they understand how autistic girls might present.

Moyse (2021:8) found that autistic girls are usually referred for assessment later than boys and are diagnosed later than boys. They may be more likely to mask or camouflage difficulties and their difficulties may be underestimated or overlooked even with a diagnosis. In addition, autistic females without a learning disability are more likely than to experience mental health issues such as anxiety, self-harm, eating disorders, suicidal ideation and attempts at suicide (Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2018; Cassidy et al., 2014). The lack of early diagnosis and resulting supports may be a factor in this.

Cassidy, Bradley, Shaw et al's (2018) research with autistic adults found that 'there are unique factors associated with autism and autistic traits that increase risk of suicidality. Camouflaging and unmet support needs appear to be risk markers for suicidality unique to (autism). Non-suicidal self-injury, employment and mental health problems appear to be risk markers shared with the general population that are significantly more prevalent in the autistic community.'

Moyse's (2021:111) participatory study with ten autistic girls found that nine had clinical levels of anxiety, half were diagnosed with depression, two had developed an eating disorder (one requiring hospitalisation) and three had been hospitalised at least once due to self-harm, suicidal thoughts or attempts at suicide. Moyse reports that 'The proposition from seven of the eight participants [in life stories, was] that the decline in their mental health was correlated at least in part with their experiences in school, leading to their absence from it'.

This evidence suggests that early interventions and support in communities and schools is critical to ensuring that autistic children and young people do not reach crisis point. The recommendations and learning from this study can be applied to providing positive support in all environments - to those who are at risk of admission, in hospital or being discharged. Moyse's research recommends (abridged):

1. " Just listen. It's not rocket science, just listen" (Daisy).
   This research has shown that too often school provision was based on assumptions, contradictions, and stereotypical notions of autism. Engaging the girls in respectful dialogue, meanwhile, revealed simple explanations for their concerns and often equally simple adjustments and solutions... Evidence of pupil voice should be present in all school or medical records about a child from the first time concerns are raised, by a parent, professional or the young person (YP), partly because the law requires it, but also because it is an indicator of them being valued by teachers and clinicians as individuals with views and rights.

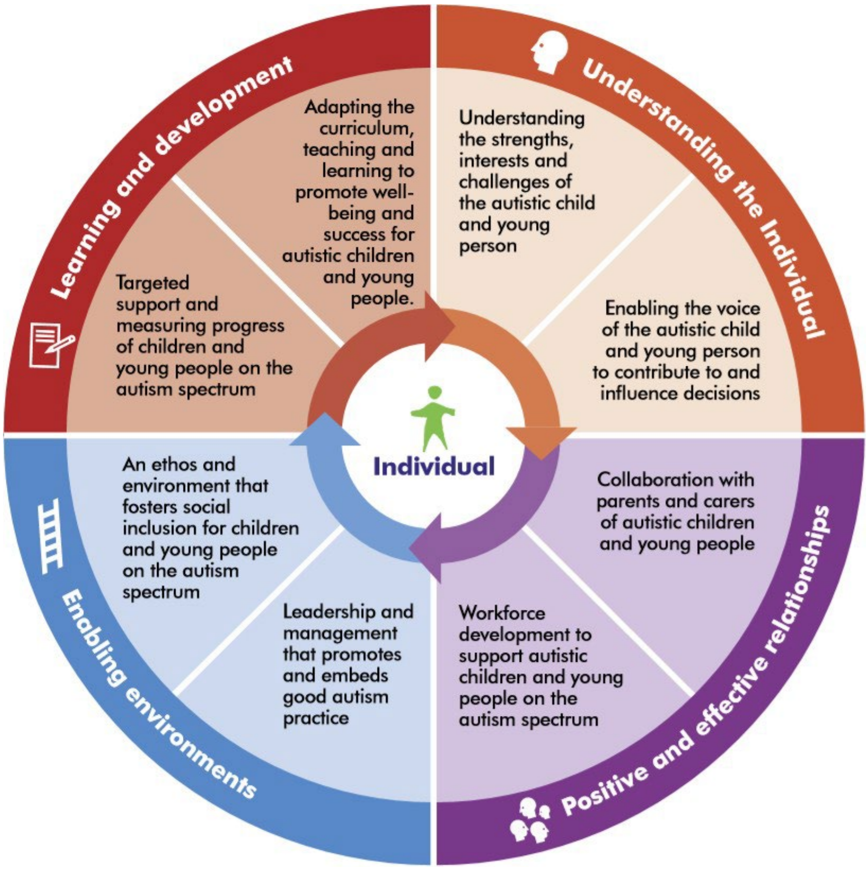
2. “Be curious” (Robyn).
   Given the propensity of many autistic CYP to mask and camouflage difficulties they encounter, and the evidence from this study that neither conduct nor achievement may be issues for autistic girls in school, seeking to understand why a YP is behaving in a particular way is important.

3. “Prioritise pupil wellbeing” (Erin)
   This research found that the girls in this study most wanted to attend a school that cared for their wellbeing more than the grades they may achieve. This is perhaps unsurprising given the impact of their negative school experiences on their mental health. Being happy and feeling accepted were not unreasonable wishes of the girls. Wanting to be taught, to feel safe and to have reduced sensory input from their environment are not unreasonable requests.

4. “Take action” (Jane)
   Whilst the girls in this study showed great perseverance and the ability to be creative and seek their own solutions, their lack of agency and absence of [appropriate] support meant resilience was challenging. Given this structure, it is essential that individual teachers lead change and act to resolve damaging situations, such as the extensive bullying identified by this research.

5. Be “more informed about being autistic, and what autism was” (Alex)
   It was apparent from the case studies and from the interviews that some school staff did not understand what it meant to be autistic. This contributed to autistic girls being referred for assessment later than necessary, and to a lack of suitable support for those with a diagnosis. Training is therefore a key recommendation… To avoid further assumptions and misunderstandings about the nature of autism, it is important that training is led by an autistic practitioner.

This image from the Autism Education Trust 'Good Autism Practice' report offers some good practice solutions that may be helpful to schools, and to commissioners and clinicians working with autistic children and young people. The recommendations align with those listed above. The full resource can be downloaded free of charge from https://www.autismeducationtrust.org.uk/



This animation tells Erin's story about her experience of school https://www.donaldsons.org.uk/walk-in-my-shoes/

Dynamic Support Registers (DSRs) are databases of autistic people and people with a learning disability or both who are at risk of inpatient admission. This register aims to guide commissioners and clinicians about the support that individuals might need to ensure they are able to remain at home, rather than be admitted to hospital.

Recommendation for community colleagues: The approach suggested by Moyse above could be applied in relation to everyone who is identified on the DSR.

> "I wasn't diagnosed before I was admitted to hospital, so I wouldn't have had a CETR (Care Education and Treatment Review). In an ideal world everyone who is at risk of admission would get a CETR. The independent panel really help people to think differently, and it's so

> important that the MDT (multidisciplinary team) meet. The different agencies coming together is so helpful. School would have said that I was doing well, and my schoolwork was fine, but the CAMHS team could see that I was in crisis. "
> Charli

In addition to barriers to diagnosis for autistic girls, in many areas waiting list for diagnosis and support are more than two years long. Anecdotal information from a hospital that screens all admissions suggests that 60% of children and young people admitted to hospital may be autistic. Several of the autistic young people who contributed to this report told us that they were not diagnosed until they were in hospital or in some cases, after discharge. This meant that they would not have been on the Dynamic Support Register and would not have been eligible for a Community Care Education and Treatment Review.

Recommendation for community colleagues: Every child and young person who is at risk of admission is added to DSR databases and has a community CETR, not just those with a confirmed diagnosis.

Recommendation for community colleagues: If it is not possible to extend this to every child and young person, it is extended to people who are waiting for a diagnosis and those who self-identify.

Some people told us that they attended Accident and Emergency centres in hospitals (A&E) in a crisis. This is often the place that people are taken when they are in crisis, as there are often no suitable alternatives – particularly out of hours.

> "A&E was just hell. I don't think I'll ever forget it. The alarms and noises were constant. The beeping was the overriding thing. I was meant to sleep. It was dark. I was in jeans and all I could think about was how they felt on me. I couldn't brush my teeth, which is a real sensory thing for me. It was skin crawling for me. It was just awful. I've not met one person that's had a good experience presenting at A&E with mental health issues. There needs to be an alternative."
> Charli

The CQC report reviewing Mental Health Services in Acute Trusts found that in emergency departments, patients were not always provided with a safe, therapeutic environment and that 'people in crisis were not given information about when they would be seen, or how long they would have to wait for an assessment or admission to hospital.' (CQC 2020:5) Both of these issues are likely to be challenging for anyone in mental health crisis but will add additional challenges for autistic people who may have sensory sensitivity and additional social and communication barriers.

Specific consideration is required to ensure that environments and services are appropriate to support autistic children and young people in crisis.

> "The community CAMHS team told me to go to A&E if it got bad. I waited for three hours in an awful sensory environment, then the A&E staff said I shouldn't have been told to go there and that they couldn't do anything. There really needs to be an out of hours CAMHS service where you can present."
> Charli

One person we spoke to was detained on a children's ward in a general hospital for a week. This was described as a particularly noisy environment with noise from other children and babies and noisy machines and nurse alarm calls.

Recommendation for community and acute service providers: Alternative, appropriate, timely, predictable support for autistic children and young people is provided in a location with a good sensory environment.

Recommendation for A&E departments: In locations where there are no alternatives to A&E, ensure that staff are aware that people are being signposted there, have good autism knowledge, and have appropriate sensory environments for those who are waiting and admitted.

Summary: Diagnosis and community and crisis support

People often end up in hospital because they don't have the right support in the community when they and their families need it.

Autistic girls are referred for diagnosis later than boys and are more likely to mask or camouflage their difficulties. They are less likely to get support in the community but proportionally, more likely to be admitted to hospital.

Early support in the community and in school is important to help people stay well and live good lives.

People who haven't been diagnosed might not be on Dynamic Support Registers and might not get a Care Education and Treatment Review. The 'eligibility' criteria could be relaxed to better support more people.

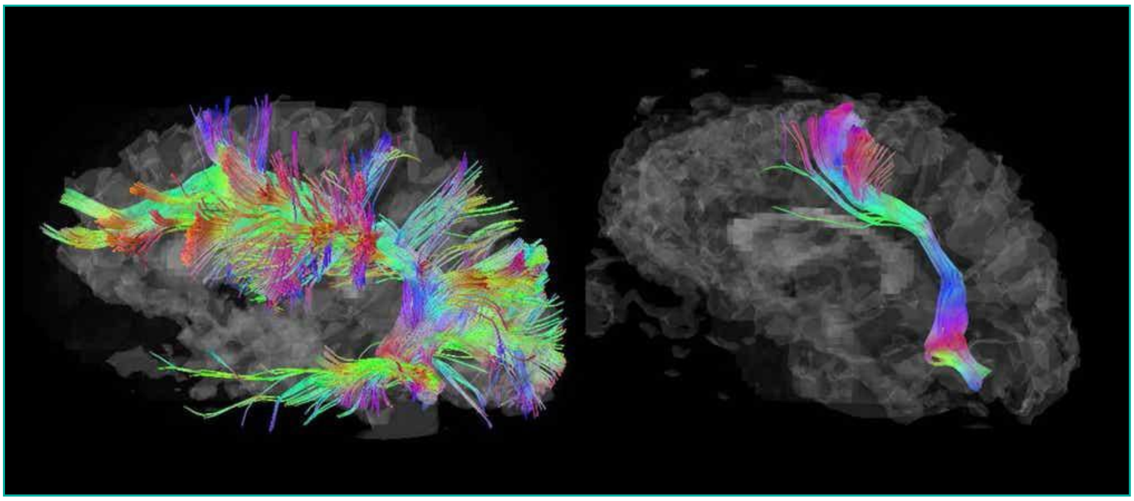
A&E isn't a good place for people to go in a crisis. Alternatives should be identified, and if this isn't possible then changes should be made to improve the environment and support people get there.

Shutdown, meltdown and restraint reduction

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.

> "Not responding to sensory needs is like not putting ramps in for someone in a wheelchair. When the environment and support is right the issues that come up are more likely to be mental health related – stuff that you're actually in hospital for."
> Caitlin

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 neurotypical person.



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. This is sometimes called situational mutism.

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. It can take significantly longer where conditions are not ideal, or where there are other factors that may exacerbate distress. The right support and a calm sensory environment can enable regulation and reduce the need for restraint or other interventions.

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

Physical intervention during this time may lead to flight or fight responses being activated. This, in turn, can lead to further expressions of distress and may escalate the situation. Giving people time, space and a reassuring presence is often the most helpful response.

> "Being threatened with restraint was difficult. I shouldn't have heard threats of a PICU referral or restraint by three male agency staff when I was already distressed."
> Beth G

The CQC report on restraint, seclusion and segregation provides an in-depth review of practices in hospitals and other settings. The report should be considered in full and includes the following:

- For 54% of the people reviewed in long-term segregation and prolonged seclusion, care and treatment were generic and were not aimed at meeting their specific needs, such as sensory needs. CQC (2020:15)
- 67% of people in long-term segregation on learning disability and child and adolescent mental health service wards were autistic.' CQC (2020:6)

- 81% of 313 wards for children and young people, and for people with a learning disability and autistic people, had used physical restraint in the month before our information request. CQC (2020:20)
- 56 out of 313 wards had used prone restraint at least once in the month before our information request. CQC (2020:20)
- Rapid tranquilisation was used in 34% (106 out of 313) of wards for children and young people and people with a learning disability and/or autism, in the month before our information request – a practice that has significant side effects and should only be used as a last resort. CQC (2020:21)
- Over a one-month period, there were 720 incidences where rapid tranquilisation was used on CAMHS and learning disability/ autism wards. It was more common on CAMHS wards where almost half of the wards (49%) that responded to the information request reported using rapid tranquilisation. CQC (2020:21)
- 3% of children and adolescent wards and 5% of learning disability and autism wards were using some form of mechanical restraint in the month before our information request. CQC (2020:22)
- There was a higher proportion of people from a Black or Black British background in prolonged seclusion on CAMHS wards, 24%, compared with 6% of all people on CAMHS wards in England. Similarly, for learning disability wards 11% of those in prolonged seclusion were from Black or Black British backgrounds compared with 5% of all people on these wards. This was not the same with long-term segregation, and we did not find the same across low-secure mental health wards. CQC (2020:25)

The report from the CQC acknowledges that restraint can re-traumatise and people and can have a lasting impact on people's mental health.

> "I used to be restrained. Being restrained when you're autistic is so much worse. It would spiral. They'd touch me and it would get worse. I'd start fighting against it for a long time. It stopped being about the original thing and more about being held."
> Caitlin

Caitlin is not alone in her experience of restraint adding to frustration and inflaming the situation. The NIHR literature review (pre-published, expected 2021) quotes Fish and Culshaw (2005), who found that most children and young people with Learning Disabilities were able to describe why restraints were used but reported that restraints didn't make them calm down, it made them frustrated and more aggressive and could trigger memories of past abuse.

Many inpatient interventions and approaches are based on a Positive Behavioural Support, or PBS model.

The 2020 study by Strydom et al reported in the BMC Psychiatry describe that 'although Positive Behaviour Support (PBS) is a widely used intervention for ameliorating challenging behaviour (CB), evidence for its use in adults with intellectual disability (ID) and comorbid autism (ASD) is lacking'. They conclude that PBS interventions are less effective in 'real world settings' than the earlier studies on 'highly selected cases' indicate.

The 2018 study by Hassiotis et al found that staff training in Positive Behavioural Support (PBS) 'did not reduce challenging behaviour'.

Understanding autism, reducing sensory and other demands, supporting self-regulation and responding appropriately when shutdown and meltdown do occur are key to reducing restrictive practice.

Recommendation: Staff training and support approaches are updated to reflect the latest research. Staff attend training delivered by autistic trainers with current knowledge and understanding of autism viewed as a sensory processing difference.

Recommendation: Individual care plans include reference to sensory needs and provide individual support to enable improved experiences and outcomes and to support restraint reduction.

Summary: Shutdown and meltdown

Sensory overload can cause or increase the likelihood of meltdown or shutdown.

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.

Physical interventions when people are experiencing meltdown or shutdown can cause flight or fight responses to be activated.

Autistic people are disproportionately represented in segregation and seclusion in mental health inpatient facilities.

People from a Black or Black British background are overrepresented in seclusion and prolonged seclusion on CAMHS wards.

Restraint can re-traumatise people and have a lasting impact on people's mental health.

Research shows that Positive Behavioural Support is generally not an effective intervention for behaviour that challenges services – training and approaches may need updating to reflect the latest research and learning.

Understanding autism and reducing sensory and other demands is important to reduce the likelihood of shutdown, meltdown and restrictive practice.

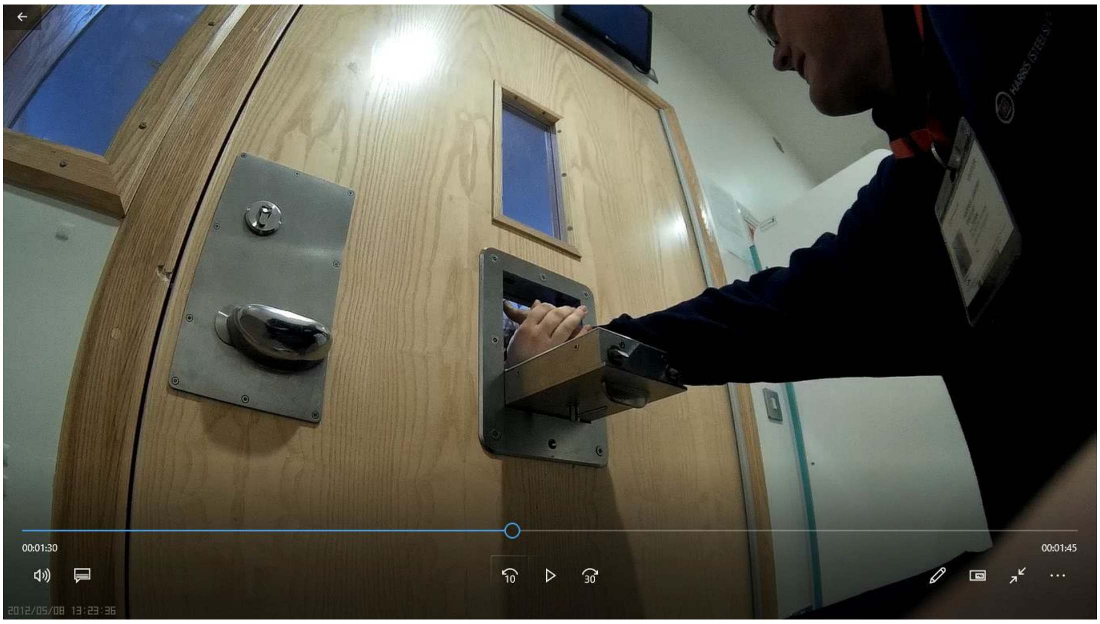
Bethany’s Story

I'm Jeremy - Bethany's dad. Beth has always been the little apple of my eye.

As Beth grew up, she was failed by numerous schools and services. Many of them well intentioned. Many of them providing good support to other people. But they didn’t understand Beth. They didn’t know about Pathological Demand Avoidance or understand autism as a sensory processing difference. They saw her signs of distress as bad behaviour that resulted in her being kicked out and moving on to the next place that would take her. Her Mum and I were terrified Beth was going to end up in a prison cell.

Instead, Beth ended up being locked away in a seclusion room in a hospital, where staff felt her behaviours were so destructive, so challenging, that the only way to manage her was with restrictive practice. I wasn’t even allowed to be in the room with her. I spent two and a half years kneeling down at a hatch holding her hand. It was horrific!

At one point Beth said to me:
'Dad I want to go to prison because if I go to prison I'll be allowed outside for an hour a day, I'll be able to see fresh air, I'll be able to see other people'.



The hospital environment was torture for Beth. It was very bright 24 hours a day, doors constantly slamming and keys rattling. People were displaying distressed behaviour so lots of shouting and screaming - quite horrific noises.

Her reactions to the sensory environment meant that therapies couldn't be provided to the level and extent that were required. Her mental health suffered horrifically. She'd become distressed; she'd rip her clothing up, she'd form a ligature. Staff would go in, sometimes groups of men, and pin her to the floor, remove her clothing and either leave her naked or force her into a what they call it a secure suit - a very stiff, scratchy, itchy, heavy garment that just added to Beth's autistic sensory torture.

All of this distress triggered more and more restrictions.

When Beth turned eighteen she had to move out of the CAMHS unit and went to a medium secure hospital in Wales. There wasn't even a hatch in the door there. The hospital said it couldn't provide the level of restriction it thought was needed and the CTR recommendation was for her to be moved to high secure - Rampton hospital.

I had a real stroke of luck at this point. I connected with Ann Memmott and she told me that it was possible to get actually autistic people to participate in and guide the care treatment review process. I was absolutely amazed because at this point in Beth's journey we had been through ... goodness 25 Care and Treatment Reviews (CTRs) and something I'd always asked for was autism expertise. I was overjoyed we were going to have this involvement.

Yasmin – Beth's commissioner

We'd always worked with clinicians and experts by experience, but I wasn't aware that autistic experts were working in that role in other regions. Jeremy let me know about Ann and her team and I got in touch with Jill at NDTi, who support their work in the SE and SW. Thankfully we were able to have her colleague Richard in the next CTR.

What it did was give a whole different perspective to Beth and how people viewed her and her needs. Really simple things that would never have crossed our minds. Richard walked into the area that Beth was in, came out and talked about a flicker in the light that was clearly a sensory issue for Beth. It needed someone else autistic to point this out.

Ann and Richard recommended things that the hospital then needed to get done. Most of these were very simple: like sellotaping acetates over some of the bright lights, staff turning their radios all the way down and not carrying the big bunches of keys. Guiding the door shut instead of just letting it slam. These quick fixes made the rest of Beth's stay at the place in Wales in terms of the sensory needs much, much better.

Because of the involvement and the benefit we'd seen of the involvement of Ann and her team we asked them to advise on the environment that Beth was moving to in the North West - and to deliver some training to that new team. That was so well received. In terms of colour scheme, lighting, all those nuances that we wouldn't necessarily have thought about - it was so beneficial.

We were overwhelmed by the input of Ann and her team. So huge thanks to Jeremy for highlighting them to me and making sure that we had them at that CTR, which was really critical.

We absolutely need to be doing everything we can to keep autistic people, like Beth, out of hospital; we know that this is not the right setting to support and care for autistic people. Once they're in hospital, if the right support is not there, there is a very real risk they will escalate through the system. Just like we saw happening to Beth.

Thankfully we were able to avoid high secure and get her to the right place. All credit to Jeremy for his perseverance and to Ann and her team for helping us to look at things in a different way.

Jeremy again:

Ann and her team saw and recommended things that I couldn't see because I'm not autistic. They suggested changes to Beth's new environment that have made a massive difference. They helped get it right. I can't say how important Ann's and the team have work has been - it is just so important.

The recommendation is to listen to people and their families. To support them to have the voice into the process, to be included as people who have got more experience than the clinicians. Those driving the processes need to really involve, listen, engage with and act on what we're talking about.

There was power in the autistic voice of Ann and the team explaining what's actually happening in that room, its potential sensory impact and describing the fix for it. It made people and services react.

It's not about putting restrictions in place. It's not about pinning Beth to the floor, it's not about locking her away because of what she's done. It's about genuinely understanding her as a person with some very specific support needs.

I'm going to leave the last word to Beth. This is my favourite picture of Beth and it is something that she said to me about the place where she currently and properly lives...

[redacted]

"People come into my world –
they aren't trying to make me go into theirs"

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.

> "As being an inpatient is such a difficult experience, staff should work with autistic patients about how they can regulate their emotions and deal with difficult emotions through self-regulation. For example, I have realised that since being in hospital practising yoga helps me to balance out my mood so that I am able to carry out my day positively and without it my mind can be all over the place. There should also be clear boundaries set out of where autistic people can go if they need to de-stress and where 'their' space is (this could include boxes for patients in communal areas to prevent clutter and people touching other belongings). Helping autistic patients to learn these coping mechanisms would be helpful both in hospital and when they leave, hopefully reducing the chance of readmission."
> Rebecca

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 often 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.

Recommendation: These suggestions should be considered with and for autistic individuals admitted to inpatient wards to support self-regulation.

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 of background noise. There are a range available, and it is important to find ones that are the best match for the person's needs.

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

Some of the young people we spoke to talked about the safety and reassurance that they felt when wearing their blanket or dressing gown but said that this had been limited by staff or by ward rules that were not flexible, understanding or supportive of their needs.

It is suggested that the use of weighted blankets may need to be considered in terms of their weight, length of time used and timing of use.

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.

Access to quiet lounges, sensory rooms and bedrooms can support this. Many of the young people we spoke to expressed a preference for being able to access their bedrooms at any time, as it is a familiar and predictable space where disturbances are limited.

> "I personally found it very hard not being allowed in my bedroom all day as, when I'm at home, if I'm feeling overwhelmed, I tend to spend some time in my room alone to calm down. I would have found it helpful to be allowed in my room even for half an hour to have some time alone."
> Beth W

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.

Access to personal belongings. We all have items that help us to feel more comfortable and at ease. People talked about the distress they experienced not being able to access personal belongings that would help them to feel safe and calm. Sometimes these items were not permitted. The reasons the items were not permitted varied, but decisions tended to be uniform and were rarely based on individual need.

> "I find it helps me regulate so well when I listen to music. I wasn't allowed my phone or headphones and it was really problematic. We weren't allowed any tech at all. There was a computer in the education room but lots of sites were blocked. There was never a proper reason – they said that social media was bad for recovery but so was being in a hospital with distressed people and no distractions."
> Charli

This is expanded on in the 'culture and approach section' on page 52.

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 (2013:59)

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.

Pets. Access to animal is positive for many people. Some hospitals have rabbits or guinea pigs. Others have visiting 'Pets As Therapy' dogs.

> "They need more animals. Therapy animals are good. I have a bearded dragon at home. It's really sensory because of his bumps. I need to be calm to hold him."
> Caitlin

Outside space. Many people find being outside and in natural very calming. Space to move away from other people, internal noises and distractions can be a good way to self-regulate.

> "I think things that are useful for autistic people would be beneficial for everyone. It would have stopped a lot of distress for a lot of people if they can take themselves away and calm down."
> Emily

A sensory room or de-stress room. Easy access to a quiet space to de-stress can be an enormously helpful tool for people to be able to self-manage. Ideally, this room will be away from areas where there is heavy footfall or other outside noise. Many people find neutral spaces beneficial, with the option of lights and other sensory stimulus.

> "I think you should just be able to walk into the sensory room instead of asking staff and waiting for them to unlock it."
> Jamie

Contact with friends and family. Maintaining important relationships is important for everyone – and especially so when autistic young people are struggling with their mental health and are in an unfamiliar environment. This is a human rights issue (see page 55 for more information on this)

> "There were 18 of us and only one phone. We weren't allowed our own phones. You just had to hope that you got the phone when other people (friends and family) were available. Other people are always waiting to use it and it was only available for limited hours."
> Charli

Summary: self-management and self-regulation

Many autistic people naturally develop ways of managing sensory overload. Hospitals should support people to understand and do what works for them.

Some ‘blanket bans’ (rules for everyone instead of decisions based on the individual) may be unlawful under the Human Rights Act. Decisions should be made based on the person and should be the ‘least restrictive’ option available. Good quality relationships at predictable times are vital for autistic thriving.

Predictable environments

The heightened sensory experience and distress which autistic people face can create a sense of chaos, which in turn triggers anxiety and panic. For many autistic people, routine and predictability help them to find order amongst this chaos, relieving the stress that they experience from their senses. This reduction in stress can enable people to engage better in the therapy and support that will ultimately help them to cope with their challenges and hopefully aid their recovery.

Predictability and structure have a major impact on every aspect of an autistic person's care in a Tier 4 CAMHS facility, from admission to discharge. Upon admission, children and young people are removed from everything they know – from the meals they eat to the place they live and the people who surround them. Even changes in small things which people may not consider to be significant, such as having to change the deodorant you wear, can cause huge anxiety.

Although this process will always be challenging for those who are autistic, it can be made easier by hospitals and community teams by addressing these challenges and working with the young person throughout the transition.

Recommendation: Work with individuals to understand what challenges they might experience with a change of location, environment and routine and consider together how these could be addressed to minimise the impact.

A big part of this is preparation, which was addressed by Beth W when discussing what could be improved in Tier 4 inpatient services:

> "(It would be helpful to have had) more notice before being admitted. I understand that this isn't always possible but wherever it is, it's really important to allow autistic people time to process what's happening and be able to fully prepare.
>
> (It would have been helpful to have had) Lots more information about what to expect in the unit. I wasn't really told anything which was really difficult due to hating uncertainty."
> Beth W

Admission to hospital is a daunting experience for anyone, and predictability can help to reduce this anxiety. This is particularly true for autistic people who are often already reliant on a consistent routine to maintain that sense of stability. As stated by Beth, advanced notice of what to expect would help people adapt to the idea of this change in routine, rather than having to face the shock of such sudden change. This notice could be given verbally, but it could also be beneficial to have a visual guide to the hospital and the routines on the ward. Many autistic people find it difficult to block out certain sounds or might be experiencing processing delays - particularly in high- anxiety situations. Having a physical copy to refer to would be beneficial as it would also allow the individual to revisit the information in their own time.

Recommendation: Support regarding the transition to hospital will ideally be tailored to the individual. It could involve an assessment of the person's normal routine and explore how aspects of it could be implemented within the hospital environment.

For example, if someone always has a shower at 8pm, but may need bathroom supervision, the hospital could ensure that a member of staff is always free at 8pm to help facilitate this. Many aspects of the individual's routine won't realistically be able to be replicated identically on the ward, but by maintaining some aspects of consistency, it can again reduce anxiety and stress.

Honesty surrounding long term planning is also as vital in creating a predictable environment, particularly around timescales. Just as many autistic people require structured days, to be able to generate a mental structure for the following weeks or even months can avoid further anxiety. In most cases, healthcare staff are unable to give accurate timescales, but effort should be made in giving some idea of how long they are intending a person to stay for, or when this will be reviewed. People who have never been admitted before could be expecting to only be there for a couple of days, whereas their doctor may be envisaging a couple of months. This transparency can enable autistic individuals to process the transition better, as they know what to expect in the longer term.

Recommendation: Ensure that all staff are honest and transparent about potential timescales and keep children and young people regularly informed of any changes to these.

Once a person has been admitted, predictability and routine are still crucial in providing quality care to autistic people. Several people we spoke to expressed the need for certainty and structure, such as Rebecca and Beth who spoke about the use of timetables:

> "A timetable would be created weekly, but this was not always adhered to and sessions could move around from week to week which made routine a challenge."
> Rebecca

> "It would be good to have a written timetable that's the same every week."
> Beth G

Timetables provide an easy-to-read, visual representation of a ward's routine. They have huge benefits when it comes to creating a predictable environment, providing a sense of security and consistency in what can feel like a place of chaos. Timetables should include meals, activities, and individual/ group sessions, to reduce the possibility of unexpected events that could cause an autistic person anxiety.

Although timetables are invaluable for people who benefit from routine, a lack of adherence to them renders them almost useless, and perhaps even detrimental. As Beth mentioned, consistency each week is important. If there is to be a change to the timetable, people should be informed as early as possible. Ideally, each young person could be given their own print out of the week's timetable at the start of the week. This would include any changes to the normal weekly structure and perhaps could even be personalised to the individual, including their own personal support sessions or groups that they are scheduled to attend. It could also include spaces for when there is no activity planned, so that the young person can structure their free time in a way that they can see visually.

Several people we talked to spoke about the anxiety created by ward rounds and being unable to settle until it has taken place. The uncertainty about timings for this taking place means that sometimes people described waiting all day in anticipation of being called at any moment. Even when it is not possible to give definite times, giving indicative times – such as between 10am and lunch, or between 1pm and 4pm, can be helpful.

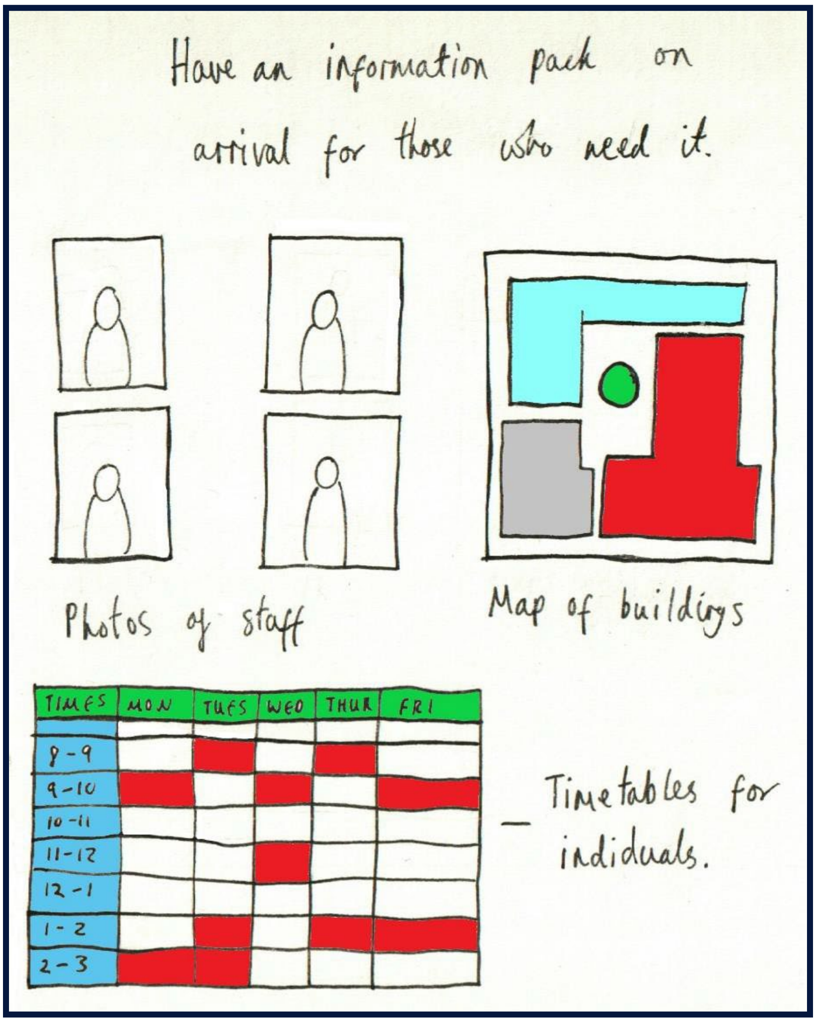
Recommendation: Use either general or personalised timetables to structure the time on the ward. This should be followed closely as possible, and children and young people should be informed of any changes as soon as possible.

Another way to maintain a sense of predictability is by enabling people to see

what members of staff will be in the following day/ night. As an inpatient, you are living 24/7 in that hospital environment. Whereas other young people see their family and teachers each day, for young people in a psychiatric hospital the staff become the trusted, regular adults in their lives.

Autistic people often find social interaction overwhelming and challenging, particularly with people who are unknown. Many hospitals use a number of agency staff, so often there will be days when the children and young people don't know some of the people looking after them. This can be difficult for autistic people who find social interactions with strangers anxiety-provoking. This issue can be helped by ensuring that the staff list for the next day is available to young people if they feel it would benefit them. Many hospitals use a whiteboard system, where the staff list for the following day/ night is written up each evening. This can also provide comfort, as naturally they grow to trust certain staff members and it can be reassuring to know that a familiar face will be in, just in case there is a sudden change or challenge. It can be especially reassuring for autistic people to know that there will be people in who understand their needs, as often misunderstanding can be a catalyst for the escalation of autistic shutdowns/meltdowns.

Recommendation: Implement a system which allows children and young people to have access to the list of staff scheduled to be in the following day. However, make sure people are aware that due to illness or unforeseen circumstances, there is the possibility of the list not always matching who will be there the next day.



TIMES	MON	TUES	WED	THUR	FRI
8-9		🟥		🟥	
9-10	🟥		🟥		🟥
10-11					
11-12			🟥		
12-1					
1-2		🟥		🟥	🟥
2-3	🟥	🟥			

Physically, the layout of the ward should remain consistent. Any changes to the decoration should be carefully thought out, avoiding stark colour changes. Likewise, areas designated for certain purposes should remain in one place. For example, a ‘quiet lounge’ should ideally remain in that same location. Naturally, each person will have their own preferred spaces within the ward, which are best suited to their interests, preferences and unique sensory needs. These areas can become safe spaces for individuals, and to adjust the purpose of these could lead to distressing changes, such as increased noise level. This can cause anxiety and it may take a long time for the individual to adjust to no longer having that safe space. Sometimes, changes are necessary or have been deemed to be in the best interest of children and young people in hospital. In this instance, people (particularly those who are autistic), should be informed as early as possible. Ideally, individuals using the space will be involved in making changes, so that they can help make the environment as sensitive to sensory needs as possible.

Recommendation: Ensure that changes made to the physical appearance or layout of the ward are kept to a minimum. If things do need to change, ensure that sensory needs are considered, and children and young people in hospital are involved and informed during the process.

Summary: Predictable environments

For many autistic people, routine and predictability help them to find order amongst this chaos, relieving the stress that they experience from their senses.

When people are admitted to hospital, they are removed from everything they know – from the meals they eat to the place they live and the people who surround them. Even changes in small things which people may not consider to be significant, such as having to change the type of deodorant used, can cause huge anxiety.

Hospitals can work with people to understand what challenges they might experience and share information to reduce the impact on people.

This could include sharing information before people are admitted and when on the ward. For example, sharing weekly timetables.

Culture and approach

Organisational culture is made up of shared values, beliefs and assumptions about how people should behave and interact, how decisions should be made and how work activities should be carried out (Chartered Management Institute, 2015). Organisational culture influences how people behave.

We heard from contributors that staff understanding of autism and approach to them as individuals were two of the most significant factors in how people felt about their time in hospital.

Recommendation: Start by listening (and then act)

> "Always listen to those who have experiences in inpatient units who are autistic. Even if they didn't know they were autistic at the time (I didn't) there are many things, looking back, that could have been done differently to make my stay less distressing."
> Beth W

Many of the issues and solutions that the autism team at NDTi identify during sensory environment reports are known and acknowledged during our visits. They have often been identified by staff and children and young people before we attend. It is interesting (and frustrating for many) that this information is often known but is not acted on.

We have heard a variety of reasons for this, including:

- It has always been like this.
- It's someone else's responsibility (e.g. facilities).
- It's an infection control issue.
- We didn't know who should make the decisions.
- Some staff don't agree this is needed.
- There is a hierarchy of patient needs – people with eating disorders (for example) are prioritised.
- I don't know why it hasn't been changed.
- It's not that bad.
- We don't have budget for this.

'What stands in the way becomes the way'. Brene Brown (2018:6)

We encourage organisations and individuals to consider how they listen and respond to issues that are identified by children and young people and colleagues. It may be helpful to explore if there are instances where the response is inconsistent or dismissive, and to understand the reasons for this.

The NIHR literature review (pre-published, expected 2021) quotes Weich et al (2020) as stating that few NHS Mental Health Trusts in England have a strategy for using patient experience data to improve services. More than a fifth said that they don't routinely collect patient experience feedback, and more than half saying that they experience difficulty in using patient experience to create change.

Collecting information from people does not necessarily lead to change. In the conversations we had with young people who contributed to this paper, we heard that they often tried to give informal feedback that was not heard or acted on.

'Leaders in hospital also need to create a culture of listening to and understanding people. This includes using continual learning about how to minimise the use of restrictive interventions. It should run from creating a ward environment that meets the needs of the people being cared for, to ensuring that the staff team has been recruited using values-based recruitment. This is essential to ensuring human rights are upheld.' CQC 2020:14

Recommendation: Make sure all staff are autism informed.

Kanner's study in 1943 identified four times as many boys as girls were autistic. A study by Lorna Wing in 1981 into Asperger syndrome found 15 times more men and boys than women and girls. In 2015 the ratio of men to women supported by the National Autistic Society's adult services was approximately 3:1, and the ratio of boys to girls in the charity's schools was 5:1. (All statistics from NAS website).

Moyse (2021: 79) identified that fewer females were referred for autism diagnosis and support and that this links to 'research literature on autistic girls who mask and camouflage'. Contributors to this paper commented that all staff need ongoing education on autism, including specific development support for all staff on female autistic presentation. This training should be led by autistic people.

> "More education for staff on autism, including education about how autistic girls can present less stereotypically, and their needs are often shrugged off because they don't 'appear' autistic."
> Emily

Autistic people are sometimes accused of being rigid and inflexible – interestingly, the same can often be said of services. We heard examples from contributors when inpatient provision had not been flexible or responsive to their circumstances or need.

The NIHR literature review (pre-published, expected 2021) quotes Reavey's (2017) report that young people often stated that inpatient environments were 'inflexible and unresponsive to their needs and that they had little choice or autonomy in unfamiliar environments'.

Routines are sometimes important for autistic people and can help to increase predictability and reduce unexpected demands. The section on self-management and self-regulation gives numerous examples of how autistic people might self-regulate and meet their own needs. Listening to and supporting this, rather than asking people to forego the items, routines or practices that are important to them and help them in order to self-regulate to meet aninstitutional timetable or policy goes against the principles of person-centred support.

Sometimes, it is necessary to ensure safety and wellbeing, but where this is the case the person should be supported to understand and to consider how else they might get their needs met. Decisions should always be made as close to the person as possible.

Services should set the example of being flexible, supportive and responsive. In all relationships, people often respond in kind. Where people feel understood, heard, seen and supported they are more likely to engage positively and benefit from the interaction.

> "Educating inpatient units about autism is vital as there are so many stereotypes and misconceptions that can affect how the changes to services."
> Beth W

Understanding autism as a sensory processing difference is a marked shift away from historic understandings that have viewed autism as a behavioural disorder. Contributors to this paper told us about the significant positive influence that staff who understood and supported them to understand their sensory needs had on their experience, and on their ability to self-manage.

> "I was extremely lucky with my community psychologist. I had weekly therapy for two years. He was amazing, a great example of how community care can work. I literally owe my life to that man."
> Charli

Information collected by NHSE (page 21) shows an increase in the number of admissions for autistic young people. Anecdotal information from three CAMHS wards that screen all children and young people who are admitted indicates that approximately 6 in 10 of those admitted are autistic.

Recommendation: Screen everyone admitted and assess those who need it. Use findings to inform individual care planning.

Screening and assessment on admission is helpful in identifying people and understanding their individual needs, and how these can be best met and supported while in hospital.

> “All staff need training on sensory awareness. I’ve always had sensory issues. When I went into hospital, I already had Sensory Integration Disorder. The staff don’t always understand, they need training on sensory awareness. Hospitals are overstimulating with the noise and smells and bright lights.”
> Jamie

Several young people who contributed to this report told us that they were not diagnosed on first admission or waited months for assessment while in hospital. Others were diagnosed much later in the community, as assessments were not always available in hospitals. Girls in particular often present with other issues or may be misidentified as having (for example) borderline personality disorders, instead of as autistic.

Recommendation: Screen everyone who is admitted for autism, using modern best-practice tools, and undertake full assessments promptly for those who need it.

> “If someone is autistic, they should get a sensory assessment. It was so important for me to understand myself and how I regulate. I’m a big OT advocate.”
> Charli

Recommendation: Assess the sensory needs of everyone who is admitted to hospital.

Recommendation: Individual care plans consider sensory need and support that is required in relation to sensory triggers.

Recommendation: Discharge plans are made early, involve the individual, and consider how support will be ‘handed over’ from inpatient to community services.

Recommendation: Personalise communication and information.

> “Communication is key. If changes are put in place in an inpatient unit make sure to get feedback from the autistic young people who experience these changes. Take into consideration what they think works well and any concerns they may have.”
> Beth W

It is estimated that most patients often meet over 100 new people in the first weeks. For those with social and communication challenges, meeting new people can add to anxiety and a sense of overwhelm. It may be helpful to engage the child or young person in understanding what support they need with this, and how they would like to approach it. Some people may prefer to get introductions out of the way, while others may prefer to reduce social demands and limit non-essential interactions. Clarity about which staff make up part of their ‘core team’, and explicit expectation setting about what interactions are required or not required with the extended team may be helpful.

> “To have had my needs as an autistic person met would have made my experience quite different. Being overwhelmed from being on the unit exacerbated my mental state and mental distress so I was probably there for longer than I would have been there otherwise.”
> Emily

An information pack on arrival that names core team members, with photos and explanations of their role can assist people in ‘placing’ those they meet. This information pack could also give an overview of other things the person may hear or need to know. This could include:

- A map of the building to support people to orientate themselves in the space.
- Names and photos of the team working with them.
- Clear expectations that are explicit and make sense (including when interpreted literally).
- Information about what alarms might sound, when, and how long they will last.
- A personalised timetable.
- Permissions and guidance about where to go with problems or questions.

Recommendation: Personalise risk management and decision making.

‘Blanket’ restrictions or ‘blanket bans’ are rules for everyone, rather than decisions that are specific to individuals and their circumstances. An example of a ‘blanket ban’ is that nobody is allowed a mobile phone. Some of these ‘blanket bans’ are unlawful and contravene the Human Rights Act.

The Human Rights Act says that public authorities have to respect and protect human rights in their actions, decisions, policies and services. This includes:

- The right not to be tortured or treated in an inhuman or degrading way (Article 3)
- The right to liberty (Article 5)
- The right to respect for private and family life, home and correspondence (Article 8)
- Right to peaceful enjoyment of possessions (Article 1)

The British Institute of Human Rights have some excellent resources and training on human rights. This link to their 'know your human rights online tool' may be useful to people who are concerned that their rights are not being upheld: https://www.bihr.org.uk/resources-for-individuals

We heard examples of 'blanket bans' from contributors. People told us that some of the rules did not make sense to them, did not meet their needs, and made their time in hospital more challenging.

> "We weren't allowed in our rooms during the day at all. At times I begged to be allowed in, because I needed some time out to recharge when I was very exhausted from being on the unit. I needed complete silence and time away from people. But this was a blanket rule that wasn't allowed to be broken. I know at times this would have been a risk thing, as I was often on 1-1 at night, but the fact this was a blanket rule, and it should have been assessed on an individual basis."
> Emily

Bates and Lymbery (2011:33 - abridged) suggest that person-centred, context-specific risk management will:

- Involve the person and the people that know them best as potential experts in keeping themselves and others safe.
- Extend the principle of 'least restrictive intervention'.
- Ensure that the assessments, interventions, monitoring and controls that are introduced to manage risk are proportionate.
- Recognise that behaviour is contextual, and that every environment will have formal or informal mechanisms for the assessment and management of risk that will influence what happens there.
- feed learning from each success and failure into a learning culture within social care services so that the organisation's understanding of safeguarding becomes increasingly nuanced and subtle rather than rule bound.

Following the steps outlined above, working with individuals, identifying the least restrictive intervention, ensuring that decisions are proportionate will support decisions that are better tailored to individuals and more likely to be compliant with the Human Rights Act.

Summary: Culture and approach

Staff understanding of autism and the support they offer makes a big difference to how people feel about their time in hospital.

It is important to listen to autistic children and young people, and to value their experience. It is important to listen to what people say and respond to what they tell staff they need.

Many staff need better training and development, and for their autism understanding to be accurate and current. This training should be led by autistic people.

Several young people who contributed to this report told us that they were not diagnosed on first admission or waited months for assessment while in hospital. Others were diagnosed much later in the community, as assessments were not always available in hospitals. Girls in particular often present with other issues. Screening and assessments for autism should be provided in all CAMHS inpatient services.

It is estimated that most patients often meet over 100 new people in the first weeks. For those with social and communication challenges, meeting new people can add to anxiety and a sense of overwhelm.

Communication and information should be provided to help people process and understand, and to help reduce uncertainty and anxiety.

Risk management and decisions should be made in relation to individuals and not for everyone regardless of circumstances.

Caitlin's story

The Ashfield Unit was very good for autism. They have a silent alarm system. Staff have alarm triggers and where there's a problem, they click a button, and it pings to pagers of the staff who aren't on observations. If there's a big problem, they use the second setting, and it sets off a loud alarm that everyone can hear. When I was there, I think it happened about once a week.

It's a really big deal if the alarm goes off. It's big and intense and very stressful. It results in me freaking out and going into meltdown or shutdown. If the alarm went off at Ashfield the staff would find me and bring me noise cancelling headphones. They'd help me get wrapped in a blanket and moved to a quieter place. They had a really good understanding of autism.

They did a Sensory Integration Assessment while I was there. The Speech and Language Therapist (SaLT) explained what was going on in my head. She was so amazing. It helped me know how to look after myself. I had a communication passport and a booklet on things that help and things that don't help. It says what to do if I go into sensory overload. It's very, very helpful.

When the environment and support is right the issues that come up are more likely to be mental health stuff that you're actually in hospital for.

In the places I went afterwards, alarms would go off multiple times every day. I don't think staff there knew what autism was. I think they thought my autism was a mental health problem, but it's not – and it's not a reason to be in hospital. The lack of understanding was detrimental to my treatment. I got restrained a lot more.

I knew from being in Ashfield what was wrong with me and what I needed. It was really hard not being able to control it and not being able to look after myself. I made massive signs on the walls so people wouldn't interrupt while I was trying to self-regulate. I made a den in my wardrobe so I could feel safe. I hung a blanket up to help block out the sound and light and to give me an enclosed space. The staff would come in and turn the lights on and make verbal interruptions and touch and shake me. The signs told them not to do these things when I was trying to calm down and self-regulate. They just didn't understand.

They had really strict routines in some of the places after Ashfield. In one place, I struggled eating in the cafeteria because it was so noisy. There were the same number of seats as beds at the hospital, so there wasn't enough space to move away from other people. You're not allowed to take a comfort item into the dining area with you. If you hadn't had breakfast by 8.30 then you didn't get to eat until lunchtime. Everyone uses the space at once and you're not allowed to eat in different rooms. There should be quieter places you can eat and there should be more flexibility. They weren't very understanding about the whole thing.

I developed problems with eating because of their restrictions. It reinforced in my head that I didn't need to eat. I thought it the hospital thought it was OK then it must be.

I still wake up thinking about stuff from hospital, and it stresses me out.

Meeting my sensory need would definitely have reduced the need for restraint. It feels so uncomfortable. I made virtually no progress in some places, because my autism was so misunderstood.

The next chapter, written from a clinical perspective by Angela Watson, the Speech and Language Therapist that Caitlin refers to explains how the Ashfield Unit at Parkview hospital put the support Caitlin describes in place.

A clinical view from Parkview Clinic, Birmingham

Angela Watson, Principal Speech and Language Therapist, Inpatient CAMHS/Deputy SLT Manager at Parkview Clinic, Birmingham Women's & Children's NHS Foundation Trust

As a I am based within an inpatient hospital, in line with the diagnostic criteria the medical diagnostic label of Autism Spectrum Disorder (ASD) is routinely used and will therefore appear within the following document. However please note that when speaking to and explaining the diagnosis to young people and their families, I would always refer to the ASD as a difference (rather than a disorder) as through this term the many strengths as well as challenges can more easily be explained.

Background Information

Following the closure of the Birmingham Children's Hospital regional Autism Spectrum Disorder (ASD) outpatient service, the remaining speech and language therapists (2.0 wte.) were redeployed to inpatient child and adolescent mental health services (CAMHS) at Parkview Clinic.

There are 3 inpatient wards at Parkview Clinic for young people typically aged between 11 to 18 years:-

- Heathlands: A 14-bedded general adolescent ward for young people requiring assessment and treatment for a range of mental health difficulties.
- Irwin: A 12-bedded ward for young people with eating disorders.
- Ashfield: An 8-bedded locked ward for young people with a range of mental health difficulties who present with a high level of risk to themselves or others.

High Prevalence of Autism and Psychiatric Illness

Given our background in autism we quickly became aware that a number of the young people admitted additionally presented with an underlying autism/social communication disorder, which for many had previously gone unrecognised. To put this in context, our annual audits compiled since 2009, indicate that despite our service not being specifically for autistic young people, around 6/10 (60%) of young people admitted to Parkview had in additional to their significant mental illness, an underlying ASD/social communication disorder. Our findings are in line with Cohen et al (1998) who identify 60% of young people presenting to CAMHS will have an underlying social communication disorder, 40% of which will previously have gone unrecognised. Furthermore, other more recent research confirms a higher incidence of mental health problems in autistic young people than in the general population. Having a language disorder is therefore a psychiatric risk factor, (Toppleberg et al 2000); up to 70% of young people with ASD are likely to suffer during adolescents with mental health problems, (Simonoff et al. 2008).

Accessing Care and Treatment during an Inpatient Admission

We were mindful, given the sensory and processing differences inherent in ASD, how socially and environmentally demanding the ward must be for a young person whose difficulties were further compounded by psychiatric difficulties.

Previously within our service there was a lack of awareness or understanding of autism amongst inpatient staff. The focus tended to be more on the signs and symptoms of the mental illness, hence when young people struggled their behaviour was typically seen as challenging and/or part of their illness; staff efforts to manage or deescalate the behaviour often served to increase their distress.

Furthermore, due to there being no defined service to cater for the needs of those young people who additionally had/were thought to be autistic, when therapeutic interventions were not tailored to support recovery within the context of the autism, the illness was often prolonged and/or recovery not sustained.

A significant need was identified within our service to improve quality of care, patient experience, safety, and clinical effectiveness for those with underlying autism. We wanted to create an environment that was beneficial and positively conducive to the recovery of autistic young people, in which their anxieties could be minimised, they and their families were fully understood and supported, and they were therefore more able to access therapies to enable recovery.

Service Development

To enable this and through the support of the Clinical Director at the time, our service registered to work towards achieving Autism Accreditation. Autism Accreditation is an internationally recognised quality standard provided by the National Autistic Society (NAS), which provides a systematic framework for continuous self-examination and development in respect of ensuring a high, quality autism service. Due to my experience and knowledge, in my role of Principal Speech and Language Therapist (SLT), I was asked to lead the process. I therefore enlisted the support of various senior members of the multi-disciplinary team (MDT) to jointly identify the components required for an ASD service to be fully embedded in practice and we prioritised those objectives that would enable our vision to be achieved.

Autism Training for all Staff

Staff training was considered to be the most effective way of empowering and ensuring a skilled workforce who, within the context of mental illness, was confident and competent in understanding and supporting young people with an underlying ASD to manage their safety and illness. With reference to the 'Autism Spectrum Disorders Training Policy and Framework,' (2006) I devised and identified the competencies for a 3-level ASD training programme, that has recently been adopted by Health Education England for rolling out via a 'Train the Trainer' approach to all inpatient services across the country. Our training is informed and illustrated by the personal experiences and accounts from patients and their families who have experienced our inpatient service. The levels of training comprise:-

- Foundation ASD Training: ½ day training intended for those with little or no prior knowledge of ASD to develop awareness of the key features of ASD, e.g. facility and administrative staff.
- Core ASD Training: 2-day MDT led training for those who work directly with the young people on the wards and who in line with their role, require more in-depth knowledge and skills to enable them to effectively carry-out their work, review and reflect on their practice, i.e. all clinical and educational staff.
- Extended/Advanced ASD Training: For all clinical staff whose role requires more in-depth ASD knowledge and skills, e.g. medics, psychologists, speech and language therapists.

In addition to the training, we identified an ASD Link Worker from each ward and the on-site school to help develop and embed a range of autism friendly practices across the service, including environmental adaptations, to further support those with an underlying ASD. It is important to note that many of the developments and changes made were equally beneficial to those not on the Autism Spectrum as they served to enable young people's understanding of the various ward processes, procedures, and expectations.

Service Improvement

Since 2013 when we first started to work towards establishing a service for those whose mental illness is further complicated by an underlying ASD, there has been a definite shift in culture. There is improved understanding and knowledge of autism reflected in the working practices/patient care across individual staff and teams. Despite our service not being specifically for autistic people, staff now readily consider and spontaneously adapt their practice to positively support and where possible minimise the impact of any social and environmental demands. Feedback from families and autistic young people who have been cared for by our service has to date been overwhelmingly positive. Caitlin's story in the previous chapter is an example of this.

We now within our inpatient service have an identified assessment, care and treatment pathway for those with ASD which runs alongside our mental illness specific care and treatment pathways.

We achieved Autism Accreditation status in 2016, reassessment is every 3 years; we were successfully re-accredited in 2019. Autism Accreditation status provides our service with formal recognition of the specialist skills staff have developed and are continuing to develop, in order to manage highly complex young people who additionally have an ASD; it promotes the high standard and quality of care we offer and demonstrates our commitment to continuously improving our service.

It is important to note, to help minimise anxiety arising from the environmental and social demands experienced within a busy ward environment, we have not tried to do things differently within our service for someone just because they are autistic. Instead, we have strived to embed an autism friendly approach across all aspects of our interactions, service and practice, which aim not only to be autism friendly but mutually beneficial to all.

Key Changes and Adaptations to Help Minimise ASD Anxiety

Pre-Admission

- Young people receive a ward specific 'Welcome Booklet' with photos and information about the ward, to help them prepare for their stay.
- Parents/carers receive a welcome booklet detailing key information related to their young person's admission, e.g. what happens on the ward, who comprises the MDT, the purpose of the various meetings such as ward round, visiting times etc.
- Parents complete a form to detail their young person's likes, dislikes, routines, preferences, sensitivities etc. to help inform us how best to support them in hospital.
- Parents complete a social communication screen of their young person's functioning both currently and pre-morbidly to enable early identification of a possible ASD.
- Young people receive an information sheet explaining what will happen when they arrive for their admission.

On Admission

- Young people receive a 'Welcome box' with various activities, wi-fi code, self-soothe items etc. to support transition into hospital.
- Young people receive an admission folder, detailing key information about their inpatient stay, e.g. who's in their team, their therapeutic timetable; what a care plan is, an information sheet about the school, advocate, chaplaincy and details and explanation of the various ward processes and procedures etc.

Environmental Supports

- Staff photo board.

- All staff wear name badges.
- The generic ward timetable is visually displayed.
- During the school holidays the weekly activity timetable is displayed.
- Names of who is/will be on shift are displayed daily.
- The meal seating plan in displayed in the dining room.
- All children and young people are offered ear defenders.
- Written information re. when the cleaners will be cleaning the rooms, vacuuming etc. are clearly displayed.
- Personalised self-care plans are developed as required, e.g. for morning routine, shower.
- There is an outside gym for young people to 'let off steam.'
- Availability of a range of sensory equipment, e.g. weighted blanket, aromatherapy oils, fidget toys, theraputty and a calming sensory space.

Supports during admission

- Use of traffic light coloured bands which young people can wear to signal changes in their mood and thereby safely seek support, (instead of engaging in unsafe behaviour). N.B. The bands link to a personalised 'feelings scale' which identifies (i) changes in an individual's behaviour which reflect changes in emotional state and (ii) ways of safely managing emotions.
- Written information sheets are available as required, e.g. to help a young person to understand and prepare for a mental health assessment, tribunal, DEXA scan, ECG, change in observation levels.
- Young people are supported by staff to complete a 'Triggers and Safety' tool, that we have devised. In relation to different sensory stimuli and with pictorial supports. Here young people are asked to identify, triggers that make them feel upset or afraid; what happens to their body when they feel upset or afraid; what do they do when they feel this way and what makes them feel better. This information helps inform appropriate, individualised care and treatment.

Impact of ASD Service Developments

Through ongoing staff training, the development within our service of an ASD-specific pathway and the changes and adaptations made to help minimise ASD anxiety, we are demonstrating our commitment to providing a high-quality service and positive patient experience for ASD patients and their families, along with greater clinical effectiveness given we now have a skilled workforce with shared knowledge and understanding of ASD. Feedback has illustrated because of our work here, young people and their families do feel understood and fully supported. Consequently, anxiety is minimised, such that they are more able to access therapy to support recovery in a timely way, thereby possibly reducing length of stay.

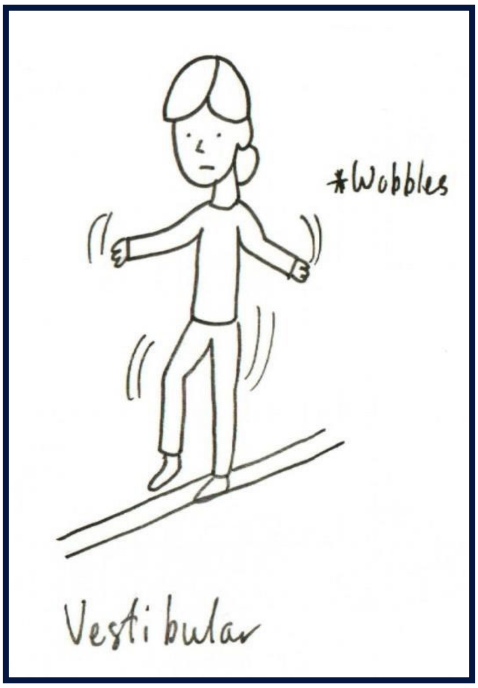
During admission, young people and their families receive psychoeducation geared towards understanding the impact of the ASD on their illness and their individual strengths and challenges. This work is aimed at empowering the young person to stay well in the future and to prevent relapse and/or the need for readmission. Our work has resulted in improved patient safety; through improved ASD informed channels of communication, staff are more able to support a young person to keep safe and well. In addition, due to improved insight into the struggles of autistic young people, staff are more skilled at deescalating situations, resulting in a reduced need for restraint.

Over the years we have received numerous positive stories from autistic young people and their families who through their admission have understood, accepted, and embraced their Autism; one former patient wrote, "I came to you at my lowest and because of all the help and support I got I was able to build myself back up better and stronger than ever before."

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'.

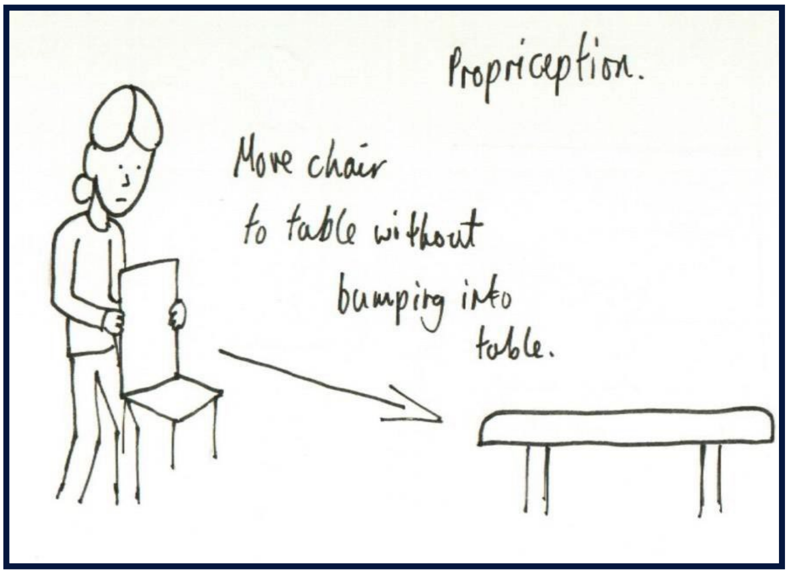
Internal sensing systems



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.



Recommendation: 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.

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 (e.g. using a knife and fork)
- gross motor control (e.g. 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 (e.g. scratching an elbow)
- Motor planning – organising and sequencing the steps of unfamiliar and complex body movement (e.g. 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. Proof et al. (2021) reviewed a large number of studies that looked at differences in autistic and non-autistic sensory processing on both the internal and external senses. Their study concluded that there are clear physiological differences in neuro-cognitive processes between autistic and non-autistic brains and that individual differences are key. They found that one of the most significant factors is likely to be making environments more accessible for those with different sensory processing needs.

Summary: Internal sensing systems

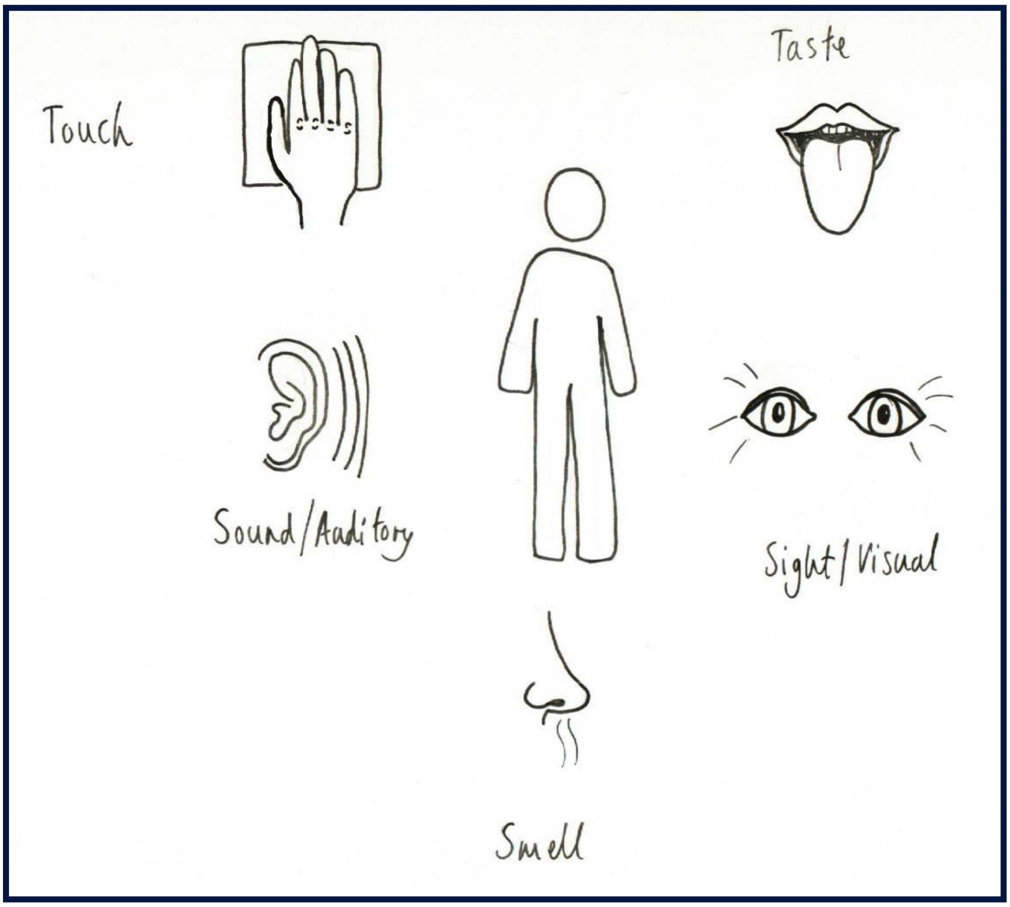
We have three internal sensing systems.

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

Proprioception is the awareness of the position and movement of the body.

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.

External Senses



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.

Contributors to this report told us that in many CAMHS inpatient units the sensory environment was chaotic. This added to the distress for many people and made it more challenging to engage in positive and therapeutic interventions. Some people told us that sensory distress meant that they were more likely to be restrained and extended their hospital stay.

> "I think the things that are useful for autistic people would be beneficial for everyone. Small changes would have stopped a lot of distress for a lot of people. It would really help to be able to move away from the noise and other people to calm down."
> Emily

Summary: External senses

Autistic people process sensory input – including things they see, hear, smell, taste and touch – differently from neurotypical people. This means that they often have a different experience of the world.

The next sections of the report give examples of how each of the senses are 'triggered' in a CAMHS inpatient hospital.

Sound

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.

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)

Sound is a major source of sensory input in CAMHS inpatient environments and was the first thing that many of the young people who contributed to this paper mentioned. People particularly talked about the distress that was caused by alarms going off, noise carrying between spaces and being impossible to get away from, the particular challenging sensory environments in dining areas and the shocks caused from doors slamming. All these things were exacerbated by staff teams not fully understanding or dismissing the impact that this had on people. This is explored more in the culture and approach section.

It is important to consider the way that noise can carry between rooms and walls. Several contributors told us that everyday noise from other people has been a challenge for them, particularly where rooms are joined. This included people talking, watching TV, listening to music or doing an activity such as cooking. 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 other people were being unreasonably loud, but that everyday sounds had a disproportionately negative impact because of their auditory sensitivity.

> "It would help to be allowed our own music. You can focus on it and cut out other sounds around you."
> Emily

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.

Alarms

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

Most mental health wards – including General Adolescent Units (GAU), specialist hospitals, and Psychiatric Intensive Care Units (PICUs) are required to have personal alarms that staff and/or children and young people activate when they need to summon other people to support them. This was one of the primary concerns that contributors to this report cited when reflecting on the sensory challenges of being in an inpatient unit.

> "The alarms go off during the day. It's not predictable – you never know when it's going to happen. I'd try not to complain but it's ear piercing and noisy. It's very stressful – the opposite of calm."
> @AutisticPB

Alarms, by design, are alarming. They push many autistic people straight into shutdown, meltdown, fight, flight or freeze. This is a stress response. It is linked to the sympathetic nervous system (fight or flight) or parasympathetic nervous system (freeze) and is automatically triggered.

> "Alarms went off a lot - up to every 30 minutes sometimes. I was on edge waiting for the alarm. I would have a panic attack every time they went off. Why do they have to sound so scary?"
> Emily

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.

> "The alarms were too loud. It wasn't easy for staff to turn them off and they went off at least a few times a day. It added to my distress."
> Beth G

Contributors to the report said that they had told staff about the difficulties that alarms caused them, but that in most cases this wasn't fully understood or appreciated. In some cases, people reported that staff minimised their experience.

Some young people have reported that staff attempt desensitisation approaches rather than enable better control of sound. This may involve the young person masking their difficulties, storing stress until it 'explodes' later, or entering into states of permanent anxiety, depression or learned helplessness. It is not our recommendation that desensitisation approaches are used, unless the young person wishes to try these. There should always be access to ways to lessen sensory input.

Recommendation: Staff are trained in autism, including the sensory experience and how differently some autistic people perceive and process auditory input.

CQC guidance (A brief guide: call systems, 2020:2) specifies that 'The call system in use should reflect the needs of the patient/service user group (eg audible systems may distress some patients/service users).'

Silent alarms are available. One model, used in Parkview (see pages 61-65) has two settings. The first setting alerts staff that are not working on the ward via a pager system. This minimises the impact to people who are on the ward but ensures that support is summoned. The second setting is for urgent support and is audible to those on the ward.

The use of silent alarms is an important, and a positive way to respond to what young autistic people are saying about the challenges and distress that audible alarms cause them.

In addition, all individuals should be assessed for their response to alarms and supported to consider what could be put in place to reduce distress that this causes when they do go off. This could include staff checking in with people, provision of sensory items, choice and control to move to other quieter areas, noise cancelling headphones etc.

Recommendation: It is strongly recommended that CAMHS inpatient hospitals use silent alarms.

Recommendation: Alarm response and support considered as part of individual care planning.

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. Many autistic people also find sensory input easier to manage if they are in control of it – so involvement in testing alarms, including setting them off, recording the test and turning them off may be a good way to support some people to better tolerate the sensory intrusion.

Recommendation: Information shared with people, as appropriate, about planned alarms and tests.

> "The noise has a massive impact. You can't switch off. Sometimes it lasts a long time. I felt distressed. It's quite intimidating having all that noise going over you. You're always waiting for the next time it will happen. "
> Jamie

Doors

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

Recommendation: 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 (also referred to as door arms) to ensure that they shut but do not slam. However, door closers can pose a safety risk and are not appropriate for all areas.

Some people find moving between spaces challenging and not being able to see and anticipate the space adds to the unpredictability.

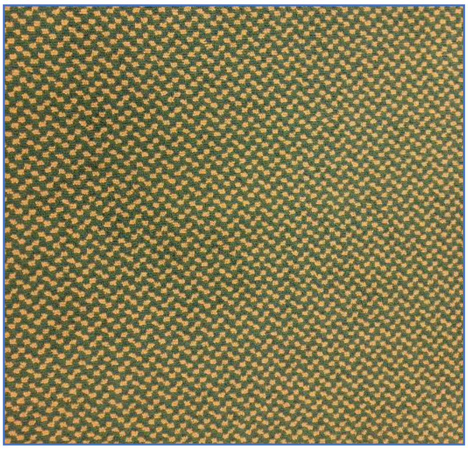
Visibility between rooms can support ease of movement between spaces.

This image was taken in a low secure unit for adults.

Recommendation: Glass panelling in and around doors can make transitions easier.

Flooring

Flooring can significantly change the sensory environment in a room. Carpet and soft furnishings can absorb sound which helps to reduce echo and noisiness.



We often visit multiple wards with the same layout but with different flooring, and the difference is very noticeable.

Patterned carpets can add to the sensory load and are likely to be best avoided.

The carpet pictured is one seen in a CAMHS General Adolescent Unit during a review of the sensory environment. Some team members found it dizzying and a significant addition to the sensory load.

Recommendation: 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.

Hard surfaces can add to the echo and 'noisiness' of a room.

Recommendation: 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 other parts of the building.

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.

During hospital visits we have often found sensory rooms on busy (and noisy) corridors, next to laundry rooms, games rooms, general use lounges or nursing stations. Sometimes it can be beneficial to have a 'quiet room' in the garden, dependent on external noise.

Recommendation: Consider what external noise is present (as well as internal noise) when considering how different rooms and spaces are used.

Recommendation: For some rooms where outside noise cannot be avoided, acoustic glass may be beneficial.

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.

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.

Ann Memmott's twitter poll (http://annsautism.blogspot.com/2021/03/most-autistic-people-dont-like-curved.html) found that about three times as many autistic people prefer straight walls to curved walls. Some autistic respondents on Twitter mentioned feeling dizzy, disorientated or nauseous in spaces with curved walls.

Recommendation: Consider how building shape, wall angles and ceiling height might impact people's experience of the space.

Recommendation: Carpet and soft furnishings can reduce the impact of this, and the addition of sound absorbing panels can help in some spaces.

Recommendation: If curved walls are a clear need for a particular autistic person or small group, consider demountable curved partitioning for a space.

Appliances, including heating

Appliances, heating and forced air 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'. In many hospitals we have visited, forced air systems play like flutes throughout the building, making different noise in different spaces. This can be significantly disruptive at any time of day but may be particularly challenging for people at night or when trying to sleep.

Recommendation: Regularly service heating and forced air systems, ask the staff servicing the systems to reduce noise and vibrations as far as possible.

Recommendation: Consider this sometimes 'invisible' or unheard background noise when allocating rooms – in our experience it varies significantly in different rooms.

Recommendation: It can be helpful to consider and agree in advance when noisy activities such as hoovering, and washing will take place.

Extractor fans in bathrooms and kitchens are often connected to turn on with lights. While extractor fans are a regulatory requirement, it is not a requirement that they are on the same circuit as lights. They can be put on a separate circuit so they can be turned on and off independently of the lights.

Recommendation: We strongly recommend that extractor fans are put on a separate circuit with separate switch - particularly in en-suites, shared bathrooms and kitchens.

Other people

A significant amount of noise in inpatient environments originates with people – both staff and other children and young people. This noise is often anticipated, but unpredictable, leaving people waiting in expectation of the next noise.

People we spoke to while writing this report told us that the cumulative effect of noise added to distress. People understood that in an inpatient unit they might expect other people to be noisy at times but said that the challenge was in the restrictions on their movement that meant that it wasn't always possible to move away from the noise.

Alarms and beeps (of fob keys) as well as doorbells were a significant issue that has been covered earlier in the report. In addition:

Keys

We heard that some staff didn't like the idea of key pouches, because they associated this with being in secure settings. However, the noise of jangling keys left some children and young people feeling as though they were in a secure setting. This adds a significant amount of noise as staff move around the building – including during checks at night.

Recommendation: Consider noise from keys and fobs and take action to reduce this noise.

Radio and TV

This was a particular issue for children and young people whose bedrooms (often their place of safety and refuge) was located close to lounge areas. The noise from radio and TV often 'leaks' out of the lounge area and along the corridors and into other spaces.

Recommendation: Radios and TVs are turned off when not in use.

Recommendation: Consider encouraging the use of headphones overnight (eg between 10pm and 7am) – even in communal spaces.

Talking

In many CAMHS buildings that we have visited, voices can be heard significant distances – including outside therapy rooms and nursing stations. Autistic colleagues with hyperacusis are able to hear detailed conversations from significant distances.

Recommendation: Consider how soft furnishings can be used to reduce echo and the distance that sound travels, where additional doors may be helpful in reducing noise, and when additional sound absorbing materials may be needed.

Expressions of distress

It's distressing to see and hear other children and young people in distress.

> "People banging was an issue. I was in a mental state where it would set me off. I was already stressed, and this got me more stressed. There was another lounge, a quiet lounge, but it was locked and there often wasn't enough staff to open the room."
>
> Emily

Recommendation: It is important for people to have space to move away from others, and access to quiet rooms and areas.

Summary: Sound

Many autistic people experience hyperacusis – 'an unusual intolerance to ordinary environmental sounds'.

Many autistic people process one thing at a time and can't 'tune out' inputs.

Sound is a major source of sensory input in CAMHS inpatient environments and was the first thing that many of the young people who contributed to this paper mentioned. Examples include:

- Alarms were a major cause of distress for many who contributed to this paper. We recommend that providers switch to 'silent' alarm systems.
- Doors can be very noisy when opening and closing. For some autistic people, this can deliver frequent but unpredictable shocks.
- Curved or slanting walls and ceilings can cause sound to echo in different directions and frequencies. This can make it difficult for some people to orientate themselves in the space.
- Heating and cooling systems often make a lot of noise that some people find impossible to 'block out'.
- Extractor fans in bathrooms and kitchens can be very noisy. We recommend that these are on separate circuits that can be turned on and off independently of the lights.
- Noises from other people. It's important that individuals have access to quiet areas.

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.

Vision can support meaning, connection and self-expression.

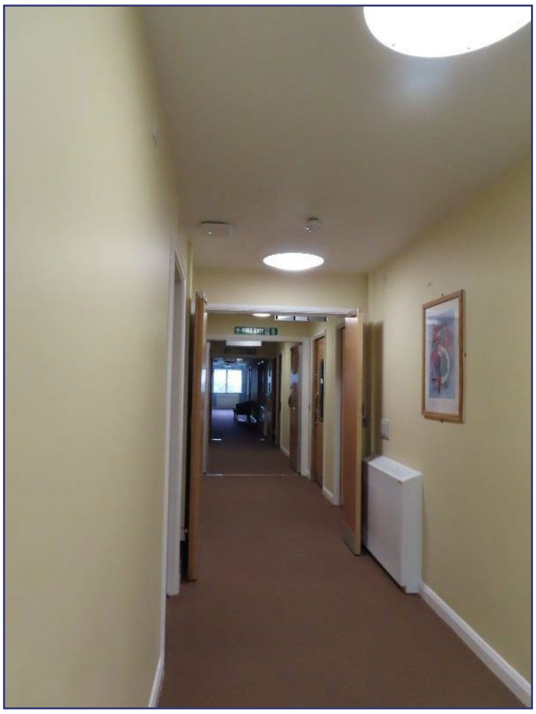
Visual stimulation can be a source of comfort and joy and can also lead to sensory overwhelm. It is possible to neutralise visual stimulation to reduce the impact of this.

Lighting

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.

The photos before illustrate how Ann Memmott (NDTi Associate) sees the entrance hall to a CAMHS ward (taken during a sensory environment review) compared to how most neurotypical people would see it. The picture on the right shows the intense colours and patterns that Ann would see. It isn't possible to show the intense flickering strobe like effect that fluorescent lighting creates.

In this environment, other sensory input becomes harder to tolerate and the cumulative effect is sensory overload. For Ann, time in this environment causes extreme exhaustion. Her brain starts to shut down and she loses the ability to



engage with other people or to communicate verbally. A scary prospect that causes physical pain.

> "The bright lights in hospital were overwhelming."
> Jamie

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.

Recommendation: Replace all fluorescent lights with alternatives – ideally halogen, or quality LED bulbs if this is not possible.

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.

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.

Recommendation: Use diffused lighting options where possible. Where this is not possible (eg for clinical or safety reasons) include alternatives to provide flexibility and comfort.

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

Recommendation: Uncover windows to provide visibiltiy to outside spaces wherever possible.

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

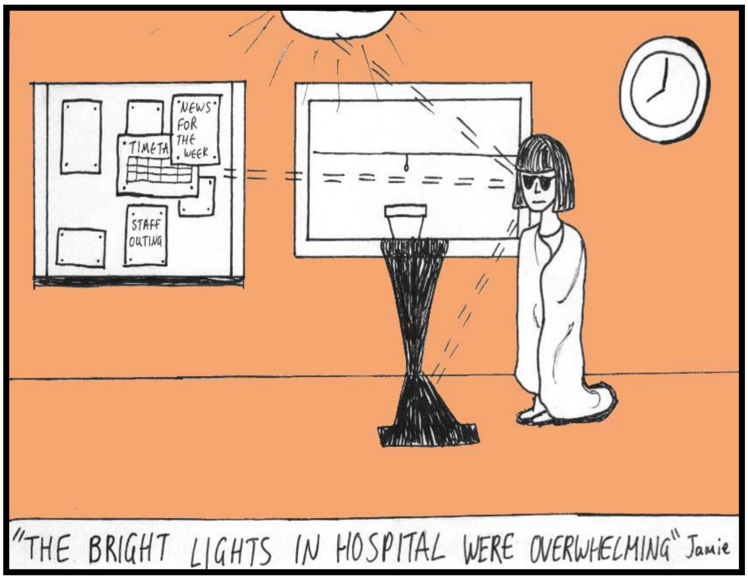
Recommendation: Ensure all natural and artificial light can be shut out – particularly in bedrooms and high support areas.

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.

Recommendation: Ensure that there are not significant changes in light levels around the building.



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.

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.

Recommendation: Use calm, neutral colours in communal areas.

Support personalisation of individual areas, such as bedrooms. Where children and young people are expecting relatively short stays in hospital, this can be supported by including notice boards and areas that posters can be put on walls.

Recommendation: Make it easy and give permission for people to personalise bedrooms.

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)

Some people like busy walls and visual stimulus – particularly where items are linked to their hobbies and interests or family life. Other people have a strong preference for a clear spaces and storage keeping items out of view.

This needs to be considered in all areas that children and young people access – including communal spaces, therapy areas, education spaces, and clinic areas.

Recommendation: Ensure there is good storage and limited visual clutter in communal spaces (including education, therapy and clinic areas that individuals access).

Some people will be noticeably distressed if their personal items are moved or touched. Where checks are necessary for safety reasons, it can help to:

- Explain to the person what is happening and why.
- Invite them to choose a trusted staff member to work with and a time that works for them.
- Don't rush, allow children and young people time to process what is happening and why.
- Wherever possible, work with the person to move their own items and to take part in the check.
- Put things back in the same place as they were found, as precisely as possible.
- Ensure that checks are proportionate – that the safety measure is necessary given the likely distress that will be caused.

Recommendation: Provide storage options for people's belongings and special interests in bedrooms.

Some people find it difficult to process depth and space. This may present as children and young people bumping into things a lot, particularly in new spaces.

Recommendation: Ensure that steps and shelves etc have clearly marked edges (a strip with in a different colour is a good way to do this) to give context to depth.

Recommendation: Support children and young people to be involved in checks on their personal spaces and private belongings.

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.

Recommendation: Support children and young people to access visual stims. Ideally, this is personalised to individual need and interest. This might include, posters, belongings and special interests being on display.

Summary: Sight

Fluorescent lights are the most challenging light source for many autistic people. The preferred lighting sources for many autistic people, after natural light, are incandescent bulbs such as tungsten and halogen. LEDs are better than fluorescent lights, but might flicker or 'hum'.

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 and entirely close out natural light, particularly in bedrooms.

Consistent lighting between areas and glass panels in and surrounding doors can help make movement between spaces easier.

Bland, pastel and plain colours make for an easier sensory environment.

Calm, clutter free environments are often easier for people to process.

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.

> “It smelt very strongly of chlorine and cleaning fluid and bleach. It was all day. It can give my headaches.”
> @AutisticPB

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.

Where strong odours are unavoidable, vapour rub, body spray or roll-on scented aromatherapy can be used 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.

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.

> “The smell of cleaning products tipped me into sensory overload. It would be good to swap these for products that don’t smell.”
> Jamie

Recommendations: 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.

Recommendation: Being able to close doors and reduce the transmission of smells between rooms can be helpful.

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

Recommendation: Ensure that sensitivity to smell is considered when allocating en-suite rooms and rooms close to communal areas, including kitchens, dining rooms and bathrooms.

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.

Recommendation: It may be beneficial for staff and visitors to avoid using perfumes and aftershaves.

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.

Summary: 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.

Problem smells might include cleaning products, laundry products, food smells and other people.

Taste

This paper focuses on the physical sensory environment in CAMHS inpatient environments. 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.

> "The dining room often made me very anxious, it took me up to 30 mins to make myself go in just because of how overwhelming it could be sensory wise. It was often quite loud as the eating disorder patients found mealtimes tricky so there was a lot of shouting and crying, there would be the sound of everyone chewing/ cutlery which I sometimes find quite difficult to deal with."
> Beth W

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 children and young 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.

Dining areas should be lit with 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.

Recommendation: Dining areas have good natural light.

Recommendation: Dining areas are lit with halogen bulbs, or quality LED bulbs and not fluorescent bulbs.

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.

In some locations, the kitchen is adjacent to the dining room and has a large serving hatch so noise from the kitchen carries into the dining room.

Recommendation: The auditory environment is considered in all dining areas and soft furnishings and sound absorbing panels added to reduce echo.

Recommendation: Where carpet isn't appropriate, acoustic vinyl flooring is used to reduce noise.

Recommendation: All chairs and tables have felt cushions added to the bottom of the legs to reduce the noise from movement of furniture.

Recommendation: Noise reducing plates and cutlery are selected.

Recommendation: Children and young people have the choice to eat at quiet times and away from other people.

Recommendation: Kitchens are separated rather than joined or through a hatch, so noise does not carry between spaces.

Smell

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

Recommendation: Children and young people have the choice and option to eat in areas away from the smell of cooking and other foods.

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.

Many autistic people have strong feelings about the texture of foods, and how foods are arranged on a plate- for example, if they're 'touching' or not.

Recommendation: Food separators are available for those that would like to use them, and serving preferences are invited and followed (for example, wet items such as beans are served in a separate bowl, or hot and cold foods are served on separate plates).

Recommendation: Ensure that seating is comfortable. Cushions with removable covers can make dining furniture more comfortable.

Recommendation: Provide cutlery options (possibly including cutlery with handles and plastic options) and understand that some people may be more comfortable eating without using cutlery.

Recommendation: Support food choices and individual control wherever possible – including for people who are on a food plan. A choice between suitable alternatives can help, even when options need to be limited for health reasons.

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).

Recommendation: Supportive seating and reduced external sensory input can make this easier for some people.

The sensory 'load' that is added at mealtimes makes it particularly important that other sensory stimulus is reduced. Therefore, it is so important that children and young 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.

> "I struggled eating in the cafeteria because it was so noisy. I got into trouble for not eating. My dressing gown was like a comfort blanket, it kept me calm, but I wasn't allowed to wear it in the cafeteria. I wasn't allowed to eat in a different room either."
>
> Caitlin

Recommendation: Children and young people are supported to choose whether they eat with other people who are eating. (Note: some children and young people may require staff support or supervision, but this could be in a quiet space away from others and from additional sensory input).

Recommendation: Children and young people are supported to consider what would help them to be more comfortable, and reasonable adjustments made to support this whenever possible.

For many neurotypical people, mealtimes are 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.

We have heard that some children and young people feel they need to skip meals rather than enter a challenging sensory environment. Other people told us that their routines did not coincide with the hospital routines, meaning that they sometimes had to miss meals.

> "In one place they wouldn't let us have breakfast if we woke up after breakfast time. They stopped serving food at 8.30, and if you missed that you didn't eat until lunchtime. I developed problems with eating because of restrictions. It reinforced in my head that I didn't need to eat."
> Caitlin

Recommendation: Children and young people are supported flexibly in a way that meets their needs.

Treatment and support for eating disorders, or recommendations specifically relating to this fall outside the scope of this report. However, it is important to acknowledge the significant co-morbidities and research gaps relating to this, as this paper references taste and young people's experiences of food and eating in inpatient hospitals.

Westwood and Tchanturia's (2017) literature review found that 'studies consistently report over-representation of symptoms of (autism) in Anorexia Nervosa', with some studies identifying up to 37% of those being treated for anorexia are also autistic. They suggest that this co-morbidity may require more intensive and/or targeted interventions. Kinnard et al (2017) found that 'many clinicians lack confidence in treating this comorbidity, which requires specific changes to treatment to accommodate the issues raised by comorbid (autism).'

Autistic people are more likely than the general population to experience Avoidant / Restrictive Food Intake Disorder (ARFID). Shea (2016) identifies that the ARFID pattern of eating is common in autistic individuals and that 'sensory sensitivity is likely to be one of the underlying causes'.

Some people have sensory sensitivity that does not meet ARFID diagnostic criteria. Some people find that food separators can be helpful at mealtimes. Many people could benefit from additional choice and control at mealtimes to ensure that they are supported to make healthy and balanced choices, while meeting their sensory needs.

> "I ate a lot of jacket potatoes while I was in hospital. It wasn't great for nutrition. Sometimes I just had a potato on its own. I won't eat tuna and they wouldn't let me have beans instead. It's really hard because there's no option to stand up for yourself and say it's part of my condition. It's not how it should have been. It was hard."
> Charli

Unfortunately, flexibility, choice and control in relation to food and mealtimes was the exception rather than the norm in the experiences of the young people that we spoke to.

> "There was no flexibility with food. It was brought over from the adult ward across the car park, and half the time it was cold. I didn't like the food, but they didn't want you cooking your own food because there wasn't enough staff. They didn't like us cooking at mealtimes because they said it discouraged other people from eating their food."
> Emily

Recommendation: Clinicians treating those with eating disorders or disordered eating, like all staff, have quality autism training led by autistic people and with reference to current research and practice.

Recommendation: Staff are supported to understand that sensory sensitivity may present in relation to food.

Recommendation: There is a focus on providing quality food, with a range of options tailored to individual need as required.

Summary: Taste

A higher proportion of autistic people than of neurotypical people have eating disorders or disordered eating.

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.

It can be helpful for people to have choice and control over where they eat, and if they eat with other people or alone. Some people may need staff support, even if they choose a lower sensory input environment.

There is an 'over-representation' of autistic people with Anorexia Nervosa and avoidant / restrictive food intake disorder. This may require more intensive and/or targeted interventions.

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.

> "It felt very clinical, like a general hospital which isn't ideal for a psychiatric unit as it just didn't feel very homelike. I remember everything feeling quite rough to touch e.g. The towels, duvet cover, carpet etc and I find it very hard sensory wise if things aren't very soft."
> Beth W

Textiles – including clothing and bedding

For people who are hyper or hypo sensitive to touch, getting clothing right can make a significant difference to sensory management. Many people will bring clothing that suits them, but this may be something to support children and young people to consider if this isn't the case. It may be helpful to explore different materials and styles – softer cloth, looser or tighter fit, cutting out tags and buying seamless socks may all enable children and young people to be more comfortable.

Sometimes children and young people are not permitted to bring their own bedding due to fire regulations. The skin is the body's largest organ. For autistic people who are hyper-sensitive to touch, having the right choice of clothing and bedding can be very important. Pillows can be very noisy when moving your head. Some materials can be scratchy and uncomfortable. Waterproof mattresses and duvets can be sticky, and noisy when moved.

Recommendation: Children and young people be invited to bring or choose their own pillows and bedding. This could also include information about standards that bedding needs to meet.

Recommendation: Invest in bedding that is as soft/smooth as possible. Consider a suitable range of options that would give children and young people a choice of materials.

Recommendation: Mattresses, pillows and bedding should be considered as a reasonable adjustment for some children and young people and waterproof options only used when required.

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.

> "I slept on the carpet for 2.5 months. I wouldn't get into bed because I was struggling with my OCD, I was struggling with having someone in the room on 1:1 with me. It was warm all the time in the bedrooms and it wasn't possible to control the temperature. I wasn't allowed my meditation app that I use to help me sleep."
> Emily

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.

Recommendation: It is also important to consider where staff will be located at night, what they might be doing, and what noise disruption this may cause for anyone trying to sleep.

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 space.

Recommendation: It is important to recognise that the impact of the unsuitable furniture can be significant for people with sensory sensitivity.

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

Some of the people who contributed to this report talked about the importance of being able to access their own belongings, including blankets. These items were often described as comfort or safety items that would support children and young people to feel calm and de-stress. Access to soft, sensory items can be very supportive, and can help to reduce contact with hospital furniture which can be cold, sticky or plastic.

Recommendation: Children and young people be supported to bring their own soft furnishing options, and use dressing gowns and blankets, including in communal areas. These can be used as a throw and can provide comfort in areas where there is not choice and control over textures or furniture.

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. Some may have difficulty standing for long.

Hypermobile joints are prevalent in autistic people. Having Hypermobility Spectrum Disorder (HSD) and Hypermobile Ehler-Danlos Syndrome (EDS) is also a common co-occurrence. (Csecs et.al. 2020). This can result in chronic pain, chronic fatigue, and frequent dislocations. Autistic individuals should be assessed for hypermobility before any restraint plans are implemented in care settings, due to the increased dangers of physical damage from restraint procedures.

> " My joints were so flexible/lax from HSD that deterioration in muscle tone through not moving much during admission caused my chronic pain to worsen and meant for two years after my legs collapsed under me constantly. I lost a lot of my mobility whilst in inpatient because I wasn't given the opportunity to go for walks and was barely moving. This not only meant two years of rebuilding my strength back after my admission, but also caused me significantly more pain that previous which impacted me hugely on a sensory level which no-one at the time could understand."
> Charli

Recommendation: Good quality supportive furniture can be helpful for children and young people with hyper-mobility.

Recommendation: Assessments are critical to ensuring that children and young people are well supported and understand how to look after themselves.

Recommendation: Children and young people are supported to stay active and mobile to maintain strength, movement, and muscle tone when in hospital.

Recommendation: Autistic individuals should be assessed for hypermobility before using any restraint procedures.

Washing

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

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. Toothbrushes and toothpaste can be a sensory barrier, as can hairbrushes and combs.

Some children and young 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'.

Recommendation: Working with individuals to understand their sensory needs and sensitivity can be helpful to exploring personal solutions that ensure children and young people are able to manage their sensory needs while also maintaining personal hygiene.

Recommendation: Adjustments to the temperature of water and room, materials to stand on getting in and out of the shower/bath, softness of the towel, smell of products etc may all be considered.

Recommendation: Timing of washing and other sensory inputs planned for the day may be helpful considerations for children and young people who find this an overwhelming sensory experience.

Recommendation: Enable a choice of toothbrushes and toothpaste, hairbrushes and combs, considering sensory needs and preferences.

Summary: 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.

Others experience hypotactility, a reduced sensitivity to touch.

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

Some of the people who contributed to this report talked about the importance of being able to access their own belongings, including blankets. These items were often described as comfort or safety items that would support people to feel calm and de-stress. Access to soft, sensory items can be very supportive, and can help to reduce contact with hospital furniture which can be cold, sticky or plastic.

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

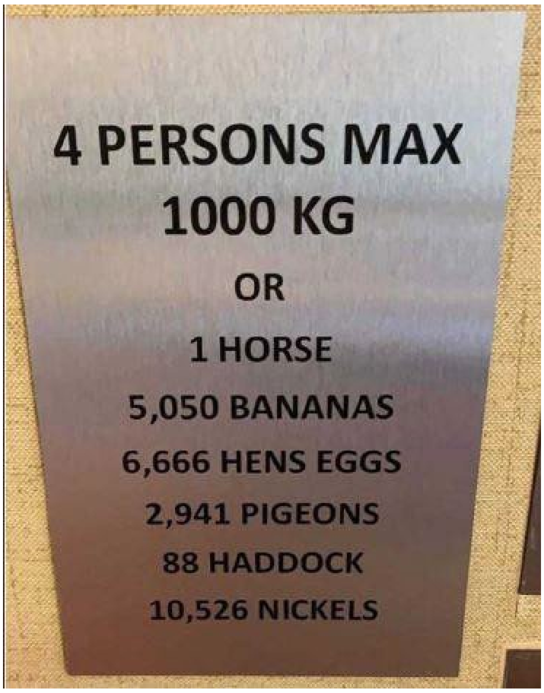
Working with individuals to understand their sensory needs and sensitivity can be helpful to exploring personal solutions that ensure children and young people are able to manage their sensory needs while also maintaining personal hygiene.

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.

Signage

Many buildings have insufficient or misleading signs. These may include door signs, directional signs and safety signs. All signs should be clear, placed in the best possible location, and be consistent. The photograph below shows a lift sign that is not entirely helpful.



This sign is a standard design for locating a fire exit. But it literally shows a man running towards an arrow that is pointing towards the ceiling. It assumes that everyone will simply know what it means.

Recommendation: Use clear written instruction as well as any statutory sign.

Shared spaces and communal living

Sharing spaces can mean limitations in choice and control for sensory stimulus, including unpredictable and uncomfortable sounds and smells, and challenges.

Shared spaces, including entrances, living rooms, kitchens, bathrooms, laundry rooms etc can also be anxiety-provoking. It can be overwhelming from a sensory perspective and may also have unpredictable social interaction demands.

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 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.

> "I found it too overwhelming to be in the main lounge most of the time, so I spent a lot of the time in the quiet room where I felt slightly safer. There weren't as many people in there and if you did go in there you had to be quiet. This made things easier sound wise. This did unfortunately lead to me feeling quite isolated as not many people came in and out."
> Beth W

People commented on the importance of being able to have private space to relax in and expressed a preference for being able to access bedrooms at any time, as this is the only space that individuals have control over.

Recommendation: Access to personal spaces can support children and young people to self-regulate. The people we spoke to acknowledged that there is a safety consideration but suggested that this should be made in relation to individual risk rather than fixed decisions.

Recommendation: Access to quiet spaces is important at all times.

People told us that it is important to be able to close doors between the different spaces and to be able to move away from other people when needed.

> "Sometimes people's needs were in conflict. For example, some people want the TV on and others need quiet. Some people stim to calm down but make a lot of noise doing it. It's important to have space and access to separate rooms."
> Emily

Buildings can be disorientating, especially in bigger buildings, when different doors and corridors look similar, and when there are limited views outside that could support orientation.

Recommendation: Clear signs may be important to support children and young people to comfortably access the space – particularly in larger buildings.

Summary: Shared spaces and communal living

Sharing spaces can mean limitations in choice and control for sensory stimulus, including unpredictable and uncomfortable sounds and smells, and challenges.

Shared spaces, including entrances, living rooms, kitchens, bathrooms, laundry rooms etc can also be anxiety-provoking. It can be overwhelming from a sensory perspective and may also have social interaction demands.

People told us it is important to be able to have private space to relax in and expressed a preference for being able to access bedrooms at any time, as this is the only space that individuals have control over.

Entrances and reception areas

Arrivals and entrances and initial greetings often 'set the tone'. A friendly greeting, being met by someone who has previously been identified, and clear instruction about what is expected on arrival can help to make arrival a positive experience.

Recommendation: A friendly greeting and clear instruction can support positive arrival experiences for patients and visitors.

Reception areas are often busy, loud and brightly lit. It can be helpful for doors to have glass panels that can be seen through and let natural light in. This helps to increase predictability – because it is possible to see into the building, and reduce the chance of a dramatic change in light levels. Both of these things can make transitions into and out of buildings easier.

Getting lighting right in this space and reducing other visual and auditory input is often benficial for reception and arrival areas.

In many hospitals, people entering the building must register at reception and visitors must store certain items in the lockers provided. People may spend some time in this area before entering the building.

Receptions are often relatively small spaces, with other people leaving or entering. There are often many doors connected to the reception space, which might add additional noise and uncertainty.

Sometimes people need to wait to be shown into the building, or for an airlock (when present) to be available. Smooth entry and exist is essential to ensure that people are not spending long times in overwhelming and unpredictable environments. This will be particularly important on first arrival.

It would be useful to establish an entry and exit policy that prioritises those that need it and clears the way when needed to ensure a smooth and quick transition.

Recommendation: Establish an entry and exist policy that will prioritise children and young people who will be disadvantaged or distressed by being required to wait in unpredictable and overwhelming environments.

Recommendation: Consider using the entry and exit at quiet times of day or staggering the use to ensure that corridors and reception areas are not busy, for example, there are likely to be more staff around the entrance at the end of a shift.

Airlocks

Common issues we experience with airlocks are:

- Long waits to access
- Noisy doors
- No natural light
- Metal key trays that clang, bang and scrape (fabric lining significantly reduces this)
- Bright 'traffic light' systems
- Lockers and other items 'cluttering' already small and stressful spaces
- Patterned carpets

Recommendation: Addressing these issues can help to ease transitions in and out of buildings.

High support and seclusion areas

For some people, accessing seclusion can be a traumatic experience. This can be exacerbated by inadequate facilities. Seclusion rooms are used when people are in extreme distress or crisis and are a risk to themselves or to other people.

Things that help to improve the sensory environment in high support and seclusion areas are similar to other areas.

Recommendations: High support and seclusion areas ...

- Are easy to access, without significant waiting or delays.
- Have good natural light from windows, ideally overlooking green areas and natural spaces.
- Have a variety of lighting options, none of which are fluorescent.

- Ability to fully control light levels – including from overhead lights, outside windows and internal windows.
- A quiet space – with consideration to all noise including heating and cooling systems, generators, nearby doors, electricity points, other support areas and corridors, ticking clocks, and supporting staff spaces.
- Leisure options and distractions, including access to TV and music.
- Outside areas – ideally quiet spaces with greenery and seating areas.
- Toilet and shower areas that can be accessed from the high support area without needing to access the seclusion room, or accessed from seclusion room without needing to pass through the high support area.
- Comfortable seating, including for those with mobility and support needs.
- Ability to control the temperature, no significant change in temperature from other support areas.
- Acoustic vinyl flooring to reduce the echo.
- Plain, neutral colours. If there are graphics in this area, this is limited to one wall, so it is possible to block out.

Education spaces

All of the recommendations that have been made for other spaces relating to the sensory environment apply here too.

In some of the hospitals that we have visited to complete sensory environment checks, we have found that classrooms have not had the same consideration as other areas – though they are in use for many hours a week.

Teaching staff should also be trained and have a good understanding of autism so sensory needs are accommodated and not confused for mental ill health or bad behaviour.

It is not uncommon for pupils to be told, for example, to look at the person who is talking. However, sensory processing can mean that for some autistic people, it is not possible to look at someone and listen at the same time. A current understanding of autism will help teachers to engage and better meet the needs of autistic students.

In classrooms it will be important to consider:

- Good natural light and non-fluorescent lighting.
- Minimising visual input by storing items tidily and in cupboards.
- Ensuring that at least one or two walls are relatively blank or neutral – this will enable children and young people to turn away from visual stimulus and focus on other things.
- That children and young people have a choice to enter and leave the space and have easy access to a quiet room nearby.
- Carpet or acoustic vinyl flooring to reduce echo and noise.

- Acoustic vinyl is used in art rooms, which can be particularly noisy and echoing spaces.
- All moveable furniture to have felt pads on the feet, to reduce the sound made when they move (not applicable if carpeted).
- Use of sound absorbing panels in big rooms and rooms with high ceilings.
- Ensuring that extractor fans can be turned on and off independently.
- Supporting children and young people to move to and work in quieter spaces as needed.
- Supporting children and young people to self-manage, including through use of noise cancelling headphones, stims, ability to keep a favourite safe item with them, and choice of seating, position, and movement.
- Furniture should be supportive.

Summary:

Entrances, reception areas and airlocks

Arrivals and entrances and initial greetings often ‘set the tone’. A warm greeting, being met by someone who has previsouly been identified, and clear instruction about what is expected on arrival can help to make arrival a positive experience.

Reducing sensory input by getting lighting right and reducing the noise from doors can help improve the accessibility of this area.

Smooth entry and exist is essential to ensure that people are not spending long times in overwhelming and unpredictable environments.

Some hospitals have ‘airlocks’ – rooms that manage and slow the entry and exit to the hospital. Airlocks can add delays and stress. Addressing these issues can help to ease transitions in and out of buildings.

Seclusion and high support areas

Seclusion rooms are used when people are in extreme distress or crisis and are a risk to themselves or to other people.

As with other areas, control over the sensory environment can help people to be more comfortable and to reduce sensory load. Access to natural light and outside space, control over lighting, leisure options and comfortable furniture can help to reduce the sensory load.

Education spaces, including classrooms

Sensory needs should be considered here too. Education rooms are sometimes overlooked, but it is important that they are neutral sensory spaces and people have good support and choice and control to consider their sensory needs.

Classrooms can be very busy visually, with other people and can also be noisy. Each space should be individually reviewed to reduce the negative impact on autistic pupils.

Admittance procedure

It is a CQC requirement that people have a health check within 72 hours on arrival.

Generally, the day of admission would not be a good time for a health check, unless there are urgent medical concerns that require immediate attention. People are likely to have had a challenging day and will have to cope with the sensory hazards between the entrance hall and the ward. They will be assimilating new information about staff and the building. They will need time to adjust and to orientate themselves.

Recommendations: We encourage teams to be flexible in their approach and consider what would work best for each person. Policies applied without individual consideration or adjustment are a potential human rights issue.

Recommendations: The CQC guidance for people to have a health check within 72 hours could be met in a more flexible way once the person has rested and settled. Giving children and young people a choice of days or times or splitting the health check over two days might make it easier for some people to tolerate and engage with.

Some autistic people are hypo-sensitive when it comes to understanding their internal feelings and messages from their body. It may be useful to explain the links between blood pressure and anxiety. Sharing information with children and young people about what is being checked and why and how the results will be useful may help people to engage more positively with the checks.

Recommendations: Introduce the idea of the health check before it is being done. Let children and young people know the reasons for the check, what will be measured and why.

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 space more comfortable 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. People we spoke to told us that limiting their access to personal belongings was distressing, likely to cause escalation of meltdowns or shutdowns, and didn't feel proportionate. People also told us that these decisions weren't explained, didn't make sense and were 'blanket' decisions, rather than individually assessed.

Recommendations: The authors of this report do not believe that it is appropriate to limit access to items connected to interests and hobbies (safety reasons notwithstanding), 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, and an additional 25% would be very upset.

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. It is however a large enough group of autistic people to be considered important in guiding thinking, discussion and planning. Link to poll and comments: https://twitter.com/AnnMemmott/status/1322089326533087232

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.

> "I was on 1:1 support and this often meant that there were men in my room overnight. Regular male staff were great, it's easier if you know them, but it was often people I'd never met before. I asked to go home because I didn't feel safe and it made me more stressed. They told me they didn't have enough female staff."
> Emily

Recommendations: Listen to what children and young people express (verbally or in other ways) to be and to feel safe.

Recommendations: Women and girls should be supported by women – particularly when they request this, and particularly on 1:1s at night. A support request from anyone relating to the gender of the person supporting should always be considered and prioritised.

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

Changes to staff 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.

Recommendations: Prioritise predictability and consistency of support and understand that this may cause distress if/when it is not possible. Support children and young people to have as much information as is helpful to them in a timely way to process changes. Work with individuals to consider their individual support needs relating to this.

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 children and young people will ask who is working and when. People ask, sometimes repeatedly, because it matters to them.

Recommendations: If maintained and accurate, a visual timetable may support children and young 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.

Summary: Admittance procedure, interests and hobbies and support

Admittance procedure

This should be done in a way and at a time that works best for the person. Unless there is an urgent medical concern it would be better not to do this on the day of arrival. It can be helpful to explain what will happen and why.

Interests and hobbies

People should have access to their belongings and things that are important to them. This can help people to feel more comfortable and less anxious.

Support

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

Women and girls should be supported by women – particularly when they request this, and particularly on 1:1s at night.

It can be helpful for staff teams to prioritise predictability and consistency of support and understand that this may cause distress if/when it is not possible. Support people to have as much information as is helpful to them in a timely way to process changes. Work with individuals to consider their individual support needs relating to this.

Summary of recommendations

Recommendations in blue relate to locations other than CAMHS hospitals

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
Sensory processing	19	The sharing of information with peers is something that services can support.		
Building support	22	Screen all inpatients for sensory needs and autism, and assess those who pass a screening threshold.		
Diagnosis	27	Data collection and recording and services need to consider a range of gender identities for everyone, and particularly for the autistic population they support.		
Community Colleagues	27	Different ‘flags’, or identifiers may be required to ensure that people who need support are not missed.		
Community Colleagues	27	Community teams and schools may also benefit from training and development support to ensure that they understand how autistic girls might present.		
Dr Ruth Moyse’s research	28-29	“Just listen. It’s not rocket science, just listen” “Be Curious” “Prioritise pupil wellbeing” “Take action” “Be “more informed about being autistic, and what autism was”		
Community Colleagues	30	The approach suggested by Moyse above could be applied in relation to everyone who is identified on the DSR.		
Community Colleagues	31	Every child and young person who is at risk of admission is added to DSR databases and has a community CETR, not just those with a confirmed diagnosis. If it is not possible to extend this to every child and young person, it is extended to people who are waiting for a diagnosis and those who self-identify.		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
Community Colleagues	32	Alternative, appropriate, timely, predictable support for autistic children and young people is provided in a location with a good sensory environment.		
A&E departments	32	In locations where there are no alternatives to A&E, ensure that staff are aware that people are being signposted there, have good autism knowledge, and have appropriate sensory environments for those who are waiting and admitted.		
Shutdown and meltdown	36	Staff training and support approaches are updated to reflect the latest research. Staff attend training delivered by autistic trainers with current knowledge and understanding of autism viewed as a sensory processing difference.		
Shutdown and meltdown	36	Individual care plans include reference to sensory needs and provide individual support to enable improved experiences and outcomes and to support restraint reduction.		
Self management and self regulation	42-45	These suggestions should be considered with and for autistic individuals admitted to inpatient wards to support self-regulation. • Hats and Caps • Sunglasses • Noise Cancelling Headphones • Leaning on walls, crossing legs, weighted blankets, weighted backpacks. • Choice and control over where to spend time • Taking time out • Access to personal belongings • Stimming • Swinging and bouncing • Pets • Outside Space • Sensory room or de-stress room • Contact with friends and family		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
Predictable environments	47	Work with individuals to understand what challenges they might experience with a change of location, environment and routine and consider together how these could be addressed to minimise the impact.		
Predictable environments	48	Support regarding the transition to hospital will ideally be tailored to the individual. It could involve an assessment of the person's normal routine and explore how aspects of it could be implemented within the hospital environment.		
Predictable environments	48	Ensure that all staff are honest and transparent about potential timescales and keep children and young people regularly informed of any changes to these.		
Predictable environments	49	Use either general or personalised timetables to structure the time on the ward. This should be followed closely as possible, and children and young people should be informed of any changes as soon as possible.		
Predictable environments	50	Implement a system which allows children and young people to have access to the list of staff scheduled to be in the following day. However, make sure people are aware that due to illness or unforeseen circumstances, there is the possibility of the list not always matching who will be there the next day.		
Predictable environments	51	Ensure that changes made to the physical appearance or layout of the ward are kept to a minimum. If things do need to change, ensure that sensory needs are considered, and children and young people in hospital are involved and informed during the process.		
Culture and approach	52	Start by listening (and then act)		
Culture and approach	53	Make sure all staff are autism informed.		
Culture and approach	54	Screen everyone admitted and assess those who need it. Use findings to inform individual care planning.		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
Culture and approach	55	Screen everyone who is admitted for autism, using modern best-practice tools, and undertake full assessments promptly for those who need it.		
Culture and approach	55	Assess the sensory needs of everyone who is admitted to hospital.		
Culture and approach	55	Individual care plans consider sensory need and support that is required in relation to sensory triggers.		
Culture and approach	55	Discharge plans are made early, involve the individual, and consider how support will be 'handed over' from inpatient to community services.		
Culture and approach	55	Personalise communication and information.		
Culture and approach	56	Personalise risk management and decision making.		
Eight senses	68	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.		
Sounds	74	Staff are trained in autism, including the sensory experience and how differently some autistic people perceive and process auditory input.		
Sounds - alarms	75	It is strongly recommended that CAMHS inpatient hospitals use silent alarms.		
Sounds - alarms	75	Alarm response and support considered as part of individual care planning.		
Sounds – alarms	75	Information shared with people, as appropriate, about planned alarms and tests.		
Sounds - doors	75	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		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
		closers (also referred to as door arms) to ensure that they shut but do not slam. However, door closers can pose a safety risk and are not appropriate for all areas.		
Sounds - doors	76	Glass panelling in and around doors can make transitions easier.		
Sounds - flooring	76	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.		
Sounds - flooring	76	When wipe-down surfaces are required, acoustic vinyl may be the best option for reducing ambient noise and creating a more comfortable environment.		
Sounds – outside noise	77	Consider what external noise is present (as well as internal noise) when considering how different rooms and spaces are used.		
Sounds – outside noise	77	For some rooms where outside noise cannot be avoided, acoustic glass may be beneficial.		
Sounds – building structure	77	Consider how building shape, wall angles and ceiling height might impact people's experience of the space.		
Sounds – building structure	78	Carpet and soft furnishings can reduce the impact of this, and the addition of sound absorbing panels can help in some spaces.		
Sounds – building structure	78	If curved walls are a clear need for a particular autistic person or small group, consider demountable curved partitioning for a space.		
Sounds - appliances	78	Regularly service heating and forced air systems, ask the staff servicing the systems to reduce noise and vibrations as far as possible.		
Sounds – appliances	78	Consider this sometimes 'invisible' or unheard background noise when allocating rooms – in our experience it varies significantly in different rooms.		
Sounds - appliances	78	It can be helpful to consider and agree in advance when noisy activities such as hoovering, and washing will take place.		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
Sounds - appliances	78	We strongly recommend that extractor fans are put on a separate circuit with separate switch - particularly in en-suites, shared bathrooms and kitchens.		
Sounds – keys	79	Consider noise from keys and fobs and take action to reduce this noise.		
Sounds – radio and TV	79	Radios and TVs are turned off when not in use.		
Sounds – radio and TV	79	Consider encouraging the use of headphones overnight (eg between 10pm and 7am) – even in communal spaces.		
Sounds – talking	79	Consider how soft furnishings can be used to reduce echo and the distance that sound travels, where additional doors may be helpful in reducing noise, and when additional sound absorbing materials may be needed.		
Sounds – expressions of distress	80	It is important for people to have space to move away from others, and access to quiet rooms and areas.		
Sight - lighting	82	Replace all fluorescent lights with alternatives – ideally halogen, or quality LED bulbs if this is not possible.		
Sight – lighting	82	Use diffused lighting options where possible. Where this is not possible (eg for clinical or safety reasons) include alternatives to provide flexibility and comfort.		
Sight – lighting	82	Uncover windows to provide visibiltiy to outside spaces wherever possible.		
Sight - lighting	82	Ensure all natural and artificial light can be shut out – particularly in bedrooms and high support areas.		
Sight - shadows	83	Ensure that there are not significant changes in light levels around the building.		
Sight - colour	83	Use calm, neutral colours in communal areas.		
Sight - colour	83	Make it easy and give permission for people to personalise bedrooms.		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
Sight - storage	84	Ensure there is good storage and limited visual clutter in communal spaces (including education, therapy and clinic areas that individuals access).		
Sight – storage	84	Provide storage options for people's belongings and special interests in bedrooms.		
Sight – storage	84	Ensure that steps and shelves etc have clearly marked edges (a strip with in a different colour is a good way to do this) to give context to depth.		
Sight - storage	84	Support children and young people to be involved in checks on their personal spaces and private belongings.		
Sight - storage	85	Support children and young people to access visual stims. Ideally, this is personalised to individual need and interest. This might include, posters, belongings and special interests being on display.		
Smell - household	86	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		
Smell – household	87	Being able to close doors and reduce the transmission of smells between rooms can be helpful.		
Smell - household	87	Ensure that sensitivity to smell is considered when allocating en-suite rooms and rooms close to communal areas, including kitchens, dining rooms and bathrooms.		
Smell – other people	87	It may be beneficial for staff and visitors to avoid using perfumes and aftershaves.		
Taste - sight	89	Dining areas have good natural light.		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
Taste - sight	89	Dining areas are lit with halogen bulbs, or quality LED bulbs and not fluorescent bulbs.		
Taste - sound	90	The auditory environment is considered in all dining areas and soft furnishings and sound absorbing panels added to reduce echo.		
Taste - sound	90	Where carpet isn't appropriate, acoustic vinyl flooring is used to reduce noise.		
Taste - sound	90	All chairs and tables have felt cushions added to the bottom of the legs to reduce the noise from movement of furniture.		
Taste - sound	90	Noise reducing plates and cutlery are selected.		
Taste - sound	90	Children and young people have the choice to eat at quiet times and away from other people.		
Taste - sound	90	Kitchens are separated rather than joined or through a hatch, so noise does not carry between spaces.		
Taste - smell	90	Children and young people have the choice and option to eat in areas away from the smell of cooking and other foods		
Taste - touch	90	Food separators are available for those that would like to use them, and serving preferences are invited and followed (for example, wet items such as beans are served in a separate bowl, or hot and cold foods are served on separate plates).		
Taste – touch	91	Ensure that seating is comfortable. Cushions with removable covers can make dining furniture more comfortable.		
Taste – touch	91	Provide cutlery options (possibly including cutlery with handles and plastic options) and understand that some people may be more comfortable eating without using cutlery.		
Taste - touch	91	Support food choices and individual control wherever possible – including for people who are on a food plan. A choice between suitable alternatives can help, even when options need to be limited for health reasons.		
Taste - proprioception	91	Supportive seating and reduced external sensory input can make this easier for some people.		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
Taste – proprioception	91	Children and young people are supported to choose whether they eat with other people who are eating. (Note: some children and young people may require staff support or supervision, but this could be in a quiet space away from others and from additional sensory input).		
Taste – proprioception	92	Children and young people are supported to consider what would help them to be more comfortable, and reasonable adjustments made to support this whenever possible.		
Taste – proprioception	92	Children and young people are supported flexibly in a way that meets their needs.		
Taste – proprioception	93	Clinicians treating those with eating disorders or disordered eating, like all staff, have quality autism training led by autistic people and with reference to current research and practice.		
Taste – proprioception	93	Staff are supported to understand that sensory sensitivity may present in relation to food.		
Taste - proprioception	93	There is a focus on providing quality food, with a range of options tailored to individual need as required.		
Touch - textiles	94	Children and young people be invited to bring or choose their own pillows and bedding. This could also include information about standards that bedding needs to meet.		
Touch – textiles	94	Invest in bedding that is as soft/smooth as possible. Consider a suitable range of options that would give children and young people a choice of materials.		
Touch – textiles	95	Mattresses, pillows and bedding should be considered as a reasonable adjustment for some children and young people and waterproof options only used when required.		
Touch - sleep	95	It is also important to consider where staff will be located at night, what they might be doing, and what noise disruption this may cause for anyone trying to sleep.		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
Touch - furniture	95	It is important to recognise that the impact of the unsuitable furniture can be significant for people with sensory sensitivity.		
Touch - furniture	96	Children and young people be supported to bring their own soft furnishing options, and use dressing gowns and blankets, including in communal areas. These can be used as a throw and can provide comfort in areas where there is not choice and control over textures or furniture.		
Touch - hypermobility	96	Good quality supportive furniture can be helpful for children and young people with hyper-mobility.		
Touch – hypermobility	96	Assessments are critical to ensuring that children and young people are well supported and understand how to look after themselves.		
Touch – hypermobility	96	Children and young people are supported to stay active and mobile to maintain strength, movement, and muscle tone when in hospital.		
Touch - hypermobility	96	Autistic individuals should be assessed for hypermobility before using any restraint procedures.		
Touch - washing	97	Working with individuals to understand their sensory needs and sensitivity can be helpful to exploring personal solutions that ensure children and young people are able to manage their sensory needs while also maintaining personal hygiene.		
Touch – washing	97	Adjustments to the temperature of water and room, materials to stand on getting in and out of the shower/bath, softness of the towel, smell of products etc may all be considered.		
Touch - washing	97	Timing of washing and other sensory inputs planned for the day may be helpful considerations for children and young people who find this an overwhelming sensory experience.		
Touch - washing	97	Enable a choice of toothbrushes and toothpaste, hairbrushes and combs, considering sensory needs and preferences.		
Signage	99	Use clear written instruction as well as any statutory sign.		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
Shared spaces	100	Access to personal spaces can support children and young people to self-regulate. The people we spoke to acknowledged that there is a safety consideration but suggested that this should be made in relation to individual risk rather than fixed decisions.		
Shared spaces	100	Access to quiet spaces is important at all times.		
Shared spaces	101	Clear signs may be important to support children and young people to comfortably access the space – particularly in larger buildings		
Entrances and reception areas	101	A friendly greeting and clear instruction can support positive arrival experiences for patients and visitors.		
Entrances and reception areas	102	Establish an entry and exist policy that will prioritise children and young people who will be disadvantaged or distressed by being required to wait in unpredictable and overwhelming environments.		
Entrances and reception areas	102	Consider using the entry and exit at quiet times of day or staggering the use to ensure that corridors and reception areas are not busy, for example, there are likely to be more staff around the entrance at the end of a shift.		
Airlocks	102	Addressing these issues can help to ease transitions in and out of buildings: • Long waits to access • Noisy doors • No natural light • Metal key trays that clang, bang and scrape (fabric lining significantly reduces this) • Bright 'traffic light' systems • Lockers and other items 'cluttering' already small and stressful spaces • Patterned carpets		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
High support and seclusion areas	102-103	• Are easy to access, without significant waiting or delays. • Have good natural light from windows, ideally overlooking green areas and natural spaces. • Have a variety of lighting options, none of which are fluorescent. • Ability to fully control light levels – including from overhead lights, outside windows and internal windows. • A quiet space – with consideration to all noise including heating and cooling systems, generators, nearby doors, electricity points, other support areas and corridors, ticking clocks, and supporting staff spaces. • Leisure options and distractions, including access to TV and music. • Outside areas – ideally quiet spaces with greenery and seating areas. • Toilet and shower areas that can be accessed from the high support area without needing to access the seclusion room, or accessed from seclusion room without needing to pass through the high support area. • Comfortable seating, including for those with mobility and support needs. • Ability to control the temperature, no significant change in temperature from other support areas. • Acoustic vinyl flooring to reduce the echo. • Plain, neutral colours. If there are graphics in this area, this is limited to one wall, so it is possible to block out.		
Admittance Procedures	106	We encourage teams to be flexible in their approach and consider what would work best for each person. Policies applied without individual consideration or adjustment are a potential human rights issue.		

Theme or area	Page	Detail (see full report for more info)	Responsible person	Date to be completed
	106	The CQC guidance for people to have a health check within 72 hours could be met in a more flexible way once the person has rested and settled. Giving children and young people a choice of days or times or splitting the health check over two days might make it easier for some people to tolerate and engage with.		
	106	Introduce the idea of the health check before it is being done. Let children and young people know the reasons for the check, what will be measured and why.		
Interests and hobbies	107	The authors of this report do not believe that it is appropriate to limit access to items connected to interests and hobbies (safety reasons notwithstanding), or to use these as a punishment or reward.		
Support	108	Listen to what children and young people express (verbally or in other ways) to be and to feel safe.		
Support	108	Women and girls should be supported by women – particularly when they request this, and particularly on 1:1s at night. A support request from anyone relating to the gender of the person supporting should always be considered and prioritised.		
Support	108	Prioritise predictability and consistency of support and understand that this may cause distress if/when it is not possible. Support children and young people to have as much information as is helpful to them in a timely way to process changes. Work with individuals to consider their individual support needs relating to this.		
Support	108	If maintained and accurate, a visual timetable may support children and young people to process and predict who will be working with them, and when.		

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.

The content for the paper was coordinated by Jill Corbyn. Chris Memmott, Ann Memmott and Kirsten Newton advised on content, approach, and involvement. Kirsten helped to tailor our information and approach to be suitable for young adults.

Chris, Ann and Kirsten worked to ensure that:

- We asked the right things – that our questions were appropriate and targeted to inpatient settings.
- We asked in the right way, providing the right information and detail to enable people to process and engage.
- We had the right support in place.
  Over the engagement period, a qualified psychologist with experience of working with autistic people was available for contributors to get support if needed. Times were advertised and all contributors had the details to make contact if needed.
- We share control and ownership of content with contributors. This included inviting people to suggest different things to include. We also give 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 their views and experiences.
- 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.

Although this is not a research paper, because we approached people to ask about their experiences the NDTi ethics framework was applied.

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

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