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Improving the Sensory Environments of Mental Health in-patient Facilities for Autistic Children and Young People

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ABSTRACT

Poor mental health—compared to that of the neurotypical child population—is a serious concern for many autistic children and young people around the world. In the UK, we have an increasing number of autistic young people receiving care in NHS funded inpatient mental health facilities. While sensory processing differences have now been added to international diagnostic criteria for autism, recent autistic-led and co-produced, practicebased research commissioned by the Children and Young People's Mental Health Taskforce and delivered by National Development Team for Inclusion has identified that knowledge of autistic sensory differences and needs is institutionally absent. In particular, the sensory environments of NHS England-funded inpatient facilities were found to present sometimes extreme challenges for autistic young people that at best hinder wellbeing and at worst exacerbate existing mental health problems: instigating a cycle of progressing upwards through increasingly restrictive settings for some. This paper shares some of this learning, gained from the consultation with young autistic people who have experience of inpatient services and autistic *Experts by* Experience working on novel sensory ward environment reviews. We first introduce the framing of autism as primarily shaped by sensory and social processing differences and outline the significance of this perspective for the in-patient care of autistic young people and children. We then provide an overview of the current sensory challenges that exist in inpatient mental health facilities for autistic children and young people. Finally, we conclude with some suggestions for areas of future research around the impact of adapting ward environments, that have promise for broader and international settings.

KEYWORDS

Mental health; autistic children and young people; sensory differences; sensory environments; NHS England

Introduction

Poor mental health—compared to that of the neurotypical child population—is a serious concern for many autistic children and young people (Crane et al., 2019; Simonoff et al., 2008; Strang et al., 2012). It is unsurprising then that in the UK, where our project was

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based, there are currently a rising number of autistic children and young people receiving care in NHS funded in-patient mental health facilities (NHS England, 2020).

There are many factors that can influence the wellbeing of autistic children and young people: things such as social stigma (Pearson & Rose, 2021; Perry et al., 2022); interpersonal victimisation and bullying (Bitsika et al., 2021; Lung et al., 2019); intersectional issues relating to race (Begeer et al., 2009; Dababnah et al., 2018; Jones & Mandell, 2020) and gender (Davidson & Tamas, 2016; Kourti & MacLeod, 2019); parent wellbeing and behaviour (Cheak-Zamora & Teti, 2015; Giallo et al., 2013) and barriers to education (Moyse & Porter, 2015) and diagnostic and support services (Westminster Commission on Autism, 2021) can all play a part. This paper takes as its focus the often overlooked influence of the sensory environment, in this case specifically within NHS-funded inpatient mental health services. Once an inpatient, an autistic child or young person has limited control over all aspects of their environment, making the significance of *getting it right* all the more important. While other research has focused on the experience and reflections of caregivers or staff, this work is based on the experiences and lived expertise of autistic young people themselves.

Autism is increasingly being understood as way of being in the world that is shaped by sensory processing differences: something which has recently been recognised by international diagnostic criteria (DSM-5; American Psychiatric Association, 2013; ICD-11; World Health Organization, 2018). Within the UK context, in-patient mental health facilities—funded by the NHS—can present sometimes extreme sensory challenges for autistic children and young people. At best, these can hinder wellbeing and at worst exacerbate existing mental health problems: instigating an upwardly progressing cycle through increasingly restrictive settings.

In this paper, we first provide an overview of autistic children and young people's mental health in the UK (where this co-produced learning took place) before setting out the relatively new framing of autism as primarily shaped by sensory processing differences in the following section. We then share some of the learning from a recent co-produced, practice-based knowledge-production project, commissioned by the Children and Young People's Mental Health Taskforce and led by the National Development Team for Inclusion (NDTi). Finally, we conclude the article with a summary of the learning and how this might be applied in children and young people's mental health inpatient settings—and hospital settings more broadly—and some suggestions for areas of future research.

In terms of our positionality, two of the authors of this paper are autistic, and one spent time in an NHS Children and Adolescent Mental Health Service (CAMHS) inpatient facility as a teenager. One of us is an adoptive parent of three children with complex needs and a Child and Family Psychotherapist. Of the two lead authors, one led the consultation with autistic children and young people and *Experts by Experience* for the original commissioned report and both were involved in the editing of findings.

Autistic young people's mental health

In the United Kingdom, one in six children aged 5–16 are understood to have a mental health problem (NHS Digital, 2020). Autistic children and young people are even more likely to experience mental health difficulties (Crane et al., 2019; Simonoff et al., 2008;

Strang et al., 2012): with half of all neurodiverse children having "probable emotional problems" (Shum et al., 2021, p. 11), and at least one in ten accessing support from NHS Children and Adolescent Mental Health Services (CAMHS—Wistow & Barnes, 2009).

Indeed, Simonoff et al. (2008) found that 70 percent of young autistic people have one co-existing mental health issue with 41 percent having two or more (though not all reached the threshold for CAMHS intervention and support). The Covid-19 pandemic has worsened existing challenges, seeing a 29 percent increase in the overall number of children and young people in contact with mental health services between March 2020 and February 2021, (Mental Health Network, NHS Confederation, 2021, p. 15). In addition, the *Reaching The Tipping Point* report (Mental Health Network, NHS Confederation, 2021) notes that health inequalities for those with neurodevelopmental differences have also increased.

When young people hit a crisis point with their mental health difficulties, intensive support within a CAMHS inpatient ward is, within current cultural approaches to supporting mental health, often seen to be required by professionals and families, including the children and young people themselves. The number of autistic children and young people in CAMHS mental health hospitals has increased significantly in recent years (NHS England, 2020). Diagnoses of eating disorders and disordered eating are also increasingly responsible for children and young people being admitted to hospital (Mental Health Network, NHS Confederation, 2021): a condition known to disproportionately affect autistic individuals, despite difficulties in determining prevalence of autism in anorexia nervosa patients (Westwood & Tchanturia, 2017). Despite the growing presentation of autistic children and young people in inpatient mental health hospitals, there are currently no specialist CAMHS beds or wards for autistic people.

There is an important debate about whether or not inpatient units are helpful for children and young people and indeed adults and if so, under what circumstances (see for e.g. Hart et al., 2008; LeFrançois, 2020; Walker et al., 2017). However, beyond this debate and focussing solely here on a reformist agenda of ensuring maximum inclusion of autistic children and young people in current inpatient units, it is certainly the case that children and young people in general often find inpatient environments inflexible, unresponsive and not supportive of mental health (Reavey et al., 2017).

The transition into an inpatient unit can be disruptive for any child or young person, particularly when (in the UK) prospective inpatients are often transported to units far away from where they live. For autistic children and young people—who often rely on familiar people, places, items and routines to an even greater extent than other children and young people—this can be especially challenging:

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 (National Development Team for Inclusion – NDTi, 2021, p. 46).

In addition, and most relevant to this present paper: the sensory environments within mental health inpatient settings can be even more challenging for autistic children and young people, leading to additional distress and cognitive demand.

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Over the past year there has been an increasing institutional awareness of and focus on sensory environments within healthcare settings. Reports and reviews from the Care Quality Commission (CQC, 2020-the independent health and social care regulator for England), the Department of Health and Social Care (Hollins and Wood, 2021), and the National Quality Improvement Taskforce for children and young people's mental health inpatient services (NDTi, 2021) have all identified the relevance of sensory environments for the wellbeing of autistic people. Considering sensory sensitivities to lighting and noise levels (though not other senses) are also noted in the National Institute for Health and Care Excellence (NICE) guidelines for support and management of autistic young people under 19 years old (NICE, 2021) and The National Autism team at NHS England recently established a set of Sensory Friendly Ward Principles (NDTi, 2021, p. 10) to support improvements in the sensory environment in mental health inpatient settings. In the following section of this paper, we introduce the relatively new framing of autism as primarily shaped by sensory processing differences, and outline the significance of this perspective for the in-patient care of autistic young people and children.

Autism as a divergent sensory profile

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, p. 55).

Since some of the earliest descriptions of autistic individuals (Kanner, 1943), atypical sensory responses have been noted. However, it is only very recently that we have come to understand these sensory differences—often termed "atypical sensory reactivity" (Hannant et al., 2016, p. 2)—as an essential component of what it means to be autistic. Responding to a growing body of persuasive modern research, including that highlighting the neurological basis of autistic differences in sensory processing across all sensory domains (see Proff et al., 2021, for recent systematic review), the latest revisions to the international diagnostic criteria for autism (DSM-5; American Psychiatric Association, 2013; ICD-11; World Health Organization, 2018) now include hyper- and hypo-sensitivity to sensory stimuli under the umbrella of restricted or repetitive behaviours.

Autistic individuals often experience complex and varied patterns of hyper- and / or hypo-sensitivity to various sensory stimuli across all sensory-perceptual domains. Combined with difficulties coordinating movement, and muscle tone and postural differences that can also be common (De Jaegher, 2013), these contribute towards a divergent bodily way of being in the world. Understanding that the sensing and perceptual worlds of autistic children and young people are often very different to those of their non-autistic peers is essential to understanding the individual, their behaviour, and their needs:

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 (Grandin & Panek, 2014, p. 70).

While the above focuses on the five primary senses (sound, vision, smell, taste, touch), these only represent those belonging to the external sensory domain. We also possess three internal senses (Kranowitz, 2016): namely interoception (tuned into stimuli such as pressure, balance, temperature, thirst, hunger and pain), our vestibular system (relating to balance and our location within a given space) and proprioception (recognising the relative position of different parts of our body). The sensory differences experienced by autistic individuals can affect all eight sensory systems, and in different ways. One autistic young person may have heightened auditory and tactile sensitivity, for example, but diminished sensory responses to smell. Another may have hyposensitivity to pain, and poor balance and proprioception. The extents to which each individual sense is affected can vary, often dependent on context.

Many autistic children and young people will also have *single attention*: otherwise known as *monotropism* (Murray, 2018, 2020; Murray et al., 2005). The typical cognitive styles of non-autistic individuals tend to comfortably entertain multiple simultaneous interests, each moderately engaged, whereas those of autistic individuals tend to maintain only very few simultaneous interests: each one highly engaged and intensely focused upon. In terms of learning and developing passionate interests and skills, a monotropic attention style is very useful (Grove et al., 2018; Milton & Sims, 2016; Wood, 2019). When mixed with existing sensory processing differences it can create a situation where an intense sensory environment is experienced as a barrage of information competing from different channels, unable to be processed together. In a bright ward, for example, under a flickering overhead light—imperceptible, perhaps, to a non-autistic staff member—an autistic young person's processing capacity may be used up, resulting in an inability to properly process auditory input, i.e. something being said to them. The *sensory load* that an autistic young person or child is able to manage at any one time may therefore be considerably less than that of a neurotypical peer.

In a meta-analysis of 14 studies, Ben-Sasson et al. (2009) found that sensory processing differences were especially prevalent among autistic and otherwise neurodivergent children aged 6–9 years, underscoring the importance of considering the sensory profiles and needs of young autistic children. It may be that these children have greater difficulties integrating more intensely experienced sensory stimuli, or it may be that they have yet to learn to *mask* or *camouflage*: to suppress natural autistic responses and to adopt learned socially-acceptable alternatives (Pearson & Rose, 2021). Masking comes at a noted cost to mental health, including increased anxiety and depression (Hull et al., 2021), autistic burnout (Raymaker et al., 2020) and suicidality (Cassidy et al., 2020), as well as tiredness, difficulty moderating mood, difficulty concentrating and needing extended periods of rest and low stimulation environments. For those autistic children and young people who *have* learned to mask their autistic traits and sensory issues—consciously or unconsciously—extra care will be needed from those around them, particularly in stimulating and stressful hospital settings, to ensure they do not hit burnout or overload (Hull et al., 2021).

Autistic young people's sensory needs and wellbeing in inpatient settings

Hospital settings are places where children and young people are often already under a degree of mental and / or physical stress and sensory challenges can significantly add to

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this. When the sensory challenges of autistic and neurodivergent children and young people are overlooked or not properly understood, additional distress is likely. In their recent report on the use and impact of restraint, seclusion and segregation measures used on autistic children and young people and those with learning disabilities, the Care Quality Commission (CQC, 2020) found that patients were regularly not having their needs met. Residential inpatient environments were not adapted to their sensory needs and they were not being offered support to communicate: reasonable adjustments legally required under the 2010 Equality Act (REF).

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, p. 13).

A recent thematic review (Hollins & Wood, 2021) found that not only was there a lack of sensory and environmental assessments, but there was also a general lack of understanding about autism in many hospitals. More than 50 percent of the people reviewed were autistic, with a further 35 percent suspected to be autistic (the review covered adults as well as children and young people). The review notes that sometimes autistic inpatients are secluded or segregated in the absence of the right therapeutic environment to cater for individual sensory need. This suggests that a disproportionate number of autistic children and young people may be being detained in seclusion and/or segregation.

Positive Behavioural Support (PBS) is sometimes utilised as a preferred method of reducing the need for restraint and seclusion (Department of Health, 2014). However, this approach is based within a behaviourist paradigm (Dunlap et al., 2008) which, necessarily, makes observations from the outside rather than being informed by an insider perspective of what it means to be autistic.

Informed, sensitive adjustments to the sensory environments of residential mental health facilities can make a significant difference to the wellbeing and recovery rates of autistic children and young people inpatients. In the following section we outline some of the learning around the sensory environments of CAMHS inpatient settings, gained from consultation with young autistic people who have experience of the services and experienced autistic team members form the National Development Team for Inclusion. Specific recommendations are also summarised in (Table 1).

CAMHS inpatient mental health settings: a sensory perspective

Background and context

The Autism Team at the National Development Team for Inclusion (NDTi) have been conducting sensory environment reviews of inpatient mental health facilities since 2019. This work was first commissioned by the NHS England South-West Learning Disability and Autism Regional Team, following reports from autistic Experts by Experience

that they were finding the sensory environments of the hospitals they were due to visit as part of their work inaccessible to the point that they were prohibitive. The autistic Experts by Experience team reported particular challenges with bright overhead lighting which it was not possible to control: either because there was limited natural lighting alternatives, and/or because the light "circuit" was shared across many rooms and turning lights off in one space would affect other rooms. In addition, they reported that the auditory environment was painfully challenging in relation to general background noise, significant echo (which also affects proprioception for some people), loudly banging doors and the frequent sounding of alarms.

The significant challenges experienced by the autistic Experts by Experience led to questions about what impact sensory environments might be having on autistic children and young people detained in hospitals longer term. The ensuing sensory environment reviews that were developed consider all the senses (both internal and external) and assess the likely impact of the environment on autistic people who may experience hypersensitivity in relation to each of these. Across the many reviews that have been done since 2019, a number of common themes were identified, both in relation to the challenges and the recommended changes. These findings were collated, along with feedback from autistic young people with experience of CAHMS inpatient mental health care, into an autistic-led report (NDTi, 2021).

Methodology

Our learning comes from a co-produced, practice-based knowledge-production project, involving autistic young people with experience of NHS England funded Children and Adolescent Mental Health Services (CAMHS) inpatient settings, and autistic Experts by Experience conducting hospital premises sensory environment reviews. Between them, these contributors to the original report (NDTi, 2021) have spent thousands of hours in inpatient settings as patients; as professionals reviewing sensory environments; as professionals reviewing individual care and treatment; and sharing learning with—and providing development support to—ward staff.

In recent years there has been a growing focus on the ethical need for—and epistemological importance of—meaningful participatory approaches within autism (Happé & Frith, 2020; Pellicano, 2020). Co-production is a process informed by a social-justice approach that brings lived experience and expertise in social issues to the centre of knowledge-production (Banks et al., 2019). It is non-hierarchical, dialogic, collaborative and inherently iterative if done well—due to the various stages of checking and challenging the shared knowledge as it is established.

The sampling of contributing collaborators was purposeful, based on the aim to hear from young autistic people with experience of placements in NHS-funded inpatient mental health hospitals or Assessment and Treatment Units. However, for reasons relating to consent, the decision was made to approach only those young people aged between 16 and 25 years old. Detailed, accessible invitation emails were sent out through known recruitment pathways (including the CAMHS Mental Health Taskforce, NHS England area teams with established working links to the NDTi and known Experts by Experience). Further snowballing sampling was undertaken via initial collaborators once they had been identified. Of the autistic young 42 🔄 G. WILLIAMS ET AL.

people who received the invite to contribute, 7 females and 2 males responded, aged between 16 and 25 years.

The project was undertaken in accordance with the NDTi's Ethical Framework, validated and overseen by the dedicated NDTi Research Team. In order to further ensure that both the approach and the relevant materials were accessible, the process was overseen by three autistic advisors (of whom one was a young person with mental health inpatient experience). Over the engagement period, a qualified psychologist with experience of working with autistic people was also available for contributors to get support if needed at specific, advertised times.

In order to make the process as inclusive as possible, contributors were invited to respond to open-ended question prompts about their experiences of spending time in NHS-funded CAMHS in-patient settings via a range of communication methods, including written responses by email; verbally by video call or telephone; visually by sharing photos or drawings; or in any chosen alternative. Three opted to communicate over video-conferencing software, while a further three chose to respond via email and the final three did both. Detailed notes were taken by the lead interviewer and cross-referenced with the reports of the original adult Experts by Experience whose difficulties entering hospital spaces had prompted the project. Themes were iteratively identified through several rounds of intuitive coding by the project leader (a co-author of this paper) and the three autistic advisors. These themes were regularly checked with contributors who had an active role in identifying further themes. Finally, contributors were invited to comment on the final draft of the findings to ensure they felt accurately and fairly represented.

Findings

Sound

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 – NDTi, 2021, p. 74)

Sound is the most significant source of sensory input in CAMHS inpatient environments for most people. The autistic young people who contributed to the "It's Not Rocket Science" report (NDTi, 2021) spoke in particular to the panic caused by alarms going off. Autistic children and young people were distressed each time the alarms sounded—often multiple times a day—but were also waiting anxiously in anticipation for the next alarm. People also reported challenges with noise carrying between spaces, with the restrictions of inpatient services and the common locking of doors meaning it was difficult or impossible to move away from noise.

As well as loud and unexpected sounds from alarms, doors and other people in distress, contributors also described the persistent and distressing nature of what might ordinarily be described as "background noise": from appliances, extractor fans, heating and forced air; outside elements such as roads; and conversations from other rooms including at some distance away. All these things were exacerbated by staff teams not fully understanding or dismissing the significant impact. Changes to the built environment such as the introduction of silent alarms, sound absorbing panels, and acoustic vinyl can all improve the auditory environment. Personal solutions such as using noise cancelling headphones or accessing alternative, controlled sounds (like music) can also support self-regulation.

Sight

My moods changed pretty quickly. It was a battle for me - the triggers and autism related meltdowns were caused by noises, lights, touch from staff and being confronted [...] I'd turn the lights off and wrap myself in a blanket to feel safe (- Caitlin).

Artificial lighting was a major source of sensory distress identified in CAMHS inpatient environments. Many autistic people have a heightened sensitivity to light (photophobia) and are more likely to be sensitive to light levels as well as the quality of lighting. Fluorescent lights give significant flicker and glare (Bogdashina, 2016) and LED bulbs vary in quality, meaning that they sometimes hum and flicker: something many of the autistic collaborators found additionally distressing. Automatic lights are commonly used within these premises, and many do not have additional switches to enable them to be dimmed or turned off.

Good natural light, a view of outside, natural space, user-controlled switches and a range of lighting options can all support self-regulation in the sensory environment. Where this isn't possible, permission to wear caps and sunglasses can both reduce visual input and glare. Clutter free environments were reported to be easier to process visually, and the use of pastel and plain colours seemed to help in minimising sensory overwhelm.

Smell

It smelt very strongly of chlorine and cleaning fluid and bleach. It was all day. It can give me headaches (Chris¹ – NDTi, 2021, p. 85)

Smell wasn't problematic for everyone who contributed to the "It's Not Rocket Science" (NDTi, 2021) report, but was a significant and frequently distressing factor for those with olfactory sensitivity. Of those autistic young people who were challenged by smells in hospital, the strong and persistent smells of cleaning materials—including laundry products—were a particular source of discomfort.

Recommendations for reducing the impact of smells include encouraging staff not to wear strong smelling perfume or toiletries; limiting the use, or managing the timing of the use of strong-smelling cleaning products in communal spaces; developing a culture of closing doors to kitchens and bathrooms; supporting people to choose and use their own preferred toiletries and laundry products; and enabling people to have access to masking smells (such as essential oil rollerballs, etc.) to cover scents that are particularly problematic for them.

Taste

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 (Beth W – NDTi, 2021, p. 88)

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Taste and texture can already be challenging sensory stimuli for some autistic people (Kranowitz, 2016). In addition, of the many hospitals our sensory reviewers have visited, and from the feedback of the young autistic people with experience of CAMHS inpatient services, dining rooms are often described as the most challenging sensory environments. They are usually very brightly lit spaces with a lot of hard surfaces meaning that sound is not absorbed but echoes in the space. Many dining areas have canteen kitchens: meaning that food is served fresh from the kitchen through an opening into the dining room. As such, sounds and smells from the kitchen add to the already high sensory load during mealtimes. In addition, many hospitals have one mealtime "sitting", requiring all patients and staff supports to be in the small space at one time. This adds to the noise, movement and the overall social and sensory load that can, for some autistic children and young people, become prohibitive to staying in the space and managing eating.

It is possible to reduce the sensory input at mealtimes by adjusting and improving the sensory environments in dining areas. Changes might include adjustments to lighting; felt pads on the bottom of tables and chairs to prevent furniture scraping across the floor; a removal of items that "hum" such as fridges and water coolers; and the addition of partitions or booths to enable people to have more privacy. Where safe to do so, many autistic people prefer to eat alone (Park-Cardoso & Soares da Silva, 2021) and might be more comfortable eating in another space or at a different time.

Touch

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 – NDTi, 2021, p. 93)

Skin is the largest organ in the body, and sensitivity to touch can add to the sensory load all the time. Clothing, temperature, atmospheric pressure and touch from other people can all cause discomfort. The young autistic people who contributed to the report shared their experience of uncomfortable textures, particularly bedding, towels, duvets and seating.

Fire regulations and infection control are both common barriers to young people being permitted to bring in their own soft and familiar bedding items. However, this can be managed with clear instruction about what labels are required for any items brought into the hospital, and when / how they are washed. Consideration of the sensory profile of materials used, and access to personal items can support people to be comfortable, and to experience sensory joy.

Interoception

"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 – NDTi, 2021, p. 14)

The interoceptive sense—which deals with information about our internal emotional state and about physical sensations such as temperature, pain and hunger—can be

particularly important for children and young people in hospital, as emotional awareness is linked to emotional regulation (Mahler, 2017). When the sensory load of an environment or situation becomes too high, this will have bearing on an individual's ability to identify and regulate their emotions. Identifying different emotions can already be difficult for many autistic people (Erbas et al., 2013), and it can be challenging to distinguish between external factors such as the environment, and internal factors such as emotions (Mahler, 2017): particularly so when external senses are overloaded.

Autistic children and young people we spoke to shared that it was hard to identify their own internal state when they were in busy, noisy, brightly lit environments and surrounded by other people in distress. In addition, they reported that the self-soothing responses and mechanisms they had developed to support emotional and interoceptive regulation are often not available to them in hospital. This included access to favourite personal belongings, being able to cover background noise by listening to music on a phone, being able to listen to meditation apps, and being able to access outside space and exercise. Where it's safe to do so, small changes such as supporting autistic children and young people to access personal items, enabling them to listen to music (on alternative devices if phones are not possible), having quiet space that is accessible at any time and ensuring that decisions are made individually rather than "blanket bans" can all significantly support self-regulation and wellbeing.

Proprioception and the vestibular system

Proprioception is the awareness of the position and movement of the body (Beardon, 2020). When it is well regulated, it tells us where we are in relation to other things, how our body is moving and how much pressure we need to use. When it is under-sensitive, it might be hard to know where the body is in space and difficult to navigate obstacles. As well as coordinating the other sensing systems-ensuring that they work together to keep us calm and alert (Kranowitz, 2016)-the vestibular system primarily supports balance (Beardon, 2020). Many of the autistic people we spoke with who had hypo-sensitive vestibular and/or proprioceptive systems found that they tended to rely on alternative senses to orientate and stabilise themselves in a space. Some autistic children and young people will want to hold rails or touch walls, others may utilise echo: and so can find high or pitched ceilings and curved walls very disorientating. A clear and clutter free environment with plenty of space to move between furniture can be helpful. Self-led supports like wearing tight-fitting clothing, using a weighted blanket, or applying pressure to the body (crossing legs, folding arms, leaning against a wall) are all methods for regulating those senses that should ideally be encouraged.

Conclusion

Autistic children and young people often possess divergent sensory experiences of the world that can, in the right circumstances, bring great joy: but, in the wrong ones, cause great distress. Spiky sensory profiles—including increased sensitivity to one sense and decreased sensitivity to another—are common. When the sensory load from a

Table	1.	Summary	of	suggested	sensory	adjustments ^a .
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Sense	Sensory stimuli with a negative impact	Positive recommendations
Sound	 Alarms Doors Other people in distress Background noise, e.g. appliances, extractor fans, heating, conversations Background external noise: roads Noise carrying between spaces Difficult or impossible to move away from noise due to restrictive setting Staff teams not understanding the impact 	 Silent alarms Sound absorbing panels Acoustic vinyl Noise cancelling headphones Access to alternative, controlled sounds (like music)
Sight	 Artificial lighting (light levels and quality of lights) Automatic lights without switches Cluttered environments 	 Good natural light Views of outside Natural space User-controlled switches Range of lighting options Caps Sunglasses Clutter free environments Pastel and plain colours
Smell	Chlorine, cleaning fluid and bleachPerfume or strong smelling toiletriesClosing kitchen doors and bathrooms	 Option to use own preferred toiletries and laundry products Access to masking smells
Taste	 Other sensory input from dining areas (e.g. noise and bright lights) Busy, communal mealtimes 	 Adjust lighting Felt pads on tables and chairs to reduce furniture noise Removing items that "hum" such as fridges and water coolers Where safe, supporting people to eat in another room or at a different time
Touch	 Clothing Temperature Atmospheric pressure Touch from other people Rough bedding, towels, duvets and seating 	 Support people to bring their own items into the hospital Consider the sensory profile of materials purchased by the hospital
Vestibular and proprioception	High pitched ceilingsCurved walls	 Ability to hold rails or touch walls Clutter-free environment and space to move between furniture Tight-fitting clothing Weighted blankets Applying pressure to the body (e.g. crossing legs) encouraged
Interoception	Limited access to personal belongings	 Access to personal belongings Access to alternative, controlled sounds (like music) Accessible quiet space Decisions based around the individual

^aAdditional recommendations are made in the *It's Not Rocket Science Report* (NDTi, 2021).

particular environment or situation becomes too high, an individual's ability to process new information dramatically reduces, often resulting in overwhelm and emotional dysregulation. As autistic children and young people get older they often learn to mask their distress responses or autistic behaviours: to the detriment of their mental wellbeing.

Implications for practice

Autistic children and young people are unlikely to thrive in hospital settings: particularly when far away from home, familiar environments and familiar people. A change in practice to better support people to remain at home and in their communities would avoid sensory and other challenges of the inpatient experience. However, our findings indicate that simple changes that reduce the sensory load, minimise overwhelming sensory inputs and support autistic children and young people to self-regulate are likely to make the space more comfortable and accessible for all. Some of these adaptations relate to ward culture (such as being mindful of jangling key chains and slamming doors, or offering alternative lighting options in bedroom spaces) and can be adopted with relative ease given the appropriate awareness-raising or training. Other more structural adaptations will require engagement with broader facilities and maintenance staff (e.g. in the case of introduction of manually-controllable, non-humming dimmer switches to currently automatically-controlled lighting).

Where it isn't possible or easy to make immediate changes to the built environment, an autism-informed approach and the consideration of sensory needs in care planning is likely to have a significant and positive impact on the comfort and wellbeing of the autistic children and young people receiving care. We always recommend engaging autistic children and young people receiving inpatient care to identify and articulate any individual sensory challenges in the environment, however not all will be able to do so. The involvement of external autistic expertise can be beneficial whether or not autistic children and young people are able to engage. Autistic involvement can provide additional independent information about the sensory environment, providing a new perspective, identification, and validation.

Implications for future research

There is plenty of scope for future research to develop and deepen our understanding of what makes a supportive sensory environment. Case study reports, for example, of individual hospitals where sensory adaptations have been made would be incredibly useful as measures of impact on the wellbeing and recovery rates of the autistic children and young people receiving care there. There is also an urgent need for more specific understanding around neurodivergent sensory responses to different types of luminaries commonly used in inpatient hospital settings, to influence technical facilities guidance and policy (see: Buro Happold and NDTi, 2021).

This present paper has reported on the learning gained from consultation with autistic children and young people and Experts by Experience in relation specifically to inpatient settings within the UK. We are currently unaware of similar programmes or pieces of research taking place in a broader global context and it would be of great interest to see how applicable this approach and learning is within other cultural contexts. International qualitative studies built around interviews with present autistic children and young person in-patients and young adults with recent experiences of these facilities would be enlightening for the planning of future service provision.

Finally, it is important to remember that not all autistic people in healthcare settings will be children or young people: the learning shared above will be equally relevant for 48 🕳 G. WILLIAMS ET AL.

inpatient and outpatient healthcare settings accessed by autistic adults, and autistic elders (who are often overlooked, see: Michael, 2016). In terms of implications for further research, it is possible that sensory sensitivities change across the lifespan and that masking behaviours also may interfere with how they are experienced or expressed. Significant sensory barriers to accessing GP services were identified among adult autistic respondents to a recent large-scale survey in the UK (Doherty et al., 2022); it would be prudent to further investigate the negative effects of in-patient and out-patient hospital environments on access to services and autistic wellbeing.

Autistic people in healthcare settings will also not necessarily be patients. Current conservative estimates suggest that between 1 in 100 (The NHS Information Centre, Brugha et al., 2012) and 1 in 59 (Baio et al., 2018) people are diagnosed autistic although many are as yet unidentified (Lai & Baron-Cohen, 2015). This is particularly true for females (Bargiela et al., 2016; Lai & Baron-Cohen, 2015), those in black and minority ethnic communities (Begeer et al., 2009; Cascio et al., 2020), those in older age groups (James et al., 2006), and potentially those whose diagnostic journey has led to treatment for eating disorders (Shea, 2016). Autistic people serve as doctors, nurses, key workers, facilities staff, therapists and in endless other roles, thus creating an autism-accessible space enables better working conditions for this often-hidden population, as well as for adult autistic patients. However, as has often been reflected on by non-autistic CAMHS staff engaged in adapting wards to make them more sensory-friendly: what is good for autistic people is often also good for non-autistic people. Any sensory environmental and cultural changes made are likely to improve the experiences of all children and young person accessing the space.

Note

1. A pseudonym.

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