

This is an Accepted Manuscript of an article published by Taylor & Francis in
Child Care in Practice, Volume 29 Issue 1 on 9 February 2023, available at:
<https://doi.org/10.1080/13575279.2022.2126437>

33 **Introduction**

34 Poor mental health – compared to that of the neurotypical child population
35 – is a serious concern for many autistic children and young people (Crane et al.,
36 2019; Simonoff et al., 2008; Strang et al., 2012). It is unsurprising then that in the
37 UK, where our project was based, there is currently a rising number of autistic
38 children and young people receiving care in NHS funded in-patient mental health
39 facilities (NHS England, 2020).

40 There are a many number of factors that can influence the wellbeing of autistic
41 children and young people: things such as social stigma (Pearson and Rose, 2021; Perry
42 et al., 2022); interpersonal victimisation and bullying (Bitsika et al., 2021; Lung et al.,
43 2019); intersectional issues relating to race (Begeer et al., 2009; Dababnah et al., 2018;
44 Jones and Mandell, 2020) and gender (Davidson and Tamas, 2016; Kourti and
45 MacLeod, 2019); parent wellbeing and behaviour (Cheak-Zamora and Teti, 2015;
46 Giallo et al., 2013) and barriers to education (Moyses and Porter, 2015) and diagnostic
47 and support services (Westminster Commission on Autism, 2021) can all play a part.
48 This paper takes as its focus the often overlooked influence of the sensory environment,
49 in this case specifically within NHS-funded inpatient mental health services. Once an
50 inpatient, an autistic child or young person has limited control over all aspects of their
51 environment, making the significance of *getting it right* all the more important. While
52 other research has focused on the experience and reflections of caregivers or staff, this
53 work is based on the experiences and lived expertise of autistic young people
54 themselves.

55 Autism is increasingly being understood as way of being in the world that
56 is shaped by sensory processing differences: something which has recently been

57 recognised by international diagnostic criteria (DSM-5, American Psychiatric
58 Association, 2013; ICD-11, World Health Organization, 2018). Within the UK
59 context, in-patient mental health facilities – funded by the NHS – can present
60 sometimes extreme sensory challenges for autistic children and young people. At
61 best, these can hinder wellbeing and at worst exacerbate existing mental health
62 problems: instigating an upwardly progressing cycle through increasingly
63 restrictive settings.

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

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

81

82 **Autistic young people’s mental health**

83 In the United Kingdom, one in six children aged 5-16 are understood to have a
84 mental health problem (NHS Digital, 2020). Autistic children and young people are
85 even more likely to experience mental health difficulties (Crane et al., 2019; Simonoff
86 et al., 2008; Strang et al., 2012): with half of all neurodiverse children having ‘probable
87 emotional problems’ (Shum et al 2021: 11), and at least one in ten accessing support
88 from NHS Children and Adolescent Mental Health Services (CAMHS – Wistow and
89 Barnes, 2009).

90 Indeed, Simonoff and colleagues (2008) found that 70 percent of young autistic
91 people have one co-existing mental health issue with 41 percent having two or more
92 (though not all reached the threshold for CAMHS intervention and support). The Covid-
93 19 pandemic has worsened existing challenges, seeing a 29 percent increase in the
94 overall number of children and young people in contact with mental health services
95 between March 2020 and February 2021, (Mental Health Network, NHS Confederation,
96 2021: 15). In addition, the *Reaching The Tipping Point* report (Mental Health Network,
97 NHS Confederation, 2021) notes that health inequalities for those with
98 neurodevelopmental differences have also increased.

99 When young people hit a crisis point with their mental health difficulties,
100 intensive support within a CAMHS inpatient ward is, within current cultural approaches
101 to supporting mental health, often seen to be required by professionals and families,
102 including the children and young people themselves. The number of autistic children
103 and young people in CAMHS mental health hospitals has increased significantly in
104 recent years (NHS England, 2020). Diagnoses of eating disorders and disordered eating

105 are also increasingly responsible for children and young people being admitted to
106 hospital (Mental Health Network, NHS Confederation, 2021): a condition known to
107 disproportionately affect autistic individuals, despite difficulties in determining
108 prevalence of autism in anorexia nervosa patients (Westwood and Tchanturia, 2017).
109 Despite the growing presentation of autistic children and young people in inpatient
110 mental health hospitals, there are currently no specialist CAMHS beds or wards for
111 autistic people.

112 There is an important debate about whether or not inpatient units are helpful for
113 children and young people and indeed adults and if so, under what circumstances (see
114 for e.g. Hart, Blincow, Thomas, H, 2008; LeFrançois, 2020; Walker, Hart and Hanna,
115 2017). However, beyond this debate and focussing solely here on a reformist agenda of
116 ensuring maximum inclusion of autistic children and young people in current inpatient
117 units, it is certainly the case that children and young people in general often find
118 inpatient environments inflexible, unresponsive and not supportive of mental health
119 (Reavey et al 2017).

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

125

126 *Predictability and structure have a major impact on every aspect of an*
127 *autistic person's care in a Tier 4 CAMHS facility, from admission to*
128 *discharge. Upon admission, children and young people are removed from*

129 *everything they know – from the meals they eat to the place they live and the*
130 *people who surround them. Even changes in small things which people may*
131 *not consider to be significant, such as having to change the deodorant you*
132 *wear, can cause huge anxiety* (National Development Team for Inclusion –
133 NDTi, 2021:46).

134

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

138

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

153 the significance of this perspective for the in-patient care of autistic young people and
154 children.

155

156 **Autism as a divergent sensory profile**

157

158 *Though autistic people live in the same physical world and deal with the*
159 *same ‘raw material’, their perceptual world turns out to be strikingly*
160 *different from that of non-autistic people (Bogdashina, 2016: 55).*

161

162 Since some of the earliest descriptions of autistic individuals (Kanner, 1943),
163 atypical sensory responses have been noted. However, it is only very recently that we
164 have come to understand these sensory differences – often termed ‘atypical sensory
165 reactivity’ (Hannant, Tavassoli and Cassidy, 2016: 2) – as an essential component of
166 what it means to be autistic. Responding to a growing body of persuasive modern
167 research, including that highlighting the neurological basis of autistic differences in
168 sensory processing across all sensory domains (see Proff et al., 2021, for recent
169 systematic review), the latest revisions to the international diagnostic criteria for autism
170 (DSM-5, American Psychiatric Association, 2013; ICD-11, World Health Organization,
171 2018) now include hyper- and hypo-sensitivity to sensory stimuli under the umbrella of
172 restricted or repetitive behaviours.

173 Autistic individuals often experience complex and varied patterns of hyper- and
174 / or hypo-sensitivity to various sensory stimuli across all sensory-perceptual domains.

175 Combined with difficulties coordinating movement, and muscle tone and postural
176 differences that can also be common (de Jaeger, 2013), these contribute towards a
177 divergent bodily way of being in the world. Understanding that the sensing and

178 perceptual worlds of autistic children and young people are often very different to those
179 of their non-autistic peers is essential to understanding the individual, their behaviour,
180 and their needs:

181 Our five senses are how each of us understands everything that isn't
182 us. Sight, sound, smell, taste, and touch are the five ways – the only five
183 ways – that the universe can communicate with us. In this way, our senses
184 define reality for each of us... What if you're receiving the same sensory
185 information as everyone else, but your brain is working differently? Then
186 your experience of the world around you will be radically different from
187 everyone else's, maybe even painfully so. In that case, you would literally
188 be living in an alternate reality – an alternate sensory reality (Grandin and
189 Panek, 2014: 70).

190

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

202 Many autistic children and young people will also have *single attention*:
203 otherwise known as *monotropism* (Murray, Lesser and Lawson, 2005 and Murray,

204 2018, 2020). The typical cognitive styles of non-autistic individuals tend to comfortably
205 entertain multiple simultaneous interests, each moderately engaged, whereas those of
206 autistic individuals tend to maintain only very few simultaneous interests: each one
207 highly engaged and intensely focused upon. In terms of learning and developing
208 passionate interests and skills, a monotropic attention style is very useful (Grove et al,
209 2018; Milton and Sims, 2016, Wood, 2019). When mixed with existing sensory
210 processing differences it can create a situation where an intense sensory environment is
211 experienced as a barrage of information competing from different channels, unable to be
212 processed together. In a bright ward, for example, under a flickering overhead light –
213 imperceptible, perhaps, to a non-autistic staff member – an autistic young person’s
214 processing capacity may be used up, resulting in an inability to properly process
215 auditory input, i.e. something being said to them. The *sensory load* that an autistic
216 young person or child is able to manage at any one time may therefore be considerably
217 less than that of a neurotypical peer.

218 In a meta-analysis of 14 studies, Ben-Sasson and colleagues (2009) found that
219 sensory processing differences were especially prevalent among autistic and otherwise
220 neurodivergent children aged 6-9 years, underscoring the importance of considering the
221 sensory profiles and needs of young autistic children. It may be that these children have
222 greater difficulties integrating more intensely experienced sensory stimuli, or it may be
223 that they have yet to learn to *mask* or *camouflage*: to suppress natural autistic responses
224 and to adopt learned socially-acceptable alternatives (Pearson and Rose, 2021).

225 Masking comes at a noted cost to mental health, including increased anxiety and
226 depression (Hull et al.,2021), autistic burnout (Raymaker et al., 2020) and suicidality
227 (Cassidy et al., 2019), as well as tiredness, difficulty moderating mood, difficulty
228 concentrating and needing extended periods of rest and low stimulation environments.

229 For those autistic children and young people who *have* learned to mask their autistic
230 traits and sensory issues – consciously or unconsciously – extra care will be needed
231 from those around them, particularly in stimulating and stressful hospital settings, to
232 ensure they do not hit burnout or overload (Hull et al., 2021).

233

234 ***Autistic young people’s sensory needs and wellbeing in inpatient settings***

235 Hospital settings are places where children and young people are often already
236 under a degree of mental and / or physical stress and sensory challenges can
237 significantly add to this. When the sensory challenges of autistic and neurodivergent
238 children and young people are overlooked or not properly understood, additional
239 distress is likely. In their recent report on the use and impact of restraint, seclusion and
240 segregation measures used on autistic children and young people and those with
241 learning disabilities, the Care Quality Commission (CQC, 2020) found that patients
242 were regularly not having their needs met. Residential inpatient environments were not
243 adapted to their sensory needs and they were not being offered support to communicate:
244 reasonable adjustments legally required under the 2010 Equality Act (REF).

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

254

255 A recent thematic review (Hollins and Wood, 2021) found that not only was
256 there a lack of sensory and environmental assessments, but there was also a general lack

257 of understanding about autism in many hospitals. More than 50 percent of the people
258 reviewed were autistic, with a further 35 percent suspected to be autistic (the review
259 covered adults as well as children and young people). The review notes that sometimes
260 autistic inpatients are secluded or segregated in the absence of the right therapeutic
261 environment to cater for individual sensory need. This suggests that a disproportionate
262 number of autistic children and young people may be being detained in seclusion and/or
263 segregation.

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

269 Informed, sensitive adjustments to the sensory environments of residential
270 mental health facilities can make a significant difference to the wellbeing and recovery
271 rates of autistic children and young people inpatients. In the following section we
272 outline some of the learning around the sensory environments of CAMHS inpatient
273 settings, gained from consultation with young autistic people who have experience of
274 the services and experienced autistic team members from the National Development
275 Team for Inclusion.

276 **CAMHS inpatient mental health settings: a sensory perspective**

277 **Background and context**

278 The Autism Team at the National Development Team for Inclusion (NDTi) have been
279 conducting sensory environment reviews of inpatient mental health facilities since 2019.
280 This work was first commissioned by the NHS England South-West Learning Disability

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

291

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

302 **Methodology**

303 Our learning comes from a co-produced, practice-based knowledge-production project,
304 involving autistic young people with experience of NHS England funded Children and
305 Adolescent Mental Health Services (CAMHS) inpatient settings, and autistic Experts by

306 Experience conducting hospital premises sensory environment reviews. Between them,
307 these contributors to the original report (NDTi, 2021) have spent thousands of hours in
308 inpatient settings as patients; as professionals reviewing sensory environments; as
309 professionals reviewing individual care and treatment; and sharing learning with – and
310 providing development support to – ward staff.

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

318 The sampling of contributing collaborators was purposeful, based on the aim to hear
319 from young autistic people with experience of placements in NHS-funded in-patient
320 mental health hospital or Assessment and Treatment Units. However, for reasons
321 relating to consent, the decision was made to approach only those young people aged
322 between 16 to 25 years old. Detailed, accessible invitation emails sent out through
323 known recruitment pathways (including the CAMHS Mental Health Taskforce, NHS
324 England area teams with established working links to the NDTi and known Experts by
325 Experience). Further snowballing sampling was undertaken via initial collaborators
326 once they had been identified. Of the autistic young people who received the invite to
327 contribute, 7 females and 2 males responded, aged between 16 and 25 years.

328 The project was undertaken in accordance with the NDTi's Ethical Framework,
329 validated and overseen by the dedicated NDTi Research Team. In order to further

330 ensure that both the approach and the relevant materials were accessible, the process
331 was overseen by three autistic advisors (of whom one was a young person with mental
332 health inpatient experience). Over the engagement period, a qualified psychologist with
333 experience of working with autistic people was also available for contributors to get
334 support if needed at specific, advertised times.

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

349

350 **Findings**

351 *Sound*

352

353 *The noise has a massive impact. You can't switch off. Sometimes it lasts a*
354 *long time. I felt distressed. It's quite intimidating having all that noise going*
355 *over you. You're always waiting for the next time it will happen (Jamie –*
356 *NDTi, 2021: 74)*

357

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

366 As well as loud and unexpected sounds from alarms, doors and other people in
367 distress, contributors also described the persistent and distressing nature of what might
368 ordinarily be described as 'background noise': from appliances, extractor fans, heating
369 and forced air; outside elements such as roads; and conversations from other rooms –
370 including at some distance away. All these things were exacerbated by staff teams not
371 fully understanding or dismissing the significant impact.

372

373 Changes to the built environment such as the introduction of silent alarms, sound
374 absorbing panels, and acoustic vinyl can all improve the auditory environment. Personal
375 solutions such as using noise cancelling headphones or accessing alternative, controlled
376 sounds (like music) can also support self-regulation.

377 **Sight**

378

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

383

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

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

398 **Smell**

399

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

402
403 Smell wasn't problematic for everyone who contributed to the 'It's Not Rocket
404 Science' (NDTi, 2021) report, but was a significant and frequently distressing factor for
405 those with olfactory sensitivity. Of those autistic young people who were challenged by
406 smells in hospital, the strong and persistent smells of cleaning materials – including
407 laundry products – were a particular source of discomfort.

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

415 ***Taste***

416 *The dining room often made me very anxious, it took me up to 30 mins to*
417 *make myself go in just because of how overwhelming it could be sensory*
418 *wise (Beth W – NDTi, 2021: 88)*

419
420 Taste and texture can already be challenging sensory stimuli for some autistic
421 people (Kranowitz, 2016). In addition, of the many hospitals our sensory reviewers have

¹ A pseudonym.

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

433

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

442 ***Touch***

443

444 *It felt very clinical, like a general hospital which isn't ideal for a psychiatric*
445 *unit as it just didn't feel very homelike. I remember everything feeling quite*

446 *rough to touch e.g. the towels, duvet cover, carpet etc and I find it very hard*
447 *sensory wise if things aren't very soft. (Beth W – NDTi, 2021: 93)*

448

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

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

460

461 ***Interoception***

462

463 “Being overwhelmed from being on the unit exacerbated my mental state
464 and mental distress so I was probably there for longer than I would have
465 been there otherwise. (Emily – NDTi, 2021: 14)

466

467 The interoceptive sense – which deals with information about our internal
468 emotional state and about physical sensations such as temperature, pain and hunger –
469 can be particularly important for children and young people in hospital, as emotional
470 awareness is linked to emotional regulation (Mahler, 2017). When the sensory load of

471 an environment or situation becomes too high, this will have bearing on an individual's
472 ability to identify and regulate their emotions. Identifying different emotions can
473 already be difficult for many autistic people (Erbas et al, 2013), and it can be
474 challenging to distinguish between external factors such as the environment, and
475 internal factors such as emotions (Mahler, 2017): particularly so when external senses
476 are overloaded.

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

489

490 ***Proprioception and the vestibular system***

491

492 Proprioception is the awareness of the position and movement of the body
493 (Beardon, 2020). When it is well regulated, it tells us where we are in relation to other
494 things, how our body is moving and how much pressure we need to use. When it is
495 under-sensitive, it might be hard to know where the body is in space and difficult to

496 navigate obstacles. As well as coordinating the other sensing systems – ensuring that
497 they work together to keep us calm and alert (Kranowitz, 2016) – the vestibular system
498 primarily support balance (Beardon, 2020). Many of the autistic people we spoke with
499 who had hypo-sensitive vestibular and/or proprioceptive systems found that they tended
500 to rely on alternative senses to orientate and stabilise themselves in a space. Some
501 autistic children and young people will want to hold rails or touch walls, others may
502 utilise echo: and so can find high or pitched ceilings and curved walls very
503 disorientating. A clear and clutter free environment with plenty of space to move
504 between furniture can be helpful. Self-led supports like wearing tight-fitting clothing,
505 using a weighted blanket, or applying pressure to the body (crossing legs, folding arms,
506 leaning against a wall) are all methods for regulating those senses that should ideally be
507 encouraged.

508 **Conclusion**

509 Autistic children and young people often possess divergent sensory experiences
510 of the world that can, in the right circumstances, bring great joy: but, in the wrong ones,
511 cause great distress. Spiky sensory profiles – including increased sensitivity to one
512 sense and decreased sensitivity to another – are common. When the sensory load from a
513 particular environment or situation becomes too high, an individual’s ability to process
514 new information dramatically reduces, often resulting in overwhelm and emotional
515 dysregulation. As autistic children and young people get older they often learn to mask
516 their distress responses or autistic behaviours: to the detriment of their mental
517 wellbeing.

518 ***Implications for practice***

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

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

542 ***Implications for future research***

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

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

559 Finally, it is important to remember that not all autistic people in healthcare
560 settings will be children or young people: the learning shared above will be equally
561 relevant for inpatient and outpatient healthcare settings accessed by autistic adults, and
562 autistic elders (who are often overlooked, see: Michael, 2016). In terms of implications
563 for further research, it is possible that sensory sensitivities change across the lifespan
564 and that masking behaviours also may interfere with how they are experienced or
565 expressed. Significant sensory barriers to accessing GP services were identified among

566 adult autistic respondents to a recent large-scale survey in the UK (Doherty et al.,
567 2022); it would be prudent to further investigate the negative effects of in-patient and
568 out-patient hospital environments on access to services and autistic wellbeing.

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

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