

# Autistica Action Briefing: Sensory Needs & The Built Environment

# AUTISTICA

Harper G, Smith E, Tavassoli T, Aitkenhead G, Collins P.

June 2019

Autistica is the UK's autism research charity. This briefing summarises the most important scientific findings about environmental adaptations for autistic people. It was developed in collaboration with leading researchers and autistic people with experience of the topic as an insight into the latest evidence.

We strongly urge the Government, public services, commissioners, local authorities and public research funders to act on this information. No single type of environment is completely 'autism-friendly'. We now must act to account for the diversity of autistic people's needs to ensure that all autistic people can exercise their right to access public spaces.

[www.autistica.org.uk/AutismStrategy](http://www.autistica.org.uk/AutismStrategy)

"I struggled through life without understanding why most public environments were completely overwhelming. My anxiety was out of control and I'd feel depleted and would need lots of recovery time. Now I have to strictly control where I go and accept that there will be times when I'll have to go home and try again another time."

## What we know

"The building is very bright, there's no quiet waiting area. How can I access healthcare if I'm struggling to communicate before I even get in the room?"<sup>1</sup>

- **Over 9 in 10 autistic people process sensory information differently to their non-autistic peers.**<sup>2</sup> For example, this could mean finding everyday sounds and textures overwhelming, difficulty recognising pain and where the body is in space, or seeking out lights and needing to move around.<sup>1,2,3,4</sup> Someone can be both hyper- and hypo-reactive to different sensory stimuli as well as experiencing sensory-seeking traits.<sup>5,6,7,8</sup>
- **Autistic people's sensory experiences are diverse and sometimes conflicting.** Some autistic people are most comfortable in stimulating environments which other autistic people find overwhelming.<sup>3,4,5,6,7,8</sup> Rather than trying to fit one stereotyped idea of 'autism-friendly', we should focus on ensuring access to a range of environments to meet different needs as well as providing accurate information to allow autistic people to make informed decisions.<sup>9</sup>
- **Difficult sensory environments can prevent autistic people from accessing public spaces and services.**<sup>10</sup> This ultimately has a knock-on effect on wider outcomes, entrenching existing inequalities. For example, autistic people regularly struggle to make the most of medical appointments due to difficulties communicating in inaccessible environments.<sup>1,3,11,12,13</sup>
- **Differences in sensory responses can also impact autistic people's health.** Multiple studies have found links between sensory reactivity, uncertainty<sup>10,14</sup> and anxiety,<sup>5,15,16,17</sup> which affects over half of autistic adults and 4 in 10 autistic children.<sup>18,19</sup> Sensory reactivity is also associated with distressed behaviour<sup>20</sup> and difficulty sleeping and eating.<sup>10,21,22</sup>

## What we need to find out

**Autistica and the Alan Turing Institute are building a citizen science platform to explore how autistic people navigate different environments.**<sup>23,24</sup> The project should help answer some of the questions that autistic people, families and researchers have highlighted as top research priorities.<sup>25,26</sup> These include:

- Which particular environments are more or less challenging for different groups of autistic people?<sup>26</sup>
- What are the perceived physiological and behavioural indicators of sensory experience for autistic people? Do these change over time or in different contexts?<sup>26</sup>
- What strategies do autistic people already use to cope with difficult environments? What strategies positively impact sensory wellbeing?<sup>26</sup>
- How can we effectively create environments which people can adjust as they use them to account for their needs?<sup>26</sup>

"When anxiety is really bad, having to go to the GP is like having to climb Everest. Then I get there and ask if they've got a quiet room. Sometimes it's yes, sometimes it's yes but it's not actually a quiet room, and sometimes it's just no."<sup>27</sup>

## What we should do now

“I feel that I have so much to offer, but often feel overwhelmed in a sensory way in my office and have to take time off which is frustrating.”<sup>1</sup>

- Autistica and the Alan Turing Institute have partnered to create a citizen science initiative exploring how autistic people navigate environments they find difficult.<sup>23</sup> At present, the funding and potential reach of this platform is limited.

Public research funders such as UK Research and Innovation and National Institute for Health Research should consider providing funding to expand the citizen science programme to provide further insight into different areas of public life. Employers, GP practices, schools, Jobcentre Plus services and other local public services should consider encouraging people to become citizen scientists and share their own experiences. Individuals who wish to take part should sign up to the project mailing list for updates.<sup>24</sup>

- The citizen science project will help build an evidence base about how to make environments more accessible to different groups of autistic people.

When data becomes available, Primary Care Networks, hospital trusts, local authorities and other public services should apply for access and ask their own research questions to gain insight into improving their own environments.

- The “priority challenges for action” underpinning the most recent Adult Autism Strategy in 2014<sup>28</sup> included: “I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am.”<sup>29</sup> Rather than implementing one idea of ‘autism-friendly’, we now need to focus on finding out what works for different groups of autistic people.

The Government’s next Autism Strategy<sup>30</sup> should encourage all Government departments and public sector bodies to join the citizen science initiative and help build our understanding of how to support the diverse needs of autistic people.

- The sensory barriers facing autistic people may not always be obvious.

Sustainability and Transformation Partnerships, Integrated Care Systems, local authorities and others involved in planning public services should work with autistic people to carry out regular sensory audits of their own environments<sup>9</sup> as part of wider assessment of accessibility for autistic people. This should then be compared against the citizen science initiative to account for the needs of a range of autistic people.

1 Autistica (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters, conducted in October 2018.

2 Green D, et al. (2016) Brief Report: DSM-5 Sensory Behaviours in Children With and Without an Autism Spectrum Disorder. *J Autism Dev Disord* 46(11), 3597-3606. <[ncbi.nlm.nih.gov/pubmed/27475418](https://doi.org/10.1007/s11861-016-1713-2)>

3 Nicolaidis, C. et al. (2015) “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. *Autism* 19(7), 824-831. <[ncbi.nlm.nih.gov/pmc/articles/PMC4841263](https://doi.org/10.1177/1362309315584263)>

4 Tavassoli T, et al. (2015) Measuring Sensory Reactivity in Autism Spectrum Disorder: Application and Simplification of a Clinician-Administered Sensory Observation Scale. *J Autism Dev Disord* 46, 287-293. <[ncbi.nlm.nih.gov/pubmed/26340959](https://doi.org/10.1007/s11861-015-0959-9)>

5 Lane S, et al. (2012) Sensory Overresponsivity and Anxiety in Typically Developing Children and Children With Autism and Attention Deficit Hyperactivity Disorder: Cause or Coexistence? *Am J Occup Ther* 66(5), 595-603. <[bit.ly/2VQgu3l](https://doi.org/10.5014/ajot.2012.66.5.595)>

6 Watts S, et al. (2016) A systematic review of the evidence for hyporesponsivity in ASD. *Rev J Autism Dev Disord* 3(4), 286-301. <[bit.ly/2H1MJL](https://doi.org/10.1007/s11861-016-1713-2)>

7 Crane L, et al. (2009) Sensory processing in adults with autism spectrum disorders. *Autism* 13(3), 215-228. <[ncbi.nlm.nih.gov/pubmed/19369385](https://doi.org/10.1177/13623093093385)>

8 Ausderau K, et al. (2016) Sensory Subtypes and Associated Outcomes in Children with Autism Spectrum Disorders. *Autism Res* 9, 1316-1327. <[ncbi.nlm.nih.gov/pubmed/27135214](https://doi.org/10.1002/aur.1524)>

9 National Autistic Taskforce (2019). An independent guide to quality care for autistic people. <[bit.ly/2Uga6lp](https://www.natf.org.uk/2019/01/24/independent-guide-to-quality-care-for-autistic-people/)>

10 Schaaf R, et al. (2011) The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *Autism* 15(3), 373-389. <[ncbi.nlm.nih.gov/pubmed/21430016](https://doi.org/10.1177/1362309310380016)>

11 Autistica (2019). Recommendations for changes to the Autism Strategy. <[autistica.org.uk/AutismStrategy](https://www.autistica.org.uk/autism-strategy/)>

12 Westminster Commission on Autism (2016). A Spectrum of Obstacles: An inquiry into access to healthcare for autistic people. <[bit.ly/29dsAeE](https://www.westminstercommissiononautism.org.uk/wp-content/uploads/2016/06/A-Spectrum-of-Obstacles.pdf)>

13 Raymaker D, et al. (2017) Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism* 21(8), 972-984. <[ncbi.nlm.nih.gov/pmc/articles/PMC5362353](https://doi.org/10.1177/1362309317703353)>

14 Autistica (2019) Research projects: Uncertainty, anxiety and sensory sensitivities in autistic adults. <[autistica.org.uk/our-research/research-projects/uncertainty-anxiety-sensory-sensitivities](https://www.autistica.org.uk/our-research/research-projects/uncertainty-anxiety-sensory-sensitivities)>

15 South M & Rodgers J (2017). Sensory, Emotional and Cognitive Contributions to Anxiety in Autism Spectrum Disorders. *Frontiers in Human Neuroscience* 11, 20. <[ncbi.nlm.nih.gov/pmc/articles/PMC5258728](https://doi.org/10.3389/fnhum.2017.01173)>

16 Green S & Ben-Sasson A (2010) Anxiety Disorders and Sensory Over-Responsivity in Children with Autism Spectrum Disorders: Is There a Causal Relationship? *J Autism Dev Disord* 40(12), 1495-1504. <[ncbi.nlm.nih.gov/pmc/articles/PMC2980623](https://doi.org/10.1007/s11861-010-0623-2)>

17 Autistica (2018). Research projects: Sensory reactivity and anxiety. <[autistica.org.uk/our-research/research-projects/sensory-reactivity-and-anxiety](https://www.autistica.org.uk/our-research/research-projects/sensory-reactivity-and-anxiety)>

18 Lever A & Geurts H (2016) Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 46(6), 1916-1930. <[ncbi.nlm.nih.gov/pubmed/26861713](https://doi.org/10.1007/s11861-016-1713-2)>

19 Simonoff E, et al. (2008) Psychiatric disorders in children with ASD: prevalence, comorbidity and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry* 47(8), 921. <[ncbi.nlm.nih.gov/pubmed/18645422](https://doi.org/10.1111/j.1469-7610.2008.01864.5422.x)>

20 O’Donnell S, et al. (2012) Sensory processing, problem behaviour, adaptive behaviour, and cognition in preschool children with autism spectrum disorders. *American Journal of Occupational Therapy* 66, 586-594. <[ncbi.nlm.nih.gov/pubmed/22917125](https://doi.org/10.5014/ajot.2012.66.5.586)>

21 Baker E & Richdale, A (2015). Sleep Patterns in Adults with a Diagnosis of High-Functioning Autism Spectrum Disorder. *Sleep* 23(11), 1765-1774. <[academic.oup.com/sleep/article/38/11/1765/2662285](https://doi.org/10.5665/sleep.3811)>

22 Mandy W & Tchanturia K (2015) Do women with eating disorders who have social and flexibility difficulties really have autism? A case series. *Molecular Autism* 6:6. <[molecularautism.biomedcentral.com/articles/10.1186/2040-2392-6-6](https://doi.org/10.1186/2040-2392-6-6)>

23 Autistica (2019) Research projects: Creating better environments. <[autistica.org.uk/our-research/research-projects/creating-better-environments](https://www.autistica.org.uk/our-research/research-projects/creating-better-environments)>

24 Autistica Turing Citizen Science Newsletter. <[tinyletter.com/AutisticaTuringCitizenScience](https://www.autistica.org.uk/newsletter/)>

25 Autistica (2016). Your questions: shaping future autism research. <[autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf](https://www.autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf)>

26 Autistica (2018, unpublished). Global Summit: Autism-Enabling Environments.

27 Autistica (2017). One Size Doesn’t Fit All Campaign. For more information: <[autistica.org.uk/get-involved/lets-work-together/one-size-doesnt-fit-all-campaign](https://www.autistica.org.uk/get-involved/lets-work-together/one-size-doesnt-fit-all-campaign)>

28 DHSC (2015). “Think Autism”: an update to the government adult autism strategy. <[bit.ly/1eel55P](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/455555/think-autism-update-2015.pdf)>

29 DHSC (2015). Think autism: updating the 2010 adult autism strategy. <[bit.ly/2CXoDYi](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/455555/think-autism-update-2015.pdf)>

30 Hansard (2019). Minister of State for Care, responding to Health and Social Care Oral Questions on 15 Jan 2019. <[bit.ly/2RppolZ](https://www.parliament.uk/hansard/commons/2019/15-january-2019/care-15-jan-2019/)>