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Article

Accepted Version

MacLennan, K., Woolley, C., @21andsensory, E., Heasman, B., Starns, J., George, B. and Manning, C. ORCID: <https://orcid.org/0000-0001-6862-2525> (2023) “It is a big spider web of things”: sensory experiences of autistic adults in public spaces. *Autism in Adulthood*, 5 (4). pp. 411-422. ISSN 2573-9581 doi: 10.1089/aut.2022.0024 Available at <https://centaur.reading.ac.uk/111401/>

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To link to this article DOI: <http://dx.doi.org/10.1089/aut.2022.0024>

Publisher: Mary Ann Liebert

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“It is a big spider web of things”: Sensory experiences of autistic adults in public spaces

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Running title: Sensory experiences of autistic adults in public spaces

Keywords: sensory processing; environments; qualitative analysis; accessibility; autism; neurodiversity

Preprint: This manuscript has been deposited to the PsyArXiv preprint server (<https://psyarxiv.com/>), <https://doi.org/10.31234/osf.io/9qadm>

Data sharing: The data has been deposited in the ReShare UK Data Service repository, <https://reshare.ukdataservice.ac.uk/855801/>

Abstract

Background: Sensory processing differences are commonly experienced by autistic individuals, and some sensory experiences can greatly impact the mental health and quality of life of individuals. Previous research suggests that adapting the sensory nature of environments may improve individual experiences and engagement with these spaces. However, knowledge about which public places are particularly disabling is limited, especially from the perspective of autistic individuals. Little is also known about what in the sensory environment makes them particularly disabling.

Method: In this participatory research study, we investigated the sensory experiences of autistic adults in public spaces. We used an online focus group method, recruiting 24 autistic adults across 7 focus groups. We applied content analysis, reflexive thematic analysis, and case study analysis.

Results: The results of the content analysis showed that supermarkets, eateries (i.e., restaurants, cafés, pubs), highstreets and city/town centres, public transport, healthcare settings (i.e., doctor's surgeries and hospitals), and retail shops and shopping centres, are experienced to be commonly disabling sensory environments for autistic adults. Whereas, outdoor spaces, retail shops, museums, concert venues/clubs, cinemas/theatres, and stadiums were identified to be commonly less disabling sensory environments. Additionally, through reflexive thematic analysis we identified 6 key principles that underlie how disabling or enabling sensory environments are: Sensoryscape (sensory environment), Space, Predictability, Understanding, Adjustments, and Recovery. We represented these principles as a web to emphasise the interconnected, dimensional spectrum of the different themes. Lastly, we used case study analysis to evidence these principles in the commonly disabling sensory environments for richer detail and context and to provide credibility for the principles.

Conclusions: Our findings have important implications for businesses, policy, and built environment designers to reduce the sensory impact of public places to make them more enabling for autistic people. By making public spaces more enabling, we may be able to improve quality of life for autistic individuals.

Community brief

Why was this study done? Autistic people often experience differences in sensory processing, such as finding bright lights and sounds overwhelming and painful. This has been linked to poorer quality of life and mental health. Not much is known about how public places could be changed to be less disabling for autistic adults.

What was the purpose of this study? We aimed to find out which public places are disabling for autistic adults due to the sensory environment, and what about these places makes them especially challenging.

What did the researchers do? We invited autistic adults to take part in online focus groups to tell us about their sensory experiences in public places. In total, 24 people took part across 7 focus groups. We analysed the data 3 ways: 1) we conducted content analysis, identifying categories of words or phrases that share meaning to find commonly disabling and enabling places; 2) we conducted reflexive thematic analysis, developing themes and sub-themes from trends in the data to understand how sensory environments can be experienced as disabling or enabling; and 3) we conducted case study analysis, to see if the themes and sub-themes were present in the commonly disabling environments.

What were the results of the study? We found that supermarkets, eateries (i.e., restaurants, cafés, pubs), highstreets and city/town centres, public transport, healthcare settings (i.e., doctor's surgeries and hospitals), and retail shops and shopping centres, were most often mentioned as being disabling sensory environments. But, outdoor spaces, retail shops, museums, concert venues/clubs, cinemas/theatres, and stadiums were most often talked about as being less disabling sensory environments. We also identified principles that can make these environments either disabling or enabling. These included Sensoryscape or the 'sensory landscape' (sensory burden, sustained and inescapable input, uncontrollable environment), Space (busy and crowded, confined the built environment is), Predictably (lack of information, inconsistent and unfamiliar, and uncertainty), Understanding (unsupportive people, misunderstanding and judgement), Adjustments (suitable adjustments, pace pressures, inflexible communication), and Recovery (space to escape, unable to recover and prepare). Last, we showed in more detail what these principles look like in the different disabling public places.

What do these findings add to what was already known? Our findings add to our understanding about how autistic adults experience public places; particularly, that there are a range of external factors linked with sensory processing differences which can make public places disabling.

What are potential weaknesses in the study? Our study could have recruited a more diverse range of autistic individuals, such as those with cooccurring intellectual disability. It is important to understand experiences from a diverse range of autistic people to ensure that outcomes from research can improve the lives of all autistic people.

How will these findings help autistic adults now or in the future? Our findings provide insights into how public places could be improved so that they can become more enabling environments for autistic people. This is important for businesses, policy, and the design of spaces to make public places more accessible, improving mental wellbeing and quality of life for autistic individuals.

Introduction

Sensory processing differences are commonly experienced by autistic individuals across the lifespan,¹⁻³ and form part of the diagnostic criteria for autism under the non-social domain.⁴ Individuals may be more or less reactive to sensory input compared to others or seek it out more, which can be experienced in a mixed pattern across auditory, visual, tactile, olfactory, gustatory, vestibular, proprioceptive, and interoceptive domains.^{2,5} Although experiencing sensory input can be enjoyable for individuals, it can also often be aversive and overwhelming.^{5,6} Consequently, sensory processing differences can greatly impact quality of life and mental health in autistic individuals.^{5,7-11}

Previous research has increased our qualitative understanding of autistic adults' sensory experiences, with associated theoretical models.^{5,12,13} A recent model depicts how sensory processing differences can lead to short-term outcomes (e.g., physical discomfort and overwhelm) and long-term outcomes (e.g., poorer mental and physical health).⁵ These outcomes are moderated by various internal factors, including level of control over self and stimuli, and current mood and energy levels, and external factors, such as implementing management strategies, and receiving support and understanding from others. Autistic people can also consider themselves as disabled, although not all autistic people identify as disabled.^{14,15} Research has traditionally focussed on disability associated with sensory processing differences being related to the individual. However, there is a shifting narrative, contributed to by neurodiversity advocates, of how autistic people can be disabled by systemic barriers in society.¹⁵⁻¹⁷ Therefore, it is important for this shift in attitudes to be reflected in research, to also examine social factors and build a more holistic picture of sensory experiences.

The sensory environment often presents a barrier for autistic adults accessing public spaces. In literature, autistic authors have written about their experiences of being excluded or uncomfortable in mainstream spaces because of sensory processing differences.¹⁸ Furthermore, qualitative research has highlighted that autistic adults can be overwhelmed by and avoid certain public places, such as large shops, hospitals, cinemas, pubs, and libraries due to the sensory environment.^{19,20} It is possible that adapting these environments will help autistic individuals to participate in public spaces. For example, research has shown that adapting the sensory environment in classrooms improved children's mood and performance.²¹ Also, autistic informed, relaxed theatre performances that adapt the environment (e.g., reducing the intensity of sensory input such as sounds and lights), are perceived to be more accessible by autistic individuals and their families.²² Furthermore, workplace accommodations for autistic people (e.g., environmental changes, such as reducing noise, minimising distractions, and making job duties more predictable, and enhancing employer and co-worker support), can contribute to improved performance as well as positive experiences in employment.²³ Thus, it is not only important to understand personal sensory processing differences and associated experiences, but also how these may interact with external factors in sensory environments to consider how public places could be adapted to be enabling for autistic individuals.

Despite autistic sensory processing differences persevering into adulthood,^{2,5,24} research has so far focused on sensory processing in children. Studies have primarily focussed on classroom

environments,^{21,25} with no known research that comprehensively examines autistic adults' experiences of public places. Understanding more about how and why certain sensory environments are disabling or enabling for autistic adults may help improve access to public places and inform future design and policy. Although the term 'accessibility' is commonly used, this concept focusses on disabled people not being excluded from spaces and being able to participate similarly to someone who is not disabled.²⁶ However, this concept may not fully encompass the environmental or social factors in spaces that can influence or cause disability. Therefore, in this study we have instead used the terms disabling and enabling environments, as this conceptualises the extent that disabled people can access spaces, whilst additionally recognising how spaces may also impact the health of a disabled person (see previous conceptualisation of disabling workplaces²⁷).

Our aims in the present study were to 1) examine the types of public places that autistic adults experience as disabling or enabling due to the sensory environment; 2) identify principles that make environments disabling or enabling; and 3) examine how these principles are reflected in public places that autistic adults commonly find to be disabling.

Methods

Design

In line with the participatory research framework,²⁸ we ensured that there was autistic involvement at all stages of the project. A member of our team is autistic, and we hosted a feedback group with 5 autistic adults to shape the interpretation of results, as well as fostering community involvement via our website (www.sensorystreet.uk) and social media. Our research was also designed to inform a public engagement event in partnership with Sensory Spectacle, that aims to educate the public about autistic adults' sensory experiences of public places. Sensory Spectacle educate about and create awareness of sensory processing differences through immersive learning. They work with children and adults to create these learning environments.

In order of authorship, the research team consisted of a Postdoctoral Researcher in Psychology (KM), a Speech and Language Therapist and Research and Engagement Officer (CW), an autistic Illustrator, Graphic Designer, and Podcaster (@21andsensory), a Senior Lecturer in Psychology (BH), an inclusive arts practice artist and facilitator and founder of Dyspraxic Me (JS), a sensory processing educator and founder of Sensory Spectacle (BG), and a Lecturer in Psychology (CM).

We adopted a qualitative research design to gain a deeper understanding of behaviours and experiences, generate new hypotheses, and to compliment and elucidate quantitative research.²⁹ We collected data through online focus groups, to uncover underlying experiences that might be common across participants.³⁰ The online approach enabled us to host participants safely during the COVID-19 pandemic, create a level of anonymity where participants could share their experiences more candidly, and include participants from different geographical locations who might not commonly be reached.³¹ It also enabled participants with different communication needs and preferences to participate, as the chat function supported text communication and webcam use was optional.

We hosted two rounds of focus groups. The first round of 3 focus groups aimed to identify places that are experienced to be disabling or enabling due to the sensory environment, and to investigate associated sensory experiences to inform the development of overarching principles. The second round of 4 focus groups examined sensory experiences related to the most commonly disabling environments identified in the first round of focus groups. To check the credibility of these findings,³² in the second round of groups we asked participants to confirm if the findings from the first round align with their own experiences.

Participants

Our study included 24 autistic participants, with 2 – 4 participants attending each focus group (see demographic information in Table 1). All participants reported having an autism diagnosis and scored above the cut-off (≥ 6) on the Autism Spectrum Quotient – 10³³ (AQ-10) ($M = 8.71$, $SD = 1.15$, range = 7 – 10), although this was not part of the inclusion criteria. Participants were recruited online via social media channels. Originally 29 participants volunteered to participate, but we excluded 1 prior to taking part for not having an autism diagnosis, and 4 participants did not attend on the day (1 was due to a last-minute schedule clash, and 3 did not provide a reason). We reimbursed participants for their time with a £20 voucher. Ethical approval was granted by the University of Oxford Ethics Committee (approval number: R74960).

Table 1
Demographic characteristics of participants

| | <i>N</i> | % |
|---|----------|----|
| Age range | | |
| 18 – 24 | 13 | 54 |
| 25 – 34 | 10 | 42 |
| 35 – 44 | 1 | 4 |
| Gender | | |
| Female | 17 | 70 |
| Male | 3 | 13 |
| Other | 3 | 13 |
| Prefer not to say | 1 | 4 |
| Self-reported cooccurring conditions | | |
| Anxiety and related conditions | 14 | 58 |
| Depressive condition | 10 | 42 |
| Eating related condition | 4 | 17 |
| PTSD | 4 | 17 |
| ADHD | 3 | 13 |
| Learning difference | 3 | 13 |
| Personality condition | 2 | 8 |
| Fatigue condition | 2 | 8 |
| Psychosis | 1 | 4 |
| No diagnoses in addition to autism | 4 | 17 |
| Prefer not to say | 2 | 8 |

Note. PTSD: Post Traumatic Stress Disorder; ADHD: Attention Deficit Hyperactivity Disorder.

Materials

We developed a semi-structured interview schedule for each round of focus groups, which included co-design with our autistic team member (see Supplementary Item 1). The schedule for the first round contained 5 primary questions, with optional follow-up and probing questions to establish more open-ended responses if needed. We developed the questions to understand the types of environments that are disabling or enabling, for instance asking, “*Which environments present sensory challenges to you?*”. The questions also aimed to find out more about the participants’ experiences of sensory aspects of these environments (e.g., “*What about the sensory environment makes you avoid/struggle to tolerate these places?*”).

The schedule for our second round of focus groups contained 8 main questions with optional follow-up questions. In the initial question, we asked if the places identified as being disabling in the first round of focus groups aligned with the participants’ experiences. In subsequent questions we then asked about the types of sensory input and situations that made these places challenging. As there may not have been time to discuss all places identified by the content analysis, our questions were structured by starting with the most identified disabling environment and continuing in descending order. However, participants could talk about the places in a different order to ensure that the data included experiences important to the participants. Throughout both groups, the researchers asked follow-up questions to clarify and expand on the experiences being shared. For the final question in all the focus groups, we invited participants to share any additional experiences based on what had been discussed.

Procedure

Firstly, we provided participants with a consent form and a short survey collecting demographic information and the AQ-10 via Qualtrics to complete. The participants could then book a slot for the online focus groups, which were one-hour sessions hosted by KM and CM or CW on Microsoft Teams. We then provided participants with the focus group schedule, code of conduct, and questions in advance (see Supplementary Item 2 for example of what we sent to participants for the first round of focus groups). Participants could communicate through either spoken or written language (or both), with no obligation to have their camera on, and they could take breaks at any point when needed. We also offered further support and accommodations for individuals to take part in this study if our proposed format was not suitable or accessible for them.

We started each focus group by introducing the study and focus group aims and outlined the code of conduct, providing participants the opportunity for questions or comments. We then asked the participants to consent to the session being recorded before commencing with the interview schedule. During the sessions, comments written in the chat were read out by one of the researchers to bring these into the discussion. At the end of sessions, we debriefed the participants about the next steps for the research and provided the opportunity to ask questions.

Analysis

We transcribed the audio from the recordings and the chat, then analysed the data using NVivo.³⁴ The data has been deposited in the ReShare UK Data Service repository: <https://reshare.ukdataservice.ac.uk/855801/>

Firstly, KM, CM, and @21andsensory conducted content analysis on the data from the first round of focus groups to identify the types of environments that participants experience as disabling, enabling, and neutral. This is a systematic approach that quantifies and describes data,^{35,36} creating categories of words or phrases that share meaning.³⁷ We used deductive, a priori coding of predefined categories (disabling environments, neutral environments, and enabling environments), with an unconstrained matrix and a successive inductive process to identify sub-categories of environments commonly identified within these overarching categories.³⁵ Consensus on the results of this analysis were agreed through a collaborative process, with researchers coding all the data and then discussing ambiguity and interpretations and reaching consensus on the final codes with the wider team.

Secondly, KM and CM conducted reflexive thematic analysis³⁸ on the data from the first round of focus groups to develop themes and sub-themes that relate to principles of sensory environments being experienced as disabling or enabling. This approach recognises the researcher's role in knowledge production,³⁸ which can be influenced by what we want to know and how the data is interpreted. It supports a reflexive process of theme development. We used an inductive approach driven by the data to iteratively identify patterns of meaning. The result of this analysis was revised and refined through a collaborative process with the wider research team and through an online feedback group session with 5 autistic adults, who either had or had not been involved in the focus groups. This session lasted for 90 minutes, and the individuals were provided with a summary report in advance of the meeting as well as suggested discussion points. Individuals were also provided with time after the session to follow up with any additional feedback they may have, and we sent a follow up summary of the changes we had made based on their feedback to allow further comments.

Finally, KM and CW conducted case study analysis on the data from the second round of focus groups. This was done to test how the principles of sensory environments are evident in the most disabling environments, defined as the cases, as identified from the content analysis from the first round of focus groups. The case study approach facilitates an in-depth exploration of a complex issue in a natural and real-life context.³⁹ We undertook a collective case study approach, testing our developed principles across multiple cases.⁴⁰ As we sought to understand if the principles of sensory environments applied to the cases, whilst establishing individual and shared meaning in the data to evidence the principles, we analysed the data from an interpretive,⁴⁰ positivist⁴¹ epistemological standpoint. The full results of this analysis are available in Supplementary Item 3.

Results

Content analysis: Identifying disabling and enabling places

Table 2 shows the categories of environments that were experienced as often being disabling/challenging, neutral, or enabling/enjoyable in relation to sensory input. The most common environments reported to be disabling in relation to sensory input were: 1) Supermarkets; 2) Eateries (e.g., restaurants, café's, pubs); 3) Highstreets and City/town centres; 4) Public transport; 5) Healthcare settings (i.e., Doctors surgeries and hospitals); 6) Retail shops/shopping centres. Whereas the most common environments reported to be enabling in relation to sensory input were: 1) Outdoor spaces; 2) Retail shops; 3) Museums; 4) Concert venues/clubs; 5) Cinemas/theatres; 6) Stadiums.

Table 2

Frequency of participants who reported to experience each environment as disabling, neutral, or enabling in relation to sensory input.

| Environment | Disabling | Neutral | Enabling |
|----------------------------------|------------------|----------------|-----------------|
| Supermarkets | 10 | | 1 |
| Eateries | 9 | 4 | |
| <i>Restaurants</i> | 6 | 3 | |
| <i>Pubs</i> | 2 | 1 | |
| <i>Cafés</i> | 1 | | |
| Highstreets/city or town centres | 6 | | |
| Public transport | 4 | 1 | |
| Healthcare settings | 4 | | |
| <i>Doctor's surgery</i> | 2 | | |
| <i>Hospitals</i> | 2 | | |
| Retail shops/ shopping centres | 4 | | |
| <i>Shopping centres</i> | 2 | | |
| <i>Shops</i> | 2 | 1 | 5 |
| <i>DIY store</i> | 1 | | |
| <i>Pet store</i> | 1 | | |
| <i>Flying Tiger</i> | | 1 | 3 |
| <i>IKEA</i> | | | 1 |
| <i>Bookshops</i> | | | 1 |
| Education environments | 3 | | |
| Cinemas/theatres | 3 | 1 | 2 |
| Theme parks | 2 | | 1 |
| Bars/nightclubs | 2 | | |
| Airports | 2 | | |
| Train station | 1 | 1 | |
| Bank | 1 | | |
| Hairdressers | 1 | | |
| Opticians | 1 | | |
| Parks | 1 | | |
| Parties | 1 | | |
| Public bathrooms | 1 | | |
| Concerts/clubbing | 1 | | 3 |
| Gym | 1 | | |
| Museums | 1 | | 3 |
| Outdoor spaces | | | 5 |
| <i>Farms</i> | | | 2 |
| <i>Beach</i> | | | 2 |
| <i>Park (with trees)</i> | | | 1 |
| Aquariums | | | 1 |
| Stadiums | | | 2 |

Thematic analysis: Principles of sensory environments

We developed 6 main themes and 15 sub-themes that made up the principles of disabling or enabling sensory environments: 1) “Sensoryscape” (Sensory burden; Sustained and inescapable sensory input; Uncontrollable environment); 2) “Space” (Busy and crowded; Confined built environment); 3) “Predictability” (Uncertainty; Inconsistent and unfamiliar; Lack of information for forward planning); 4) “Understanding” (Misunderstanding and judgement; Unsupportive people); 5) “Adjustments” (Inflexible communication; Pace pressures; Unsuitable adjustments); and 6) “Recovery” (No space to escape; Unable to recover and prepare).

We developed a visual image to represent the overlapping and interrelated nature of these themes, which was further highlighted by the autistic adults in the feedback group (Figure 1). This was designed by @21andsensory, an autistic graphic designer on the research team, and represents the themes as an interconnected, dimensional web, with the distance from the centre representing a spectrum from enabling to disabling. The main themes are labelled to reflect this spectrum, whilst the subthemes are labelled to represent the most disabling aspects of each category.

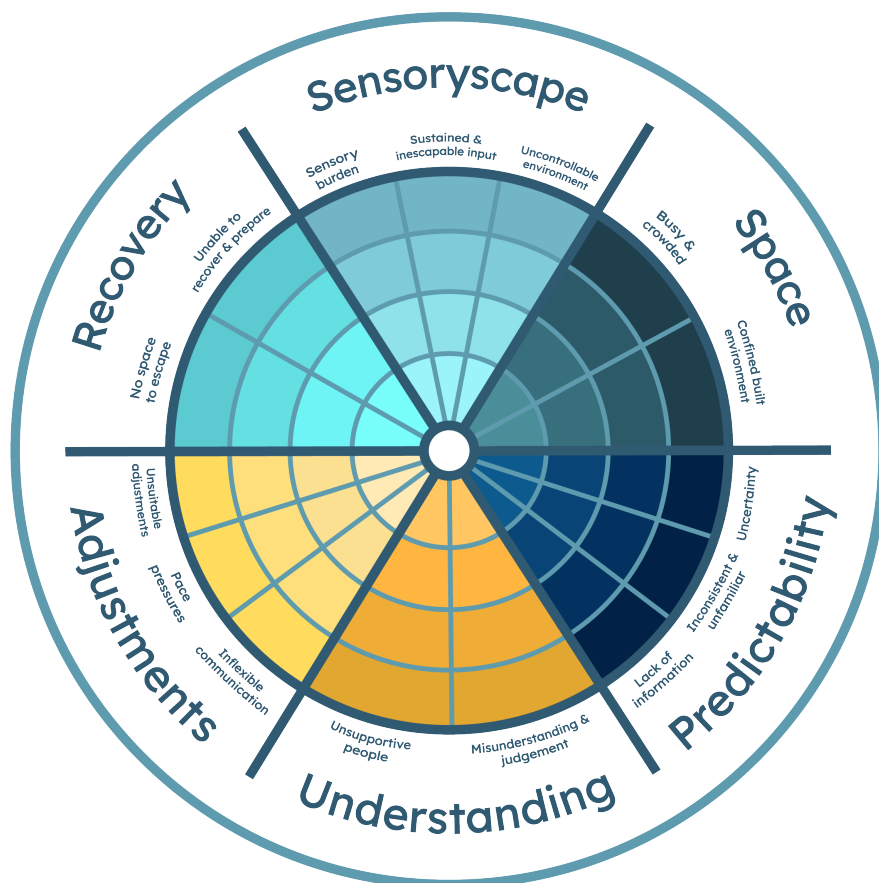


Figure 1

Graphical representation of the principles of sensory environments including the main themes and sub-themes developed from the reflexive thematic analysis. For each subtheme, the outer segments of the web (darker shaded colours) represent more disabling environments (e.g., a higher sensory burden with an array of aversive sensory input), whereas segments closer to the centre (lighter shaded colours) represent more enabling environments (e.g., a lower sensory burden with reduced or less aversive sensory input). Figure reproduced from <https://osf.io/vtqr8> under a CC-BY 4.0 license.

Sensoryscape

Many of the autistic adults described features of the sensory environment that are more disabling or enabling, which we have termed 'sensoryscape'. Individuals discussed how the sensoryscape could be impacted by the burden of sensory input, how sustained and unavoidable the sensory input is, and how much control the individual has over the environment.

Sensory burden

Many autistic adults described the high burden of intense and multisensory input in certain public places and how this can be overwhelming and disabling. Individuals described the burden in environments that have layers of uni-modal and multi-modal sensory input (e.g., sounds, lights, and scents), and also how particular sources of intense sensory input, such as sudden loud sounds and strong scents could be overwhelming. Conversely, individuals noted how reducing the burden of sensory input in environments, such as by reducing the amount or intensity of sensory input, can make these places more accessible.

"It's like a multitude of things and there's a big, I always envisage it is a big spider web of things that might affect me in a sensory environment, and I want to say to people, it's about actually looking at all those little things that build up, being able to... reduce those little things as well" [SS05].

Sustained and inescapable sensory input

Having to experience sustained sensory input and not being able to avoid or escape from it was described to be overwhelming and disabling. Furthermore, individuals noted the difficulty of prolonged exposure and feeling trapped in environments that had a higher sensory burden.

"I think that's particularly true in places like train stations where you're waiting for something, you can't leave, you've got to wait... it becomes really overwhelming... this is what we see when people are waiting to have... hospital appointments or something they're worried about, you can't leave because you don't know when you will get that opportunity again, and you want it, you want to be there and do the thing you're there for, but it's all piling on top and creating that sort of, you know, maelstrom of sensory and anxiety all going on and and that's where the problems then start to happen..." [SS11].

Uncontrollable environment

Some of the autistic adults noted that environments could be more accessible if certain sensory elements could be controlled, for instance, by being able to adapt the brightness or volume of sounds within the space. Being able to control the environment could reduce the burden of the sensory input so the environment is less overwhelming and more accessible.

"You know, just being able to have an option of like turning the self-checkout voice off, like, I sometimes don't need that extra stimulation, that could be the one thing that makes me feel like

I can lose it sometimes with a meltdown, often just being able to just have control over those sounds would be great” [SS05].

Space

Many autistic adults discussed how feeling closed in and crowded in a space could make public places a more challenging sensory environment compared to open, quiet spaces. This was influenced by the busyness and proximity of other people as well as how confined the space felt due to the built environment.

Busyness and proximity

Environments with lots of people in close proximity were described to be challenging due to the increase in auditory, tactile, and visual input. Individuals discussed that they often preferred places that were less busy and would try to visit environments at quieter times as sharing spaces with fewer people made places more accessible.

“... I think quite often environments like museums like gyms are often so busy and overwhelming and you don't necessarily know until you get there... so being able to visibly see on a website because a lot a lot of the time they are putting up - these are our quiet hours - less people go and then you can also see quite often whether it is high medium or low availability or whether it's booked out and so you can use that to plan to go during a time that works best for you” [SS01].

Confined built environment

Some autistic adults noted that the built environment could make the sensory environment more overwhelming by increasing the feeling of being closed in and surrounded by people and sensory input. Conversely, individuals noted that open environments can be more accessible by reducing the sensation of being closed in.

“I love going to bookshops. They tend to be quite quiet and particularly ones where the shelves are all quite spaced out from each other, so you're not kind of crammed in against other people” [SS03].

Predictability

Many autistic adults described how predictability was an important factor associated with sensory input and the accessibility of public places. Individuals discussed this in terms of the uncertainty, consistency and familiarity of environments and sensory input, as well as the benefit of having information available in advance to increase the predictability of an environment.

Uncertainty

Many of the autistic adults described how uncertainty could lead to challenging sensory environments becoming overwhelming. This included uncertainty about how long they had to remain in the environment, the types of sensory input present, and the frequency of aversive stimuli. Uncertainty about the layout and procedures of the environment also contributed to the cognitive load of an already challenging location.

“But you never quite know where you're going to sit and if it's it's going to be the same place and it's still very noisy it's one of those things that we were talking about earlier where you can just about endure but you have to psych yourself up to go and then you have to like rest afterwards and quite often I end up having to leave early 'cause I just can't take any more noise” [SS10].

Inconsistent and unfamiliar

Individuals described how they know what to expect in consistent and familiar environments, making these sensory experiences less unpredictable. Conversely, inconsistency across environments, such as supermarket or restaurant chains, can make them more unpredictable.

“... my local [supermarket], I've gone there for like 7 years and they've never changed the layout, and so I've always found [this supermarket] actually alright. I know where we go, we go around the same way every time, we get basically the same things. A couple of weeks ago they completely changed the layout, and I went in... and I just walked straight out... there's all the things sensory things in a supermarket, the noises, the air conditioning, the cold fridges, but you can manage that when you know what's coming, and it's easier” [SS08].

Lack of information for forward planning

Some autistic adults discussed how they could reduce the unpredictability of a challenging sensory environment by planning in advance of visiting. This can also help individuals to avoid experiences and areas that may be aversive due to sensory inputs. Individuals described how environments could be more accessible when there was information available online, such as the location's layout, the procedures, and the goods and services available. This could also be useful for when familiar environments change so that individuals can prepare for the unpredictability of the altered environment.

“I think for me I always find it a lot easier, again, like predictability, so if there's - like for example online if they have like, like a website which details like what it looks like, what the kind of environment is like, I find that a massive improvement and it really helps me to be able to kind of get an idea of what it's like before I go and then I feel better” [SS02].

Understanding

Many of the autistic adults described the importance of staff and the public understanding sensory processing and autism to make public places more accessible. Individuals recalled facing

misunderstanding and judgement about their sensory processing needs and dealing with unsupportive people including both staff and the public. They also discussed their experiences of camouflaging their sensory challenges and coping behaviours to avoid judgement from others.

Misunderstanding and judgement

Several autistic adults described experiencing misunderstanding and judgement about their sensory processing differences and being autistic. They recalled how people can lack understanding and stigmatise both autism and sensory processing differences. Individuals also described how they can feel judged by other people in public places for their responses to the sensory environment, their access needs, and their self-guided strategies such as stimming and using fidget toys.

“I think a common misconception is that... all autistic people are the same and have the same sensory triggers, which just isn't true. Like, what might affect someone pretty badly doesn't affect someone else at all and everyone kind of has different perceptions of what they're okay with and also at different times. Like, what could affect an autistic person one time, doesn't bother them the next time because it depends on like what other stuff is going on for them... They think that, like for example, all autistic people don't like loud noises... but it's not actually true... it's a lot more down to the individual and the circumstances at the time” [SS12].

Unsupportive people

Staff in public places were described to lack knowledge of sensory processing and autism, which is a barrier to being able to receive support and access requirements in these environments. Individuals noted that staff could benefit from training to better understand autism, so that they can be more understanding and supportive of autistic people.

“... I made it clear that I was autistic, and I might need some help with getting around the airport... I find really hard sometimes to navigate and be able to understand where I am and it just gives me a lot of anxiety, and they didn't understand the Sunflower [Lanyard] scheme^a which I was quite surprised by... and they didn't, didn't help me at all and I'd asked for assistance, and they didn't. I think being able to contact someone and they say, okay, we can help, you know, being more consistent with help” [SS05].

Additionally, some autistic adults described camouflaging in public places to avoid judgement from others, such as by trying to 'appear normal' when feeling overwhelmed by sensory input and not wanting to be perceived as being 'difficult' for having specific needs. This could limit their use of self-guided strategies that can help them regulate when feeling overwhelmed by the sensory environment, such as stimming and using fidget toys. However, some individuals noted that certain places were more accessible if they felt that their behaviours appeared 'appropriate' in the environment.

^a The Sunflower Lanyard scheme was introduced as a way for people with hidden or invisible disabilities to discretely communicate that they may need help, support, or more time in public places <https://hiddendisabilitiesstore.com/about-hidden-disabilities-sunflower>

“I think neurotypical people don't realise that when we're trying not to show a sensory environment is affecting us, because we don't want to be perceived to be “difficult” about asking for the lights to be turned off or for the radio to be turned down, it really drains us so you've not just got the sensory input but you have also then got all the effort going into the ‘no, no, no, I'm fine, honest, I'm fine’ so that then means that we have an even shorter period of time we can cope with the situation, so it's more likely to go wrong quicker” [SS11].

Adjustments

Many of the autistic adults discussed how the lack of suitable adjustments can increase the inaccessibility of sensory environments, while reasonable adjustments can improve accessibility to certain public places. These included inflexible communication methods, pace pressures, and unsuitable adjustments that are not tailored to individual needs.

Inflexible communication

Several autistic adults described how there was an expectation in public places to use spoken language to communicate, which could be challenging and anxiety provoking to navigate. Some individuals described how feeling overwhelmed by the sensory environment impacted their ability to use speech to express themselves. Additionally, many autistic adults described how public places that do not accommodate different communication needs and preferences can be disabling and impact individuals accessing goods and services. Some individuals described how using resources to support communication without spoken language would be beneficial, such as ordering and checking into places using mobile apps, and public places providing signs to assist communication.

“Something that I have found a bit easier because of COVID is the fact that in like a lot of restaurants now you sort of can order online like while you're in the restaurant. You can use that like an online tool and be able to order the food to you rather than having to speak to someone which could be quite overwhelming when you're already in a noisy environment. So, I found that quite helpful” [SS02].

Pace pressures

Some of the autistic adults described how the burden of the sensory environment can mean they need extra time to process and to consider their choices and needs without feeling pressured. Individuals reported that busy public places generally have a faster pace which can be challenging, but also that other people could make them feel pressured to go at a faster pace.

“... it feels like well, when I go shopping anyway, it feels like I'm being rushed or pushed into you know trying to finish tasks” [SS06]

Unsuitable adjustments

Many autistic adults described how existing adaptations for autistic people feel tokenistic and are inadequate for their needs, and that suitable, tailored adaptations are lacking. Some individuals noted

how existing schemes fail to improve accessibility to public places. For instance, quiet hours, with fewer people and reduced sensory input, help improve the accessibility of the environment, but they are infrequent and at unsuitable times for many. Additionally, schemes such as the Sunflower Lanyard scheme are generally misunderstood, and fail to generate access to support for individuals in public places. Some autistic adults noted that adjustments should consider the needs of the individual by communicating with them to understand how they can be supported - but improving accessibility to public places for autistic people does not feel like a priority.

“... there needs to be more definite source of information, ‘cause I feel like you can Google how to make shops more accessible for autistic people and you kind of get the same advice often and often it's not very comprehensive or that educational, that there's a lot of diversity within autism. It often says this is what the things that people with autism need, but actually often it's a big spectrum of people and I think this definitely, if even it's government issued as well, would be really helpful” [SS05].

Recovery

Many autistic adults described the need for recovery when becoming overwhelmed by the sensory environment. Some individuals noted the necessity of breaks to prepare and recover from burdensome sensory input, and many discussed the need for designated spaces to escape from sensory input away from other people.

Unable to prepare and recover

Some autistic adults noted how they need to have time to take breaks to recover when feeling overwhelmed by the sensory environment in challenging public places, which can provide the opportunity for preparation to carry on.

“... things just exhaust me in ways they don't with other people you know I I went to an animal farm for my mum's birthday and we went to feed donkeys and things and I had a nice time because I got to feed donkeys, but it was exhausting and I slept for like 18 hours afterwards and I cannot go anywhere for very long because I get tired so I could never do a whole day at the farm or a theme park or something” [SS10]

No space to escape

Associated with the need to recover and prepare, many autistic adults described the need for environments to have designated spaces they can escape to. Individuals discussed the difficulty of being trapped in an environment with sustained aversive sensory input and the need to be able to take breaks in a space with seating and reduced people, sounds, and lighting.

“I think that having like a quiet room can apply to like so many different places, even places like concerts, concert halls and things like that, and I think a lot of people might think, well, if you have these sound sensitivities then why would you be going to a concert? But I think that we

should have, like the equal opportunity to still like enjoy those things, but also have kind of, a backup area if we get overwhelmed” [SS01].

Case Studies: Examining the principles in disabling environments

We developed case studies to evidence the above principles in 5 commonly identified disabling sensory environments: 1) Supermarkets; 2) Eateries; 3) Highstreets and City/town centres; 4) Public transport; 5) Healthcare settings. Table 3 provides a summary of the case study for supermarkets to demonstrate how disabling and enabling aspects of the principles are reflected in the most identified disabling environment (full case study results are available in Supplementary Item 3).

Table 3

Summary of case study analysis evidencing the 6 principles in supermarkets, the most identified disabling environment. We also developed case studies in other commonly disabling sensory environments: Eateries; Highstreets and City/town centres; Public transport; Healthcare settings.

| Case: Supermarkets | |
|---------------------------|--|
| Sensoryscape | High sensory burden, sustained and inescapable input, and uncontrollable environment |
| Example | Bright unnatural light, shiny floors, visual information from products; noise from checkouts, customers, trolleys, announcements, and background music; smells. Quiet hours can be more enabling as this reduces the burden of the sensory input. |
| Space | Busy and crowded, and confined built environment |
| Example | People often brush up against you. Can be more tolerable at quieter times and if the built environment is more spread out. |
| Predictability | Uncertainty, inconsistent and unfamiliar, and lack of information |
| Example | The layout and arrangement of products is often changed, which heighten sensory challenges. Would be helpful to know about changes in advance (e.g., map of new layout) as knowing the layout in advance can limit the time spent in an overwhelming sensory environment. |
| Understanding | Unsupportive people, and misunderstanding and judgement |
| Example | Staff lack understanding of sensory processing and autism, which makes it difficult to access support. Individuals feel judged for accessing existing supports (e.g., quiet hours). This could be improved by training staff in autism and sensory processing, but also supporting improvements in customer awareness. |
| Adjustments | Unsuitable adjustments, pace pressures, and inflexible communication |
| Example | Feeling overwhelmed by the sensory environment can make the fast pace and spoken language requirements at staffed checkouts challenging for individuals. Self-checkouts or scan-as-you-shop can be more enabling as speaking to staff can be avoided. The Sunflower Lanyard currently seems tokenistic as it does not result in adequate adjustments and quiet hours should be made more widely accessible for a range of individuals. |
| Recovery | No space to escape, and unable to prepare and recover |
| Example | Individuals can feel trapped in some supermarkets and unable to escape for a break if feeling overwhelmed (e.g., if there are barriers at checkouts). |

Discussion

We investigated autistic adults’ sensory experiences associated with public places. We found that supermarkets, eateries (i.e., restaurants, cafés, pubs), highstreets and city/town centres, public transport, healthcare settings (i.e., doctor’s surgeries and hospitals), and retail shops and shopping centres, are commonly disabling sensory environments for autistic adults. Additionally, we found that

outdoor spaces, retail shops, museums, concert venues/clubs, cinemas/theatres, and stadiums are commonly more enabling sensory environments for autistic adults. Furthermore, we identified 6 key principles of sensory environments: Sensoryscape, Space, Predictability, Understanding, Adjustments, and Recovery, that form an interconnected web that underlie the extent that public places are disabling or enabling. Through case study analysis, we evidenced the credibility of these principles across several commonly disabling sensory environments, providing richer detail and context pertaining to these different public places. The full case study results are available for the top 5 disabling environments in Supplementary Item 3.

Our results indicate that burdensome multi-sensory input, either with high intensity input or input across several domains (e.g., visual, auditory, tactile), are associated with disabling public places. Although the presence of some aversive input, such as sounds and bright lights, seem to be commonly challenging for individuals across different disabling environments, experiences of other types of input were more unique to individuals and contexts. Existing research has highlighted the complex and individual nature of sensory experiences in autistic adults, which can be influenced by external and internal factors across time and contexts.⁵ In reality, individuals do not engage with public places in isolation, and exposure to ongoing sensory input across contexts, intertwined with other factors, such as level of support and understanding from others, can influence how an individual tolerates an environment. Although built environment research has indicated the importance of considering sensory input in design, such as lighting, colours, and acoustics,⁴² the results of the present study also highlight the need for consideration of a multitude of social factors that may interact with sensory processing differences and how an individual is affected by an environment.

Our findings also highlight adaptations that public places could make to minimise the impact of challenging sensory input for autistic adults to make them more enabling. Adjusting the sensory burden of spaces can improve access to events and environments for autistic individuals, as shown in research examining relaxed theatre performances.²² In some environments it may not be feasible to reduce the burden of the sensoryscape - especially busy, multisensory public places that are uncontrollable, such as highstreets and city centres. However, our results highlight that there may be other adaptations that could reduce the impact of these challenges and make places more enabling, for instance, providing opportunities for recovery, increasing staff awareness and understanding, and making suitable adjustments. Designated spaces that provide a break to recover from sensory input could be an important adaptation for public places, as previously highlighted as a high priority for autistic theatre-goers²² and proposed as a design consideration for autistic individuals in built environment research.⁴² Additionally, delivering staff training on autism and sensory processing could importantly improve support and acceptance of autistic individuals who may become overwhelmed by sensory input in public places, as knowledge of autism has been shown to positively influence attitudes about autism.⁴³ Improving acceptance could help reduce the need for autistic individuals to camouflage behaviours, such as regulatory stimming, that could help them tolerate challenging sensory environments.⁴⁴ Further, staff training could improve the provision of suitable adjustments in public places, such as communication and pace adjustments. Although there are some existing schemes aimed at improving

accessibility to public places, such as autism/quiet hours, the Sunflower Lanyard scheme, and quiet/sensory rooms in certain contexts (e.g., football stadiums), it is not yet clear whether these are fit for purpose and suitable for the heterogeneous autistic population. Thus, work in partnership with autistic individuals and other stakeholders from the start of the design process is needed to inform adaptations and new building and space design that can make them enabling and accessible for autistic people.

Furthermore, our findings indicate the importance of increasing the predictability of commonly disabling public places, as unpredictability and uncertainty may increase the burden of the sensory environment. Many autistic individuals find uncertainty challenging⁴⁵ and they may be more likely to be hypervigilant and to interpret uncertain or unpredictable information, such as sensory input, as threatening.^{46,47} This can then contribute to the conditioning of anxiety in autistic individuals.^{9,48,49} The benefit of providing advance information for autistic individuals is widely acknowledged and often employed in classrooms through strategies such as visual timetables.⁵⁰ As highlighted by our findings, public places could also make adaptations to improve the amount of information available in advance to lessen the uncertainty of these environments, such as providing information of procedures, maps, and images that can be viewed in advance on websites or when entering spaces. Examining the impact of adaptations to public spaces could be an important future direction for study to understand more about how these changes can make public places more enabling.

Limitations

Online research allows a diverse range of people to participate, regardless of location, and supports different communication needs to some extent, by allowing communication through either spoken or written language. However, this approach would have limited participation opportunities for those without digital access, or those with cooccurring intellectual disability who would have needed additional support to participate online. A recent meta-analysis suggested that, on average, 33% of autistic people have co-occurring intellectual disability, although the estimates ranged from 0 to 70% across studies.⁵¹ However, these individuals are often underrepresented in autism research.⁵² Additionally, our primary recruitment method of using social media may have further limited our participant demographic, such as by not reaching older adults as the majority of our sample were below the age of 35 years. Although autism research with older adults is growing, only 0.4% of published research has examined this population in the last decade.⁵³ Understanding experiences across a range of individuals is especially important as sensory processing differences may vary across the autism spectrum,⁵⁴ and certain individuals may be more likely to experience distress and exclusion, such as those who are non- or minimally-speaking. Subsequently, different types of adjustments and support in public places may be required, which was highlighted by participants in the present study, who noted that what may be disabling for one individual, may not be disabling for another. Therefore, future research should also aim to understand sensory experiences of public places from individuals that are not commonly included in research, such as older adults and those with intellectual disability and who have differences in communication (e.g., non-speakers and non-speaking spellers).

Additionally, this study did not collect formal data as to the geographical location of the participants. It is understood that our study contains a primarily UK sample of adults, however, there were at least a couple of participants located in other countries. For this study, we see it as a strength that we were able to include a diverse range of participants using the online focus group method. However, as results may not generalise across countries, it is also important for future research to examine similarities and differences between geographical locations.

Lastly, although we have explored how sensory experiences relate to both disabling and enabling environments, the disabling aspects of public places were examined with a more in-depth lens to consider how public spaces can be improved. Aversive sensory experiences have long been the focus of research, often neglecting the array of enjoyable sensory perceptual experiences reported in autistic accounts.⁵⁵ Sensory seeking may be a positive experience beneficial for autistic wellbeing. Qualitative research has highlighted how autistic people seek out a range of sensory input, such as certain music, that can be soothing in times of dysregulation.^{5,12} Recent work has also indicated that although autistic people perceive hyperreactivity to sensory input to be more of a cause of anxiety, sensory seeking is perceived to be more of an effect, further supporting its regulatory function.⁵⁶ Thus, it is important to understand more about positive sensory experiences, and learn from autistic experiences of enabling public places, to improve the wellbeing of autistic people.

Conclusion

This research improves our understanding about how the sensory aspects of public places are experienced by autistic adults. We developed 6 principles of sensory environments that underpin whether public places are experienced as disabling or enabling. This research has implications for improving the accessibility of public places for autistic people, to ensure they can fairly access goods and services, social connections, and appropriate healthcare - all of which are critical for quality of life.

Acknowledgments

We thank all the participants who shared their experiences in the focus groups, and the members of the feedback group (Sarah O'Brien, Aimee Fletcher, Sarah Gale, Sarah Miller, and Emma Nielsen) who shaped our interpretation and presentation of results. We also thank Autism Berkshire for advertising the study on our behalf, as well as all other individuals and groups who shared information about the study to their networks.

Authorship confirmation statement

CM, BG, BH and @21andsensory obtained funding for the study. All authors contributed to the research design. KM, CM and CW conducted the focus groups and KM, @21andsensory, CM and CW analysed the data. KM drafted the initial manuscript and @21andsensory designed Figure 1. All authors contributed to the interpretation of results and approved the final manuscript.

Authors' disclosure

Becky George is the founder of Sensory Spectacle, which provides training, workshops, and immersive learning. All other authors have no conflicts of interest to disclose.

Funding statement

This research was funded in whole, or in part, by the Wellcome Trust [grant number 204685/Z/16/Z and an Enriching Engagement Award to CM].

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