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

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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.

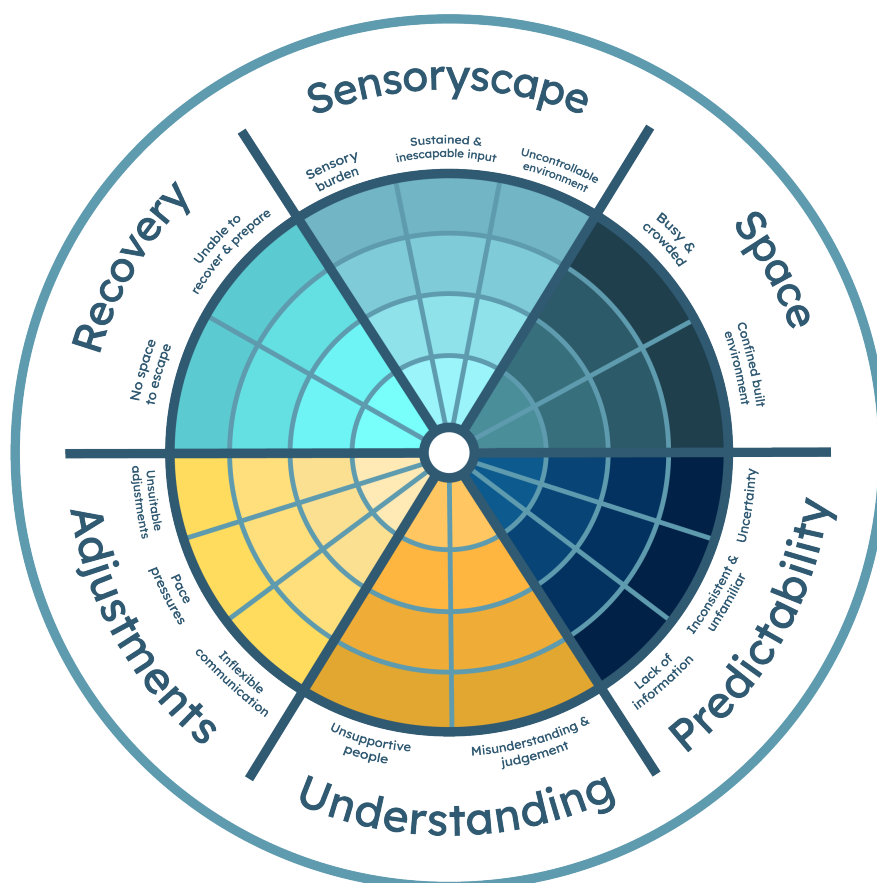


Figure 1

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.

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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.

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Supplementary item 1: Focus group interview schedules

Focus groups round 1

You can give multiple answers to each question, and you can raise your virtual hand or write comments in the chat in response to what others have said.

1. Which environments present sensory challenges to you?
2. Are there any places you particularly avoid/struggle to tolerate because of sensory aspects of the environment?
 - a. *What about the sensory environment makes you avoid/struggle to tolerate these places?*
 - b. *What changes could be made to improve sensory aspects of these environments?*
 - c. *Pick a type of environment and tell me how you would make it better*
3. Are there any places you like going because of sensory aspects of the environment?
 - a. *What about the sensory environment makes you like these places?*
4. What do neurotypical people often not know about sensory processing differences?
5. Anything else you would like to tell us about experience

Focus groups round 2

1. In previous focus groups, autistic people said that the following places commonly present sensory challenges for them:
 - Supermarkets
 - Eateries (e.g., restaurants, cafés, pubs)
 - City or town centres, highstreets, or public streets
 - Public transport (e.g., trains, buses)
 - Healthcare settings (e.g., doctor's surgeries and hospitals)
 - Retail shops/shopping centres (e.g., on a Highstreet or in a retail park)

Does this align with your experiences? If not, please tell us what is different for you.

Are there any other places, that we have not mentioned, that are especially challenging for you due to the sensory environment?

We would now like to find out more about how you experience these places. *Please note, due to the session being for 1 hour, we may not have enough time to talk about all the places.*

2. We would like to find out more about your experiences of supermarkets.
 - What sensory aspects of supermarkets can make this environment challenging/inaccessible for you?
 - What are the features/circumstances of supermarkets that can make it a more positive/accessible sensory experience for you (if any)?
 - In an ideal world, how could supermarkets be adapted to make it a more positive/accessible environment?
 - *What type of supports or services would you want to see in supermarkets to support autistic people?*
3. We would like to find out more about your experiences of eateries (e.g., restaurants, cafés, pubs).
 - What sensory aspects of eateries (e.g., restaurants, cafés, pubs) can make this environment challenging/inaccessible for you?
 - What are the features/circumstances of eateries (e.g., restaurants, cafés, pubs) that can make it a more positive/accessible sensory experience for you (if any)?
 - In an ideal world, how could eateries (e.g., restaurants, cafés, pubs) be adapted to make it a more positive/accessible environment?
 - *What type of supports or services would you want to see in eateries (e.g., restaurants, cafés, pubs) to support autistic people?*
4. We would like to find out more about your experiences of city or town centres, highstreets, or public streets.

- What sensory aspects of city or town centres, highstreets, or public streets can make this environment challenging/inaccessible for you?
 - What are the features/circumstances of city or town centres, highstreets, or public streets that can make it a more positive/accessible sensory experience for you (if any)?
 - In an ideal world, how could city or town centres, highstreets, or public streets be adapted to make it a more positive/accessible environment?
 - *What type of supports or services would you want to see in city or town centres, highstreets, or public streets to support autistic people?*
5. We would like to find out more about your experiences of public transport (e.g., trains, buses).
- What sensory aspects of public transport (e.g., trains, buses) can make this environment challenging/inaccessible for you?
 - What are the features/circumstances of public transport (e.g., trains, buses) that can make it a more positive/accessible sensory experience for you (if any)?
 - In an ideal world, how could public transport (e.g., trains, buses) be adapted to make it a more positive/accessible environment?
 - *What type of supports or services would you want to see in public transport (e.g., trains, buses) to support autistic people?*
6. We would like to find out more about your experiences of healthcare settings (e.g., doctor's surgeries and hospitals).
- What sensory aspects of healthcare settings (e.g., doctor's surgeries and hospitals) can make this environment challenging/inaccessible for you?
 - What are the features/circumstances of healthcare settings (e.g., doctor's surgeries and hospitals) that can make it a more positive/accessible sensory experience for you (if any)?
 - In an ideal world, how could healthcare settings (e.g., doctor's surgeries and hospitals) be adapted to make it a more positive/accessible environment?
 - *What type of supports or services would you want to see in healthcare settings (e.g., doctor's surgeries and hospitals) to support autistic people?*
7. We would like to find out more about your experiences of retail shops/shopping centres (e.g., on a Highstreet or in a retail park).
- What sensory aspects of retail shops can make this environment challenging/inaccessible for you?
 - What are the features/circumstances of retail shops/shopping centres that can make it a more positive/accessible sensory experience for you (if any)?
 - In an ideal world, how could retail shops/shopping centres be adapted to make it a more positive/accessible environment?
 - *What type of supports or services would you want to see in retail shops to support autistic people?*
8. Based on what we have discussed today, is there anything else you would like to tell us about your sensory experiences of certain places?

Sensory Street



Contents:

1. Information about the project
2. Objectives of the Focus Group
3. People involved in the Focus Groups
4. Focus Group Plan
5. Example Code of Conduct
6. Focus Group Possible Questions
7. What is a Microsoft Teams Meeting?

1. Information about the Project

Sensory Street is a Wellcome Trust funded project at the University of Oxford. We want to work with the autistic community to create an event to help people experience what it is like to have sensory processing difficulties in a creative and interesting way. In our focus groups we want to learn more about what it means to be an autistic person with sensory processing difficulties, how the sensory aspects of an environment can affect you and how we can help people to learn about sensory processing in autism.

2. Objectives of the Focus Group

- Identify locations that present significant sensory challenges for autistic people
- Understand the sensory aspects of the environment associated with specific locations that present the biggest challenges
- Understand more about what enabling adjustments for a sensory environment might look like
- Learn about which audiences autistic people would like to be better informed about sensory needs

3. People Involved in the Focus Groups

The focus groups will consist of up to six people. There will be two people from our research team in each focus group. Keren will be at all the focus groups and will be leading the group. Keren will ask the questions while the other researcher (Catherine or Cathy) will be monitoring the chat and doing the recording. The other people in the group will be autistic people invited to the session by email.

Sensory Street



Keren



Catherine



Cathy



4. Focus Group Plan

1. Introduction of group members
 - a. Keren and Catherine or Cathy (depending on group)
 - b. Group members will be asked to introduce themselves - name and where you are from and/or interests. You do not have to do this if you do not want to or you could add this information into the chat
2. Introduction to the group
 - a. We will discuss the purpose of the group and our objectives
 - b. We will talk about the terminology that we will use in the group such as autistic person vs. person with autism Respect terminology people use
 - c. We will remind you that you can leave if you want to at any time or take a break and then come back later
 - d. We will discuss the timings/structure of the session and what to expect. We expect the group to last approximately one hour
3. Rules of the Group
 - a. We will read out some possible rules of the group (these are outlined below)
 - b. At this point we can discuss any of these rules and agree any additional rules based on how we want to work and what we agree is appropriate
4. Discussion where people can share your thoughts and experiences.
 - a. Possible questions for this section are outlined below. We expect to ask all of these questions during the focus group but this may not be necessary depending on people's responses. We also may ask follow-up questions based on people's answers

5. Example Code of Conduct (Group Rules)

1. To ensure everyone gets a chance to speak, we will ask you to:

Sensory Street



- a. Mute your microphones until it is your turn if possible. This will reduce unnecessary background noise.
 - b. Indicate when you wish to speak by raising a 'virtual hand', or by waving your hand or alerting in the text chat. Keren will let you know when you can come on and speak. But we want to create a discussion so please indicate you would like to speak at any point
 - c. If Keren feels like the conversation is going off-topic, or that others need to convey their opinions, then she may move on to another person / topic. She will let you know if she is going to do this.
2. There is no requirement to be visible on video if you do not feel comfortable. However, we will ask you to verify who you are via audio. After this point you can use the chat function to communicate in the group if you prefer.
3. If you want to say something in response to someone, please raise a 'virtual hand' or type in the chat sidebar until it is your turn to speak. We can also read out any questions or comments for you. And Cathy/Catherine will bring comments from the chat into the discussion and ask if you would like to expand
4. Do not send private messages to anyone other than the hosts of the group. This is so we are aware of all conversations that are happening.
5. This is a positive online space. If the session is becoming negative or distressing, the hosts will step in.
6. Please keep your phone on silent throughout the session
7. Please feel free to mute the session and take a break from main chat discussion if you need. You can message the hosts privately if you would like to let them know you are doing this.
8. This is a safe space. Members may speak about their own experiences so please do not share sensitive information that others may disclose in the session.
9. If you disclose something of concern in the session, one of the hosts will reach out to you individually.
10. Everyone experiences the world differently. It is okay to have differences, and differing opinions will be treated respectfully. Please respect other people's opinions and how they identify.

Sensory Street



11. Please do not swear or use rude language.
12. If you do or say something inappropriate on video, audio or chat, we will remove you from the session and again, reach out to you individually.
13. Please do not forward on any invites to the session. Only people who have applied and been accepted will be admitted.
14. Make sure that there is nothing in your background that you do not want to be seen by others. You can choose to blur your background or use a virtual background if you prefer

6. Focus Group Possible Questions

You can give multiple answers to each question and you can raise your virtual hand or write comments in the chat in response to what others have said

1. Which environments present sensory challenges to you?
2. Are there any places you particularly avoid/struggle to tolerate because of sensory aspects of the environment?
 - a. *What about the sensory environment makes you avoid/struggle to tolerate these places?*
 - b. *What changes could be made to improve sensory aspects of these environments?*
 - c. *Pick a type of environment and tell me how you would make it better*
3. Are there any places you like going because of sensory aspects of the environment?
 - a. *What about the sensory environment makes you like these places?*
4. What do neurotypical people often not know about sensory processing differences?
5. Anything else you would like to tell us about experience

7. What is a Microsoft Teams Meeting?

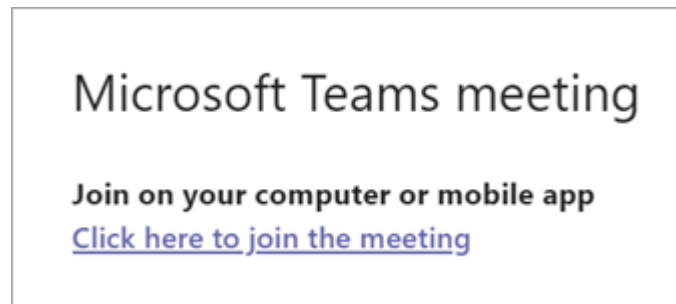
For this project we aim to use Microsoft Teams to host our virtual focus groups. This platform works in a similar way to Zoom, and you can choose to use the chat function, video and audio to interact with people throughout the session.

We have chosen to use Teams where possible as it means that the recording of the session will be encrypted and can be stored securely within the University's IT system. The meeting organiser will be able to control who can record the meeting, meaning that you cannot be recorded by other people in the group without your consent.

Sensory Street

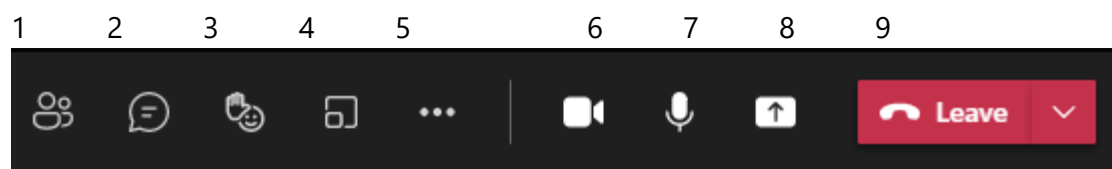


You will be invited to join the team meeting via a link which may look like this:



Click on this link to join the meeting either online or through the desktop app. If you have the app already it should open there automatically. If you do not have a Teams account you should have the option to add your name and join as a guest. At first, you may go to a lobby where a person in the meeting can admit you to the call.

Teams functions in a similar way to other video platforms such as Zoom. In the top corner you should have a toolbar that looks like this:



1. This will show you all the participants in the group
2. This will show you the meeting chat
3. Here you can react to the conversation, such as by raising your hand
4. This one enables people to create breakout rooms
5. This button enables you to use additional actions such as changing your view of the group or adding a background effect. Not all of these options may be available to you as a guest
6. Here you can turn your video on/off. There is also the option to blur your background or add a virtual background
7. Here you can turn your microphone on/off
8. Here you can share your screen to show information. The Microsoft whiteboard is also included here
9. You can use this button to leave the meeting if you wish

Supplementary item 3: Case study analysis results

Supermarkets

Sensoryscape

Supermarkets were commonly described as being an overwhelming multi-sensory environment, for instance one of the autistic adults stated: *"The noise, lights and all senses to be honest! They make it feel like the building is closing in on me"* [SS07]. Several individuals mentioned the bright, unnatural lighting in supermarkets due to the lack of windows, for example one said: *"I think it's the lighting... because there's never like natural light there's always like very bright lamps and they're always like white or yellow, but very very bright"* [SS24], and they went on to add that the brightness can be accentuated by the built environment such as the floor being *"... shiny so the light like reflects from the ground. No matter where you see there's a lot of light"* [SS24]. Additionally, people identified that the tall shelves filled with products could present an overwhelming amount of visual information.

Individuals also described the difficulty of there being lots of different sounds, including checkouts, other customers, trolleys, announcements, and background music:

"... what makes a supermarket challenging I think is... just the noise... you can just hear everything, so you hear people, you hear like beeping, you hear like people pushing stuff, like you just hear everything. It's very overwhelming" [SS04].

There may be additional sensory input that could increase the burden, for instance a few individuals also noted struggling with the smell in supermarkets, for example one individual noted: *"I tend to avoid some shops because of the smell, they're not that efficient in cleaning the vegetable areas"* [SS19].

Some of the autistic adults described how steps to limit the burden of sensory input could make supermarkets more accessible. For example, one individual noted:

"I know a lot of supermarkets are starting to adopt sort of like autism hours and quiet hours and things like that, which is a really nice step and I think largely, you know, having less lighting and, you know, having no sort of music and turning off the noises on checkouts and things like that is really good" [SS24].

Space

Supermarkets were commonly described to be challenging due to them being busy with customers. For example, one individual described them as: *"There being so, so, so many people around you and bumping into you and everything... the possibility of like, being touched suddenly makes me jump and freak out a lot... and in a crowded space and it's harder to avoid that"* [SS09]. One participant mentioned that *"Larger supermarkets, which are maybe more spread out, I find these a little easier, but really they all present a challenge"* [SS13].

A few of the autistic adults described how supermarkets were less challenging when they were less busy, and one individual suggested that being able to see a supermarket's busy times online was a good way to know when it was more accessible:

"I quite often use - in Google... if you have a shop, you can add the times where there's most people and less people, so I often use that function to see when there's no people in the shop. So, if the shops more can utilise that tool, so you know when to show up" [SS19].

Predictability

Supermarkets were described as unpredictable, which can make it difficult to plan ahead and could add to the difficulties in an already overwhelming sensory environment. Supermarkets often change their layout without warning, maintaining a sense of unfamiliarity and making forward planning challenging, for example, one individual noted: *"One of the things that I find really difficult is that some supermarkets more than others love to completely reorganise everything on what seems like a fortnightly basis... [it] just adds that extra challenge" [SS04].* Knowing the layout and item's locations in supermarkets was discussed as being important to limit the time spent in the environment, and participants suggested that maps of the layout inside the store or online would be a helpful way to remove some of the space's unpredictability:

"... it would be really great if you could look online and like find a layout of the store in advance so that you could then write a shopping list that was like in vaguely the right order, and know where you like, know what route you had to go to get the things you wanted, like I feel like that would be helpful" [SS20].

Understanding

Individuals noted that staff in supermarkets often seem to lack understanding of sensory processing and autism which can make it difficult to access support. Some individuals suggested the benefit of staff training, for example one individual stated: *"I think what could be helpful... you know like you go in shops, and you get these first aiders, I think they should have almost someone like an autism champion, like especially dedicated" [SS15].* Not having understanding or knowledgeable staff was described by one individual to prevent them from accessing designated supermarket quiet hours as they may be perceived as not fitting the 'autism stereotype'. They stated: *"I would feel judged by them. That I wasn't like in need of going to the supermarket like in a quieter time" [SS17].* But also, individuals reported being judged by other customers and felt that supermarkets could support wider awareness: *"I've had other shoppers' comment on my stimming before, so a sign that makes people aware of that could be good. Kind of like the "not all disabilities are visible" signs on disabled toilets" [SS14].*

Adjustments

Some individuals described the difficulty with checkouts due to feeling rushed and having to communicate with checkout staff when overwhelmed due to the sensory environment. For example, one individual described:

MacLennan, Woolley, @21andsensory, Heasman, Starns, George & Manning. (2022). "It is a big spider web of things": Sensory experiences of autistic adults in public spaces

"I always have trouble having to talk to the cashier at the end of it because I've been so stressed out and I've been trying to focus on like blocking all this stuff out as well as like trying to remember and calculate how much everything in my basket costs and I guess like I'm so overwhelmed, that by the end I just can't talk to anybody so uhm getting at the end and having to talk to a cashier at all, I just can't do it..." [SS09].

Supermarkets were described to be more accessible when they have alternative checkout options, such as scan as you shop and self-checkouts, which can reduce the added burden of communicating with staff and feeling rushed. For instance, one individual stated: *"I find the checkout really hard as it feels really pressured. I prefer it when the supermarket has the option to scan as you go so this process isn't needed" [SS13].*

Supermarkets recognise and offer some adaptations, such as quiet hours and the Sunflower Lanyard Scheme to indicate hidden disabilities. But these were reported to have limitations, such as the Sunflower Lanyard, which *"feels more just of a token gesture rather than any kind of like meaningful like accommodation" [SS04].* Although the premise of such schemes was praised, *"better recognition of the sunflower lanyard is needed" [SS13],* and quiet hours should be more widely accessible:

"I do feel that we need that more dedicated time for autistic people and it it should be like given quite a variety of times not just very limited 'cause I think sometimes mornings can be trickier for some, uhm, so I think sometimes having it at times like evenings, afternoons" [SS15].

Recovery

A few individuals mentioned the worry of not being able to escape from supermarkets if feeling overwhelmed or if needing a break:

"One of the things that I find really difficult is that a lot of smaller shops have gone back to putting barriers where the checkouts aren't open, and obviously it's to prevent theft, but then it means that if you actually are feeling distressed and you need to go and take a break and get outside you can't get out... just the feeling of being trapped in, and so when I walk past even if I see that it's a shop that does that, I just won't go there because that instantly makes me panic just in case I get a bit overwhelmed inside the store" [SS04].

Eateries

Sensoryscape

Eateries, such as cafés, restaurants, and pubs, were described by autistic adults to be challenging multisensory environments. Eateries can have a range of different smells which can be challenging, for instance, cafés were described to have an "intense smell" such as the overpowering smell of coffee. Many of the autistic adults also described the difficulty with auditory input in eateries, with one stating: *"I do wish that they'd keep noisy coffee machines in the back with the rest of the kitchen stuff so its quieter" [SS14].* Additionally, background noise was described by many to be difficult, such as people

conversing alongside noise from the kitchen and waitstaff. One autistic adult reported: *“I never go out to eat anymore. The environment is just too loud. The layering of noises, such as people chatting on top of coffee machines or plates clashing is really difficult”* [SS13].

Some of the autistic adults described how eateries could be more enabling if they reduced some of the sensory burden, such as by having *“dim lighting”* [SS14]. One individual also reported eateries would be more enabling if there was *“No music while eating. With it, I can never know when I am full or not. It makes it hard for me to have a conversation with someone”* [SS07].

Space

Eateries were commonly described to be challenging as they are often busy with people and the spacing of the tables means sitting near others and *“...you feel like too closely packed in”* [SS17]. This was described to be especially challenging due to the increased sound levels. Having the tables more spaced out could help reduce the auditory burden:

“So, I went to [a restaurant] and it was lovely because there was just so much space in between all of the tables and I just found that just sort of helped with the noise, because obviously I didn't have people really close to me that were really loud... I just found the setting of having my like space between myself and other people it just brought my anxiety down I just felt a lot calmer just... feeling like I had my own personal space” [SS18].

Predictability

The sensory environment of eateries was reported to be increasingly challenging due to the uncertainty of procedures, as well as regarding the food, that could sometimes be made inconsistently. Some individuals described how having information in advance about eateries could reduce the uncertainty and make them more enabling, such as being able to access detailed menus online, images and details of the layout, or information about the procedures. One individual described:

“...they had a thing on their website and like all their social media where they'd like taken pictures of what the cafe like looks like now and they'd written out the process of like how it worked... rather than just kind of being expected to know how it works... so you could like see that ahead of time so it wasn't suddenly like oh this is a lot of new information at once so that was helpful” [SS20].

Some of the autistic adults described how consistency and predictability of the food and drinks was important. As one individual noted *“...if my food comes and it's not as how I want it, or how I expect it to be, I can't eat it”* [SS18]. One individual described how eateries that produce consistent food can make them more enabling:

“... we go to chains because we know it's reliable so once we know what we like, you know what you're getting because its standardised and you know if they are going to change the recipe or add new things they make a song and dance about it so you know... you just know

because it's reliable and its consistent you don't actually have to think because you know what you're going to get..." [SS04].

Understanding

Some of the autistic adults reported that in eateries they can feel misunderstood and judged by staff. This was often to do with having specific requirements for the food and drinks that align with sensory preferences, as one individual noted: "...there's a lot of awkwardness around like being a picky eater" [SS04]. A couple of individuals also noted that they worried about feeling judged if they didn't have someone to support them to order or explain what they need:

"I need like I need someone else with me to help explain to the person at the counter 'cause, I just I just get so worried if I like if I do anything, people will think I'm I'm weird and they'll realise I'm autistic and it might cause a scene and I just like I I get scared even to ask like 'can I have a half portion' because I can't eat that much and stuff and I don't know what to do if like the person at the cashier says like no or they ask more questions" [SS09].

Adjustments

Many of the autistic adults described how eateries commonly do not accommodate for communication or processing differences, which made them disabling environments. Some individuals described the fast pace of restaurants, with one identifying: "...when they're taking the order, I think I need time [for] processing" [SS20]. Eateries were also commonly reported to not offer suitable adjustments for autistic individuals with sensory differences:

"I feel like a lot of restaurants and eateries and stuff have like one opinion of disability and it's that they need to have a wheelchair accessible toilet... that's all they do... I feel like a lot of them don't have any idea of how to help someone with ASD..." [SS14].

However, some of the autistic adults described adjustments that have or could help. For instance, the introduction of ordering using an app due to COVID-19 was helpful to avoid communicating using spoken language with staff: *"I find that really [it's] just great just sitting down, using an app, I can take my time of what I'm gonna- I don't speak to anyone, and I find that really beneficial" [SS18].* But that the apps should have *"more options to be able to like give details and stuff" [SS09]* so that food and drink can be easily customised to accommodate individual needs and preferences. However, a few individuals also suggested that eateries could introduce other measures to adjust for individual pace and communication needs, such as having signs on the table: *"Maybe a sign that you could just lay on the table explaining that people may need to be more patient with you" [SS13].*

Recovery

Some of the autistic adults described that due to eateries being overwhelming sensory environments, they would be more enabling if there was access to an area that had a lesser sensory burden, such as being quieter and with less people. One individual reported: *"A quiet area would be useful" [SS13]* and

also added it would be useful to have “*dedicated areas which are blocked off from other people*” [SS13]. Another individual reported that a separate area could help “...*lower the sensory aspect of it...*” [SS17].

High streets, and city/town centres

Sensoryscape

High streets and city/town centres were described by many autistic adults to be challenging due to the highly burdensome and sustained multisensory input. Some individuals reported that there are often many layers of noise, for instance one individual noted: “...*there is a lot of noise... there are a lot of buses, and people selling stuff at the street, always, and that yeah it's very loud*” [SS24]. Some individuals also described how even though natural light could sometimes be better than indoor lighting, highstreets and city/town centres without shade can be difficult. One individual noted: “*Yes, more shade. Even sunglasses don't help the brightness for me*” [SS07]. Additionally, a few individuals noted the challenge of being exposed to different scents, for instance: “...*walking through areas with lots of food stalls, the smells of all the foods combined with petrol fumes is sickening*” [SS14]. Some of the autistic adults also described how highstreets and city/town centres could be visually overwhelming due to the amount of people combined with other elements, such as advertising and shop displays. One individual noted: “*I keep my eyes down so as to not overwhelm myself*” [SS14].

Space

Many of the autistic adults described how highstreets and city/town centres can be challenging sensory environments due to being busy and crowded spaces. For instance, one individual noted: “*City centres can be really difficult. Large groups of people talking loudly. People bump into one another and there is no personal space*” [SS13]. This individual also went on to describe what others had also reported in that narrow pavements made the crowds more challenging:

“In an ideal world the streets would be wide, and the shops would be set back off the streets. I find it difficult when people stop to look in shop windows, creating groups of people who are trying to move around them” [SS13].

Predictability

Some of the autistic adults described how highstreets and city/town centres could be difficult to predict and make the sensory environment more challenging. One individual noted: “*The environment is too unstructured. I suppose rules can't be imposed to make it a better experience*” [SS13]. The unpredictable movement of the crowds was also described to add to the sensory burden. One individual reported:

“It really annoys me when people can't pick a side of the road to walk down... when people [are] just constantly waving, like, zig-zagging across the pavement and I'm trying to just give them plenty of room to come past, it just drives me mad” [SS04].

Some individuals described how the sensory impact of highstreets and city/town centres could be lessened if these places were more predictable. For instance, one individual suggested the sensory impact could be improved by introducing: *“One-way systems where if you're walking in one direction you're on one side of the street, but it probably wouldn't work as no one respected them during covid either”* [SS14]. They also went on to suggest: *“I also think, plenty of warning for areas with food stalls/markets, with signs around the areas so I don't accidentally walk into them”* [SS14].

Furthermore, a few individuals noted how it would be beneficial to access more information in highstreets and city/town centres to forward plan and reduce the uncertainty. One individual noted: *“...it would be good if municipalities could be better on creating maps where it shows like how the areas are different and so on, so you don't have to create this mental image before you visit a place, but just have it there, [e.g.] here's a lot of people, here's where most people are, and here's where the best shops are...”* [SS19].

Adjustments

Some of the autistic adults described how there currently aren't suitable adjustments in highstreets and city/town centres. However, a few individuals expressed the need for some form of support for autistic individuals because of the disabling sensory environment. One individual described how a help/information point could be useful:

“I think you know more like help guides or like desks, point of contact like... if you going to an indoor mall or a shopping centre you have like an information thing, I think if there was more out in the open as well... if you were feeling a bit disorientated or lost or frazzled then you have something nearby to reach and can ask for some help and there'll be somewhere nearby even to like say 'ohh there is a shop nearby' or 'there is a telephone box nearby', especially if those are not so familiar, and uhm, or someone to like just have that time and just to check in and see if everything is okay” [SS15].

Recovery

Some of the autistic adults described how highstreets and city/town centres can be disabling because there isn't an opportunity to escape from aversive sensory input. Some individuals noted the need for a designated space or quieter area to be able to take a break and recover. One person noted: *“Well you can't force people to not be in town or things like that so I guess just make it possible for us to retreat somewhere, or something, I don't know I don't know what but create spaces where we can retreat to.”* [SS19]. Additionally, another adult reported: *“Maybe quiet outdoor areas with benches. A place where you can just sit and be calm”* [SS13].

Public transport

Sensoryscape

Public transport, such as trains and buses, were described by some autistic adults to have burdensome and inescapable sensory environments. Individuals reported that public transport can have multiple sensory challenges. For instance, most public transport is covered in litter [SS14], and *“...the smell and just the, just the notion that it's not clean, the seats are not clean is one of the biggest thing, I mostly stand up on the train 'cause it's so nasty”* [SS19]. But also that *“the textures of the seats...”* [SS13] are uncomfortable. Additionally, there is little ability to control the sensory environment, as a lot of input comes from other passengers, as noted by one individual: *“I find it difficult to control my environment as well and that sort of causes a lot of uhm issues for me. So yeah, public transport is not my friend”* [SS18].

Space

Many of the autistic adults described how public transport could be disabling due to trains and buses being busy and having to sit close next to other people, as one individual noted: *“I haven't used public transport for years. I find it difficult to sit in such close proximity to someone I don't know”* [SS13]. One autistic adult described how public transport could be improved if it was possible to have more space:

“More seats that are just one by themselves, or like a sign that says the very front seats on buses (the ones that are isolated) are reserved for people with sensory difficulties, in the same way where it says give up your seat for people less able to stand” [SS14].

Predictability

A few of the autistic individuals described how public transport could be a disabling sensory environment due to the uncertainty and inconsistency of the timetable, especially if delays are not communicated. As one individual noted: *“I find trains easier because they run on more strict timetables and if they're delayed it says the new estimated time of arrival, whereas with buses you just have to hope for the best”* [SS14]. Additionally, another individual also described this challenge and the importance of having this advance information:

“It's so important that you get the information in time when a train or a bus is cancelled, things like that, and also that the information is available, if it's not on the phone, perhaps you can just have a digital board on the bus stop. Perhaps too expensive but it will be nice if you have it everywhere and not only there by the main bus stop in the centre” [SS19].

Understanding

Some of the autistic adults reported that public transport can present disabling sensory environments due to lack of staff understanding, which can limit the support received. One individual noted: *“People who work on public transport should maybe have some idea about how to support those with autism. I*

find talking at the front of a bus very stressful” [SS13]. Additionally, a couple of individuals noted that they could feel judged by accessing adjustments and strategies that they need. For instance, one individual noted that public transport needs: *“Signs where people with hidden disabilities can sit. I would feel judged sitting in the disabled area of a bus, people might confront me to ask if I actually have a disability”* [SS13]. Another individual described how they felt they could not engage in their coping strategies as they felt they would be judged by other people:

“...I've got able to go on like short journeys and stuff but when it's a long journey on the bus I stress out a lot and I find it harder to do coping strategies like putting in headphones or fiddling with a fidget toy or something 'cause I always worry I'm being weird and people are gonna think I'm odd... so I'm not confident enough to take fidget toys with me out out out to places and I wish I could be” [SS09].

Adjustments

Some of the autistic adults described how public transport commonly lacks reasonable adjustments for autistic individuals with sensory processing differences, which can make them inaccessible. One individual noted that: *“Some bus drivers aren't either nice or patient at all.”* [SS16]. Additionally, another individual noted that public transport could be more accessible if it commonly accommodated: *“Being allowed to just press a button on a screen for what type of ticket I want instead of speaking”* [SS14].

Recovery

Some of the autistic adults described that due to nature of public transport and it being difficult to escape the environment when needed, these environments could be more accessible if there was access to a specific space or area that had less burdensome sensory input. One individual noted that it would be helpful to have access to a silent carriage without having to buy a premium ticket:

“...it would be really nice if they, like in trains, if they could have silent compartment like they have in [first class], but the tickets are more expensive, but so yeah it would be nice if we could if we who is autistic could get also get to use the silent part in the train, but not paying the high prices...” [SS19].

Healthcare settings

Sensoryscape

A few of the autistic adults described how healthcare settings, such as doctors' surgeries and hospitals, often have a range of aversive sensory input. For instance, one individual described: *“...fluorescent lights... they make a humming noise to me that everyone else says they can't hear at all, and it really overwhelms me...”* [SS09]. They also went on to describe other auditory challenges, such as: *“...[there's] a lot of people talking at once, so it's hard to figure out what the person in front of you is saying 'cause there's so much echoing, echoing sound of everyone else...”* [SS09]. Another individual described the overwhelming amount of visual information:

“...they have a lot of boards that have a lot of information about like, medical conditions and kind of healthy eating and research studies you could take part in and then they've also got two big like screens that flick through at quite a rapid pace of like lots of different information, and if you sit in the waiting room for any kind of amount of time like kind of taking that on board uses up a lot of capacity...” [SS20].

Additionally, a few individuals noted that there are challenging scents that can be overwhelming, such as, *“...the chemically type smell...” [SS09]*, as well as food scents. One individual noted: *“... the smell of the food coming up to the ward would literally make me vomit. I was like, it's so overpowering, so I had in a care plan for them to not open my door or not call me for the mealtimes...” [SS18]*. Furthermore, a couple of the autistic individuals described the difficulty of having to endure the sensory environments and not being able to escape when waiting for an appointment or medical care. One individual noted:

“In doctor's surgeries specifically, um having to to wait in a queue or to wait in a waiting room for a long time, it sort of accentuates all of these problems because... I'm stuck there; I'll have to wait and I have nothing to occupy my time. I'm just getting focused on all of these things that are sensory, and overwhelming me, and it feels like the the waiting time is much longer than it really is” [SS09].

Space

One of the autistic individuals described how waiting rooms are easier to tolerate now they have less crowded seating due to COVID-19, as usually it can be challenging to sit close to other people:

“...also one thing that I really like about COVID, which I know you're not meant to like things about COVID, but our doctors, like the chairs are a lot more separated out than they used to be, like if they could keep some of the chairs so that you're not like sat super close to people, that would be great for me”

Predictability

A couple of the autistic adults described how the unpredictability of healthcare settings can make the sensory environment more challenging, for instance not knowing how long you will have to wait in waiting areas and endure sensory input. One individual noted the need to know how long they would be waiting: *“...the uncertainty of like if if things don't happen at the time you're expecting then... you don't know how long you're going to be waiting and it just gets scarier and scarier” [SS09]*. Whilst another individual described how unknown delays in their appointment times can cause anxiety:

“I find, uhm, I really struggle with the times of appointments. So if my appointment is at a certain time, and it goes over that time, it really badly triggers my anxiety and I literally start flicking up my phone every few seconds, and every minute that goes by I just get more and more anxious...” [SS18].

One of the individuals also described the challenge of navigating unfamiliar and unpredictable food tastes and textures when they were in recovery in hospital,

"I couldn't deal with any new textures when I was that unwell, I couldn't even contemplate, well, I struggle when I'm well to try new foods and to try different brands of things, I'm not expecting like, and not knowing the taste or the texture of what that food is going to be like. That's really bad like that, that's just something I really struggle with" [SS18].

Understanding

One of the autistic adults described their experiences of medical staff not understanding autism and how this might affect their support needs:

"Uhm, I was recently in hospital 'cause I struggle with my mental health... I was on an uhm mental health ward, and I found that that the NHS today haven't got a clue about how to deal with people who've got mental health problems and autism. And I felt like when I was in hospital, I'd have the most basic, I don't know, things that you would think that people would understand that would be triggers, like when they check on you - shining a torch in your face in the middle of the night when it's completely pitch dark - how painful that was for me, and how often they used to do it even though I used to say it was very painful. So, I had a lot, A LOT of sensory triggers, and then sort of people looking at me as if to say why is she kicking off? Why is, why is this a problem? Why am I emotionally responding the way I was? But it was because of their lack of knowledge of autism. So, when I was in hospital, it was completely, just, they just didn't get it. I had a lot on my care plan that had to be explained to people and even then, things still weren't followed" [SS18].

But this individual also highlighted the importance of staff understanding what they might need and how this can mean they can get important accommodations built into their care plan:

"...when I was in hospital uhm I did have those accommodations made for me and I was allowed to bring like things from home 'cause I'm like, when I'm stressed out, I go dry and crunchy and that's it, so I'd like rich tea biscuits and other things. So, I had those accommodations made for me when I was in hospital that I could bring my stuff in" [SS18].

Adjustments

A few of the autistic adults described how communicating with spoken language in healthcare settings can be challenging due to the sensory environment as well as the pressure of having to communicate your medical needs. One individual mentioned how being able to check in using digital technology reduced the requirement to communicate with reception staff: *"they've got like a touch screen where you sign yourself in so you don't even have to talk to the receptionist, which is great" [SS18].* A couple of individuals described how written communication of their needs for medical staff and the outcomes of appointments by medical staff can be useful to ensure everything is effectively communicated if feeling overwhelmed. For instance, one individual noted: *"...when I go to the GP if there's like important*

things that I need to remember, she writes things down for me, so that if I'm like, 'cause sometimes I can be like too overwhelmed to have processed what she's saying, but like don't necessarily know that that's the case" [SS20]. Additionally, a different individual noted:

"...I can become nonverbal at times when I go into a doctor's so, I get so stressed out that I literally just can't speak, so I've had that happen to me once and uhm, I then uhm, just wrote everything down on a piece of paper and I actually walked into the doctor's surgery... and uhm, I literally just handed the notepad over... and I just said I I have severe anxiety at the moment, and these are all my symptoms, uhm, I'd really appreciate it if you could just read this and then ask me any questions that you need to" [SS18].

Recovery

A couple of the autistic adults noted that there is rarely a designated space to escape from sensory input in waiting areas, without the risk of missing the appointment. One individual described how having this sort of space would be very beneficial:

"...having a place that you can go to which is like a quieter environment, that to me would be just amazing, that I wouldn't have to sit and endure this, it is almost like it is suffering and enduring that environment, I think that would be really beneficial for me" [SS18].

This individual also went on to describe a time when they were supported by staff to access a quieter space when they were becoming overwhelmed, and that this was helpful:

"...my one doctor surgery that I went to uhm, the receptionist, she was really lovely and she could see that my anxiety was escalating and she actually put me in in in in a spare like sort of nurse room, there's like a spare room, and she said if you want to wait in in that spare room just to sort of try and calm yourself down 'cause I can see that you're becoming really agitated, and that helped so much more" [SS18].