

Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings

Abstract

Autistic people experience significant health disparities and reduced life expectancy. Barriers to accessing healthcare are associated with adverse health outcomes. Autism training and healthcare professionals' knowledge about autism is variable, and heterogeneity among autistic people leads to additional educational and clinical complexities. Autism remains nebulous for many practitioners, who are unclear about communication differences, access needs or life experiences common to autistic people. Healthcare environments can be challenging for all patients but autistic people may require specific accommodations to allow equitable access. The authors have developed a simple framework which may facilitate equitable clinical services at all points of access and care, using the acronym 'SPACE'. This encompasses five core autistic needs: Sensory needs, Predictability, Acceptance, Communication and Empathy. Three additional domains are represented by physical space, processing space and emotional space. This simple yet memorable framework encompasses commonalities shared by autistic people.

Key words: Autism; Autistic adults; Healthcare; Healthcare access; Healthcare inequities; Reasonable accommodations

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Introduction

Autistic people experience significant health disparities and reduced life expectancy (Hirvikoski et al, 2016). Well-described difficulties accessing healthcare for autistic people include patient–provider communication challenges, sensory difficulties, and systemic factors such as resource and time constraints (Mason et al, 2019; Walsh et al, 2020). Barriers to accessing healthcare are associated with adverse health outcomes (Doherty et al, 2022). The 7-fold increase in suicide rate across the range of autistic profiles and support needs, and up to 40-fold increase in mortality from neurological conditions such as epilepsy, are shocking. However, premature mortality from conditions unrelated to autism, such as cancer, circulatory, respiratory, digestive and endocrine diseases, is more unexpected (Hirvikoski et al, 2016).

Autism knowledge and training is variable (Zerbo et al, 2015; Unigwe et al, 2017). Heterogeneity among autistic people leads to additional educational and clinical complexities. Thus, autism remains nebulous for many practitioners, who are unclear about communication differences, access needs or life experiences common to autistic people. The UK government has committed to 'improving understanding and acceptance of autism within society' and 'tackling health and care inequalities for autistic people' as part of *The national strategy for autistic children, young people and adults: 2021 to 2026* (HM Government, 2021). However, while statutory requirements mandate reasonable adjustments to facilitate equitable access, translating theory into practice remains challenging (Shaw et al, 2022a). Increasing pressures on clinical services impact professional development opportunities (Frenk et al, 2022).

Autistic SPACE

The authors' aim was to create a simple framework promoting accessibility without adding to current clinical burdens. This is called 'Autistic SPACE', shown in **Figure 1**:

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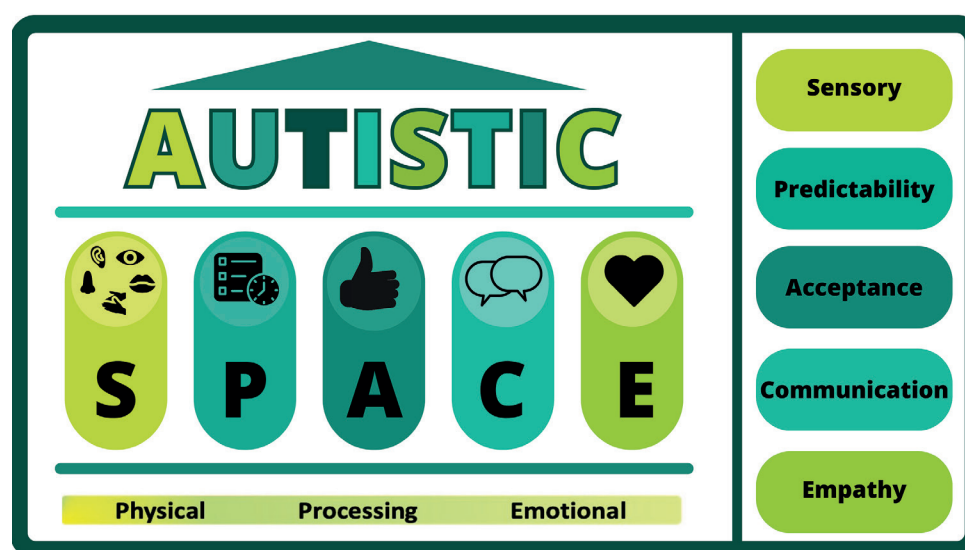


Figure 1. The Autistic SPACE framework.

- Sensory needs.
- Predictability.
- Acceptance.
- Communication.
- Empathy.

The term Autistic SPACE, first used in 1992 (Sinclair, 2005), colloquially refers to places and events where autistic needs are prioritised, such as the annual autistic-led conference ‘Autescape’ (<http://www.autescape.org>). The authors have adapted the term to provide a memorable acronym which encompasses the breadth of autistic experience and healthcare access needs, offering a potential solution to address knowledge gaps.

Sensory needs

Autistic people experience the world differently (Royal College of Psychiatrists, 2020). Sensory sensitivities are common to almost all autistic people (MacLennan et al, 2022), but the pattern of sensitivities varies (Lyons-Warren and Wan, 2021). Autistic people can be sensory avoidant, sensory seeking or both (Royal College of Psychiatrists, 2020); hypo- or hyper-reactivity to any sensory modality is possible (Tavassoli et al, 2014) and a person’s sensory responsiveness can vary depending on circumstances (Strömberg et al, 2022). A ‘sensory diet’ provides scheduled sensory input which can aid physical and emotional regulation (Hazen et al, 2014). **Table 1** outlines sensory considerations.

Sensory issues (**Table 1**) can make healthcare environments totally inaccessible (Strömberg et al, 2022). Sensory stresses are cumulative and also additive with other sources of distress, such as communication challenges. Sensory overload commonly leads to involuntary reactions known as meltdowns or shutdowns (Belek, 2019). Environmental sources of stress may be imperceptible to non-autistic people and, therefore, consequent distress can be misunderstood (Phung et al, 2021). This commonly leads to a misfocus on ‘challenging behaviour’ – particularly for autistic people who do not use speech to communicate, or those with co-occurring intellectual disabilities (McDonnell et al, 2015). Even for autistic people who are usually articulate, sensory stress can reduce the ability to communicate and, in extreme cases, can lead to a transient inability to access fluent speech (Cummins et al, 2020). Addressing sensory issues is, therefore, the first step towards meaningful accessibility.

Predictability

Autistic people need predictability and may experience extreme anxiety with unexpected change (Royal College of Psychiatrists, 2020). This underlies the autistic preference for routine and structure. Healthcare is an unpredictable environment with unpredictable outcomes. Access is facilitated when predictability is maximised. Waiting is difficult

Table 1. Autistic sensory differences

Sensation	Considerations
Sight	Visual sensitivities are common. Bright lighting (particularly fluorescent) is a common challenge. Visual stimuli which may go unnoticed by non-autistic people, such as the flickering of fluorescent lighting or computer screens, an overhead rotary fan, or highly patterned surfaces, may all cause sensory stress
Sound	Autistic people experience auditory sensitivities and auditory processing differences. Environmental noise can cause intense distress, particularly when sudden or unexpected. Sounds unnoticed by non-autistic people, such as the humming of electrical equipment, may be perceived by autistic people without 'fade' (where inconsequential sounds are no longer noticed over time). Autistic people may not filter out environmental sounds and therefore may struggle to hear a conversation in a noisy room
Smell	Autistic people are often highly sensitive to smell and may perceive olfactory stimuli that others do not. Common and usually inoffensive smells may be perceived as highly noxious. In contrast, some autistic people are hyposensitive to smell and may enjoy smelling pungent objects
Taste	Autistic people may be hypo- or hyper-sensitive to taste, needing either highly flavoured or very bland food. Food texture is important, as is predictability (see below). Autistic people commonly enjoy colloquially termed 'same foods', which may explain a limited diet and negative reactions to a change of brand or recipe for a known brand of food
Touch	Tactile sensitivities range from inability to tolerate the sensation of certain fabrics to an inability to be touched, particularly by strangers. This leads to predictable challenges in a medical consultation where physical examination is required. Knowing the tactile sensitivity profile of a patient is helpful because difficulties commonly arise with light touch, whereas a strong deep touch may be more acceptable
Temperature	Thermal sensitivity is common and may lead to apparently inappropriate or out of season clothing. The range of tolerated temperatures is likely to be person-specific
Proprioception	Proprioception appears different for autistic people. Some may need lots of proprioceptive input leading to a tendency to climb, swing, rock or jump. Others will avoid such movements and may experience balance difficulties during day-to-day activities
Interoception and pain	A particular challenge for some autistic people is accurately interpreting internal bodily sensations. This can lead to difficulties noticing hunger, thirst, tiredness, or a need to urinate or defaecate. Difficulties with pain perception can lead to unrecognised injuries but it must be emphasised that while reduced pain sensitivity occurs for some, others experience increased pain sensitivity, and this should never result in under-treatment of pain for autistic patients

for autistic people, especially for an unknown duration in the sensory stress of a typical healthcare waiting-room, emergency department or inpatient ward (Doherty et al, 2022). Interacting with unknown people is also challenging (Doherty et al, 2022). Providing the maximum possible information in advance about the physical environment, staff, consultation process and planned procedures is likely to reduce anxiety (Shaw et al, 2022a). Any unavoidable or unexpected changes will be more easily accepted if explained clearly and openly.

Acceptance

Beyond simple awareness, there is a pressing need for autism acceptance. A neurodiversity-affirmative approach recognises that neurodevelopmental differences are part of the natural range of human development (Shaw et al, 2021) and acknowledges that attempts to make autistic people appear non-autistic can be deeply harmful (Bernard et al, 2022). This does not exclude inherent or environmental disability. Regardless of a person's individual profile of strengths, challenges and support needs, stigma and stereotypes are damaging to autistic people. A more holistic approach, in which autistic characteristics are understood and accepted, is preferable – particularly in terms of mental health outcomes (Pellicano et al, 2022; Shaw et al, 2022b).

While individual in nature, autistic behaviour can, in some ways, be quite different to non-autistic behaviour – repetitive behaviour or 'stimming' is common and usual (Kapp et al, 2019; Charlton et al, 2021). Autistic people also focus attention differently, with a monotropic thinking style (Murray et al, 2005), which can manifest in a healthcare context as perseveration, repeated questioning or focus on a specific aspect of their care (Doherty et al, 2021). Detailed factual information may be requested (Haydon et al, 2021).

Acceptance leads to appropriate accommodations, including understanding that so called ‘challenging behaviour’ is usually a response to autistic needs not being adequately met (McDonnell et al, 2015). Furthermore, acceptance means acknowledging the responsibility on carers and healthcare providers to make adaptations, rather than expecting autistic people to adapt to an environment designed for the non-autistic majority (Haydon et al, 2021).

Communication

Autistic people communicate differently. Many use fluent speech, but may experience challenges with verbal communication at times of stress or sensory overload (Cummins et al, 2020; Haydon et al, 2021). Others do not speak or may use few words (Brignell et al, 2018). Many non-speaking or minimally speaking autistic people use augmentative and alternative communication (AAC) methods, including visual cards, writing or electronic devices, which should be facilitated (Zisk and Dalton, 2019). Phone apps such as ‘Emergency Chat’ may also be beneficial. Most autistic people have difficulty using telephones, so a flexible approach to appointment booking or services such as preoperative assessment facilitates access (Doherty et al, 2022).

Language use and comprehension is highly variable. Questions may be answered directly, without reference to implied meanings. Literal interpretation of words and phrases is usual (Doherty et al, 2021). Clear, unambiguous language is therefore required – avoiding hints, metaphors or vague information (Haydon et al, 2021). Unambiguous safety-netting is also required, with precise instructions on when and under what circumstances to return following discharge (Shaw et al, 2022b).

Non-verbal communication is different for autistic and non-autistic people. Differences in the use of gaze, eye contact, gestures and posture can lead to erroneous interpretation if autistic communication is not understood and accepted (Royal College of Psychiatrists, 2020; Doherty et al, 2021). The traditional signs of distress or pain, for example, may not be evident (Haydon et al, 2021). An autistic person might tolerate a painful examination silently without even wincing, leading a healthcare provider to misinterpret findings (Haydon et al, 2021). Therefore, it may be necessary to specifically instruct an autistic patient to indicate tenderness.

Empathy

Despite common assumptions to the contrary, autistic people do not lack empathy (Fletcher-Watson and Bird, 2020). It may be experienced or expressed differently, but this is perhaps the most damaging misconception about autism (Hume and Burgess, 2021). In fact, many autistic people report experiencing hyper-empathy, to the point of being unable to deal with the onslaught of emotions, leading to ‘shutdown’ in order to cope (Hume and Burgess, 2021). A bi-directional, mutual misunderstanding occurs between autistic and non-autistic people, termed ‘the double empathy problem’ (Milton, 2012). As such, non-autistic healthcare providers may struggle to empathise with autistic patients, particularly where communication training is generally conducted from a neuronormative, non-autistic perspective, in which the needs of autistic people are not considered (Bradshaw et al, 2021).

Recognising this challenge and making a particular effort to consider the perspective of the autistic patient is the first step towards bridging this gap. Directly asking an autistic person for their interpretation of events is appropriate rather than making assumptions based on non-verbal communication. Checking comprehension verbally and ensuring both parties have a shared understanding of treatments plans or goals will facilitate successful engagement. Increasingly skillful communication with autistic patients will develop as practitioners ‘improve their expertise in autism through training and experience, and particularly, by familiarity with the autistic world’ (Royal College of Psychiatrists, 2020).

Wider spaces

The concept of space is also useful in three other domains of autistic experience.

Physical space

Autistic people may need more physical space (Strömberg et al, 2022). Proximity to others, particularly within touching distance, is often difficult to tolerate (Doherty et al, 2022; Strömberg et al, 2022). Tactile defensiveness can lead some autistic people to react physically, particularly when already anxious or overwhelmed (Smirni et al, 2019; Royal College of Psychiatrists, 2020), so attention to physical space can facilitate a successful consultation. Rather than seeking to ‘desensitise’, it is better to avoid such noxious stimuli, even when these might be considered innocuous by a non-autistic person.

Processing space

This is the additional time required to process new information or unexpected changes. Compared to non-autistic people, making decisions, responding to questions or accepting suggestions may require longer (Royal College of Psychiatrists, 2020; Vicario et al, 2020). Understanding this aspect of autistic experience and having the patience to wait is invaluable. It may appear that an autistic person is not answering or did not understand, and so the temptation is to repeat or rephrase the question, both of which can re-start the processing time thus further delaying resolution (Haydon et al, 2021). This is complicated by the fact that some autistic people, particularly those with co-occurring attention deficit hyperactivity disorder, may have become distracted (Young et al, 2020), so a simple prompt such as ‘are you still thinking?’ can sometimes be helpful.

Emotional space

Identifying, processing and managing emotions can be challenging (Cai et al, 2018), particularly when autistic ways of expressing emotions are not understood or accepted (Brewer et al, 2016). Sensory overload or overwhelming emotions may lead to autistic meltdown or shutdown. Considering this will minimise risks, but if it occurs, the best approach is often to allow space to recover. Commonly, such situations are inadvertently escalated (Phung et al, 2021). Where a non-autistic person might be soothed by a gentle touch, the same gesture might be intolerable to an autistic person, leading to a defensive or aggressive reaction (Smirni et al, 2019). The priority in such situations is to ensure safety, minimise environmental sensory input, and offer no unnecessary words – providing space and time to recover (Haydon et al, 2021).

Table 2 summarises the authors’ recommendations for supporting Autistic SPACE in practice and improving healthcare for autistic people.

Conclusions

Healthcare settings are challenging for everyone – particularly when systems are under pressure in terms of staffing and resources. Recognising the specific, additional challenges for autistic people, and in particular the adverse consequences when these are not considered, may allow autistic people to access and tolerate difficult healthcare environments. Using the acronym ‘SPACE’, as a framework to understand and accommodate autistic needs, facilitates meeting statutory requirements, and may ultimately reduce the healthcare inequities which contribute to excess mortality in this vulnerable group.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

Positionality

The authors of this framework and article are all leading members of Autistic Doctors International with key lived experience and insight into both accessing and providing healthcare as and for autistic people.

Table 2. Recommendations for supporting Autistic SPACE in practice

SPACE framework aspect		Recommendations for implementation
Sensory	Sight	Turn off or turn down artificial lights
		Remove flickering or oscillating environmental features
		Avoid highly stimulating decor
		Promote the use of sunglasses
	Sound	Consider environmental sounds
		Reduce auditory clutter
		Avoid conversation in noisy environment
		Promote the use of noise-cancelling headphones and/or ear plugs
	Smell	Avoid wearing perfume or highly scented cosmetics or toiletries
		Avoid aerosols or chemical 'air fresheners'
		Avoid highly scented cleaning products
		Consider ventilation, open windows where possible
	Taste	Respect sensory preferences when considering nutrition
		Consider taste and texture of medications
		Consider non-standard medication formulations where necessary
	Touch	Ascertain tactile preferences and modify examination technique
		Avoid casual touch
		Promote sensory-friendly clothing choices
		Sensory aids such as weighted blankets may be helpful
	Temperature	Consider environmental temperature
		Adjust temperature where required
	Proprioception	Understand the need for proprioceptive input
		Avoid making inferences from unusual body posture
	Interoception and pain	Ask directly about internal sensations but understand that answering may be difficult
		Pay attention to verbal reports of pain where possible
		Be aware that non-verbal expression of pain may be different
		Consider the need for adapted pain scales
Predictability		Give realistic information in advance
		Ensure clear and accurate directional signage in physical spaces
		Provide photographs or videos of the physical environment and staff
		Allow waiting in a familiar environment (eg a patient's own car or outside)
		Ensure care is provided by staff familiar to the patient where possible
Acceptance		Neurodiversity-affirmative approach beneficial
		Understand autistic stimming and monotropic thinking patterns
		Facilitate need for detailed factual information
		Understand distress behaviour

Table 2. Recommendations for supporting Autistic SPACE in practice (continued)

Communication	Understand autistic verbal and non-verbal communication differences
	Know that communication ability is reduced by anxiety and sensory stress
	Clear unambiguous communication required
	Avoid phone-based appointment systems
	Promote use of augmentative and alternative communication (AAC)
Empathy	Recognise that autistic people feel empathy but may display it differently
	Empathy towards autistic patients may be more challenging for non-autistic healthcare providers
Physical space	Expect a need for increased personal space
	Avoid proximity to other people where possible
Temporal space	Allow increased time to respond to questions
	Allow increased time for decision making
Emotional space	Expect differences in emotional expression
	Allow restorative solitude to recover (without additional input) if distressed

Key points

- At least 1–2% of the population are autistic – most are adults, most do not have intellectual disability.
- Significant barriers to healthcare are experienced by autistic people, with associated adverse health outcomes.
- On average, autistic people die between 16 and 30 years younger than non-autistic peers.
- The acronym 'SPACE' offers a simple framework for autism-specific accommodations: Sensory needs, Predictability, Acceptance, Communication and Empathy plus physical, processing and emotional space.

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