

In this article...

- Sensory issues that can influence how people with autism experience care environments
- Use of an environmental checklist to make care settings more accessible to people with autism
- Simple changes to the physical environment that can make care settings more autism friendly

Creating accessible healthcare environments for people with autism

Key points

People with autism die on average 12 years earlier than the general population

Many people with autism have sensory issues that can affect how they access health services

Health services must consider the physical environment in which care is delivered to ensure it is accessible to people with autism

Simple changes, such as low-arousal colours or soft lighting, can help make environments more autism friendly

Core training to raise staff awareness and improve communication also helps to improve access to services for people who have autism

Author Stephen Simpson is senior autism practitioner, South West Yorkshire Partnership NHS Foundation Trust.

Abstract Over 1% of the UK population has a diagnosis of autism and, of this group, half will also have a learning disability. Studies show that people with autism die 12 years earlier than the general population and one reason is poor access to health services. Many people with autism have sensory issues that can affect how they access healthcare so staff need to consider the physical environments in which care is delivered to ensure they are accessible to people with autism. This article describes a checklist that can be used by nurses and other health professionals to make healthcare environments more autism friendly.

Citation Simpson S (2020) Creating accessible healthcare environments for people with autism. *Nursing Times* [online]; 116: 1, 48-50.

It is estimated that 1.1% of the UK population has a diagnosis of autism and half of these will also have a learning disability (Brugha et al, 2012). However, autism itself is not a learning disability and many people with autism have average or above-average intelligence; some will have a diagnosis of high-functioning autism or Asperger's syndrome, which identifies this.

Nurses and other health professionals are likely to encounter patients with autism in various healthcare settings. There will also be patients whose autism is undiagnosed, misdiagnosed or referred to as neurodiversity (classifying it as a form of human diversity rather than a pathological condition) – distinct from a neurotypical (non-autistic) presentation. Others will have additional needs, such as a physical disability or mental health condition.

There is evidence that patients with learning disability, autism and/or other neurodiverse conditions have poorer health outcomes and a shorter life expectancy than the general population. The report *A Spectrum of Obstacles: an Inquiry*

into Access to Healthcare for Autistic People highlighted the findings of a Swedish study suggesting people with autism who do not have a learning disability die on average 12 years earlier than the general population (Westminster Commission on Autism, 2016). The figure is even higher for those who have an additional learning disability (Mencap, 2018; Mencap, 2012).

The Equality Act 2010 requires healthcare providers to make reasonable adjustments to ensure everyone has equal access to their services. This includes removing barriers that may prevent people from accessing the care they need – failure to do so is unlawful discrimination. Reasonable adjustments can include changes to the environment where healthcare is delivered to accommodate the needs of people with autism; Ainsworth and Blair's (2017) guide serves as a useful guide.

This article describes an environmental tool, the Checklist for Autism-Friendly Environments. Developed by South West Yorkshire Partnership NHS Foundation Trust, it helps nurses and other health professionals to think about the healthcare

Clinical Practice Innovation

environment and how to make it more accessible for patients with autism.

Challenging environments

Creating an environment that all patients can access is a guiding principle for the NHS. National Institute for Health and Care Excellence (2016) guidance on autism in adults states that health professionals should: “In all settings, take into account the physical environment in which adults with autism are assessed, supported and cared for, including any factors that may trigger challenging behaviour.” Nurses should look at the settings where care is delivered and consider how they could affect the wellbeing of people with autism – remember, patients will have individual difficulties and preferences, so it is important not to over-generalise or make assumptions about how individuals will react.

The impact of the environment on people with autism cannot be underestimated. Many will have sensory difficulties, such as hypersensitivity to noise and light, causing them to avoid crowded areas or going out on bright days. Others may be hyposensitive to pain, and may not realise how serious an injury is because their pain threshold is so high.

People with autism who are hypersensitive to noise may, for example, find even a ticking clock irritating and any high-pitched noise distressing. This can lead to challenging behaviours, especially for those who also have learning disabilities or mental health needs, who may not understand the reason for the noise. Such behaviours may include extreme aggression and



Cluttered spaces and harsh/fluorescent lighting can be distressing for people with autism

self-injurious actions, leading to a deterioration in health. This can be illustrated by the case of a six-year-old boy with autism who regularly became distressed in the GP surgery waiting room, causing him to resort to behaviours ranging from covering his ears to self-harm.

As a result, some people with autism can become isolated and choose not to access certain healthcare environments because they find them too disturbing or distressing. Even in “friendlier” environments, they may become preoccupied with distracting elements, such as cluttered furniture, buzzing computers and radiators, reducing their concentration and focus. The process of gathering accurate information or carrying out

healthcare interventions cannot be effective in these circumstances, which can compromise care and, ultimately, lead to poorer outcomes.

First contact

Before a patient with autism arrives in a clinical area, staff should consider how best to make contact and communicate with that person. Some people with autism have difficulty speaking on the telephone and arranging appointments, as well as poor organisational skills. It is important to identify and address these challenges as soon as possible to prevent a first-line barrier to care. Sending text messages and letters may be more appropriate than a telephone call.

Whatever mode of communication is used, information should be presented in a concise, clear manner to avoid ambiguity and confusion. Giving approximate times can cause people with autism great anxiety and it is important to avoid using figures of speech – these may be taken literally. Some patients will struggle with face-to-face communication, including making eye contact and processing verbal information, so it is important to allow enough time to explore this in the initial consultation.

Environmental checklist

Health professionals, including nurses, have a duty of care to their patients and must ensure that healthcare assessments or interventions are appropriate, accessible, effective and evidence based (Nursing and Midwifery Council, 2019). This includes ensuring healthcare environments are as friendly and accessible as

Table 1. Part A: checklist on visual aspects of the environment

	Have you considered the following:	Yes	No
1	Whether colours are low arousal, such as cream and pastel shades, rather than vibrant colours such as red?	X	
2	If the environment is cluttered with furniture? (“People with autism find it helpful if furniture is kept to the sides of a room and the central space is kept clear” (Nguyen, 2006)	X	
3	Whether the environment has overly patterned shapes and surfaces?		X
4	If there are other features, such as curtains, blinds and pictures, which could be distracting or distressing to someone who is hypersensitive?	X	
5	Whether staff’s clothing or jewellery could be visually disturbing where there is hypersensitivity?	X	
6	Whether the environment has fluorescent or harsh lighting, as opposed to more-subtle lighting alternatives?		X
7	The effect of sunlight from windows or skylights, light at different times of the day and reflective surfaces?	X	

possible. To do this requires an audit of places and practices.

First developed in 2009, the Checklist for Autism-Friendly Environments allows staff to carry out such an audit, helping them to address health inequalities that affect people with autism. Following further development, in 2017 South West Yorkshire Partnership NHS Foundation Trust piloted the tool across a variety of clinical settings. The checklist has now been endorsed by the National Autistic Society and NICE, and can be downloaded free of charge along with accompanying tools and guidance from the link at the end of this article. Nurses and other health professionals can use it to:

- Raise their awareness of the challenges people with autism can experience from the physical environment;
- Identify problem areas that have been overlooked;
- Plan simple changes to the care environment that can make it more accessible to people with autism.

Few health professionals are experts in autism or related conditions and, although staff can use specialist sensory assessments to record people's individual needs and preferences, these can be time-consuming to complete (Bogdashina, 2016). This generic checklist is quick and easy to use, and allows nurses and other staff to assess different care settings and make simple adjustments to create autism-friendly environments.

How the tool is used

The environment can be any setting where care is delivered. This could be a community clinic, consultation room, ward or any therapeutic venue, including the patient's own home. Busy communal areas, such as reception areas and waiting rooms in outpatient and inpatient settings, can be particularly problematic for people with autism. As such, staff should consider completing the checklist for all care settings.

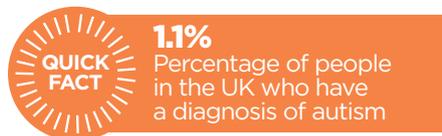
The checklist is divided into two parts:

- Part A (core requirements - an example of which is outlined in Table 1) is for all services to complete and can be used in any healthcare environment. It includes sections on:
 - Sensory sensitivities, encompassing sight, smell, hearing and body awareness;
 - Communication;
 - Escape from stressful situations;
 - The need for staff awareness training.
- Part B (enhanced) is for specialist services that care for people with

autism who have mental health needs or a learning disability. It includes more detailed questions around:

- The sensory environment;
- Enhanced awareness;
- Understanding autism through theory of the mind and flexibility of thought patterns and behaviours.

The checklist has been designed to allow staff to review whether they can make environments friendlier for people with autism and raise awareness of how they might be able to make changes. The discussions and solutions that emerge are more important than the checklist score, and are recorded in a separate section. This leads to the creation of an environmental plan, which should be reviewed annually.



Results of the pilot

The trust's attention deficit hyperactivity disorder (ADHD) and autism service piloted the checklist in different clinical settings, such as clinic rooms, waiting areas etc. When these were in buildings not owned by the trust, the results were fed back to site managers. Manygates Clinic, in Wakefield, stands as an example of a trust-owned building that underwent changes as a result of the checklist. Completing the checklist for the three clinic rooms and the waiting room provided an excellent opportunity to reflect on how to make the environments more accessible. This was used to create an environmental action plan, which is reviewed on a regular basis.

The team found most changes were easy to make and involved no building work, although there were some challenges, such as budget constraints and time. It was also difficult to meet the needs of all patients as their sensory profiles differed: for example, some liked bright colours, while others preferred lighter, pastel shades. However, the main aim was to make the environment more accessible, not to meet everyone's personal preferences. Simple measures identified included:

- Providing autism-awareness training for all reception/frontline staff;
- Introducing alternative lighting, for example, lamps to provide dimmer light;
- Eliminating smells, including those from cleaning materials and air

fresheners;

- Replacing loud, ticking clocks with silent ones;
- Improving signage throughout, so it is clear what each room is used for;
- Ensuring temperatures are pleasant – not too warm or too cold – and can be adjusted to individual needs;
- Identifying quiet areas that allow people to get away from crowded waiting rooms if things become too stressful.

Two of the most important changes involved communication:

- Considering the best way to communicate with a patient, either before an appointment or on the day;
- Asking all patients at the start of the appointment whether the environment is comfortable for them and anything needs adjusting.

Conclusion

The ADHD and autism service won the 2018 South West Yorkshire Partnership Trust Excellence in Improving Care Award for this work. Using the checklist to review the care environment and make simple adjustments can make a big difference to people who have autism. **NT**

- The checklist and further guidance is available to download free of charge from: southwestyorkshire.nhs.uk/services/autism. A short film introducing the checklist can be viewed on YouTube at Bit.ly/YouTubeAutismFriendly

References

- Ainsworth V, Blair J (2017) *Ten Rules for Ensuring Autistic People and People with Learning Disabilities Cannot Access Healthcare...And Maybe What to Do About It*. Shoreham-by-Sea: Pavilion Publishers.
- Bogdashina O (2016) *Sensory Perceptual Issues in Autism and Asperger Syndrome: Different Sensory Experiences - Different Perceptual Worlds*. London: Jessica Kingsley Publishers.
- Brugha T et al (2012) *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey*. Bit.ly/ICHSCAutismPrev
- National Institute for Health and Care Excellence (2016) *Autism Spectrum Disorder in Adults: Diagnosis and Management*. nice.org.uk/cg142
- Nguyen A (2006) *Creating an Autism-friendly Environment*. London: National Autistic Society.
- Nursing and Midwifery Council (2019) *The Code: Professional Standards of Practice and Behaviour for Nurses, Midwives and Nursing Associates*. Bit.ly/NMCCCode2019
- Mencap (2018) *Treat Me Well: Simple Adjustments Make a Big Difference*. Bit.ly/Mencap2018
- Mencap (2012) *Death by Indifference: 74 Deaths and Counting: A Progress Report Five Years On*. Bit.ly/Mencap2012
- Westminster Commission on Autism (2016) *A Spectrum of Obstacles: An Inquiry into Access to Healthcare for Autistic People*. Bit.ly/WCASpectrum