

Breaking down barriers

Joanne Brooks explains how to improve access for children on the autism spectrum.

There are over 500,000 people in the UK with autism, that's around one in 100 people, so it's likely every practice will have several children and adults with autism on their patient register. Diagnosis rates are increasing as the condition becomes more widely recognised, but still only a fraction of those affected has a formal diagnosis. Access to timely and appropriate healthcare is one of our society's driving goals and should be available to all, regardless of circumstance or ability.

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people and how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share main areas of difficulty, their condition will affect them in different ways. Some people with autism are able to live independent lives but others may need a lifetime of specialist support.

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The three main areas of difficulty for people on the autism spectrum are social interaction, social communication and social imagination. They usually find it hard to recognise and understand other people's feelings, interact with others, form friendships and use and understand verbal and non-verbal language. They tend to stick to a narrow, repetitive range of activities and



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prefer to have a fixed daily routine.

People with autism often experience sensory differences, with either hyper- or hypo-sensitivity to some sounds, smells, tastes and light. These factors may also be accompanied by additional learning difficulties. Autism is sometimes described as a 'hidden disability'; people on the autism spectrum may be difficult to identify, as their condition may not be immediately noticeable. While each individual with autism has very specific and varying needs, a better general understanding of autism can make all the difference to their experience of the healthcare system.

A practice managers' role

Going to the doctor can be stressful for anyone, however it can be more so for someone with autism or for parents or carers taking their children with autism to the GP. The most important thing is to know how autism affects the individual you are likely to come into contact with, and plan for their particular requirements. This may

not always be possible if you are not made aware of a formal diagnosis but by making a few practical adjustments, you can improve access for all.

Practice managers play a key role in managing the ongoing improvement of the surgery experience for all patients, and overall medical management for people with autism. The two main areas for you to focus on are 'staff awareness' and 'patient access'. Both are equally important to ensure a smooth and anxiety-free experience for your patients with autism.

Knowledge is power

There are many things you can do to help promote awareness of autism among practice staff and to make sure the most up-to-date information is available to them.

You probably have responsibility for staff training, so make sure autism-specific training is offered to all staff, including receptionists (as the first point of contact with patients). The Autism Education Trust publishes useful information about good practice at [www. **www.**](http://www.autismeducationtrust.org.uk)



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autismeducationtrust.org.uk/gpprofessionals and the National Autistic Society publishes many valuable publications for patients and practice staff at www.autism.org.uk/gp

Check staff correctly code patients' notes so that the register is accurate. Special needs may be recorded on a pop up screen on the patient database (for example, the EMIS package), so all practice staff may be alerted to a person's particular requirements such as hyper-sensitivity to physical touch, or a note about a child's special interest. This may help to ease communication.

The practice may like to consider holding regular update sessions on autism where information may be shared and staff experiences discussed. This would also be a suitable forum to look at any relevant feedback given by patients (verbal or written).

Research by the National Audit Office shows 80 per cent of GPs want more training in autism. The National Autistic Society offers specific training for health professionals as well as a range of conferences and seminars. For full details visit www.autism.org.uk/training or www.autism.org.uk/conferences

Have copies of any local resource books/leaflets that can be read by people with autism and parents / carers while they are waiting. Resources suitable for children would also be helpful. You will find a list of your local support groups at www.autism.org.uk/directory

It can be helpful to discuss any autism related challenges that have been faced in practice meetings so all staff can be involved in improving patient experiences and outcomes.

To raise awareness of autism generally, you might want to consider making the National Autistic Society, or your local autism support group, the beneficiary of any charity fundraising activities you are organising. Fundraising is a good way to engage people in a particular cause, and promoting details on a notice board shows everyone that autism is an important issue for all surgery staff.

As previously suggested, it is important to have a feedback system in place so that

patients can share their views on good and not so good experiences. Suggestions may help you make improvements for everyone's benefit.

You can ensure a clear referral pathway is in place so GPs making referrals for people with autism know exactly where to send them depending on the circumstance. This will lead to a prompt service for the individual and reduced anxiety levels.

Access to the building

People on the autism spectrum can feel particularly uncomfortable about the unknown. It can therefore be helpful to provide new patients with information about the surgery in advance so they have some idea of what to expect before they arrive.

You might create an 'About the surgery'

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leaflet, using plenty of pictures and photographs, to offer information about the surgery layout, waiting rooms, consultation and treatment rooms and the surgery staff a new patient is likely to encounter.

When patients with autism arrive at the surgery, they may be agitated or distressed by certain noises, light levels or simply by having to wait.

It is helpful for receptionists to be aware of this and to be flexible and understanding in their approach.

If you have the space, you could provide a separate quiet waiting area where people with additional needs may wait. If even this is too much for them, a special arrangement could be considered which allows the person to wait elsewhere, such as in their car, and for the receptionist call them when they can be seen.

It is also sensible to offer patients with additional needs appointments at quiet times of the day, unless urgent attention is required.

Access to the GP/nursing staff

It is helpful if the GP, nurse or other health

professional is alerted to a person's specific needs **before** they enter the consultation room, as it may not be possible to look in detail at the person's medical history prior to their appointment slot.

A flag on the person's notes would be helpful for the receptionist and the GP.

A person with autism might have communication difficulties that make it difficult to express themselves so it is important to make allowances for this.

An extended appointment time for patients with autism, including children, would be helpful for GP and patient.

The style of communication you use with a patient on the autism spectrum should be clear and simple, use visual prompts where possible, visual demonstrations and writing things down can also be helpful.

Language should be kept literal and direct, avoid idioms, which people with autism tend not to understand.

If the person with autism is not able to say how best to communicate with them, and a carer is present, do ask the carer, but be sure to direct all questions to the patient, even if answers are coming from the carer.

Investigations such as blood tests may take longer if a patient has sensory difficulties, for example someone hyper-sensitive to touch may find even a light touch painful. Equally, some people with autism may have a very high pain threshold, and not be distressed by physical contact at all.

It is important to understand the particular needs of individual patients and plan accordingly.

Access to information

It is important to provide relevant and current information to your patients about local services and support groups.

You could develop an area about autism on the practice notice board or website providing a 'one-stop-shop' for all information people might need. It should list information specific to your local area such as local support groups and how people can access support after a diagnosis, as well as general information for people with disabilities such as disability allowance guidance and advice on what people should do in a crisis. ■