CET

COMPETENCIES COVERED

Dispensing opticians: Standards of Practice, Communication, Refractive Management, Paediatric dispensing

Optometrists: Standards of Practice, Communication

A practice perspective on autism

By Andrew Millington BSc MRes MCOptom

Autism is a condition characterised by problems with social communication and interaction, and restricted and repetitive patterns of behaviour[1]. It is defined by the National Autistic Society as: "*a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them*"[2]. It is a spectrum disorder, meaning that individuals are affected in different ways and to different levels of severity.

Autism affects approximately one per cent of the population, though studies vary, and it appears that incidence is increasing. However, this may be due to better awareness and older, more able individuals seeking diagnosis. More males are affected than females (4:1) and whilst it is not genetic there do appear to be familial tendencies[3].

The National Institute for Health and Care Excellence (NICE)[4] has produced a series of referral criteria for GPs who suspect that a child may be autistic (**Box 1**). This is not a diagnostic tool but a referral based on suspicion and risk factors in the same way that the NICE glaucoma referral guidelines are applied.

DIAGNOSIS AND CLASSIFICATION

A diagnosis of autism is usually made by a team of professionals including a psychiatrist, a speech and language therapist and a specialist psychologist[5] and is based on criteria listed in DSM-5, the Diagnostic and Statistical Manual of Mental Disorders.

Figure 1: Lack of social skills and interaction are a feature of autism

The updated criteria were published in May 2015[6] and replace DSM-IV. They differ from the previous criteria in a number of ways: DSM-5 now specifically recognises the spectrum nature of the condition, and adopts ASD (autistic spectrum disorder) as the umbrella term. It also differs by recognising two behavioural characteristics of ASD.

The previous classification (DSM-IV) considered autism to consist of a triad of impairments: difficulty with social communication; difficulty with social interaction; and difficulty with social imagination (**Figure 1**). DSM-5 recognises these impairments as difficulty with social communication and interaction – but also adds unusually restricted, repetitive behaviours and interests. It is worth considering how these two autistic traits might affect us in practice.

This article has been approved for 1 CET point by the GOC. It is open to all FBDO members, and associate member optometrists. The multiple-choice questions (MCQs) for this month's CET are available **online only**, to comply with the GOC's Good Practice Guidance for this type of CET. Insert your answers to the six MCQs online at www.abdo.org.uk. After log-in, go to 'CET Online'. **Questions will be presented in random order.** Please ensure that your email address and GOC number are up-to-date. The pass mark is 60 per cent. The answers will appear in the April 2017 issue of *Dispensing Optics*. The closing date is 14 March 2017.

C-54040

Box 1: Autistic traits identified in the NICE autistic referral guidelines

Social interaction and reciprocal communication behaviours

Spoken language

Spoken language may be unusual in several ways:

- *Very limited use*
- *Monotonous tone*
- *Repetitive speech, frequent use of stereotyped (learnt) phrases, content dominated by excessive information on topics of own interest*
- *Talking 'at' others rather than sharing a two-way conversation*
- *Responses to others can seem rude or inappropriate*

Interacting with others

- *Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space*
- *Long-standing difficulties in reciprocal social communication and interaction: few close friends or reciprocal relationships*
- *Reduced or absent understanding of friendship; often an unsuccessful desire to have friends (although may find it easier with adults or younger children)*
- *Social isolation and apparent preference for aloneness*
- *Lack of awareness and understanding of socially expected behaviour*
- *Unable to adapt style of communication to social situations, for example, may be overly formal or inappropriately familiar*
- *Subtle difficulties in understanding other's intentions; may take things literally and misunderstand sarcasm or metaphor*
- *Makes comments without awareness of social niceties or hierarchies*

Eye contact, pointing and other gestures

- *Poorly integrated gestures, facial expressions, body orientation, eye contact (looking at people's eyes when speaking) assuming adequate vision, and spoken language used in social communication*

Unusual or restricted interests and/or rigid and repetitive behaviours

- *Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking*
- *Preference for highly specific interests or hobbies*
- *A strong adherence to rules or fairness that leads to argument*
- *Highly repetitive behaviours or rituals that negatively affect the young person's daily activities*
- *Excessive emotional distress at what seems trivial to others, for example change in routine*
- *Dislike of change, which often leads to anxiety or other forms of distress including aggression*
- *Over or under reaction to sensory stimuli, for example textures, sounds, smells*

Lorna Wing was one of the pioneers of autistic research[3]. She did much of the early work describing the condition and identified four communication styles, which illustrate the difficulties with social communication[7].

The four types of social behaviour are:

- an aloof group who behave as though other people do not exist;
- a passive group who do not initiate social interaction;
- an active but odd group who make active approaches to others; and
- an overly formal, stilted group who are highly able but excessively polite.

The aloof group do not respond to any advances that you make. They may be passive and allow objective tests, such as retinoscopy and ophthalmoscopy, but they tend not to respond to visual stimuli such as the Cardiff Acuity Test, which relies on preferential looking. They may not even fixate on a flashing light or react to stimuli, such as a ball thrown towards them.

A normal eye examination and dispensing relies on interaction between the optician and the patient; there are the history and symptoms which elicits any problems and various subjective tests and measurements that we perform. Although there are also objective techniques, such as retinoscopy, it is difficult to assess vision if someone does not react to a stimulus. This is because a preferential looking test relies on the subjective judgement of eye movement. Even gross field assessment and binocular assessments can be difficult and ineffective.

For these patients, we rely on our observational skills such as watching how someone walks into the room and how they investigate new surroundings. This can give clues to visual function. Although they may appear unresponsive when being tested, these patients will often use quick sideways glances or may appear fascinated by their fingers flapping in front of their face – but then surreptitiously look around the room.

The passive group do not initiate social interaction but do accept contact from others. They may well respond verbally to questions but are likely to exhibit traits such as echolalia, which is simply repeating the last sound/words heard. This can be delayed and mean they repeat a noise from earlier that day or from days, weeks or even months before. They may also have their own conversation, not responding to your questions but talking at you about their favourite subject. This type of patient needs to be told what to do. It may feel rude to say, "Sit there", but it is giving a precise, easily understood prompt.

An active but odd individual may well initiate a conversation but then suddenly go off at a tangent paying little regard to what the other person is saying. There seems to be no pattern to the conversation, no understanding of the 'rules' of conversation,

such as turn taking and following a train of thought or responding to your prompts and questions.

The overly formal individuals tend to be older teenagers or adults as they have 'learnt' the rules of polite society. They may expect to shake hands with everyone every time that they meet them, or they may introduce themselves to you several times a day. There is no innate understanding of how politeness and conversations work. Instead, they will decode your words and body language, work out the appropriate response from their rules and then reply.

They tend to be excessively polite and can find social situations difficult, especially when body language does not correspond to the words spoken, such as making polite chit chat while having your arms crossed and scowling because you are cross with someone.

AUTISM IN PRACTICE

Some of the difficulties with social interaction and social imagination that may be encountered in practice can be illustrated by looking at the NICE referral guidelines.

EYE CONTACT

A neurotypical individual (the term that the autistic community has coined to label the rest of us) will feel that they are not being listened to, or taken seriously, if the person asking them questions is not making eye contact and gazing at a point in space. However, many people with an ASD find eye contact uncomfortable and difficult. It is an area where they are encouraged by family, carers and professionals to practise their skills as it is recognised as important for social acceptance. I have seen children who have gone from no eye contact the first time I saw them to almost normal eye contact after a number of years.

The amount of eye contact, and how comfortable someone is with it, is something that I will note on my record card. It is also something that I will ask parents or carers about when I first meet an autistic patient. If someone gets very distressed with eye contact, it can potentially hinder a successful examination and dispensing such as taking a PD or segment height measurement.

It is also something I do because not giving eye contact is something I find especially difficult. It can be useful to pick a point on their forehead, or one of their ears, to talk to. Interestingly, the converse is also true that some patients may give you inappropriately long eye contact which can also be disconcerting.

PERSONAL SPACE

We all feel little uncomfortable when someone invades our body space but you need to realise that for an austistic individual, it may be an unconscious action. Alternatively, they may not allow you to get close enough to them to perform the tests and measurements that you need. It is always worth explaining to patients what you are going to do – but even more so for one with an ASD.

REDUCING STRESS

The First Then paradigm is very useful[8]. It is used to reduce distress and anxiety in ASD and is something that we regularly see in practice between parents and children: "If you are good we will go for a McDonalds". First, the desired behaviour: being good; then the reward: McDonalds. Teachers and carers work hard at establishing the First Then Paradigm with ASD children. Initially, it is visual using a First Then board but later can become conceptual, although at times of stress the visual prompt may be required.

A more complex form of this is the visual timetable. Many individuals struggle with the concept of time and need the reassurance of structure. As people with ASD tend to be very visual, the concept of a visual timetable was developed. These may represent a whole week or a whole day, or may be for individual tasks such as a visit for an eye examination.

Pictures of the staff that they will meet, where they will sit and the equipment that will be used can be sent or given to the carers, and can be incorporated into the visual timetable for that patient. It is also useful to provide a written report and this can be adapted to make it visual.

AWARENESS AND UNDERSTANDING

Most of our patients will have an innate sense of how to behave when they come to see us. There is an expectation that they will need to answer some questions, read a letter chart and try on glasses. However, we may find that in ASD the behaviour is different. It may just be communication problems or apparent rudeness or even a seeming misunderstanding of expecting you to have their new glasses ready instantly, rather than having to wait for them to be produced.

Other individuals may not tolerate waiting or may not wait patiently or quietly, or they may not respect the privacy of other patients. For these patients, it is useful to be able to offer a 'no wait' appointment. This might mean booking them in at the start of the day, or immediately after the lunch break. It may be giving them a long appointment slot for example from 2-3pm but getting them to come in for their appointment at 2.10pm so you can guarantee that you will be free. It isn't uncommon for carers to phone from the car and then to go out and collect the patient when you are ready for them.

REPETITIVE BEHAVIOURS AND INTERESTS

This may become apparent from the unusual communication style, such as the passive or active but odd groups, or may only become apparent if you hit the 'trigger'. This is something to be aware of when asking about hobbies and interests as a lack of social awareness and understanding means that they may well not stop talking until they are interrupted. This can work in your favour as an animation of dinosaurs, for example, can be

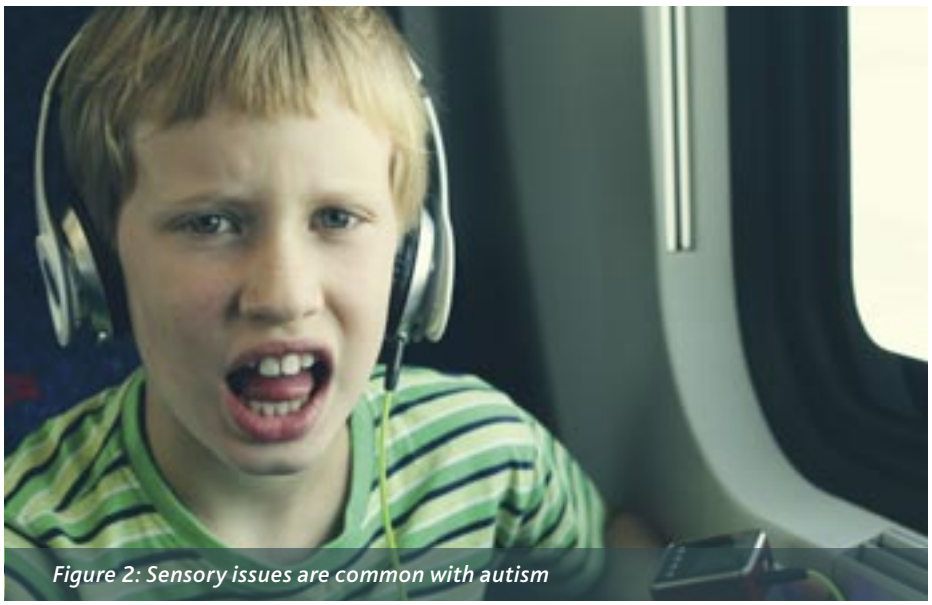

Figure 2: Sensory issues are common with autism

Figure 3: Autistic patients may become stressed if they have to wait to be seen

a great fixation target especially if you ask the child to name each species.

SENSORY ISSUES

Sensory issues are common with ASD3 (**Figure 2**). They can be over or under (hyper or hypo) sensitive and this can affect all the senses. This is not a permanent state, and one of the strange things is that a person may be both hyper and hypo sensitive at the same time. A slight brush against the patient, such as moving their hair to put a frame on, may cause great distress whereas as a firm solid hold such as a hug may be comforting.

In practice, it is always wise to ask someone, even if they are non-communicative, if it is alright to do something. This not only asks their permission but warns them that it is going to happen. For instance, with ophthalmoscopy I will say, "I am going to shine this bright light at you. Is that ok? It will get very close, like this. I would like to put my hand here. Is that alright?" This may seem a little long winded, but it only takes a couple of seconds and may make the test a lot easier.

Another very useful tip is to provide a reference for how long things are going to take. People on the autistic spectrum have difficulty with the concept of time (**Figure 3**) and many of them are very literal in their understanding so phrases such as, "This will only take a minute" or "Back in a second", become meaningless.

For ophthalmoscopy, which is disconcerting and can be unpleasant, I will tell the patient that I am going to look at their eyes until (usually) mum finishes counting to 30 and then I will stop. In practice, you have to stick to your side of the deal and make sure that you do finish at 30. In the early stages of practising, this can seem problematic as you might not have finished everything that you need to. There needs to be an acceptance that it is a compromise and my notes will often reflect this with reminders to myself for next time, such as 'Do ophthalmoscopy on left eye first', 'Limited view this time'. It also highlights another aspect of how important the ongoing relationship with your patient is.

Each individual appointment needs to be seen in the context of their lifelong eyecare. This is not an excuse to be sloppy or lax, but a reminder that as long as you have professionally done as well as you can, and have been practising to your best ability and the individual has benefitted on some level for having seen you, that it has been a successful appointment.

SUMMARY

Seeing patients with an ASD can be a challenge but as with any experience that takes you out of your comfort zone, it can also be hugely rewarding. A few simple tips can go a long way to easing the experience for both you and your patient, and many of the skills will be useful in everyday practice. Many of the autistic traits are perfectly normal and we all exhibit some of them from time to time, so it will become a useful skill set to have.

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ANDREW MILLINGTON is a part-time clinical tutor in the Cardiff School of Optometry and Vision Sciences and principal tutor on two current post-graduate modules. He is one of the three optometrists working regularly in the Special Assessment Clinic, runs the lecture programme in Special Needs for the undergraduate module, and the Professional Awareness practicals specialising in communication skills. He also has his own independent practice in Chepstow. The Special Assessment Clinic earned the inaugural Award for Clinical Excellence by the National Autistic Society in 2013.