

### **LEARNING DOMAINS**



PROFESSIONALISM



### **PROFESSIONAL GROUPS**



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This CPD session is open to all FBDO members and associate member optometrists. Successful completion of this CPD session will provide you with a certificate of completion of one non-interactive CPD point. The multiple-choice questions (MCQs) are available online only from Wednesday 1 February 2023. Visit www.abdo.org.uk After member login, scroll down and you will find CPD Online within your personalised dashboard. Six questions will be presented in a random order. Please ensure that your email address and GOC number are up-to-date. The pass mark is 60 per cent.

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# Autism and eyecare accessibility

### By Dr Ketan Parmar PhD MSci (Optom) MCOptom

n the last few years, there has been increased interest about populations with special requirements, including autism. Although autistic people can have a co-occuring learning disability, autism is not a learning disability itself. This is likely to be a common misconception and can cause autistic people to be poorly understood and incorrectly supported. This article provides a background to autism, autistic sensory experiences, autism and vision, and recommendations for

### WHAT IS AUTISM?

Autism is a lifelong neurodevelopmental condition which affects social interaction, communication and behaviour; **Table 1** gives some typical examples of such challenges. These impairments have stressful impacts on the day-to-day living of autistic people<sup>1,2</sup>. Autism is not a learning disability itself, but about one

providing autism-friendly eyecare.

third of autistic people have a co-existing learning disability<sup>3</sup>. Globally, 0.6 per cent of the population is autistic<sup>4</sup>. In the UK, approximately 1.1 per cent of adults<sup>5</sup> and 1.57 per cent of children<sup>6</sup> are diagnosed as autistic. There appears to be a gender imbalance, with up to four times more males diagnosed as autistic than females<sup>7.8</sup>.

The UK diagnostic criteria for autism are laid out in the International Statistical Classification of Diseases (ICD-11)<sup>9</sup> and Diagnostic and Statistical Manual of Mental Disorders (DSM-5)<sup>10</sup>. In summary, these are:

- a. Impaired social communication and interaction
- b. Restricted or repetitive patterns of behaviour
- c. Symptoms must be present in the early developmental period but not necessarily fully manifest
- d. A clinically significant impairment of social ability, occupational capability or in another area of function

SOCIAL	<ul> <li>Does not always respond to their name</li> <li>Inability to initiate conversations or continue them</li> <li>Unable to understand simple questions and instructions</li> <li>Poor expression of emotion and poor understanding of others' emotions</li> <li>Poor judgement of a social environment and may approach it in the wrong manner</li> </ul>
COMMUNICATION	<ul> <li>Poor eye contact and a lack of facial expression</li> <li>Delivers speech in an unusual manner, either robotically or like a song</li> <li>Difficulty interpreting non-verbal signals</li> <li>Inability to understand the context of words with double meaning</li> </ul>
BEHAVIOUR	<ul> <li>Repeats movements or activities which could cause self-harm</li> <li>Displays coordination issues with walking or hands</li> <li>Poor ability to imitate</li> <li>Unwillingness to break routines</li> <li>Altered sensory sensitivity</li> </ul>

**TABLE 1:** Examples of the social, communication and behavioural challenges that autistic people can experience<sup>10</sup>

e. These impairments cannot be better explained by intellectual disability or global developmental delay

### AUTISM AND SENSORY EXPERIENCES

The majority of autistic people have altered sensory reactivity<sup>11,12</sup> – meaning they experience sensory stimuli differently to non-autistic people. They can be hyperor hypo-sensitive to sensory stimuli.

### Hypersensitivity describes an excessive response to sensory stimuli, such as:

- Visually focusing on fine details in an object rather than the object as a whole
- Intolerance to the feel of particular textures or types of clothing
- Finding tastes of certain foods overpowering, so developing a restricted diet
- An inability to cope with certain scents, for example, strong perfumes
- Difficulty ignoring background noise

### Hyposensitivity describes a dampened response to sensory stimuli, for example:

- An inability to visually detect some features of objects
- An ability to tolerate more pain that usually expected
- A liking for extreme tastes, such as very spicy food
- Failure to notice strong smells
- Gaining pleasure from loud noises

Additionally, autistic people can display sensory seeking behaviours such as excessive touching of object edges or fascination with reflections<sup>13</sup>. Altered sensory reactivity largely takes the form of hypersensitivity for autistic individuals<sup>14</sup>. Research has shown the degree of altered sensory reactivity increases with the severity of autism  $^{\rm 15}$ but not age<sup>16,17</sup>. Importantly, sensory issues are lifelong<sup>18</sup> and affect each sense individually<sup>19,20</sup> as well as multisensory processing  $^{\scriptscriptstyle 21,22}.$  The impact of these can vary from stressful to pleasant, depending on the nature of the  $resultant \ experience^{{\tt 23,24}}.$ 

### HEALTHCARE ACCESSIBILITY FOR AUTISTIC PEOPLE

Autistic children and young adults are 11 times more likely<sup>25</sup> – and autistic adults five times more likely<sup>26</sup> – to develop poor health compared to the general population. It is therefore unsurprising that autistic people are expected to access healthcare more often<sup>27-30</sup>. However, significant issues surround healthcare provision to this population<sup>31, 32</sup>. A survey conducted by the Westminster Commission on Autism<sup>33</sup> found that 74 per cent of autistic, parent-advocate and professional respondents felt that the autistic population received poorer healthcare compared to non-autistic people. This could be because some of

I YPE OF IMPACT	EXAMPLES
PHYSICAL "[visual hypersensitivity is] a gradually fatiguing thing"	<ul> <li>Sleeping difficulties, especially during summer months, due to hypersensitivity to lights</li> <li>Feeling drained and tired, impacting functionality</li> <li>Negative physiological responses, such as experiencing pain from bright colours or lights</li> </ul>
MENTAL "I feel like my genetics are just really bad codes, just full of defects and errors"	<ul> <li>A negative belief of being 'different' and less able</li> <li>A sense of not being normal, compared to non-autistic people</li> </ul>
<b>EMOTIONAL</b> "It [visual hypersensitivity] just makes me generally stressed all the time and less able to deal with other things"	<ul> <li>Distress</li> <li>Anger</li> <li>Anxiety</li> <li>Feeling overwhelmed</li> <li>Positivity acknowledging the advantages of some visual hypersensitivities</li> </ul>

TABLE 2: Examples of the physical, mental and emotional impacts of visual sensory experiences on autistic adults<sup>37</sup>. Quotes are taken from Parmar *et al*<sup>87</sup>

the physical symptoms of health issues presented by autistic people are erroneously attributed to features of autism<sup>34</sup>.

In comparison to non-autistic people with or without other disabilities, autistic individuals experience greater barriers to accessing healthcare<sup>35</sup>. Raymaker *et al*<sup>35</sup> found that the top five barriers to healthcare for autistic people were:

- Fear and anxiety
- Slow information processing, which means they cannot have a real-time conversation with healthcare professionals
- Cost implications
- Sensory issues
- Communication challenges with service providers

Interviews conducted by Nicolaidis et al<sup>36</sup> with autistic adults, and individuals who supported autistic people in a healthcare setting, concluded that autism-related factors, such as verbal communication deficits and sensory sensitivities, impacted service use for the patient. Lack of autism knowledge, incorrect assumptions about abilities of patients, and unwillingness to adapt, created barriers on the part of service providers. The complexity of the healthcare system, physical features of healthcare settings and stigma about autism, created system-level barriers.

Dern and Sappok<sup>31</sup> arranged meetings involving autistic adults who could verbally share their personal experiences, and autism professionals who spoke on behalf of autistic adults who could not verbally share their experiences. Discussions highlighted that the sensory and communication issues surrounding autism need to be understood by service providers to make sure that their services are autism-friendly. Arranging appointments by phone call is difficult for autistic people. Proximity to strangers, sensory issues and stress due to uncertainty create challenges in waiting areas. Sudden touch during the examination causes discomfort. Communication during appointments is testing due to literal thinking, lack of time to think and respond to questions and general issues with communication.

### CPD

### AUTISM AND VISION

AUTISTIC VISUAL SENSORY EXPERIENCES

Autistic adults can experience a variety of visual symptoms<sup>37</sup>. The majority are sensory and due to different aspects of light (bright, fluorescent and spot lighting), strong colours, patterns, motion and visual clutter (i.e. lots of stimuli in the visual field). These vary from person to person, and can occur alone or as part of a larger multisensory experience.

Although non-autistic people would probably experience some of these symptoms, it is the challenge in daily activities, such as the consequent inability to visit public places (e.g. hospitals and supermarkets) or use public transport, which seems greater for autistic people.

Visual sensory issues negatively impact physical, emotional and mental wellbeing, as presented in **Table 2**. Autistic adults feel less inclined to partake in social activities, partially due to visual sensory issues. For some autistic adults, their visual sensory characteristics can be an advantage. For example, hypersensitivity to detail allows autistic people to spot patterns in data easily, or see features in landscapes which non-autistic people may miss when painting.

Autistic people try to control the negative effects of visual experiences<sup>37</sup>. Coping strategies can involve adapted lighting in artificially lit environments, avoiding situations which provoke visual sensory experiences, choosing specific eyewear which prevents distraction (e.g. spectacles with thinner rims or rimless), and just trying to cope as well as possible.

Where coping is difficult, some autistic people have accessed unproven management options such as tinted lenses which claim to have a calming effect in this population. An example of this can be seen at: www.read123.co.uk/en/the-use-of-

colour-therapy-and-coloured-lenses-inautism

#### OPTOMETRIC CONDITIONS IN AUTISTIC PEOPLE

Although visual acuity is comparable between autistic and non-autistic people<sup>38</sup>, autistic people are at greater risk of developing optometric anomalies including higher refractive errors, strabismus and amblyopia<sup>39,40</sup>. **Figure 1** provides a summary of optometric A significant refractive error has been noted in up to 44 per cent of autistic youngsters. Specifically, astigmatism ≥1D has been found in 18-26 per cent of autistic children<sup>45-47</sup> compared to eight per cent of non-autistic children<sup>45</sup>

The prevalence of strabismus is 8.6-60 per cent amongst autistic children<sup>48-54</sup> compared to 0-5 per cent in non-autistic children<sup>48,53-55</sup>.

Between 10-11 per cent of autistic children have been recorded as amblyopic<sup>49,51</sup> relative to a global prevalence of 1.92 per cent<sup>56</sup>

Near point of convergence has been found to be significantly extended amongst autistic children compared to non-autistic children<sup>48,53</sup>

Significant accommodative lags have been found in 17.4 per cent of autistic children compared to 4.9 per cent of non-autistic children<sup>48</sup>

#### FIGURE 1: A summary of reported prevalence of optometric anomalies amongst autistic people, mostly children<sup>45-56</sup>

research in young autistic participants, having an upper age of 20 years. Many of them also had a co-existing learning disability.

Parmar *et al*<sup>41</sup> addressed the lack of research about optometric anomalies in autistic adults without learning disabilities. The outcomes of this study, conducted with 24 autistic adults, suggest this population is more likely to develop a significant change in refractive correction, and present with binocular vision (e.g. accommodative insufficiency and infacility) and visual stress issues.

Overlaps have been identified between the symptoms of visual stress and common eye problems such as uncorrected refractive error and binocular vision anomalies<sup>42-44</sup>; it is possible that some autistic visual sensory experiences have a similar link.

### EXISTING RESOURCES

FOR ACCESSIBLE EYECARE If autistic people are more likely to develop optometric issues, they can be expected to access eyecare regularly. SeeAbility offers resources for providing accessible eye examinations to autistic children, and autistic people with learning disabilities<sup>57</sup>. The College of Optometrists has professional guidance on seeing autistic patients, based on research regarding autistic children and mainly focused on what would happen in the testing room<sup>58</sup>. Neither of these cater to autistic adults who do not have a learning disability.

To address this, Parmar *et al*<sup>59</sup> conducted focus groups with autistic adults to understand the key challenges they face when accessing eyecare services. This facilitated recommendations for eyecare providers on how to deliver autism-friendly services. The next section discusses key challenges and recommendations for eyecare providers to keep in mind when seeing autistic patients, as well as dispensingspecific recommendations<sup>57-59</sup>.

### HOW CAN I PROVIDE AUTISM-FRIENDLY SERVICES?

#### **1. IMPROVE YOUR**

UNDERSTANDING OF AUTISM You should consider undertaking autism awareness training. Having a basic awareness of autism will allow you to appreciate the challenges that an autistic person could face in your practice. This will help you consider adaptations for an autism-friendly service.

Autistic people can feel anxious about eye examinations. They can be made to feel relaxed by you simply introducing yourself, being patient, explaining procedures well and not providing too much information at once. It is a good idea to have an 'autism champion' amongst your practice staff. This is someone who has an advanced understanding of autism. They can be a point of contact for autistic patients. Practice staff can seek their advice on autism-friendly adaptations.

# Need help understanding information about your health and social care?

Here's **five things NHS & social care services <u>MUST</u> do** for you...



**If your needs are not being met...** Let the service know! You have a right to receive information in a way you can understand it. If that's not happening, you should contact the service and ask them to address it.

You can also feedback to Healthwatch Suffolk on www.healthwatchsuffolk.co.uk, or call freephone 0800 448 8234.



FIGURE 2: A summary poster (*produced by Healthwatch Suffolk*) of the five requirements of the Accessible Information Standard for NHS and social care services<sup>62</sup>

### 2. AUTISM-FRIENDLY

**PRACTICE OPERATION** Entering an optometric practice can be stressful for autistic people, partly because of glaring reflections from displayed spectacle frames and uncomfortable lighting. Autistic people can be hypersensitive to lots of sound or movement, and can feel anxious among lots of people. Identify patterns of quieter periods in your practice and offer appointments during these times to autistic patients.

You could have 'quiet times' akin to some supermarkets, when practice lights are dimmed and the practice music is turned off. Similarly, consider whether autistic patients could be offered a 'quiet area' in your practice to wait instead of a busy waiting area, or possibly have them taken into the testing room straight away.

It is commonplace in ophthalmic clinical settings for different staff members to be responsible for stages of the patient's appointment. Knowing that autistic adults experience anxiety when meeting new people, this type of patient journey is very uncomfortable and has been identified as a barrier to healthcare<sup>31,36,60</sup>. Therefore, having to interact with different staff during an eye examination can cause significant stress.

Try and conduct most of the appointment between the optometrist

and a member of dispensing staff. The optometrist can conduct pre-screening tests as well as the eye examination. The dispensing optician can fully manage any spectacle dispensing.

Having to go to different rooms is also anxiety provoking for autistic patients, because they have to get used to a new environment. Review your eye examination process and consider how the number of room changes could be minimised during an appointment.

Autistic patients may become overwhelmed with the variety of stages, staff and tests involved in an eye examination. If this is evident then propose spreading the appointment over two (or more) visits. Offer the option to return another day to arrange new spectacles.

#### **3. TRY TO PROVIDE**

**PRACTITIONER CONTINUITY** Due to the social difficulties linked with autism<sup>9</sup>, autistic adults commonly feel anxious when communicating with strangers. Therefore, staff continuity is important across successive eye examinations for autistic adults. Autistic people feel more confident with a professional that they see regularly, regardless of their competence. Seeing the same practitioner (optometrist and dispensing optician) allows autistic adults to feel relaxed and respond better. The practitioner would also have built a relationship with the autistic patient over a series of examinations, and therefore better understand their requirements.

#### **4. PROVIDE AN ELECTRONIC**

**APPOINTMENT BOOKING OPTION** Many autistic people do not like speaking to strangers over the phone. They often must build up courage to make a phone call to eyecare providers in order to arrange an appointment. For some autistic people, it serves as a deterrent, making them delay important healthcare until it is unavoidable or someone else can make the phone call for them. Therefore, your practice should provide an alternative such as an online booking portal or appointment request form (e.g. as part of your practice website), or the option for patients to communicate with the practice by email. Appointment reminders are also preferred by text, letter or email.

### CPD

### 5. ACCESSIBILITY OR

SPECIAL REQUIREMENTS Autistic adults have noted that optometric practices do not routinely ask patients about special requirements which is a legal requirement as per the Accessible Information Standard<sup>61</sup>. This law, in effect since August 2016, ensures people with a disability, impairment or sensory loss receive information which they can easily understand, and any required communication support. Figure 2 summarises the five requirements of the Standard for NHS and social care services. NHS England provides further information about this standard online: www.england.nhs.uk/about/equality/equa lity-hub/patient-equalitiesprogramme/equality-frameworks-andinformation-standards/accessibleinfo

You could add a free-text field to your electronic booking form asking about special requirements. Additionally, you could give examples of adaptations you are able to offer, such as extended appointments and quiet periods. For autistic patients who are comfortable booking appointments via telephone, ensure you seek accessibility information as part of the conversation. Review this information prior to the appointment. Doing so will allow you to understand any factors which may influence the eye examination.

### 6. PROVIDE 'WHAT TO EXPECT DURING

YOUR APPOINTMENT' INFORMATION Autistic adults feel anxious about visiting optometric practices and having an eye examination. This is due to the uncertainty of what they will have to face, who they will have to interact with and the lasting impacts the visit may have. To reduce autistic patients' eye examination anxiety, help them prepare for their visit by sending information about what the appointment will involve, which staff they will meet and the different processes they will undergo. This can take the form of an information sheet with pictures accompanying room, staff and test descriptions. You could provide a list of questions that may be asked during the appointment.

Researchers at the University of Manchester have produced resources which you can provide to autistic patients: https://sites.manchester.ac.uk/autismand-vision/patient\_resources Additionally, guidance on getting to the practice (e.g. maps, travel routes, public transport options) can reduce travel anxiety. Some autistic people may prefer to visit the optometric practice in advance of their appointment, as an opportunity to familiarise themselves with the setting.

When an autistic patient arrives, sit with them in a quiet space and run through what will be involved in the appointment. Mention having to go to different rooms, which staff they will meet and any delays to the clinic.

7. ESTABLISH A GOOD RAPPORT The quality of communication plays a large part in the rapport created by eyecare professionals, which autistic adults have said needs improvement. It is important that you introduce yourself and describe what you will be doing. For example, "My name is Ketan and I will be helping you choose a new pair of spectacles". You should ensure a kind tone and friendly behaviour. Be reassuring and avoid rushing the autistic patient. It is also important to be aware of the autistic patient becoming stressed or overwhelmed.

### 8. DISPENSING-SPECIFIC RECOMMENDATIONS

Accessibility challenges vary from one autistic person to another. Therefore, adaptations which are ideal for one individual may not be as effective for another. When considering how the spectacle dispensing process can be more autism-friendly, you should revisit the patient's accessibility requirements. Additionally, allow the autistic patient to have an input on the dispensing process by asking them about anything they may find uncomfortable, what works well for them and the usefulness of any adaptations you are planning.

Being unsure of what to expect or what to do can make autistic people feel stressed. They can think very literally<sup>27</sup> and may only provide relevant information if specifically asked<sup>31</sup>. Review your questioning techniques to ensure you are asking simple questions and not making any assumptions of understanding.

Autistic people like being given clear and detailed information. But, too much information at once can be difficult to process. Therefore, go through the spectacle dispensing process in a stepby-step manner. For example, discuss lens choices, then spectacle frames and finally lens tints and coatings. When performing any dispensing procedures, ensure you explain: (a) what test is being conducted; (b) how it will be conducted; (c) why it is important; (d) what equipment will be used (if any); and (e) what the autistic patient exactly needs to do. Offer autistic patients the opportunity to ask questions.

Due to the sensory challenges that autistic people are prone to<sup>11</sup>, certain procedures during spectacle dispensing can be extremely unpleasant. Procedures requiring close proximity (e.g. measuring pupillary distance with a pupillometer) can be uncomfortable. Skin contact from instruments (even a PD rule) is challenging. Additionally, practitioners wearing strong perfumes can be very distracting. Autistic adults have to work hard to override the consequences of



FIGURE 3: A scale can be drawn onto frames' dummy lenses, before being placed on the patient's face, to determine vertical and possibly horizontal centration

sensory issues and be able to attend to instructions and questions.

Think about if procedures which provoke sensory issues or anxiety could be replaced or conducted differently. If it is not possible to eliminate such procedures, then try to minimise the patient's exposure to the uncomfortable stimulus, and ensure clear explanations and advance warning so that the patient knows what to expect.

### HERE ARE SOME SPECIFIC POINTS FOR CONSIDERATION:

- Unless assistance is sought, avoid constantly watching or hovering around autistic patients when they are selecting new spectacle frames. This can make them feel anxious and under pressure
- If the dispensing area is busy and the autistic patient appears to be impacted by this, take them to a quieter area to take spectacle measurements and discuss lens options
- During the spectacle dispense, take relevant facial measurements so that the frame can be set up accurately for collection. These measurements may include length to bend and head width. Doing this will lessen the need for the frame to be adjusted multiple times during collection, minimising the number of times the patient has to take the frame off and therefore reducing stress
- During fitting, allow the patient to put on the frame themselves. Handling the frame will let them better expect what the frame may feel like on their face (e.g. the temperature and weight). If the patient is particularly sensitive to the temperature of the frame, especially if it is metal, then warm it slightly using a frame heater so that it is more comfortable to touch. Equally, allow the frame to cool to a comfortable temperature after any adjustments
- To measure vertical and possibly horizontal lens centration, draw a scale onto the frames' dummy lenses (see Figure 3), before placing it onto the patient's face. You could use photographic methods too, if available in your practice. These methods can prevent stress caused by having additional objects close to the autistic patient's face, and a dispensing optician in close proximity

- Autistic people can be distracted by spectacle rims in the visual field.
   Rimless spectacles, frames with thinner rims or larger eyesizes (if appropriate for the spectacle prescription) may be more suitable
- If the weight of spectacles is likely to provoke touch hypersensitivity, then consider titanium or rimless frames, or frames with minimum rim thickness
- Autistic people can be hypersensitive to bright environments. A neutral tint could help to reduce discomfort. Of course, if the individual drives then this would influence the density of the tint which can be incorporated into any distance spectacles
- If procedures which might cause sensory or anxiety issues cannot be avoided, then clearly explain what the procedure will involve and provide a demonstration. For example, hold a frame rule at the bridge of your nose to show how pupillary distance will be measured

### **KEY MESSAGES**

Autism influences the day-to-day living of individuals. Having a basic understanding of this neurodevelopmental condition can allow eyecare professionals to appreciate the challenges and advantages an autistic person may face. This will subsequently, and importantly, influence how autistic patients are supported.

Eye examinations can be challenging for autistic people and considerations need to be made concerning the whole practice visit for an autism-friendly service. Examples of good practice are considering communication strategies and how to adapt procedures to respond to patient needs. Implementing simple changes can easily reduce, if not overcome, many of the barriers to eyecare services for autistic people.

You can find out more about the author's research on autism, vision and eyecare here:

https://sites.manchester.ac.uk/autismand-vision. This website also contains resources for autistic patients to help them prepare for an eye examination (which eyecare providers can freely use), and recommendations for eyecare providers for autism-friendly services as presented in this article. **DR KETAN PARMAR is an optometrist** specialising in autism, vision and accessible eyecare. He graduated from the University of Manchester in 2022 as Doctor of Optometry having investigated autistic visual sensory experiences, barriers to eyecare for autistic people and possible links between autism and optometric conditions. His general interests in academia and clinical optometry include binocular vision, general optometry and communication/patient care. Currently he is a research optometrist at Eurolens Research, but also practises as a locum optometrist, and teaches

undergraduate optometry students.

### LEARNING OUTCOMES FOR THIS CPD ARTICLE

### **DOMAIN: Professionalism**

**13.2:** Promote equality, value diversity and be inclusive in all your dealings and do not discriminate against autistic patients.

### **DOMAIN: Communication**

**1.5:** Where required and possible, modify your care and treatment for autistic patients to support their needs and preferences without compromising their safety.

**2.3:** When working with autistic patients, be alert to unspoken signals which could indicate the patient's lack of understanding, discomfort or lack of consent.



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