Communicating with an individual on the autism spectrum

Information sheet for optometrists & practice staff

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Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects an individual throughout their life. Individuals on the autism spectrum commonly have difficulties with language and communication, social interactions and have limited or repetitive interests. A diagnosis of ASD may be made from the age of 2 to 3 years but may be made later depending on the degree to which the child's communication and social skills develop.

Examining a child on the spectrum can require tailored approaches from health care professionals. The purpose of this information sheet is to give some insight into establishing a level of communication that facilitates the optometric examination. The following information is of particular relevance to a young child with limited/no language; however, the strategies may be employed for all age groups.

**Autism**

The prevalence of autism disorder is estimated at 1:100 with a predilection for males (4:1). Typically a child will be referred for assessment by a clinical psychologist, paediatrician and speech pathologist when they fail to develop language (50 words by age three), exhibit repetitive behaviours (for example, repeatedly opening/closing doors), lack social engagement (eye-contact) and lack poor imaginative play (for example, pretending a banana is a telephone).

Common key features of an individual on the autism spectrum are:

- Delay in language and lack of communication
- Lack of reciprocal social behaviour
- Repetitive and restricted behaviours
- Lack of imaginative or creative play

For the clinician, understanding these difficulties and how to work with and around them in the consulting room is the key to enabling the optometric examination. Initially this may be limited to simply establishing a level of vision and binocular status, but with time more elements of the test can be incorporated.
The current DSM-V definition of ASD now encompasses the previously recognised conditions of Asperger’s disorder, pervasive developmental disorder not otherwise specified and childhood disintegrative disorder. The Australian Bureau of Statistics (2012) estimated that 115,400 Australians (0.5%) had autism. This was a 79% increase on the 64,400 people estimated to have the condition in 2009. The ABS also estimated approximately 33,000 children aged 5-9 years with ASD with an overall prevalence of 1% of the population. Males were 4 times more likely than females to have the condition, with prevalence rates of 0.8% and 0.2% respectively.

Therefore, optometric practices will encounter children and adults on the spectrum or may examine individuals in specialist schools or in residential care.

Consulting room set-up and useful equipment

Reducing the number of potential distractions in the consulting room will help maintain the child’s attention. Consider covering equipment that won’t be used and minimise near-by clutter with only the items required for the examination to hand. Some useful additions to the consulting room can help with examining the child with ASD:

- Two pairs of children's glasses with either the R or L eye tinted. This helps with occluding one eye at a time and in turn-taking when measuring vision.
- A hand held IR paediatric auto-refractor will help determine the refractive status without the need for mydriasis which is one procedure that may cause significant distress to the child as they are unlikely to understand the reason for the blurred vision and when it will end.
- A digital clock or count down timer that the child can see so that they are aware of how much longer the test will take.
- Many children may like to fidget and so a soft ball or something tactile that the child can hold during the sight-test to reduce their anxiety can be useful.
- A visual timetable illustrating what will happen in the examination that can be given before the child comes to the practice. An example is provided at the end of these notes and provides an overview of a visit to the optometrist and using drops. Rehearsing what will happen beforehand will help the child to understand the order of things and when the procedure will end.

The autistic mind and communication approaches

When examining a child or adult on the spectrum it may be helpful to understand in part how they relate to others. One way of thinking of autism spectrum disorder is as presenting difficulty with ‘Theory of Mind’ (ToM). ToM is the ability to put yourself in the shoes of another, to understand how another may think or feel from their perspective. Those on the spectrum have difficulty in understanding what another person may be wanting or feeling. Therefore, when relating to an individual on the spectrum it is important to communicate in a manner that gives no ambiguity in thought or emotion.

Another account is the Weak Central Coherence (WCC) model of autism that is an inability to integrate speech, language, emotion and context into a coherent whole perception. This inability to see the big picture or grasp the gestalt contributes in part to the observed repetitive and restricted areas of interest. Therefore, when giving instruction or communicating with an individual with autism the examiner should be direct and minimise distractions to maintain their attention on the task at hand in its simplest form. Processing of multiple bits of information is difficult for those with ASD.
These models provide a framework with which to base communication with those on the spectrum. The two key principles here are:

- Keep everything as simple as possible from the environment to any instruction (WCC)
- Be direct and exact with your communication (ToM)

An example to illustrate how a simple instruction can be misread by a child with autism:

*When a five year old boy was playing table pool, he was told to 'put the ball in the pocket' the boy responded by picking up the ball and placing it in his trouser pocket and smiling.*

**The parent/guardian**

The parent/guardian is the key: It is they who would have developed a 'way in' to communicating with their child. Talk to them, explain perhaps what it is you want their child to do, and they may have a word or phrase that the child will respond to such as 'use your words' or 'now you' to act as a prompt for the child to speak.

Although some children with ASD are hypersensitive to touch many are very sensual and will be comforted by a parent or you simply holding their hand and letting them explore its texture. This tactile manoeuvre often helps calm the child by displacing some of their attention to the feel of another's hand.

Many children with ASD will respond to praise or approaches where they obtain higher levels or points so use this (for example, 20 points for this eye and twenty points for that eye so that equals? Or next level/stop is? How many levels/stops today)? Discuss with the parent/guardian if they have any similar strategies to help engage their child with an activity to help move from one activity to the next. To disengage a child if they become fixated on a task, try counting down to a final stop point then moving on to the next task.

- Talk to the parent/guardian to find out what 'works' with their child - their interests / likes / dislikes etc.
- Try to have the parent close so they can hold the child’s hands or a soft ball that that the child can hold during the test

**Providing instruction**

Developing communication is the first priority for a child who has been diagnosed with ASD. Approximately one third of children with ASD never develop language and remain 'non-verbal'. However, being non-verbal does not mean they lose the ability to communicate. Communication is an exchange of ideas, emotion or thoughts that can be verbal – I say something or non-verbal – I shrug my shoulders / wink to indicate a feeling. Speech pathologists work on this notion with a child on exchanging something (a word or picture) first in order to get what they want to express or desire. The principles of exchanging or turn taking can be implemented into the optometric examination routine when communicating with a child.

When communicating with a child with ASD, consider that their verbal age may be 3-5 years less than their chronological age. One of the major communication landmarks is the ability to construct a 'two-part' sentence by using 'and' or 'but' such as: "the dog has a bone and he looks hungry." This complex sentence is beyond many children on the spectrum until the age of eight or more. Thus any directions need to be limited at most to a one part instruction for example, 'Sitting down', 'Chin here', 'Reading'. Any attempt to develop a conversation around school or favourite TV shows will be too confusing owing to the complex nature of
the language and difficulties in combining information. Repeating an instruction may also help direct a child’s attention to the task at hand. For example, 'looking, looking, looking….good now reading, reading, reading’. Overall keep any language simple and keep it direct.

Speech pathologists will often use pictures or visual timetables / storyboards to help explain what will happen next. An example is below created using an online platform (Widgit.)

![Visual Timetable Example](image)

Such visual cues act in two ways. One is that they provide a visual cue to the written word and when coupled with the spoken word help the child develop language and communication. Visual schemas also provide a way to communicate using symbols / figures. Developing visual timetables for their practice may help optometrists seeing many children with limited communication.

Other means of communication such a Makaton (www.makaton.org/) are also popular whereby a gesture, a picture and a word are used to communicate. Learning some simple gestures used by Makaton will help if being used by the child. Another strategy is Picture Exchange Communication System or PECS (www.pecsaustralia.com/). PECS builds on an approach of exchanging a picture for what the child wants. If a child is non-verbal they may pick a picture of a drink to indicate they want a drink. The parent / guardian then uses this picture as a means of developing language by saying 'drink'.

The main syntax used in developing the expression of needs or wants is that first you must say a word then something happens. So the general formula for developing language and communication is First X then Y (for example, first sitting then looking, first this eye then that eye.) The optometrist can use this approach to get the child to do something, for example by first Mummy doing something, then Charlie. This turn taking acts to show the child what they need to do, for example look at a Titmus chart or put on some glasses. Using this strategy of first this then that is a helpful way to progress through the routine.

The optometrist may need to wait 20-30 seconds before they get a response if this is the time required for the child to process information. Try not to ‘jump in’ or talk further during this period.

When giving any instruction to the child be direct and make eye-contact - sit in front of the child- do not talk over their head or to the screen or their parent / guardian. They need all the cues possible to initially register that you are talking to them and so a direct face to face / eye-to-eye approach helps.

**Summary of communication tips**

- Use the form: "First X then Y" Use Turn taking
- Be direct and simple with language
- Make direct eye-contact
- Give time for a response
Echolalia

One of the features of ASD for some individuals is the echoing of words or phrases. This is why it is important to use short – one part sentences as only the last part is often understood. It also means that some children with ASD will echo what is said, often the last word they hear. Therefore, asking ‘better first or second?’ would result in 'second' as the echoed last part response. The optometrist needs to be aware that some children with ASD echo speech when considering a response from a child. Objective tests should be used to the extent possible.

- Some children with ASD will echo or mimic what they have heard, so their responses may not be reliable responses to a question you have posed.

Familiarisation

One difficult area that some individuals with ASD have is coping with, or adjusting to, a change in routine or pre-made plans. This can create anxiety as their being unsure of what will happen next, and not being able to express this anxiety, can create uncertainty and fear. Therefore, the recommendation is to be prepared to do nothing other than let the child familiarise themselves with the environment – the doors, the people, the exits, the number of steps, the function of the buttons on the examination chair, the sounds of the environment, the location of the light switches and exits.

For some children with ASD, once they are secure in knowing the space and what will happen the examination can progress with greater ease. This may mean the initial consultation is simply getting the child to look at the age-appropriate visual test and seeing if you can get a verbal or non-verbal response.

Over time as the child learns the routine – first checking vision, then eyes open, then reading numbers, etc. - you will be able to gradually add additional tests to the examination.

- It may take repeat visits before a child is able to follow what is required in the routine of a full examination.
- Be prepared to gradually develop the test routine as their confidence and understanding grows.

Avoid conflict

Children on the spectrum lack social skills and the means of communication. The unpredictability of toddlers in the waiting room or difficulty in sharing with other waiting children could be causes of conflict between the child with ASD and other children. It can be useful to try and schedule a child with ASD at a time when other children are not likely to be present in the waiting room. Some parents/guardians and their children use ‘ear-defenders’ that muffle sound to minimise the distress that some children with ASD feel with unpredictable loud sounds and as a precaution against triggering an ‘inappropriate response.’

- Try and see the child on time and minimise time in the waiting area
- If needed send a text to the parent / guardian when you are ready, so they don't need to wait in the waiting room

Time

Giving the child a clear end time is important as they know exactly how long they must sit in the chair. This also helps to alleviate stress as the child knows when the test will end and they can move onto the next activity as part for their routine. If you say a test will take 2
minutes then you will have exactly two minutes. If you say we will end at 11.00AM then you will need to end no later than 11.00AM. Be precise and exact - children with ASD typically have a ‘black or white’ view of the world. (This view of the world can also impede a response as for some children if they are uncertain of what is the ‘right’ answer, they will say nothing.)

- Have a digital countdown clock in the room so they child can count down the minutes to the end of the test

**Billing**

Consultations for children with autism can be billed against any of the standard items on the Optometrical Services Schedule of the Medicare Benefits Schedule (MBS) where the eligibility criteria are met. There are also two MBS specific items that optometrists can bill, where the eligibility criteria is met, for children that require diagnosis or are being treated for a Pervasive Developmental Disorder (PDD) or eligible disability. The eligibility criteria for these items are overviewed below.

In order to bill these items, practitioners are required to be registered with the Department of Human Services and meet the credentialing requirements for provision of these services. The child must not be an admitted patient of a hospital and the service must be provided to the child individually and in person.

**Item 82030**

- The purpose of the visit is to assist the referring practitioners with their diagnosis; or
- The practitioner contributes to the child’s treatment plan; and
- The child must be aged under 13 years of age; and
- The service must last at least 50 minutes in duration; and
- The items are limited to a maximum of four services per patient, consisting of any combination of the following items – 82000, 82005, 82010 and 82030
- Full Scheduled Fee: $87.95 85% Benefit: $74.80

**Item 82035**

- The child must be diagnosed with PDD or an eligible disability; and
- The child must have received a PDD or disability treatment plan (while aged under 13 years); and
- The child needs to have been referred for provision of services consistent with the treatment plan; and
- The child must be aged under 15 years of age; and
- The service must last at least 30 minutes in duration; and
- The items are limited to a maximum of 20 services per patient, consisting of any combination of items – 82015, 82020, 82025 and 82035
- Full Scheduled Fee: $87.95 85% Benefit: $74.80

Full details of these and other items above are at

Final words

For many parents/guardians taking their child with ASD to choose shoes or to get a hair-cut can be stressful, and contemplating a visit to the optometrist may also be daunting. Be understanding of their feelings, the behaviour of their child and the approaches needed to support the child undergo an eye examination. They may have not considered an eye and vision examination, presuming that if their child can’t speak they can’t do an eye-test. There may be too many other priorities such as developing language and social skills and accessing support at the time of diagnosis and so an eye-examination may fall on the ‘another time’ list. Be prepared for anything in the consulting room. For example, a child may race in and dive to the skirting board to switch off all of the power points because that is what they routinely do, or they may want to tell you the route they took on the bus, or tell you the same information repeatedly.

I hope these insights may help you develop a routine for examining a child or adult on the spectrum so that they are comfortable and that you are able to do the test required to ensure they receive appropriate care. When glasses are prescribed, children will wear them without any issues as they simply become another part of their daily routine. In my experience there are no rates of any specific visual problems in an ASD individual compared to the 'normal' population.

Further Reading


Visual Timetable - Visiting the optometrist

First I will go to the optometrist

then I will have an eye test

for 20 minutes. Then I will look at

some glasses then finish
Visual Timetable - Eye Drops

1. First I will have drops in my eyes then it will be fuzzy for

2. two hours then it will be clear again.