Communicating with people with Autism Spectrum Disorders (ASD)

A resource prepared by the Intermediary Pilot Program

Background and Overview

Autism spectrum disorders (ASD)

ASD is a lifelong, neurodevelopmental condition. Symptoms are present across contexts and typically emerge or are evident from early childhood. Approximately 1 in 100 people in Australia are estimated to have some form of ASD.[i] Currently, men are 3-3.5 times more likely than females to be diagnosed with ASD.[i,ii]

Historically, a range of diagnostic terms have been used to describe ASD, including Autistic Disorder, Asperger's Syndrome/Disorder and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). Currently, based on the Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5) and the International Statistical Classification of Diseases and Related Health Problems-11 (ICD-11), the diagnosis of Autism Spectrum Disorder encompasses all such conditions.[iii]

People with ASD may experience co-morbid health conditions.[iv] ASD can co-occur with intellectual disability and/or language impairment. Although estimates vary, it is thought that between 30-70 per cent of people with ASD may also have an intellectual disability [iv,v,vi] whilst a small percentage may demonstrate above average intelligence.[vii] Difficulty in social communication forms part of the ASD diagnostic criteria but people with ASD may also have co-occurring spoken language difficulties. However, the unique communication profiles of people with ASD may vary considerably from one individual to the next.

Research evidence suggests that mental illness is more common among people with ASD than in the general population.[viii] Estimates suggest that 50–70 per cent of people with ASD may experience co-occurring mental health conditions, most commonly ADHD, anxiety disorders, depression and/or obsessive compulsive disorder.[ix,x]

Symptoms of ASD

The word 'spectrum' encapsulates the fact ASD presents in a wide variety of different ways from one individual to another and may vary across the lifespan of an individual with ASD. While an individual's symptoms may change over time as they develop and gain more life experience, ASD is a lifelong disability.

There are some core common symptoms typically associated with the disorder across a range of areas of function, including:

Social communication and interaction

People with ASD may demonstrate reduced or no interest in engaging in verbal interactions or show a lack of understanding into the typical 'to and fro' of conversation. They may dominate conversations, provide redundant information or fail to pick up on verbal and non-verbal social cues displayed by their communication partners. Eye contact may be reduced or absent. They may seek others out in order to have their needs met, but otherwise be content in their own world. It is common for people with ASD to experience difficulties developing and maintaining friendships and relationships.

Repetitive behaviours and restricted patterns of interest

People with ASD often experience difficulty understanding the thoughts and intentions of others. Insisting on particular routines and focussing on a limited range of interests can make their everyday experience more predictable and less anxiety provoking. Individuals with ASD may find it difficult to deviate from these routines, particularly where no prior warning is given. Restricted interests are common in ASD, and there may be a very intense focus on these, to the point they impact upon daily activities and functioning.

Rigid thinking patterns are also common in ASD. Individuals may perceive or view something a

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particular way and be unable to deviate from that perspective. This can result in misunderstandings and conflict and can be upsetting to the individual involved if they are unable to see the other person's perspective.

Sensory seeking and avoidant behaviours

Sensory processing issues are common in ASD and form part of the diagnostic criteria, with about 90 per cent of individuals with ASD presenting with atypical sensory experiences.[xi] People may present with sensory seeking or avoidant behaviours, or a combination of both. These behaviours may be present across any of the senses (sight, sound, touch, smell, taste, proprioception/movement and vestibular) and can be to the point of distraction and, in some instances, significant distress.

Language

There is a considerable amount of variation in the language ability of people with ASD. This ranges from those who have limited or no verbal communication and use alternative or augmentative communication, to others with verbose language and complex vocabulary. Atypical language is common (e.g. repetitive language and vocalisations lacking meaningful intent). Some people with ASD may have significant discrepancies between their receptive language (understanding language) and expressive language (spoken use of language) skills. Gaining an understanding of an individual's language profile assists the effectiveness of communication with that individual.

Cognitive profile

The cognitive ability of individuals with ASD can also vary considerably. Some people have high average cognitive ability, whilst others may present in the Intellectual Disability range. It is common for an individual with ASD to have a scattered cognitive profile, in some instances with splinter skills in specific areas. For example, visual processing ability may be well above average whilst language comprehension is significantly impaired, or they may have difficulty with higher executive functioning related tasks such as attention and organisation but have an immaculate memory for detail.

Common issues

There is a broad range of presentations among people with ASD, however the following common difficulties may be observed:

- may appear disinterested, nonchalant or completely oppose interaction with others, and this can be misperceived as a poor attitude
- may fail to pick up on social nuances or unspoken social rules, at times resulting in confusion, feeling 'hard done by' and possible conflict around how a situation plays out
- lack of flexibility in thinking, resulting in only being able to see or interpret spoken language or a situation in one specific way
- rigid thinking patterns, concrete interpretation of language, sometimes resulting in blunt responses
- may struggle to understand the perspective and needs of others and therefore fail to contribute relevant or adequate information in an interaction without being asked explicitly
- eye contact, facial expressions and gesture may be absent, exaggerated or incongruent with the content of discussion
- difficulty interpreting non-verbal communication used by others, for example failing to recognise when rising intonation is used to imply a question, and therefore not responding
- processing of language can be difficult, particularly long, complex questions, or the use of abstract language
- difficulty using expressive language in a concise manner. Excessive and redundant information can be provided and an individual with ASD may dominate the conversation
- repetitive behaviours such as rocking, pressing buttons or page flicking may be distracting to an interaction
- the need to follow specific routines and rituals can be distracting and can prevent the smooth flow of an interaction required for a specific purpose. For example, if an appointment that has been made clashes with the daily routine of having a coffee at a particular time in a particular place, this may negatively impact the proceedings

- emotional dysregulation is common, and it can be difficult to regain attention and composure, particularly if the individual is in a state of heightened anxiety or distress
- sensory seeking and sensory avoidant behaviours can be problematic. For example, if an unexpected noise, or a noise the individual finds difficult to tolerate, such as sirens, is suddenly heard, emotion can become dysregulated, and attention impacted.

Case Example 1: Ben

Ben is a 27-year old male with a diagnosis of ASD, and Generalised Anxiety Disorder. Ben takes medication to assist in managing his anxiety. Ben has a well-established daily routine and does not cope well when this is changed. Ben speaks in short sentences and the information he provides is often limited. His understanding of language is good. Ben is avoidant of eye contact and displays sensory sensitivity to light, becoming agitated and distracted, and covering his eyes.

Based on assessment, strategies recommended for communicating with Ben in the court environment included:

- ensuring Ben has adequate notice regarding the upcoming change to his daily routine as a result of the impending Court Hearing, to assist in minimising emotional dysregulation
- fully familiarising Ben with the Court process and providing a visual schedule as a reference to him, regarding how the day will proceed and what he needs to do
- consider the regular time anxiety medication is taken so that this can be coordinated with the time of the Special hearing in a way that optimises the benefit of the medication. Allow for breaks as required
- following his response to questions, asking Ben whether there is anything further to add, or asking explicit questions if inadequate information has been provided
- allowing Ben to wear tinted glasses during the Special Hearing. Provide adequate scope for Ben to take a break if the lighting and intensity of direct questioning through the video link becomes too much.

Case Example 2: Elly

Elly is a 10-year-old female with a diagnosis of ASD. Elly presents with a strong vocabulary, though sometimes provides excessive information in her responses. She answers with confidence, yet has delays in her receptive language skills, thus her responses can be tangential or unrelated to the question. Elly is pedantic about vocabulary and can become extremely upset very quickly if she perceives somebody has used the wrong word or phrase. Elly focussed best when a weighted blanket was in place on her lap.

Based on assessment, strategies recommended for communicating with Elly included:

- use terminology for key words based on Elly's preferences, to minimise unnecessary disruptions as a result of emotional dysregulation. For example, refer to Elly as 'Elly', not 'Eleanor' as she does not like to be addressed by her full name
- remind Elly at the beginning of the Special Hearing that it is important for her to listen carefully to the questions and then answer them. Inform her that at times, the interviewer may need to ask the question again, or in a different way, to help understand what Elly is trying to tell them
- ask single part, direct questions using question words such as 'Who…?', 'When…?' 'Where…?' and 'Did…?' Do not ask multi part questions or questions beginning with 'how' or 'why'. Do not use abstract language or statements posed as questions
- ask questions seeking additional information in an explicit manner, if her response was not clear
- do not use negatives during questioning and do not use traditional puttage
- allow Elly to use a weighted blanket throughout the Special Hearing.

Strategies

The information below outlines general strategies that can be adopted by representatives of the court to enhance communication with people diagnosed with ASD:

- plan according to the individual's needs and abilities; do not make assumptions about the individual's cognitive or language ability or limitations
- where possible, provide the opportunity for a brief meeting with the individual ahead of the formal proceedings
- ensure adequate preparation is given. Inform the individual of what the process will be, then refer back to the stage in the process they are up to, as appropriate
- consider the use of visual tools such as a chart listing or displaying who will be in the Court room, a chart with options to request repetition, a break etc and visual timelines
- do not use statements posed as questions (rising intonation to imply a question) as people with ASD may not pick up on this
- allow additional processing time
- avoid the use of ambiguous language
- where responses to questions are unclear, repeat back to the individual what you understand them to have said, then make a clear request as to what additional or clarifying information is required
- acknowledge responses and if additional information is required, explain this is needed in order to help those asking the questions understand more clearly
- insight into the perspective and emotional experience of others (i.e. inferring 'why') is often difficult for individuals with ASD. Use extreme caution when engaging in questioning of this nature and maintain awareness of the limitations the individual may have in this area
- if something unexpected happens, be prepared to explain this to support the individual with ASD in maintaining emotional stability
- include planned breaks to assist in emotional regulation in order to enhance the overall efficiency of the Special Hearing. Be prepared to offer additional breaks if required
- remain open-minded regarding the individual's use of non-verbal communication such as eye contact, facial expression and intonation patterns. Non-verbal communication may be used in unconventional ways and it is important to respond neutrally to this
- be mindful and accommodating of sensory needs and preferences.

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