



## Teenagers with High Functioning Autism (HFA) & Asperger's Disorder (AD) – Going to school

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Autism Spectrum Disorder (ASD) is a group of conditions with social disability as the core feature. These conditions are now recognized as more common than previously believed. Recent research suggests that the rise in detected prevalence of ASD has been most pronounced among those without intellectual disability (Kim et al. 2011; US CDC 2012). In Australia, Autism Spectrum Disorder (including Autistic Disorder, Asperger's Disorder and High Functioning Autism) is estimated to affect up to 1 in 160 (Wray and Williams, 2007). Although the presenting symptoms change with maturation, they continue to be a major source of difficulty for many. Most students with ASD find school challenging at some time or other. This can be the case no matter what the type of school; specialist or mainstream, primary or secondary. For those high functioning students attending mainstream secondary school, the continuing challenges of ASD (difficulties with communication and social skills, emotional and behavioural difficulties) combined with the added demands of secondary school indicate that support needs are ongoing. These young people are not growing out of their ASD, they are growing with it.

### Do we need to think about students having HFA or AD? Why not just call it ASD and treat them all the same?

You are probably aware that the recent DSM-5 has removed the categories of Asperger's Disorder and Autistic Disorder and incorporated them into the broader category of Autism Spectrum Disorder (ASD) (APA, 2013). \*See Factsheet on DSM-5 and ASD for more information. According to the DSM-5 those who already have a DSM-IV diagnosis should be relabeled with ASD but services that have a requirement for regular review will require a reassessment according to DSM-5. Individuals who have developed their identity and adjusted to having Asperger's Disorder or High Functioning Autism may be confused and troubled by these changes and we do not know yet how this will work out for them and their families.

So should we still even talk about HFA and AD? I would say yes, most definitely. The key to successfully teaching and working with a student with HFA or AD lies in having a good understanding of who they are, how they think and how their symptoms affect their daily life and learning. Remember, students who have been given these diagnoses during

childhood are now adolescents who regard their HFA and AD symptoms as being part of who they are. Below is a description of each of these disorders and their core features during childhood and adolescence.

### **Autistic Disorder (autism)**

American psychiatrist Dr. Leo Kanner introduced the word “autism”, derived from the Greek word ‘auto’ or ‘self’ to the scientific community. Kanner first described the core features of autism in his paper of 1943 in which eleven children with ‘autistic disturbances of affective contact’ showed a distinctive and previously unreported pattern of symptoms that included an inability to relate to people and situations; failure to use language for the purpose of communication; obsessive desire for the maintenance of sameness in the environment (Kanner, 1943). These three core symptoms have remained central to the diagnosis of autism. Approximately 30% of persons with DSM-IV Autistic disorder (autism) have overall cognitive abilities in the normal range and are referred to as “high functioning”, but still usually have the pattern of a relatively wide scatter of abilities.

#### **1. Social impairments**

Qualitatively impaired social interactions were the focus of Kanner’s original clinical description of children with autism (Kanner, 1943). A distinctive pattern of atypical social interactions remains a core feature of autism. Impairments in interpersonal relationships include a reduced responsiveness to or interest in people, an appearance of aloofness and a limited or impaired ability to relate to others. The child with autism may not seek physical comfort, but attachment to their parents and caregivers is apparent. It is not simply the case that children with autism do not develop social relating skills, it is more true to say that the quality of the relationship is abnormal. Children with autism may show very little variation in facial expression in response to others, generally have abnormal eye contact and in early childhood they tend not to engage

in social imitation such as waving bye-bye and pat-a-cake games. They rarely develop an age-appropriate empathy or ability to understand that other people have feelings. Their ability to make friends is absent or distorted and they are usually unable to play reciprocally with other children. All children with autism show social impairments, however, the nature of these impairments can vary and may modify as the child grows older. There may be an increase in interest in other people and the development of some social skills often learned in a mechanical or inflexible manner. For example, a teenager may lurch toward a stranger who is walking past him to try and shake his hand because he has been taught to greet people with a hand shake. Adolescents with autism usually have to learn about social skills and personality development without the opportunity of peer group discussion and support that is available to typically developing adolescents (Howlin, 2005).

#### **2. Communication skills**

Impairments in both verbal and non-verbal communication skills are often the cause for parents of children with autism to be first concerned and seek help (Howlin and Asgharian, 1999). Children with autism usually have markedly delayed and disordered speech with approximately half failing to develop functional speech. Children with autism also have an impaired ability to use gesture and mime. In those children who develop functional language, the pattern of development and usage is strikingly odd. Tone, pitch and modulation of speech is often unusual and the voice may sound mechanical and flat in quality with a staccato delivery. Some speak in whispers or too loudly, sometimes developing an unusual accent. Their understanding of spoken language is often literal and they fail to comprehend underlying meaning and metaphor such as “shake a leg”, or “pull your socks up”. A teacher may say to a late year 7 class “Get a wriggle on!” This type of comment is likely to confuse the young person with autism rather than act as a reminder to hurry up. Abnormal use of words and phrases is a common symptom of autism.

Echolalia (repetition of language spoken by others) is one of the most noticeably unusual aspects of speech. It can be either the immediate repetition of what has just been said, or the delayed repetition of phrases. Some children repeat advertising jingles, or large pieces of dialogue from DVDs or conversations they have overheard, for no apparent reason. Echolalic speech may serve some function, for example keeping an instruction in mind through repetition, or be used as a means of replying to a question. Language comprehension (receptive language) deficits in autism are also present in early childhood and continue into adolescence. Poor understanding is probably linked to social difficulties and impairments in social understanding. Inability to express needs by words or gesture, or a significant difference in the adolescent's ability to use words compared to their level of understanding of the verbal responses of others, is a source of frustration and can cause distress or disturbed behaviour.

Adolescents with HFA usually develop a wide vocabulary and expressive verbal skills but often show difficulty with the pragmatic or social use of language. They may continue to have impaired ability to initiate conversation, communicate reciprocally with others and maintain the "to and fro" of a conversation. The adolescent with HFA more likely to talk at you rather than with you, to intrude and talk out of context and use speech as a means to an end rather than engage in a social conversation.

### 3. Ritualistic and Stereotyped Interests or Behaviours

In his original account of autistic disorder, Kanner described children with stereotyped motor mannerisms, repetitive play and behaviours, non-functional routines and rituals and an obsessive desire for the maintenance of sameness (Kanner, 1943). Children with autism usually have rigid and limited play patterns with a noticeable lack of imagination and creativity. They may repetitively line up toys, sort by colour, or collect various objects such as pieces of string, special stones or objects of a certain colour or shape. Intense attachment to these

objects can occur with the child showing great distress if these objects are taken away or patterns disrupted. Older children may develop play that superficially appears to be creative, such as re-enacting the day at school with dolls and teddies, or acting out scenes from favourite DVDs. Observation of this type of play over time often reveals a highly repetitive, formalised scenario that does not change and cannot be interrupted. Children with autism rarely involve other children in their play unless they are given a particular role in a controlled situation. Howlin (1998) drew a parallel between the pervasiveness of the language disorder in autism and the child's inability to develop normal, imaginative play patterns. The stereotypes seen in language are also observed in the repetitive, non-social and ritualistic play of children with autism.

Ritualistic and compulsive phenomena such as touching compulsions and rigid routines for daily activities are common. There is often an associated resistance to change in routine or the environment so that the child may become extremely distressed if, for example, a new route is taken going to school, the furniture in the house is rearranged, or the child is asked to wear new clothes. Hand and finger mannerisms and repetitive complex body movements of a stereotyped kind such as hand flapping or tip toe walking are common. There is often a fascination with movement of objects such as spinning a plate or wheel. Close visual scrutiny of the fine detail of an object such as the edge of a table, or pattern of spokes on a wheel is common as is the collection of objects such as buttons or twigs. Many adolescents with HFA have unusual preoccupations that they follow, often to the exclusion of other activities. These may involve a fascination with bus routes or train timetables in association with repeatedly asking questions to which specific answers must be given.

### Asperger's Disorder

Independent of Kanner, Austrian Psychiatrist Hans Asperger published a paper that reported on a group of children and adolescents with what he described as "autistic psychopathy" (Asperger, 1944). These school-aged boys had problems

with social interaction, unusual and intense interests, behavioural problems and clumsiness, but no significant delays in cognitive or language development. DSM-IV-TR (2000) provided criteria for a differential diagnosis of Asperger's Disorder and Autistic Disorder based on exclusionary criteria, that for Asperger's Disorder there is (i) no clinically significant general delay in language and (ii) no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood. The two core areas of impairment in Asperger's Disorder are impaired social interaction and restricted repetitive and stereotyped patterns of behaviour, interests and activities. The disorder must cause clinically significant impairment in social, occupational, or other areas of functioning, and finally, the child must not meet criteria for another PDD or schizophrenia (DSM-IV-TR, APA, 2000).

Some typical features of children with Asperger's Disorder include:

- Acquisition of language follows a normal or even accelerated pattern, but content of speech is abnormal. It may be pedantic and centre on one or two favourite topics. The social use of language (pragmatics) is usually impaired
- Little facial expression, vocal intonation may be monotonous and tone may be inappropriate
- Impairment in two-way social interaction including an inability to understand the rules governing social behaviour. May be easily led
- Problems with social comprehension despite superior verbal skills
- Very rigid, prefer structure
- Well developed verbal memory skills, absorb facts easily, generally good level of performance at maths and science
- Highly anxious with a dislike of any form of criticism or imperfection
- Motor skills are often impaired with general gross motor clumsiness and difficulty with fine motor skills including

hand writing

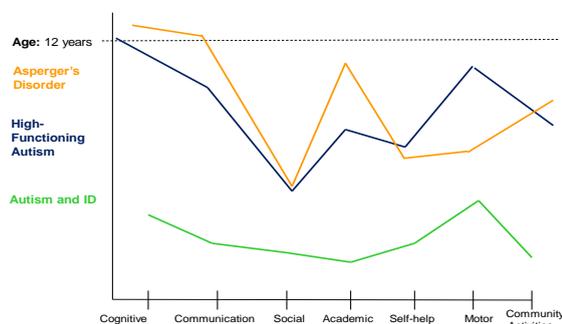
Because language develops and cognitive skills are not delayed, Asperger's Disorder tends to be diagnosed later than autism in young children. Neither ICD-10 (WHO, 1992) nor DSM-IV-TR (APA, 2000) stipulates the criteria for age of onset as they do for autism. However, in his original paper, Asperger described children as having difficulties by the age of two. Parents of young children with autism often recognize problems with behaviour and in particular, language development by about 18 months to two years of age. Because children with Asperger's Disorder do not have delayed early language, or problems with cognitive development, there are few early signs that all is not well. It is more usual for parents to become concerned about their child's emerging unusual or odd behaviour and social development but these tend to be identified later, usually from about 3 to 4 years of age. Diagnosis of Asperger's Disorder may not occur until the child has attended pre-school or school. This is probably because the child's social and behavioural problems become more noticeable when the child is seen with peers in a more structured social setting where there are more demands for social interaction.

## Cognitive development

IQ scores on standardised tests of intelligence of children with autism typically show an unusual and distinctive pattern of performance with deficits in verbal sequencing and abstraction skills and better rote memory skills. Tasks requiring manipulative, visuo-spatial skills or immediate memory may be performed well, such as Block Design and Object Assembly. These skills may be the basis of "islets of ability" such as musical ability. Children diagnosed with Asperger's disorder may also have an uneven developmental profile with better language skills and poorer motor skills. Adolescents with HFA and Asperger's disorder continue to have difficulties with social skills and accessing community activities. They may also have a discrepancy between their IQ score and their ability to achieve academically at school because

social and behavioural difficulties get in the way of learning and adapting to school life. Children diagnosed with Asperger's Disorder do not have an intellectual disability (IQ >70), yet may have a scattered profile of abilities with strengths in verbal skills but poorer non verbal performance skills and motor clumsiness. Children with Asperger's Disorder are likely to have more right brain functional problems and children with autism more left brain (language based) cognitive difficulties (Rinehart et al. 2002). Students with HFA and AD usually appear quite capable because they can absorb facts and figures and have extensive knowledge in specific areas that interest them. However, they do have difficulty in some areas such as social cognition, difficulty with abstract thought and concepts and have academic difficulty in the areas of problem solving, concept development, reading comprehension, making inferences and judgments, and organisational skills. Because they have difficulty with cognitive flexibility, they are rigid thinkers which leads to poor adaptation to change and they may continue to have difficulty with cause and effect, particularly in the context of a social interaction.

The diagram below shows three learning profiles. One for an adolescent with HFA and overall average intelligence (IQ >70), one for an adolescent with Asperger's disorder and one for an adolescent with autism associated with an intellectual disability.



## Health issues

There is a growing literature about the co-occurrence of mental health difficulties

(Witwer and Lecavalier 2010), particularly anxiety disorders, in higher functioning adolescents with ASD (deBruin et al. 2007; Joshi et al. 2010). Adolescence can sometimes bring the development of symptoms such as aggressive and oppositional or obsessive compulsive behaviour, and an increase in anxiety, tension and mood disturbance.

Depressive illness is not uncommon and is probably due to a combination of the development of some degree of insight as well as hormonal and central nervous system (CNS) functional changes.

The prevalence of anxiety problems in school-age children and adolescents with ASD is in the range of 40–45 % (White et al. 2009), considerably higher than prevalence of anxiety disorders in epidemiological studies of children and adolescents in the general population. The symptoms of anxious behaviour include fear of separation from familiar people, specific fears or phobias (e.g. certain sounds, smells, objects, animals), resistance to change (e.g. new clothes, food, routines), panic and emotional distress for little or no apparent reason, tenseness, shyness and irritability. These co-morbid symptoms of anxiety, apart from the distress they cause the young person, have the potential to disrupt education, further impair social interaction and create management problems and stress for the parents and teachers. The identification of anxiety in an adolescent with ASD creates an opportunity for management. Psychological treatments, particularly cognitive and behavioural approaches are effective treatments. Pharmacological treatments, such as selective serotonin re-uptake inhibitors and tri-cyclic anti-depressants may also reduce anxiety in children. Psychological treatments might need some modification in order to compensate for language impairment, and the effectiveness of pharmacological treatments need to be

confirmed using baseline and follow up records of target symptoms.

There is a relatively increased risk for the development of seizures in adolescence. Estimates indicate that that 25% to 40% of people with ASD develop epilepsy before the age of 30 and there is an increased risk for boys.

Around 30% or more of children with autism have significant problems with distractibility, inattention, impulsiveness, fidgetiness and motor over activity which is more than you would expect to see in children of their intellectual level of development. Fortunately, these symptoms, which also interfere with learning and social interactions, generally reduce as the child matures. If ADHD symptoms worsen or appear for the first time in a teenager with autism, then this is an indication of another problem such as anxiety about change or stressful events, or an emotional response to a stressful life event such as serious illness in a parent. Sometimes episodic disruptive behaviours or ADH symptoms might indicate the onset of epilepsy symptoms or even an illness such as urinary tract or ear infection.

### **Managing at secondary school**

Students with HFA and AD at mainstream secondary school, may experience difficulties because of their ASD symptoms but also because of the level of social skills required to interact with teachers and students throughout the day and their response to these social and emotional demands. The young person's learning and thinking style and symptoms of HFA or AD may also make it more difficult to cope at school where skills are needed to manage stressful situations, be well organised, cope with change, and limit or "turn off" special interests or preoccupations. The risk of being bullied or teased or socially manipulated continues and may even escalate at this time. It is a priority to ensure the safety of

the adolescent at school. Protection from bullying and teasing is of primary importance. All of these situations and demands contribute to making going to secondary school and coping with school harder for adolescents with HFA and AD.

**NB:** Although adolescents with HFA and AD share some common features, no two individuals are the same. The pattern and extent of difficulties change with development so it is important to combine what we know about the core features of HFA and AD and additionally consider knowledge of the current specific interests, abilities, interpersonal skills and mental health status of each student.

It is important to be mindful of the fact that as yet there is no clear intervention or treatment that ensures a positive outcome for adolescents as they enter adulthood. Below is a quote from the recent US healthcare research and quality report (Lounds Taylor et al., 2012) that investigated interventions for adolescents and young adults with ASD.

"Given the number of individuals affected by ASD, there is a dramatic lack of evidence on best approaches to therapies for adolescents and young adults with these conditions. In particular, families have little in the way of evidence-based approaches to support interventions capable of optimizing the transition of teens with autism into adulthood. Most of the studies identified were of poor quality; while the five fair-quality studies were primarily of medical interventions. Behavioral, educational, and adaptive/life skills studies were typically small and short term and suggested some improvements in social skills and functional behavior." (Lounds Taylor et al., 2012)

### **Parents and teachers: Talking and working together**

Ideally, parents and teachers should be equal partners in the process of

developing educational goals. A collaborative home-school partnership should lead to better understanding of the adolescent's abilities at home and school; foster a team approach to programme planning and educational goals and establish effective communication processes between home and school.

A collaborative relationship between teachers and parents is based on an understanding that:

- Family members are usually the most stable, influential, and valuable people in the lives of adolescents with ASD.
- Parents can provide the teacher with information about how ASD currently affects their son/daughter, their profile of strengths and weaknesses and information on the effectiveness of strategies and programming ideas based on experience of previous events.
- Adolescents with ASD have difficulties in their ability to generalize behaviours and skills across time, people and settings. Therefore, effective intervention is based on strategies employed across *all* environments.
- Teachers have expertise in classroom management, teaching strategies and programme design but they also need specific information about each student with ASD.

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Autism Speaks is working with the National Center for Learning Disabilities, PACER's National Bullying Centre and Ability Path in partnership with the new documentary film *BULLY* to raise awareness about how bullying affects children with special needs. For more information see: [Autism Speaks: Combating Bullying](http://www.autismspeaks.org/family-services/bullying) <http://www.autismspeaks.org/family-services/bullying>

There are a number of factsheets about ASD at the DEECD Autism Friendly Learning website Resources page. These cover topics relating to young children as well as adolescents with ASD <http://www.education.vic.gov.au/about/programs/needs/Pages/autismfactsheets.aspx>