

What is Asperger's Syndrome?

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Asperger's Syndrome (AS) is a newly recognised neurological disorder. Although the disorder was identified in 1944 by Hans Asperger it did not receive widespread attention until the 1990s; consequently many adults with the disorder remain undiagnosed. It is considered to be part of the range of autistic spectrum disorders and affects people in very varying degrees of severity.

AS is characterised by severe and sustained impairment in social interaction. It affects individuals' ability to understand another person's feelings, emotions and thoughts, and affects their social intuition, social obligations and social conscience. It may affect their ability to interpret their own emotions and feelings. The individual with AS may also have restricted and/or repetitive patterns of behaviour, interests, and activities. Poor motor skills and co-ordination may also be present. These deficits affect socialisation of the individual in *all* situations and result in them lacking adaptability and flexibility, especially in new situations. Individuals with AS have a normal IQ and many individuals (although not all) exhibit exceptional skill or talent in a specific area.

In many areas of their lives individuals with AS appear to have a high degree of functionality but yet can be naive. They are often viewed as eccentric or odd and can easily become victims of teasing and bullying. While language on the surface appears to be normal, individuals with AS often have deficits in pragmatics and prosody. They can be extremely literal and have difficulty using language in a social context.

In the long-term, in comparison with the 'normal population', individuals with AS show higher levels of anxiety and obsessional symptoms and have an increased risk of depression, suicidal ideation, and explosive tempers. These problems do require long-term surveillance to ensure appropriate medical or psychological treatment is available and accessed if required.

What is the incidence of Asperger's Syndrome?

Asperger's Syndrome is more common in males, with at least four times as many boys affected as girls. It occurs in approximately 3-7 per 1,000 population (approximately one in 250 people). The National Autistic Society estimates that in Britain there may be 208,000 people with a diagnosis of Asperger's Syndrome.

What causes Asperger's Syndrome?

The short answer is no-one knows what causes Asperger's Syndrome but some theories suggest that it has a genetic foundation and that it is an abnormality in brain function. AS is thought to be a dysfunction within the frontal lobes of the brain, the area where the social brain is located.

Asperger's Syndrome overlaps with a number of other developmental disorders and consequently some children may be misdiagnosed as having Attention Deficit (and Hyperactivity) Disorders (ADD & ADHD), Oppositional Defiant Disorder (ODD), or Obsessive-Compulsive Disorder (OCD).

How is Asperger's Syndrome in adults diagnosed?

A clinician or a team of clinicians who have experience and expertise in Asperger's Syndrome and related conditions should make a comprehensive assessment and evaluation. This team may include a behavioural neurologist, psychiatrist, a clinical psychologist and/or an educational psychologist.

A comprehensive evaluation is needed for three reasons:

1. To establish an accurate diagnosis.
2. To evaluate for the presence of coexisting medical or educationally disabling conditions.
3. To rule out alternative explanations for behaviours and/or relationship, occupational or academic difficulties.

The assessment for Asperger's should review the individual's developmental history, medical history (including past and present symptomatology, psychiatric history and prescribed medications) educational, social and employment histories and the individual's general ability to meet the demands of daily life. The interview is intended first to identify evidence of core AS symptoms and then to ensure that the history of these symptoms is both chronic and pervasive. The assessment should gather information from significant people within the individual's life such as a parent or partner and should survey behaviour from a variety of settings such as college, work and home. Psychological testing to determine any cognitive or learning weaknesses that may underlie functional impairment may also be carried out.

Why is it important to identify Asperger's Syndrome in adults?

Growing up with undiagnosed Asperger's Syndrome can be traumatic for many individuals. For some, the diagnosis and education that follows an assessment / evaluation can be extremely helpful and a healing experience. Proper diagnosis can help adults put their difficulties into perspective and also to understand the underlying reasons for their lifelong struggles. Adults with Asperger's Syndrome have often developed negative perceptions of themselves and may regard themselves as "weird", "crazy," or "mad." Correct diagnosis and effective treatment can help improve self-esteem, work performance and skills, educational attainment and social competencies.

What are the DSM 1V Diagnostic Criteria for Asperger's Syndrome?

DSM IV Diagnostic Criteria: Asperger's Syndrome

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
1. Marked impairments in the use of multiple non-verbal behaviour such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 2. Failure to develop peer relationships appropriate to developmental level
 3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest to other people)
 4. Lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 2. Apparently inflexible adherence to specific, non-functional routines or rituals
 3. Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
 4. Persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairments in other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g. single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

What are the indicative behaviours?

Asperger's Syndrome affects individuals uniquely. People with moderate to mild Asperger's are most likely to have partners and children, and also are often able to hide their difficulties from people outside of the close family. Other individuals with AS will have significant social and communication difficulties.

An individual with AS may display several or many of the following characteristics and to varying degrees:

- Deficiencies in social skills, such as inappropriate social approaches, lack of empathy
- Difficulty realising when others are in trouble and need help

- Difficulty recognising the emotions, feelings and thoughts of others
- An inability to consider others' viewpoints
- Limited interest in friendships
- Difficulty with all aspects of communication:
 - # Pragmatic language dysfunction
 - # Difficulty reading non-verbal cues, interpreting and using body language, determining appropriate body space/distance
 - # Limited ability in conversation
 - # Takes language literally
- Difficulty in comprehension of meaning and social reasoning
- Difficulty with transitions and changes, resistive of change, rigid, preference for routines and consistency
- Obsessional traits
- Narrow range of interests/idiosyncratic special interests
- Overly sensitive to sounds, tastes, smells and sights
- Associated motor co-ordination difficulties
- Normal or above normal IQ
- Difficulty managing their own negative feelings, especially anxiety, anger and depression

Adults with AS are susceptible to having various psychological difficulties. Often they are a result of the individual's difficulty coping with their AS and the stress, anger, frustration, confusion, anxiety and fear that they feel. These additional difficulties are often misinterpreted, misdiagnosed, misunderstood and mistreated, especially if the underlying AS is undiagnosed or is not adequately understood.

Some of the most common additional difficulties include the following:

- Anger outbursts (physical or verbal aggression, verbally threatening behaviour)
- Agitation and restlessness
- Increase in obsessional/repetitive activities/thoughts/speech
- Low mood / "depression"
- Apathy and inactivity
- Onset of uncharacteristic, bizarre behaviour or thoughts
- Increased movement difficulties

It is very common for professionals involved to focus on the presenting symptoms and behaviours and arrive at an incorrect diagnosis such as:

- Schizophrenia
- Psychosis
- Manic-Depression
- Mood Disorder
- Obsessional Compulsive Disorder
- Depression
- Severe Challenging Behaviour

How should Asperger's Syndrome be managed?

If the underlying difficulties or needs of the person with AS are not understood they can be 'treated' or 'managed' inappropriately and the impact can be devastating and extremely distressing. The solutions for each individual with AS are different and will depend on their personality, interests, circumstances and experiences.

An understanding of some of the reasons which make adults with Asperger's Syndrome so vulnerable to psychological breakdowns is necessary in order to find appropriate solutions to assist in overcoming difficulties. The difficulties are a complex interaction between an individual's internal characteristics relating to having Asperger's Syndrome, and external factors relating to life events and experiences, adulthood, independence and expectations.

The external factors which contribute to the difficulties include:

- not having a diagnosis, or explanation
- no readily available group of reference
- others not understanding Asperger's Syndrome and its implications
- loss of routine, structure, occupation and external life plan
- increase in independence
- accumulation of experiences of failure
- little or limited support networks
- increased need for internal motivation and drive
- increased self-awareness of limitations and differences
- increased gaps between intellectual, cognitive skills and social, self-help skills.

The internal factors which make individuals with Asperger's Syndrome vulnerable to the significant psychological distress and the development of additional difficulties include:

- decreasing internal motivation
- rigid ways of thinking
- limited distractions from negative/obsessional thoughts
- limited insight into own difficulties or reasons
- poor coping strategies
- low threshold for tolerance of stress, frustration and anger
- poor self-identity, understanding and esteem.

To manage, reduce and prevent further difficulties it is important to focus on underlying causes which will be different for different individuals. The approach/intervention needs to be holistic with multi-dimensional strategies which aim to:

Provide

- diagnosis and explanation
- support with understanding of Asperger's Syndrome
- explanation and education of significant others, professionals, employers and service providers
- relevant daily occupation and routine
- plans and goals
- concrete strategies for reducing/preventing anxiety
- support and advice for increasing tolerance and developing coping strategies
- opportunities and experiences to increase self-esteem
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Increase or encourage

- daily routine and structure
- goal-planning and achieving
- regular physical exercise
- stimulating occupations and activity
- participation in structured social group activity

Reduce

- stress
- anxiety
- pressure
- boredom
- isolation

Achievement of the above requires understanding, co-operation and sustained effort from various parties including the individual, the family members, professionals from social and health services, and other organisations. The whole process will become easier as the understanding of Asperger's Syndrome and of the individuals' vulnerability and needs increases, and are accepted and acknowledged widely by everyone involved.

Useful Contacts:

National Learning Network

Assessment Service

National Learning Network
Block A
Institute of Technology
Blanchardstown
Dublin 15
Tel: 00 353 1 8851386
E-mail: denise.richardson@innovations.itb.ie
Web: www.nln.ie

Aspergers Syndrome

Carmichael House
4 North Brunswick Street
Dublin 7
Tel: 00 353 1 8780027
Web: www.aspire-irl.com

Dyspraxia Association of Ireland

c/o 389 Ryevale Lawns
Leixlip
Co Kildare
Tel: 00 353 1 2957125
E-mail: dyspraxiaireland@eircom.net

National Learning Network

Head Office
Roslyn Park
Beach Road
Sandymount
Dublin 4
Tel: 00 353 1 2057344
Fax: 00 353 1 2057376

The Dyscovery Centre

4a Church Road
Whitchurch
Cardiff
CF14 2DZ
Tel: 029 2062 8222
Fax: 029 2062 8333
E-mail: dyscoverycentre@btclick.com
Web: www.dyscovery.co.uk

Dyslexia Association of Ireland

1 Suffolk Street
Dublin 1
Tel: 00 353 1 6790276
Web: www.dyslexia.ie

Hyperactive/Attention Deficit Disorder Family Support

Carmichael House
4 North Brunswick Street
Dublin 7
Tel: 00 353 1 8748349
E-mail: hadd@eircom.net

