

Autism

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What is Autism?

Autism is a developmental disability. The National Autistic Society point out that the definition of autism has changed over the years and that it may continue to do so as understanding of the condition continues to develop.

The following diagnostic criteria for 'Autism Spectrum Disorder' are quoted from the current version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5):

'Persistent deficits in social communication and social interaction across multiple contexts'

'Restricted, repetitive patterns of behavior, interests, or activities'

'Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life)'

'Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning'.

'These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.'

The DSM is a handbook used by health and care professionals in the USA and many other parts of the world as a guide to diagnosis and treatment of mental health conditions. There is no single test for ASD and many experts believe that there isn't one specific cause.

The International Classification of Diseases (ICD-11), a global categorization system for physical and mental illnesses, published by the World Health Organization, describes ASD as follows:

'ASD is characterised by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual's age and sociocultural context. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities.'

'Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities.'

Dual diagnosis

Having a diagnosis of autism and Down's syndrome is sometimes referred to as 'dual diagnosis'. A person who has Down's syndrome may have a different additional diagnoses, so dual diagnosis may not automatically mean they have autism but the phrase tends to be used in this way.

It is now widely accepted that the two conditions can, and do, co-exist. Research over the last 10 to 20 years has shown that anywhere between 5% and 39% of people who have Down's syndrome will also have autism.

It would appear that the diagnosis in people who have Down's syndrome is often made later (between ages 5 and 8 years) than perhaps would be more typical than in the general population.

A brief history

In the 1980s the general consensus was that dual diagnosis of Down's syndrome and autism was certainly uncommon, if not impossible. It was assumed that these individuals had greater cognitive impairment rather than autism. This was a view that persisted well into the late 1990s.

During the 1990s we began to see case studies describing autism traits in people who have Down's syndrome. In 1995 Howlin, Wing and Gould published a paper about the recognition of autism in children who have Down's syndrome. Within another ten years, systematic investigations of autism in Down's syndrome were being published in academic journals (e.g. Capone et al. 2005 & Molloy et al. 2009). These studies tended to focus on attributes such as behaviour and communication. In the 2010s studies were undertaken around screening for autism in children who have Down's syndrome and the prevalence of dual diagnosis (e.g. Di Guiseppi et al. 2010).

Studies such as Warner et al. 2014, initiated by the DSA, provided evidence that people who have a dual diagnosis may present differently to people who have a single diagnosis of either Down's syndrome or autism.

More recently, we are seeing studies looking at the needs of children and families. The DSA supported a study by Dr Katie Lambert in 2019 looking at how parents of children who have Down's syndrome experience and make sense of their child's additional diagnosis of autism.

Is what I'm seeing autism?

People who have Down's syndrome are individuals who will have a wide range of skills and abilities. Whilst we have mentioned that there is now widespread acceptance that people who have Down's syndrome can also have autism, the dual diagnosis is not always an easy one for professionals to make.

People who have Down's syndrome but no autism may have some similar behaviours to people with autism.

Below are some common difficulties that are seen in people who have Down's syndrome as well as people who have Down's syndrome and autism.

Sensory differences

People with dual diagnosis may experience some sensory differences. For instance, this may refer to noise, touch, textures and smells.

Behavioural issues

These may include running away, hitting, biting, self-harming like head banging, difficulty with change.

Repetitive and/or restricted interests and behaviours

These can include playing with objects and toys repetitively. This may involve spinning, twirling, lining up and arranging them in patterns/order. People may rock or hand flap and make repetitive sounds and use words out of context.

Social interaction and communication

A person's social interaction and communication will be impacted by a number of things including sensory impairment.

People who have dual diagnosis may have more difficulties with understanding verbal and non-verbal communication and recognising their own and other's emotions.

Regardless of the level of learning disability, it is important to take into account the individual's developmental functioning when looking at the degree of social impairment.

Whilst people who have Down's syndrome without autism may experience some of the things mentioned above, it is likely they will be less prominent, less frequent, less intense and less impactful than in people who have a dual diagnosis.

Why should I seek a diagnosis?

Requesting an assessment for autism is a personal decision and below are some reasons why people might seek a diagnosis.

- It may help professionals, family and friends to get a better understanding of the person.
- It may help with accessing more appropriate support.
- It may change the strategies used to support the person.
- It may help those around the person look at whether there need to be adjustments to their environment.

Meeting needs

The needs of the person who has Down's syndrome should be met regardless of any potential diagnosis. Autism strategies are helpful for people who have Down's syndrome irrespective of a dual diagnosis. These include:

- structure, consistency, and repetition
- visual representation of information (e.g. timetables) in as concrete form as possible
- managing transitions and changes (big and small)
- time to process information to prevent information overload
- thinking about (and utilising/building upon) the strengths of the individual
- hands on learning by seeing and doing
- teaching of social skills
- support to deal with any sensory issues
- use of social stories
- video modelling

You may be using some of these already. Everyone is different but you can tailor these strategies to the individual needs of the person you care for.

Any input and support a child receives at school should very much be based on their assessed need and not specific diagnostic labels. Getting appropriate support to meet your child's needs should not be dependent on getting a diagnosis of any kind. Provision at school should be based on assessed need alone.

Next steps - assessment and diagnosis

Please see our factsheet 2 about assessment and diagnosis for further information.

References and further reading

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