

This is autism

Original title: Det här är autism

Author: Eric Zander

Translation: Semantix

Autism is a functional impairment. People who have autism have difficulty interacting and communicating with others and have restricted and repetitive patterns of behaviour, interests and activities.

Autism often occurs together with other functional impairments or disorders, such as ADHD, language impairment, intellectual impairment and epilepsy. Most people with autism are of average intelligence, but all levels of intellect, from exceptionally high intelligence to severe intellectual impairment, occur. A few people with autism develop no or only limited spoken language, while others have language skills that are normal for their age or well-developed.

Autism in different diagnostic manuals

There are two international diagnostic manuals where diagnoses within the autism spectrum are described. One is the American DSM-5 manual, the other is the World Health Organization's ICD-10 manual.

In the DSM-5, the term autism spectrum disorder (ASD) has replaced the earlier, separate diagnoses used in the DSM-IV-TR: autistic syndrome, Asperger's syndrome and pervasive developmental disorder without further specification. In the Swedish version of the DSM-5, Mini-D 5, autism spectrum disorder has been translated as autism. Instead of autism, it is common to use the English abbreviation ASD in Swedish as well.

When an autism diagnosis is made in Sweden, the criteria from the DSM-5 are often used. However, when the diagnosis is entered in a medical file, it is encoded according to the ICD. The current version, the ICD-10, uses the following diagnostic terms: childhood autism, Asperger's syndrome and atypical autism. According to the preparatory work for the new version, the ICD-11, the diagnoses that used to be separate will be merged, just like in the DSM-5, into one diagnosis: autism spectrum disorder. The ICD-11 is expected to be published in 2018.

How is autism expressed?

Autism is a development-related functional impairment. This means, among other things, that age, language level and intelligence affect how autism symptoms are expressed in different individuals. The symptoms are most apparent during childhood but with training and support, people with autism can compensate for the difficulties they have in certain circumstances.

According to the DSM-5, autism can present the following symptoms:

- persistent deficiencies as regards capacity for social communication and social interaction
- limited and repetitive patterns of behaviour, interests and activities.

Social interaction

Difficulties with social interaction and social communication are expressed or have been expressed in the following areas:

Social reciprocity. Social reciprocity means the ability to interact with others and share thoughts and feelings. This can be seen early on in young children with autism since the child takes little or no initiative as regards interaction, does not share feelings with others, and mimics the behaviour of others less frequently or not at all. Children who talk use language in a more one-sided and less mutual way, for example, they say the names of objects and ask for things instead of conversing and sharing feelings and experiences with others. Adults with developed speech find it difficult to know how and when to start a conversation and what one should say and not say in different situations. Some adults learn how to compensate for their difficulties by consciously devising and using learned strategies in social situations which most other people deal with automatically using their social intuition. This requires a lot of mental energy and can create anxiety.

Non-verbal communication. With young children, it can sometimes be seen that the child does not make eye contact, nor point at, show or fetch objects to share their interest with others. Sometimes, it can be seen that the child does not turn to look when other people point at something, nor does the child turn to look at something that other people are looking at. A person with autism often uses few gestures and there is little spontaneous gesticulation in their communication and sometimes none at all. In adults with well-developed language, the deviations may be more subtle, for example, the way eye contact, gestures and other non-verbal communication are used and coordinated with speech.

Developing, maintaining and understanding relationships with others.

Social interest may be limited or abnormal or non-existent. In young children, this can be particularly obvious and be apparent, for example, by the child not playing flexible games of pretence with other children or by doing so to a lesser extent than expected. Children who are somewhat older may play with others but only if the others follow very specific rules for how the game should be played. Adolescents and adults often have difficulty understanding how to behave with other people in different situations. Sometimes they would rather do activities on their own, or socialise with significantly younger or older individuals. Many would like to have friends but they do not really know what friendship implies nor how to go about making and keeping friends.

Restricted and repetitive behaviour

A tendency to do things in a limited or repetitive manner is expressed or has been expressed in at least two of the following areas:

Repetitive or stereotyped behaviour of various types. For example, waving the hands or wiggling the fingers in an abnormal way, using objects in a repetitive manner (spinning, lining up) or using language in a repetitive and odd way (stereotyped use of words, phrases or tone of voice, confusion of pronouns, echolalia, i.e. immediately repeating the last thing another person said).

Strong obsession with routines and resistance to change. Some people are very badly affected by changes in routines or their daily timetable, even small changes, or by, for example, changes in how certain things are done. They may be obsessed with following routines and sticking to rules meticulously; they may talk and think in an almost ritualistic way with little scope for variation, for example, ask the same questions over and over again even though they know the answer.

Obsession with limited interests which are unusual in intensity or focus. It is primarily the intensity that is unusual, but the area of interest in itself can also be unusual. A child can be obsessed with toilet seats or vacuum cleaners or with dinosaurs and English kings, while an adult may have a strong interest in, for example, languages or timetables.

Unusual reactions or interests associated with smell, sense of touch, sight or hearing. Some people may be excessively interested in smelling or touching objects or surfaces, be fascinated by objects that spin or sparkle and the like. Some may be hypersensitive or hyposensitive to different sensory input, and, for example, may have very strong negative reactions to certain common sounds or be noticeably insensitive or sensitive to cold, heat or pain. Very strong reactions and routines of this kind are often associated with limited and abnormal eating habits.

Many adults with good intelligence and well-developed language learn how to conceal their limited and repetitive behaviour. However, for some people, their intense special interests may also be a source of joy and may give rise to positive opportunities during their education and later in their professional lives. It is common that people who had considerable problems within these areas as a child, no longer do so as an adult.

Other difficulties for people with autism

Autism often occurs together with other functional impairments, psychiatric diagnoses and disorders. They affect how autism is expressed and what sort of support the person with autism needs. The following are examples of other concurrent diagnoses or disorders:

- intellectual impairment (mental retardation)
- language impairment
- medical or genetic conditions (such as fragile X syndrome, tuberous sclerosis, neurofibromatosis, epilepsy)
- psychomotor anomalies (catatonia)
- attention deficit hyperactivity disorder, obsessive compulsive disorder, depression or anxiety disorders.

When can autism be detected?

Autism starts in early childhood but may not be noticed until later. We are still not able to identify signs and know for sure that a child has autism until earliest at the end of the first year of life. It becomes apparent in many children through a decrease in their social behaviour and through their language development gradually slowing down or becoming abnormal. But for some, it may not be until school age or even later that the symptoms become so apparent and debilitating that other people notice them. With the methods currently used, a child is rarely diagnosed with autism before the age of 18 months. It is still the case that some people do not get a diagnosis until they are adults.

What causes autism?

Autism is caused by a large number of known and unknown biologically based abnormalities in the brain. These affect the brain's way of taking in, processing and interpreting information, i.e. the cognitive functions. It is the abnormal cognition that leads to difficulties in social interaction and to limited and repetitive behavioural patterns.

There is often a strong genetic and hereditary component in autism but it has also been shown that several known biological environmental factors are associated with an increased risk of autism. Some examples are infections, diseases or certain medication during pregnancy. The risk also increases if the mother has been exposed to environmental pollutants or pesticides and if the parents are of a higher age.

How common is autism?

In recent years, the number of people with an autism diagnosis has increased significantly and today 1-2 % of the population of Sweden have an autism diagnosis. Common explanations for this increase is that the term autism has been broadened so it now includes more people, and that the medical profession has become better

at detecting and diagnosing autism, but it cannot be ruled out that autism may also have become more common. More boys than girls are diagnosed with autism. There has been speculation whether the gender difference in the number of people diagnosed with autism reflects a real difference in the incidence of autism or if girls are being diagnosed too seldom since their symptoms are not as easily recognisable as those presented by boys.

What can be done?

At present, the most effective interventions for autism are those that focus on changing behaviour. They are based on knowledge from the field of learning psychology about how people with autism best learn things. There is still no effective medical treatment for autism symptoms. The goal of the interventions is to enhance the person's quality of life and ability to function independently by building on strengths and compensating for difficulties with the help of learning, training, and support. It is also important that the person is in a suitably adapted environment with other people who have an understanding of and knowledge about autism. The need for support varies greatly between individuals and can also vary a lot at different stages in life. The basic approach is that autism is a lifelong functional impairment and that people with autism often, but not always, will need some form of support or intervention throughout their life.

Diagnostic investigation

Interventions and support for people with autism are to be based on each person's specific functional profile and need for support. The first step is usually to get a diagnosis. Due to the large variation in functional ability in people with autism, it is not enough to simply state that the diagnostic criteria are met. In order to achieve a meaningful description of the person's support needs, a team consisting of at least a doctor and psychologist need to make a broader assessment of the individual's functional ability. An all-round developmental assessment consists of a detailed description of the person's level of development, ability to do activities of daily life, language skills, ability to interact with others, and quality of life. This statement then serves as the basis for individual customised interventions. For most people, the description of their functional capacity needs to be followed up once or a few times as the person develops.

Early intervention

The general view is that it is important to detect autism as early as possible since some research has shown that early interventions have more effect the earlier they are introduced. There are still no effective screening methods for early detection, although a number of methods are used in different countries. With the methods currently used, autism can only be diagnosed after one year of age, but the diagnosis is usually made later on when the child starts preschool or school. It is recommended that preschool children be given habilitating interventions after an individual assessment, for example, comprehensive and intensive learning programmes based on applied behavioural analysis. Such programmes often involve several hours of training every day. Many children may also benefit from less time-consuming programmes or more focused interventions, such as various communication-supporting programmes and purely play-based programmes. During the preschool years, these interventions are carried out in the home and at the preschool in collaboration between parents, preschool and habilitation.

For older children, adolescents and adults with well-developed language and good intelligence, there are various types of programmes for training social skills. School children often need to be in an autism-friendly school environment that offers additional support.

Writer

Eric Zander, PhD, psychologist, Center of Neurodevelopmental Disorders at Karolinska Institutet (KIND), Lund University, Department of Child and Youth Psychiatry, Department of Clinical Sciences, BUP KIND, Stockholm County Council, BUP Helsingborg Psykiatri Skåne, Region Skåne.

References and links

Autismspektrumtillstånd. Diagnostik och insatser, vårdens organisation och patientens delaktighet – En systematisk litteraturoversikt. (2013). Swedish Council on Health Technology Assessment.

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5 ed.). Arlington, VA: American Psychiatric Association.

Swedish translation: Mini-D 5 Diagnostiska kriterier enligt DSM-5. Stockholm: Pilgrim Press.

Bölte, S., & Hallmayer, J. (2011). Autism Spectrum Conditions. FAQs on Autism, Aspergers Syndrome, and Atypical Autism Answered by International Experts. Commonwealth, MA, Göttingen, Germany: Hogrefe Publishing.

Lai, M. C., Lombardo, M. V., & Baron-Cohen, S. (2014). Autism. *Lancet*, 383 (9920), 896-910.

World Health Organization [WHO] (1993). The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research. Geneva, WHO.

www.socialstyrelsen.se/klassificeringochkoder/diagnoskodericd-10/psykiatrikoder

www.ki.se/kind/start

www.barnsutveckling.se

www.autismforum.se