

1/9 2004

An introduction to autism

Original title: Introduktion om autism

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Autism is characterised by severe and pervasive impairments in several important areas of development: reciprocal social interaction and communication as well as behaviour, and imagination. In order to be diagnosed with autism, the behavioural symptoms in all of the above-named areas must be present by age 3. Even if the parents often notice that something is wrong during infancy, it is very difficult to diagnose autism before the age of eighteen months. This is because the behavioural symptoms used to establish the diagnosis have not clearly emerged developmentally until that age.

The majority of children with autism also have a learning disability (mental retardation), although a few have average intelligence. Many also have epilepsy, and visual and hearing impairment are over-represented in this group. Persons with Asperger's syndrome, which is a condition resembling autism, have average or above average intelligence.

Roughly estimated, 1 - 2 children per thousand have autism, which means that about one hundred children are born with autism every year in Sweden. Autism and the other pervasive developmental disorders (autistic-like conditions), or in other words the entire autism spectrum, adds up to at least 6 children in every thousand in Sweden. The same figures are seen in other nations worldwide. Many more boys than girls have autism.

What causes autism?

Autism is a behaviourally-defined condition, but is caused by a number of different known and unknown biologically based brain dysfunctions that affect the developing brain's ability to handle information. Autism is a neurodevelopmental disorder. There is a genetic component in many cases. The different way of processing information, such as perceiving, processing and interpreting information, learning new things and behaving in a well-adapted way, leads to the behavioural deviations that can be observed.

The presentation of autism

Social interaction

The most striking aspect of autism is often the difficulties with reciprocal, social interaction. Even from a very early age, the infant may have difficulties using and understanding eye contact, facial expressions, gestures, intonation, etc, while in contact with other persons. Many children with autism show no social or emotional reciprocity and do not spontaneously

share their joys with their parents nor seek them out for comfort. Children with autism are not always interested in children of the same age, but even if they are, they usually have difficulties in making and keeping friends.

Communication

Persons with autism have a delay in or a lack of language development, which they do not compensate for by using other nonverbal means of communication. About half of the children with autism never develop speech. There is great variation among the children who do. Some only use single words. Others use many words and speak correctly, but mostly repeat stock phrases or things others have said regardless of the situation. A smaller number have a well-developed and spontaneously spoken language.

Yet all have difficulties in initiating and maintaining conversation, and all have deficiencies in understanding language. Especially impaired is the understanding of language's deeper meanings. Even among those who have a large vocabulary and converse spontaneously, it is common that they have a fixed and literal interpretation of language.

Behaviour

Children with autism often engage in a restricted range of behaviours, interests and activities in a repetitive and stereotypic way. For example, they may concentrate intensively on an activity such as spinning the wheels on a toy car or lining up toys time and time again, but much more seldom engage in spontaneous and varying games of pretend and role playing. Fixations on different objects are common, as well as fixations on very complicated habits and routines that must be repeated in exactly the same way each time. A departure from such a routine or ritual can cause an outburst of despair or rage. Any sort of change, such as something being in a different place or something being done in a different order than usual, can also be hard to tolerate for a person with autism. Slightly older, more well-gifted children may especially have periods of one-sided and narrow interests such as time tables, others' birth dates, the population of all Swedish towns, etc. It is also common for children with autism to continuously wave their hands, rock back and forth and walk on tiptoe.

In addition to the diagnosed-based behaviours in the three areas named above, other symptoms are also common with autism: over-sensitivity or under-sensitivity for certain sounds, touches, odours etc; periods of hyperactivity; sleeping and eating disorders, etc. None of these are required for a diagnosis of autism.

Large variations

Persons with autism often differ greatly from each other in many ways, even though the effect of having autism is always serious. For example, the degree of autism is said to vary from severe to mild; similarly the level of abilities can vary from severe learning disability to having above average intelligence. It is also common that persons with autism have other conditions

such as various genetic syndromes, epilepsy, depression or attention-deficit/hyperactivity disorder, to name a few. A person may thus have severe autism as a component in a multiple impairment together with a moderate or severe learning disability, with epilepsy, and thus be maximally disabled, or have a lesser degree of autism and a high level of ability. The variations in the degree of severity of the behavioural expressions for autism are large and also dependent on the individual's personality, age and level of development.

What can be done?

Autism is a life-long disability. There is currently no known cure for autism. On the other hand, many children with autism can develop significantly with early, well-planned and individually tailored educational efforts in specially adapted settings. One of the primary objectives is to help the child develop functional communication. The educational approaches must focus on knowledge about the unique ways that children with autism learn. Various ABA strategies (Applied behaviour analysis) as well as the structured teaching method in the TEACCH-model (Treatment and Education of Autistic and related Communication Handicapped Children) are examples of such specially-tailored educational strategies for persons with autism.

Early identification, assessment and diagnosis are the first step. The next step is to provide accurate information for, and education of, parents and other concerned persons as soon as possible. These, together with promptly applied supportive measures that are both well-planned and individually tailored, are the long-term basis for being able to help the child to develop. A specially adapted nursery school and subsequent schooling are important prerequisites for the child; similarly an adapted home environment and daily activities are equally important for the adults. Adolescents and adults may need continued access to educational measures to further develop skills that aim to increase independence and participation, even if these measures had been introduced early. High-functioning persons may require different types of assistance in organizing their studies and access to various forms of tailored daily activities.

As adults, and for the rest of their lives, most persons with autism are in need of extensive assistance and support. However, some persons may become relatively independent.

The autism spectrum or pervasive developmental disorders (PDD)

The autism spectrum is an umbrella term for many diagnoses with similar symptoms.

Autistic disorder is the full syndrome within the autism spectrum. It is often abbreviated to "autism". Most people with autism also have a learning disability. Yet even persons with average intelligence may have autism. This is often referred to as high-functioning autism or a high-functioning person with autism, which is a more correct term.

Asperger's syndrome (or **Asperger's disorder**) is autism in persons with average or above average intelligence without the severe linguistic difficulties seen in autism.

Pervasive developmental disorder NOS (NOS = not otherwise specified) or atypical autism are often used as synonyms. These diagnoses mean that the person does not fulfil all the criteria for autism or Asperger's syndrome, but nonetheless has serious difficulties of a similar nature.

Childhood disintegrative disorder is very rare and means that a child develops autism after the age of 2 or 3 years of age. The child has a normal development up until this.

How many individuals have autism?

The exact proportion of the population with autism or any of the other conditions within the autism spectrum is still unclear. There is no database of persons with autism in Sweden. Based on a review of the studies in this field, the following estimates can be made.

Autism

It is estimated that 1 - 2 children per thousand have autism. This means that there are at least 1,500 - 3,000 children aged 4 - 17 years of age with autism in Sweden. The corresponding figures in Stockholm County are 300 - 600 children.

The entire autism spectrum

The best estimate for the entire autism spectrum is 6 persons per thousand. For Sweden, this means approximately 9000 children, while in Stockholm County there are about 1,600 children and adolescents between the ages of 4 and 17 years. There is greater uncertainty concerning the number of children with Asperger's syndrome, but it is a larger group than those with autism.

There are still virtually no studies about how many adults have autism or the other pervasive developmental disorders.

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