

The spectrum of autistic disorders

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For decades after Kanner first described 'early infantile autism' in 1943, it was thought to be rare. Then, in the 1990s, autism became headline news because of the measles, mumps and rubella vaccination scare and fears of an 'autism epidemic'.

This article outlines the history of ideas concerning the nature of autism and changes in the diagnostic criteria. The clinical features and what is known about causes and epidemiology are described. Finally, ways of helping children and adults with these conditions are considered.

HISTORY OF CONCEPTS

Descriptions of individuals with behaviour patterns resembling autistic disorders can be found in the historical literature. As these patterns were strange and without outwardly observable cause, ideas about their nature were influenced by contemporary beliefs. Explanations have included fairy changelings, extreme holiness and being reared by wolves (Frith, 2003).

Kanner's syndrome

In the first part of the 20th century, current psychiatric theories were invoked to explain strange behaviour in children, and the terms 'childhood psychosis' and 'childhood schizophrenia' came into use. Some authors tried to define specific behavioural syndromes. Among these was Kanner (1943), who adopted the label 'autism'. With insight ahead of his time, he first suggested that autism was caused by congenital absence of the normally innate social instinct. Later, influenced by the psychoanalytical views current at the time, he wrote that autism was caused by abnormal child-rearing by cold, distant, intellectual parents. This view caused much distress to the families involved. In 1949, he changed from the view that autism was a unique syndrome separate from all other conditions to the belief that it was the earliest form of schizophrenia. Later, following the publication of many scientific studies of autism, Kanner expressed doubt about his earlier theories.

Kanner's essential diagnostic criteria were social aloofness and indifference, and elaborate repetitive routines observable within the first 2 years of life. He also described the idiosyn-

cratic language or, in some cases, mutism. Kanner's criteria were very narrow but other authors have suggested different criteria that have considerably widened the definition.

Asperger's syndrome

In 1944, Asperger described a group of children with a behaviour pattern he called 'autistic psychopathy'. Asperger wrote in German and his work did not become well known in English-speaking countries until the 1980s (Wing, 1981; Asperger, 1991; Frith, 1991). The children had inappropriate social interaction, fluent grammatical language used for monologues rather than conversation, and a narrow range of special, often intellectual interests.

Hypothesis of the autistic spectrum

While carrying out an epidemiological study of autism, Wing and Gould (1979) recognized the behaviour Asperger described in some of the children they saw. They also identified children with Kanner's autism, but found many more with mixtures of features from both these so-called syndromes. As a result, they developed the hypothesis of a spectrum of autistic disorders characterized by a triad of impairments of social interaction, communication and imagination associated with a narrow, repetitive range of activities (Wing and Gould, 1979; Wing, 2002). This was considerably wider than the previously published criteria for autism.

In the tenth edition of the *International Classification of Diseases*, ICD-10 (American Psychiatric Association, 1994), and the fourth edition of the *Diagnostic and Statistical Manual*, DSM-IV (World Health Organization, 1993), the term 'pervasive developmental disorder' is used as a general category covering various diagnostic subgroups, including Asperger's syndrome and autistic disorder. However, such attempts to define specific syndromes among the whole spectrum have not proved clinically useful.

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There is too much overlapping of features to allow for neat separation. Children can change with age, for example, fitting Kanner's syndrome in early childhood and Asperger's syndrome later. If behavioural subgroups are precisely defined, too many children with similar needs are left without a diagnosis. Some biological causes of autistic spectrum disorders are known but there is no clear relationship between those that are currently known and details of the overt behaviour pattern (Gillberg and Coleman, 2000). The term autistic spectrum disorder is somewhat wider than pervasive developmental disorder, is concerned only with behavioural features and is not subdivided into named syndromes.

DIAGNOSTIC CRITERIA

Social interaction impairment

Human babies are, from birth, aware of and interested in other humans. Those with autistic spectrum disorders lack this social instinct from birth, or lose it in their early years (*Figure 1*). Some remain aloof and indifferent throughout their lives. Some passively accept social approaches, while some make active but inappropriate approaches regardless of other people's feelings. Some want to make relationships but are impeded by the lack of understanding of the subtle, unspoken rules of social interaction.

Social communication impairment

Impairment of communication affecting both comprehension and use of speech, vocal intonation and body language varies from no communication to fluent, grammatical speech that is used mainly or only to talk about special interests. Communication problems are obvious among those who are more disabled but tend to be more subtle among the more able people.

Social imagination impairment

In children, impairment of imagination varies from no pretend play to elaborate play that is repetitive in form and engages others, if at all, only to do the bidding of the child concerned. Some have repetitive acting out of roles, copied from real or fictional people or animals. More able older children and adults may have an elaborate but rigid fantasy world with no or very idiosyncratic social content. In the most able, their inner world may be limited to their own narrow interests although they may be truly creative in their own sphere (Wolff, 1995). Asperger (1944) wrote that traits of his syndrome were necessary for success in the arts or sciences. However, whatever the form of the impairment of imagination, it severely affects the development of the

'theory of mind' – that is the ability to imagine what other people are thinking and feeling (Frith, 2003). It also limits the person's capacity to predict the consequences of his/her own actions.

Repetitive activities

The narrow repetitive pattern of activities associated with the triad of impairments varies from simple bodily movements, such as flapping hands and arms, jumping or spinning round, through repetitive actions with objects to absorption in specific intellectual interests.

OTHER CLINICAL FEATURES

As well as the diagnostic criteria for the autistic spectrum there may be indifference, distress or fascination in response to any kind of sensory input. Poor coordination and peculiar gaits and postures are common. A follow-up study found that perhaps one in ten or more develop marked catatonic and parkinsonian features in adolescence or early adult life (Wing and Shah, 2000).

Because the social world is hard for them to understand, people with autistic spectrum disorders often have very high anxiety in social situations. They may react with challenging behaviour such as aggression to others, destructiveness or self injury. The more able adolescents and adults may develop psychiatric illnesses (Wolff, 1995; Nylander and Gillberg, 2001). Depression is particularly common in those who become aware that they are different from other people.

The triad of impairments can be associated with any developmental, physical, psychological or psychiatric condition (Gillberg and Billstedt, 2000). Epilepsy is common, especially in those with learning disabilities. The triad can be associated with any level of intelligence, from severe learning disability to genius level. Profiles of abilities are typically patchy, occasionally showing one remarkable isolated skill.

UNDERLYING CAUSES

The 1960s saw the beginning of a scientific approach to autism. As a result of research in the



Figure 1. An 18-month-old typically developing, sociable child trying, but failing, to attract the attention of a 15-year-old socially aloof boy with autism, who is interested only in spinning the pen in his hands.

field it became widely accepted that autism was caused by unusual patterns of brain development and that complex genetic factors were of major importance (Gillberg and Coleman, 2000; Rutter, 2000; Baird et al, 2003). Medical conditions that are prenatal, such as tuberous sclerosis, maternal rubella or untreated phenylketonuria, or post-natal, such as encephalitis, are associated with autism in a minority.

The precise nature of the brain dysfunction and which genes may be involved are still uncertain. Unproven theories of other possible causes abound, including the latest worries about immunization against mumps, measles and rubella (MMR) and other vaccinations. Advances in brain imaging techniques are needed to answer the many unsolved questions (Frith, 2003).

EPIDEMIOLOGY

The first epidemiological study of autism was carried out by Lotter (1966). He used Kanner's very strict criteria and found a prevalence among children of 4.5 in 10 000. Rates found in subsequent studies have shown a marked tendency to rise. The rate quoted in a report published by the Medical Research Council (2001) was 60 per 10 000 for children under 8 years. However, the increase has occurred together with considerable widening of the diagnostic criteria for autistic disorders, increased awareness of these conditions among professionals and the lay public, acceptance of the fact that autistic spectrum disorders can occur together with any level of IQ and with any other condition, and development of specialist services for children and adults.

Combining the results of the Camberwell study with studies carried out in Gothenburg, Sweden, covering children born between 1956 and 1983, gave a prevalence for the whole spectrum of 90 per 10 000 (Wing and Potter, 2002). This is higher than virtually all of the rates quoted recently. The studies covered children born from 1956 to 1983. MMR was introduced in Sweden in 1982 and in the UK in 1988. These findings do not support either the fears of an autism epidemic or the possibility that autistic disorders are caused by MMR immunization (Fitzpatrick, 2004).

WAYS OF HELPING

Autistic disorders are lifelong conditions. Improvements in skills and behaviour often occur with increasing age, although adolescence can be a difficult time (Wing, 2002). No treatments, physical or psychological, that can cure autistic disorders have yet been developed. Many claims have been made for different methods but none has yet been validated (Howlin, 1997).

However, much can be done to improve the quality of life for individuals and their families (Howlin, 1998; Wing, 2002).

Diagnosis

The first step is to recognize and diagnose the presence of an autistic spectrum disorder and any associated conditions as early in childhood as possible. The diagnosis is made on the developmental history from a parent or other carer, using a semi-structured interview schedule designed for this purpose, plus observation of behaviour in structured and unstructured situations (Wing et al, 2002). Psychological assessment is needed to define the profile of skills and disabilities.

Medical

There are no medical or psychological tests for autistic disorders. Medical investigations are appropriate to confirm suspected associated conditions, such as epilepsy, tuberous sclerosis, fragile X or other disorders (Baird et al, 2003).

There are no medical treatments for autistic spectrum disorders but associated conditions, such as epilepsy, may be treatable. Psychotropic drugs are often used for challenging behaviour or for associated psychiatric disorders but the results vary considerably among individuals. Careful monitoring is essential. Medication should not be continued if it is not effective.

Psychological and environmental

As children, people with autistic spectrum disorders require education. As adults they need occupation, leisure activities and places to live. These requirements are the same as for everyone else. People with autistic spectrum disorders are special because they do not understand the subtle, ever-changing, unwritten rules of social life, so everyday life tends to be a terrifying ordeal. They cope much better and are much calmer and happier if their daily routine is structured, organized and predictable (Mesibov, 1997). They need to know exactly what is going to happen now and in the immediate future. Their comprehension of language, especially of metaphors and abstractions, tends to be poor.

Visual presentations are much easier for them to grasp, so visual timetables and visual illustrations of tasks to be performed, events occurring in the near future or how to behave in specific social situations are all valuable aids (Gray, 1998). Programmes for people with autistic disorders have to be adapted to the skills and disabilities of each person. Needs vary with level of ability, but the requirement for structure, organization and making abstract ideas concrete is the same for all.

Teachers, carers and other professionals require specialized training and experience (Jordan and Jones, 1999). Parents have to learn the hard way but they too benefit from teaching, for example, the Early Bird programme run by the National Autistic Society (Shields, 2001).

Services

There is much debate concerning specialist vs integrated services. The latter are often recommended for ideological rather than practical reasons. With skilled support, some children and adults can fit into mainstream schools or open employment, but others manage only in specialized services. Both types of provision are needed.

OUTCOME

Some individuals with IQs in the average to high range who have skills that can be used in paid employment become independent as adults and may marry and have children. Those who make up their own minds to fit into ordinary life do best. Others with equal ability continue to need support through their lives, as do virtually all those with learning disabilities.

CONCLUSIONS

The autistic spectrum is a much broader concept than Kanner's autism. Its essential features are biologically caused, mainly genetic impairments of social interaction, communication and imagination, together with a marked tendency to repetitive activities, manifested in a wide range of ways. The spectrum can be associated with any other condition and any level of ability. There are no curative treatments but individuals are calmer, happier and more able to use any skills they may have if their daily life follows a structured, organized, predictable routine. **HM**

Conflict of interest: The author is a founder member of the National Autistic Society, and part-time consultant psychiatrist for the National Autistic Society Centre for Social and Communication Disorders.

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KEY POINTS

- Autistic spectrum disorders are behaviourally-defined developmental conditions resulting from brain dysfunction from biological causes.
- The spectrum is characterized by a triad of impairments of social interaction, communication and imagination, associated with a repetitive pattern of activities, all of which can occur in a wide range of manifestations.
- The triad can occur together with any other physical or psychiatric disorder and with any IQ, from severe learning disability to genius level.
- Complex genetic factors have been shown to be of major importance in aetiology in most cases but specific medical conditions, such as tuberous sclerosis, can be identified as the cause in a small minority.
- There are no physical or psychological diagnostic tests for autism, as distinct from any associated medical conditions, so diagnosis is made on the history of the pattern of behaviour as it develops from infancy onwards.
- Integration into mainstream services is difficult or impossible for some, so specialist as well as mainstream services are needed.
- There are no curative treatments but the quality of life can be improved by the provision of appropriate education, occupation and leisure and a structured, organized, predictable routine for daily living.
- Most need varying degrees of support throughout life but some with higher ability achieve partial or full independence as adults.