

# Autism

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## WHAT IS AUTISM?

Autism is a syndrome consisting of a set of developmental and behavioural features that must be present for the condition to be diagnosed. The core features of autism include impairment in three main areas of functioning:

- social interaction;
- communication;
- patterns of behaviour, interests and activities (which become restricted, repetitive and stereotyped).

Kanner first described these core features in his paper of 1943, in which 11 children with 'autistic disturbances of affective contact' showed a distinctive pattern of symptoms:

- inability to relate to people and situations;
- failure to use language for the purpose of communication;
- obsessive desire for the maintenance of sameness in the environment.

The DSM-IV diagnostic system (American Psychiatric Association, 1994) emphasises that symptoms may change throughout life and that behaviour problems can range from mild to severe.

## WHAT CAUSES AUTISM?

The cause of autism is unknown. It is a biological condition probably due to a number of causes acting together, rather than one specific cause.

We do know that children are probably born with autism. It certainly becomes obvious within the first 30 months of life. Autism affects the person throughout life.

## **Some history**

In the 1950s and early '60s some people (e.g. Bettelheim, 1967) argued that autism was a schizophrenic withdrawal from reality and advocated residential centres for children, and their removal from their family. Cold and rejecting parents were said to be causing autistic behaviour in their children, and residential programmes were seen as a means of undoing autistic behaviours and establishing appropriate behaviours in their place. The treatment involved individual psychotherapy with the child with autism, and attempts were made to change the parent's attitude and make them acknowledge their role in the development of the child's condition. Bettelheim referred to such a child as the 'empty fortress'. This 'psychogenic' theory and its treatment approaches fell from favour because they were not supported by evidence from systematic studies.

In the 1970s, new research highlighted basic cognitive deficits and organic brain dysfunction. This became known as the 'nature' theory of causation of autism and the bulk of the evidence pointed to a neurological (brain) dysfunction in children with autism.

Support for genetic influences on autism came from the research by Folstein and Rutter (1977), who undertook a study of 21 pairs of same-sex twins, one or both of whom had autism. This study pointed to the "importance of brain injuries, especially during the perinatal period, which may operate either by themselves or in combination with a genetic disposition involving language. Both mode of inheritance and exactly what is inherited remain uncertain."

## **Recent brain research**

It is assumed that people with autism probably share certain features of abnormal brain function, but the nature of this underlying neural pathology remains elusive and controversial.

Various findings suggest that autism is a disorder that encompasses both subcortical and cortical levels of brain processing. Abnormal brain activity and arousal levels, deficits in the ability to respond accurately to sensory input, abnormal event-related potentials measured in the brain, impairment of left hemisphere functioning, pathophysiology of the temporal lobe and specific structural abnormalities have been investigated.

Current research points to abnormalities in brain systems that are subserved by brain-stem structures such as the cerebellum and limbic system, and there is evidence that the brains of people with autism are often underdeveloped and immature. Some researchers have reported increased head circumference and brain volume, but these findings have not been linked to clinical features such as severity of autism or IQ.

Neurotransmitters such as serotonin have also been implicated but abnormalities that have been found have not been shown to be specific to autism; the only consistent finding is an elevation of whole-blood serotonin levels in about 25% of individuals with autism. The significance of this is unclear, although it has been suggested that developmental mechanisms in the brain might be affected.

Current neurobiological theories postulate single or multiple primary clinical deficits in higher-order cognitive processing abilities – for example involving language, social understanding and emotional insight – and the involvement of the cerebral cortex in the final common pathway for the clinical symptoms.

Future research is needed to define:

- the pathophysiology of the clinical syndrome of autism;
- the developmental pathophysiology of the structural and functional brain abnormalities that underlie the clinical syndrome;
- the genetic mechanisms that trigger the disruption in brain development that leads to these abnormalities.

## **Recent genetic research**

Recent genetic research has attempted to address the issues of transmission of vulnerability to autism and the nature of the autistic phenotype. There is now no doubt that genetic factors play an important, if not central, role in the causation of autism, although the precise genetic mechanisms have not been determined. Evidence points to not a single gene but the interaction of at least three abnormal gene sites.

Autism is three to four times more common in males. The chance of having a first child with autism is less than 1:1000 but reduces to probably about 1:50 with a second child, particularly if it is male. People with autism have an increased likelihood of a family history of learning problems, speech delays, aloofness and social eccentricity, obsessional behaviours and depression.

It is anticipated that advancement in molecular genetics will help in the understanding of how the genes involved lead to autism, whether there is an interaction between specific environmental features and genetic susceptibility,

and why there is variation in the cognitive impairment that is associated with autism.

## **What we now know about the causes of autism**

Research over the past 40 years has clarified a number of issues about the causes of autism. The psychogenic causation theory of the 1950s has been found to be lacking in evidence and has been dismissed. Evidence has made it clear that autism is a neurodevelopmental disorder involving deficits in basic cognitive and information processing, affection, communication and social skills. However, many questions remain unanswered regarding the neuropathophysiology of autism and the mode of genetic inheritance.

## **Associated medical conditions**

There is a frequent association between autism and a number of medical conditions that affect the brain, such as:

- tuberous sclerosis and congenital rubella;
- pre- and perinatal trauma, and neonatal asphyxia;
- certain acquired encephalopathies and brain malformations;
- metabolic disorders such as phenylketonuria (PKU), histidinaemia and Lesch–Nyhan syndrome;
- a number of genetic conditions and chromosomal abnormalities, including fragile X, tuberous sclerosis, De Lange syndrome, Joubert syndrome, Williams syndrome and hypomelanosis of Ito.

Most importantly, there is an approximately 30% risk of developing seizures through childhood to early adulthood. The majority of persons with autism have non-specific abnormal electrical brain activity shown on an electroencephalogram (EEG).

Some other medical conditions that lead to intellectual disability are rarely associated with autism, noticeably Down's syndrome and cerebral palsy.

The nature and meaning of the association between autism and these various other neurobiological conditions has yet to be determined.

## **HOW COMMON IS AUTISM?**

Prevalence estimates for autism have been gathered for over 30 years. At least 23 prevalence studies were reported between 1966 and 1997. These studies

used varying diagnostic criteria as definitions of autism changed over time, and their population samples differed in size and type.

Recent studies with the most rigorous ascertainment methods have consistently yielded rates of about 9 per 10,000. Gillberg (1997), who computed a mean of the numerous studies conducted worldwide since 1985, reported a prevalence rate for autism of 10–12 per 10,000. These studies all adopted a broader definition of autism than that used in earlier work. In the most recent review, of 19 prevalence studies from 10 different countries, covering the period from 1966 to 1996, Fombonne (1998) estimated that the average figure is about 5 per 10,000. It has been suggested that the prevalence of autism is increasing, however; improved community awareness and assessment may have increased the number of cases identified.

As mentioned above, autism is three to four times more common in males than females.

## DIAGNOSIS

Because the cause of autism is unknown, diagnosis relies upon matching the child's behaviour patterns and development with the diagnostic criteria. Autism usually emerges in early infancy but the diagnosis of autism remains especially difficult before two years of age, when language skills become more obvious.

In 1980, the third edition of the American Psychiatric Association's *Diagnostic and Statistical Manual* (DSM–III) introduced the diagnostic term 'pervasive developmental disorder' (PDD) to cover a group of disorders of development, including autism, that presented with abnormalities and impaired functioning across the social, cognitive, emotional and language domains. These impairments were present from the first few years of life. The fourth edition, DSM–IV, includes five categories of pervasive developmental disorder: autism, childhood disintegrative disorder, Asperger's disorder, Rett's disorder and pervasive developmental disorder – not otherwise specified (PDD-NOS).

### Autism spectrum disorders

The term 'autism spectrum disorders' is also in current use, but its definition lacks the level of international agreement attached to pervasive developmental disorders. For some, 'autistic spectrum disorders' refers to a group of different autistic-like conditions, a similar concept to pervasive developmental disorders. For others, 'autistic spectrum disorders' refers to a unitary concept of autism,

conveying the notion of a spectrum of severity, from the aloof intellectually delayed child with ‘Kanner-type autism’ at the severe end through to intelligent, less severely disturbed children with Asperger’s disorder (or Asperger syndrome) at the other end.

The problem with the latter approach relates to what is being defined as severe to mild. Is it IQ level, or language ability, or obsessional behaviour, or social impairment? Young people with Asperger’s disorder may have the intelligence on IQ testing of a typical child but may have severe impairment in social behaviour and crippling obsessions. Therefore, the concept of severity relates to multiple cognitive, social and behavioural domains and has limited if any value if applied to a child with a pervasive developmental disorder.

There is now a general international consensus regarding the features and behaviours that are required to make a diagnosis of autism; these are defined in both the tenth revision of the World Health Organization’s *International Classification of Diseases* (ICD–10) and DSM–IV (see Box 1.1).

## ASSESSMENT

It is clear from the DSM–IV diagnostic criteria that the diagnosis requires a comprehensive, multi-disciplinary assessment, comprising at least:

- developmental and family history;
- observation of the child’s behaviour and interaction with others;
- a medical assessment, including tests for known causes of developmental delay (e.g. chromosome analysis) and hearing tests;
- a cognitive assessment using appropriate tests, such as the Psychoeducational Profile – Revised (PEP-R; Schopler *et al*, 1990) and the Wechsler Pre-school and Primary Scale of Intelligence – Revised (WPPSI-R; Wechsler, 1989);
- a structured language assessment;
- a structured assessment with tools such as the Autism Diagnostic Observational Schedule (Lord *et al*, 1989), clinician-completed rating scales like the Childhood Autism Rating Scale (CARS; Schopler *et al*, 1980), and parent- or teacher-completed checklists like the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1992);
- comprehensive and sensitive feedback to the parents and carers about the diagnosis as the first step in developing a plan of intervention and services required.

**Box 1.1. DSM-IV criteria for autistic disorder**

**A.** A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
  - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
  - (b) failure to develop peer relationships appropriate to developmental level
  - (c) 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)
  - (d) lack of social or emotional reciprocity
- (2) qualitative impairments in communication as manifested by at least one of the following:
  - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
  - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
  - (c) stereotyped and repetitive use of language or idiosyncratic language
  - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
  - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - (d) persistent preoccupation with parts of objects

**B.** Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

**C.** The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Source: American Psychiatric Association (1994: pp. 70–71).

## **Assessment instruments**

Over the past 40 years various instruments have been developed specifically to assist in the diagnosis of autism and measurement of associated behaviours. Because the cause of autism is unknown, diagnosis relies heavily upon behavioural description, observation of the child's behaviour patterns and history of development being matched with the diagnostic criteria. Therefore assessment instruments assist in the screening for autism, standardisation of diagnosis and measurement of change.

Contemporary assessment instruments are usually administered in one of three ways: a checklist or rating scale completed by a trained clinician, based on behavioural observation (e.g. the CARS, Autism Behaviour Checklist); a structured parent/carer interview administered by a trained clinician (e.g. the Autism Diagnostic Interview, ADI, or Autism Diagnostic Observation Schedule, ADOS); or a parent/carer-completed questionnaire (e.g. the Developmental Behaviour Checklist; the Autism Screening Questionnaire).

No one instrument is able to undertake all the tasks of diagnosis, behavioural description, measurement of response to treatment or change over time, and serve as a screening instrument. At present clinicians and researchers must evaluate an instrument's ability to meet a specific purpose and choose the appropriate psychometrically sound instrument(s) from the range available.

## **HOW DOES AUTISM AFFECT CHILDREN?**

### **Social impairments**

One of the key features of autism is abnormality in interpersonal relationships, which may include reduced responsiveness to or interest in people, an appearance of aloofness and a limited or impaired ability to relate to others.

Infants with autism do not assume a normal anticipatory posture or put up their arms to be picked up and often do not seek physical comfort. However, they do show selective attachments to their primary carers. It is not simply the case that infants with autism do not develop social relating skills. It is more true to say that the quality of the relationship is abnormal.

Children with autism show very little variation in facial expression in response to others, generally have abnormal eye contact and tend not to engage in social imitation such as waving bye-bye and pat-a-cake games.

They rarely develop an age-appropriate empathy or ability to understand that other people have feelings. Their ability to make friends is absent or distorted and they are usually unable to play reciprocally with other children.

All children with autism show social impairments; however, the nature of these impairments can vary and may change as the child grows older. For example, there may be an increase in interest in other people and the development of some social skills, although these are often learned in a mechanical or inflexible manner.

## **Communication skills**

Impairments in both verbal and non-verbal communication skills are often the reason for parents of children with autism to be first concerned and seek help.

Children with autism usually have markedly delayed and deviant speech; approximately half fail to develop functional speech. Research supports the notion that approximately 50% of children with autism will eventually have useful speech. Children with autism also have an impaired ability to use gesture and mime.

In those children who do develop language, the pattern of development and usage is strikingly deviant. Tone, pitch and modulation of speech are often odd and the voice may sound mechanical and flat in quality, with a staccato delivery. Some children speak in whispers or too loudly, and some develop an unusual accent.

Their understanding of spoken language is often literal and they fail to comprehend underlying meaning and metaphor such as 'shake a leg', or 'pull your socks up'.

Abnormal use of words and phrases is a common symptom of autism. Echolalia (repetition of language spoken by others) is one of the most noticeably deviant aspects of speech. It can be either the immediate repetition of what has just been said, or the delayed repetition of phrases. Some children repeat advertising jingles or large pieces of dialogue, perhaps days later, for example from videos, for no apparent reason. Echolalic speech may serve some function.

Children with autism often confuse or reverse pronouns. Kanner (1943) originally attributed this to echolalia; however, more recent research has found that this problem relates to the deficits that children with autism have in understanding the perspective of another, joint attention and difficulty conceptualising the notion of self and other.

Some children have idiosyncratic speech and neologisms such as 'door go by' when asking to go outside, or calling a drink a 'dorfla'.

Language comprehension (receptive language) deficits in autism are also of great importance. Poor understanding is probably linked to social difficulties

and impairments in social understanding. An inability to express needs by words or gesture, or a significant difference in the child's ability to use words compared with their level of understanding of the verbal responses of others, is a source of frustration and can cause distress or disturbed behaviour.

Even those children with autism who develop a wide vocabulary and expressive verbal skills show difficulty with the pragmatic or social use of language. They have an impaired ability to initiate conversation, communicate reciprocally with others and maintain the 'to and fro' of a conversation. The child with autism is more likely to talk at you rather than with you, to intrude and talk out of context and to use speech as a means to an end rather than engage in a social conversation. Howlin (1998) described the 'failure to use communication for social purposes' as the most characteristic feature of the language deficit in autism.

### **Play and imagination**

Children with autism usually have rigid and limited play patterns with a noticeable lack of imagination and creativity. They may repetitively line up toys, sort by colour, or collect various objects such as pieces of string, special stones or objects of a certain colour or shape. Intense attachment to these objects can occur, with the child showing great distress if these objects are taken away or patterns disrupted.

Older children may develop play that superficially appears to be creative, such as re-enacting the day at school with dolls and teddies, or acting out scenes from favourite videos. Observation of this type of play over time often reveals a highly repetitive, formalised scenario that does not change and cannot be interrupted.

Children with autism rarely involve other children in their play unless they are given a particular role in a controlled situation. Howlin (1998) drew a parallel between the pervasiveness of the language disorder in autism and the child's inability to develop normal, imaginative play patterns. The stereotypies seen in language are also observed in the repetitive, non-social and ritualistic play of children with autism.

### **Ritualistic and stereotyped interests or behaviours**

Ritualistic and compulsive phenomena are also common, such as touching compulsions and rigid routines for daily activities. There is often an associated resistance to change in routine or the environment, so that the child may become extremely distressed if, for example, a new route is taken to school, the furniture in the house is rearranged, or the child is asked to wear new clothes.

Hand and finger mannerisms and repetitive complex body movements of a stereotyped kind such as hand flapping or tiptoe walking are common. There is often a fascination with moving objects, such as spinning a plate or wheel. Close visual scrutiny of the fine detail of an object such as the edge of a table, or the pattern of the spokes on a wheel, is common, as is the collection of objects such as buttons or twigs. Many children with autism, especially in middle to late childhood, have unusual preoccupations, often to the exclusion of other activities. These may involve a fascination with bus routes or train timetables in association with repeatedly asking questions to which specific answers must be given.

### **Associated features**

Many other abnormalities are associated with autism, such as unusual dietary habits, sleep disturbance, abnormalities of mood and self-injurious behaviour. Perceptual abnormalities, such as lack of response to pain, heightened sensitivity to sound and preoccupation with tactile stimulation, are also common. These associated features are not specific to individuals with autism and may occur in other children with intellectual disability.

### **Cognitive abilities and IQ**

Although Kanner (1943) stated that children with autism possessed normal cognitive potential and 'islets of ability', it is now clear that the majority of children with autism have intellectual disability. A recent review of the literature found that in most epidemiological samples approximately 50% of cases exhibit severe intellectual disability, 30% mild to moderate disability and the remaining 20% have IQs in the normal range.

Low IQ scores are more likely to be associated with the development of epilepsy. One-third of intellectually disabled children with autism develop epilepsy, while only approximately one in 20 of those with normal intelligence do.

The IQ scores of children with autism often show an unusual and distinctive pattern of performance on standardised tests of intelligence. Individual profiles usually show a wide scatter of abilities, with deficits in verbal sequencing and abstraction skills, while rote memory may be better. Tasks requiring manipulative, visuo-spatial skills or immediate memory, such as block design, object assembly and the Seguin formboard, may be performed well. These skills may be the basis of 'islets of ability', such as the musical ability shown by a few children with autism. Around 20% of children with autism have overall

cognitive abilities in the normal range and are referred to as 'high functioning', but still usually have the pattern of a relatively wide scatter of abilities.

The cognitive deficit is as much social as intellectual and linguistic. Rutter (1983) contended that these cognitive deficits are basic to the condition of autism and not secondary features. It has been found that such deficits are present in virtually all children with autism and that they constitute the most powerful predictors of functioning in later adolescence and early adult life.

Cognitive deficits are a fundamental aspect of the disability of autism.

## DOES AUTISM CHANGE OVER TIME?

Yes, autism does change over time.

Stone (1997) described the classic picture of autism in a pre-school child as one who exhibits a marked lack of interest in others, failure in empathy, and absent or severely delayed speech and communication.

Marked resistance to change, restricted interests and stereotyped movements may develop or become more noticeable after three years of age.

The form and degree of features may change markedly as the child grows older but the core social, communication and behavioural difficulties persist. Many parents find the pre-school years most difficult to manage, but with early intervention and education, improvement can be expected.

With education and training, primary-school-aged children usually become more socially responsive and communication skills increase. Self-stimulatory behaviours, problems in coping with change and transitions, and disruptive or compulsive behaviour may increase at this time.

Adolescence can also bring the development of symptoms such as aggressive and oppositional or obsessive-compulsive behaviour, and an increase in anxiety, tension and mood disturbance. Depressive illness is not uncommon and is probably due to a combination of the development of some degree of insight as well as hormonal and central nervous system (CNS) functional changes.

There is an increased risk of the development of seizures in adolescence. Estimates indicate that 25–40% of people with autism develop epilepsy before the age of 30. Gillberg and Steffenburg (1987) noted an increased risk for boys.

## What is the long-term outcome?

Outcome or follow-up studies of people with autism in later life are few. Venter *et al* (1992) studied higher-functioning adolescents and adults to determine the role of cognitive and behavioural factors in predicting later social-adaptive

and academic achievement. They found that early verbal skills were the best predictor of both academic functioning and adaptive behaviour later in life. Gillberg and Steffenburg (1987) followed 46 cases into early adulthood and found that 60–75% had relatively poor outcomes in social adjustment. Of these, about half were institutionalised.

During adulthood, the majority of persons with autism are likely to require some support. For example, one study found that two-thirds of the group were in day or residential treatment programmes. A minority are able to work and live independently and have some social contact and friendships. Another minority deteriorate or otherwise need high levels of care.

It is usually those adults who have higher levels of cognitive and communication skills who are able to live independently and remain in employment; however, some difficulties with social interaction remain. The majority of people with autism will experience behavioural, emotional and social problems throughout life, but nevertheless will make some developmental improvement and progressively become more independent.

Unfortunately, in the young child with autism, there is no way of knowing with confidence what the developmental trajectory will be.

## **DO YOUNG PEOPLE WITH AUTISM HAVE ADDITIONAL EMOTIONAL AND BEHAVIOURAL PROBLEMS?**

Children and adolescents with autism have high levels of anxiety and mood disturbance, disruptive and self-absorbed behaviour as well as communication disturbance and social relating problems. The high levels of emotional and behavioural disturbance persist throughout childhood and adolescence.

### **Antisocial behaviour**

Antisocial behaviours that require social intention and awareness, such as lying, stealing, hiding, lighting fires and refusing to go to school or work, are seldom seen in autism, as they require a degree of social knowledge and skill beyond the ability of most young people with autism. However, behaviour perceived by others as antisocial may occur in persons with autism, particularly in those with higher intellectual abilities, as a manifestation of an obsessional preoccupation or self-stimulatory activity without social intent or understanding of the impact on others. For example, one young man regularly set fire to the hay shed on the family farm because he enjoyed the sight, sound and smell of the flames.

## **Disruptive behaviour**

Disruptive behaviour, such as tantrums, noisiness, abusiveness, impatience, aggression, self-injury and stubbornness, is problematic for clinicians, family and teachers alike.

In the school setting, disruptive behaviour has been found to relate directly to a loss of productive learning time. Disruptive behaviours are also likely to contribute to failure of integrated placement in a mainstream school and the need for more restricted placement in a special school. High levels of disruptive behaviour also contribute to parental burden and are the main reason for placement of children into respite care or residential care.

## **Anxiety**

Young people with autism often have a high level of anxiety. The symptoms of anxious behaviour include fear of separation from familiar people, specific fears or phobias (e.g. of certain sounds, smells, objects, animals), resistance to change (e.g. new clothes, food, routines), panic and emotional distress for little or no apparent reason, tenseness, shyness and irritability. These comorbid symptoms of anxiety, apart from the distress they cause the child, have the potential to disrupt education, further impair social interaction, and create management problems and stress for the parents and carers.

The identification of anxiety in a child with autism creates an opportunity for management. Psychological treatments, particularly cognitive and behavioural approaches, are effective. Pharmacological treatments, such as selective serotonin reuptake inhibitors (SSRIs) and tricyclic antidepressants, may also reduce anxiety in children. Psychological treatments may need some modification in order to compensate for language impairment, and the effectiveness of pharmacological treatments needs to be confirmed using baseline and follow-up records of target symptoms.

These comorbid emotional and behavioural problems are not confined to young children with autism, but remain a challenge for parents and carers at least into adolescence. Further follow-up studies are required to follow the changes in psychopathology into adult life.

## **Depression**

Adolescents with autism are at increased risk of suffering depression and mood disturbance, with associated symptoms of irritability, sleep and appetite disturbance (including weight loss), obsessional thoughts and preoccupations, compulsive behaviours, psychomotor retardation, and thoughts of suicide with a potential

to act on these thoughts. These symptoms of mood disorder are likely to impair their education and school adjustment, further handicap their already compromised social interactions and interfere with the quality of their family life.

Depression responds to psychological treatments such as cognitive therapy, relaxation training, and pleasant events scheduling, modified according to the intellectual ability of the young person. Rewarding experiences, reduction of stress at home and school, and attention to parental mental health are helpful. Antidepressant medication may also be necessary if the depression is severe or persistent.

## **Attention deficit hyperactivity disorder**

Distractibility, lack of concentration, impulsiveness, poor planning ability, disorganised behaviour, fidgetiness and motor overactivity are common symptoms in young people with autism but may decrease with maturity. Management requires a broad approach, including planned, structured, time-limited activities in simple steps, limitation of the amount of environmental stimulation, planning for change, communication programmes (e.g. visual systems), behaviour modification, relaxation and perhaps medication.

## **APPROACHES TO TREATMENT**

There is no cure for autism. Many treatment approaches and therapies have been reported during the past four decades, often without strong empirical evidence of benefit. Many of these were based on specific theories of causation. Some came and went quickly, such as swimming with dolphins. Others slowly became outdated, such as aversive therapies, as knowledge increased and social approaches to disability and ethics changed.

Current treatment usually consists of well-designed, multi-disciplinary, structured treatment programmes that incorporate developmental approaches with early intervention, special education, behavioural management, social and communication skills training, and psychotropic medication when indicated. Treatment must be a collaborative approach between the family/carers and the professionals involved in the child's care.

## **Behavioural approaches**

Behavioural approaches to the education, treatment and management of young people with autism have been successfully used for the past three decades. It

is now clear that behaviour management techniques lead to a reduction in difficult behaviour and may increase social, communicative and cognitive skills in some people with autism.

### ***Traditional approaches***

In traditional behaviour management the target behavioural problem is studied, then the environment is manipulated in such a way as to increase, decrease or maintain the behaviour. This is referred to as the 'ABC approach'. The target Behaviour to be managed is described and then either the Antecedents or the Consequences (or both) of the behaviour are manipulated. For persons with autism the treatment programme comprises a set of procedures designed to reduce behavioural excesses (e.g. self-stimulation, obsessions, self-injurious behaviour) and to increase behavioural competencies (e.g. attention to task, language and social skills). Current behaviour management combines the teaching of new skills with the suppression of undesirable behaviours. There are several ways of encouraging and increasing new behaviours. Some commonly used methods are described below.

#### *Positive reinforcement*

This is the easiest and most often used method of strengthening a behaviour. By following the target behaviour with a pleasant event, we are increasing the likelihood of that behaviour occurring again. One of the trickiest things here is to work out what the child actually finds pleasant! We must not assume that others, particularly children with autism, will share what we find pleasant and rewarding. For example, we may find attention in the form of a hug and a kiss very pleasant, but for the child with autism this may actually be experienced as unpleasant and overwhelming.

#### *Time out*

This strategy is widely known and used to decrease undesirable behaviours in young children. The underlying principle is that most people like to be rewarded with attention or some other positive feedback when a behaviour has occurred. If that behaviour is met with no positive reinforcement, and the child is actually removed from any opportunity for attention, the behaviour is less likely to happen again. The child may be taken to another room or merely sent to another part of the room and ignored for a short time. This method does rely on the child being able to link the two events, that is no attention because of what the child has just done. For some children with autism, the removal to a quiet and empty space may actually be rewarding and lead to an increase in some behaviour in order to achieve isolation.

Time out can be effective as a ‘circuit breaker’ for both child and parent when a break or separation is needed to stop a situation from escalating: it may give the parent and child time to cool down, and the parent a chance to think through how best to respond. Time out is best used in conjunction with methods that teach new or replacement behaviours.

### *Prompting*

This is a procedure that is used when the required behaviour does not exist at all. The child is guided to perform the response. There are a number of ways to prompt a child.

Physical prompts are literally ‘hands on’ attempts to encourage the new behaviour. For example, if the new behaviour required is for the child to eat using a fork rather than fingers, the physical prompt will involve putting your hand over the child’s on the fork and helping to stab the food and lift it to the mouth.

Verbal prompts involve telling the child what to do, for example, ‘Stab your food with the fork’. Verbal prompts need to be very explicit and concrete at first. It is not sufficient to say ‘Use your fork’, as it does not tell the child exactly what to use the fork for (e.g. not to poke the cat!).

Pointing can also be used to prompt the correct response.

Eventually the prompt will fade and become unnecessary. At first a combination of prompts is usually required. For example, a physical prompt will be combined with a verbal prompt that clearly tells the child what to do as the child is doing it. As the behaviour improves, the physical prompt may be dropped and a point and verbal prompt used instead.

Subtle prompts can be used very successfully with older children where a new behaviour has been learnt but the child still needs just a little cue or reminder of what to do. For example, in the classroom, a child who continually shouted out enthusiastically to contribute to the class had to learn to put up his hand and wait for the teacher to say his name. The cue he continued to need was simply the teacher raising a finger to indicate that he needed to raise his hand. The benefit of a small cue is that it helps the child without being obvious to everyone else.

### *Shaping*

This method involves encouraging and reinforcing successive approximations of the new behaviour until the behaviour is learnt. For example, if the child is unable to wave bye-bye, any attempt to raise a hand or arm in response to your waving bye-bye is rewarded. It may begin with only a slight movement. As the child gets better at raising an arm and moving a hand, you wait until

both occur before giving the reinforcer. The child learns that more is expected, in gradual steps, until the whole wave is learnt.

Shaping is a useful method to use with young children at any developmental level. It does not require the child to have an existing level of speech or comprehension of speech. Shaping can be used without spoken instructions, although praise and encouragement through words usually accompany the reinforcer. It does require some ability in the child to attend and imitate an action.

### *Chaining*

This is a useful way of teaching a more complex behaviour or task and involves breaking it down into small steps. The steps are then taught one at a time. As each step is learnt, the next is taught. You cannot miss steps, or teach them out of logical order.

Self-help skills, such as dressing, are often taught using this method, for example pulling up pants. The task has a lot of different steps that need to be thought about and written down. If you are forward chaining, you start with the first step, which may be picking the pants up in both hands. The next step may then be lifting one leg to step into the pants, and so on. If you are using backward chaining, you teach the other way around and start with the last step, which would be the final pulling up of the pants.

Chaining breaks down the task into tiny steps that do not overwhelm the child and you work through one step at a time until the whole task has been learnt. Success builds on success as each step is mastered. This method is very successful when teaching young children with few skills and little language.

### ***Understanding the communicative function of difficult behaviour***

More recent approaches try to understand the *function* or *purpose* of particular behaviour and what the person is trying to tell us, that is, the *communicative function* of the behaviour. Current behaviour management programmes for persons with autism take into account more than the ABC approach, by considering: individual variables, environmental factors and how the ability to communicate is affecting behaviour.

For example, disruptive behaviours such as aggression, self-injury and stereotypes may have as many as five communicative functions:

- to indicate the need for help or attention;
- to escape from stressful situations or activities;
- to obtain desired objects;
- to protest against unwanted events/activities;
- to obtain stimulation.

If the communicative function of the behaviour can be determined, then it is possible to teach a substitute behaviour that helps the person to get the message across more appropriately.

## **Early intervention**

There have been numerous approaches to early intervention for children with autism. These include: home-based and school-based programmes; integrated and specialist autism settings; length of intervention varying from 4 to over 40 hours per week. Most treatments have been reported to lead to gains in symbolic play, language and social interaction. Early intervention programmes employ both behavioural and special education techniques. Professional teaching support is vital for those family members and carers who are working on treatment programmes at home, as they are generally intensive and demanding.

Recent claims that highly intensive behaviourally based interventions (over 40 hours per week, for two years or more) lead to recovery or normal functioning are controversial. Behavioural interventions probably lead to improvements, particularly in scores on IQ tests; however, suggestions that initial benefits are maintained over time require replication. Longer-term evaluations are needed, particularly those that measure social communication and interaction, conceptual abilities, obsessional and ritualistic behaviours, and the additional emotional and behavioural problems associated with autism.

The specific effects of early intervention require further study, particularly the effects of different treatments and the responses of subgroups of children with autism, such as lower- and higher-functioning children.

## **Teaching and special education**

Special educational programmes for children with autism are individually designed by teachers using a problem-solving approach to address specific needs. These programmes aim to provide predictable, consistent and highly organised teaching situations in the classroom. The child's specific cognitive profile needs to be considered; for example, the use of visual-based rather than verbal instruction will improve the outcome for a child with good visual-motor skills. The response to teaching is related to the severity of intellectual and language impairment; however, most children make some gains when behavioural methods and special educational approaches are used.

The move to integrate children with autism into as normal a learning situation as possible is generally appropriate. Placement in mainstream or special

education schools generally depends upon the child's intellectual level. Integration is desirable in principle, but some children with autism will have difficulty without close supervision and support. Without adequate special resources and teaching, children with autism are at risk of becoming more isolated and unoccupied, or may become more disruptive and disturbed.

## **Communication skills programmes**

It is not possible to put appropriate intervention programmes (either language or behavioural) in place without careful assessment of the person's current level of cognitive and language functioning. Lower-functioning or non-verbal people with autism also require assessment of possible communicative intent in their behaviour (e.g. the child who hits himself when he wants an activity to stop). For those who have speech, it is also important to assess pragmatic (social) speech abilities. Recently, more attention has been paid to the effects of communication problems on behaviour in order to replace inappropriate behaviour with more effective communication, such as a picture system.

### ***Augmentative communication***

Augmentative communication helps those who are non-verbal to communicate by using other systems. These systems are called 'augmentative' because they augment or increase the strength of the person's power to communicate. Visual systems using simple pictures and line drawings, signing systems and also photographs are often used to augment communication for children with autism. People must be carefully assessed to determine which system will suit them best. The choice of system to help improve communication will depend upon level of cognitive and language ability.

Systems frequently used are signing, the Compic (computer-generated pictures) system, and also photographs and objects.

### ***Signing***

Signing was probably the first alternative system used with non-verbal children with autism. At first, the signing systems used by the deaf were taught, but these are complex systems that include finger spelling of words and the use abstract concepts. In the early 1980s, a simpler system called Makaton was devised to use with children with intellectual disability. This system has varying degrees of difficulty, but at its easiest level the signs learnt are simple and concrete and there is no use of difficult finger spelling. Many of the first signs learnt use only one hand. For example, the sign for 'drink' uses one hand in the shape of a cup that is lifted to the mouth and tilted as if the child were having a drink.

One advantage of signs is that they are very portable and do not require the child to carry around equipment. Another advantage of establishing a signing system is that it has been found to encourage speech in children, rather than what many parents fear – that it will reduce the chance of their child talking. However, signing is not widely understood in the community and the child may not always be well understood outside the circle of those who can sign. Signing does also require that the child can attend to the person teaching the signs and also imitate an action.

### *Compic (computer-generated pictures)*

This system is used successfully in many teaching programmes. Compics are very simple and clear line drawings that represent a wide range of objects, actions, feelings and so on. They can be used initially at a very simple but practical level with young children, who learn to point at the picture or show the picture to indicate their needs. When children are familiar with a number of these pictures, they can be put into a wallet of pictures that the child carries around and takes out to indicate particular needs. Children gradually build up a vocabulary of pictures to meet their own special needs. Compic programmes are widely available in computer software format and as loose-leaf books. Compic pictures are easily understood by everyone and do not require the child to learn and remember complex actions, as does signing. Children who have low cognitive skills can generally use a picture system in a simple way to communicate more effectively.

### *Photographs*

Photographs of objects and people in the child's world can be used effectively with lower-functioning children who cannot master the use of symbols or line drawings. Use of photographs usually requires that the child first learns to match an object with a photograph of that object. The child learns that the photograph represents the object. The photograph must be simple, clear and uncluttered. After the child has learnt to match photographs and objects, the more complex concept of matching photographs and activities or actions can be taught.

Once the child is able to recognise a number of photographs, a photo vocabulary can be built up in the same way as a Compic vocabulary. Photographs can be used to help the child understand timetables or the steps involved in completing an activity. For example, the classroom may have photographs of the day's activities pinned to the wall. When each activity finishes, the child may put away that photograph. Similarly, when the child is required to get dressed, the steps involved may be pinned to the bedroom door in the correct sequence so that they can be easily followed.

### *Objects*

Objects can be used in a similar way to photographs with children who have difficulty understanding photographs. Object timetables are useful. Objects that represent activities can be laid out or stuck on the wall to show the child what happens next. For example, a crayon may mean work at the table, and the next object may be a juice box straw that represents that snack time comes after work.

A great advantage of photographs and objects is that children can attend to them for as long as they need to, and can also return to them to refresh their memory. This is not possible with a sign, where, once the sign has been demonstrated, it has gone.

## **Social skills programmes**

Social impairment in autism affects most aspects of the person's functioning. The approaches used to treat social difficulties vary according to the needs of each person with autism, particularly the level of cognitive ability, age and the nature of the social impairment. For example, the young child with autism who is aloof and withdraws from social contact requires a very different programme to an older, more able adolescent who attempts to join in with others but shows little empathy or reciprocity. Areas covered may include social isolation, understanding about friends and strangers, social play skills, interacting with peers, understanding rules and when they may be broken, understanding emotions, and increasing imaginative and social imitative play.

Treatment for young children with autism initially involves the teaching of social skills according to specific, inflexible rules that can be learnt in specific situations, such as 'You only talk to people you know, not strangers'. As children grow older, social skills training may include the use of:

- *Picture scripts*. These are drawings that represent social situations and how to handle them. They are used to rehearse social situations and teach a range of appropriate responses.
- *Social stories*. These help children to understand social situations and routines, and to make judgements about a social situation on an individual basis. Details are gathered about a problem situation (the target), the person's abilities, interests and responses, and others involved. These details are used to form a story. The person is given information about the situation and how to respond. Stories can be written, or presented as videotapes or audiotapes for those who cannot read.
- *Social skills groups*. The involvement of competent peers can be helpful to teach social interaction skills. Role-play activities and the use of videotapes are

helpful in teaching and practising social interaction skills and enable people with autism to observe their own behaviour and practise correct responses.

## Pharmacotherapy

The use of medication should occur only as part of a comprehensive management plan that includes approaches to improving communication, behaviour management, education, social skills training, structuring of daily routine and parent support.

There is empirical evidence of variable quality regarding the effectiveness of drugs in the treatment of various behaviours, symptoms and psychopathological disorders associated with autism.

Drugs should be used only after assessment and diagnosis have defined the symptoms or disorder. To some extent, the use of any treatment is experimental; therefore when using drugs it is necessary to record baseline and follow-up descriptions of the target symptoms, for example the use of a behaviour checklist in order to demonstrate change. Baseline assessment of abnormal movements helps distinguish these from any later drug-induced movements.

Regular enquiry regarding possible side-effects is also necessary. Compliance with treatment is improved when the family or carers and the person with autism are involved in regular reviews of management.

### Anxiety

- Tricyclic antidepressants (TCAs) (e.g. imipramine) but not when there is a history of heart disease, due to potential cardiotoxic effects, or epilepsy.
- SSRIs (e.g. fluoxetine, paroxetine, sertraline). Excitation, disinhibition, nausea and headache may be troublesome side-effects.
- Neuroleptics (e.g. haloperidol, risperidone, phenothiazines) in low dose, but only as a last resort, because of potential neurological side-effects (dystonia, akathisia, dyskinesias), weight gain and, rarely, blood disorders.
- Buspirone. There is some limited evidence for its efficacy.

### Depression

- SSRIs.
- TCAs for older adolescents.

### Obsessive-compulsive symptoms

- SSRIs.
- TCAs, particularly clomipramine and imipramine, but these may unmask epilepsy.

### ***Frustration, rage, aggression, disruptive behaviour and withdrawal***

- Neuroleptics (haloperidol is the drug of choice).
- Naltrexone – may reduce self-injurious behaviour and hyperactivity. Monitor liver function.
- Anticonvulsants (e.g. valproate, carbamazepine) may improve learning. Monitor liver function.

### ***Cycling mood disorder***

- Lithium – requires regular monitoring of serum drug level and renal function. Avoid dehydration. Lithium may also reduce self-injurious behaviour and aggression.
- Anticonvulsants (as above).

### ***Attention deficit hyperactivity disorder symptoms***

- Stimulants (e.g. dexamphetamine). Symptoms need to be unequivocal. Frequent side-effects (mood disturbance, irritability, worsening hyperactivity, withdrawal and stereotypies, insomnia and tics) limit usefulness.
- Neuroleptics.
- TCAs (see above).
- Buspirone.
- Naltrexone.

## **Some points to remember about treatment**

- Detailed assessments and behaviour, language, cognitive and social skills baselines must be completed before any treatment programme can begin so that change can be documented.
- Intervention must be sensitive to the realities of the development and skills of each child with autism if it is to be effective. For example, the use of signing is not indicated if the child is unable to imitate or use gesture.
- Given our current state of knowledge, there is not necessarily only one way to manage a child with autism: there may be a variety of ways of approaching management.
- A multi-modal approach to treatment is more likely to promote development, improve behaviour and reduce stress experienced by the child and family.
- When treating behavioural problems it is important to understand and deal with the underlying causes, antecedents and consequences.