# 1

# Autism: an overview

**This chapter:**

- **Provides a brief history of autism including discussion of theories causation, diagnostic criteria and changes in prevalence**
- **Presents current understanding of the condition through the conceptual models of the triad of impairment, mind-blindness, difficulties in executive function, difficulties in central coherence and difficulties with processing sensory information**
- **Considers the rapidly changing field of autism**

## Kanner and Asperger

It is in the seminal work of Leo Kanner (1943) that we first find the word autism applied to an identifiable group of youngsters who shared common characteristics representing a unique and specific condition separate to any other childhood conditions. A year later, Hans Asperger (1944) working in wartime Austria, reported a group of adolescents who, although of average or above average intelligence, shared the same features of social ineptitude, inflexible thought patterns and idiosyncratic use of language. In the immediate aftermath of war, it was Kanner's work which received wider publicity and engaged the scientific community in further studies of causation and definition.

Kanner's initial work focused on 11 children, eight boys and three girls, who at the time he was writing were all under the age of 11. Kanner identified in these children many of the features of autism we would recognise today including

- 'the inability to relate themselves in the ordinary way to people and situations'
- 'the absence of spontaneous sentence formation'
- 'insistence on sameness' (Kanner, 1943: 242–5 passim).

Moreover Kanner recognised that despite the variation among the individual children he was studying, there existed sufficient common characteristics to denote a specific condition. He says

> The eleven children (eight boys and three girls) whose histories have been briefly presented, offer, as is to be expected, individual differences in the degree of their disturbance, the manifestation of specific features, the family constellation, and the step-by-step development in the course of years. But even a quick review of the material makes the emergence of a number of essential common characteristics appear inevitable. These characteristics form a unique 'syndrome,' not heretofore reported, which seems to be rare enough, yet is probably more frequent than is indicated by the paucity of observed cases. (Kanner 1943: 241–2)

and, in articulating this notion of a singular condition comprised of a range of manifestations, Kanner prefigured the complexity of the condition which was to gradually emerge over the coming decades.

The circumstances of war entailed that Asperger remained unaware of Kanner's paper and use of the term 'autism' when publishing his own work. Asperger used the same label to describe four children aged between 6 and 11, who showed marked difficulties in social integration despite apparently adequate cognitive and verbal skills. Asperger drew a distinction between his patients' lack of social contact and the withdrawal of children with schizophrenia by highlighting the fact that children with schizophrenia displayed a progressive withdrawal whereas his patients showed this aloofness from the outset. Asperger (1944) stressed that difficulties with social interaction were the defining feature of his conditions but also provided a comprehensive list of symptoms and features, including:

- difficulties in interpreting non-verbal communication such as facial expressions and body movements
- peculiar use of language
- obsessive interests in narrowly defined areas
- clumsiness and poor body awareness
- behavioural problems
- familial and gender patterns.

In many respects Asperger's original work had little influence on the field of autism until the 1970s. Then, as notions about autism evolved to incorporate a broader spectrum (Gillberg 1985; Wing and Gould 1979), so the group associated with Asperger began to be included in the debate. Because of the distinctions between the two original groups studied, it became usual to describe people of lower cognitive ability as classically autistic, or as experiencing Kanner's autism, whereas more able individuals were seen as experiencing Asperger's Syndrome.

It is important to note at this point that the relationship between autism and Asperger's syndrome remains a controversial arena for discussion (Cohen and Volkmar 1997). The basic standpoints are:

- Kanner's autism and Asperger's syndrome are part of a spectrum of associated conditions known as autistic spectrum conditions. People with Asperger's syndrome represent a high-functioning group within the spectrum.

- Asperger's Syndrome is distinct from other conditions. High-functioning autism is not the same as Asperger's syndrome; there are qualitative differences in the condition.

Studies which have attempted to identify criteria which discriminate between autism and Asperger's syndrome have yielded mixed results. We must recognise that understanding of autism is still at a very early stage in its evolution and consensus over the precise demarcation of groups will remain problematic for some time to come. As educators, our primary concern does not lie with diagnostic distinctions but rather with the features of the condition(s) which adversely affect a student's ability to learn; our focus must remain here.

## Causation

Early ideas of causation were obscure and confusing. It must be remembered that Kanner was a psychiatrist operating in the climate of psychoanalytic thinking which had come to dominate in the 1940s. Consequently, thinking around the cause of autism began to form around theories of parenting and in particular the role of the mother in nurturing the child. Fortunately, by the mid-1960s the work of Rimland (1964) and others demonstrated that autism had a biological basis and should be regarded in the same way as any other condition.

Today, the question of causation remains complex with research focused in three key areas, namely:

- psychology

- neurology

- genetics.

Each of these fields may be characterised as follows:

- Psychology – related to an individual's cognition, perception and understanding. Research has focused on language, memory, spatial awareness, sensory perception, social awareness, empathic awareness.

- Neurology – related to the dysfunction of particular structures of the brain and the neuro-chemicals which transmit information within the brain. The commonality of symptoms across the spectrum has led researchers to investigate a unique underlying neurobiology.

- Genetics – related to the inherent characteristics which make up an individual. The Autism Genome Project (AGP) has successfully identified a number of genetic locations associated with autism. Recent research from AGP indicates that scientists are moving towards an understanding of how each of these genetic factors interlink with one another.

While investigations in each of these key areas is essential for furthering our understanding of autism, the differing perspectives held by researchers in each discrete field can lead to confusion. Furthermore, definitions of the term 'cause' may vary significantly among researchers just as the phenomena being studied may be wide ranging. Consequently, there are a variety of different, sometimes conflicting, theories of causation.

For our purposes as educators, it is necessary to take a pragmatic view on this issue. Based on what we know, it is reasonable to see autism as *a behaviourally defined developmental condition resulting from neurological characteristics caused by genetic factors*.

If we ask 'what causes autism?' our answers lie along a complex chain of events defined by several levels of causation. A geneticist answering the question may refer to the locus of genetic events; a neurologist will reference brain pathologies determined by those events; and a psychologist will point to the developmental issues impacting on an individual as a consequence of their neurological make-up. Our understanding, as educators, is best informed by taking account of this complexity and attempting to integrate each level of causation in order to produce a picture of the whole child.

A further point to consider is that at each level there may be a number of possible causes. Therefore, there may be a *number* of genetic factors, a *variety* of possible brain pathologies and a *range* of developmental impairments which lead to the spectrum of behaviour we term autism. Indeed, the fact that there are perhaps many permutations of causation may well account for the breadth of the spectrum and the 'fascinating peculiarities' (Kanner 1943) of each unique individual with autism.

## Diagnosis

In 1980 the American Psychiatric Association published the third edition of their *Diagnostic and Statistical Manual of Mental Conditions*, known generally as DSM III, which considered infantile autism as a subgroup of associated conditions termed 'pervasive developmental disorder'. Following a series of revisions to include the more subtle features of autism, a system for diagnosis was published in DSM IV (1994). This framework forms the basis for diagnosis currently used by many paediatricians.

The other system of classification used by many clinicians is the World Health Organization's 'International Statistical Classification of Diseases and Related Health Problems', or ICD. The edition known as ICD 10 (1993) was the first edition that did not consider autism as a form of psychoses, marking an important point of arrival for the field of autism. ICD 10 (1993) classifies autism as one of several pervasive development conditions ensuring that the basis for diagnosis agreed upon by each of the major systems used by clinicians is developmental.

However, despite the adoption of these systems, the issue of diagnosis remains extremely problematic. This is because autism is defined by what we can see, that is, an individual's behaviour. There is no clear 'marker' which can be clinically obtained and therefore diagnosis reflects the opinion of the diagnostician following observation and interviews with care givers. While for many children, the nature of their condition lends itself easily to diagnosis, there are many children for whom the picture is not clear. This might be for several reasons, including:

1 the manifestation of those features cited as diagnostic criteria in DSM IV and ICD 10 is inconsistent, appearing in certain contexts and apparently not in others

2 the child's condition is complicated by other difficulties such as profound and multiple disabilities, severe learning difficulties, mental health problems or generally poor health

3 the child's developmental history is not fully known, therefore diagnostic tools reliant on developmental checklists are compromised

4 the symptoms of autism may change with age and developmental progress – nevertheless, autism remains a lifelong condition.

In cases such as these the child may remain without a diagnosis for long periods of time. The effect of this can be significantly damaging, with youngsters not able to access appropriate care and education and parents remaining in a diagnostic limbo. However, we must recognise the difficulties faced by diagnosticians, given the broad-ranging spectrum embraced by the condition and the complexity of the individuals within that spectrum.

## Prevalence

Recent studies have suggested that early estimates of the prevalence of autism were conservative. Research during the 1990s and into the present century shows significant annual rises in the prevalence of autism with as many as 60 people per 10,000 reported by some researchers (Wing and Potter 2002). The reason for this marked increase is as yet unproven, but may be accounted for by the following factors:

- changes in diagnostic criteria
- the evolution of a concept of a wide spectrum of autistic conditions
- increased awareness and therefore identification of the condition
- possible environmental causes.

Whichever factor, or combination of factors, is in operation, the fact remains that we are finding increasing numbers of children with autism in our schools, an issue which must be urgently addressed. Scott et al. (2002) reported prevalence of 60 per 10,000 of the school population for 5–11-year-olds, while Baird et al. (2006) proposed a figure of 116 per 10,000 of the child population. The National Autistic

Society presents the figure of 1 per cent of the general population and cautions that this may well be a conservative estimate.

Finally, a marked gender bias is consistently reported in studies of prevalence with figures varying from a ratio of 4 males to every 1 female to 8 males to every 1 female. The strong genetic basis for autism bears out these notable gender differences.

## Models of autism

Since Kanner's seminal work, there have been a number of models proposed which have sought to explain the prevalent features and characteristics of autism. Each of these models has arisen from a particular paradigm for understanding human psychology and reflects the theoretical background they have emerged from. Consequently, in exploring these models of autism it is important to consider them as providing insights into a particular aspect of autism and not as offering a single global and comprehensive understanding. Our aim should be to try and accommodate these models in a construct of autism which is then applied to the individual and the context we are living or working with. Crucially, we should employ these models to help us understand the experiences of the individual with autism from their perspective, as a tool to support empathy in our practice.

A helpful starting point is Lorna Wing's notion of the **triad of impairments** (Wing and Gould 1979). This model, based on clinical experience and extensive research, recognises core deficits in the areas of

- social interaction
- communication and
- imagination,

and crucially indicates that the severity and manifestation of these fundamental impairments will vary significantly:

> we found that all children with 'autistic features', whether they fitted Kanner's or Asperger's descriptions or had bits and pieces of both, had in common absence or impairments of social interaction, communication and development of imagination. They also had a narrow, rigid, repetitive pattern of activities and interests. The three impairments (referred to as the 'triad') were shown in a wide variety of ways, but the underlying similarities were recognizable. (Wing 1996: 25)

The strength of Wing's model is that it is flexible enough to embrace the full range of the autistic spectrum while remaining conceptually coherent and focused on these three core deficits. A diagrammatic representation of the triad might look something like Figure 1.1, in which the dark grey circle represents impairment in social communication, the pale grey circle impairment in social understanding and the white circle impairment in imagination. Autism occurs where all three circles intersect.

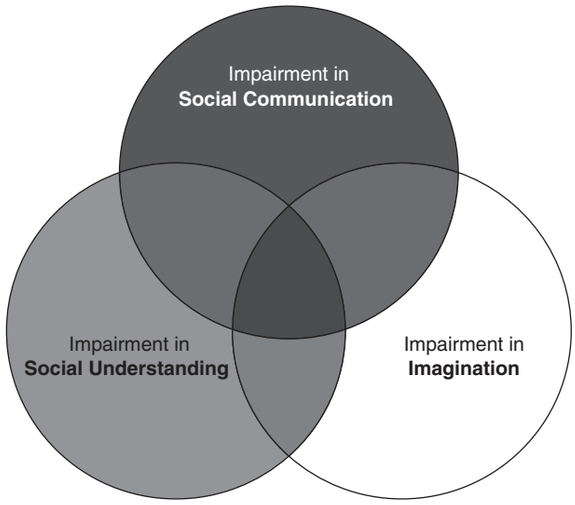


**Figure 1.1** The triad of impairment

For educators, in both mainstream and specialist settings, Wing's model allows us to see each child's condition uniquely. While it is necessary for all three impairments to be present, the degree to which each of these components affects the person with autism varies from individual to individual. For some people, one element of the triad may be particularly marked, while others may show significant difficulties across two components and hardly any in the third. For certain people, the overall impact of the triad may be profound, whereas for other people the effects may be comparatively manageable. The infinite possible combinations and permutations of the triad accounts for the huge breadth of the autistic spectrum and the great variety found within it.

A further benefit of this model for educators is that it enables us to reflect on our practice and the environments we practise in from the perspective of a person with impairments in these three crucial areas. Schools are essentially *social* settings which operate through the medium of *communication* and depend upon an *imaginative* negotiation of an infinitely complex and unstable environment. If a person experiences fundamental problems in these key areas, it is little wonder that, regardless of their cognitive potential, schools are difficult places to be.

Another important idea to consider is **mind-blindness** (Baron-Cohen 1990; 1995) which is based on the view that people with autism lack a 'theory of mind'. Simon Baron-Cohen argues that a theory of mind, that is, the ability to appreciate the mental states of oneself and other people, is a prerequisite to effective functioning in social groups. The argument continues that as the human race evolved and societies became increasingly complex and subtle, so the capacity for greater 'social intelligence' increased in order to allow us to process information about the behaviour of others and respond accordingly. This 'adaptive' behaviour is usually evident in children from around the age of 4 onwards. However, children with autism seem to lack the ability to 'think about thoughts' (Happe 1994) suggesting they are impaired in specific but, crucially, not all, areas of socialisation, communication

and imagination. As educators we might see the lack of a theory of mind emerging as an inability to grasp the social etiquette of the classroom, an apparent lack of feeling towards peers or a failure to share the excitement that other children may feel. Quite simply, children with autism cannot get inside other people's heads, therefore their understanding of others is profoundly limited.

Early developmental difficulties which may be associated with mind-blindness include problems in infants showing joint attention skills (Sigman et al. 1986), usually evident by 14 months of age and the later failure of children with autism to engage in pretend play (Leslie 1987), which normally emerges between 18 and 24 months old. As a theory of mind is not usually fully developed before 4 years of age, difficulties in these two areas may be seen as early indicators of subsequent problems. In the normally developing child, sharing attention with another person shows an awareness of the separateness of another person's thoughts. Joint attention skills incorporate monitoring or directing the focus of attention of another person through pointing, gestures and gaze monitoring and are invariably absent in the child with autism. Similarly, the ability to engage in pretend play depends upon having a concept of another person's 'mental attitude' (Cohen and Volkmar 1997) towards an object or activity, that is, an awareness that they are pretending too. The failure of this skill to emerge prefigures difficulty in the realm of appreciating other people's thoughts, that is, mind-blindness. For educators, these early signs may be evident in pre-school settings as infants and children appear to be disinterested in activities which captivate other children and fail to engage in the shared fun of pretend play.

The third element which educators need to be aware of relates to the difficulties people with autism have in the area of **executive function**. Executive function is the mechanism which enables us to move our attention flexibly and easily from one activity or object to another. It allows us to plan strategically, solve problems and set ourselves objectives so that we can control our behaviours in planned and meaningful ways (Norman and Shallice 1980). The absence of such a mechanism determines that all our actions are controlled by the environment in response to cues and stimuli, leading to apparently meaningless activity. Without executive function, actions and behaviours compete for dominance in a disorganised and inconsistent manner leading to an inability to plan and execute goal-generated behaviour. In a school setting, this emerges as highly distractible behaviour coupled with a dependence upon ritual and routines and an apparent disregard for the school timetable or the completion of tasks.

A fourth concept which educator's need to consider is that known as **central coherence theory** (Frith 1989). This notion relates to our natural impulse to place information into a context in order to give it meaning. It is usual for human beings to take an overview of things, to look for the 'big picture' and assimilate the detail into that whole. However, people with autism tend to focus on the detail rather than the whole, picking out the minutiae rather than understanding the 'big picture'. It has been found that people with autism show superior abilities in finding the 'embedded figures' from pictures (Shah and Frith 1983) and that children with autism are better able to recognise the identity of familiar faces from a part of the picture than their non-autistic peers (Campbell et al. 1995). Similarly children with autism fail to use context clues when reading (Happe 1994) often mistaking the meaning homophones, for example tear – as in drop – for tear – as in paper. While

some of these examples refer to superior ability, this superiority denotes a failure to appreciate the whole and accounts for the piecemeal way in which people with autism acquire knowledge and the unusual cognitive profile presented by many people with autism. Educators may detect the lack of central coherence in the narrowed interests of children with autism, in the ways in which students with autism are often unable to generalise skills or the way in which children with autism often display areas of relative strength described as islets of ability.

A fifth and critical aspect of autism that educators must consider relates to the all pervading impact of **sensory processing** in students with autism. Historically, some degree of sensory difficulty associated with autism had been noted as far back as Kanner's work. However, it is in recent years that difficulty in processing sensory information has gradually come to be recognised by many as a further defining feature of autism. Researchers such as Olga Bogdashina (2003) have focused attention on the sensory-processing difficulties experienced by people with autism, while the work of writers such as Donna Williams (1992) and Wendy Lawson (2000) has provided powerful personal testimony into the impact of these difficulties. More recently, it has been argued that impairments in sensory processing can be regarded as the source of other difficulties commonly associated with autism. Whatever position we might take, sensory-processing difficulties have a profound and pervasive impact on people with autism and must be recognised as such.

Sensory processing difficulties emanate from neurologically based features which determine that people with autism are often either hyper-sensitive or hypo-sensitive to sensory stimuli. Consequently, a person might be extremely sensitive to particular sounds, repulsed by certain smells and tastes, easily distracted by the visual environment or resistant to tactile sensations. Equally, a person might appear not to hear the loudest noises, be prepared to eat or mouth almost anything, apparently not notice the world around them or be able to withstand extremes of temperature or physical pain. Crucially, the same person may have any combination of these features and their presentation may be variable.

Experiencing hyper-sensitive or hypo-sensitive responses to sensory stimuli determines that a person is unable to effectively filter, balance and integrate the sensory input they receive. Consequently, they are bombarded by a cacophony of stimuli which they cannot process effectively into a coherent understanding of their environment. In order to cope with this onslaught of sensory information, people with autism are likely to 'mono-process', that is, focus on one sensory channel. This results in the person being unable to process more than one element of sensory input at a time. Therefore, the person may not be able to look at someone else while they are listening to them or sit still while they are looking at something.

The implications of this for the person with autism are profound and far-reaching. Forming relationships, remaining safe in a chaotic environment and learning in the rich and varied stimulus of the modern classroom are all severely compromised by the inability to process sensory input effectively and consistently. It is little wonder that this feature of autism has assumed such importance over the last few years.

The concepts described above represent part of the conceptual framework which underpins current thinking in the field of autism. It is important to consider this

framework as developing dynamically as our knowledge of the condition increases. However, the ideas discussed above are well founded and remain established as significant agents in our understanding of autism and are of particular use to the educator engaged in identifying those features of the learner which represent relative strengths and those which present the learner with challenges. Whatever way we choose to view the learner with autism, we must adopt a holistic view which incorporates those qualities that support their progress, those elements of the condition that can be a barrier to their learning and, crucially, the person in and among the conceptual framework.

## A changing context

The field of autism is currently among the most active domains in terms of research and the development of ideas and practice across the world. Geneticists, psychologists, neurologists, educators, legislators and social care commissioners and providers are making significant progress towards improving outcomes for people with autism, and people with autism are consistently proving themselves to be valuable and valued members of society.

In England, the Autism Act came into force in November 2009 and became the first piece of UK legislation focused on a specific condition. This Act placed a duty on the government to produce an autism strategy for adults by April 2010 and to issue statutory guidance to local authorities and local health bodies in respect of supporting the needs of adults with autism by the end of 2010. It is important to recognise that there is a long journey from legislation to an improved quality of life; nonetheless, it is encouraging to consider that the young people educators are working with today will experience better opportunities as adults than those of previous generations.

Legislative bodies in other areas of the UK have addressed the development of a national approach to autism. As far back as 2002 the Welsh Assembly was working on a strategic plan for autism while, more recently, the Scottish government produced a draft Scottish Autism Strategy. This governmental intent across the UK indicates that there is a clear recognition of the need to address the needs of people with autism in a strategic and coherent manner.

Alongside these legislative changes, there are distinct societal changes that will hopefully lead to a better quality of life for people with autism. Increased coverage in the media has led to a greater public awareness of the condition and although some of that coverage may be lurid or sentimental most of it serves some purpose in promoting an understanding of autism. As public awareness grows it is likely that acceptance of the condition and its associated strengths will grow proportionately.

Of course it is not only the media that can support this process of increasing awareness. Organisations such as the National Autistic Society, the Scottish Society for Autism, Autism Cymru, the Autism Education Trust and a plethora of regional and local autism societies are unstinting in their promotion of the understanding of autism and provide support networks for parents and professionals alike.

This increasing social awareness is coupled with significant breakthroughs in the fields of scientific and medical research. The Autism Genome Project is a large scale international collaboration which is endeavouring to identify the genetic architecture of autism. The AGP has published over 200 papers on autism since 2003 with scientists from over 50 research centres working together. Phase One of the project which ran from 2004–2007 established the world's largest gene bank for autism, providing the most comprehensive database of autism available. This Phase of the project also produced the most comprehensive genome scan into the genetics of autism.

Phase Two of the AGP was launched in 2007 and focused on identifying meaningful genetic variants associated with autism. The final set of reports from Phase Two began emerging in the Summer of 2010 and papers relating to this period of research are continuing to be published as the AGP endeavours to secure funding for a Third phase of research.

The momentum behind research into the genetic nature of autism is replicated in other medical and scientific fields as researchers seek to identify causative factors and interventions which might ameliorate the condition. Recently, the Medical Research Council reported a pioneering approach to diagnosis in adults using brain scan technology, while a burgeoning body of research is focused on developing nutritional interventions for people with autism (MRC Press release 10 August 2010 and www.mrc.ac.uk/Newspublications/News/MRC007083).

Autism remains an enigmatic condition deeply rooted in the most complex of aspects of humanity. However, the context around autism is rapidly evolving as new learning gathers speed, propelling our understanding of autism forward in what is potentially an exciting and beneficial future.

### Key points for reflection

- In what ways has our understanding of autism developed since Kanner's original work in 1943?
- Visit the Autism Genome Project's website in order to keep up to date with important discoveries in this area.
- Think about a child or young person with autism who you know. Try and integrate the various models of autism described in this chapter to develop a holistic understanding of that person.

## Further reading

1 Bogdashina, O. (2003) *Sensory Perceptual Issues in Autism and Asperger Syndrome: Different Sensory Experiences, Different Perceptual Worlds*. London and Philadelphia, PA: Jessica Kingsley. A critical text in supporting our understanding of the profound and lifelong effect of sensory processing difficulties; provides the very useful Sensory Profile Checklist – Revised (SPCR).

2 Lawson, W. (2000) *Life Behind Glass: A Personal Account of Autism Spectrum Disorder*. London and Philadelphia, PA: Jessica Kingsley. A beautifully written account from the frontline, describing the experiences of the individual with autism from their perspective as a 'permanent onlooker'.

3 Williams, D. (1992) *Nobody Nowhere*. London and Philadelphia, PA: Jessica Kingsley. A moving personal narrative focusing on the isolation experienced by the writer in a strange and confusing world.

4 Wing, L. (1996) *The Autistic Spectrum*. London: Constable and Robinson. A seminal text which stands the test of time and is a must for anyone starting out in the field.

## Useful links

1 www.aspiedebi.com

2 www.autism.org.uk

3 www.autismgenome.org

4 www.autismeducationtrust.org.uk