Learning objectives

This chapter will help readers to:

- understand autistic spectrum disorders;
- explore the criteria for identification and assessment;
- gain some insights into the branches of research and proposed changes to the Diagnostic and Statistical Manual of Mental Disorders (DSM) V; and
- understand intervention strategies.

BACKGROUND AND HISTORY OF AUTISTIC SPECTRUM DISORDER (ASD)

The last twenty years has witnessed a significant rise in the number of children diagnosed with autism. Of that there is absolutely no doubt. It has been suggested that ten years ago 1 in 500 children were diagnosed with autism; today the figure is 1 in 110 (Pinto et al., 2010). Similarly in the USA the Center for Disease Control (CDC) found in studies conducted in 2007 that the incidence rate of ASD is higher than the rates found from studies conducted in the USA during the 1980s and early 1990s. The CDC survey (http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a2.htm) assigned a diagnosis of ASD based on health and school records of 8-year-olds in 14 communities throughout the USA. The CDC estimates that 2–6 per 1,000 (from 1 in 500 to 1 in 150) children have an ASD. The risk is three to four times higher in males than females. Today the proportion of boys diagnosed with autism is around 60% of new cases, and this is more or less in line with that of 10–20 years ago.

In the UK estimates also indicate that the prevalence of autism is high. The figures suggest almost 40 in every 10,000 are autistic and 116 per 10,000 for the entire autistic spectrum (Baird et al., 2006). There is some debate on whether this increase represents a true increase in the prevalence of autism or whether it reflects changes in the criteria used to diagnose autism, along with an increased recognition of the disorder by
professionals. Many questions, hypothesis and accompanying explanations have been put forward for this dramatic rise in autism. These range from environmental factors to better and more accurate detection and neurobiological, chemical and emotional influences, or even misdiagnosis. Whatever the cause of this increase there is a need for teachers, parents and professionals to collaborate and work towards effective and life-long intervention. This chapter looks at these issues and challenges and suggests some responses to them.

HISTORICAL ASPECTS

The term ‘Kanner’s syndrome’ was first assigned to autism following the work of Dr Leo Kanner in 1943 of the Johns Hopkins Hospital in the USA. He studied a group of 11 children and introduced the label early infantile autism into the English language. At the same time a German scientist, Dr Hans Asperger, described a milder form of the disorder that became known as Asperger syndrome (Asperger, 1991). This latter group was characterized by Asperger by their social and communication deficits, their obsessions and dependence on rituals and routines. Kanner’s syndrome was characterized by abnormal communication, abnormal social communication, ritualistic and stereotyped behaviour and resistance to change (Howlin, 2002). This is shown in detail in the International Classification of Diseases and Related Health Problems (ICD-10) (WHO, 1992) which stated, for example, that ‘abnormal or impaired development’ needs to be in one of the areas of receptive and expressive language, social attachment and reciprocal social interaction, and functional or symbolic play, and should be evident before the age of 3. ICD-10 also goes on to show specific symptoms in each of these categories (for example, in social interaction, a failure to make eye contact and inappropriate facial expression (body posture and use of gesticulation). In communication, for example this would be a delay in spoken language and a failure to sustain conversational exchange and, in play, a preoccupation with non-functional elements of play.

Thus these two disorders are also described in DSM IV TR (fourth edition, text revision) (APA, 1994) as two of the five pervasive developmental disorders (PDD), more often referred to today as ASD. All these disorders are characterized by varying degrees of impairment in communication skills and social interactions, and restricted, repetitive and stereotyped patterns of behaviour. The three PDDs that relate to autism are:

- autistic disorder (also called autism, classic autism and AD);
- PDD-NOS (pervasive developmental disorder – not otherwise specified); and
- Asperger’s disorder (also called AS, Asperger’s syndrome and Asperger syndrome).

DSM V (IMPLEMENTATION IN 2013)

A number of issues rise from these three differing PDDs, and these issues will gain more attention when DSM IV is replaced with DSM V in 2013. For example, DSM IV
categorizes autism as a mental health disorder, but there is some debate about whether this classification is appropriate as some may classify it as a language disorder. Additionally, there still remains some confusion on whether autism and Asperger’s syndrome represent different conditions.

The draft for ASD is as follows:

Must meet criteria 1, 2, and 3:

1 Clinically significant, persistent deficits in social communication and interactions, as manifest by all of the following:
   a. Marked deficits in nonverbal and verbal communication used for social interaction
   b. Lack of social reciprocity
   c. Failure to develop and maintain peer relationships appropriate to developmental level

2 Restricted, repetitive patterns of behavior, interests, and activities, as manifested by at least TWO of the following:
   a. Stereotyped motor or verbal behaviors, or unusual sensory behaviors
   b. Excessive adherence to routines and ritualized patterns of behavior
   c. Restricted, fixated interests

3 Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities) (http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94)

Significantly, the draft version of DSM V indicates that one of the issues mentioned earlier will be addressed, as one of the changes in the draft DSM V is the loss of the Asperger’s label, which has always been recognized as part of the autistic spectrum. Additionally, the draft version indicates that the category PDD-NOS will no longer exist as a separate category and will be subsumed into the ASD label in the same way as Asperger’s.

Yet Howlin (2002) suggests there are a number of factors that differentiate between autism and Asperger’s syndrome. She suggests the prevalence rates may be higher for Asperger than for autism. She also suggests that the research indicates that there is often a significant difference in ages when children from the two groups are first diagnosed. In the autism group she suggests that the average age of diagnosis was 5.5 years, while in the Asperger group it was 11.3 years, and almost all (88%) of the children in the study with autism had been diagnosed before 10 years of age compared with only 45% of the Asperger group. At the same time it can be argued that the obvious similarities between the two syndromes suggest that they lie in the same continuum or spectrum. Asperger’s syndrome is often considered to be a type of ‘high-functioning’ autism, but there is some clinical controversy about whether it is a milder form of autistic disorder or a distinct disorder. Additionally, the term ‘high-functioning’ can be misleading as it does not necessarily translate to lower needs. This can have considerable implications for intervention and the allocation of resources.
CHARACTERISTICS OF ASDS

There are a number of key characteristics of ASD. The most prevalent are as follows:

Verbal and non-verbal communication:

- **Speech and language skills**: these may begin to develop but then lost, or they may develop very slowly or they may never develop. It has been estimated that around 40% of children with ASDs may not talk at all unless intensive early intervention is in place.
- **Communication**: gestures may be used or outstretching of the arm instead of attempting to use language. It may be difficult or impossible to imitate sounds and words.
- **Echolalia**: this is repeating something heard. For example, if you ask, 'Are you ready?' the response may be, 'Are you ready?' instead of answering the question. The repeated words might be said right away or much later and may be repeated over and over.
- **Non-verbal communication**: they may have difficulty in using gestures, such as waving goodbye, or using facial expressions to convey meaning.
- **Speech**: there is often an unusual pitch and rhythm in speech.

Social interaction:

- **Attention**: some people with ASDs may prefer to be left alone, showing no interest in people at all. They may not notice when people are talking to them.
- **Fitting in**: some people with ASD might be very interested in becoming part of a group, but do not know how to conduct themselves and relate to others. Difficulty ‘joining in’ is common in ASDs because they find it hard to ‘read’ or understand other people.
- **Peer group**: children with ASD may not relate to their own age group and prefer the company of adults or older children.
- **Eye contact**: some people with ASD make no eye contact or are less responsive to eye contact. Some may use peripheral vision rather than looking directly at others.
- **Facial expressions**: children with ASD may have difficulty in responding to or understanding facial gestures.
- **Tactile sensitivity**: children with ASD might not like to be held or cuddled, or might cuddle only on their terms. They can be sensitive in terms of touch.
- **Self-control**: they may have difficulty in controlling emotion and excitement

Repeated and unusual behaviours, interests and routines:

- **Ritualistic behaviours**: people with autism may have ritualistic actions that they repeat over and over again, such as spinning, rocking, staring, finger flapping and, in some cases, hitting themselves.
- **High anxiety state**: they can show intense anxiety or an unusual lack of anxiety. Anxiety, fear and confusion may result from being unable to ‘make sense’ of the world in the usual way.
- **Gait**: they can display unusual postures, walking or movement patterns.
- **Routines**: they might fiercely depend on routines and want things always to stay the same, and minor changes in the environment or in daily routines might trigger acute distress or fear.
Responses to sensations:

- **Stimulation processing**: they may have difficulty in making sense of environmental stimulation. People with ASD may have both auditory and visual processing problems, and sensory input may be scrambled and/or overwhelming to them. Sensory sensitivities vary in autism from mild to severe hyper and hypo-sensitivities.

- **Sensory stimulation**: they may have unusual sensitivities to sounds, sights, touch, tastes and smells.

**RESEARCH**

There is now considerable activity in the research field concerning explanations for autism and ASD and there is certainly too much to be discussed in any detail in this chapter. This chapter, however is more concerned with the issues and the challenges rather than recounting the details of research findings although, as we note, some of these issues will stem directly and indirectly from these. What is particularly staggering is the number of local initiatives taking place as well as major national and international projects. This can be noted when looking at the policy documentation of different areas of the country. For example, in Ireland, the report of the Task Force on Autism (2001), which was one of the earliest policy initiatives in the field, laid the groundwork for local research run by teachers, psychologists and parents. It recommended that, as a matter of urgency, research be conducted into the national prevalence of autistic and asperger disorder (p. 7). The report also suggested that formalized Department of Education and Science–university partnerships should be established to develop appropriate programmes for people with ASDs and that research should be carried out on methodologies and approaches, on the benefits of various clinical interventions and on the specific components of teacher and classroom assistant training, as well as on curricular interventions and strategies. The report suggested there needs to be a systematic evaluation of all pilot projects.

It is this connection between international and national initiatives and local pilot studies or policy studies that needs to be synchronized. If there are no local initiatives or clear policies to guide parents (and teachers), they may grasp at some sensational newspaper headline story offering new treatments and cures for autism and may select these, even though they may not be scientifically validated. It was interesting that the Republic of Ireland in their task-force report made considerable efforts to include parents at all stages of assessment and provision. For example, one of the recommendations was the introduction of Statutory Child and Adult Family Support Plans for those with an ASD. This multiagency co-ordination was also profiled in the Additional Support Needs Act 2004 in Scotland in terms of the development of co-ordinated support plans. While the Act does make it clear that a child does not necessarily need to have a diagnosis or disability to be considered as having additional support needs, it is also quite clear that people with an ASD will be considered as having a disability. This means that the parents of children who have been diagnosed with an ASD will need to ensure that their child receives the additional support necessary. The implication of this is that labels in themselves, although they can be helpful, will not necessarily guarantee addition support.
In England and Wales the Special Educational Needs Disability Act 2001 (SEND Act) highlights the need for schools to make reasonable adjustments and that failure to make reasonable adjustments so that students have equal access to admission arrangements and to education services is unlawful. The reasonable adjustments duty requires schools to anticipate the barriers that disabled students, such as those with autism, may face. The National Autistic Society in the UK has provided an example of this where a boy with autism became anxious when the fire alarm sounded. There may have been reasonable adjustments the school could have made to prevent this. For example, staff at the school could have been trained about autism, about strategies to avoid difficulties and about how to overcome difficulties if they did arise. The pupil could have been given training for social situations and strategies for coping when the fire alarm is raised (http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1760&a=13883). It is clear, therefore, that legislation, policy and training all have a major role to play in ensuring that the needs of students with ASD are met.

THEORETICAL PERSPECTIVES

According to Pellicano (2007), the three main theories that relate to ASD are the theory of the mind (the ability to recognize one’s mental states and that of others), the theory that relates to executive functioning (which involves independent and responsible thinking and dealing with new situations) and the theory of information processing (particularly relating to coherent and organized thought processes). But Pellicano also suggests that these accounts fall short of providing a full picture of ASD.

EARLY DETECTION AND GENETIC EXPLANATIONS

It is interesting to review data on the early detection of autism and particularly theories on causes. Roberts (2010) suggests that one of the recent achievements in this field is the possibility of identifying the neurobiological manifestations of autism as early as 9 months. She suggests that between 9 and 15 months infants with autism begin to withdraw and, with training and precise indicators, we could be looking at detection around that age range. This will clearly have a profound effect on the child’s developing competencies. As Roberts suggests at this age one is more likely to be able to modify the association pathways of the developing brain before they are too firmly established. Despite the clear biological case for ASD, according to Gillberg and Coleman (2001: 111), ‘there are as yet no reliable and valid biological markers for autism’.

There is, however, vigorous activity in the field of genetics in relation to ASD. The Autism Genome Project (which includes 50 academic institutions from 15 countries collecting data from 8,000 people and 1,600 families) represents a significant breakthrough in this area. The result is, as Szatmari (2010) claims, that more progress has been made in the last five years than in the fifty years previously (see also Pinto et al., 2010). He suggests that 90% of autism arises from a result of genetic differences. The researchers in the project have located a considerable number of target genes which appear to play
a role in how nerve cells communicate with each other. This is a current area of focus in early detection and may lead eventually to intervention and preventative work.

IDENTIFYING ASD

There are a great many issues and a great deal of controversy in the diagnosis of autism. These issues include either (or both) late diagnosis or misdiagnosis. There are examples of autism being misdiagnosed for attention deficit hyperactivity disorder (ADHD), auditory processing disorder, Rhett's syndrome, hearing difficulty, language disorders, speech delay, developmental delay and selective mutism. It is important therefore that a diagnosis should not rest on one test, or even one professional, but should be a multidisciplinary team approach using a range of assessment methods. A good example of this is in British Columbia where the Sunny Hill Health Center has a multidisciplinary team located at the Autism Spectrum Disorder Clinic. This team undertakes assessments for autism for children of all ages that are designed to meet individual needs, and it undertakes school planning and medical and/or behavioural management and links with the British Columbia Autism Assessment Network.

ASSESSMENTS PROCEDURES

The procedures for identifying autism should be clear to parents and they, themselves, should have an important role in this process. Ideally the process should include the following:

- An examination and evaluation of the child’s sensory status (hearing, vision (including visual skills such as tracking), depth perception and auditory skills (such as source matching and auditory discrimination)).
- Interviews with parents, teacher and, where appropriate, the child.
- Direct behavioural observation in multiple settings.
- Completion of checklists by or with parents or caregivers.
- Formal psychometric evaluation of the child’s cognitive, social, emotional, behavioural and adaptive functioning.
- An evaluation of literacy and numeracy readiness or attainment.
- An evaluation of the skills involved in the activities of daily living.
- A functional analysis of targeted behaviours (in cases where behavioural difficulties have been identified).
- An evaluation of learning style (e.g. preference for verbal or visual).
- An observation and evaluation of instruction (for example, how the child best scans and focuses to receive visual information, attention and concentration on tasks).
- An analyses of their problem-solving approaches.
- An examination and evaluation of the child’s gross and fine motor skills, of sensory integrative functioning and lateral dominance.
Autistic Spectrum Disorder: Challenges, Issues and Responses

- An evaluation of mental-health status and possible affective disorder.
- An assessment of the child’s social status with peers.

It is important to note that the characteristics of children with ASD will vary greatly in severity from individual to individual. According to the National Institute of Mental Health (NIMH) in the USA, following an assessment using observations and test results, the specialist should only make a diagnosis of autism if there is clear evidence of poor or limited social relationships; underdeveloped communication skills; and repetitive behaviours, interests and activities. People with autism will normally have some impairment within each of these categories, although the severity of each symptom may vary. The NIMH diagnostic criteria also require that these symptoms appear by the age of 3.

**TESTS AND STRATEGIES**

In an interesting and forward-thinking discussion paper on autism in 1997 for Lancashire County Council in the UK, Connelly asserted that keeping the diagnosis of autism as a medical one may be helpful but it can cause confusion and ‘can cause immense problems in terms of local people prepared to take on this role. ‘I think [one] should accept that in local circumstances … local arrangements should be made to accept diagnosis by such groups as our own’ (p. 13). This statement does capture the potential for conflict between the medical professionals and educational and psychological assessors. As the report goes on to say, however, ‘with good liaison between various agencies … it is not important who makes the diagnosis’. It appears that the emerging consensus and best examples of practice in different countries are in fact those areas that have specially trained psychologists in the field of autism working collaboratively as part of a diagnostic team with other professionals and medical personnel. A number of medical authorities have taken initiatives for diagnosing autism. For example, in Scotland the National Health Service have convened a Scottish Intercollegiate Guidelines Network (SIGN) (2007). In their report of July 2007 (http://www.sign.ac.uk/pdf/sign98.pdf) they advocate the benefits of the diagnostic criteria of ICD-10 and DSM IV (see earlier in this chapter) and they quote three studies (e.g. Klin et al., 2000) that agree that using DSM IV or ICD-10 will make the diagnostic procedure more reliable. They also suggest that the aim of specialist assessment is to formulate a multiagency management plan ‘leading to an appropriate programme of supportive intervention’.

Although there are commonly used tests for autism, it is important to reiterate that a test alone will not be sufficient to diagnose autism accurately. It is also important to contextualize the assessment for practice and that interventions should result from the assessment as well as a diagnosis – if appropriate.

**INTERVENTION**

Just as in the area of assessment the often marked difference in perspectives between the medical and educational professions can be noted in intervention. This is an ongoing
issue but with increasing legislation and a task group looking at the area of autism, there now appear to be more concerted and collaborative efforts by the range of professionals who are involved in ASD. We are aware that there is no known and unequivocally accepted cure for ASD. There are, however, a vast number of therapies and interventions designed to remedy or modify specific symptoms, and these can bring about substantial improvement in many cases. Ideally the most effective intervention is one that coordinates ‘therapies’ and ‘interventions’ that meet the specific needs of individual children. Most educational and healthcare professionals agree that the earlier the intervention, the more likely a desirable outcome will result.

**IMPACT ON LEARNING**

The characteristics of ASD noted earlier in this chapter do mean that children in the ASD spectrum will have considerable challenges in learning. As a result they will need specific teaching methods in a sensitive and carefully planned environment. For example, in the educational setting they may show the following:

- An inability to imitate sounds, gestures and gross or fine motor movements that are all necessary for learning, particularly in the early years.
- An inability to focus on the task at hand. Some children will have a very short attention span or concentrate only on one thing obsessively.
- Difficulty working collaboratively with others in the class.
- Difficulty with abstract ideas, such as in using items or toys to represent real objects (make-belief play and role play).
- Difficulty grasping the concept of time and the order of events.

There are in fact numerous learning challenges that can be experienced by children in the ASD spectrum. Howlin (2002) notes the vast range and diversity of approaches that are used with children with ASD. These include auditory integration training; a range of different types of behavioural approaches; cranial osteopathy; dietary and vitamin treatments; facilitated communication; and Gentle Teaching (McGee, 1985; Jones and McCaughey, 1992) – a non-aversive method of reducing challenging behaviour that aims to teach bonding and independence through gentleness and respect. Other well-known methods include Holding Therapy – the aim of which is to provoke a state of distress until the child will feel a need for comfort though holding (Howlin, 2002).

Music therapy has become accepted as a useful intervention for people with autism since it was introduced to the UK in the 1950s and 1960s by such practitioners as Juliette Alvin, Paul Nordoff and Clive Robbins. Nordoff and Robbins describe significant changes in the communicative and social behaviour of individuals with autism who took part in music therapy (http://www.nordoff-robbins.org.uk/http://www.nordoff-robbins.org.uk/). In November 2005 the Nordoff–Robbins Research Department hosted a research symposium entitled ‘Evidence-based practice and music therapy: a further perspective’, with a keynote presentation by the sociologist,
Tia DeNora, on the role of music therapy. One of the many resulting publications offered stringent advice and procedures for empirical evaluations and randomized control trials of music therapy (Nordoff and Robbins, 2009). This publication has been internationally helpful in offering snapshots of current research supporting the use of music therapy.

Woodword (2004) found that music therapy can play an important role for the parents of children with autism by fostering relationships and developing positive interactions, and Gold et al., (2006) found that music therapy may help children with ASD to improve their communicative skills. This theme is advanced by DeNora (2006) from health and sociological perspectives. Other therapies that have been noted include pet therapies; physical exercise; psychotherapy and sensory integration therapies. Some of the key points on intervention are commented on below.

EDUCATIONAL/BEHAVIOURAL INTERVENTIONS

There has been a recent increase in interest in verbal behaviour therapy in particular (Barbera, 2007). This type of therapy can be controversial because it is based on a philosophy – applied behaviour analysis (ABA) – which is an intensive, one-on-one, highly structured behaviourist programme. It is usually utilized by trained therapists employing intensive skills-oriented training sessions to help children with ASD develop social and language skills. ABA is based on the work of Ivor Lovaas, and studies such as McEachin et al. (1993) provide supportive evidence for its use. It is an intervention that is costly in terms of time as it can take around 40 hours a week of one-to-one intervention and it is unlikely to fit into the normal pattern of the inclusive school unless special arrangements are made. Barbera (2007: 162) however suggests it has considerable benefits for all children with ASD and remarks:

some may ... try to convince you that your child is too high functioning or low functioning to benefit from ABA ... My experience tells me differently. It does not matter where your child falls on the spectrum – ABA ... can help.

FACTORS TO CONSIDER

When selecting therapies/intervention for autism, the following factors need to be considered:

Educational:

• Provision – extent of inclusion/specialist provision.
• Curriculum issues – is full curriculum offered/extent of differentiation?
• Is the individual education plan (IEP) appropriate and the classroom management strategies that are in place?
• Interventions and specialist therapies – the availability of verbal/behaviour approaches and other specialist programmes.
Home:
- Challenges and issues at home.
- Support available for parents and siblings.
- Links with school.

Social:
- Social models of disability – community support.
- Concept of neurodiversity – the role of individual differences – spectrum of differences rather than disabilities.

Post-school:
- Support available.
- Needs of young person – further education and the workplace.
- Issues for the family.

The above points raise some of the issues that can become a challenge for the young person and their school and family in relation to ASD. To discuss these here would be beyond the scope of this chapter but we have included at the end of this chapter a list of useful websites of relevant organizations that discuss and advise on these issues. Some have been referred to throughout this chapter and their work is both current and impressive. It is this sort of endeavour and supportive advice based on sound professional principles that can provide both hope and inspiration to all involved in this field.

In view of the number of behaviours, the spectrum from mild to severe and the proposed changes to DSM IV, which indicate that the category of Asperger’s should not be used, it has been decided not to include a case study in this chapter because this may be misleading. But it is important to keep in mind the insightful and penetrating comment made by Rita Jordan (2010) when discussing intervention for children with ASD: ‘treating them equally does not mean treating them the same, but treating them differently to ensure equal access.’

**SUMMARY**

- The prevalence of autism has increased in recent years, but the cause of this increase is subject to debate.
- The criteria for the identification and assessment of autism are due to change as a result of the redrafting of DSM IV. DSM V is due to be implemented in 2013.
- Autism and Asperger’s syndrome are different disorders that lie somewhere on the same continuum.
- There are a range of specialized approaches that can be used for assessment, testing and intervention.
Further Reading


Jordan, R. (1999) Autistic Spectrum Disorders: An Introductory Guide for Practitioners. London: David Fulton. This book has been reprinted a number of times and is an excellent resource. It is written for practitioners working in the field of autism and related disorders (including Asperger’s syndrome) and it offers an overview of understandings of these disorders from a behavioural, biological and psychological perspective.


University of North Carolina School of Medicine (n.d.) Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) (Appendix 2). Chapel Hill, NC: University of North Carolina, School of Medicine. Assessment criteria, checklists and tests.

Useful Websites

Autism Society, USA http://www.autism-society.org/site/
Autistic Society, Canada www.autismsocietycanada.ca
Mind Blind www.mindblind.co.uk
National Autism Association, USA http://www.nationalautismassociation.org/
National Autistic Society, UK www.nas.org.uk/
The US Department of Health and Human Services has a federal Interagency Autism Co-ordinating Committee. One of the committee’s key functions is developing a strategic plan for spectrum disorder research http://sacramento.bizjournals.com/sacramento/stories/2010/04/26/daily69.html


References


