Definitions of autism, common features and relevant legislation

Introduction

In an era of increased inclusion within society in general, early years practitioners are under increasing pressure to accept more and more young children from a range of backgrounds and with a range of individual needs. Current legislation and policy also emphasise the importance of providing effectively for all children.

I would suggest that all children have individual needs which change according to their age, circumstances and life events. Some changes will result in a short-term additional need, such as settling in to an early years setting, whilst other needs will be much longer term, such as autism.

This chapter will explore general issues of special needs and early years provision before narrowing the focus to begin unravelling the specific range of autistic spectrum disorders. Through clarifying definitions and identifying common features, readers will develop an understanding of ‘the autistic world’. This knowledge, combined with the information gained from subsequent chapters will give practitioners increased knowledge of how best to support children with autism and their families. The requirements of current legislation and policy will be discussed.
together with the more general definitions of SEN.

Throughout my own working practice with young children with autism I would conclude that whilst such children may have offered me the greatest challenges, they have also given me the greatest rewards, and for that reason they deserve the best that practitioners can offer.

Developments in special needs

Research continues to inform our knowledge and practice and has led to considerable progress over the past century, resulting in many changes in government policy and, subsequently, legislation.

In the early twentieth century, people experiencing learning difficulties were deemed to be ineducable and terms such as ‘idiots’ and ‘imbeciles’ were commonly used to describe them. Sadly, such terms still exist and are used by a minority today. Within my own working practice I have preferred to discuss ‘individual needs’ in a more inclusive way as I consider that all children are different. Some are tall, some wear glasses, some have autism, some are visually impaired, but they are all primarily children. If society is developing a more inclusive philosophy then we should rid ourselves of terms such as ‘special needs’ and ‘special educational needs’, as our society should be accepting of all and provide for all. If we continue to consider children as having special needs and adapt our provision to accommodate them, we are not demonstrating real inclusion. This issue will continue as long as the government continues to produce separate legislative and guidance documents which segregate or exclude.

However, others may argue that without such separate documentation, effective legislation and provision could not be assured. We therefore continue to work within a ‘labelling’ framework that can bring its own problems. When welcoming a new child with special needs into our setting we may well have a report informing us of the specific difficulties experienced plus areas of strength and weakness. As practitioners it is then very easy to form inaccurate impressions about the child which affect our practice, and we may overlook any additional difficulties the child may be experiencing, but we should always remain vigilant and open-minded to other possibilities. Our expectations should remain high, but realistic, and we should be aware of any possible additional difficulties. For example, children with autism can also experience deafness. The key is to remain open-minded and ensure regular observations and assessments are an ongoing part of our working practice.
Developments in early years provision

In the early twentieth century whilst the value of pre-school provision had been acknowledged in Europe, within the UK there was no statutory pre-school provision for our youngest children. At the start of the twenty-first century we still do not have statutory provision for all children but developments are ongoing and are certainly moving in the right direction.

As far back as 1929 an education enquiry committee highlighted the differing needs of children under five and therefore the need to offer a separate nursery education, but at that stage no monumental changes were forthcoming. At the start of the Second World War, however, changes began but the 1944 Education Act (Ministry of Education, 1944), which had supported an expansion of nursery education, was overtaken by world events. During the war the need for some supported provision became imperative:

During the Second World War the government supported pre-school provision by way of grants, predominantly to release women to war-related workplaces as the majority of the male workforce was fighting for their country. In addition, the women needed to supplement the poor wages sent home by their husbands. (Wall, 2003a: 5)

After the war pre-school provision continued through a period of expansion but very much at a local, as opposed to national, level in response to local needs. As a result we are left with a diverse array of provision that varies geographically. There is not, as yet, equality of access for all children and their families to a full range of early years settings.

Additional factors, such as changes in housing policies, also affected the future for our youngest children. For example, in the 1950s and 1960s high-rise flats were built in many large towns and cities throughout the country. For young families with young children this meant that a simple trip to the park or shops became a major event, especially if the lift was out of order. This resulted in many families with young children being isolated from their local communities for considerable periods of time, thus limiting social and educational opportunities for both parents and children alike.

In the 1960s the playgroup movement became firmly established in the UK. Responding to local need, playgroups predominantly opened in village halls and community centres offering part-time social play sessions to local 3- and 4-year-olds. Over subsequent years the Pre-School Playgroups Association (PPA) evolved (now the Pre-School Learning Alliance, PLA) which initiated local networks and training for playgroup workers as well as campaigning on behalf of the early years.
Since the 1960s we have seen the development of family centres, funded jointly by education and social services, or by voluntary organisations; early excellence centres; 4-year-olds being accepted into nursery classes attached to and funded by schools; Sure Start centres and Children’s Centres. The resultant range of early years provision is considerable and is well documented elsewhere (Pugh, 2001; Wall, 2006), but is not necessarily consistent with equality of access for all. It will, as previously indicated, vary according to what is available in each neighbourhood. This variance should be further unified in the future.

Autism

Autism, like many other conditions or disorders, can affect people in a variety of ways, but is a lifelong developmental disability. I would suggest that unless practitioners have a good knowledge and understanding of autism then they may not be able to provide appropriately, and may inadvertently compound a child’s difficulty through lack of knowledge.

What is autism?

As a developmental disability autism can affect children, and adults, in a variety of ways and in varying degrees. Children with autism may be referred to as ‘aloof’ or ‘withdrawn’ as they appear uninterested in the world around them. Unlike other children the lack of desire to be part of so-called ‘normal’ everyday life presents practitioners and parents with an immediate barrier – how to access the world of the child to enable support and appropriate provision. If a child does not want to interact with anyone and only wishes to play with a box of toy trains, then how can we begin to plan to ensure progress?

In 1943 Leo Kanner presented a clinical paper highlighting the key features of children with ‘early infantile autism’, thus naming the condition, which previously had been accepted as an extreme mental disorder, considered by some to be the result of very poor mothering which caused the child withdrawing into him/herself.

Kanner’s article recorded the outcomes of 11 case histories, concluding that whilst some of the characteristics demonstrated by the children could be closely linked to existing syndromes or conditions, there was a clear indication of a separate and unique condition emerging. These characteristics included:

- lack of desire to communicate verbally;
- echolalic verbal utterances;
- fear in strange or unexpected situations;
lack of imaginative play activities;
• repetitive behaviours demonstrated.

Kanner also concluded that for some children the condition, or at least the predisposing conditions, were evident from birth whilst for other children the characteristics would not emerge until 2 or 3 years of age, and often in a regressive manner, that is, they appeared to develop skills which later disappeared. Wing (1976) suggests that Kanner’s reference to early infantile autism is ‘inappropriate’:

Kanner’s own preferred name ‘early infantile autism’ is not entirely appropriate since, in some cases an otherwise typical syndrome has developed during the second or third year of life. ‘Early childhood autism’ is probably not the most satisfactory term, since it does not carry the implication of an inevitable onset from birth and it does suggest that the autism is ‘maximal’ in early life and may improve later. (1976: 21)

Some would extend such a debate to suggest the term ‘autism’ itself is misleading, as Bleuler (1919) had identified autism as ‘one of the fundamental symptoms of schizophrenia’ (Wing, 1976: 11). Wing continues to highlight a key difference between Bleuler’s and Kanner’s usages of the term, describing Bleuler’s understanding of those with autism as demonstrating ‘an active withdrawal from contact with the world’ (1976: 11), whereas Kanner’s understanding outlined an ‘inability to relate’. This difference is still significant today as our understanding of autistic behaviours focuses on the lack of desire or perceived need to interact with others, more in line with Kanner’s work. This was also discussed by Rutter and Schopler (1978).

Asperger’s syndrome
Following Kanner’s paper in 1943, Hans Asperger highlighted a similar condition, Asperger’s syndrome, whereby children and adults demonstrating many features of autism appear quite able intellectually. Siegel (1996) summarised a fundamental difference between autism and Asperger’s syndrome: ‘most AS individuals have more mild impairments, higher IQs (especially higher verbal IQs), and a better ability to adapt than most autistic people’ (1996: 113). However, as Asperger’s work and findings evolved at a time of war, little was known about it until the early 1990s when Frith published a translation of Asperger’s paper, and since then the term has been used more widely.

There are many adults today who have only in adulthood been diagnosed as having Asperger’s syndrome. Able to attend mainstream schools and to secure later employment, these adults may have difficulties with, or feel uncomfortable in, social situations and often demonstrate precision, or repetitive behaviour patterns, in many aspects of their lives. Attwood
(1998) succinctly highlights the common features of Asperger’s syndrome: ‘A lack of social skills, limited ability to have a reciprocal conversation and an intense interest in a particular subject are core features of this syndrome’ (1998: 13).

**Defining autism**
Perhaps settling on one definition of autism is seeking the impossible as a vast array of definitions have been offered over the years. However, three classic features, which should all occur, arise in every definition and are often combined with repetitive and stereotypical behaviours. The impairments are in social interaction, communication and imagination.

![Diagram of the triad of impairments](image)

Figure 1.1 The triad of impairments.

Impairments in one or more of the above areas would not in itself warrant a diagnosis of autism. The final consideration is that the features must be present before the child reaches the age of 3. These three characteristics of autism are generally known as the triad of impairments (see Figure 1.1).

Over the past 20 years, as more knowledge has been gained from research and provision for children with autism has progressed, it has become common to hear of the ‘autistic spectrum’ extending from severe autism through to Asperger’s syndrome. What should always be remembered is that no two children with autism will present the same characteristics to the same degree, just as no two children are the same. The important key is for practitioners to increase their knowledge and understanding of autism so that children with autism that attend their settings can be supported and provided for in a way that will enable them to work towards their full potential. As with all children, talking to parents, observing the child, identifying their strengths, likes and dislikes, combined with knowledge and understanding of autistic spectrum disorders, will all inform planning and respond to the child’s individual needs. Effective planning
related to the individual needs of the child is the key for providing for
counties with autism, and even the child diagnosed with severe autism can
benefit considerably, thus enhancing future opportunities and moving
them away from the severe autism diagnosis on the autistic spectrum.

The government guidance document *Autistic Spectrum Disorders: Good
Practice Guidelines* (DfES/DoH, 2002) offers the following description of
autistic spectrum disorders:

Autistic spectrum disorder is a relatively new term to denote the fact that
there are a number of subgroups within the spectrum of autism. There
are differences between the subgroups and further work is required on
defining the criteria, but all children with an ASD share a triad of impair-
ments in their ability to:

- Understand and use non-verbal and verbal communication
- Understand social behaviour which affects their ability to interact with
  children and adults
- Think and behave flexibly – which may be shown in restricted, obses-
  sional or repetitive activities. (s. 2.1)

Perhaps a more accessible definition is offered by the National Autistic
Society (NAS, 2008a):

Autism is a lifelong disability that affects the way a person communicates
and relates to people around them. Children with autism have difficulty
in relating to others in a meaningful way. Their ability to develop friend-
ships is generally limited as is their capacity to understand other people's
emotional expressions. Some children, but not all, have accompanying
learning disabilities. All children with autism have impairments in social
interaction, social communication and imagination. This is known as
the triad of impairments.

**Prevalence of autism**

Figures relating to the prevalence of autism vary and the fact that autism
has become increasingly understood over the past 20 years has resulted in
an increase in such figures. This should not necessarily be interpreted as an
increase in the prevalence of autism in children, more as an indication of
increased knowledge and understanding.

Prevalence figures are further complicated by identifying those with classic
autism, Asperger's syndrome or even pervasive developmental disorder –
not otherwise specified (PDD-NOS). It can be difficult to discriminate
between autism and PDD-NOS as many similar characteristics may appear.
It therefore depends on the skills of the professional undertaking the diag-
nosis. Siegel (1996) summarises the key differences:

Generally, PDD, NOS can be thought of as essentially constituting a less
severe, or less fully symptomatic form of autism. Research studies have
shown that autism and PDD, NOS often have the same profile of symp-
toms but that the symptoms tend to be less numerous and less severe in
the child diagnosed with PDD, NOS. (1996:15)

Considering England only, Lotter (1967) presented the rate for autism at
that time as 4.4 per 10,000 people, whilst just over ten years later Wing and
Gould (1978) presented a rate of 4.9 per 10,000 people. More recently, the
National Autistic Society (NAS, 2008b) estimated that across the whole
spectrum of autistic disorders the rate is 91 per 10,000. All studies agree that
the incidence in boys is greater than that of girls and a reasonable average
would be 1:4, girls to boys. For practitioners, the reality is that they will be
likely to meet several children with autism during their professional career,
whether in schools or early years settings.

Signs of autism
The NAS (2008a) summarise the signs of autism as:

Children with autism exhibit a wide range of behaviours. Essentially
though, the child will have difficulty relating to others and making
friends; difficulty in communicating (some children may not talk at all);
and be unable to engage in imaginative play. Other signs include obses-
sions, fears, a lack of awareness of danger, ritualistic play and behaviour,
inappropriate eye contact, hypersensitivity to sound, light etc., spinning
objects and hand flapping. A child does not need to show all these signs
to be diagnosed as autistic and some children who do not have autism
may exhibit some of these behaviours.

Some young children with autism will have developed along accepted
developmental paths in the first 24–36 months of their life, but often
speech development may have been a little delayed (which is not uncom-
mon in young children, and especially in boys). Similarly a child’s social
skills could be delayed. Noticeable changes may then arise and initially
these changes may be slow to appear, but at some point parents will begin
to see elements of regression such as:

• new words may be used by a child a few times and then disappear;
• the child begins to repeat words, phrases or the ends of sentences spoken
to them in a ‘parrot-like’ fashion (echolalia);
• the child becomes more withdrawn, preferring solitary play;
• the type of play becomes less imaginative and more repetitive, e.g. only
playing with six cars and persistently lining them up;
• increased fear of new situations and people;
• resistance to change in routine;
• the child may no longer give direct eye contact but look out of the cor-
ner of his/her eye at people or objects (peripheral vision);
• the child may develop an obsessional fascination with one object, e.g.
light switches or doors;
• lack of fear or awareness of danger;
• sensitivity to some sensory stimuli, e.g. refusing to eat ‘lumpy’ food, averse to loud noises.

For those children who demonstrate autistic tendencies from birth, the following signs are indicative of an autistic spectrum disorder:

• baby does not develop eye contact, appearing uninterested when adults or objects approach;
• difficulty with sleeping or perfect ‘sleeper’;
• prolonged periods of extreme placidness;
• lack of babbling noises or sounds;
• no desire to be picked up;
• may seem agitated if cuddled.

However, one or more of these signs could mean acceptable, but delayed, development or be indicative of another disorder. For example, a placid baby may seem a bonus for many parents, but if the child does not develop babbling noise then this may be a sign of a hearing impairment. For such reasons a diagnosis of an autistic spectrum disorder in the first year of life is considered inappropriate. During the period from 12 to 24 months these tendencies then become more developed and often it is the parents who notice their child’s unusual patterns of behaviour. Signs at this stage could include:

• lack of interest in exploratory, exciting play;
• the child seeming comfortable in his/her own world with no apparent need for any interaction with other children or adults;
• being difficult to understand. The child may appear distressed but parents are unable to ascertain the reasons as no meaningful speech has evolved;
• unusual movements that may occur, such as hand-flapping, rocking or placing hands over ears;
• play being repetitive and apparently unimaginative;
• lack of development of pretend play;
• still resisting changes in routine and fearful of new situations;
• sensitivity to some stimuli becoming more pronounced;
• inability to interpret gestures or facial expressions;
• inability to understand language other than literally, e.g. ‘Jump in the bath’ can be interpreted by the child as a request to jump up and down in the bath, whereas the adult simply means ‘It’s time to have a bath’.

At this point many difficulties may emerge for the family and friends as the child’s, as yet undiagnosed, autistic behaviours may resemble that of a misbehaving child. Such situations can be severely compounded by the reactions and comments of family and friends or members of the public. Issues relating to the families of children with autism will be further explored in Chapter 2.
Characteristics of autism

If we reflect on the triad of impairments presented earlier (Figure 1.1) we can begin to translate the signs of autism into the three areas of difficulty indicative of an autistic spectrum disorder to help clarify autistic characteristics, although practitioners should remember that key characteristics will vary in intensity from child to child:

1. Social interaction:
   (a) avoids eye contact;
   (b) lack of desire to interact or play with other children or adults;
   (c) appears oblivious to the world around them;
   (d) is not interested in being picked up, played with or cuddled;
   (e) lack of co-operative or parallel play;
   (f) lack of desire to establish relationships and friendships;
   (g) unable to interpret or understand people’s feelings and emotions;
   (h) does not respond to affection or being touched or appears to over-react.

2. Social communication (speech, language and non-verbal communication):
   (a) lack of useful language;
   (b) lack of desire to communicate with others around them;
   (c) echolalia;
   (d) inability to understand non-verbal communication such as gestures and facial expression;
   (e) inability to understand the process of conversation;
   (f) if speech develops, it will be delayed and may demonstrate unusual speech, unusual or monotonous tone and/or patterns of speech;
   (g) may talk about a topic incessantly and at inappropriate times;
   (h) may be able to use language appropriately in one situation but be unable to transfer the language into an alternative situation.

3. Imagination:
   (a) lack of imaginative play;
   (b) play may be rigid, stereotypical and repetitive;
   (c) resistance to participate in imaginative play situations;
   (d) repetitive and/or obsessive behaviours;
   (e) difficulties and anxieties coping with changes to routines.

In addition to the characteristics above, the following may be observed:

- repetitive movements such as hand-flapping, rocking or covering ears or eyes;
- unusual response to stimuli. Children with autism may be over- or under-sensitive to some sensory stimuli. Examples would include: refusal to eat ‘lumpy’ food or combined foods such as sandwiches; aversion to common noises such as a dishwasher or vacuum cleaner; apparent lack of awareness of cold and heat (this raises particular issues of possible danger);
- difficulties with poor or delayed motor co-ordination – gross body and/or
fine/motor;
• unusual responses to ‘normal’ situations;
• self-harming or inappropriate behaviour, such as overaggressive play;
• erratic sleeping patterns;
• a skill that the child excels at – usually in art, knowledge of a film, music or mathematics. Children with such an exceptional skill are known as ‘autistic savants’.

Case Study
Toby arrives at your setting

Toby is 3 and is awaiting an appointment with the local consultant paediatrician for a full developmental assessment. The health visitor has expressed concerns regarding his lack of verbal communication and withdrawn nature. The report given to the setting suggests that Toby demonstrates ‘autistic type tendencies’.

When Toby first enters the setting he is screaming and flapping his hands. Once inside he spots the home corner and runs towards it, opening and shutting each and every door repeatedly and noisily. A member of staff goes to say hello to him but he ignores her and continues to bang the cupboard doors. Other children in the setting are uneasy about the noise from the door-banging and the non-verbal noises Toby is making.

Toby’s mum speaks to the setting manager saying she is so relieved that Toby has been accepted into the setting as she is desperate for any help she can be given. She hands over Toby’s cup as he refuses to drink from any other and will become distressed if encouraged to use another cup. Mum also provides his own snack for breaktime, as he has a range of food intolerances, plus his favourite toy train which he needs to hold at all times.

At breaktime Toby refuses to sit with the group and screams throughout singing time.

Consider the following:
1. What support is needed for Toby’s mum?
2. How are you going to support Toby’s settling-in period?
3. How are you going to begin to involve Toby in other activities?
4. How will you deal with the reactions of other children in the setting, and their parents?
5. Do you feel your staff have sufficient understanding of autism to respond to his needs effectively?
6. Who would you contact for additional support in addressing Toby’s needs?

As can be seen, this scenario raises a whole range of important issues that must be thought through and addressed to ensure Toby’s needs are met. It is a summary of my first encounter with a young child with autism and, at that time, I was at a loss as to how to provide for this little boy. I was aware that my knowledge and understanding of autism should be extended considerably, and rapidly, if I was going to continue working effectively with him.
From the above case study we can see that Toby’s difficulties were unfamiliar to the staff of the setting and this raises a key point for all practitioners. We cannot be experts in every type of disorder, syndrome and difficulty a child can experience but, as long as we are prepared to recognise this and improve our own knowledge and understanding, we will continue to provide the best opportunities we can for the children we work with.

To clarify our understanding of autism, Szalavitz offers a succinct description of the reality:

Imagine a world where every sound jars like a jackhammer, every light is a blinding strobe, clothes feel like sandpaper and even your own mother’s face appears as a jumble of frightening and disconnected pieces. This, say neuroscientists Kamila and Henry Markham of the Swiss Federal Institute of Technology in Lausanne, is how it feels to be autistic. (2008: 34)

Causes of autism
Research is ongoing to discover the causes of autism, but as yet, no definitive answer can be offered. Genetic factors and problems with brain development are, however, believed to be closely linked. The following is offered by the NAS (2008b):

The exact cause or causes is/are still not known, but research shows that genetic factors are important. In many, perhaps most, cases, autistic spectrum disorders may also be associated with various conditions affecting brain development, such as maternal rubella, tuberous sclerosis and encephalitis. Onset is almost always from birth or before the age of three ...

Similar or linked disorders
As previously discussed, autism can include signs and symptoms that are also indicative of other disorders and conditions, hence the need for thorough and detailed diagnostic procedures by highly qualified professionals. The following conditions should provide a useful summary for practitioners and can be split into two categories:

1 Conditions within the autistic spectrum.
   (a) Asperger’s syndrome. Difficulties with social interactions but not normally delayed in speech and language development. Children with Asperger’s syndrome demonstrate normal or high levels of intelligence and are thus at the more able end of the autistic spectrum.
   (b) PDD-NOS. Pervasive developmental disorder – not otherwise specified does not have a clear definition and is explored when difficulties allied to autistic difficulties are present but no other explanation can be offered. The key difference is that with PDD-NOS the autistic symptoms are not as well developed or not all the features of an autis-
tic diagnosis are present. It may be that a diagnosis of autism is sought or suggested but that with detailed and thorough assessment, not all autistic criteria are met.

(c) **Childhood disintegrative disorder or Heller’s syndrome.** As the name suggests, childhood disintegrative disorder can be diagnosed when a child who has followed the expected developmental path appears to regress, or their childhood appears to ‘disintegrate’. However, unlike regressive autism, the regression often does not begin until the child is 3 years or over.

(d) **Rett’s syndrome.** Rett’s syndrome only affects girls and is suggested as affecting only 1 per 10,000 children (Trevarthen et al., 1998). Again a pattern of expected development occurs, but only in the first few months of life, followed by a period of regression affecting speech and language, social, behavioural and physical development. All children with Rett’s syndrome develop severe or profound learning difficulties. Due to the similarities between Rett’s and autism many children can benefit from interventions and strategies used to support children with autism. Again care should be taken with the diagnostic process, as indicated by Siegel (1996): ‘Between the second and fifth or sixth year of life, when Rett’s syndrome is usually first diagnosed, the girl may also meet diagnostic criteria for Autism or PDD because of a marked lack of social relatedness and the presence of other features of autism’ (p. 22). Siegel suggests that this social relatedness often fades over subsequent years and adolescents can develop more appropriate social skills.

(e) **Semantic pragmatic disorder (SPD)** describes a ‘developmental language disorder’ (Shields, 1998), but it is now contested by some as to whether semantic pragmatic disorder is:

... in fact, an appropriate diagnosis, or merely a descriptive term for the nature of communication difficulty found in verbal people with autism. Research findings indicate that semantic pragmatic disorder does belong within the autistic spectrum and has the same underlying triad of socio-cognitive deficits as high-functioning autism. (Shields, 1998)

However, other organisations consider that SPD should be ‘viewed as a discrete specific learning difficulty which can occur in the absence of other autistic symptoms or impairments’ (SEN Teacher, n.d.).

(f) **Pathological Demand Avoidance syndrome (PDA)** is ‘increasingly becoming recognised as part of the autistic spectrum’ (NAS, 2008c) and, like autism, is a lifelong disability. The main features are:

• obsessively resisting ordinary demands;
• appearing sociable on the surface but lacking depth in understanding;
• excessive mood swings, often switching suddenly;
• comfortable in role play;
• language delay, seemingly as a result of passivity, but often with a
good degree of ‘catch-up’;
• obsessive behaviour, often focused on people. (NAS, 2008c)

2. Conditions linked with autism but not within the autistic spectrum.
   (a) Childhood schizophrenia. For many years autism and schizophrenia were considered to be similar, overlapping conditions. However, studies in the 1960s and 1970s concluded the debate by highlighting a number of significant differences between schizophrenia and autism. Most importantly, hallucinations, unreasonable and inappropriate behaviour combined with normal development of speech and the lack of learning disabilities are a few of the key indicators of schizophrenia which are not usually associated with autism. However it is possible, although rare, for a child to have schizophrenia and autism.

   (b) Landau-Kleffner syndrome. Children with Landau-Kleffner syndrome also appear to develop according to expected pathways, but a later regression between 3 and 8 years of age affects speech and language development, and is usually preceded by the onset of seizures. Characteristics include: affected language comprehension and expressive speech plus behavioural difficulties. Landau-Kleffner syndrome:

   ... occurs most frequently in normally developing children who are between 3 and 7 years of age. For no apparent reason, these children begin having trouble understanding what is said to them. Doctors often refer to this problem as auditory agnosia, or ‘word deafness.’ The auditory agnosia may occur slowly or very quickly. Parents often think that the child is developing a hearing problem or has become suddenly deaf. Hearing tests, however, show normal hearing. Children may also appear to be autistic or developmentally delayed. (NIH, 1998)

   (c) Specific language disorders. Young children with specific speech and language disorders may also experience difficulties in social skills and social interactions caused by the effects of the speech and language disorder. For example, a young child with an expressive language difficulty may prefer to remain silent or use limited speech to avoid being misunderstood by others around him/her. Clearly this can also affect their emotional development. For such reasons a diagnosis of autism may be considered but through detailed assessment, based on a speech and language therapy assessment, an appropriate diagnosis should follow.

   (d) William’s syndrome. William’s syndrome affects approximately 1 in 25,000 and is present from birth (WSF, 2007). Facial features are characterised by a small nose and chin, a wide mouth with full lips and apparent swelling surrounding the eyes. In addition, teeth are undersized and have gaps between them. Babies with William’s syndrome often have difficulties feeding due to poor muscle tone, and difficulties with sucking and swallowing. They also suffer from more severe colic than other babies. Children with William’s syndrome also experience delayed development (including speech and language problems) and
learning difficulties; however, many will develop speech as they mature but this may appear as the repetitive use of language.

(e) *Prader-Willi syndrome.* Prader-Willi syndrome, which affects boys and girls (estimated prevalence 1 in 22,000 (PWSA, n.d.) is defined as a genetic disorder involving poor muscle control, extreme hunger and a lack of sense of being full, short stature, incomplete sexual development, cognitive disabilities, problem behaviours (PWSA, n.d.). Caused by a chromosome disorder, children with Prader-Willi syndrome will be delayed in expected developmental milestones from birth. The feeding difficulties experienced as a baby will be replaced later with a desire to eat constantly, often leading to chronic obesity which can be life threatening.

(f) *Fragile X syndrome.* Fragile X is a chromosomal abnormality which has been linked with autism and, generally speaking, the effects on boys are significantly greater than those on girls. Cumine, Leach and Stephenson highlight the link with autism: ‘Fragile X features most prominently in its association with autism, in that 26% of the Fragile X population children with severe learning difficulties also have autism’ (2000: 27). The behavioural characteristics of Fragile X include a wide range of difficulties with learning as well as social, language, attentional, emotional and behavioural problems (Fragile X Society, 2007). In addition boys with Fragile X syndrome will experience severe learning difficulties, whilst girls will experience moderate difficulties with learning. Physical characteristics include large, prominent ears and an elongated face.

(g) *Angelman syndrome.* Also caused by a chromosome defect wherein some similarities can be seen between Angelman syndrome and autism. However, children with Angelman syndrome invariably have severe learning difficulties. Sometimes this syndrome is referred to as ‘Happy Puppet’ syndrome as children present with a smiling face and hold their arms out stiffly rather like a puppet.

The preceding list of disorders linked with autism, and/or those that sometimes appear with autism in children is considerable but not exhaustive. It should give practitioners an understanding of those more frequently presented.

**Legislation and guidance**

**Developments in special needs legislation**

Although in current legislation practitioners work within definitions and labels of ‘special needs’, ‘special educational needs’ and ‘children in need’, I would suggest that whilst such terms may support appropriate provision, they may also give rise to difficulties. As long as we continue to regard special needs provision as separate and discrete from mainstream provision, which includes the government’s continued production of separate documentation for special needs, then we are not inclusive. Separate legislation
and guidance excludes, not includes. If we consider the work we undertake with children with autism, we observe and assess their strengths, likes and dislikes and use this information to inform our planning and interventions. This is not different or adapted practice for children with special needs but positive and effective early years practice for all children.

Historically, developments in special needs legislation have seen the most rapid changes during the past 30–40 years. During the nineteenth and early twentieth centuries those with special needs were usually regarded as ineducable. Through the 1920s and 1930s Freud’s work was becoming established and renowned. Linking adult behaviours and feelings to experiences in early childhood offered explanations for some difficulties experienced by adults and began to inform society that such people were not ‘imbeciles’ but were suffering from illness.

During the period 1970 to 2000 the key changes came through:

- Education Act (DES, 1970)
- Warnock Report (DES, 1978)
- Education Act (DES, 1981)
- Children Act (DoH, 1989)
- Education Act (DfEE, 1993)
- Code of Practice (DfEE, 1994)
- Nursery Education and Grant Maintained Schools Act (DfEE, 1996)
(See Wall, 2006, Chapter 1 for further details)

Current legislation and guidance

The sheer quantity of legislation, guidance and policy initiatives since 2000 is immense, so for ease of understanding readers are directed to the timeline offered at the end of this chapter for a chronological list and only key documents will be discussed in this section.

The Special Educational Needs and Disability Discrimination Act or SENDA (DfES, 2001a) was followed by the Special Educational Needs Code of Practice (DfES, 2001b). A graduated approach to identification and assessment was introduced through Early Years Action and Early Years Action Plus for children under 5 years old, and School Action and School Action Plus for those in Key Stage 1 and above. The Code of Practice states that:

> Once practitioners have identified that a child has special educational needs, the setting should intervene through Early Years Action. If the intervention does not enable the child to make satisfactory progress the SENCO may need to seek advice and support from external agencies. These forms of intervention are referred to (below) as Early Years Action Plus. (DfES, 2001b: s. 4:11)

The Code of Practice included chapters on identification and assessment
and, for the first time, a whole chapter on provision in early years settings. In addition there is a strong emphasis on provision occurring within effective multidisciplinary networks, thus providing a ‘seamless’ service to young children and their families. Other initiatives within the Code include a stronger influence on effective partnerships with parents and involving the children in their own assessments and reviews.

The definition of special educational needs within the current Code of Practice states that:

Children have special educational needs if they have a learning difficulty which calls for special educational provision to be made for them. Children have a learning difficulty if they:

(a) Have a significantly greater difficulty in learning than the majority of children of the same age; or
(b) Have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority;
(c) Are under compulsory school age and fall within the definition at (a) or (b) above or would do so if special educational provision was not made for them. (DfES, 2001a: s. 1:3)

As well as the Code of Practice the DfES produced several additional guidance documents to support practitioners:

- **Special Educational Needs Toolkit** (DfES, 2001c);
- **Inclusive Schooling: Children with Special Educational Needs** (DfES, 2001d);
- **Access to Education for Children with Medical Needs** (DfES, 2001e);
- **Autistic Spectrum Disorders: Good Practice Guidance** (DfES/DoH, 2002).

The last one will clearly be of great interest to those working with children with autism and offers practitioners two guidance booklets: 01 Guidance on Autistic Spectrum Disorders and 02 Pointers to Good Practice. These will be referred to in later chapters.

The *Autism: Rights in Reality* report (Broach et al., 2003) highlighted the difficulties experienced by children and adults with ASDs and their families, concluding that:

... many people with autistic spectrum disorders and their families are still missing out on rights and entitlements enjoyed by the rest of society. Government should focus on the needs of those groups affected by autism that are particularly excluded from current services. Many of the changes needed to better support people with autistic spectrum disorders are relatively minor. Much of this support would prove cost effective in the long term. The first economic study of the UK costs of autism estimated the average additional lifetime cost to be £2,940,538 per person. (2003: 3)
In 2003 *The National Autism Plan for Children* was published by the NAS which sets ‘out a vision of what a good service for the child with suspected and proven autism/ASD would look like’ (NAS, 2003: 4). The report also ‘focusses attention on the need to raise standards in childhood disability services as a whole, in education, health and social services’ (NAS, 2003: 5). This groundbreaking report clearly laid the way for future changes at national level and may well have influenced later policies and legislation, but in my own experience I have sadly seen little reference to this significant piece of work.

Arguably the most significant document to emerge in 2003 was the *Every Child Matters* (ECM) agenda (DfES, 2003) which reviewed the existing situation and research of the time relating to the lives and experiences of children and young people. This research identified, amongst other things, that there were half a million disabled children and 17% of school-aged children had SEN (Wall, 2006: 11). A barrage of further documents emanated from ECM including *ECM: Change for Children* (DfES, 2004a), but each document had the same aim – to outline changes needed to secure better outcomes for all children. The five outcomes identified were to: be healthy; stay safe; enjoy and achieve; make a positive contribution; and achieve economic well-being (Wall, 2006: 12).

A key part of ECM was the *National Service Framework* (DoH/DfES, 2004) which stated that: ‘The 10-year programme is intended to stimulate long-term and sustained improvement in children’s health. The NSF aims to ensure fair, high quality and integrated health and social care from pregnancy right through to adulthood’ (DoH/DfES, 2004). This extensive document was further supported by a host of additional documents relating to specific groups of the population, each giving guidance as to expectations to ensure progress and improved standards for all, wherever they live, whatever their age and whatever difficulties they may be experiencing. Ambitiously the NSF aims to ensure that by 2014 the standards set down will have been met across the board. Time will tell! As part of the NSF the document *NSF: Autism* was produced (DoH/DfES, 2004) showing a pathway through a child’s life from age 3, when difficulties are first identified, right through to his transition to adulthood. At every stage the action needed is documented and matched to the NSF standards (of which there are 11 in total).

The ECM framework was supported through the Children Act 2004 (DfES, 2004b) which legislated for some of the key changes eg Directors of Children’s Services, improved interagency working systems and practices, integrated inspections and the Children’s Commissioner. The Act also reviewed child protection procedures and identified strategies to reduce the number of children ‘slipping through the net’ (Wall, 2006: 12).
The year 2004 also saw the key document, *Choice for Parents, the Best Start for Children: A Ten Year Strategy for Childcare*, which addressed issues relating to family life, bringing up children and work issues. The report highlighted four key areas for change:

- Choice and flexibility (to balance work and family life)
- Availability (of childcare)
- Quality (of childcare)
- Affordability (of childcare) (HM Treasury, 2004: 1)

In the same year the *Early Support Programme* (ESP) was introduced as ‘the Government programme to achieve better co-ordinated, family focused services for young disabled children and their families. It’s a national programme that is being introduced and used in local authorities, hospitals and community-based health services across England’ (DCSF, DoH and Sure Start, 2009). As one of the many documents that comprise the whole package of resources there is a parents’ booklet: *Early Support: Information for Parents: Autistic Spectrum Disorders (ASDs) and Related Conditions* (DfES, 2006a), offering straightforward information and further contact sources for parents, who can find a diagnosis, or even suggestion, of autism to be severely traumatising.

The government’s revised strategy for SEN, *Removing Barriers to Achievement* (RBA) was published in 2004 (DfES, 2004c) taking into account many of the recommendations of the Audit Commission’s report: *Special Educational Needs: A Mainstream Issue* (Audit Commission, 2002a). Key issues raised in RBA included: early identification; removing barriers to learning; raising expectations and achievements; and delivering improved partnerships and interagency working. National SEN Advisers were also created in 2004.

Then followed a series of documents relating to improvements in the children’s workforce with the *Common Core of Skills and Knowledge for the Children’s Workforce* being published in 2005 (DfES), setting out the required knowledge and skills levels required for members of the children’s workforce in each of the following areas:

- Effective communication and engagement
- Child and young person development
- Safeguarding and promoting the welfare of the child
- Supporting transitions
- Multi-agency working
- Sharing information (DfES, 2005: 4)

In 2006 the NAS published their report *Make School Make Sense* (NAS, 2006), highlighting the realities for parents/carers of children with autism and the constant battles they engage in, and concluding that:
This report has demonstrated the extent of the struggle that many families face as they try to secure an appropriate education for their child. This needs to change. All children with autism have the potential to learn, achieve and make a positive contribution to school life and this report highlights examples of good practice that enables them to do so. Local and central government now need to take action to ensure that good practice becomes standard practice for all children on the autistic spectrum. (NAS, 2006: 44)

So despite a raft of policies and strategies the experiences of children with ASDs are still well below acceptable levels.

The five outcomes of ECM are central to the Childcare Act 2006 which formalises:

...the important strategic role local authorities play through a set of new duties. These duties will require authorities to improve the five Every Child Matters (ECM) outcomes for all pre-school children and reduce inequalities in these outcomes; secure sufficient childcare for working parents; and provide a better parental information service (Sure Start, 2008).

The Autism Research Coordination Group was formed ‘to provide a framework whereby the greater coordination of autism research activity can lead to more informed policy development in areas affecting people with autism’ (DfES, 2006b: 4). Their first annual report clearly highlighted the need for continued and increased high level research to be supported to inform future governmental changes in policy and thus changes in practice.

In 2007 the government launched The Children’s Plan (DCSF, 2007a) aiming to:

...strengthen support for all families during the formative early years of their children’s lives, take the next steps in achieving world class schools and an excellent education for every child, involve parents fully in their children’s learning, help to make sure that young people have interesting and exciting things to do outside of school, and provide more places for children to play safely. (2007a: 1)

The Early Years Foundation Stage also emerged in 2007 and came into force in September 2008.

The EYFS combines the existing Birth to Three (B2T), Curriculum Guidance for the Foundation Stage (CGFS) and the National Standards for Under 8s Daycare and Childminding (NSDC), and offers one pack of information for all practitioners working with children aged from birth to five years of age and their families. The EYFS is a central part of Choice for Parents, the Best Start for Children: A Ten Year Strategy for Childcare (HM Treasury, 2004) and
the Childcare Act of 2006 and underpinning the EYFS are the five outcomes from Every Child Matters (ECM) (DfES, 2003).

These outcomes are to be met by:

- setting the standards for the learning, development and care
- ensuring equality of opportunity and anti-discriminatory practice
- creating the framework for partnerships with parents and other professionals
- improving quality and consistency across the sector
- laying secure foundations for the future of the children.

(Adapted from DfES, 2007: 7)

The EYFS is based on the fundamental belief that ‘all children deserve the best possible start in life and support to fulfil their potential’ (DfES, 2007: 7). The CD-Rom supplied as part of the EYFS contains an endless source of additional information for practitioners and policy makers but arguably the sheer volume of material is unmanageable to even the most avid of readers.

The government’s strategy for children with disabilities was further enhanced by the emergence of Aiming High for Disabled Children: Better Support for Families (HM Treasury/DfES, 2007) which highlighted that disabled children are less likely to achieve their full potential without appropriate and improved support systems. With an investment of £340 million such improvements are to be put in place to ensure greater access to services, more responsive support and higher quality support for all disabled children. The benefits to their family members will also be significant.

A report from the Foundation for People with Learning Disabilities, entitled The Economic Consequences of Autism in the UK (Knapp et al., 2007) makes quite staggering reading as it sets out to reveal the real costs of the impact of autism on people in the UK. The report concludes:

The aggregate national costs of supporting children with ASD were estimated to be £2.7 billion each year, and also … that a greater availability of effective early interventions may reduce the impact of ASD on the UK economy as well as improve quality of life for people with ASDs and their families. (Knapp et al., 2007: 2–3)

Also in 2007 the Inclusion Development Programme (IDP) was introduced, stating that:

Over four years, the IDP will develop and deliver a programme of Continuing Professional Development (CPD) designed to strengthen the confidence and expertise of mainstream staff in early years settings and
in Primary and Secondary schools in ensuring the progress and achievement of pupils with Special Educational Needs (SEN). (DCSF, 2007)

In 2009/10 the IDP focus will be on ASDs and as long as all practitioners and teachers receive appropriate training then we may see positive progress.

The Bercow Report (DCSF, 2008a) reviewed services for children and young people with speech, language and communication needs and made specific references to ASDs. The report identified five areas where improvements were most needed: understanding the importance of the need to communicate; improved early identification and intervention; services to respond to the needs of the family; joint working between agencies; and, improved equity of access to appropriate support. In total 40 recommendations were made to secure improved provision for all children and young people experiencing difficulties in this area. As a result an action plan has now emerged: Better Communication (DCSF, 2008b), outlining the means by which these aims will be met to ensure improvements to services. However, autism is barely mentioned within an excellent document which sadly remains fairly generic. Arguably a missed opportunity.

More recently the government has produced their 2020 Children and Young People’s Workforce Strategy outlining planned targets for 2020, namely that ‘all those who work with children and young people will be: ambitious, excellent, committed and respected’ (DCSF, 2008c: 6). This long awaited rise in the status of early years working will be welcomed by everyone in the field. Further, the strategy identifies key areas in which the government will work, including: ‘... ensuring that people in the workforce have the skills and knowledge they need to support children who are particularly vulnerable, including those who are looked after, are disabled or have mental health needs’ (DCSF, 2008c: 7). The DCSF has also published their statutory guidance to support the Childcare Act (2006): Raising Standards–Improving Outcomes (DCSF, 2008d).

The government also published the Quality Standards for SEN and Outreach Services (DCSF, 2008e) offering 16 standards by which local authorities can monitor the quality of their services. This again supports the five ECM outcomes and recognises that SEN services are crucial for supporting children to reach their maximum potential. Standard 14 specifically relates to staff experiences, knowledge and competencies and supports ongoing training and professional development (p. 19). Yet the focus of any training will depend on what is most needed and may not be ASD related.

Finally, at the time of writing, the most recent publications are Healthy
Lives, Brighter Futures: The Strategy for Children and Young People’s Health (DCSF, 2009) with a clear focus on improving the health of the nation’s children, and Next Steps for Early Learning and Childcare (HM Government, 2009) which updates the 2004 10-year Childcare Strategy and again calls for ongoing challenges to be addressed, including more support for families, access to early years learning opportunities, the quality of provision, information for all and financial support for those who need it. Hopefully this may result in continued improvements for children with ASDs and their families, but time will tell.

Clearly the government is committed to improving provision for all young children, including those with special needs but it could be suggested that the publication of such a vast amount of more and more detailed documentation will not on its own ensure effective provision.

The rate of policy changes has accelerated at a tremendous rate, as summarised by Action for Children (2008):

There have been over 400 different initiatives, strategies, funding streams, legislative acts and structural changes to services affecting children and young people over the past 21 years. This is equivalent to 20 different changes faced by children’s services for every year since 1987. What is more, the ‘churn’ is increasing rapidly. Half of the developments identified began in the past six years. Three quarters have come in the past 10 years.

Such documents take time to read, assimilate and disseminate to all staff members and, thus, training for practitioners must be a priority. In my own experience the amount of documentation to emerge since 2000 has become totally unmanageable and whilst the aims and vision of each may well be laudable, the time and attention needed to make sense of each and every one of them is arguably impossible. Further, any potential improvements to autistic provision is not, as yet, evident.

Summary

Within this chapter the developments in early years provision have been examined to highlight the range of diverse settings available to parents of young children. Sadly the range of accessible settings within any one locality will probably differ from neighbouring localities and thus equity of access to provision is still an issue. The developments within special needs provision were also explored and highlighted the transition from separate special school settings to the current more inclusive system in which practitioners are expected to be able to provide for increasing numbers of children with special needs. The issues of training and funding will remain concerns if we wish to ensure that all early years practitioners
can provide effectively for the individual needs of all children.

Autistic spectrum disorders were then explored to offer the reader increased understanding and knowledge of this range of disorders. The triad of impairments, definitions of autism and the signs of autism in young children should support practitioner knowledge and were linked back to the three areas of impairment that form the triad. The example of Toby was introduced to relate the listing of signs and characteristics to the reality of the children that we may work with. The rather brief résumé of legislation and guidance summarised the current situation and clearly highlighted the sheer volume of documentation that exists. The increasing evidence from autism research repeatedly informs us that more needs to be done, but the government’s focus is clearly on the early years and education issues, although it must be acknowledged that much of the special needs related documentation does include those on the autistic spectrum. It is clear that the move towards increasing inclusion continues to progress, but this can only be successful if all practitioners are trained, thus ensuring more effective provision for our young children with autism.

### Key issues
- Practitioners may need to increase their knowledge and understanding of autism to provide effectively for children with autistic spectrum disorders.
- Effective provision for children with autism is not different practice but positive and effective early years practice for all children.
- Current legislation, policies and guidance cover special needs, special educational needs, providing for children on the autistic spectrum, disability discrimination and human rights.
- Within the current move towards increased inclusion there are still significant issues to be addressed.

### Suggestions for discussion

**Item 1**
Initiate a discussion of training of all those working in your setting. Consider the following:
- knowledge of current legislation and guidance;
- knowledge and skills to provide for the needs of all the children within your setting;
- knowledge and understanding of autistic spectrum disorders;
- abilities to provide for the needs of children with autism in your setting.

**Item 2**
In the light of the above discussion, review training needs for the future.
Item 3
Focus on one child with autism that you either are currently working with or have worked with previously and consider:
• Do you feel you have sufficient understanding of their difficulties to provide appropriately?
• Does your planning respond directly to their needs?
• Could improved knowledge of autism improve your provision for the child?

Suggested further reading


Useful websites

Advisory Centre for Education (ACE)
www.ace-ed.org.uk

Autism Independent UK (formerly the Society for the Treatment of the Autistically Handicapped)
www.autismuk.com

Department for Children, Schools and Families (DCSF)
www.dcsf.gov.uk

Disability Rights Commission (DRC)
www.drc.org.uk

Independent Panel for Special Educational Advice (IPSEA)
www.ipsea.org.uk

National Association for Special Educational Needs (NASEN)
www.nasen.org.uk

National Autistic Society
www.nas.org.uk

National Children’s Bureau, Early Childhood Unit,
www.ncb.org.uk
**TIMELINE OF SIGNIFICANT LEGISLATION, REPORTS AND GUIDANCE SINCE 2000**

For further information, internet searches would take you directly to the documents.

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<th>Author</th>
<th>Title, aims and key issues</th>
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