

Craig Barlow | Consultancy & Training

UNDERSTANDING AUTISM

Course Notes

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UNDERSTANDING AUTISM

A Brief History

Working in the USA, Leo Kanner recognized that a number of children referred to his clinic had in common and unusual pattern of behaviour, which he named *early infantile autism*. In 1943. He gave detailed descriptions of the children's behaviour. The selected certain features as crucial for diagnosis .These were profound lack of effective (emotional) and contact with other people; inattentive insistence on sameness in their self-chosen, often bizarre and elaborate repetitive routines; muteness or mild abnormality of speech; ventilation with and dexterity in manipulating objects; high levels of Visio-spatial skills or rote memory, in contrast to learning difficulties in other areas; unattractive, alert, intelligent appearance.

He later suggested that the first two of these features were sufficient for diagnosis. He also emphasised that the condition was present from birth or within the first 30 months of life. Kanner believed his syndrome was unique and separate from other childhood conditions. Interest in cannas work grew slowly at first and then more rapidly and is now the focus of research in many countries.

In 1944, Hans Asperger, in Austria, published his paper on a group of children and adolescents with another pattern of behaviour. The features that he selected as importance were naive, inappropriate, social approaches to others; intents circumscribed interest, in particular subjects such as railway timetables; good grammar and vocabulary, but monotonous speech used from monologues, not a two-way conversation; or motor coordination; the level of ability in the borderline, average or superior range, but often with specific learning difficulties in one or two subjects; a marked lack of common sense.

Although the problems, presents a very early. Parents are often unaware of them until their child is over three years old. Asperger believed that his syndrome was different from Kanner's autism, though he acknowledged many similarities.

Due largely to the Second World War. There was a long delay before, his work was published in the English literature. That's, it is only in the last 20 years, that Asperger's Syndrome has become well-known outside continental Europe.

In 1962, the first voluntary associations to be formed anywhere in the world the parents and professional workers concerned with autism was set up in the UK and the USA. Although originally the focus was on Kanner's autism, it seemed became clear that there were many children, who did not precisely fits in his descriptions, but who had similar problems and needed similar kinds of help. As a result of the efforts

of such societies, with the help of publicity through the media, the existence of autistic conditions have become much better known to the general public and people with autistic disorders and appeared in fictional stories such as the film *Rain Man* and *The Curious Incident Of The Dog In The Night-Time*.

In the 1970s, Judith Gould and Lorna Wing examined all children under the age of 15. In one area of London, who had any kind of physical or learning disability or abnormality of behaviour, however mild or severe. They identified a group with typical Kanner's autism, but found more that had many features of autistic behaviour and who did not precisely fit his criteria. There were a few who had the pattern described by Asperger, whose work was not familiar to the research is. Gould and Wing have pointed out that in if they had included children in mainstream schools, they certainly would have found is more with Asperger's syndrome.

There have been many changes in ideas on the nature of autistic conditions over the years. Towards the end of the 19th century, the possibility of insanity occurring in children was suggested by the psychiatrist Henry Maudsley. This word has no precise meaning, that tends to be used as a general label the behaviour that is bizarre and strange. Disorders that are now considered to be in the autistic spectrum fitted this description, and were classified as childhood psychoses.

In the first decades of the 20th century, the theories of the psychoanalysts effectively attitudes of professionals and the public at large. After Kanner published he is work on early infantile autism , many believed that autism was an emotional, not a physical disorder, and that the way the parents had brought up their children had caused all of the problems. The effect was disastrous. It exacerbated the parents distressed at having a child with behaviour that they could not understand and make them feel guilty and damaged any confidence they may have had in their ability to help their child.

It was not until the 1960s that fresh ideas on the nature of autistic disorders began to emerge. Research into normal child development and language disorders as well as work on Kanner's autism especially that by Michael Rutter and his colleagues, produced major changes. This work shows that the behaviour of children with autism makes sense if viewed as a cue to disorders of aspects of development, starting from birth or the early years of childhood. Growing knowledge of the way the brain functions and the things that can go wrong, has made it clear that the cause is physical, and nothing to do with the parents of child rearing methods. Few people now blame parents, but traces of old ideas still linger among some professionals and some laypeople, still causing much distress for the parents who meet these attitudes.

Some child psychiatrists considered the autistic disorders were forms of childhood schizophrenia. However, a series of studies by Israel Kolvin and his colleagues in the 1970s demonstrated the differences between autism and the very rare condition of schizophrenia, occurring in childhood. In the 1970s and 80s, the idea that

Kanner's autism was part of a wider spectrum of autistic disorders began to be seriously considered.

The changes in ideas about autistic disorders can be seen in the history of the two international systems of classification of psychiatric and behavioural disorders. These are the international Statistical Classification Of Diseases And Related Health Problems (ICD) published by the World Health Organisation and the Diagnostic Statistics Manual (DSM) of the American Psychiatric Association. The first editions of the ICD did not include autism at all. The eighth in 1967, edition mentioned only infantile autism is a former schizophrenia in the ninth 1977 included it under the heading of childhood psychoses. The 10th and current edition of the ICD as the fourth and current edition of the DSM. Take the modern view that there is a spectrum of autistic conditions and that they are disorders of development, not psychoses. The name used in both classification systems is *pervasive developmental disorders*. Most parents in the UK do not like this term and find it confusing. They prefer Autistic Spectrum Disorders and this will be the term used during this course.

What Is Autism?

The following notes have been adapted from "What is Autism?" and "What is Asperger Syndrome" National Autistic Society 2008

Autism is a lifelong developmental disability. It is part of the autism spectrum and is sometimes referred to as an autism spectrum disorder, or an ASD. The word 'spectrum' is used because, while all people with autism share three main areas of difficulty, their condition will affect them in very different ways. Some are able to live relatively 'everyday' lives; others will require a lifetime of specialist support.

The three main areas of difficulty which all people with autism share are sometimes known as the 'triad of impairments'. They are:

- difficulty with social communication
- difficulty with social interaction
- difficulty with social imagination.

These are described in more detail below.

It can be hard to create awareness of autism as people with the condition do not 'look' disabled: parents of children with autism often say that other people simply think their child is naughty; while adults find that they are misunderstood.

All people with autism can benefit from a timely diagnosis and access to appropriate services and support.

The What are the characteristics of autism?

The characteristics of autism vary from one person to another but are generally divided into three main groups.

Difficulty with social communication

People with autism have difficulties with both verbal and non-verbal language. Many have a very literal understanding of language, and think people always mean exactly what they say. They can find it difficult to use or understand:

- facial expressions or tone of voice
- jokes and sarcasm
- common phrases and sayings; an example might be the phrase 'It's cool', which people often say when they think that something is good, but strictly speaking, means that it's a bit cold.

Some people with autism may not speak, or have fairly limited speech. They will usually understand what other people say to them, but prefer to use alternative means of communication themselves, such as sign language or visual symbols.

Others will have good language skills, but they may still find it hard to understand the give-and-take nature of conversations, perhaps repeating what the other person has just said (this is known as echolalia) or talking at length about their own interests.

It helps if other people speak in a clear, consistent way and give people with autism time to process what has been said to them.

Difficulty with social interaction

People with autism often have difficulty recognising or understanding other people's emotions and feelings, and expressing their own, which can make it more difficult for them to fit in socially. They may:

- not understand the unwritten social rules which most of us pick up without thinking: they may stand too close to another person for example, or start an inappropriate subject of conversation
- appear to be insensitive because they have not recognised how someone else is feeling
- prefer to spend time alone rather than seeking out the company of other people

- not seek comfort from other people
- appear to behave 'strangely' or inappropriately, as it is not always easy for them to express feelings, emotions or needs.

Difficulties with social interaction can mean that people with autism find it hard to form friendships: some may want to interact with other people and make friends, but may be unsure how to go about this.

Difficulty with social imagination

Social imagination allows us to understand and predict other people's behaviour, make sense of abstract ideas, and to imagine situations outside our immediate daily routine. Difficulties with social imagination mean that people with autism find it hard to:

- understand and interpret other people's thoughts, feelings and actions
- predict what will happen next, or what *could* happen next
- understand the concept of danger, for example that running on to a busy road poses a threat to them
- engage in imaginative play and activities: children with autism may enjoy some imaginative play but prefer to act out the same scenes each time
- prepare for change and plan for the future
- cope in new or unfamiliar situations.

Difficulties with social imagination should not be confused with a lack of imagination. Many people with autism are very creative and may be, for example, accomplished artists, musicians or writers.

Other related characteristics

Love of routines

The world can seem a very unpredictable and confusing place to people with autism, who often prefer to have a fixed daily routine so that they know what is going to happen every day. This routine can extend to always wanting to travel the same way to and from school or work, or eat exactly the same food for breakfast.

Rules can also be important: it may be difficult for a person with autism to take a different approach to something once they have been taught the 'right' way to do it. People with autism may not be comfortable with the idea of change, but can cope well if they are prepared for it in advance.

Sensory sensitivity

People with autism may experience some form of sensory sensitivity. This can occur in one or more of the five senses - sight, sound, smell, touch and taste. A person's senses are either intensified (hypersensitive) or under-sensitive (hypo-sensitive).

For example, a person with autism may find certain background sounds, which other people ignore or block out, unbearably loud or distracting. This can cause anxiety or even physical pain.

People who are hypo-sensitive may not feel pain or extremes of temperature. Some may rock, spin or flap their hands to stimulate sensation, to help with balance and posture or to deal with stress.

People with sensory sensitivity may also find it harder to use their body awareness system. This system tells us where our bodies are, so for those with reduced body awareness, it can be harder to navigate rooms avoiding obstructions, stand at an appropriate distance from other people and carry out 'fine motor' tasks such as tying shoelaces.

Special interests

Many people with autism have intense special interests, often from a fairly young age. These can change over time or be lifelong, and can be anything from art or music, to trains or computers.

A special interest may sometimes be unusual.

Learning disabilities

People with autism may have learning disabilities, which can affect all aspects of someone's life, from studying in school, to learning how to wash themselves or make a meal. As with autism, people can have different 'degrees' of learning disability, so some will be able to live fairly independently - although they may need a degree of support to achieve this - while others may require lifelong, specialist support. However, all people with autism can, and do, learn and develop with the right sort of support.

Other conditions are sometimes associated with autism. These may include attention deficit hyperactivity disorder (ADHD), or learning difficulties such as dyslexia and dyspraxia.

Who is affected by autism?

Autism is much more common than most people think. There are over half a million people in the UK with autism - that's around 1 in 100 people.

People from all nationalities and cultural, religious and social backgrounds can have autism, although it appears to affect more men than women. It is a lifelong condition: children with autism grow up to become adults with autism.

What is Asperger syndrome?

Asperger syndrome is a form of autism, which is a lifelong disability that affects how a person makes sense of the world, processes information and relates to other people. Autism is often described as a 'spectrum disorder' because the condition affects people in many different ways and to varying degrees.

Asperger syndrome is mostly a 'hidden disability'. This means that you can't tell that someone has the condition from their outward appearance. As in autism in general, people with the condition have difficulties in three main areas. They are:

- social communication
- social interaction
- social imagination.

While there are similarities with autism, people with Asperger syndrome have fewer problems with speaking and are often of average, or above average, intelligence. They do not usually have the accompanying learning disabilities associated with autism, but they may have specific learning difficulties. These may include dyslexia and dyspraxia or other conditions such as attention deficit hyperactivity disorder (ADHD) and epilepsy.

With the right support and encouragement, people with Asperger syndrome can lead full and independent lives.

What are the characteristics of Asperger syndrome?

The characteristics of Asperger syndrome vary from one person to another but are generally divided into three main groups.

Difficulty with social communication

People with Asperger syndrome sometimes find it difficult to express themselves emotionally and socially. For example, they may:

- have difficulty understanding gestures, facial expressions or tone of voice
- have difficulty knowing when to start or end a conversation and choosing topics to talk about
- use complex words and phrases but may not fully understand what they mean
- be very literal in what they say and can have difficulty understanding jokes, metaphor and sarcasm. For example, a person with Asperger

syndrome may be confused by the phrase 'That's cool' when people use it to say something is good.

In order to help a person with Asperger syndrome understand you, keep your sentences short - be clear and concise.

Difficulty with social interaction

"I have difficulty picking up social cues, and difficulty in knowing what to do when I get things wrong."

Many people with Asperger syndrome want to be sociable but have difficulty with initiating and sustaining social relationships, which can make them very anxious. People with the condition may:

- struggle to make and maintain friendships
- not understand the unwritten 'social rules' that most of us pick up without thinking. For example, they may stand too close to another person, or start an inappropriate topic of conversation
- find other people unpredictable and confusing
- become withdrawn and seem uninterested in other people, appearing almost aloof
- behave in what may seem an inappropriate manner.

Difficulty with social imagination

"We have trouble working out what other people know. We have more difficulty guessing what other people are thinking."

People with Asperger syndrome can be imaginative in the conventional use of the word. For example, many are accomplished writers, artists and musicians. But people with Asperger syndrome can have difficulty with social imagination. This can include:

- imagining alternative outcomes to situations and finding it hard to predict what will happen next
- understanding or interpreting other peoples thoughts, feelings or actions. The subtle messages that are put across by facial expression and body language are often missed
- having a limited range of imaginative activities, which can be pursued rigidly and repetitively eg lining up toys or collecting and organising things related to his or her interest.

Some children with Asperger syndrome may find it difficult to play 'let's pretend' games or prefer subjects rooted in logic and systems, such as mathematics.

Other related characteristics

Love of routines

To try and make the world less confusing, people with Asperger syndrome may have rules and rituals (ways of doing things) which they insist upon. Young children, for example, may insist on always walking the same way to school. In class, they may get upset if there is a sudden change to the timetable. People with Asperger syndrome often prefer to order their day to a set pattern. For example, if they work set hours, an unexpected delay to their journey to or from work can make them anxious or upset.

Special interests

People with Asperger syndrome may develop an intense, sometimes obsessive, interest in a hobby or collecting. Sometimes these interests are lifelong; in other cases, one interest is replaced by an unconnected interest. For example, a person with Asperger syndrome may focus on learning all there is to know about trains or computers. Some are exceptionally knowledgeable in their chosen field of interest. With encouragement, interests and skills can be developed so that people with Asperger syndrome can study or work in their favourite subjects.

Sensory difficulties

People with Asperger syndrome may have sensory difficulties. These can occur in one or all of the senses (sight, sound, smell, touch, or taste). The degree of difficulty varies from one individual to another. Most commonly, an individual's senses are either intensified (over-sensitive) or underdeveloped (under-sensitive). For example, bright lights, loud noises, overpowering smells, particular food textures and the feeling of certain materials can be a cause of anxiety and pain for people with Asperger syndrome.

People with sensory sensitivity may also find it harder to use their body awareness system. This system tells us where our bodies are, so for those with reduced body awareness, it can be harder to navigate rooms avoiding obstructions, stand at an appropriate distance from other people and carry out 'fine motor' tasks such as tying shoelaces. Some people with Asperger syndrome may rock or spin to help with balance and posture or to help them deal with stress.

Who is affected by Asperger syndrome?

There are over half a million people in the UK with an autism spectrum disorder - that's around 1 in 100. People with Asperger syndrome come from all nationalities, cultures, social backgrounds and religions. However, the condition appears to be more common in males than females; the reason for this is unknown.

What causes Asperger syndrome?

The exact cause of Asperger syndrome is still being investigated. However, research suggests that a combination of factors - genetic and environmental - may account for

changes in brain development.

Asperger syndrome is not caused by a person's upbringing, their social circumstances and is not the fault of the individual with the condition.

Some Facts and Figures

Incidence: the incidence for autism is approximately 4-10 per 10 000, for Asperger's incidence is approximately 20-25 per 10,000.

Sex ratio: show of males to females with autism is approximately 4:1, for Asperger's approximately 9:1.

IQ: 75% individuals with autism have learning disabilities. By definition those with Asperger's syndrome have IQ in the normal range. However, individuals with learning disabilities, who exhibit traits of Asperger's Syndrome which makes the strict application of the definition somewhat problematic.

Language development: autistic individuals are likely to have language impairments. Individuals with Asperger's syndrome, although they may show peculiarities in the use of language, usually develop grammatical speech by the age of five years.

The difficulties associated with autism greatest in the autistic child, specifically before the age of five. Autistic children learn to adapt and compensate their difficulties. Autistic people will continue to experience difficulties, particularly in terms of social adjustment, and also over issues of repetitive behaviour and changes to routine etc. A number of individuals, particularly those with severe learning disabilities, will display behaviour problems such as self injury and aggression. Although autism per se does cause these problems behavioural problems may also reflect the difficulty that such people have in coping with demands, a communication deficits, and the inability to comprehend behaviour, thoughts and feelings and expectations of those around, as well as their own thoughts and feelings.

Autistic individuals are particularly vulnerable to emotional problems such as anxiety and depression.

KEY CONCEPTS

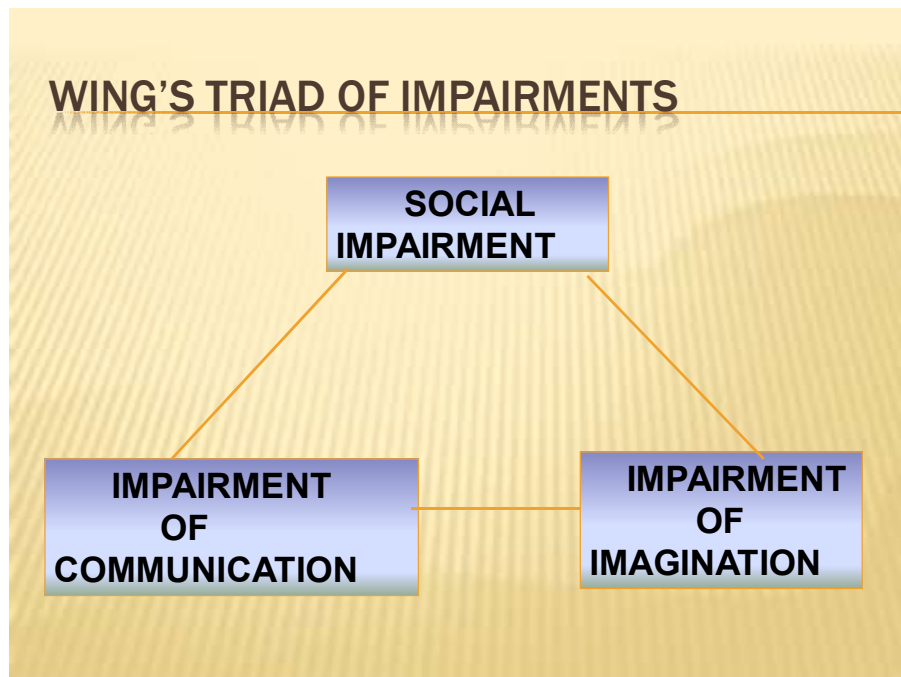
Theory Of Mind: this is the ability to attribute mental status, leaves, desires, intentions to ourselves as well as other people. This is how we understand and predict behaviour. In autistic people, this ability is impaired. The deficit is illustrated through the now famous Sally Anne experiment:

“ we used to dolls, Sally and Anne, and acted out a little scenario: Sally has a basket and Anne has a box. Sally has a marble as she puts it in her basket. She then goes out. Anne takes out sallies marble and put it into her box Sally is away.

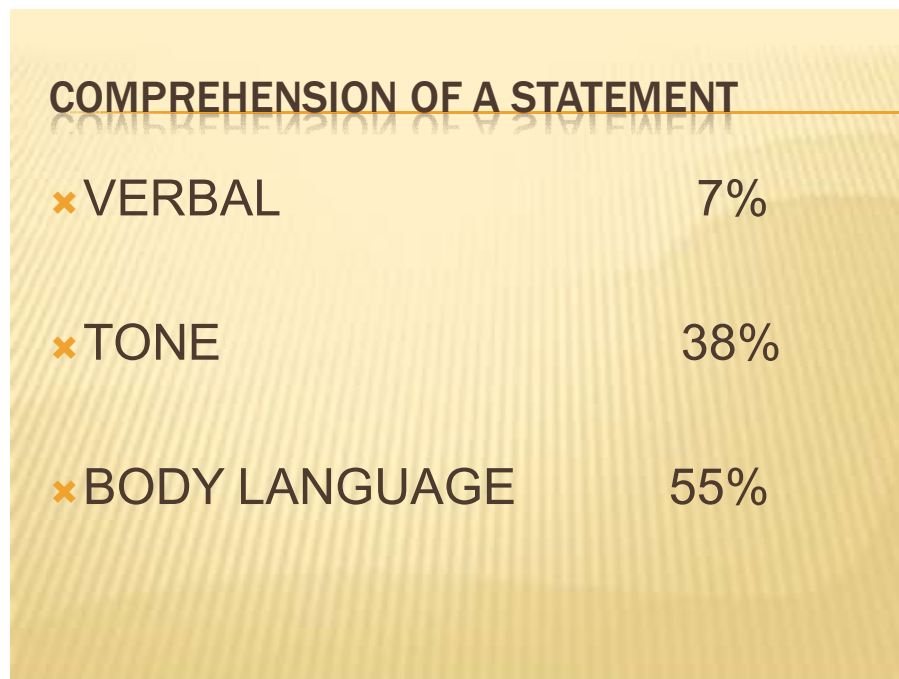
Now, Sally comes back and wants to play with a marble. At this point, we asked the critical question: where will Sally looked at the marble? The answer is of course in the basket. This answer is correct, because Sally has put the marble in the basket and has not seen it being moved. She believes the marble is still where she put it. Therefore she will still look in her basket even though the marble is not there any more.

Most non-autistic children gave the correct answer, that is, they pointed to the basket. In contrast, all but a few of the autistic children got it wrong. They pointed to the box. This is where the marble really was, well of course Sally did not know it was. They did not take Sally's own belief into account.” (Uta Frith 1989).

Wing’s Triad of Impairments (Lorna Wing and Julia Gould)



Understanding



INTERVENTIONS

What is the SPELL framework?

This is a framework for understanding and responding to the needs of children and adults on the autism spectrum. The framework is also useful in identifying underlying issues; in reducing the disabling effects of the condition; and in providing a cornerstone for communication. It also forms the basis of all autism specific staff training and an ethical basis for intervention. The acronym for this framework is **SPELL**. SPELL stands for **Structure, Positive** (approaches and expectations), **Empathy, Low arousal, Links**.

SPELL

The SPELL framework recognises the individual and unique needs of each child and adult and emphasises that planning and intervention be organised on this basis. A number of *interlinking themes* are known to be of benefit to children and adults on the autism spectrum and that by building on strengths and reducing the disabling effects of the condition progress can be made in personal growth and development, the promotion of opportunity and as full a life as possible. They are:

Structure

The importance of structure has long been recognised. It makes the world a more predictable, accessible and safer place. **Structure** can aid personal autonomy and independence by reducing dependence (eg prompting) on others. The environment and processes are modified to ensure each individual knows what is going to happen and what is expected of them. This can also aid the development of flexibility by reducing dependence on rigid routines. **Structure** plays to the strengths of a sense of order and preference for visual organisation commonly associated with the autism spectrum.

Positive (approaches and expectations)

It is important that a programme of sensitive but persistent intervention is in place to engage the individual child or adult, minimise regression and discover and develop potential. In this respect it is important that expectations are high but realistic and based on careful assessment. This will include the strengths and individual needs of the person, their level of functioning and an assessment of the support they will need. Try to establish and reinforce self-confidence and self esteem by building on natural strengths, interest and abilities.

It is vital that assessments are made from as wide a perspective as possible and that assumptions are made on the basis of painstaking assessment and not superficial enquiry. These should include a view of the barriers in accessing opportunity. For example, many people on the autism spectrum may have difficulty with oral communication, leading to an underestimation of their ability and potential. Conversely some may have a good grasp of speech but this may mask a more serious level of disability.

Additionally, many people with autism may avoid new or potentially aversive experiences but through the medium of structure and **positive**, sensitive, supportive rehearsal can reduce their level of anxiety, learn to tolerate and accept such experiences and develop new horizons and skills.

Empathy

It is essential to see the world from the standpoint of the child or adult with on the autism spectrum. This is a key ingredient in the craft of working with children and adults with autism. Begin from the position or perspective of the individual and gather insights about how they see and experience their world, knowing what it is that motivates or interests them but importantly what may also frighten, preoccupy or otherwise distress them.

To make every effort to understand, respect and relate to the experience of the person with autism will underpin our attempts to develop communication and reduce anxiety. In this, the quality of the relationship between the person and supporter is of vital importance.

Effective supporters will be endowed with the personal attributes of calmness,

predictability and good humour, **empathy** and an analytical disposition.

Low arousal

The approaches and environment need to be calm and ordered in such a way so as to reduce anxiety and aid concentration. There should be as few distractions as possible. Some individuals may require additional time to process information, especially if this is auditory. They have additional sensory processing difficulties; they may need extra time to process information or we will need to pay attention to potentially aversive or distracting stimuli, for example noise levels, colour schemes, odours, lighting and clutter. Information is given with clarity in the medium best suited to the individual with care taken not to overload or bombard.

Some individuals may be under responsive to sensory experiences and actually seek additional sensory sensations. Again this is best achieved with an approach where the input can be regulated.

Low arousal should not be confused with no arousal. It is of course desirable that individuals are exposed to a wide range of experiences but that this is done in a planned and sensitive way. It is recognised that for the most part the individual may benefit most in a setting where sensory and other stimulation can be reduced or controlled. Additionally, supplementary relaxation and arousal reduction therapies, Snoezelen, music and massage, sensory diet, etc may be helpful in promoting calm and general well-being and in reducing anxiety.

Links

Strong links between the various components of the persons life or therapeutic programme will promote and sustain essential consistency.

Open **links** and communication between people (eg parents and teachers) will provide a holistic approach and reduce the possibility of unhelpful misunderstanding or confusion or the adoption of fragmented, piecemeal approaches.

The people with autism, their parents or advocates are very much seen as partners in the therapeutic process. **Links** with the mainstream, through curriculum and other experiences, enable the individual to participate in a meaningful way in the life of the wider community.

The SPELL framework can be applied across the autism spectrum, including Asperger syndrome. It provides a context for and is complementary to other approaches, notably TEACCH (Treatment and **E**ducation of **A**utistic and related **C**ommunication Handicapped **C**Hildren).

The principles and concepts guiding the TEACCH system have been summarised as:

- Improved adaptation: through the two strategies of improving skills by means of education and of modifying the environment to accommodate deficits.
- Parent collaboration: parents work with professionals as co-therapists for their children so that techniques can be continued at home.
- Assessment for individualised treatment: unique educational programmes are designed for all individuals on the basis of regular assessments of abilities.
- Structured teaching: it has been found that children with autism benefit more from a structured educational environment than from free approaches.
- Skill enhancement: assessment identifies emerging skills and work then focuses upon these. (This approach is also applied to staff and parent training.)
- Cognitive and behaviour therapy: educational procedures are guided by theories of cognition and behaviour suggesting that difficult behaviour may result from underlying problems in perception and understanding.
- Generalist training: professionals in the TEACCH system are trained as generalists who understand the whole child, and do not specialise as psychologists, speech therapists etc.

(Extract from Approaches to autism: an annotated list published by The National Autistic Society, 1993/revised 2003)