

CHAPTER 2

OVERVIEW OF AUTISTIC SPECTRUM DISORDERS: IMPLICATIONS FOR EDUCATIONAL PROVISION

This chapter outlines the nature of Autistic Spectrum Disorders and the general implications for education provision.

WHAT IS AUTISM?

2.1 An Autistic Spectrum Disorder is a complex developmental disability that essentially affects the way a person communicates and relates to people. The term 'autistic spectrum' is often used because the condition varies from person to person. Asperger syndrome is a condition at the more able end of the spectrum. At the 'less able' end of the spectrum is Kanner's syndrome, sometimes referred to as 'classic autism'.

2.2 'Me and Asperger Syndrome

When I was 8 I found out about Asperger Syndrome or AS and since then my life has changed completely. Before that life was very hard for me. Life was depressing.

I always knew I was different and that I wasn't like other children. It's hard to say exactly how I knew. I detected some differences and I felt that things were not the same for me as for other children. Other children seemed to behave differently, but I didn't know why. At that time, although I felt different I felt normal about being different. I thought I was the normal one and that

*it was the other people who were different, not me.
Which is a perfectly feasible way of thinking'.
(Kenneth Hall, Age 10, from his own book "Asperger
Syndrome, the Universe and Everything",
Jessica Kingsley Publishers, December 2000).*

*'He wandered about smiling, making stereotyped
movements with his fingers, crossing them about in the
air. He shook his head from side to side, whispering or
humming the same 3-note tune. He spun with great
pleasure anything he could seize upon to spin... When
taken into a room he completely disregarded the people
and instantly went for objects, preferably those that
could be spun... He angrily shoved away the hand that
was in his way or the foot that stepped on one of his
blocks...'* (Kanner 1943)

2.3 The condition and behaviour patterns associated with "early infantile autism" were first described by child psychiatrist, Leo Kanner (1943). According to Kanner, the main features of this condition include severe social impairment, communication, rigidity of thought processes and ritualistic patterns of behaviour. At much the same time in Europe, a very similar group of children were described by Hans Asperger (1944) and characterised by their odd, naïve, and inappropriate social behaviour, long-winded pedantic speech, poor non-verbal communication, narrow interests and poor motor co-ordination skills. They were also described as having difficulty in applying skills in a flexible, functional way. The work of both Leo Kanner (1943) and Hans Asperger (1944) form the basis of our understanding of Autistic Spectrum Disorders today. While there has been much debate around the definition of autism, and Asperger syndrome in particular, it is now generally accepted that both autism and Asperger syndrome fall within a broader group of social and communication disorders, commonly known as Autistic Spectrum Disorders (ASD).

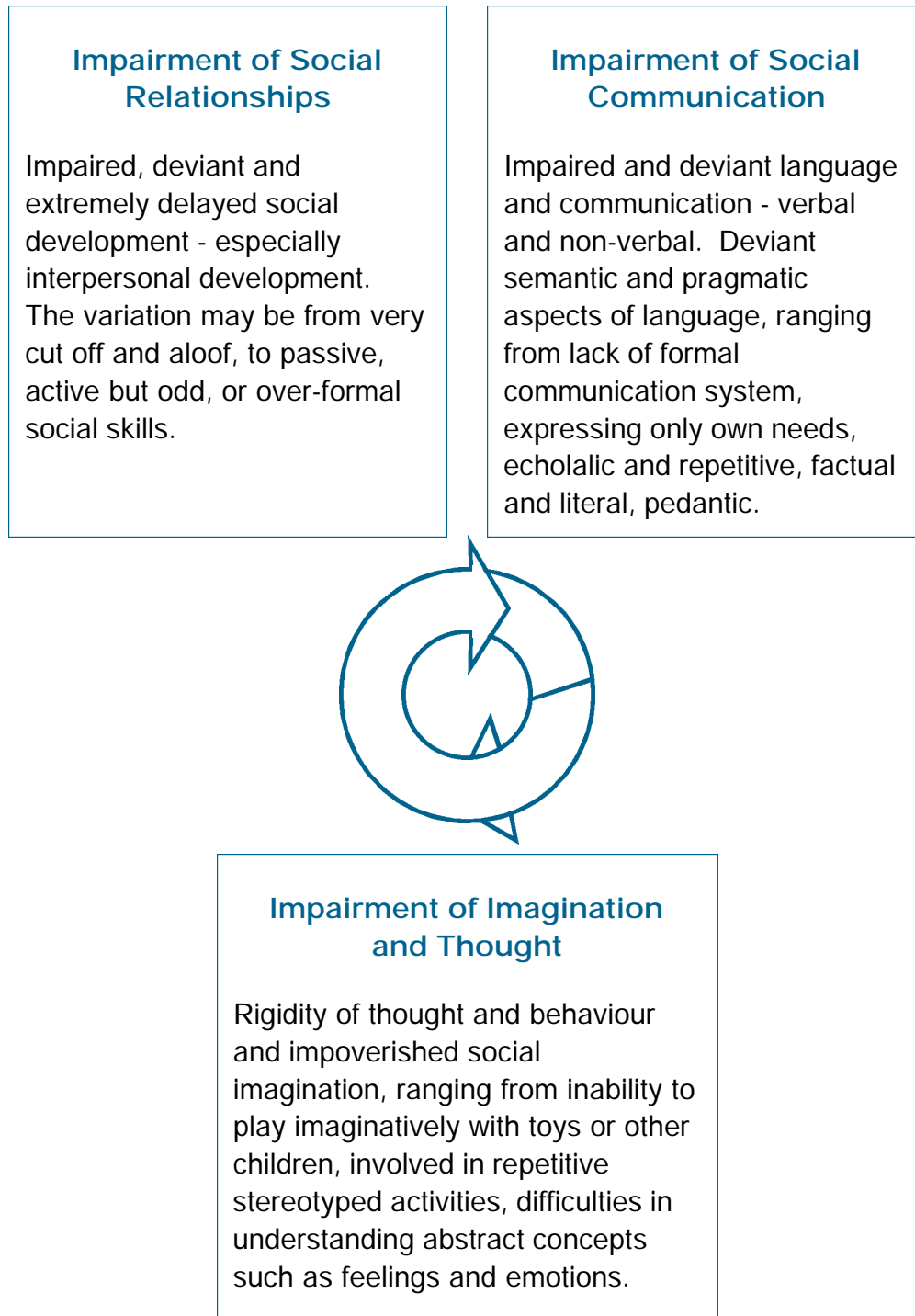
2.4 One of the most significant contributions to the clinical understanding of autism as a spectrum disorder, has been that of Lorna Wing (1979). After conducting an intensive epidemiological

study, Wing concluded that social impairment is a disorder of development and that the different manifestations, whether or not they are named as syndromes, are all part of a 'spectrum' of related disorders. Wing found that there were 3 areas of development associated with this social impairment, forming a cluster of features that provide diagnostic criteria for the identification of autism. This cluster is referred to as the triad of impairments (see Figure 1 overleaf) (Wing and Gould, 1979):

- ❖ impairment of Social Interaction;
- ❖ impairment of Social Communication;
- ❖ impairment of Social Understanding and Imagination.

Figure 1

Wing's Triad of Impairments



2.5 Autism is now generally recognised as a complex developmental disorder of lifelong duration which affects the individual in varying degrees of severity. The concept of a spectrum reflects the varying nature of each individual's autism experience which does not fit neatly into Kanner's or Asperger's descriptions. The "autistic spectrum" is preferred to the term "pervasive developmental disorders", first used in the 1980s, but currently found confusing as most children's profiles of skills and impairments are usually patchy rather than pervasive. The term "Autistic Spectrum Disorders" (ASD) is used in most contexts in this report.

2.6 Individuals within the autistic spectrum differ in how severely they are impaired in each of the triad areas - some will have significant difficulties in all areas, while for others, their difficulties may appear to be quite subtle. Some people with the condition may also have accompanying learning difficulties, while others are much more able, with average or above average intelligence (Wing, 1996). Similarly, linguistic skills range from those who display complex, grammatically correct speech to those who have none. Despite all the wide-ranging differences, everyone with the condition has difficulty with social interaction, social communication and social imagination. In addition, there are variable features which may be displayed by some, but not all, individuals with autistic spectrum disorders. These include specific language difficulties, eating problems, sensitivity to sound, touch, smell or taste, fine and gross motor difficulties, attention difficulties, behaviour problems and/or special skills (Wing, 1996).

2.7 Sadly, there is no known cure for autism but appropriate support and education in the early years can greatly improve later functioning, and can help those who are affected to live their lives with as much dignity and independence as possible. The parents of children with ASD are faced with numerous problems, mostly resulting from the social, communicative or obsessional difficulties that are fundamental to the disorder.

2.8 Reviews of epidemiological studies using various definitions of classic autism provide rates ranging from 3.3 to 16.0 per 10,000. There are relatively few studies which include the broader definition of Asperger syndrome. The UK National Autistic Society's latest figure for

the prevalence of the full range of Autistic Spectrum Disorders is 91 people in every 10,000 (Approx. 1 per 100). These figures include people at the more able end of the spectrum who may not need specialist services and support but will still benefit from early recognition and sympathetic understanding of their special needs and unusual patterns of skill. Figures for Northern Ireland indicate that nearly 1000 children and young people have been identified as having an ASD. While prevalence and incidence rates will be considered in more detail in Chapter 4, it is significant to record at this stage that many professionals report an increase in the number of individuals referred for diagnosis and assessment.

2.9 Two questions arise: is there a genuine increase in the numbers of individuals presenting themselves with the condition or is there another explanation? And where, on the autistic spectrum, are the numbers increasing? It is difficult to give definite answers, as health, social and educational services do not usually define those with ASD as a distinct grouping. Additionally, those with an ASD can be considered by different government departments according to their age, ability and home area, making it difficult for any one department or professional to have access to information on the total population with autism. It is also notable that diagnostic tools vary across the various professionals.

2.10 ASD can be caused by a variety of conditions that affect brain development and occur before, during and after birth. The conditions include, for example, maternal rubella, tuberous sclerosis, anoxia and encephalitis; fragile X chromosomal abnormality is found in a small proportion of children with ASD. Genetic factors are important in cases though the sites of the relevant genes have not yet been identified. Recent concerns have been raised about vaccinations as being a possible cause (Wakefield, 2000); however, the Medical Research Council (April 2000) concludes that there is no new evidence to suggest a causal link between measles, mumps and rubella (MMR) vaccination and autism. Further research by Ross (2000) found that the rate of incidence is no higher among vaccinated children. In a further commentary, Frank De Stephano and Robert Chen of the United States Center for Infectious Disease Control and Prevention note that autism has a strong genetic component and that the

associated defects probably occur prior to birth although diagnosis only happens later. While the debate remains, it is beyond the scope of this report to comment further.

2.11 As indicated above, the set of 3 core components, known as Wing's triad, is the basis for the diagnosis of autism (Rutter and Schloper 1987). Health professionals, since the late 1970s, use 2 main classification systems to diagnose autism: the International Classification of Diseases (ICD-10) and DSM-IV. Asperger syndrome, by contrast, did not reach the ICD or the DSM classifications until the 1990s, and there is still some confusion over the diagnostic criteria as to whether it differs from high functioning autism. DSM-IV, for instance, excludes the diagnosis of Asperger syndrome if the child also fulfills the criteria for autism, whereas ICD-10 is more equivocal. Within the areas identified by ICD, however, there is huge variability. As with all psychiatric diagnostic criteria, the criteria are more effective when used by a trained and experienced clinician as part of the overall evaluation of data rather than as a checklist for autism.

2.12 All people with autism have their individual characteristics and personality. The condition may, therefore, appear different in the same child at different ages, and with different cognitive levels in children. Because of this variability and also because it is difficult to disentangle problems in social interaction, communication and ritualistic or obsessive behaviours, it is best to use tools or instruments that specifically test for the presence of autistic symptomatology (Howlin, 1998). In clinical practice, it is common for individuals to exhibit a mixture of features of classic autism and Asperger syndrome. It is more useful, when diagnosing for educational purposes, to indicate levels of ability than to identify children into theoretical diagnostic subgroups. Perhaps of equal importance is the need to clarify diagnostic procedures to secure early diagnosis, which is now well regarded as the most significant variable in a positive prognosis (Lovaas, 1987; Mesibov, 1997). It is the Task Group's conclusion that early and precise diagnosis is crucial to educational planning and outcomes; this issue is considered in Chapter 5 in some detail.

2.13 ASD can occur in association with other physical or psychological disabilities, including cerebral palsy, Down's syndrome or

other chromosomal disorders. ASD often co-exists with dyslexia, language disorders, general learning difficulties and visual or hearing impairment. Among adolescents and adults, psychiatric illnesses, including anxiety and depression, can complicate the impact of the ASD. For diagnostic purposes, it is important to identify other co-morbid conditions as they may impinge on the child's learning and have important implications for treatment and prognosis.

2.14 The whole nature of autism ...is that every kind of impairment in autism has links with every other impairment in the syndrome. They all overflow into and pervade each other, and it is indeed the interaction between the parts of the syndrome which is most characteristic of autism (Newson, 1997).

2.15 Diagnosis, as a consequence, should include an accurate and comprehensive assessment from which appropriate educational and health intervention can be developed.

IMPLICATIONS FOR EDUCATIONAL PROVISION

2.16 Education remains the one treatment approach with the best 'track record' for dealing with the difficulties associated with autism. It is not just a matter of 'access' to education as a statutory right for children with autism, but about how education can have a central role in 'remediating' the effects of autism (not curing it) and improving the quality of life for individuals throughout their life span (Jordan, 1997).

2.17 The Warnock Report (1978) and the subsequent Education Act 1981, the Education (Northern Ireland) Order 1996, and the Special Educational Needs Code of Practice (1998) identify the general goals of education as the same for all children, irrespective of ability or condition. The challenge for educationalists is to bring educational goals into harmony with the individual needs of the child. The individual needs of a child with an ASD must therefore be identified, and responded to, in any educational programme in relation to the curriculum content, the teaching strategies and approaches used, and

the settings where the educational programmes are to be carried out and applied. In order to modify the impact of autism and to ensure the effective educational development of children with ASD, it is crucial to understand the nature of autism and the impact on the individual.

2.18 The Task Group contends that understanding the nature of autism provides an effective basis on which practical approaches can be constructed.

2.19 The ASD impairments will affect each individual differently but they all will experience difficulties in relation to:

- ❖ communication;
- ❖ social interaction;
- ❖ learning;
- ❖ behaviour;
- ❖ sensory stimuli;
- ❖ anxiety and stress¹.

2.20 Individuals with autism differ as much from one another as they do from their non-autistic peers. Individuals with ASD share the basic impairments. However, each impairment will show contrasting variation in depth, and the interplay with the other impairments will determine the type of educational programme necessary to secure progress.

Communication Impairments

2.21 Many children with ASD do not acquire speech; some remain silent while others use speech in repetitive fashion and mostly without purpose. Those children with higher functioning autism or Asperger syndrome tend to have a highly developed vocabulary but have problems with the use and understanding of language, particularly in

¹ (Teaching students with Autism: A Resource Guide for Schools. British Columbia, Ministry of Education, Special Programs Branch 2000)

the area of interpersonal communication. Language difficulties may include:

- ❖ lack of appreciation of the social meaning or function of communication: in particular, the tendency to talk at rather than to others;
- ❖ poor understanding/use of speech, gesture, facial expression, bodily posture or voice pitch or intonation;
- ❖ literal understanding/use of words;
- ❖ variation in the use of speech from an absence of speech to a repetitive use of words and/or muddling of the sequence of words;
- ❖ lack of eye contact;
- ❖ monotone quality of voice;
- ❖ restricted vocabulary;
- ❖ undue repetition of a topic;
- ❖ inability to maintain a conversation.

2.22 In Northern Ireland, there is a scarcity of speech and language therapists and the indications are that this situation will continue.

2.23 Accordingly, the Task Group findings indicate the need to:

- ❖ ensure comprehensive speech and language assessment and input to the overall intervention programme for the child with ASD;
- ❖ prioritise communication within an individual programme;
- ❖ ensure that speech and language therapists are trained to address the specific needs of children with ASD;

- ❖ secure sufficient speech and language therapists to meet the needs of the ASD population in Northern Ireland.

Social Interaction

2.24 Individuals with ASD vary in their abilities to mix socially and consequently to benefit from social interactions; in particular, they have difficulty establishing relationships or friendships. It has been theorised that individuals with ASD are not able to understand others' perspectives or indeed to understand that others have a perspective which can differ from their own. As a consequence, individuals with ASD tend to remain aloof, passive or 'active but odd' in their social behaviour and have a tendency to play in unusual ways and without imagination. Parents of children with ASD report this as an area of most concern and are often at variance with teachers in this regard. (ETI Asperger Survey 2000)

2.25 The implications for educational intervention include the need for a social skills curriculum as a core element in developing appropriate programmes for promoting appropriate social behaviour. Individuals with ASD do not develop social skills naturally or incidentally.

2.26 The Task Group considers that it is crucial to include social skills training in all intervention programmes for children and young people with ASD.

Learning

2.27 ASD span the intellectual spectrum and are frequently associated with learning difficulties. Individuals with ASD are known to have deficits in many cognitive functions yet not all functions are equally affected. Current research identifies the following common learning difficulties:

- ❖ paying appropriate attention to or focusing consistently on tasks or activities;
- ❖ thinking and reasoning abstractly;

- ❖ planning, organising and solving problems;
- ❖ understanding language and expressing thoughts, particularly feelings and emotions.

2.28 As a consequence a child with an ASD may experience a variety of problems including generalising learning, literal understanding of language and an inability to “join in” with peers in activities such as play or team games.

2.29 ASD individuals demonstrate huge variation in their learning profiles; some may excel at visual-spatial tasks and recalling simple information; they learn and remember best information presented in visual form but have problems comprehending oral or written information. Connor (1999) suggests the need for teachers and others who provide educational intervention to ensure provision reflects:

- ❖ a visual structure and constant routine;
- ❖ an individual approach to intervention;
- ❖ a sensitivity to the child’s autism and anxiety level;
- ❖ a simple and clear use of language.

2.30 The Task Group considers that individuals with ASD have a mixed pattern of learning strengths and weaknesses which must be identified to ensure effective differentiation of provision.

Behaviour

2.31 Individuals with ASD often display unusual behavioural characteristics. The individual with an ASD frequently exhibits stereotyped behaviours, including a resistance to change and a distinct insistence on sameness. Other characteristic behaviours include:

- ❖ restricted interests and preoccupations with particular objects or movements;

- ❖ repetitive mannerisms eg hand-flapping or spinning objects;
- ❖ unusual reactions to certain situations or stimuli.

2.32 A minority of children with ASD display extremely challenging or aggressive behaviour (see Chapter 10).

2.33 Intervention should focus on the development of strategies which structure the environment to provide the child with a sense of security conducive to learning appropriate behaviours in a range of settings.

Sensory Stimulation

2.34 Individuals with ASD respond differently to sensory stimulation; the responses vary from restrained sensitivity to over-sensitivity and may fluctuate unpredictably. Some children with ASD do not like being touched or may over-react to certain textures, including food. Some may find certain sounds or smells, innocuous to others, quite painful; other children with ASD may use smell to explore their surroundings, cover their eyes or stare for lengthy periods when they see shiny objects. Some children with ASD may be clumsy, dyspraxic or engage in constant spinning beyond that which others can tolerate.

2.35 The implications for intervention include the need for teachers to understand the sensory difficulties children may experience as a consequence of their autism, and to set appropriate targets to address each child's sensory needs.

Anxiety and Stress

2.36 Parents and teachers often report on their children's stress and anxiety, ranging from withdrawal to a bedroom to an outburst of emotion on return from school. At its worst, teenagers, particularly those with Asperger syndrome, experience panic attacks and extreme emotional anxiety and fear. For some individuals the consequences can be increasing isolation, a lack of identity of self and a lack of ability to integrate emotions and consequences.

2.37 Intervention programmes need to address the issue of anxiety and stress as a normal consequence of ASD. Appropriate support must be provided to counsel the individual with ASD, to enable him or her to cope with and manage difficult situations. Access to expertise on ASD within the mental health programme of care provided by Health and Social Services should be an integral part of the provision made for the individual.

CHAPTER 2

**OVERVIEW OF AUTISTIC SPECTRUM DISORDERS:
IMPLICATIONS FOR EDUCATIONAL PROVISION****RECOMMENDATIONS**

In this chapter the Task Group has noted many implications of ASD for educational provision. The Group makes the following broad recommendations about how these implications should be taken into account by those who are engaged in planning and developing provision, in providing training for staff, and in teaching children and young people with ASD. Some of these recommendations are expressed in greater detail in later chapters.

Recommendation 2(i)

Educationalists should recognise that education has a central role in 'remediating' the effects of ASD and improving the quality of life for individuals throughout their lifespan.

Recommendation 2(ii)

The central factor in educating an individual with ASD is to understand the nature of the disorder in order to facilitate learning and social inclusion: teachers, parents and others planning educational programmes for individuals with ASD should have an understanding of ASD.

Recommendation 2(iii)

Early diagnosis should be available and should include an accurate and comprehensive assessment from which appropriate educational and health interventions are developed, and should also include identification of co-morbid conditions.

Recommendation 2(iv)

Teachers and others contributing to programmes should be provided with relevant information arising from the diagnostic assessment process.

Recommendation 2(v)

Comprehensive speech and language assessment and input to the programme is essential: the deployment and training of speech and language therapists should reflect this.

Recommendation 2(vi)

Social skills training should be provided as an essential element of intervention programmes for children and young people with ASD.

Recommendation 2(vii)

The learning strengths and weaknesses of children and young people should be identified to ensure effective differentiation of provision: an emphasis on visual communication, simple and clear use of language and constant routine are of particular value when teaching children with ASD.

Recommendation 2(viii)

Interventions should focus on the development of strategies which structure the environment to provide the child with a sense of security conducive to learning appropriate behaviours in a range of settings.

Recommendation 2(ix)

Teachers and others should understand the sensory difficulties which children may experience as a consequence of ASD and set appropriate targets to address each child's sensory needs.

Recommendation 2(x)

Intervention programmes should address the issue of anxiety and stress as a normal consequence of ASD.