

## CHAPTER 3

**APPROACHES, PERSPECTIVES AND DEBATES:  
IMPLICATIONS FOR EDUCATIONAL PROVISION**

This chapter presents the Task Group's review of the main approaches to intervention and considers the implications for the development of effective educational provision.

**INTRODUCTION**

3.1 Autism is a subject which provokes much debate within many professions, parent groups and voluntary bodies, and in the popular and specialist media. This chapter will focus on issues which are of particular relevance to the development of educational policy in respect of ASD provision. These are:

- ❖ approaches to treatment and intervention for children with ASD including the issue of intensity of provision;
- ❖ inclusion;
- ❖ the role of educationalists in diagnosis and intervention; implications for educational provision.

3.2 In spite of the significant improvement in ASD provision over the past 10 years, there are a number of limitations and difficulties in the current provision. These are highlighted below and considered further in the following chapters. Current limitations indicate that:

- ❖ there is more to be done to ensure effective provision for children and young people with autism;
- ❖ there remain unresolved difficulties among ELBs and professionals concerning methodologies and approaches which make it imperative that there are

clear policy directives to inform practice and promote consistency across the boards;

- ❖ there is a need to focus on training professionals and others who work closely with individuals with ASD;
- ❖ there is a need to work more closely with parents and parent bodies to secure their active participation in the planning, management, delivery and evaluation of services and to reassure them that statutory provision will meet their children's needs.

3.3 Exclusive adherence to one method of support for children with ASD is rare in Northern Ireland. Frequently, the child and the family will be receiving support from a number of people from different professional backgrounds such as medicine, speech and language therapy, occupational therapy, social services, teaching, psychology and voluntary organisations. Usually this support is not provided within the context of a co-ordinated programme which is designed specifically for children with ASD, although both PAPA and Barnardo's have established small-scale early intervention schemes (the Keyhole Project and the Forward Steps pre-school service). However, two of the major approaches have been the subject of much debate and discussion locally and are described below in some detail. The TEACCH programme (Treatment and Education of Autistic and related Communications-Handicapped Children) is very widely promulgated in Northern Ireland, and many aspects of the programme are employed, along with other methods, in special and mainstream schools for pupils of all ages. Applied Behavioural Analysis (ABA), sometimes referred to as the Lovaas approach, focuses mainly on early intervention, especially during the pre-school years. It is the preferred approach for a small but significant number of parents. The latter approach has given rise to disagreements between parents and boards, and some parents have appealed to the Special Educational Needs Tribunal in order to have the boards fund Lovaas-type programmes for their children. The chapter will also comment on other commonly used methodologies, including the Picture Exchange Communication System which is gaining favour here, and will provide an overview of Keyhole and Forward Steps which are locally-developed projects in the

early stages of implementation. Reference is made to relevant literature and submissions to the Task Group. To conclude the chapter the Task Group sets out basic principles which should underpin the development of services for children with ASD.

### Approaches to Treatment and Intervention for Children with Autistic Spectrum Disorders

3.4 There are many forms of intervention and treatments for children with Autistic Spectrum Disorders, and there is much debate about which of these are effective. Some evaluations of approaches to treatment and intervention for children with ASD distinguish between biological, behavioural and cognitive methods and indicate the relative merits of each. Other evaluations attempt to derive principles or guidance on which evaluations of approaches can be made. It is impractical to comment in detail on the excess of approaches currently being marketed; this review is restricted to comments on the main approaches used here and aims to establish a set of criteria pertinent to Northern Ireland and capable of securing effective provision and choice of approaches. The Task Group is mindful, however, of the need for professionals to update information about other approaches which are being marketed as appropriate ASD interventions. Readers wishing to examine further the variety of approaches in use are referred to Jordan et al (1998), Heflin and Simpson (1998), NFER (2000) and Dawson and Osterling (1997) for more detailed evaluations. It is not the intention of this report to validate particular approaches for the sake of the approaches, but to reason, from a review of the ASD literature and current legislative directives, for a set of guiding principles from which provision, including strategies and appropriate approaches, can be developed. What is of concern to the Task Group is the need to demonstrate to parents of children with ASD that their children have a right to effective educational provision from the point of diagnosis.

3.5 Heflin and Simpson (1998) in their paper discussed 27 approaches available in the United States. The approaches ranged from some where there is little or no evidence to back up claims of effectiveness to some which have been validated by research evidence. In Great Britain, Rita Jordan et al (1998) prepared a report

for the Department for Education and Employment in which they reviewed the research on the effectiveness of a wide variety of approaches. Both sets of authors are among many who conclude that no one approach has been proven to be the best approach for all children on the autistic spectrum. Heflin and Simpson put the case as follows:

*“We firmly believe that there is not a single method that should be exclusively used to meet the varied needs of children and youth with autism and their families. Indeed, in our opinion, the most effective programs for students with autism are those that incorporate a variety of best practices, including careful evaluation of the effects of various methods.” (Page 207)*

3.6 Rita Jordan et al (1998) stressed that there were methodological weaknesses in all the evaluative studies which she reviewed and these made the results difficult to interpret. As a result, she concluded that

*“... there is no really strong evidence that one approach for a child with an ASD is better than another although there is a consensus of findings that early intensive education that involves the parents and includes direct teaching of essential skills with an opportunity for planned integration, can produce significant changes in children with an ASD” (page 7).*

*“Science has little to say about the individual case. Autism is so variable and individuals with an ASD so different, that a particular child may benefit from a particular approach at a particular time, regardless of what overall conclusions can be drawn from the research evidence.” (Page 119)*

3.7 Jordan et al conclude,

*“an inspired and dedicated teacher (whether this is a professional or a parent) can often succeed against the odds, with whatever approach he or she believes in”*

3.8 Heflin and Simpson point out that federal law permits schools in the United States the choice of methodologies and those schools with well-established methodologies are more likely to succeed in settlements of disputes when they include the following key factors:

- ❖ the availability of a developed programme;
- ❖ provision of appropriate intensity;
- ❖ an emphasis on meaningful outcomes;
- ❖ the creation of an individually-tailored programme.

3.9 Discussion of the various methods described below draws substantially on the factors suggested by Heflin and Simpson and, in particular, on the potential of an approach to address the triad of impairments, involve parents and provide opportunities for the child with an ASD to learn alongside non-ASD peers.

3.10 Teaching the child to play with objects and others is a critical component of any early services programme. Additionally, given what is known about normal childhood physical activity facilitating the growth of neurons and consequently improved neurological patterns, structured gross motor activities are vital on a daily basis. Music is often a natural accompaniment to some physical activities, and can provide further sensory input of benefit to the child. Incorporating various kinaesthetic stimuli, eg sand, water, can increase attention to objects and activities, can have a positive effect on the child's development. In summary, all of the things that normally developing children are interested in, and that are offered to them in pre-school programmes, will be of benefit to the child with an ASD. The difference will be in the planning, manner and frequency of delivery of these normal activities.

### The TEACCH Approach

3.11 Division TEACCH was founded in 1972 at the University of North Carolina (Lord and Schopler, 1994). It provides services for children and adults with autism and related developmental disorders throughout the State of North Carolina, USA. The programme is a

state-wide, community-based programme for children and adults with autism and communication disabilities. TEACCH services are both centre- and outreach-based. There is a demonstration pre-school classroom within the medical school, but other educational services are provided within the school and programmes in the communities within which the children and adults live. A major goal is to provide continuity of services from pre-school to adult life. The TEACCH team has been researching and developing their philosophy and system over the past quarter-century and have identified 7 key principles:

- ❖ **Improved Adaptation** - through the 2 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 assessment of abilities.
- ❖ **Structured Teaching** - it has been found that children with Autistic Spectrum Disorder 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.

3.12 A significant feature of the TEACCH approach is structure which helps the child to feel settled and relaxed. The approach addresses difficulties in organisation, memory, auditory processing and making transitions. There is an emphasis on positive strategies of behaviour management. It is based on an understanding of the difficulties the autistic person may have with communication, social interaction and flexibility. The approach recognises that people with ASD may find it easier to respond to and learn from information which is presented visually. It enables development towards independence but with adults in control, setting goals. It involves the family. TEACCH does not claim to cure autism, or to bring about recovery from autism, but it provides a supportive environment for people with autism whereby many of their difficulties can be circumvented and they can be enabled to live and learn without undue stress and anxiety.

3.13 TEACCH is used with people from all parts of the autistic spectrum and offers continuing support with the primary aim of enabling them to live, as far as possible, as independent members of the community.

3.14 TEACCH in its complete form is not evident in Northern Ireland. However, the 1998-2000 ETI Survey of Provision for Pupils with Severe and Profound Learning Difficulties indicated that, *“the teachers surveyed were knowledgeable about the principles of TEACCH, and demonstrated considerable practical application of the approaches in their classrooms”* and *“In the majority of cases, this has led to successful improvements in the pupils’ ability to settle to work, to access the curriculum and to develop routine, positive learning habits”* (page 16). A recent independent review of the Barnardo’s Pre-school Programme which relies heavily on TEACCH concludes that the children involved made substantial improvements on a wide range of motor, perceptual and cognitive processes (Sheehy, 2001).

3.15 The application of TEACCH principles is also evident in many mainstream schools and other special schools and units. Mainstream school teachers are not likely to have had access to a specific training course on TEACCH, but where they have attended a training course on ASD or have been given advice by a specialist advisory teacher, outreach teacher or an educational psychologist they are likely to have been exposed to some TEACCH principles. There is evidence of the effectiveness of the TEACCH approach in improving communication and behaviour and the quality of life of the children with ASD, their carers and teaching and support staff. (Sines et al, 1996; Jordan et al, 1998.) Heflin and Simpson (1998) conclude, *“TEACCH components of structuring the environment and implementing structured teaching continue to be regarded as instrumental in educational programs for students with autism”*. The approach can be used in the mainstream classroom and with different degrees of intensity.

3.16 TEACCH is not perceived as an exclusive approach. In Northern Ireland professionals often combine TEACCH strategies with other methods such as the Picture Exchange Communication System, Sensory Integration and Music Therapy. PAPA in conjunction with Division TEACCH has facilitated the training of local trainers so that the boards can aim towards becoming self-sufficient with respect to training needs. A number of parents and professionals, in their submissions to the Task Group, indicated their preference for the approach and requested further parental and professional training and implementation of the TEACCH approach.

### Applied Behavioural Analysis

3.17 Behavioural interventions for children with autistic spectrum disorders were pioneered in the 1960s by Dr Ivar Lovaas. The proponents of this method suggest that behavioural interventions may help improve the lives of individuals with autism by helping them acquire complex skills such as language, play, self-help and social skills (Lovaas 1981). The principles of the Lovaas programme are described by Dawson and Osterling (1987). They refer to the underlying principle as that of applied behavioural analysis, based on Skinnerian operant conditioning, and to the initial phases of the

programme involving intensive, home-based, 1:1 discrete trial training for 40 hours weekly. Lovaas (1987) noted that a 40-hour programme was much more effective than a 10-hour programme, and that the use of “aversives” was also associated with more successful outcomes. Parents receive training and advice so that the programme can be maintained virtually all the child’s waking hours. Parents and other adult helpers share the delivery of the programme. The first year focuses on reducing self-stimulatory or aggressive behaviour, developing compliance, and encouraging imitation and play. In the second year, the emphasis moves to expressive language and interactive play. Access is arranged for the child to pre-school group settings and s/he is taught skills necessary for peer interaction. In the third year emotional expression, pre-academic tasks, and observational learning are emphasised. Aggression or self-stimulatory behaviours are countered by employing strategies such as ignoring, time out and shaping.

3.18 Proponents of ABA cite references to indicate that intensive long-term behavioural treatment has been shown to enhance the intellectual, academic, social, and emotional functioning of children with ASD (Lovaas, 1987; McEachin et al, 1993). Schreibman (2000) claims that treatments based on behavioural methods are enjoying the broadest empirical validation for effectiveness for individuals with autism. Schreibman comments further:

*“While it is appreciated that there is no ‘one size fits all’ treatment for children with autism there is as yet no established protocol for relating specific child, family, target behaviour, and treatment variables to individual treatment regimes. Future research needs to include well-conceived and methodologically rigorous investigations allowing for the determination of these important variables”.*

3.19 Svein Eikeseth in a description of the Lovaas programme (1997) identified 9 factors which should be included in such a behaviour-analytic treatment programme:

- ❖ **Behavioural Emphasis** - the implementation of scientifically-based procedures.
- ❖ **One-to-one Instruction** - instruction should be in 1:1 without distractions.
- ❖ **Mainstreaming** - considerable effort should be put into mainstreaming the children with their peers to mirror appropriate behaviours and avoid initial placement in special education.
- ❖ **Comprehensiveness** - behavioural analysis should target all areas of deficiency such as language, play, leisure, academic and intellectual skills, self-help skills, and social interaction and friendship.
- ❖ **Intensity** - Lovaas (1987) provided a group of 19 autistic children with approximately 40 hours of behavioural treatment per week for 2 or more years. This group is reported to have made significantly greater gains in IQ than those children who received 10 hours or less intervention.
- ❖ **Family Participation** - to encourage transfer of language and other skills established in the clinic and special classrooms to home and community settings parents must be involved in the child's treatment and taught to use behavioural techniques.
- ❖ **Early Intervention** - Lovaas and colleagues recommend that treatment should begin as early as possible and ideally before the child is 42 months old.
- ❖ **Individual Differences** - recognition that there are large individual differences in autistic children's responses to behavioural treatment.

- ❖ **Non-aversive Interventions** - contemporary behavioural treatment for children with autistic spectrum disorders does not involve the use of aversive procedures.

3.20 In Northern Ireland, PEAT (Parents' Education as Autism Therapists) advocates the use of Applied Behavioural Analysis. PEAT was established in 1997 with the mission to help children and young people to realize their potential by providing Applied Behavioural Analysis training and support to their parents and carers. A smaller number of parents in Northern Ireland have been supported by LEAP (London Early Autism Project). LEAP is a London-based project, which is affiliated with the Wisconsin Early Autism Project, which in turn is reported to be the largest replication site for Lovaas' research in the world.

3.21 Some parents fund ABA early intervention programmes from their own resources. ABA early intervention programmes vary in cost, but the more intensive programmes can cost well over £20,000 per year per child. The Education and Library Boards remain cautious about supporting intensive ABA early intervention programmes. No board provides an early intervention service which is as intensive as the Lovaas approach, and so when parents seek support for such a service the boards are dependent on external providers and have not taken steps as yet to become self-sufficient in this respect.

3.22 ABA is not only used in programmes for young children. It can be used with older pupils as well. In some local schools for children with Severe Learning Difficulties behaviour strategies from the Institute of Applied Behavioural Analysis are used with apparent success with pupils who exhibit challenging behaviour. The IABA puts particular stress on the avoidance of situations and techniques which may fuel confrontations. Some teachers at other SLD schools have recently received IABA training, which they are now applying with pupils with challenging behaviour, and autism.

3.23 There has been considerable controversy about the Applied Behavioural Analysis approach in Northern Ireland and internationally. Proponents of ABA argue that children with Autistic Spectrum

Disorders should, while they are still very young, be offered up to 40 hours per week of intensive one-to-one home-based behavioural training, because, it is claimed, nearly half of them will, as a result, achieve normal educational and intellectual functioning.

*3.24 “There is evidence that the longer treatment lasts, the larger the client’s gains. Furthermore, in most instances of treatment of autism and pervasive developmental disorders (PDD), relapse will occur when the treatment is terminated. The only exception to that occurs with early and intensive behavioural intervention. A sizable minority of children with autism who started treatment before the age of 4 were successfully mainstreamed and appear recovered.” (Lovaas, in Maurice et al 1996, page 242)*

3.25 Lovaas indicates therefore that it is only if the intensive treatment begins when the child is still under 4 years that there is a possibility of recovery. Local professionals who work with young children suggested to Task Group members that they would have grave reservations about being involved in subjecting such young children to such an intense behavioural programme for fear of causing some kind of psychological damage. Some local professionals have also suggested that it may be difficult to remain within guidelines on Child Protection (DE Circular 1999/10) while conducting Lovaas-type programmes. Lovaas-type programmes may involve the therapist working alone with the child, and may include the application of very assertive control techniques, as described for example by Catherine Maurice (1993, p. 240). Lovaas (in Maurice et al 1996 p. 242) reassures readers that aversives are no longer used, and describes an alternative method of dealing with tantrums, in which the therapist or parent is advised to work through the tantrum behaving as though it was not happening, and preparing for the child’s assaults by wearing a bathing cap to prevent hair-pulling and wearing heavy covers over arms and legs to minimize damage from bites or kicks. Even though this approach does not involve the administration of any punishments as such, many professionals would feel very uncomfortable about engaging in such a therapy strategy. Parents, however, may take a different perspective. If they have reason to hope

that use of such intensive and sometimes tough techniques may bring about permanent “recovery” from autism, they may find it difficult to sympathise with the concerns of professionals, and view their concerns as being trivial in comparison with the potential good long-term outcomes for the child.

3.26 The Task Group considers that while there is such strength of feeling about ABA and the approaches used by some of its proponents to promote its use, there is a danger of losing sight of the needs of the children by focusing too much on winning the methodological argument. As a consequence, some parents and professionals may reject the approach in its entirety even though behavioural methods are viewed by many researchers as an appropriate approach to supporting children with autism.

3.27 Heflin and Simpson (1989) comment,

*“ideally the community of reasonable parents and professionals associated with individuals with autism will eventually recognize ABA and discrete trial training as effective tools. We are also hopeful that ABA and discrete trial training will be recognised as being most effective when used in conjunction with other individually determined best practices methods”.*

3.28 Jordan et al (1998) report on a study evaluated by Ozonoff and Cathcart, which indicated that, *“a short (4 month only) TEACCH programme can be effective in improving scores (in conjunction with some ABA schooling) over and above that of a group doing ABA alone.”* Harris and Weiss (1998 quoted in NECTAS Resources Collection on Autism Spectrum Disorders, Whaley and Shaw 1999) make a distinction between early intensive behavioural intervention and “applied behavioural analysis”. The authors insist that ABA is essential in the treatment of every child with autism: they list the common features of early interventions as “a rich ratio of adults to children, opportunities for integration with normally developing peers, careful planning for the transition from specialised programmes to more normalised programmes, opportunities for family involvement, and a well developed curriculum”. The authors note that these

qualities characterise all effective programmes for young children with autism, not just those using an ABA approach. Indeed, the logic of intensive behavioural programming is based on the fact that no single treatment programme is sufficient to optimise treatment outcome (Lovaas 1996). It is not surprising, therefore, that educational providers are unsure of prescribing single approaches and for the most part encourage the use of good practice ASD strategies and supportive therapy provision for inclusion in any programme.

3.29 What is clear is that both parents and professionals require training in behavioural techniques and are fully involved in the implementation of the programme of intervention. Martha Zigler, in her article "One Mother's Reflection" and in her presentation to the North-South Autism Task Groups (2000) offered 4 emerging themes which are worthy of repeating:

- ❖ respect for people with autism has increased greatly;
- ❖ writers from a variety of perspectives strongly agree that children must be assessed individually and have their interventions and educational strategies individually tailored;
- ❖ most writers agree that what works best in the education of children with autism is a combination of more than one approach, even though one approach is likely to dominate. Several also advocate inclusion of techniques such as sensory integration, speech and language therapy and facilitated communication for older children still not speaking. All agree that a structured environment is necessary and all emphasise the importance of integration with peers as early as possible;
- ❖ parents and other family members are seen as critical partners in the education of the children, often doing much of the teaching directly or indirectly.

### The Picture Exchange Communication System (PECS)

3.30 The Picture Exchange Communication System (PECS) (Bondy and Frost, 1994) was developed within the Delaware Autistic Programme in the USA and employs the use of pictures to encourage the child's initiation of communication rather than responding to prompts. The aim is to acquire skills in everyday settings that can be developed both at home and in a school. The system is inexpensive, does not require complex materials or manuals or highly skilled training. It can be used in the classroom, the home and a variety of settings. The outcomes reported to date are promising and indicate improvements in communication ability, including the development of speech. Heflin and Simpson (1989) comment:

*"PECS is an empirically sound method that has excellent utility in developing communication skills in both non-verbal students with autism and limited communication students with autism."*

### The Keyhole Early Intervention Project

3.31 The Keyhole Early Intervention Project is designed for young children aged 2<sup>1</sup>/<sub>2</sub>-3<sup>1</sup>/<sub>2</sub> years and it operates in one district of Northern Ireland. There are 3 aspects to the project:

- ❖ home visiting;
- ❖ parent and professionals training;
- ❖ parental workshops.

The aims of this eclectic project are to provide parents with training and support to their children to develop appropriate social skills and to enhance their participation in pre-school provision. Families receive 18 home visits over an 11 month period and support to follow an individual family plan. The project is at the early stage of development and is being evaluated by the University of Ulster at Jordanstown. The project has merit in that it involves parents fully at all stages and is underpinned by the belief that the child's developmental and autistic needs are critical to planning effective intervention.

## Forward Steps

3.32 The Forward Steps programme developed by Barnardo's is a service for pre-school children with autism operating in the greater Belfast, Bangor and Newtownards areas. The service provides:

- ❖ home-based support;
- ❖ training for parents;
- ❖ short-term assessment;
- ❖ pre-school playgroup placement of 12 hours per week;
- ❖ inclusion within community services.

The programme based on TEACCH emphasises the visually structured approach and aims to help children to access their local playgroup.

## Intensity

3.33 The issue of intensity of approach remains controversial. Strain (2000) claims that there is little evidence that more is better. He suggests the following elements of intervention as more important indicators of success than the total number of hours:

- ❖ the quality of teaching;
- ❖ the competence of the teachers;
- ❖ the degree of continuity across teachers and settings.

3.34 The Task Group contends that decisions about intensity should be made on the basis of multi-disciplinary assessment of the needs of the individual child, his/her well-being and health, and parental choice and resources. A number of writers suggest that the best examples of pre-school provision offer an all-round service, teaching programmes ranging from 15-30 hours weekly and total intervention services ranging from 20-42 hours weekly. While research studies (Lovaas, 1987) indicate that 10 hours is inadequate to effect significant improvements, there is growing evidence that children with ASD

improve significantly with 20 hours per week intensive support (Anderson et al, 1987). In their clinical practice guidelines for early intervention, the New York Department of Health recommend that intensive behavioural programmes include a minimum of approximately 20 hours involving systematic use of behavioural teaching techniques, intensive 1:1 direct instruction and extensive parent additional hours of intervention. The guidance indicates that considerations in deciding the intensity and frequency of intervention should include:

- ❖ the age of the child;
- ❖ the severity of the autism;
- ❖ the rate of progress;
- ❖ other health considerations;
- ❖ tolerance of the child for the intervention;
- ❖ family participation.

3.35 What is unquestioned is the need to provide intensive support at an early age, to train both professionals and parents in ASD techniques, including behavioural analysis, and, importantly, to provide support from the point of diagnosis.

3.36 Keogal (2000) points out that programmes which oblige the parents to adapt to the programme requirements increase parental stress, while programmes which adapt to family lifestyles and routines actually decrease family stress and result in greater gains in child communication.

3.37 The Task Group notes that parental stress should be taken into consideration when decisions are made in respect of intervention.

### Inclusion

3.38 In Northern Ireland, pupils with ASD may be found in almost every type of mainstream school, special school and special unit, and there are some who are tutored at home because schooling has not been successful. 44% of pupils with ASD attend mainstream schools,

36% attend schools for children with severe learning difficulties and 20% attend other types of special schools and units attached to mainstream schools (see Chapter 4). There is no ASD specialist school or unit, although some classes within SLD schools are specialist ASD classes. A very small number of pupils attend residential ASD specialist schools in England and Scotland.

3.39 While many educationalists and parents will support integration for all pupils with some other forms of learning difficulty, eg all children with moderate learning difficulties, the Task Group have not come across arguments for full integration for all pupils with ASD for all of their period of education. This is perhaps because it is recognised that the mainstream school can, for some ASD pupils, be an extremely stressful place, in part because of the complex social and curricular demands. It has been said that for the autistic person, dealing with people is like doing quadratic equations in your head since so many judgments have to be worked out like problems. In the Survey of Pupils with Asperger Syndrome 1999-2000, conducted by the Education and Training Inspectorate, it was noted for example that:

*“A few of the pupils were reported as displaying serious signs of depression, and visits to a clinical psychologist were not uncommon...” and “Parents reported that their children were particularly tired on returning from school, and often were stressed and exhausted. Worry was associated with isolation and lack of friends.”*

3.40 It is commonly accepted that these social problems often become more acute as the pupil progresses through the post-primary phase of education. The Task Group also were informed by parents and schools about some pupils exhibiting behaviour which is so challenging that it is not always possible for staff to cope even in the small classes of an SLD school. There is no doubt that many pupils with ASD can and do benefit from mainstream education. It is also clear that if mainstream education is to be successful for more pupils with ASD then there is still much more to be done, at school organisation level and at individual teacher level, to make mainstream schools more inclusive (see Chapters 7 and 8).

## Debates about Diagnosis and Intervention

3.41 In Chapter 1 the report highlighted the confusion that may arise as a result of different criteria and different diagnostic instruments being used by different professionals. Diagnosticians also differ in their willingness to diagnose at a very early age. Most would recognise that early diagnosis, if followed by early intervention, is of benefit to the child. On the other hand, the younger the child, the greater the risk of making a misdiagnosis of ASD. There is much variety with respect to which professional disciplines are involved in diagnosis. In Northern Ireland, diagnosis may be carried out by individual professionals, or multi-disciplinary teams. The teams may include psychiatrists, paediatricians, clinical psychologists, speech and language therapists, occupational therapists, and educational psychologists.

3.42 The Warnock Report (1978) encouraged professionals in the field of education to assess and detail the special educational needs of children rather than label them as members of a category. Subsequent legislation abandoned the use of category labels such as ESN (educationally subnormal), Maladjusted, Delicate etc. Many educationalists saw this as a progressive step, and perceived the medical model, ie diagnosing and labelling, to be one which was not appropriate in the field of education. Over time, however, diagnosis and labelling have become commonplace again. These labels are generally applied by medical professionals but it is often educational professionals who are challenged to provide appropriate educational solutions for the problems being experienced by the child. Medical labels are now extensively used in educational contexts, eg Attention Deficit with Hyperactivity Disorder, Dyspraxia, and, of course, Autism, Asperger syndrome, and Autistic Spectrum Disorders (ASD).

3.43 A key reason for the resurgence of diagnostic labels may be that it is frequently easier to argue for extra resources if the child has a named disability of some form, rather than a list of special educational needs. An equally compelling reason is that parents and some people with ASD put value on having a diagnosis. This presents a professional dilemma for those, such as educational psychologists, who are committed to the principles of equity and of making provision

according to need rather than making provision according to label. The autistic spectrum is a very wide one. Some children on the spectrum do not need resources beyond what the ordinary mainstream school can provide, and at the other extreme, some can overstretch the resources of even the most generously-provided special school. Most educational psychologists therefore focus on examining the special educational needs of the child and leave the diagnosis and application of the label to health professionals. They would hold the view that the presence of a diagnosis of ASD does not, per se, clarify what, if any, special educational needs the child will have. On the other hand, close examination of the diagnostic criteria for ASD reveals that the condition is one which is very much a psychological disorder related to impairments of perception, thinking, imagining, feeling, and communicating, and this suggests that the main form of "treatment" for the child will be educational in nature. Several SLD school principals expressed the view that schools put a high value on having a thorough educational psychological assessment of children with ASD. It is evident therefore that the educational psychologist must play a major role in the assessment. Philip Whitaker, a Senior Educational Psychologist in Leicestershire, told the Task Group that it was common practice in his Local Education Authority for educational psychologists actually to diagnose ASD. In the same discussion, however, a paediatrician drew attention to the danger of failure to notice additional medical disorders if educational psychologists diagnose outside the context of a thorough paediatric assessment.

3.44 As will be detailed in Chapter 5, the current trend in Northern Ireland and elsewhere is very strongly towards multi-disciplinary and multi-agency diagnosis and assessment, ie various professionals from Health and Social Services and from Education are involved. It is evident that it is generally accepted that the diagnostic label should be used. Even within multi-disciplinary diagnostic clinics, however, practice varies with respect to which professionals actually take responsibility for making the diagnosis. Where educational psychologists are members of a multi-disciplinary team they can provide information about the child, often gathered in another context such as the child's school, and they may thus assist accurate diagnosis. Even if educational psychologists do not formally take responsibility for diagnosis, they still have a vital role to play in making

explicit the special educational needs of the child and thus providing information upon which the child's teacher and others can act when devising the education plan. The Task Group considers that diagnosis should strive to be multi-disciplinary and commends the expansion of such teams across Northern Ireland.

### Features of Good Practice

3.45 The Task Group regards as crucial the need to remain abreast of new research and evidenced-based approaches while at the same time offering the best of what current research and parental choice suggest. Strain (1998) recommends that providers require the best available information in order to make effective decisions about intervention. He cites 4 assumptions as a basis for general intervention planning:

- ❖ children with autism are children;
- ❖ children with autism grow up;
- ❖ children with autism have families;
- ❖ children with autism live in communities.

3.46 The assumptions appear simplistic but are fundamental to provision and indicate the need for co-operation among the educational, health and social services, providing in holistic fashion for the broader needs of children with autism and their families. Strain further suggests:

- ❖ young children with autism should be provided with regular and planned opportunities to interact with typical same-aged peers;
- ❖ teaching for young children with autism should be carefully planned, executed and evaluated;
- ❖ young children with autism and their families require a level of intervention to match their needs;

- ❖ young children with autism and their families require services delivered across many different contexts;
- ❖ young children with autism should be provided with a scope and sequence of instruction that covers all areas of developmental needs;
- ❖ young children with autism should be enrolled in intervention services as early as possible;
- ❖ the challenging behaviour of young children with autism should be addressed with positive, proactive strategies.

3.47 The Task Group endorses the principles set out by Strain and find favour with his comments,

*“In such a field of rapidly expanding knowledge, it is the fool who insists upon and speaks with absolute certainty.”*

*“Regrettably, it is also in the nature of a young field to suffer from extravagant claims and the zealous marketing of one size fits all models of intervention.”*

3.48 It is evident that there are a number of approaches which result in improvements in skills for children with ASD. What is important for the DE and the ELBs, is to secure effective levels of intervention and appropriate structures to guarantee a range of services which will meet the needs of all children within the autistic spectrum. For most parents in Northern Ireland, the main focus of interest is not on which of the major methods is on offer to them, but on whether they are being offered well co-ordinated support at all. In Northern Ireland the quality and extent of support for the child and family at pre-school level is very variable (see Chapter 5).

3.49 The Task Group findings indicate the need to secure provision which is underpinned by 3 factors:

- ❖ the nature of the child's ASD should be central to identifying an individual educational profile upon which provision can be based;
- ❖ given the diversity of autistic spectrum disorders, teachers and others involved in teaching provision should be knowledgeable about the nature of autism and the core teaching strategies which reflect this knowledge;
- ❖ teachers and others should have a breadth of skills and knowledge of the various strategies and main approaches to securing improvement in the child's long-term prognosis.

3.50 The Task Group notes Dawson and Osterling's (1997) 6 elements which are common to effective intervention programmes:

- ❖ curriculum content indicating skills which need to be taught;
- ❖ a structured environment which includes strategies for generalised learning;
- ❖ predictability and routine to help the child transfer from one activity to another;
- ❖ a functional approach analysing and dealing with behaviour;
- ❖ plans to enable the child to transfer successfully from pre-school to school setting;
- ❖ family involvement as central to the overall programme.

3.51 The Task Group additionally finds the following features identified across the approaches as examples of useful practice:

- ❖ an emphasis on 1:1 planning and work;
- ❖ staff and parental training;
- ❖ an emphasis on communication;
- ❖ an emphasis on visual approach;
- ❖ an emphasis on developing skills for independence;
- ❖ an emphasis on mainstreaming and access to peer curriculum;
- ❖ an emphasis on recording and evaluating outcomes.

3.52 In conclusion, the Task Group considers that Strain's recommendations can be adapted to provide ELBs and schools with 6 critical considerations as a legitimate basis for strategic planning of ASD services:

- ❖ the significant outcomes of a strategy or approach as value for the input of time, resources and expense;
- ❖ the capacity of the strategy or approach to blend with existing provision and current educational principles;
- ❖ the potential of the strategy or approach to secure peer curricular access;
- ❖ the flexibility of the strategy or approach to address the needs of children across the education phases, including special and mainstream schools;
- ❖ the potential of the strategy or approach to involve and accommodate variations in family needs;
- ❖ the use of the strategy or approach to meet sibling and family needs.

## Implications for Educational Provision

3.53 In this chapter the Task Group has considered debates about the various approaches to meeting the needs of children with ASD, about intensity of provision, about inclusion and about the role of educational psychologists in the processes of diagnosis and assessment of special educational needs.

3.54 Heated debate about which approaches are the most effective is likely to continue but it is clear that early diagnosis and intervention are essential, as is continuing evaluation of the approaches that are used. What is evident is that positive outcomes of programmes are a consequence of intensity and consistency of intervention between the home and the school. Effective provision should address the individual's ASD and provide access to the curriculum of his/her peers.

3.55 In the absence of consensus among researchers that any one approach is for all the children the best, most children with ASD are likely to be in receipt of eclectic forms of support or single forms at different periods in their development. It is important that the approaches offered are evaluated as appropriate to the needs of the child and the family, and the choice of approaches not determined solely by considerations of cost or profit, professional or administrative convenience or demands of advocates for the exclusive use of one particular approach.

3.56 There is consensus that, regardless of method used, the programme on offer to very young children should be very thoroughly designed, characterized by high quality and well co-ordinated teaching and therapy and a high degree of parental involvement of a type which is compatible with the needs of the family. Although such programmes should be intense, intensity should not be equated simply with total number of hours given to the programme. There should be thorough recording of progress made and programmes should be evaluated.

3.57 It is apparent that many pupils with ASD can benefit from mainstream education but many of these will require specialist support, and their teachers will require training. ELBs, in partnership with the

voluntary sector, will need to continue to develop support and training services and evaluate their effectiveness.

3.58 It is evident that mainstreaming will not be successful for all pupils with ASD at all stages of their development. ELBs will need to consider the creation of some specialist ASD provision.

3.59 A number of different professions are involved in diagnosis and assessment and in meeting the needs of young children on the spectrum. If intervention is to be successful then multi-disciplinary and multi-agency collaboration is essential.

3.60 The Task Group has not found evidence that there is one simple answer to the question of how to cater for the needs of children with ASD, but, on the contrary, has found evidence that this is a field of endeavour which is developing rapidly and one where a variety of approaches should be encouraged within a framework where the importance of evaluation must be stressed. It would be inappropriate therefore for the Task Group to recommend one particular method. The Group recommends the application of a number of basic principles to underpin the development of services for children with ASD.

## CHAPTER 3

**APPROACHES, PERSPECTIVES AND DEBATES:  
IMPLICATIONS FOR EDUCATIONAL PROVISION****RECOMMENDATIONS****Recommendation 3(i)**

The Task Group finds preference for no single approach but concludes that single methods by themselves may not address effectively the triad of impairments associated with ASD. The Group concludes that intervention programmes should be child-centred rather than method-centred, and should address the observed and unique needs of the child and any variation in these which occurs over time and across settings and situations.

**Recommendation 3(ii)**

The Task Group recommends that provision should include strategies and approaches matched to the needs of individual children and delivered in home-based and centre-based settings, as indicated by multi-disciplinary and multi-agency assessments in which parents are fully involved.

**Recommendation 3(iii)**

The Task Group recommends 7 principles to underpin planning of provision by the Education and Library Boards:

Provision should be:

- ❖ based on current research indicating best practice in respect of achieving meaningful outcomes, providing value for input of time and resources, and promoting independence and inclusion;

- ❖ inclusive of a range of methods and approaches which have been shown to be effective or which are judged by those who work with children with ASD to be worthy of evaluation;
- ❖ determined by, and regularly reviewed by, multi-disciplinary, multi-agency teams which include parents as well as appropriately trained professionals from the ELBs and HSSBs, and which respond promptly to requests for assessment and intervention;
- ❖ reflective of the individual's needs profile, and any changes in these needs over time and across different contexts and reflective of the needs of the family;
- ❖ compatible with the Department of Education's pastoral care, including child protection guidelines (Circular 1999/10) and the United Nations Convention on Human Rights (Article 4);
- ❖ provided by appropriately trained professionals, and by parents who have also had appropriate training;
- ❖ subject to review, evaluation and inspection by the Education and Training Inspectorate.