



Local Government Association

making a difference:

early interventions for children with autistic spectrum disorders

by Jennifer Evans, Frances Castle and Shanee Barraclough,
National Foundation for Educational Research,
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making a difference: **early interventions for children** **with autistic spectrum disorders**

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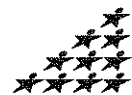
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INVESTOR IN PEOPLE



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Executive Summary

Background

There is a consensus of opinion that early intervention in the educational careers of children with special educational needs helps alleviate later difficulties. This is particularly the case for children identified as having an autistic spectrum disorder (ASD) and there is also growing awareness and agreement that these children need specialist interventions and access to expert support. Most local education authorities have an eclectic approach to provision, with a combination of generic provision and discrete methods and approaches, each of which has its distinct characteristics. The National Foundation for Educational Research, under the educational research programme of the Local Government Association, undertook a research project to examine the implementation, operation and perceived impact of the range of interventions offered to children with autistic spectrum disorders up to the age of seven (the end of key stage 1).

Research aims

The research was carried out in two phases. The first phase attempted to ascertain the level of identification of ASD for children up to the age of seven years, the types of provision being made for them, issues of parental support, and inter-agency communication and collaboration. The second phase focused on specific interventions offered by local education and health authorities, the ways in which children's progress was tracked, and the evaluation of the interventions.

Research methodology

Phase 1 data were collected via short questionnaires to all local education authorities in England and Wales, follow-up telephone interviews with the respondents in 30 LEAs and case-study visits to nine LEAs selected to reflect differing contexts and approaches. Phase 2 of the research looked in more detail at examples of specific types of intervention offered in the case-study LEAs. Eight of the nine LEAs from Phase 1 participated in this phase of the research. In each, the NFER research team studied a particular type of provision from among the range offered in the authority to children in this age group. Up to six children from each provision were identified and parental permission obtained for their inclusion in the project. In addition, providers and parents were asked to fill in Childhood Autism Rating Scale (CARS) and a Skills and Behaviour Checklist.

Findings from questionnaires

- ◆ One third of LEAs were unable to supply figures concerning the number of children with ASD aged 2–7, while the number of identified children appeared to be quite small in those LEAs that could supply the information,. In most LEAs, the number aged 5–7 was greater than those aged 2–5 , which suggests that some children's problems were not being identified until they reached school.
- ◆ Some LEAs appeared to have extensive and well-functioning links with a whole range of agencies (including health, social services and voluntary groups) to develop services for children with autistic spectrum disorders and their families. These LEAs had multi-agency working groups considering the whole issue of early identification and intervention.
- ◆ Provision for this age group appeared to be patchy and under-developed. The most frequently mentioned provision was specialist provision in mainstream schools or special schools.
- ◆ A large proportion of children identified on the autistic spectrum in this age group were receiving their education in mainstream schools.
- ◆ Almost half the LEAs that responded to the questionnaire had some form of specialist provision for autism for the age group.
- ◆ Many of the LEAs were aware of the gaps in their provision and were taking steps to plan future developments.

Findings from telephone interviews

- ◆ Differences in approaches to policy and provision were heavily influenced by the contexts within which the LEAs were working; a major point of difference was between urban and rural LEAs.
- ◆ For some LEAs, there was an absolute shortfall in the amount of provision they had for these two age groups – the under-fives and five-to-seven-year-olds; for others, the range of provision was limited.
- ◆ Most LEAs reported that their schools used a range of teaching approaches, including TEACCH and the Picture Exchange Communication System (PECS).
- ◆ The level of knowledge and expertise of teachers and classroom assistants working in this area of need and training for them was seen as an important issue and the lack of training places as a problem.
- ◆ There was a variety of concerns about inter-agency relationships.

- ◆ A key issue for many local authorities was that some parents of children with autistic spectrum disorders were increasingly seeking alternative provision because they were not satisfied with what the LEA was able to offer.
- ◆ The lack of support for parents when their child was undergoing assessment and diagnosis was another issue raised as well as behaviour management at home.

Findings from the case studies

- ◆ Identification of younger children appeared to be becoming more effective in all the case-study areas and some form of multi-professional assessment was seen as good practice in all the nine case study areas.
- ◆ Making a diagnosis and communicating this to parents was seen as a sensitive issue. Some professionals preferred to talk about 'social communication disorder' or 'pervasive developmental disorder' rather than use the term 'autism'.
- ◆ On the whole, relationships between professionals in education, health and social services appeared to be positive. However, there were often problems at the strategic level about funding of provision, developing joint approaches and the responsibilities of the various agencies for different aspects of support and provision.
- ◆ Four models of provision were exemplified by the nine case studies, including provision mainly in special schools, specialist provision *within* special schools, specialist school or unit for autism, and specialist bases in mainstream schools.

Findings from Phase 2: Studies of interventions

- ◆ The range and amount of provision available for younger children with autistic spectrum disorders are varied and variable. The arrangements made are responses to pressures and demands arising out of local situations.
- ◆ Placement in a particular provision is often related more to local circumstances and availability than to an exact match between children's needs and what is on offer.
- ◆ Placement is less of an issue than expertise. Children with similar levels of difficulty can thrive and make progress in a range of different provision.
- ◆ Parents who felt confident about the level of training and experience in autism of the people working with their children were generally satisfied with the placement.

- ◆ Parents who could see that their children were making progress in their provision, however minimal, were anxious to maximise the gains by ensuring that their children had access to a *sufficient level* of intervention.
- ◆ Some LEAs were offering a *package of provision*, which included home-based one-to-one programmes combined with some time in a nursery or play-group setting with support. The crucial issue here was the drawing together of the discrete elements of the package into a coherent programme and the presence of a key worker to enable this to happen.
- ◆ In all the provisions studied, children's individual progress was monitored to decide on the next steps of their programme. However, this information was not usually aggregated to form judgements about the effectiveness of particular programmes or provision.

Recommendations

- ◆ Compatible data-bases to record cases of ASD should be set up for education and health authorities at a local and national level in order to get reliable estimates of prevalence. This would help LEAs and health authorities to plan more effectively for this group of children.
- ◆ There should be protocols agreed between health and education professionals for diagnosis and subsequent discussions with parents about the range of options available.
- ◆ Providers should continue to offer a range of approaches as appropriate to the needs of each child. Continuous monitoring and adaptation of the interventions should be carried out to ensure to ensure that the most effective combination of approaches is offered to maximise every child's potential.
- ◆ All staff who are likely to come into contact with children with ASD need to be adequately trained and up-dated. A whole-school approach needs to be adopted, and should include peers as well as staff.
- ◆ All areas, which have not already done so, should set up a working party that includes representatives from education, health, social services and the voluntary sector to develop services for children with ASD and their parents.
- ◆ Local education authorities should endeavour to offer a range of provision to meet local needs in as flexible a way as possible. For younger children, in order to avoid delay, this should be available on an assessment basis, if a statement is being prepared.
- ◆ Family support offered by education or social services should be available as and when parents need it.

- ◆ All those who may have some responsibility for children with ASD require awareness training and this should be routinely offered. Staff working closely with children with ASD should be required to undertake specialist training and this should be regularly up-dated.
- ◆ A key worker with knowledge and expertise in autistic spectrum disorders should be assigned to support each family to enable them to access the right programme of support and to facilitate communication between the various professionals making provision and the family.
- ◆ LEAs should put in place procedures for tracking children's progress in their various provisions and their response to the interventions offered (see Appendix 2 for an example of a tracking document). Data should be collected over time and analysed to make some evaluation of the effectiveness of provision.

1. WHAT IS AUTISM?

1.1 The autistic spectrum

Autism was first defined and systematically described by Kanner in the 1940s (Howlin, 1998). He distinguished the following three major features of autism – the ‘triad of impairments’ – (Wing, 1988) which have remained essential to the diagnosis since that time:

- ◆ a failure to interact or relate socially
- ◆ a failure to use language for the purposes of communication
- ◆ an obsessive desire for sameness which manifests itself in stereotyped, repetitive activities.

At around the same time, Asperger described a similar group of children who shared the same features, but who were of above average intelligence and did not have delayed language, although their use of language was unusual. These children became known as having Asperger syndrome (Frith, 1991). Since the work of Kanner and Asperger, epidemiological studies and other research have refined the criteria for autism and the definition has broadened to include a greater number of children. A study by Wing and Gould (1979) led to the notion of a triad of impairments in autism, the children being impaired in social interaction, social communication and social imagination. More recently, Wing (1996a) has suggested that the term autistic spectrum disorder (ASD) would best demonstrate that there are several subgroups, all of which share the triad, but which differ from one another. These subgroups include Asperger syndrome, classical or Kanner’s autism, high functioning autism, Heller’s syndrome and semantic pragmatic disorder. Children with an ASD vary in terms of their intellectual ability from above average intelligence to those with severe learning difficulties, and also in the severity of their autism from mild to severe.

All children with an ASD, irrespective of their level of ability, will have difficulties in:

- ◆ their ability to understand and use non-verbal and verbal communication
- ◆ their ability to understand social behaviour which, in turn, affects their ability to interact effectively and appropriately with other children and adults
- ◆ their ability to think and behave flexibly (i.e. to know how to adapt their behaviour to suit specific situations).

There is evidence too that some children with an ASD have a different perception of sounds, visual stimuli, smell, touch and taste, which can

interfere with learning. They may also have additional difficulties (e.g. cerebral palsy, sensory impairments, dyslexia or Down syndrome).

The two diagnostic classification systems commonly used to decide whether a child has an ASD (ICD-10, WHO (1992) and DSM IV, ASP (2000)) make a distinction between the various subgroups under the overall heading of Pervasive Development Disorder (PDD), and it is the behavioural features of autism and Asperger syndrome (the triad of impairments) which appear to distinguish them from other forms of PDD. Each part of the triad has to be present in order to be able to make a diagnosis of autism. Whether these disorders can be said to be a 'spectrum' is still debated, but those working with children in medical and educational settings currently find the concept a useful one for understanding and managing the treatment and education of the children.

Behaviours associated with autism and Asperger syndrome

Autism can occur in individuals with a wide range of cognitive ability, although the DSM criteria state that: 'in most cases there is an associated diagnosis of Mental Retardation, commonly in the moderate range (IQ 35-50)'. Those with higher levels of cognitive ability are sometimes referred to as having 'high functioning autism' and there is currently a debate about whether there are any significant differences between children with 'high functioning autism' and those with Asperger syndrome (Howlin, 1998; Sandberg *et al.*, 1993; Kugler, 1998). A cluster analysis by Prior *et al.* (1998) indicated that Asperger syndrome, high functioning autism and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) could be considered as part of a 'spectrum of autistic-type disorders, rather than clearly distinct categories, with the spectrum based on the severity of behavioural and cognitive/communicative impairment' (p. 899). Table 1 (adapted from Howlin, 1998, p. 102) indicates that the differences between the two groups manifest themselves as a range of behavioural problems but that the underlying deficits are similar.

A child with an ASD might attend a mainstream school, a generic special school or unit, or a school or unit specific to autism. Teaching less able children with an ASD can present a considerable challenge for staff, and children with these problems are most likely to be educated in special schools. The majority of able children with an ASD will attend mainstream school, with a minority attending schools or units specifically for those with Asperger syndrome. The majority of children with ASD and learning difficulties currently attend generic special schools for pupils with learning difficulties. Obtaining accurate figures on the percentage of children with an ASD in each type of setting is very difficult, if not impossible, as no central records are kept of this nature within most local education authorities (LEAs) and many children with an ASD have not been identified as such.

Table 1 Problems associated with autistic spectrum disorders

Area of difficulty	Less able children may	More able children may
Communication - In communicating effectively - In understanding communication in all forms (e.g. facial expression, gesture, speech)	Communicate by crying or hitting Not seek attention Not show emotional and physical states to others Be confused by others' requests	Use echolalic speech Ask repetitive questions
Social understanding - Inability to know what another person is thinking - Inability to work out what is appropriate to do or to say	Withdraw and find others aversive Try to make contact but inappropriately Act in ways which seem antisocial	Find conversational skills difficult to acquire Say and do things which are socially inappropriate Want friends but be unsure of how to make them
Flexibility of thinking and behaviour - A need to be in control of situations - Difficulties in adapting to changes in familiar routines	Resist the demands of others Engage in repetitive activity Resist change and become very distressed	Have an obsessional topic of conversation Try to set and keep to own agenda Be very distressed by change

The policy and provision within LEAs vary and the specific educational needs of these children are different, so that a detailed assessment of the individual child is necessary to determine which school is most appropriate. With the current policy of including children with special educational needs (SEN) in mainstream schools, an increasing number of children with an ASD will attend mainstream school. Most children identified as having an ASD will be recognised within the school as having needs which are additional to or different from those of their peers and should have an individual education plan (IEP). Some children may require more support than is usually provided from within a school's resources and may need a formal, statutory assessment, leading to a statement or a record of needs.

Autism usually manifests itself within the first two years of life but is often not formally diagnosed until much later. Howlin and Moore (1997) found that the average age for diagnosis was 5.5 years for autism and 11.3 years for Asperger syndrome. There is evidence that the age of diagnosis is falling, as professionals become more aware of the symptomatology of the disorder (Howlin and Moore, 1997). Children with Asperger syndrome, whose acquisition of language is not delayed, are less likely to be picked up until they move into more social settings, such as play group or infant school, as it is then that their problems in comprehension and in formal social relationships begin to be more obvious.

1.2 Prevalence

The prevalence of autistic spectrum disorders is a matter of debate. Most researchers suggest that 'classic' Kanner autism is present in about five per 10,000 children and adults. Taking a broader definition, a study by Arvidsson *et al.* (1997) found a rate of 31 per 10,000 3–6-year-olds on the autistic spectrum in one suburb in Göteborg in Sweden. Of these, 10 per 10,000 were 'classic' Kanner autism. Wing (1996b) argued that there was no clear evidence for or against an increase in prevalence, but figures she quotes based on two studies, one carried out in the 1970s in Lambeth, London (Wing and Gould, 1979), and the other in the 1990s by Ehlers and Gillberg (1993), in Göteborg, which focused on Asperger syndrome, appear to give higher figures than Arvidsson *et al.*'s later study. Combining results from the two earlier studies, Wing suggests a prevalence rate of 91 per 10,000 children under 16 at any level of IQ. Wing (1996b) also suggests that the higher prevalence rates she has discovered, result from an increase in diagnosis of children with severe learning difficulties and autism, who formerly would have been placed in special schools or other institutions without referral for a formal diagnosis of autism. At the other extreme of ability, higher functioning children with Asperger syndrome might well have been labelled 'odd' or as having behavioural difficulties in the past, without the underlying causes of their behaviour being recognised. They may have been placed in schools for children with emotional and behavioural difficulties. This is now less likely, although it may still happen in some cases.

Fombonne (1997b) casts doubt on these higher prevalence figures, suggesting that his review of more than 20 epidemiological studies which have been carried out over the last 30 years (Fombonne, 1997a) leads him to conclude that the rate of childhood autism is five in 10,000 children, and for other conditions which might be on the autistic spectrum the rate is 10 in 10,000 children. He argues that the difficulties in providing an operational definition of Asperger syndrome make it impossible to estimate its prevalence accurately (Fombonne, 1997a).

Wing and Gould (1998) challenge this view and, although they agree that the rate of 'classic' Kanner autism found in their 1979 study was five per 10,000 children with IQ under 70, their estimate of other autistic spectrum disorders was 15 per 10,000. They offer anecdotal evidence in support of Ehlers and Gillberg (1993), who found 35 in 10,000 children of average or

higher ability with Asperger syndrome, and a further 36 in 10,000 who were socially impaired and could be included in the spectrum. If this were the case, 91 in 10,000 children (or almost one per cent of all children across the ability range) would be classed as on the autistic spectrum.

While it is clear that much more work needs to be done to ascertain the level of autism in the population, it is also clear that the perception among professionals working with children with developmental difficulties and special educational needs is that the numbers are increasing. A recent study in the UK, in the West Midlands (Powell *et al.*, 2000), reported on the *incidence* (i.e. new cases diagnosed within a specific time frame) rather than the *prevalence* of autistic spectrum disorders. Their study of children under five years old in two health districts found an increase in incidence of classic autism of 18 per cent per annum, and of other ASDs of 55 per cent per annum. They argue that there may be a small overall trend to increasing prevalence but that it is more likely that the increase is due to the greater awareness and willingness of paediatricians to make an early diagnosis of ASD. Their estimate of the *prevalence* of ASD in the West Midlands for 1–5-year-olds was 16.2 per 10,000 for classic autism and 17.5 for other ASDs, giving a total rate of 33.7 per 10,000 for all ASD. However, this study focused on younger children and therefore it is likely that the rate for Asperger syndrome diagnosed after the age of five years will be higher than the 17.5 per 10,000.

One clear trend, though, is that the rate of ASD in males is much higher than that in females. The Powell *et al.* (2000) study found a ratio of 5.7:1. Arvidsson *et al.* (1997) found a ratio of 4.5:1 for childhood autism. Other studies have found a rate of 2:1 male to female. Baron-Cohen and Bolton (1993) suggest that, across countries and age groups, males are three or four times more likely than females to be on the autistic spectrum. The differences in rates across the various studies can be explained by the age ranges of the children involved and the type of ASD studied.

The lack of reliable information about prevalence had led to a number of local studies, including one carried out for Wakefield Borough Council (Brown, 1999). This study showed a current rate of identification in that borough of 25 per 10,000 pupils, but predicted that this was likely to rise to between 49 and 67 pupils per 10,000 by 2009. Responses to a national questionnaire sent out by Wakefield indicated a prevalence rate of 20 per 10,000, with a range of 7–40 per 10,000 across LEAs in England.

There are a number of serious problems with calculating prevalence rates and predicting future demand for services. One is that rates and types of diagnosis vary widely between health authorities and also between individual paediatricians and other diagnosticians. Secondly, the definitions and diagnostic criteria for autism are fluid and qualitative in nature, relying primarily on the observation and categorisation of behaviour; thus there is the possibility of both under- and over-diagnosis. Currently, reported incidence rates in the UK seem to be well below the 91 per 10,000 suggested by the most authoritative studies by Wing and Gould (1979) and Arvidsson *et al.* (1997). This indicates that the rate of identification may rise and that the demand for services could increase.

1.3 Autism and learning

Autism is a developmental disorder which, as discussed above, manifests itself through a 'triad of impairments'. It is characterised by severe problems in the areas of communication and social understanding and by inflexibility and obsessional or ritualistic behaviours. It can co-occur with other conditions or sensory impairments (such as Down syndrome or hearing loss) and can be associated with cognitive impairment (70–75 per cent of people with autism have some associated learning disabilities and around 50 per cent have an IQ below 50 (Howlin, 1998)). An understanding of the difficulties in learning to which this combination of factors gives rise is crucial to providing effective educational experiences for this group of children.

Even those children of average or above average intelligence are significantly affected by their autism. They may have developed high-level skills in some areas but are likely to have great difficulties in interacting successfully with others and in communicating their needs effectively. School is therefore a highly stressful environment for them. Their intellectual ability and academic skills may mask their autism and so they might not be identified as having an ASD and may instead be labelled as aloof, an eccentric or a loner. Some may challenge staff when they feel particularly anxious or in an effort to follow their special interests and may then be labelled as naughty, defiant or challenging.

Communication difficulties

Difficulties in communication for children on the autistic spectrum range from those who have no communicative speech at all, and who find difficulty in communicating through signs and gestures, through those whose language may consist of 'echolalia' – repetition of words or phrases they have heard, but not always in context or with communicative intent – to those who have well-developed language, but whose speech may be formal or stilted and who may be obsessed with talking about their favourite topic. The difficulties which non-verbal children have in communicating wants or needs can lead to extreme tantrums and other bizarre behaviour, and so developing communication for these children is a key requirement of any early educational intervention. Approaches include: Makaton signing; using symbols, including pictures and objects of reference; and encouraging communication through, for example, the Picture Exchange Communication System (PECS).

The development of communicative speech in those who have some language is also a key requirement. Some children may appear to have a wide vocabulary and to be using language to communicate their needs, but will have difficulty in understanding others. Thus teachers and others may assume that they understand abstract ideas or complex instructions when, in fact, they do not. Children with autism operate at a very concrete or literal level of language and have difficulty in understanding the subtle nuances of, for example, irony or jokes. More able children on the autistic

spectrum, who are likely to be educated in mainstream schools, may have significant difficulties with communication, which go unrecognised or are interpreted as uncooperative behaviour.

Difficulties in social understanding

This second aspect of the triad of impairment results in children with autistic spectrum disorders finding social interaction extremely difficult, if not distressing. They find it very difficult to understand or to learn the basic rules of social engagement or the kinds of behaviour which are acceptable or not acceptable in various social situations. They respond to these difficulties either by remaining aloof and shunning all social contact or by making attempts to interact which are perceived by others as odd or inept, and which may elicit a negative response. Some more able people with autism have written quite movingly about their experiences of being perceived as different and of their difficulties in making sense of the social world (e.g. Grandin, 1992). Karen Gold writes of Clare Sainsbury, whose book, *Martian in the Playground: Understanding the Schoolchild with Asperger's Syndrome* (Sainsbury, 2000), won the 2000 NASEN Book Award: 'Her greatest horrors were playtime, PE and the lunch queue – all involved noise, social interaction, physical contact and incomprehensible rules' (Gold, 2000, p. 9). For children with lower cognitive ability or more severe autism, these problems with social communication manifest themselves at an early stage. For more able children and those with less severe autism, they may remain undiagnosed for many years, as was the case with Clare Sainsbury.

Underlying some of the difficulties which children with autistic spectrum disorders have with social communication is what Baron-Cohen (1995) has termed *mindblindness*. This denotes the difficulties which they have in empathising or understanding what other people might be thinking or feeling about a situation. Since a large amount of social interaction is predicated upon this sort of understanding (or joint understanding), this makes the formation of social relationships very difficult for these children. They have difficulty in interpreting the non-verbal social signals that others use, such as tone of voice, facial expression and gesture, and so fail to act on these as expected. They often appear to be tactless or unfeeling and thus give offence to others.

Difficulties in thinking and behaving flexibly

It has been suggested (Jordan, 1997; Howlin, 1998) that the repetitive and obsessional behaviour often manifested by children with autistic spectrum disorders is caused by the stress and anxiety created by not being able to make sense of the world around them. It is suggested that they retreat into these behaviours as a way of controlling the chaotic stimuli which they are receiving, and that rituals and routines make them feel safe. Baron-Cohen and Bolton (1993) suggest that such behaviours may be due to abnormalities in the frontal lobes of the brain. Whatever the reason for such difficulties, rituals such as hand-flapping and spinning or extreme reactions to changes in routine (such as taking a new route to school), need to be addressed by

those offering educational interventions, as they prevent more productive learning and result in individuals and their families leading very restricted lives.

The triad of impairments

Each of the difficulties described above has to be present for a diagnosis of autistic spectrum disorder to be made. Jordan (1997) suggests that the ways in which these elements of the triad combine, together with the cognitive level of the child, mean that the profile of strengths and difficulties of each individual will differ, and therefore the appropriate educational interventions for each individual will differ although there will be some common elements. The next section of the report will look at the educational interventions commonly available for children with autistic spectrum disorders and research findings about the effectiveness of these approaches. It will draw substantially on a report prepared for the Department for Education and Employment (DfEE) by Jordan *et al.* (1998).

1.4 Educational interventions

This section will focus on the most commonly used approaches in English schools and other settings for children with autistic spectrum disorders. It will describe the main features of each intervention, the rationale upon which it is based and the results of any evaluations which have been published. It is important to note that, in practice, many settings will offer a range of interventions to each child, depending upon the analysis of the child's need by the professionals working with him or her.

Division TEACCH (Treatment and Education of Autistic and related Communications Handicapped Children)

The main feature of the TEACCH approach is structure. The rationale behind this is that the particular learning needs of children with autism are characterised by organisational difficulties, distractibility, sequencing problems, inability to generalise and uneven patterns of strengths and weaknesses (Mesibov, 2000). Thus a highly structured approach creates an environment in which they are able to function more easily and which helps to relieve their anxiety and stress by offering a predictable routine and a less distracting environment. Key components of this approach are as follows.

Classroom layout

A classroom environment which is clearly set out with areas for particular activities or resources and is clearly marked. For many children with an ASD, it is helpful if the classroom layout remains largely unchanged. Where the child has to change classrooms during the course of a day, it may be helpful if s/he sits in the same position within the room.

Timetable

A clear visual timetable for each child showing what is going to happen throughout the day. This might be shown in symbols, photographs or the written word, depending on which of these the child is most able to understand. The child would be taught to work through the timetable and to place the picture or symbol for the task in a finished container at the end of the task. Time for special interests or activities can be included and staff may introduce a symbol to represent 'activity not known' or 'choice' to encourage the child to become flexible and deal with options.

Work systems

The child is given visual information on where s/he can find his/her work and the resources required to do this, where s/he should do the work and what s/he should do when this is finished. Some children may need to be given a particular area to work in (often called a work-station) which is relatively free of distractions.

Instructions for the tasks

The child is given clear, visual instructions for each task. Details might be given on the sequence involved and how long the child should spend on the task, and an incentive for the completion of the task might be shown.

Elements of the TEACCH approach are widely used with children with autistic spectrum disorders in schools in the UK, both mainstream and special, and, in particular, the use of visual timetables and other visual clues (e.g. objects, photos, pictures, words) to help students organise and sequence their activities, both at home and in their educational setting. There are few reliable evaluations of the TEACCH method (Jordan *et al.*, 1998), but some indications of its effectiveness in improving behaviour and communication skills.

Behavioural approaches

The underpinning rationale of these approaches is 'applied behaviour analysis' or ABA, by which skills are broken down into discrete steps and then used as a teaching programme for a child. 'Discrete trial learning' is where each of these steps is presented to the child as a learning goal and successful completion is reinforced by a reward. This is a very basic behavioural approach and is used in some combination in a variety of settings for children with learning difficulties, including autism.

Jordan *et al.* (1998) present some of the criticisms of a strict 'discrete trial learning' approach. They suggest that such approaches do not teach in a way which allows the child to develop an understanding of the tasks and that they may not lead to more generalised applications of the skills learned. There is also the criticism that the breaking down of skills into small steps may render them meaningless.

The most notable application of ABA is that developed by Ivar Lovaas (Lovaas, 1987). This is usually offered as a home-based, intensive, early intervention programme, although there are now a few independent schools using similar methods. The programme is offered on a one-to-one basis by tutors who are trained and monitored by supervisors who, in their turn, are supported by consultants. The intervention consists of the child being taught new skills or behaviours during a number of sessions, which may last 10 to 15 minutes, followed by a play session. Correct responses to the stimuli (for example, learning to stack three blocks) would be followed by a reward and verbal praise. Undesirable behaviour would be ignored, or responded to by shouting 'No'.

There have been a number of evaluations of the Lovaas approach which seem to show that, for some children, it is effective in addressing the autism to the extent that they can attend a mainstream school without support. However, there have been a number of criticisms of the methodology of these studies. For example, in the study reported by Lovaas (1987), three groups were used: one experimental group which received 40 hours per week of ABA; one control group (CA) which received 10 hours per week of ABA, plus other local services; and one control group (CB) which received no specified treatment. However, the control groups were not equivalent, in that the children in control group A were six months older and had a lower mean IQ on average than the children in the experimental group. In addition, there were eight girls in the CA group and only three girls in the E group, with 19 children in total in each group. In addition, different measures of IQ were used in the follow-up studies, so that IQ gains could not be said to be valid. Nevertheless, 47 per cent (nine out of 19 children) who received 40 hours per week of ABA were able to attend mainstream schools. In the control groups one child out of 40 was able to attend mainstream school. However, it is not clear which parts of the programme led to the gains for the experimental group. There was no discussion on which children are most likely to benefit from the approach, nor of the characteristics of the children who did less well.

The conclusion that can be drawn is that intensive ABA approaches can be effective for some, but not all, children with autistic spectrum disorders. Connor (1998) has reviewed a range of behavioural early intervention programmes for children with autism and concluded that the Lovaas programme is not unique, and that various other pre-school interventions exist, which contain similar elements and might be equally effective.

Interactive or naturalistic approaches

There are a number of approaches, currently used in schools, which focus on social interaction and building relationships between children with autistic spectrum disorders and their teachers and carers or parents. One such approach, which is becoming increasingly used in schools for children with autistic spectrum disorders is Intensive Interaction (Nind and Hewett, 1994; Nind, 1999). The approach was originally used for teaching students with severe difficulties in learning and relating to others, and has more recently

been used with children on the autistic spectrum who have similar difficulties. It is modelled on the processes of care giver–infant interaction in which the first stages of sociability and communication develop. Thus it is not based on a series of behavioural tasks or goals, but on developing interactive ‘games’ which create mutual pleasure for the child and the care giver and on allowing the child to take the lead and the care giver responding to and sharing in the child’s activities.

This approach has similarities to a home-based approach, originating in the USA, which some parents in the UK are using. This is the Option programme (Kaufman, 1976). In this programme parents set up a special room in their home in which the child spends most of his or her time. Parents and others working with the child will work in the room on activities in which the child wishes to engage. The philosophy of the approach is to accept the child’s behaviour and to work and play alongside the child to build up rapport and to support the development of the child’s social and intellectual abilities.

Some educational settings also offer musical interaction therapy, in which making music offers opportunities for children to develop relationships and express emotions. This approach has been developed over a number of years at a local autistic society school, in the UK, in Nottingham (Christie *et al.*, 1992). Like Intensive Interaction, it is derived from a developmental approach which recognises that the development of normal communication happens through a process in which the baby and familiar adults negotiate a series of increasingly complex interactions wherein the baby takes a very active part. The intention of the sessions is to develop early communication and interactive skills. The child’s key worker or parent works with the child and a second adult plays an instrument to support and facilitate the interaction between the two. The adult tries to ‘tune in’ to the child by joining in and copying his/her actions or sounds as if they were intentional attempts to communicate. This approach is used in some schools and by some speech and language therapists. It has been evaluated by Wimpory *et al.* (1995) and forms part of an early intervention package currently being evaluated.

The research evidence for the efficacy of Intensive Interaction and the Option approach is currently limited. Nind (1999) provides a case-study example of a young man of 28 offered Intensive Interaction, which gives some measures of improvement. She also refers to two narrative case studies of younger children, which give qualitative evidence of improvement and some data from a questionnaire survey of teachers who have used Intensive Interaction. However, as yet, there has been no systematic study of its effectiveness with younger children on the autistic spectrum. The Option approach also offers some case-study evidence of improvement but, as yet, again no systematic experimental studies.

The rationale or philosophy underlying interactive approaches focuses on a social rather than behaviourist model of learning. It stresses acceptance of the child with autism and not imposing behavioural change through a series of discrete taught tasks. However, obviously change is looked for and

encouraged and those who espouse this method suggest that behavioural change brought about through interactive methods is more likely to be generalisable and sustained than that brought about by ABA approaches, although there are no comparative studies to support this claim.

It has been suggested that, in practice, behaviourist and interactive approaches have more similarities than differences. Each reinforces desirable behaviour by praise and rewards and each tries to extinguish undesirable behaviour through ignoring or offering diversions (or, in the case of ABA, by negative responses). However, those using behaviourist approaches would be more likely to impose tasks and behaviours, whereas those using interactive approaches would be more likely to wait until a child seemed to show a positive preference for an activity.

Daily Life Therapy (DLT)

Until recently, the DLT intervention was not available in the UK, although over 20 children from the UK have been financed by their LEAs to attend a Higashi school in Boston, USA. The key components of the approach, which originated in Japan, are: instruction that is group orientated; highly structured routines; learning through imitation; physical exercise; and a focus on art forms (Quill *et al.*, 1989). There are significant differences between the Higashi model as practised in Japan and that practised in Boston. A key difference is that, in Japan, the school is integrated and non-residential and autistic and non-autistic children are educated together (Upton, 1992). There is currently no robust research evidence about the efficacy of Daily Life Therapy. No studies using comparable control groups have been published; however, two independent schools in the UK are using elements of DLT and both are being evaluated. Some of the components of Daily Life Therapy (e.g. the emphasis on physical exercise) are being offered in other schools for children with autism.

The Waldon Approach

The Waldon Approach focuses on 'learning how to learn' and uses a developmental model based on the spontaneous independent play of very young children. The aim is to maximise the child's intrinsic motivation and adaptability, through a strong emphasis on active movement. Waldon sessions are often combined with other teaching approaches in educational settings.

Picture Exchange Communication System (PECS)

The PECS involves the use of pictures in a way different from that used in other communication schemes, such as TEACCH. The pictures are used to request objects or activities that the child wants, and to encourage the child to initiate a request, rather than to respond to a question about what they want. So, for example, the teacher would wait for a child to offer a picture of a desired object, such as a drink or item of food, rather than to ask the child if s/he wants a drink or something to eat. The objective of the system

is for the child to initiate communication, rather than merely to respond to the teacher. This system is becoming more widely used in a range of pre-school and school settings and in the home. Some evaluations of PECS have been carried out in the USA, and Webb (2000) has reported on the results of introducing PECS to six young children with autism and severe learning difficulties.

Augmentative communication

There are a number of ways in which systems such as the use of pictures, symbols, objects of reference and signing can function not just as a precursor of speech, but to support communication for those who have some speech but who still have difficulties with comprehension. Children with autism can be helped by visual representations and this is why pictures and symbols can still play a part, even when children have acquired speech.

The *EarlyBird* programme

EarlyBird is an autism-specific, three-month, early intervention programme for parents of pre-school children with an ASD. It started as a pilot project in 1997 and contains elements from other approaches (e.g. TEACCH; Hanen). It focuses on understanding autism, communication and the analysis of behaviour and uses video of the child and his/her carer(s) as a basis for the sessions. The programme works with a group of six families at a time. One or two carers from each family may attend the programme and these may be mother and father, parent and grandparent, or any other combination of people closely involved in caring for the pre-school child. A weekly commitment is necessary, together with homework between sessions. The team members have been trained in the programme and usually form part of an existing service in the area, which allows follow-up after the programme ends.

The programme has been evaluated from the start and the outcome measures included both formal assessments and parental satisfaction data. The initial efficacy study was completed in the summer of 1999 (Hardy, 1999).

1.5 Early intervention

Much emphasis has been placed on the importance of early intervention for pupils with special educational needs (Bronfenbrenner, 1974; Cameron, 1986; Norwich, 2000) and, for many with severe difficulties, diagnosed in the first year of life, there have been systems in place for some time to take account of their needs. For example, Portage is used extensively to support parents whose children have been diagnosed with sensory or physical impairments or with severe developmental problems.

Clearly, for children with an ASD, early intervention is also important. Until relatively recently, most pre-school children with an ASD were engaged in other pre-school interventions developed for children with a range of special

needs, such as Portage. However, in the last two or three years professionals working with pre-school children with an ASD have started to develop autism-specific interventions which have been followed at home or at child development centres or in nursery settings. The National Portage Association has adapted its materials specifically for this group. The National Autistic Society (NAS) has developed a programme for parents called *EarlyBird*, and in other areas the pre-school visiting services and other practitioners working in the early years have developed their own packages of interventions. There is a growing consensus on the key elements of pre-school programmes. A review by Dawson and Osterling (1997) of a number of successful pre-school programmes developed in the USA identified the following as being important:

- intensity – the programme should be followed for at least 20 hours per week
- curriculum should focus on understanding and use of language, learning style, play with toys and social interaction using normally developing children as models
- the teaching environment should be predictable, using visual clues, and with opportunities for one-to-one work and generalisation of skills
- a functional approach to problem behaviour should be taken
- transitions from home to school and nursery to school should be carefully planned
- parents should be involved with the intervention.

Howlin (1997) has reviewed the evidence about long-term outcomes for people with autism and has concluded that there is little evidence of a 'cure' but that:

appropriate treatment and education are clearly essential in helping to minimise or avoid secondary behavioural problems and to ensure that children develop their existing skills to the full. Intervention in early childhood can have a major impact on the quality of life in adulthood, and is likely to prove far more cost effective than crisis management in later life (p. 69).

She suggests that a successful intervention programme will involve a wide range of different approaches, depending on a child's skills and disabilities, and also on family factors.

Howlin's views on the cost-effectiveness of early intervention are supported by an analysis of the costs of autistic spectrum disorder carried out by Knapp and Jarbrink of the Centre for the Economics of Mental Health (2000). They calculated that:

- the annual cost of autistic disorder in the UK is at least £1 billion;
- the average additional lifetime cost resulting from autism and associated learning disabilities is estimated to be £2,940,538 per person;

- the greatest costs are for living support (70 per cent) and day activities (14 per cent); much less is spent on education (7 per cent). Evidence suggests that even moderate increases in educational provision could potentially result in major savings in later living costs.

1.6 Inclusion and mainstreaming

Recent government policy, as described in the Green Paper *Excellence for All Children* (DfEE, 1997), has indicated that LEAs should be working towards meeting the needs of the majority of children with special educational needs in mainstream schools. Wing (1996a) has estimated that 3.6 pupils in 1,000 in mainstream schools are on the autistic spectrum (quoted in Harrison, 1998). Given that there is a trend to identify more children with autistic spectrum disorders, and for more LEAs to seek to maximise inclusion, it is reasonable to assume that the proportion in mainstream schools will increase.

The National Autistic Society has conducted a survey of parents, carers and people with autistic spectrum disorders about their experiences of inclusion (Barnard *et al.*, 2000). They have adopted a wider definition of inclusion than merely the provision of education in mainstream settings: 'We wanted to look at the wider picture: inclusion in society – a broad concept of social inclusion...' (p. 5).

The survey (which analysed responses from 1,000 questionnaires) showed that a wide range of settings was offered to pupils with autistic spectrum disorders. These included: specialist schools for autism; non-specialist special schools; specialist units attached to mainstream schools; and mainstream placement with or without support. On the whole, parents were satisfied with their child's placement (73 per cent reported that they were satisfied). Parents of pupils in specialist settings (whether special school or special unit attached to a mainstream school) were most likely to be 'very satisfied'. Those with children in unsupported placements in mainstream schools were least likely to be 'very satisfied'. Quotes from parents indicated that the key factor was the knowledge and understanding of staff who came into contact with the child, rather than the specific setting in which this took place. Thus parents of children in non-specialist special schools were less likely to be positive about their child's education.

One worrying finding was that 21 per cent of respondents reported that their child had been excluded from school at some time, and this proportion rose to 29 per cent of children with higher functioning autism, who would be more likely to be in mainstream schools. The most common reason given was that the school was unable to cope with the child because specialist staff were absent or unavailable (Barnard *et al.*, 2000). This finding should be placed in the context that it is more likely that respondents who had negative experiences will respond to this type of questionnaire. The authors of the report conclude that:

The evidence therefore demonstrates that staff training and expertise in autism is key if the needs of each individual child are to be met; also that each child should have access to appropriate levels of support. The type of school may be important in some instances because the particular needs of the child may require a very specific setting. But the overall finding of this survey highlights the need for relevant training and expertise for staff and appropriate support for the child as being of paramount importance (p. 7).

A number of LEAs have produced guidelines for mainstream schools on supporting children with autistic spectrum disorders (e.g. Smith and Dorney-Smith, 1999; Cumine *et al.*, 1998; Leicestershire County Council, 1998). The focus of these is to explain the nature of autism and the implications this has for learning and behaviour. Connor (1999) provides a helpful list of the issues of which mainstream teachers and support assistants need to be aware when teaching children with autistic spectrum disorders:

- the lack of generalisation of learning
- the lack of incidental learning
- the literalness of understanding
- difficulty in becoming involved in group activities, including play and games
- possible reaction to over-stimulation
- the range of meanings that may be applied to observed behaviours which might otherwise be seen as simple naughtiness or non-compliance, such as:
 - to indicate the need for help or attention;
 - to escape from stressful situations;
 - to obtain desired objects;
 - to demonstrate a lack of understanding;
 - to protest against unwanted events;
 - to gain stimulation (Connor, 1999, p. 84).

Connor suggests a range of strategies for classroom teachers and assistants to support the learning and behaviour of children on the autistic spectrum. These include:

- providing a clear structure and set daily routine
- using clear and unambiguous language
- addressing the child individually at all times
- providing warning of any impending change of routine or switch of activity
- recognising that a change in behaviour or manner may reflect anxiety or stress

- protecting the child from teasing at free times and providing peers with some understanding of his or her disability
- giving clear, simple requests or instructions
- emphasising visual cues and signals and *aides-mémoire*
- allowing some access to obsessive behaviour as a reward for positive efforts in class (Connor, 1999, pp. 84–85).

Such adaptations are quite common in specialist settings but require some sensitivity and understanding of the nature of autism, and may be seen as less easily achieved in mainstream. For this reason, staff training and a whole-school approach are key elements of any inclusion strategy for pupils with autistic spectrum disorders, since support for their needs is likely to impinge on all aspects of the school routine, including playtimes, assemblies and school trips as well as classroom settings. This type of concerted whole-school approach is probably more easily achieved in a primary setting, and mainstream placements in secondary schools are often more problematic.

Some specific interventions which have been used to support the process of inclusion and acceptance by peers are 'circles of friends' (Whitaker *et al.*, 1998) and 'social stories' (Rowe, 1999). Whitaker and colleagues describe the use of circles of friends in seven primary and secondary settings. Groups of six to eight volunteers joined a circle with one pupil with autism for weekly meetings to support and model positive interactions and social behaviour. Feedback indicated that both the pupils with autism and the volunteers benefited from the encounters. There was improved social integration and higher levels of peer contact for the focus pupils, along with reduced anxiety and improved behaviour. Volunteers reported increased levels of empathy and improved understanding of the problems faced by the focus pupil, enhanced self-esteem and improved group participation (Whitaker *et al.*, 1998).

Rowe (1999) gives an example of the use of social stories to help modify the behaviour of a child in a mainstream primary setting. The boy refused to eat his lunch with other children because they were too noisy. The story, which was read to him every day before lunch, told of him getting ready for lunch, eating his lunch with others and remaining calm and quiet. This enabled him to get through lunchtime with no problems.

The *de facto* inclusion of children with milder forms of autistic spectrum disorder has always been a feature of the school system, since many children have not had their problems recognised and have been seen as 'strange' or 'awkward', rather than having special educational needs – the '*Martian in the playground*' (Sainsbury, 2000). Increasing awareness of the more subtle manifestations of the disorder, as well as increasing acceptance of a wider range of special needs in mainstream schools, will highlight the need for better understanding and training of all those involved. However, not all those on the autistic spectrum will be able to have their needs met in mainstream settings. Siddles and Collins (1997) call for a 'continuum of

education provision for a spectrum of need'. Nevertheless, increasing understanding, advice and training may make it possible for a larger proportion of pupils with autistic spectrum disorders to have their needs met in more inclusive settings.

1.7 Key questions for LEAs and other service providers

The above brief review of what is currently known about autistic spectrum disorders and educational interventions raises a number of questions for LEAs and other providers. These include:

- ◆ What is the prevalence of autistic spectrum disorders in the child population?
- ◆ Is prevalence increasing, or are increasing numbers the result of more sensitive screening and better diagnosis?
- ◆ What are the most effective forms of early intervention for pre-school and younger school-aged children?
- ◆ Does early intervention lead to better long-term outcomes?
- ◆ Do resources put into early intervention result in savings at a later stage?
- ◆ How can families best be supported?
- ◆ Are specialist settings more effective than integrated ones for pre-school and younger school-aged children?

The research reported in the next section has attempted to address some of these questions. The research was carried out between January 1999 and March 2001 and was funded by the Local Government Association.

2. PROJECT AIMS AND METHODOLOGY

2.1 The research aims

The research, funded by the Local Government Association (LGA) as part of its educational research programme, was undertaken in two phases during 1999 and 2000. The first phase consisted of a mapping exercise, which attempted to ascertain the level of identification of autistic spectrum disorders for younger children (up to the age of 7 years) and the types of provision being made for them, issues of parental support, and inter-agency communication and collaboration. The second phase focused on specific interventions offered by a sample of LEAs and health authorities and the ways in which children's progress was tracked and decisions made about the effectiveness of the interventions offered.

The aims of the research were focused on early identification and provision for children between the ages of 2 and 7 years and reflected some of the questions raised by the preceding analysis. These were:

- ◆ to explore the ways in which autism is identified and the effect that these have on subsequent educational interventions;
- ◆ to describe the ways in which parents are supported following identification and the effect that these have on subsequent educational interventions;
- ◆ to investigate inter-agency collaboration in relation to children with autism and the effect this has on subsequent educational interventions;
- ◆ to examine the relationship between interventions before the start of statutory education and interventions following this;
- ◆ to study a range of interventions and ascertain their effectiveness in relation to specific groups of pupils;
- ◆ to make recommendations regarding effective provision for children in the first two years of compulsory schooling identified as being on the autistic spectrum.

2.2 Research methodology – Phase 1

Questionnaire survey

At the start of Phase 1, a brief questionnaire was sent to all local education authorities in England and Wales requesting details of:

- number of children aged between 2 and 5 (pre-school) and 5 and 7 (KS1) identified as on the autistic spectrum;
- the provision being made for pre-school and key stage 1 children on the autistic spectrum;
- whether there were established links between the LEA and health and social services for this group of children;
- whether there were any recent or ongoing developments in provision for this group.

Seventy-four replies were received, a response rate of 43 per cent, representing all types of LEA—inner and outer London boroughs, metropolitan authorities, unitary authorities and shire counties.

Telephone interviews

In order to obtain more detailed information about the issues and problems involved in developing provision, the research team carried out a series of telephone interviews with respondents to the questionnaire in 30 LEAs and their colleagues in the health and social services. The interviews covered the following topic areas:

- understandings of the concept of autism
- working definitions of autistic spectrum disorder
- key players at the pre-school stage
- provision available at the pre-school stage
- transition to school from pre-school provision
- key players for younger pupils in school (KS1)
- provision available at key stage 1
- inter-agency communication and collaboration
- support for parents
- policy development
- raising awareness of ASD
- key issues and problems.

From these interviews a number of key themes emerged which were further explored in depth in nine case studies.

The case studies

The nine case-study LEAs were chosen to reflect differing local authority contexts and approaches. All the LEAs concerned were actively involved in developing their services for children with autism, although some were

more advanced in this process than others. The criteria for choice of LEAs were:

- ◆ **geographical and structural, to include:**
 - a London borough
 - an inner city borough
 - an urban LEA outside London
 - a mainly rural LEA
 - a new unitary authority.
- ◆ **patterns of provision:**
 - outreach and inclusion
 - specialist schools and units
 - good inter-agency planning and/or provision
 - active working groups on autism
 - key workers/coordinators
 - respite care
 - DLT, Lovaas or Option programmes
 - parental influence/involvement.

The nine LEAs and health authorities finally chosen included three LEAs which had made up a former shire county and now consisted of one shire and two unitary authorities; three shire LEAs, one of which had been subject to local government reorganisation; an outer-London borough; an inner-London borough; and a metropolitan borough in the north-west of England.

The respondents for each area included:

- ◆ **from the education service:**
 - teachers, heads and learning support assistants in schools, units and nurseries (mainstream, special and autism specific)
 - pre-school services staff – Portage and pre-school advisory teachers
 - outreach and support teachers
 - LEA-based staff for special education – psychologists, advisers, planning and policy officers, special educational needs officers
- ◆ **from the health service:**
 - Child Development Centre staff – speech and language therapists, paediatricians, clinical psychologists
 - psychiatrists
 - joint-funded personnel (e.g. social workers)
- ◆ **from social services:**
 - pre-school support services
 - nurseries

- respite care
- opportunity group staff
- disability team members
- joint-funded posts
- ◆ **from the voluntary sector:**
 - local NAS branches
 - parent support groups for autism
 - general special educational needs parent support groups
- ◆ **parents and carers.**

Data-gathering methods and analysis

Open-ended interviews were carried out, using a semi-structured interview schedule. In all, 173 interviews were carried out across the nine case studies. The interviews were taped and transcribed and subjected to a thematic analysis.

2.3 Research methodology – Phase 2

The aim of Phase 2 of the research was to look in more detail at examples of specific types of intervention offered in the case-study LEAs. Eight of the nine LEAs from Phase 1 participated in this phase of the research. The ninth LEA was already engaged in evaluating its provision for this age group, and so decided not to participate because this would have led to overload for parents and practitioners. The aims of this phase of the project were:

- ◆ to study a range of interventions for younger children with autistic spectrum disorders (i.e. children between the ages of 2 and 7 years old)
- ◆ to study the ways in which pupil progress was monitored in the various settings
- ◆ to develop a framework for tracking pupil progress and to evaluate its usefulness as part of the process of monitoring the effectiveness of provision.

Each of the eight participating local authorities chose a particular type of provision from among the range that they offered to children in this age group. Up to six children from each provision were identified and parental permission obtained for their inclusion in the project. The provisions were:

- an autism resource base in a primary school
- a pre-school home-visiting service
- a specialist primary school for autism
- two integrated nurseries

- an assessment class in mainstream
- specialist provision in a school for pupils with severe learning difficulties
- a Portage language project
- a nursery in a child development centre
- a mainstream primary school
- Lovaas home-based programmes.

It must be made clear that these were not the only options available for children in these LEAs, but focusing on one type of provision enabled the research team to look in more detail at the range of children provided for, and the decision-making processes involved in making provision.

Interviews were carried out with the parents, the providers (i.e. those in direct contact with the child – teachers, nursery nurses and speech and language therapists) and with the managers of the service. The interviews focused on:

- ***The history of the child's provision*** (how long he/she had been in the provision and what provision had been made *before* the current provision was offered).
- ***Views about the current provision*** (how the decision was made to place the child in the provision, who was funding the provision, what specific programmes were being offered to the child and how these matched his/her needs).
- ***Measuring and monitoring progress*** (what outcomes were sought for the child, what progress had been made, what evidence was used to demonstrate progress).
- ***Other provision*** (whether the child was receiving any provision/ interventions other than those offered in the setting, whether it was felt that other interventions might be useful).
- ***Appropriateness of provision*** (whether it was felt that the current provision was meeting the child's needs, what might be the next stage of provision for the child).
- ***Relationships between parents and providers*** (channels of communication, support given to parents to help with their child's difficulties, involvement of parents in the interventions used in the provision).
- ***Tracking progress*** (views about the most useful sorts of information to be shared between professionals and parents to assess whether provision was effective).

In addition, providers were asked to fill in the Childhood Autism Rating Scale (CARS) (Schopler *et al.*, 1988) and parents and providers were asked to complete a Skills and Behaviour Checklist designed by Glenys Jones, consultant to the project (Appendix 1).

3. FINDINGS FROM THE QUESTIONNAIRES AND TELEPHONE INTERVIEWS

3.1 Questionnaire findings

Numbers of children aged 2–7 on the autistic spectrum

Many of the authorities responding to the questionnaire could not supply numbers of children in these two age groups on the autistic spectrum. One-third (22 out of 74) did not have this information. This was sometimes due to the fact that statistics were not kept in this form (ie not broken down into age groups or into particular special educational needs types). In some newly formed LEAs there was a problem, in that detailed information was not available from the former LEA. Whatever the reason, this seems to be a serious gap in information, since planning provision and developing services cannot take place in the absence of such information.

For those LEAs which could supply the information, the numbers identified appeared to be quite small. Of course, this is related to the size of the pupil population in the LEA, but the LEAs which could supply figures had identified an average of 13 children aged 2–5 and 20 aged 5–7 with an autistic spectrum disorder. In most LEAs, the numbers aged 5–7 were greater than those aged 2–5, which indicates that some children's problems were not being identified until they reached school. This is quite likely, since some types of autistic spectrum disorder (particularly Asperger syndrome) do not get picked up until children enter school. However, there were some LEAs where the figures for 2–5-year-olds were considerably higher than for 5–7-year-olds, which might indicate that the health authorities and pre-school workers in those areas were beginning to identify children much earlier and to communicate their diagnoses to the LEAs.

There were a number of LEAs (21 out of 52) which had very low levels of identification recorded (i.e. fewer than 10 children in each age group). Some of these appeared to have no children under 5 years old recorded. This may have been a result of the ways in which LEAs and health authorities kept their records, but it raises the question as to whether there was under-identification in those LEAs.

As can be seen from the totals in Table 2, not all the LEAs which had some information on numbers of children had information for both age groups. There appears to be slightly more information for the younger group, which may be explained by the ways in which the LEAs recorded special educational needs.

Table 2 Numbers of recorded children with ASD in 74 LEAs

Number of cases identified	LEAs identifying 2–5 year-olds	LEAs identifying 5–7 year-olds
None	2	–
1–5 cases	11	6
6–10 cases	14	11
11–20 cases	11	12
Over 20 cases	9	15
Not known	27	30
Total responses	74	74

As can be seen from the totals in Table 2, not all the LEAs which had some information on numbers of children had information for both age groups. There appears to be slightly more information for the younger group, which may be explained by the ways in which the LEAs recorded special educational needs.

Whatever the explanation for the lack of information, it is evident that there are no clear data on the prevalence of autistic spectrum disorders in many LEAs and that planning early interventions will be hampered by the lack of robust information about the numbers and needs of this group of children. As discussed in section 3.1 above, estimates of prevalence vary, and it appears that numbers are increasing. Thus it is vital for there to be some robust data gathered by LEAs and health authorities and for some centralised database to be set up to record and to track outcomes for this group of children.

Links between education and other agencies for children on the autistic spectrum

As might be expected, all the LEAs had links with health services, although one reported no links for children aged 5–7 with autism. Some pointed out that the links were for all children with special educational needs, not just for autism. Some reported that links with social services were ‘developing’, which suggests that such links are relatively new. Many LEAs reported that links with voluntary organisations were also beginning to be developed.

Some LEAs appeared to have extensive and well-functioning links with a whole range of agencies, including health, social services and voluntary groups, to develop services for children with autistic spectrum disorders and their families. These LEAs had multi-agency working groups considering the whole issue of early identification and intervention. Some LEAs also reported that they had personnel who were part of a multi-disciplinary child development team based in the health sector. Close links

of this sort were not reported in most of the LEAs, and it may be that this indicates that parents and children do not receive a well-coordinated response to their needs.

Provision for pre-school children on the autistic spectrum

Provision for this age group appeared to be patchy and under-developed. Most frequently mentioned was specialist provision in mainstream schools or special schools. Portage was available for this group of children in 21 LEAs. Other provision included supported placement in mainstream nurseries or playgroups. Lovaas was mentioned by 11 LEAs, each of which had one or two children following a Lovaas programme. Table 3 shows the numbers of LEAs mentioning different types of provision, and total numbers in such provision across all the LEAs.

Table 3 Provision for pre-school children on the autistic spectrum reported in 74 LEAs

Type of provision	No. of LEAs	No. of children
Portage/Early Years Team	21	128
Specialist provision either in mainstream or special school	37	226
Lovaas	11	33
Supported placement in nursery or playgroup	17	138
Child Development Centre	11	56
Home tuition	2	2
Out-borough provision	6	30
Early Years Centre (Social Services)	5	25
Unit for Communication Disorders	1	18-24 places
Not known	24	

The information given by the LEAs was patchy and many were not able to provide details of numbers in the different types of provision. There did appear to be some specialist provision in 37 LEAs, either in a special or mainstream school setting. But 24 LEAs could not supply information about their provision and the numbers of children receiving provision. Again, unless there is a clear sense of what provision is available and what the demand for different types of provision might be, there will be significant weaknesses in LEAs' ability to plan for the needs of this group of pre-school children.

Provision for pupils aged 5–7 years on the autistic spectrum

As can be seen from Table 4, a large proportion of children identified on the autistic spectrum in this age group were receiving their education in mainstream schools. Almost one-third of these received support from an outreach service. The remainder had been allocated support in school. This appeared to be the most common form of provision, although it was by no means universal, since only 47 authorities mentioned it, mostly those authorities which identified larger numbers of pupils and which had a broad range of provision. It seems that authorities which identify smaller numbers tend to focus their resources on specialist and more segregated provision.

It is interesting that in seven authorities, one or more children in this age group were still following Lovaas programmes, sometimes funded by parents and sometimes in conjunction with mainstream school placement.

Independent and out-of-authority provision was used by 16 and 17 authorities respectively. Some of the out-borough provision was the result of recent local government reorganisation, where pupils were in provision which was now located outside the area of the local authority concerned.

Almost half the LEAs that responded to the questionnaire had some form of specialist provision for autism for this age group. Many had a range of provision which included specialist schools and units, placement in schools for pupils with severe or moderate learning difficulties, mainstream provision with support and outreach. However, there was still a significant proportion (21 per cent) who could not supply any information about provision for this group of children.

Table 4 Provision for pupils aged 5–7 years on the autistic spectrum

Type of provision	No. of LEAs	No. of children
Specialist school or unit	36	260
SLD/MLD school	42	211
Mainstream school	47	542
Independent specialist school	16	41
Outreach support	10	161
Language unit	11	41
Residential special school	1	—
Out-borough provision	17	41
Lovaas programme	7	13
Unit for Communication Disorders	1	18–24 places
Complex difficulties school	1	11
EBD school	1	3
Observation and Assessment Unit	1	3
Not known	16	

Development of provision

Many of the LEAs were aware of the gaps in their provision and were taking steps to plan future developments. Reviews of provision for special educational needs, or of provision for autism in particular, were being carried out in 22 LEAs. Many of these were the new unitary authorities which were wanting to develop a distinctive response to the needs of pupils in their area. Areas for development mentioned by LEAs included:

- increasing the number of places for children with autism in special and mainstream schools
- recruitment of specialist staff
- developing an outreach service
- improving joint working with other agencies
- developing jointly funded provision with health and social services
- funding for Lovaas programmes
- appointment of a specialist educational psychologist or advisory teacher to develop the service
- provision of training for mainstream staff
- development of a specialist school for 2–19-year-olds as a centre of excellence
- developing units attached to mainstream schools
- setting up a support group for teachers working with pupils on the autistic spectrum
- collaboration across LEAs to develop regional provision
- development of more home-based programmes for pre-school children.

The above list reflects the growing recognition in LEAs of the needs of children on the autistic spectrum. There is an awareness of the need to plan and develop services, both within the LEA and collaboratively across LEAs and with health and social services. The areas of development listed represent significant gaps in provision for younger pupils and a growing recognition of the prevalence and range of autistic spectrum disorders among the pupil population.

3.2 Telephone interviews

The main issues which arose out of the telephone interviews with key informants in education, health and social services in 30 of the LEAs which had responded to the questionnaire were as follows.

The LEA context

Differences in approaches to policy and provision were heavily influenced by the contexts within which the LEAs were working. A major point of difference was between urban and rural LEAs. In urban areas there had not always been pressure to develop provision within an LEA if neighbouring LEAs had facilities which could be bought in. In addition, there were often independent providers which LEAs could use. Consequently, the recent upsurge in interest and pressure from parents had highlighted the gaps in provision in some urban LEAs and had led to pressure from parents for home-based programmes, such as Lovaas and Option.

In rural LEAs there were different pressures, but there had been more of a tradition of making provision in mainstream schools and of providing outreach support. However, there was a recent problem for some county LEAs and new unitary authorities, in that provision had been lost when the old shire counties had been partitioned and lack of local provision had become a problem. For small authorities and those with widely dispersed populations, there was a problem of how to make the most effective provision to meet the needs of a small but challenging group of pupils.

There were also tensions for some LEAs which were highly committed to providing inclusive education, in that there was some pressure from parents and schools to make specialist provision for pupils with autistic spectrum disorders, particularly those with very challenging behaviour. In addition, it was only fairly recently that pressure from parents and voluntary organisations had built up to such an extent that making provision for this group had become a priority.

Lack of appropriate provision

This was clearly a problem in many of the LEAs. There appeared to be increasing numbers of children diagnosed as having an autistic spectrum disorder, although the level of prevalence did not seem to be as high as that suggested by Wing (1996b). Nevertheless, all those interviewed reported that there had been a significant increase in their areas. This was attributed to a combination of factors, including better and earlier identification and increased awareness on the part of parents, health visitors and teachers about the manifestations of autistic spectrum disorders. Many of the more subtle forms of autism may have gone undiagnosed in the past, or been misdiagnosed as behaviour or emotional difficulties. Also, many pupils with severe learning difficulties and autism may not have had their problems properly recognised.

The question of whether there was also a real increase in prevalence, rather than just an increase in knowledge and awareness leading to higher numbers being identified, was not clarified by the respondents. Most suspected that there was an underlying increase, but had no data on which to base this judgement and so were cautious about making it.

For some LEAs, there was an absolute shortfall in the amount of provision they had for these two age groups – the under-5s and 5–7 year-olds. For others, the range of provision was limited. For example, the only provision for under-5s might be Portage or supported provision in a playgroup. There were also shortfalls in the availability of well-qualified and experienced staff which limited the extent or rate at which provision could be expanded. Many of the LEAs in this sample of 30 had recently opened, or were planning to open, new provision for 5–7-year-olds. There was significantly less development planned for the younger age group, where provision still appeared to be *ad hoc* and limited.

When considering how to develop provision, LEAs were confronted with a number of dilemmas, for example, should they provide integrated or segregated provision? Some have opted to create a 'centre of excellence', mainly within an urban setting, where travelling distance is not an issue. Others, in more rural areas, have opted for an integrated model and created 'resource centres' or 'enhanced specialist provision' in a number of schools. There is also an issue about whether expertise should be located in one place, or whether specialist teachers should have an outreach function and be able to support pupils with autistic spectrum disorders in a range of settings. These models of provision will be discussed in more detail in the section reporting on the case studies.

One aspect where lack of adequate provision was found in all the authorities was that of respite care and social support for parents. There were schemes for respite and parental support in most areas but there were not enough to meet need. The schemes ranged from overnight residential provision to child-sitting schemes for short periods. There were strict eligibility criteria for most forms of provision of this type, which meant that many parents did not have access, because their children's disabilities were not seen as a priority by social services. In some areas, despite evidence of great need, cut-backs in already limited provision were being proposed.

Teaching approaches

Most LEAs reported that their schools used a range of teaching approaches; they were often described as 'eclectic'. TEACCH was mentioned by most respondents as being used in some form in most provision and the Picture Exchange Communication System (PECS) was also being widely adopted, as more teachers and speech and language therapists were being trained in its use. The Applied Behaviour Analysis (ABA) approach was not as frequently mentioned, although some LEAs were funding Lovaas therapists whom parents were engaging privately for their pre-school children. Other approaches used included: Waldon, Intensive Interaction and Option. Questions were raised about the effectiveness of the different teaching

approaches and how effectiveness and cost-effectiveness could be evaluated, as some types of intervention were much more intensive, and thus much more expensive, than others. LEAs had not generally carried out these types of evaluation.

Training

Questions were raised about the level of knowledge and expertise of teachers and learning support assistants (LSAs) working in this area of need. Training was seen as an important issue and the lack of training places as a problem. As autistic spectrum disorders were becoming more recognised, and the need for provision acknowledged, it was perceived that there was a lack of sufficient expertise in LEAs and health authorities (particularly among speech therapists). Some LEAs provided in-house training for teachers and LSAs. Quite often, those who had become 'experts' in their LEA had followed their personal interest in autism and had sought training wherever it was available. Thus many had done the Birmingham University Distance Learning course in autism. Others had been on short courses for TEACCH or PECS or awareness-raising courses run by the NAS or their local autism society. There was a sense that staff were keen for more training and information and that demand was overtaking supply.

Inter-agency issues 1: Health *versus* Education

There were a number of concerns raised about the relationship between health and education for this group of children, which probably also reflect wider issues around early identification of children with developmental delay and sensory/motor problems, as well as some specific issues to do with autism.

On the whole, LEAs reported their relationships with colleagues in the health sector to be good and improving. For the target group of children, the education sector often relied on medical colleagues to provide a diagnosis of 'autism'. Both services used the concept of the 'triad of impairment' as a guide to decision-making about individual cases. However, there were some tensions about diagnosis, in that the terminology used often varied between health and education, so that, for example, a paediatrician might use the term 'pervasive developmental disorder' and the educational psychologist or early years specialist might then feel inhibited about talking to the parent using the term 'autism' or 'autistic spectrum disorder'. There was also sometimes a mismatch between health practitioners' use of diagnostic terms which were, in effect, labels and the more needs-based approach of educational psychologists and teachers who would be focused on the child's functional and educational needs.

There were also concerns about the level of identification and a sense that there were mismatches between education and health which led to over- or under-identification. This problem was alleviated in some areas by the inclusion of an educational psychologist in the assessment process carried out by a child development clinic. Also, in some areas joint working parties

across education, health and social services had been set up to discuss issues of early identification and intervention for pre-school children on the autistic spectrum.

One issue which was of concern was that there was often a hiatus between the diagnosis given by health professionals and the offer of support for parents or provision for the child. In authorities which had a good service, there was a seamless transition from health to education, in which Portage and other early years services worked collaboratively to offer support and intervention. But if communication was poor, parents could be left with no support or intervention for many months.

There are, of course, also structural and organisational differences between local and health authorities which lead to difficulties in promoting joint approaches. These are long-standing problems and not specific to autism.

Inter-agency issues 2: Education *versus* Social Services

It was reported that, on the whole, this group of children and families was not a priority for social services intervention, despite the huge stresses on family life which can be brought about by coping with a child with an autistic spectrum disorder. As reported above, sufficient respite care was often not available. Child-care arrangements were difficult, because of the challenging behaviour of many children with autism. Because there was no physical problem involved, it was difficult to access many of the provisions available via social services to parents of children with other types of disabilities.

Social services did not generally play a role in the identification or assessment of children with autism in most authorities, although there were exceptions to this (see case studies). It appeared that relationships between education and social services departments were often problematic, because education staff believed that special educational needs in general, and this group in particular, whose families were under great stress, were not prioritised by social services departments.

Inter-agency issues 3: Voluntary Organisations

Many LEAs reported that they worked closely with voluntary organisations and welcomed their involvement and used their expertise. The National Autistic Society was well regarded as a source of information and support for parents. There were also many local support groups for parents of children with special needs in general, as well as autism-specific groups. LEA personnel would attend meetings if invited and make presentations if requested to do so.

Inter-agency issues 4: Multi-disciplinary work

Multi-disciplinary work goes on at several levels within public sector organisations such as education, health and social services. At the practitioner level, relations between the various professionals working with

children with autism were found to be generally effective. Pre-school advisory teachers worked well with speech and language therapists and with Portage workers. Clinical psychologists were often key professionals and gave advice and support to colleagues in health and in education. Educational psychologists were not always as well tied in to multi-disciplinary teams, but in some areas they were becoming part of the assessment teams in pre-school child development centres. Social workers were on the whole not well represented, although there were some examples of social workers employed as part of child development teams.

It was more often at the policy and management levels that multi-disciplinary work was found to be problematic. This was because, at this level, there were other priorities which impinged on decision-making. The geographical areas and funding mechanisms of health and local authorities are different and this leads to problems of aligning policies and planning for a client group, such as children with autistic spectrum disorders, whose needs span the health/education divide. One area had made a joint appointment of a policy officer whose role was to ensure consistency across health and education and social services in developing children's services. There were some problems for professionals in understanding the roles and responsibilities of other professionals, and in being able to phase their work effectively, so that, for example, speech therapists and teachers or classroom assistants were working effectively on language programmes for children with autistic spectrum disorders across a range of settings.

On the whole, it was found that individual relationships were good and effective but that there were still systemic problems to be overcome.

Parental issues

A key issue for many local authorities is that some parents of children with autistic spectrum disorders are increasingly seeking alternative provision because they are not satisfied with what the LEA is able to offer. There have been a number of high-profile cases which have gone to the Special Educational Needs Tribunal involving parents who wanted to secure Lovaas therapy or provision at the Higashi School in Boston, USA, for their children. The LEA respondents felt that there were various reasons for this increase in pressure from parents. First, in the absence of provision for children diagnosed as on the autistic spectrum at the pre-school level, an intensive home-based programme, such as Lovaas, has obvious attraction for parents. Secondly, parents are becoming much better informed about the options available, often through the use of the internet, and often have firm ideas about what provision might best suit their child and will challenge professionals' opinions. LEA officers thus considered it important to have a clear rationale for the range of provision on offer from the LEA, in order to be able to demonstrate to parents that expertise was available in the LEA and that children would have access to good-quality provision to meet their needs. It was also important that there were clear identification and assessment procedures, so that parents were not left unsupported and uninformed about their child's needs and what the LEA and health authority were proposing.

The lack of support for parents when their child was undergoing assessment and diagnosis was another issue raised by respondents. It was felt that parents often did not have access to support, particularly after diagnosis. Often, parents did not want to join support groups at this stage, nor to go to meetings. One of the case-study health authorities offered parents access to counselling by a clinical psychologist but, on the whole, it was felt that parents were not adequately supported at this stage. Pre-school teacher-counsellors, advisory teachers and Portage workers were able to offer support once a child began to receive services, but this did not always happen immediately a diagnosis was made.

Another time when it was felt that parents would need support was at the point of transition from one phase of education to another – in this case, from pre-school into school provision when decisions had to be made and parents were faced with a number of questions and dilemmas: for example, was segregated or integrated provision best for their child? Should intensive programmes, such as Lovaas, be abandoned when a child started school? How would their child cope with a change of location and staff? Who would be the key worker who would help them and their child through the transition?

Finally, an ongoing problem for parents was the management of their child's behaviour at home. The lack of support and respite care has already been mentioned. What was also needed, it was felt, was support and advice regarding strategies parents could use in the home. Also, the need for support for siblings should be acknowledged.

3.3 Summary of issues arising from the telephone interviews

The main issues arising from the telephone interviews were explored in more detail in the nine case-study LEAs and their associated health authorities and social services departments. These were, in summary:

- ◆ the concept of autism – how it was understood and used by all those working in the area;
- ◆ inter-agency problems and developments – differences in structures, priorities, time-scales, funding mechanisms and commitment;
- ◆ issues for parents and families – support, communication and need for information;
- ◆ provision available in LEAs, health authorities and social services departments – appropriateness, scope, effectiveness, cost and availability;
- ◆ teaching approaches and their effectiveness–evaluation, philosophical bases and consistency of approaches between different professional groups;
- ◆ training – lack of expertise, availability of training appropriateness of training;
- ◆ planning future developments in provision.

4. FINDINGS FROM THE CASE STUDIES

4.1 Understandings of the concept of autism

Definitions and prevalence

Most respondents used the concept of the 'triad of impairment' (Wing and Gould, 1979) when asked to describe their definition of an autistic spectrum disorder – namely problems with communication, social functioning and flexibility. They gave examples of lack of speech, lack of interest in social contact, ritualistic behaviours, and so on. But it was clear from what a range of professionals in health and education were saying, that diagnosis of autism is not a precise science and that children could present with autistic features along a continuum from severe to mild. For example, a paediatrician described the process of diagnosis thus:

Interviewer: *And what, what would alert you to that [possible autism]? Or is that too complicated?*

Paediatrician: *Yeah, I mean, when the child's looking..... A number of things. With the parents, often they say 'My child is fine till about eighteen months and then he stopped speaking'. Or they might say 'Well he will only do this. He will only go one way to the park'. Or 'He really loves Thomas the Tank Engine'. And then we'll start to then tease out things like an obsessional behaviour, ritualistic behaviour, or looking at social interaction. Or it might be when I'm chatting with the parents, observing the child, clearly he doesn't see me as a person...I could be anything... Sometimes I'll have a colleague with me who does some of the developmental assessment, and I'll be observing that at the same time. And then I might wonder if the child has got severe communication problem that makes it hard for the child to relate, or is it that we have a child who may have severe learning difficulties who is in a sense in his own world? So it's a number of factors, I mean it's certainly, it might be, thinking back to the early stages, history of things like feeding, or behaviour or, you know, that first year in a bit more detail.*

Her colleagues, a clinical psychologist and a speech therapist, were also quite fluid in their methods of diagnosis:

So that's what I mean, if you just go by the triad, you will miss a lot, and therefore I am not keen on the triad. I'm also not very keen on the idea of the autistic spectrum, because I think it is narrowing things down, and it is not stimulating...it is not stimulating thinking and hypothesis. I use the term myself, if I write for the BMA or whatever, or write reports on autistic

spectrum disorders, but I think the term itself is not helpful, because we know that on the autistic spectrum it's very likely that there are a number of conditions that we have not even identified yet.

(Clinical Psychologist)

However, these more fluid diagnoses concerned the more subtle forms of autism – higher functioning autism and Asperger syndrome:

It sounds appalling to say, but it's very easy to diagnose a classically autistic child. But the communication and socialisation (I mean we're talking about behaviour, but that is very much included as part of behaviour), that perhaps we should say, you know, make it quite clear that the communication, the imaginative or representational play and the socialisation are obviously vital areas we're looking at.

(Speech Therapist)

So there is agreement about 'classic' Kanner autism, but more difficulty in diagnosing the more subtle manifestations of the disorder. Nevertheless, there is a growing recognition that children with milder forms of autism are experiencing quite profound learning difficulties and that early identification of their needs can ensure that appropriate provision is made for them:

I think their needs change and, yeah, it seems to be that as they, perhaps they have the right learning environment, that some of the problems that they did experience that caused the label to be given to them, diminish. I suppose in other cases, other problems override, you know, sort of take over, and certainly with Ben, his ability to understand and use language properly, is to the forefront, which is why people say that it's much more of a severe communication disorder than the original diagnosis of autism. Certainly when he was a sort of a 2–3-year-old, then he looked like a very typical autistic child: you know, very angry, very frustrated...unable to make relationships with anyone, even his family. And given a good period of intervention has made tremendous strides, and, you know, hence he's been holding his own in mainstream, albeit with a lot of support.

(Teacher in an assessment class)

One of the outcomes of a broader definition of autistic spectrum disorders, coupled with an increased sensitivity of teachers and health professionals to the more subtle forms of the disorder, is that there is a general impression that there is an increase in prevalence of autism. Most professionals, when asked, said that they were now seeing many more cases of autism, but were not sure whether this represented a real increase, or whether it was simply that they were better at identifying it, or both. A number of professionals who had been working with young children over many years, as play advisers and teachers, said that they were now seeing many more children presenting with autistic-like problems.

It is also the case that parents are now much better informed than they used to be and have access to information over the internet. The combination of

an increase in identification and increased parental demand for provision has led many LEAs to set up working parties to look at autism and to develop new forms of provision to meet the increasing demand. This was the case in many of the LEAs studied in the present research.

4.2 Identification, assessment and diagnosis

Identification

Identification of younger children appeared to be becoming more effective in all the case-study areas. More children in the younger age group were being identified with problems and being referred by health visitors and early years workers in nurseries and other pre-school provision. Awareness among health visitors had grown as a result of training, but sometimes GPs were not quite as aware and might block referral to a paediatrician for diagnosis. Speech therapists were also now more aware of the signs of an autistic spectrum disorder.

New forms of assessment, such as the Checklist for Autism in Toddlers (CHAT) (Baron-Cohen *et al.*, 1996), were being used for screening in some areas, but their usefulness depended on the age at which screening took place. The CHAT is designed to be used at 18 months, but in one of the case-study areas health visitors were modifying it to be used with slightly older children (22-month-olds) in order to fit in with their cycle of screening.

There was some concern that increased awareness might lead to over-identification and that some children might be wrongly diagnosed. What was seen as crucial was good communication between health and education services, so that referrals were made promptly and children were seen as soon as possible.

Assessment

Some form of multi-professional assessment was seen as good practice in all the nine case-study areas. This took different forms. For example, in one area there was a multi-professional discussion of all children referred to the paediatrician with developmental delay. This involved speech therapists, clinical and educational psychologists, doctors, health visitors and pre-school advisory teachers. The assessment, however, was delegated to one or two professionals deemed to be most appropriate. In other areas, the multi-professional assessment took place over four or five days, which were spread over several weeks, with all professionals in the child development team seeing the child during that time. There might also be additional visits to a child's home and/or educational setting. Some respondents felt that not all children needed to be seen by the whole team of professionals, since autism was not as complex as some other forms of developmental delay.

Example of one health authority's approach to assessment

The child development centre was housed in a purpose-built building in the grounds of the local hospital. It consisted of a suite of rooms which was used for assessment, a parents' room with tea and coffee making facilities and a crèche where siblings could be looked after. Children are assessed over a period of four or five days by a team of professionals who will see them in as naturalistic a setting as possible. They will be observed with parents and siblings, as well as being assessed individually. The team will consist of paediatrician, health visitor, speech and language therapist, clinical psychologist, educational psychologist, Portage worker or other early years provider.

When the assessment is complete, a key worker will be nominated to talk to the parents and discuss the diagnosis and proposed intervention with them. Thus there is a one-stop shop for parents, and they appear to be very satisfied with it. One parent's comment was: 'You really feel as though they have all talked to each other and you don't get different messages from different people.'

Diagnosis

Making a diagnosis and communicating this to parents was seen as a sensitive issue. Some professionals preferred to talk about 'social communication disorder' or 'pervasive developmental disorder', rather than use the term 'autism'. However, parents seemed to need a more specific diagnosis in order to feel that they could move forward and gain information about their child's condition and begin to make decisions about appropriate interventions.

And I think it was hinted at a few times, and then if I actually asked outright 'Is he autistic, is it autism?', they said 'Oh no, no, it's nothing like that.' And I found that really frustrating.

(Parent of a child in mainstream assessment class)

Q: What was the diagnosis?

A: PDD. That's what everybody is diagnosed here.

Q: By the paediatrician?

A: Yes

Q: Did you find that helpful?

A: Yes, very helpful. The biggest conundrum that I find with this thing, because obviously I've read now and found out, is that you don't want the child labelled, but if you haven't got a label, you can't get any help. And the conundrum of that seems to be the whole crux for parents. We found without a diagnosis, you can't access anything, yet you don't want a diagnosis that's going to condemn your child to a life of something that may not be quite true.

(Parent of a child in a specialist school for autism)

There was concern in some of the case-study LEAs about whether the diagnosis was given to parents by doctors in a way that was helpful in terms of initiating discussions about educational provision (see below).

4.3 Inter-agency communication and collaboration

On the whole, relationships between professionals in education, health and social services appeared to be positive. However, there were often problems at the strategic level about funding of provision, developing joint approaches and the responsibilities of the various agencies for different aspects of support and provision. There was, for example, much frustration expressed about the limited role which social services were able to play in supporting parents, although, at the same time, a recognition that cut-backs in social services funding had led to a reduction in, for example, respite care. This had been a political rather than a professional decision. Nevertheless, there was a feeling among professionals and parents that social services did not properly recognise the extreme stress that some parents of children with autistic spectrum disorder were suffering.

Another key relationship which gave rise to some problems was that between speech therapists and teachers. It was recognised that speech therapists had valuable expertise to offer but often this was not properly communicated and shared with teachers. Also (again, a systemic problem), there appeared to be a shortage of speech therapists in most areas, which led to a patchy and unreliable service. Headteachers talked about speech therapists taking holidays during term time, so that children missed vital sessions. When speech therapists took maternity leave, there was often no replacement. The difference between a culture where provision has to be made every day for every child and one which is more individually client-based led to some difficulties. However, where things worked well and there was good communication and collaboration between speech therapists and teachers, together with a continuity of provision, the service was seen to be very effective and was highly valued.

One long-standing problem (and not just for autism) was who should give advice to parents about the most appropriate provision for their child. Parents will canvass a number of opinions, as well as finding their own information; and there was often some concern in LEAs about the role of doctors in making recommendations, if these contradicted some of the LEA's policies about provision, or if they put too much pressure on some types of provision which were in limited supply. There was also the cultural difference, mentioned above, of the 'individual client' focus of health professionals and the wider group or service-oriented view of educationalists.

However, these problems need to be placed in the wider context of good relationships between, for example, clinical psychologists and schools, outreach service staff and speech therapists. In addition, there was a recognition that, at the strategic level, it was vital to have inter-agency input into reviewing and planning provision. Thus many of the areas had joint working parties developing policy and provision for autism. One LEA had a jointly funded post across education, health and social services to support the development of Children's Services Plans. In one of the areas, the new shire county and the two unitaries which made up the former shire county continued to meet to develop the service for autism.

4.4 Support for parents and families

Support for parents and families was identified as an important issue in all the case-study areas. Some parents felt that they had a good service from all the professionals they had talked to, and the professionals had communicated well to each other. Thus there was a seamless service which had given parents confidence in the ability of health, education and social services to meet their needs and be responsive to their suggestions and opinions. However, for other parents, there had been a more contradictory and confusing pattern of response. Some parents had not received services from their LEA or other provider at an early enough stage and had therefore felt unsupported. This had led some of them to seek alternative provision, such as a Lovaas programme.

There was an awareness among LEAs that parents needed support as quickly as possible. One LEA, as already mentioned, had set up an *EarlyBird* scheme to support parents soon after diagnosis of their child's difficulties. Other support from teacher/counsellors and Portage workers was also available in most LEAs. In one authority the pre-school service had produced a very attractive series of small books which explained the problems of children with autism in a way that young children could understand and relate to (Campbell and Gregory, 2000a, b, c and d). Voluntary organisations were also a valuable source of support and parents would be put in touch with these by staff in health, education or social services.

The problems with social services support have already been mentioned but other issues, such as help with claiming allowances and help with behaviour management, were also mentioned as areas where social services could have an input. One problem mentioned by some respondents was a lack of specialised advice and support for parents if their children were in mainstream schools. Some of the special schools offered a range of after-school activities and therapies, as well as sibling support groups and weekend activities for families, but these were not so readily available for families of children in mainstream provision.

Parents often wanted help in the management of challenging behaviour; because of the nature of their child's difficulties, it was often difficult to find carers who were able to cope. An innovative scheme for parental support with challenging behaviour was offered in one health authority by the child and adolescent mental health service, which demonstrates the ways in which a multi-agency approach to meeting needs can be effective.

A home intervention project for managing behaviour

The home intervention project was a three-year funded joint project between social services and the health authority. The purpose of the project was to take children who had failed to make sufficient progress in modifying their behaviour in an out-patient setting because the parents needed more support to make the changes at home.

Intensive support was put in at the beginning of the programme – every evening after school for two hours, and half a day at the weekend – to get a management

programme under way, such as setting limits, or the management of self-injury. Once the parents could see that it was possible to make the change, they gradually took over doing the programme and other agencies, social services or MENCAP were brought in to support. They carried on, with the support of the mental health team, and took over the programme in the community. The mental health team were phased out at that point.

4.5 Early intervention

There were many forms of early intervention from health, social services and education departments and each area had its own pattern of provision. There was some form of home visiting service in each area. This might take the form of Portage support or visits from an advisory teacher or teacher/counsellor. This was not an intensive intervention, as visits from Portage workers or advisory teachers tended to be fortnightly or monthly and were seen as opportunities to advise on or model strategies for parents or carers to use. However, a package of support which included Portage home visits and support for children in an opportunity group or play group was viewed very positively by parents:

No, as I say, I feel quite positive about it, because I think I've been so bad, and he's done so well, which I feel is very much down to all early help that we had. It was really the Portage and one-to-one at playgroup and things. It was that sort of intensive help that has made a massive difference.

(Mother of a 5-year-old in an assessment class)

Speech therapists were often involved with the children. Some had specialist expertise in ASD, but many of those working in the community did not. Speech therapy was variously delivered in local clinics and child development centres. It was not always clear whether there was good liaison between speech therapists and others making provision for the child. Some parents had given up on speech therapy, because they did not feel it was delivered in such a way that it was benefiting their child. There is a need for speech therapists to be better integrated into teams of professionals who are supporting children with ASD in the settings in which they are placed (i.e. in playgroup, nursery or school). In two of the interventions described in more detail in Chapter 5, speech therapists were based in the schools and were an integral part of the team.

Clinical psychologists were key staff in a number of the case-study areas. Some had a specific interest and expertise in ASD and worked closely with other colleagues in developing provision. In one of the case-study areas, the clinical psychologist had been a key person in setting up the resource base which became the basis of the LEA's provision, making regular visits to see children and to offer support and training to staff.

One area had recently started a project based on the NAS *EarlyBird* programme to offer support to parents of younger, newly diagnosed children

and their parents. This was to fill a gap that they perceived in their service where younger children did not have access to their outreach provision until they had been given a statement. This was a 10-week programme including workshops and home visits.

Another home-based intervention of a more intensive kind, used by some parents in some LEAs, was the Lovaas programme. This was organised in different ways in different LEAs. Some operated a fairly distanced approach whereby they were funding the provision but left it to parents to find Lovaas workers and supervisors. Others were more 'hands on' and employed the workers directly and were beginning to train supervisors themselves. There is still an ambivalence about appearing to sanction and give credibility to an intervention which is expensive, yet has not been demonstrated to be more effective than other, less costly, forms of intervention. In addition, some of those working in health and education settings had reservations about the ethics of the approach and its methodology.

In a number of cases, the Lovaas provision had been approved by a tribunal ruling. In talking to parents, it emerged that Lovaas was not necessarily seen as the only effective treatment for autism. Often parents had resorted to Lovaas out of a sense of frustration that their child had not been offered what they saw as sufficiently intensive or effective support. Opting for Lovaas was seen as a way of forcing LEAs to make provision:

No, I should have gone to the early years centre as well, but even the pre-school adviser who was there every time said there was nothing she could do. So we nearly got Portage for Alex, but then, what happened was, there was this shortage of Portage workers anyway, and they didn't have money to pay them. This is what I was told. I really could have done with something.

(Mother of a 5-year-old receiving Lovaas)

This child was also offered a nursery place in a school for pupils with severe learning difficulties, but his mother also felt that this was not appropriate:

Well, she was the speech therapist at the time, and I went to see her, and chat to her to ask for support because I couldn't cope, and she said 'Well you have obviously got to the point where he needs some instruction. He has got to go into school. What would be the reception class, I think, the nursery class, and it was just so inappropriate. There were children there about the age of 8. They couldn't walk. They were strapped to their chairs...but it wasn't appropriate at all. I couldn't see how he could benefit from anything from there.

The key issues for parents in early interventions appear to be: the appropriateness of the provision, the expertise of the staff involved, its perceived effectiveness and its availability and frequency.

The range of pre-school settings for children with an ASD in the nine case-study LEAs included:

- an assessment centre in a specialist school
- nursery classes in schools for pupils with severe learning difficulties
- nursery classes in schools for pupils with moderate learning difficulties
- special classes and groupings in mainstream nursery schools
- special groupings within social services day nursery provision
- opportunity group
- nursery located in a child development centre
- Portage home visiting
- home visiting by nursery nurses.

Some of the provision was specialised for ASD, while some was generic and dealt with a range of developmental delay. Some, like opportunity group provision, provided one-to-one support but none of the staff was a qualified teacher or therapist; they may have been given some advice from a Portage worker or pre-school advisory teacher but they were basically playgroup workers. The social services nurseries had NNEB-qualified staff but none of these had specialist training in developmental delay or autism, although they had developed expertise through their involvement with the children.

4.6 Provision in schools

Provision in school for 5–7-year-olds also varied. There was some specialist provision in a number of settings – these included specialist schools and units; schools for pupils with learning difficulties, with either special classes for pupils with ASD or where pupils were placed in general special educational needs settings; and mainstream placements, either on an individual basis with support or in small groups with a specialist teacher. Some areas had a large outreach team supporting a wide range of children with ASD; others had one or two teachers who were specialists and spent some time in schools and units and some time on outreach work. A number of the LEAs were providing systematic training for teachers and LSAs who had responsibility for pupils with ASD and a high level of expertise among such teachers and LSAs was developing.

The organisation of provision

The models exemplified by the nine case studies are reproduced below:

- Model 1:** Provision mainly in SLD and MLD special schools. Developing provision in selected mainstream schools.
- Model 2:** Specialist provision *within* special schools (MLD or SLD), plus outreach support for children in mainstream schools.
- Model 3:** Specialist school or unit for autism.
- Model 4:** Specialist bases in mainstream schools, plus outreach support for children in mainstream and special schools.

Model 1: Low level of specialism

Children with autism in:

Residential special school

MLD/SLD school or nursery
but not
in specialised group

Mainstream school or nursery
but not
in specialised group

Model 2: Developing level of specialism

Children with autism in:

MLD/SLD school in specialised setting

Mainstream school, part specialised – part integrated

Mainstream school with outreach and in-class support

Model 3: High level of specialism within one setting

Children with autism in:

Specialist school outside the LEA

Specialist school or unit + nursery within the LEA

Other settings, specialist or mainstream but with no specialist support

Model 4: Specialism across a range of settings

Children with autism in:

Specialist base in mainstream school with opportunities for inclusion

MLD/SLD school or nursery with some specialist settings + outreach support + inclusion

Mainstream school or nursery with in-class support and outreach

Model 1

The model existed in many LEAs where specific provision for pupils with ASD was just beginning to be developed. Formerly, only children at the severe end of the spectrum would have been identified and their needs met in a segregated, special school setting, most probably a school for pupils with severe learning difficulties. Alternatively, such children would have been placed in residential special schools in the independent sector. Children with milder forms of autism and Asperger syndrome would have been educated in special schools for children with moderate learning, or emotional and behavioural, difficulties. Many may not have been given a diagnosis of their problems. Some of these children would have been in mainstream schools, without being identified.

More recently, with a growing awareness of the needs of children with ASD both in mainstream and special schools, LEAs have begun to develop provision in mainstream schools—mostly with very small numbers of children and a high ratio of teachers or support assistants. For younger children, usually with severe autism and learning difficulties, provision would be made in nursery classes in special schools or in playgroups with one-to-one support for the child. Most local authorities also offered some kind of home visiting service where a teacher or Portage worker visits the home and suggests ways in which the parents can support their child's development. Most children with an ASD would also receive some speech therapy but not necessarily from a speech and language therapist specialised in treating ASD.

As greater expertise and interest in this area has grown, some local authorities were moving from model 1 to model 2 provision, with the emphasis on making specialist provision within existing settings and on developing outreach support to help schools develop their own provision.

Model 2

The LEAs in the NFER study which were actively developing provision were, on the whole, working towards the second model. They had appointed a specialist teacher and/or educational psychologist who was working with schools to develop their expertise and provision. A number of the LEAs had identified mainstream schools which had the potential to be 'autism sensitive' and to work creatively with children with less severe difficulties. These schools would have a small number of children (maybe one in each year group), who would be supported by a specialist teacher and classroom assistants, but who would spend a proportion of their time in the main class with their age-appropriate peer group. The school would have a designated area to which the pupils could withdraw if they became too distressed by being in a large class. The role of the support teacher would be to work with the class teachers and the pupil to develop an appropriate learning environment, and also to provide advice and support for other mainstream schools in the LEA who might have one or two autistic pupils placed in them, as a result of parental preference.

LEAs who were operating this model were also developing provision *within* special schools, so that an SLD or an MLD school might have put together a group of pupils with autism with whom they might be working on a specific programme, such as TEACCH or PECS. The development of such groups was a response to a growing awareness that a typical highly stimulating special school environment was not necessarily the best setting for pupils with autism, who need a great deal of structure, a less distracting environment and a high level of one-to-one interaction with their teacher or learning support assistant (LSA).

Model 3

Some LEAs were addressing the issue of provision for autism by setting up highly specialised schools or units to provide for some children with an ASD. This was often in response to their previous practice by which a significant number of children had been educated outside the local authority concerned in independent or in other LEAs' provision. Some of these highly specialised schools were very expensive and so LEAs had responded to this by opening their own highly specialised provision to demonstrate to parents their ability to meet the child's need within the LEA. Such specialist schools have experienced staff and offer a whole-school environment which is structured to meet the needs of children with an ASD. This is a segregated setting but opportunities for some inclusion may be offered.

The examples studied in the NFER research had not yet developed an outreach function, so that the expertise residing in the school or unit was not yet being used to support other children who might have autistic spectrum disorders, but who were in other settings either special or mainstream schools. Thus children who had received a diagnosis and had been able to obtain a place in the school or unit were being well catered for, whereas children who did not fit the admission criteria, or for whom there were no more spaces left in the specialist school or unit, were in generalist provision in special or mainstream schools without any specialist support. The outreach function whereby expert advice is available to staff attempting to meet the needs of children in generalist settings is clearly a crucial element in making adequate provision.

Model 4

The model was found in LEAs where there had been considerable development in provision for autism over a number of years and where the needs of the whole range of children on the autistic spectrum were addressed. There was an acknowledgement that there was a need for specialised settings for some children, at least for part of the time. There was also a commitment to inclusion and a recognition that there were a number of children on the spectrum whose needs could be met within mainstream with some outreach support from an advisory teacher and some support from a classroom assistant. At the other end of the cognitive range, there were children with autism in SLD schools who needed specialist input, but within a special school environment. This model recognised the range of cognitive ability

and presentations of autism among children, and attempted to offer a range of provision to meet these. In one LEA the service had been developing over 20 years and had adapted to meet the changing understandings of autism, as well as parental wishes and the emergence of a demand for home-based approaches, such as Lovaas and Option.

4.7 Inclusion

Inclusion is a big issue for those working with children with ASD. Some children are likely to be in mainstream schools anyway, because their academic level is average or above, and the school is willing and able to be flexible and differentiate where necessary. However, the current policy of inclusion is steering LEAs away from segregated provision, and it was clear that for some children in the case-study LEAs a mainstream placement would be quite a challenge for them, their teachers and helpers, and for the other children in the school. In some LEAs, pupils with ASD were in special classes within special schools.

Some examples of inclusion

The NFER team found no examples of specialist settings for very young children (under 5 years), apart from examples of children following Lovaas programmes in their own homes. Children under 5 with autism were typically provided for in nursery settings, either with children who had other types of special needs or in mainstream integrated nurseries or playgroups. Often, it was reported that the presence of one or more children with autism in the group presented severe challenges to staff who were neither trained nor sufficiently resourced to be able to support them appropriately. In one LEA, where children with special needs were placed in social services nurseries, the two nurseries concerned had created special groups of children with autism and operated a highly structured routine for them with a lot of emphasis on social communication, which was distinctively different from the regime operating in other parts of the nursery.

Mainstream schools

There were several examples in the NFER study of pupils with autism attending mainstream schools. In one area of a city there was a Roman Catholic primary school which had five children with an autistic spectrum disorder – one in each of the five year groups. The children were supported by full-time classroom assistants and mealtime assistants during playtimes. The teachers in the school were supported by a deputy head/special needs coordinator who wrote individual education programmes for each child, with an emphasis on social learning and communication, and liaised with parents. The children appeared to be well integrated and worked in their age-appropriate groups on the normal National Curriculum timetable. The role of the classroom assistants was to make sure that they understood the tasks they were asked to do, to keep them on task and to do some one-to-one work with them if it was felt to be needed. The oldest of the group was

about to transfer to a secondary school. This school had built up its own expertise over the years, as a response to local parents who wanted a Catholic integrated education for their children. The children in the school all had some speech, although two of the younger ones were more severely autistic than the school had provided for previously.

In several schools in rural areas, LEAs had been developing 'autism sensitivity'. Schools had volunteered to take a small number of autistic children (up to five in a school of 250–300) who were included into their age-appropriate groups and given in-class support, plus some extra support from an advisory teacher. These developments were seen as an alternative to young children spending long hours travelling to specialist provision or spending time away from their families in residential provision. In some cases, children were included successfully with their peers and, able to cope with the demands of a mainstream class, if teachers and support staff were sensitive to their need for structure and clear direction. Other children in the class were also a key ingredient of successful inclusion, if they were able to support the child with autism and accept their difficulties with social interaction. In other cases, the extent of inclusion was minimal, with children 'tuning out' or spending all their time one-to-one with the classroom assistant.

There were also some examples in the NFER study of special classes for 5–7-year-olds with special needs in mainstream schools. These classes performed a diagnostic and assessment role for some children whose needs were unclear. Many of these children had social communication problems and an uncertain diagnosis of autism but, as the teacher quoted in a previous section noted, many of their symptoms disappeared once the child had begun to be able to use speech to communicate. It may be that the English tradition of starting full-time formal education at 4 and 5 years old does not allow children with communication difficulties to overcome these problems, except in a more nurturing, developmental setting. Some of the children in this particular class were still thought to have autism but were able to make the transition into the mainstream at age 7, because they had made some gains in language and social communication and were in a school which was sensitive to their needs. Thus initial segregation and an emphasis on language development, speech therapy and social communication had enabled many of the children in these special classes to overcome their difficulties to the point where they could be placed in mainstream classes, albeit with a high level of classroom support.

Autism base with some inclusion

It was seen as necessary to provide for some children, at least some of the time, in a base which could create an environment to meet their needs, and allowed them to begin to acquire language and social skills and to integrate when it was felt they were ready to do so, and for as long as it was useful. So the autism base had links with a number of mainstream schools, where children would be included for some of their day or week. If problems arose, the children could be brought back into the base. Teachers and support

assistants from the base would be available to support both children and staff in the inclusive settings.

The bases appeared to take children with quite severe autism, not all of whom were able to make the transition into mainstream or to benefit from limited inclusion – these were sometimes moved on into special schools. The criterion for placement in a special school seemed to be whether a child had a degree of cognitive impairment more appropriately provided for in a school for pupils with learning difficulties. The changing clientele of the autism bases meant that the amount of inclusion they were able to offer was declining, as the more able and less severely autistic children were increasingly likely to be placed in mainstream schools.

However, for those based in special schools, efforts were made to offer inclusion if it was felt to be appropriate and that the child might gain some benefit. Some special school staff reported unexpected gains for children whom they had thought would gain little from inclusion but whose parents or the LEA had pushed for it.

4.8 The availability of appropriate provision

The number of children identified with ASD has increased significantly in recent years, leading LEAs (including the NFER case-study LEAs) to expand their range of provision to enhance the expertise of their staff. However, some LEAs were still trying to meet the current demand appropriately. Some forms of provision (for example, the resource bases and enhanced specialist provision in mainstream schools) were relatively new and their effectiveness is still to be evaluated. Other forms of provision (for example, specialist groupings with special schools) are a response to the perception among teachers that pupils with autism and other significant learning difficulties present a particular challenge and need a particular environment in which to learn effectively. As more becomes known about autism and its manifestations, more innovative and creative solutions will probably be found and the range of provision enhanced. Those LEAs which have been developing provision over a number of years have a much wider range available than those which have recently started their development.

4.9 Planning and prioritising

In all the areas, decisions had to be made about how services for autism should develop. There were many dilemmas and questions:

- ◆ Should the LEA develop specialist provision or move towards an outreach approach?
- ◆ Should the LEA fund Lovaas programmes and, if so, how should these be organised and evaluated?

- ◆ Should money be put into early intervention or support for children at secondary school?
- ◆ Should autism be approached differently from other types of special educational needs when planning provision?
- ◆ Should children with autism be included in mainstream schools?
- ◆ Will widespread training and awareness-raising lead to over-identification and mis-identification?
- ◆ Should pupils with SLD and autism be in SLD or autism-specific provision?
- ◆ Should children with Asperger syndrome be in mainstream or special provision?
- ◆ How can health authorities be persuaded to provide more speech therapy across the range of settings in which pupils with ASD are located?
- ◆ How can social services be persuaded to put more resources into respite care for families of children with ASD?

The ways in which the LEAs responded to these dilemmas and challenges varied depending on local circumstances. Some newly formed LEAs had found themselves lacking in provision and needing to develop alternatives to those which they had formerly used. This had led to some innovative ideas about 'resource bases' and 'enhanced specialist provision' in mainstream schools. In some SLD and MLD schools, groupings of pupils with ASD had been formed to provide a sympathetic learning environment for pupils who found the general special needs provision difficult to cope with. Often, the planning of this type of provision was carried out at the school rather than the LEA level. Many of the LEAs had focused on early years and primary provision in more inclusive settings and were now seeking to make provision in secondary mainstream schools. In some cases, tribunal decisions had upset LEAs' plans and priorities and they were wondering how to respond to future requests for provision which was not normally available in the LEA.

4.10 Enhancing awareness and expertise

The NFER case-study LEAs were aware of the need to offer training and support to teachers and LSAs working with children with ASD. Some LEAs had initiated a support group for teachers and LSAs in both mainstream and special settings which met regularly to discuss problems, successes and new approaches.

Many of the teachers involved in provision for children with autistic spectrum disorders had pursued their own interest in the topic by taking courses, such as the distance learning courses in autism offered by

Birmingham University or Master's degrees in special needs with autism as the topic for their dissertation work. Several of those working in health authorities had undertaken doctorates in the area of autism. Thus there is a growing level of knowledge and expertise among those working in the field.

There was some difference of opinion about whether wider dissemination of information about ASD to all teachers and support staff was necessary. Some felt that special educational needs coordinators should receive some training but that it was not needed for all teachers. However, a whole-school approach to special needs would require all teachers to be aware of the needs of children with autism on roll. In the health and social services also, it was felt that there was a need to enhance awareness and understanding. There may be an opportunity here for some joint training across services, so that the approaches of different professionals could be made known and understood.

One group for whom training was important, but for whom it was not always available, was that of learning support assistants. Some of those working in specialist provision appeared to be well trained (some were qualified teachers), but in areas where they were used for one-to-one support for pupils in mainstream, they generally had only a minimal training, although some had previous experience with pupils with ASD (one or two were mothers of children with ASD). However, it would seem to be important for LEAs to offer adequate training for LSAs and to try to maintain a register of suitably qualified LSAs, so that expertise would not be lost if pupils move on to other schools and LSAs have to be redeployed.

4.11 Teaching approaches and their effectiveness

Most of the provision in the case-study LEAs used a composite of teaching approaches, best described as 'eclectic'; thus it is very difficult to judge the effectiveness of particular approaches, especially when pupils may also be on special diets or taking medication such as Secretin or Ritalin.

To evaluate both settings and teaching programmes, long-term tracking of pupils will be necessary and some basic common measures and methods of tracking and recording pupils' progress need to be set up. In Phase 2 of the project, described in Chapter 5, the NFER team looked in more detail at a range of early interventions and teaching approaches used, and explored the ways in which children's progress could be tracked and the effectiveness of provision evaluated.

5. FINDINGS FROM PHASE 2: STUDIES OF INTERVENTIONS

5.1 Range of interventions studied

As described in the methodology section of the report, a number of interventions in the nine case-study LEAs were chosen for detailed study, and interviews carried out with a range of providers and parents. This chapter will give some details of the interventions in practice and the views of parents and providers about their efficacy.

The provisions were:

- an autism resource base in a primary school
- a pre-school home-visiting service
- a specialist primary school for autism
- three integrated nurseries
- an assessment class in mainstream
- specialist provision in an SLD school
- a Portage language project
- a nursery in a child development centre
- a mainstream primary school
- Lovaas home-based programmes.

5.2 Characteristics of the children receiving the interventions

Tables 5–13 give some basic demographic data about the characteristics of the children in the provisions studied. They give the diagnosis as recorded by parents and providers, CARS scores for each child which are based on the ratings given by the providers, and the provision the child was receiving before he or she was allocated the current provision. This is a 15-item behavioural rating scale developed to identify children with autism and to distinguish them from other children with a developmental disorder. It also includes a rating of severity of their autism. Ratings can be made from classroom observations and from parents' reports and written reports or psychological assessments. Any of these can be used as long as they include information on all 15 scales. In making the observations, the rater makes comparisons with that of a normal child of the same age. When behaviours are noted which are not normal, the peculiarity, frequency, intensity and duration should be noted in order to arrive at the rating. The range of total

scores is from 15 to 60, with 15 representing normality. Following the tables, we present an analysis of the similarities and differences in the children's profiles as recorded in a skills checklist completed by parents and carers, their CARS scores and their current placement.

Table 1 Resource base in mainstream primary school

Age	Sex	Diagnosis	Age at diagnosis	CARS score	Previous provision	Speech
5.10	M	Autism. Significant communication difficulties	3.3	35 (mild moderate)	Portage	Yes
6.11	F	Social communication disorder	3.9	36 (mild moderate)	Nursery school	Yes
7.0	M	ASD. Specific development disorder of speech and language	2.8	47 (severe)	Nursery school	Yes
6.9	M	High-level autism or Asperger syndrome	4.9	32 (mild moderate)	Mainstream	Yes
6.9	M	ASD. MLD. Visual impairment	4.5	60 (severe)	Nursery school	Yes
5.3	M	ASD	3.6	45 (severe)	Playgroup	Emerging

Table 2 Pre-school home visiting service (as part of a package of interventions)

Age	Sex	Diagnosis	Age at diagnosis	CARS score	Previous provision	Speech
4.3	M	ASD	3.0	N/A	Opportunity class	Emerging
2.10	F	Fragile X. Infantile autism	13 months	44 (severe)	Opportunity class	No
3.10	M	ASD	2.3	46.5 (severe)	N/A	No
3.8	F	Autism	2.8	30 (mild)	Opportunity class Playgroup	Emerging
4.2	M	N/A	3.0	33 (moderate)	N/A	Emerging
4.6	M	Autistic	3.0	37 (severe)	Playgroup	No

Table 3 Specialist primary school for ASD

Age	Sex	Diagnosis	Age at diagnosis	CARS score	Previous provision	Speech
5.7	M	Communication disorder (1997). Autistic (1999)	2.6 4.0	41 (severe)	None	Emerging
5.6	M	PDD	2.5	41 (severe)	S. Services nursery	Emerging
5.0	F	PDD	2.4	47.5 (severe)	S. Services nursery	Emerging
4.8	F	PDD	2.6	44 (severe)	Playgroup	Emerging
4.5	M	PDD	1.10	55 (severe)	S. Services nursery	No
6.4	M	Global developmental delay with features of PDD	4.0	28.5 (non-autistic)	Playgroup	Emerging

Table 4 Integrated nursery

Age	Sex	Diagnosis	Age at diagnosis	CARS score	Previous provision	Speech
4.0	M	Autism	2.10	33 (mild/moderate)	Portage Opportunity group	Emerging
3.10	M	Autism	Approx. 2.0	52.5 (severe)	Portage	Emerging
4.7	M	Autism	N/A	47 (severe)	Opportunity group	No
4.10	M	Some characteristics of autism	3.0	39.5 (severe)	N/A	Emerging
5.6	M	Autism	2.6	39.5 (severe)	Opportunity group	Emerging

Table 5 Portage language project

Age	Sex	Diagnosis	Age at diagnosis	CARS score	Previous provision	Speech
3.7	M	Autistic	2.0	35.5 (mild moderate)	CDC/ Private nursery	Emerging
3.3	M	ASD-Asperger syndrome	2.6	27 (non -autistic)	Opportunity group Mainstream nursery	Emerging
3.8	M	ASD/Severe communication disorder	2.0	33 (mild moderate)	Playgroup	Yes

Table 6 Child Development Centre nursery

Age	Sex	Diagnosis	Age at diagnosis	CARS score	Previous provision	Speech
4.5	M	ASD	3.0	42.5 (severe)	None	Yes
3.6	M	ASD	2.6	26 (non- autistic)	None	Emerging
4.0	M	ASD	2.9	41 (severe)	Private nursery	No

Table 7 Assessment class in mainstream

Age	Sex	Diagnosis	Age at diagnosis	CARS score	Previous provision	Speech
6.5	M	Asperger syndrome	N/A	26.5 (non- autistic)	Playgroup Nursery	Yes
6.3	M	ASD	4.2	31 (mild moderate)	Private nursery	Yes
6.6	F	Complex communication disorder with some ASD	4.2	36.5 (severe)	Opportunity group	Emerging/ Yes

Table 8 Specialist provision in SLD school

Age	Sex	Diagnosis	Age at diagnosis	CARS score	Previous provision	Speech
8.3	M	Severe Communication Disorder	5.0	32 (mild/moderate)	Mainstream primary school	Yes
8.9	M	Autistic	4.5	48.5 (severe)	Main SLD school	Emerging
8.11	M	Autistic	4.0	55.5 (severe)	MLD school and main SLD school	No

Table 9 Mainstream primary school

Age	Sex	Diagnosis	Age at diagnosis	CARS score	Previous provision	Speech
6.11	M	Communication Disorder on Autistic Spectrum	3.0	34 (mild/moderate)	CDC	Yes
7.8	F	Communication Disorder on Autistic Spectrum	4.0	33.5 (mild/moderate)	Assessment unit in mainstream	Yes
9.2	M	Communication Disorder on Autistic Spectrum	6.9	35 (mild/moderate)	SEN nursery provision	Yes
9.5	F	Communication Disorder on Autistic Spectrum	4.0	35.5 (mild/moderate)	Assessment unit in mainstream	Yes

5.3 Analysis of child characteristics and provision

In the same way as there was wide variation in the provision studied, there was wide variation in the pupils. An analysis of the CARS and checklist was undertaken to establish any differences or similarities in the characteristics of the pupils in the same provision. All of these scores must be treated with caution as they were rated by different respondents within different LEAs, making different types of provisions.

Mainstream or specialist provision?

It is noticeable, for example, that in the resource base in mainstream primary school, five out of the six children had speech and one had emerging speech,

whereas in the specialist primary school, five out of six children had emerging speech and one had no speech. It might be assumed that the CARS score on the latter would tend to be higher than in a resource base in a mainstream school, but the mean scores are virtually identical at 42.8 and 42.5 respectively and, in each case, these figures are affected by one particularly high score. On this basis, then, there would appear to be little difference in the profiles of the pupils in the specialist primary school and the mainstream primary resource base. The range of CARS scores is also not unlike for these two categories of provision: from 28.5 to 55 and from 32 to 60 respectively. However, in the mainstream provision three pupils fall into the mild-moderate range, while all but one pupil in the specialist provision are in the severe range. In the case of each of these two provisions, there is one particular outlying and, perhaps, unexpected example – i.e. the score of 60 (top of the scale) in the mainstream resource base and the score of 28.5 (non-autistic) in the specialist provision. As suggested already, there will be individual differences in the way in which the CARS has been scored, depending on the scorer.

What is being measured?

In the case of one pupil, there were marked differences in the apparent levels indicated by the CARS scores and the skills checklist, from which might follow quite different perceptions about the pupil. On the CARS the pupil is scored at the most severe level in all areas, while on the skills checklist both parent-completed and provision-completed skills checklist indicate the acquisition of some skills in: dressing, eating, toileting and washing, play activities and activities involving another person.

The CARS and checklist measure different things and use different terminology. However, 'Severely inappropriate interest in, or use of, toys and other objects' (CARS) does suggest very different behaviour from 'Plays throw and catch; rides and steers a trike' (skills checklist). It would appear, then, that, whatever records are kept as a means of tracking pupils, there will be differences arising from the completion of records by different people.

In the case of the very low-scored pupil on the CARS, scored as non-autistic, fewer differences were suggested between the CARS and the skills checklist. In two areas of the CARS – activity level and body use – this pupil was scored as having 'age-appropriate behaviour', and in two further areas – object use (including toys) and 'taste, smell, and touch response and use' – as less than 'mildly abnormal'. On the skills checklist, scores were high in areas of self-help and, even in speech and language, two word phrases which are communicative were indicated, along with copied sentences. The pupil was described as having 'emerging speech'. The indications were also that this pupil had already developed skills in:

- writing – he can write his name and other words from memory without help;
- drawing – including drawing a person;
- social behaviour – he smiles and is willing to participate.

On this basis, a placement in a specialist ASD school for this pupil might seem surprising. However, the area in which this pupil was awarded his lowest score on the CARS was that of 'Level and Consistency of Intellectual Response' in which he was considered to display 'moderately abnormal intellectual functioning', although the CARS descriptor does allow that 'the child may function nearly normally in one or more intellectual areas'. It would appear therefore that the principal areas of need for this pupil to be met by the specialist provision were his 'emerging speech' and his intellectual functioning. Thus, while in a number of areas his functioning was not too different from that expected for his peer group, so that the appropriateness of his specialist provision might be queried, there are, clearly, needs which may be more difficult to meet in a mainstream setting, in particular those relating to his emerging speech. Provision such as PECS would be less likely to be available in a mainstream setting, and there was a speech therapist attached to the school also, so provision might be more extensive than it would be in a mainstream school. This was important as the pupil's diagnosis was 'Global Developmental Delay with features of pervasive developmental disorder'. Importantly also, there was parental satisfaction with the provision.

Assessment classes

As might be expected, all the pupils included in the mainstream primary provision had CARS scores in the mild-moderate range, with all the scores being very close, and all these pupils had speech. The scores for pupils in the assessment class in mainstream school ranged from 26.5 (non-autistic) to 36.5 – just within the severe rating. The apparent difference in the range of scores in the two types of provision was perhaps not surprising, because while both establishments were mainstream schools, the latter was an assessment class where the pupils were described as having 'an uneven educational profile' and the rationale for the class was to plan their long-term educational needs. Similarly, the completed skills checklists indicated that the pupils in mainstream classes had more consistently advanced skills in the areas of dressing and feeding than was the case for pupils in the assessment class. In one case, however, 'use of fingers only to eat' was recorded, and in another the use of special cutlery. Clearly, the LSA provision will be important with respect to such skills in mainstream classes and these could be regarded as issues for inclusion. It is also noticeable that all the pupils in mainstream were able to go to the toilet unaided. While it might also be expected that a greater degree of flexibility would be possible in the skills required for pupils admitted to the assessment class, it is also noticeable that in terms of overall provision these pupils received less in the way of shared support than the pupils in the mainstream classes.

The impact of early intervention

The age of diagnosis of pupils on the autistic spectrum and the need for early identification and early intervention were issues raised during interviews and formed the basis and rationale for the introduction of some of the provisions examined during fieldwork. Within the sample of pupils,

there was some indication that those involved in the earliest interventions – pre-school home visiting, Portage and child development centre nursery provision – tended to have their special needs recognised as on the autistic spectrum at an earlier age than those in some of the other provisions. It may be therefore that the existence of such early intervention aids early identification, as well as early provision.

The range of provision and pupils within it was extremely wide. It is essential that assessment is carried out and records maintained even if there is inconsistency among provisions. (A suggested format is included in Appendix 2).

5.4 Report on the provisions studied

This section will report on the various placements and interventions studied in the second phase of the NFER research. Discussion focuses on implications of the various types of provision for early intervention and the ways in which pupil progress can be tracked and the provision evaluated.

Resource base in mainstream school

Background

This was one of two resource bases for autism set up in two primary schools in the LEA, two years prior to the NFER research. Each resource base provided 10 places for children on the autistic spectrum aged between 3 and 11 years. There were two full-time teachers, one nursery officer and five LSAs. Speech and language therapy was also offered; the LEA employed its own speech and language therapists within the Learning Support Service. The base was staffed at the highest level (according to Circular 11/90: DES, 1990) to enable one-to-one teaching of the most challenging children.

Criteria for access to the provision

Children had to have a diagnosis of autistic spectrum disorder, including complex needs and challenging behaviour. The only other criterion was parental preference.

Description of the provision made

Children were on the roll of the mainstream school and spent some of the school day in their mainstream classes. Each child had an individual timetable which gave details of when they would be in class (i.e. in mainstream) and in the base. The amount of time spent in mainstream varied from full-time for all activities to playtime and lunchtime only.

Staff in the base used visual timetables and Makaton as appropriate. There was Circle Time, a focus on physical activity and a sensory room where children were taught relaxation techniques. The speech and language therapist worked closely with base and class teachers, setting communication

targets in line with National Curriculum targets; the aim was for speech therapy to be an integral part of the school day.

All teachers and assistants who worked with pupils with ASD spent time in both the base and mainstream classes.

Measuring and monitoring progress

Progress was monitored using termly individual education plans, reviewed and rewritten termly with long-term targets discussed at the Annual Review. Details on all the children were kept in the school in large lever-arch files kept in the deputy head's office; there was also a current folder for day-to-day record keeping. Information was shared among the whole team – class teacher, educational psychologist and speech and language therapist – who use a small steps approach, and the CARS and the NFER pre-verbal communication schedule for assessing progress. The speech therapist also used the *Pragmatics Profile* and the *Rapid Screening Test for Derbyshire* and the Reynell 3. A whole battery of information was held by the school on each child and the same tests were used, including those mentioned above, as well as standard assessment tasks (SATs) and baseline assessment.

Communication with parents

Communication with parents was on a day-to-day basis through daily news-sheets, rather than home-school diaries and staff phoned or visited parents if they needed to discuss something in detail. When children were offered a place in the base, parents had to sign a form agreeing to meet with a member of staff every three weeks, either at the school or at home. Professionals worked with the families to help them to understand and support the needs of their children. There was a parents' group, but many of the parents preferred individual discussions. Parents were given copies of individual education plans and were involved in discussions about their child's programme, rather like the approach used in Portage.

Parental views

Parents had a good general awareness of the programme offered to their child in the base and in school, but did not get involved in the detail and did not replicate at home what was being done in school (most reported that their children would resist this and would prefer to 'do their own thing' at home).

Parents also had a general awareness that their child was making progress, especially in areas such as behaviour and communication. They appreciated the daily report sheet on their child and the monthly meetings with staff to discuss progress. On the whole, they were happy with their child's placement, although they thought that more intensive one-to-one help, such as speech therapy, would be beneficial.

From the parents' perspective, obtaining a place for their child at the base had been a matter of luck, rather than the result of a careful series of decisions. This is probably due to the fact that the bases were new and only became available at the time their children were about to enter school.

Professional views

Those professionals working with the six children concerned felt that the children were appropriately placed and that their needs were currently being met. There was some concern about the future placements for the children, as there was currently no provision for autism at the secondary phase, although this was under review by the LEA.

Monitoring progress and assessing effectiveness were done on an individual basis for each child, but there was no plan to assess the overall effectiveness of the provision *vis-à-vis* other forms of provision. As each child had his or her individual programme, which might consist of different elements of resource base and mainstream class time, plus speech therapy and teaching of social skills, it would be difficult to disentangle the elements.

Emerging themes and issues

Issues identified as important for the progress of children by both professionals and parents included:

- ◆ Lack of provision during long holidays, which led to a reversal of progress and disorientation for the children;
- ◆ Problematic progression – there was no comparable provision at the secondary phase;
- ◆ A negative parental response to home-based intensive programmes, such as Lovaas and Option, but a positive one towards Portage and the support it offers;
- ◆ Difficulties in getting a child's needs recognised, especially if they had Asperger syndrome or high functioning autism.

It was also suggested that video tapes would be a good way of monitoring progress – short clips taken every few months.

Pre-school home visiting service

Background

The pre-school home visiting service was relatively new, offering a package of provision for pre-school children which included:

- weekly or fortnightly home visits (1–2 hours) by a specialist teacher to plan teaching programmes with the parents and monitor progress;
- up to 10 hours per week teaching in the home by a specialist nursery nurse;
- (for children under 3 years) five hours per week attendance at an opportunity class or other pre-school setting;
- (for children aged 3–4 years) up to 12.5 hours per week attendance at a mainstream or special school nursery with appropriate support.

Currently, the service was staffed by a senior advisory teacher, three visiting teachers and four specialist nursery nurses, but demand was outstripping supply and it hoped to expand.

Criteria for access to the provision

All the children would have a diagnosis of autism from a paediatrician and an assessment of their level of autism using the CARS and an assessment of their cognitive levels. The level of provision offered depended on these assessments and on what other provision was being made. For example, if a child was in nursery provision for five mornings per week, he or she might not also receive 10 hours of home visiting.

Description of the provision made

Each child received one-hour sessions from the visiting specialist nursery nurse in the child's home, with toys and games brought by the nursery nurse who modelled the ways in which the parents could work with their child. The approach taken was eclectic, depending on the child's needs, i.e. a combination of interactive approaches focusing on communication, behavioural approaches and language development. The service had developed many visual aids and visual support for children, and techniques such as moving from left to right and clearly signalling the end of tasks, but did not follow the TEACCH approach exclusively.

Children also had sessions in an opportunity group or nursery class. The nursery nurses also saw the children in the nursery, to give support, to assess their progress and to ensure continuity of approach, and also support children in difficult situations (e.g. when the child visited the dentist).

Measuring and monitoring progress

Assessment started with a pre-school developmental profile, completed with the parent, and a PEP-R test. Each child had an individual education plan based on emerging skills and targets were set in three areas – social interaction, communication and play; the opportunity group or nursery class aim at similar targets. A weekly record sheet gave details of what the nursery nurse had done with the child in that week. The pre-school individual education plan was used as a tracking document; it gave details of what the child can do now, the next step, suggested activities and materials, and general comments. Video recordings were also used as evidence and for training purposes.

There was a clear view that early intervention would have positive results in terms of children's ability to make progress in a school setting (whether special or mainstream), but since the children were having a range of different interventions (including some on special diets and some taking secretin), it was not possible to assess/ascertain the contribution of each intervention. Nevertheless, progress on targets on the individual education plan was an indication that the interventions offered by the nursery nurses on a consistent basis were effective.

Communication with parents

Communication with parents was mainly face-to-face, as nursery nurses saw the parents at home, giving them advice about the skills they were working on in the expectation that the parents would carry out the programmes with their children.

A monthly or half-termly meeting between the visiting teacher, nursery nurse and the parents reviewed progress and set new targets. There was a weekly support group for parents (an opportunity group) with the nursery nurses; the children could learn group skills and parents could support one another.

Parental views

All the parents interviewed reported that their children had made marked progress since the home visiting had started. Typically, a child who would not sit or concentrate to do puzzles or carry out tasks became willing to do so for an hour at a time. Parents also reported improved communication skills, in that their children were more able to make their needs known through symbols and pointing, although speech was still at an emergent stage.

Most of the parents felt that their children needed more sessions than they were currently receiving (most were receiving two or three one-hour sessions per week). One parent felt that her child had already made such good progress that he would make even more progress with a more intensive programme and had already therefore decided to put him on a Lovaas programme. This was not because she thought that the programme content would be better, but that the child would be getting 15 hours per week of one-to-one, rather than the three he was currently receiving. This parent subsequently withdrew her appeal to the tribunal for Lovaas provision when she was offered extra sessions of the LEA's programme.

Parents felt well supported by the intervention and by the opportunity to meet as a group once a week. However, several pointed out that there was a hiatus between diagnosis and acceptance on the programme and this had left them for up to six months with no support.

Professional views

The advantages that professionals saw in the approach favoured by the service were that children were offered a package of support which was built around their individual needs and parents would be closely involved in the interventions offered to their children. The intervention would start as soon as the children had been diagnosed and referred by the paediatrician. This meant that specialist help was being offered at an early stage. However, as demand for the service was beginning to outstrip its ability to respond, some children were receiving fewer hours in order that more children could be supported. Other advantages included the specially trained nursery nurses and specialist teachers.

Emerging themes and issues

- ◆ A gap between diagnosis and the start of the intervention was mentioned by several of the parents as problematic (but this might have been because the service had only been recently introduced).
- ◆ The coherence of the support offered across a range of settings and having a 'key worker' in the nursery nurse were key positive features.

- ◆ Parents would have liked more one-to-one sessions in the home.
- ◆ The ongoing support and specialist training of the nursery nurses were important element in maintaining the quality of the service.
- ◆ The lack of provision during the long holidays was seen as likely to be detrimental to children's progress.
- ◆ Having an opportunity group where parents of a child with autism could meet and their children have a chance to be in a group setting was seen as very positive.

Specialist primary school for pupils with autistic spectrum disorders

Background

The primary school was a purpose-built school specialising in early years assessment for children with complex special educational needs and the teaching of primary-aged pupils with autism. The main function of the early years department was assessment; it had 32 part-time places in two nursery classes, each staffed by one teacher and two nursery nurses, with eight children in each class per session.

The criteria for admission were that the children had an ASD and complex special educational needs identified by health professionals and assessed by an educational psychologist. In addition, younger children with severe communication disorders could be admitted, part-time or full-time; they would be expected to move on to the primary department. Other children would be assessed and placement decided after an assessment: some moved on to special schools and others into mainstream school with support.

The primary department took children from the age of 5 with 36 full-time places for pupils with autism in the primary department and six additional places in the early years department. Within the primary department there was an adult to child ratio of 1:2/3. In the early-years department there was also one full-time class for eight reception-aged children who required further assessment and intensive teaching within a small group setting. Thus there was a high adult to child ratio throughout the school. The pupils were grouped by key stage and level of learning difficulty.

Criteria for access to the provision

All children in the primary department had a diagnosis of autism or Pervasive Developmental Disorder (PDD) – the terminology preferred by the health authority to autism or autistic spectrum disorder – but causing some problems for the education professionals and some confusion for parents.

Description of the provision made

Children received a range of interventions depending on their individual needs, including TEACCH, PECS, music therapy, speech and language therapy, occupational therapy and Intensive Interaction, and were taught in both group and individual settings. Each child had access to either the

foundation or National Curriculum, modified to suit his/her particular needs and each had an individual education plan.

There were four speech and language therapists attached to the school, funded partly by the health authority and partly by the LEA. At least one had a special interest and expertise in autism. All worked closely with the class teachers and nursery nurses, worked individually with children, sometimes led group language activities, and liaised closely with parents and carers.

Measuring and monitoring progress

There was close monitoring of the children's responses to the interventions using a system of post-it notes recording 8–10 mini-observations each day and collating them at the end of the day for each child. Data were used to evaluate the children's daily plans. Weekly sheets were also used for observation of Circle Time and inside/outside time; and individual education plan monitoring sheets were completed once a week. Each child had an annual review. Photographs and video clips recorded children's social interactions. Thus there was a range of formative assessment informing adaptation of the interventions, as well as a longer-term assessment every year. The information on each child was kept by the school.

Communication with parents

Parents had a clear idea of their child's needs and what specific programmes the school had in place to meet the needs. Parents' knowledge came from their own observations and from information given by the school. The school had a home-school diary which parents found a very useful way of communicating with the school. Parents could go into the school at any time to see teachers and could observe their children from behind a two-way mirror. There was a parents' room, the base for a parents' support group. Other opportunities for communication were parents' evenings and the annual review meeting. One parent described the communication as 'a running dialogue all the time'.

Parental views

Parents were very positive about the provision offered and felt it was meeting their children's needs. There appeared to be effective communication between the teachers and parents, which meant that parents felt that they knew what the aims of the provision were and how it was designed to meet the needs of their child.

Parents signalled their unhappiness with the diagnosis of PDD, which they found 'wishy-washy' and 'unhelpful'. Most of the children in the sample were on special diets or taking secretin and/or vitamin supplements. It was expected by the parents that their children would remain in the provision throughout their primary years, so they had not yet started to think about transition to secondary provision, although they were aware that there was no similar provision in the authority for secondary-aged pupils.

Professional views

Professionals were happy about the ways in which progress was monitored and tracked for individual pupils. There were good systems for sharing information and ensuring continuity of approach.

Emerging themes and issues

- ◆ Are there good links between previous provision and the current provision?
- ◆ What happens to children who cannot access this provision?
- ◆ Who has an overview and evaluation of the range of provision available, especially as regards early interventions?
- ◆ One child in the provision scored in the non-autistic range on the CARS. What are the criteria for gaining priority access to the provision?
- ◆ Do all children need to stay at the school for all their primary years?

Integrated nursery provision***Background***

The authority provided three integrated nurseries for children with special educational needs, including those with autistic spectrum disorders, from the age of 2 years and 9 months. One of these was on the site of a former special school and opened as a nursery about five years before the NFER research. The second was an independent nursery where the authority bought places for children with special educational needs. There was an opportunity group at both of these nurseries. The third nursery was on the site of a special school for pupils with severe, profound and multiple learning difficulties. It also had a special key stage 1 class for children with ASD. The two LEA nurseries offered six places per session for children with special educational needs in a group of 26 children. The independent nursery took nine children with special educational needs in a group of 25. An audit of the numbers of children with an ASD had been conducted by the educational psychologists, and professionals from education and health met at the child development centre to discuss plans for individual children.

Criteria for access to the provision

Children have to have a statement in order to gain a place at the integrated nurseries. The sample of children included in this study did not generally start in the provision until they were between 3.5 and 4 years old. Thus the placement in this provision could be quite short. The Portage service supported children prior to integrated nursery placements and there were close links between Portage home visitors and nursery staff.

Description of the provision made

Since the provision was not autism-specific, but general for special educational needs, the style of provision varied across the three nurseries.

One had a more structured approach, whereas another was less directive. Each of the children had an individual education plan and the following package of provision was offered:

- attention groups and language groups
- key worker and small group system
- clear structure to the sessions with time line in symbols
- Makaton symbols used
- PECS.

Staff were offered training and had been on a variety of courses including those run by the National Portage Association, workshops on Intensive Interaction and TEACCH. There was a continuous programme of training in ASDs for LSAs. There were named specialists in ASD within the educational psychology, the speech and language therapy and the psychiatry services.

Measuring and monitoring progress

At the time of the NFER visit, a research project was being undertaken within the LEA by a specialist speech and language therapist to evaluate the effectiveness of an intervention designed to promote communication.

Staff in the nurseries were free to write individual education plans as they wished. From a brief examination of the children's files, it appears that there were broad aims and some specific targets, but less recorded on how these might be achieved in terms of strategies used, how often and by whom. There appeared to be no common format across the three nurseries for recording daily and weekly progress and assessing when new targets might be set.

Communication with parents

There appeared to be good daily face-to-face communication with parents, and parents reported that they felt well-supported by the nurseries. However, there was less in the way of more formal written reports, although photographs were used to show parents what activities their child was participating in. Staff had explained to parents what aspects of their child's development they were working on, and had shared with them ways of supporting the child at home, such as the use of PECS and Makaton symbols.

Parental views

Parents were very positive about the nurseries. They felt that they had had a choice about which nursery their child should attend and that the staff in the nurseries were supportive and were offering their child appropriate provision to meet his or her needs. The parents appreciated being able to attend free training courses on interventions for autism. They also felt supported in making the decision about future placement for their child, once he or she reached school age.

Emerging themes and issues

- ◆ Does anyone have an overview of the range of provision made in the LEA and are steps being taken to monitor the quality and appropriateness of this?
- ◆ Do parents receive a coherent message from the range of professionals with whom they come into contact?
- ◆ Parents are concerned about the length of the school holidays and the effect this has on their children's progress.
- ◆ Have all staff had appropriate training in the approaches they are using?
- ◆ Are consistent criteria used for allocating provision and deciding on future placement?
- ◆ Should common monitoring and tracking documents be used for all children with ASD to ensure that there is consistency of decision-making?
- ◆ How can parents be given support as soon as their child receives a diagnosis of ASD?

Portage language project

Background

This was a relatively new project, only five months old at the time of the NFER fieldwork; it had been running for a term on a trial basis. It started as a response to an increase in the number of children identified with ASD and the fact that many of those were not being referred as early to the Portage service as children with other forms of developmental delay. By the age of 2.5–3 years, when a diagnosis of ASD might have been made, there is usually some other provision in place for this group of children.

The provision was jointly funded by social services, education and health and managed by the LEA's pre-school advisory teacher, who was also the Portage supervisor for the area. However, the funding did not cover the usual amount of Portage provision per pupil: the Portage worker was seeing seven children with an ASD in the amount of time normally allocated to two. However, all the children concerned were in receipt of other provision.

Criteria for access to the provision

The provision was designed for those children with social/communication difficulties, usually, though not exclusively, ASD. Children were principally referred by the child development centre or by the community paediatrician. Generally speaking, the children who received the Portage language provision would not be eligible for Portage on a regular basis because of the additional pre-school provision which they were already receiving. The cut-off for regular Portage provision was when a child had five other sessions out of the home per week.

Description of the provision made

The children received a two-weekly or three-weekly visit, frequently to the pre-school provision. The Portage worker supported and worked with the support worker in the pre-school attached to the pupil for two to five sessions per week. The full Portage checklist was not used, but the focus was on language and social development. The Portage worker had, for example, introduced PECS for one child. This had been started at the pre-school provision but had been transferred to the home and, for the duration of the setting-up period, weekly visits were being made. This child had three days out of the home in other provision. There were anomalies around the amount of support to which pupils were entitled in pre-school. For example, in a mainstream nursery one of the pupils was being supported along with three others by the same person, whereas those attending private nursery or playgroup were allocated an individual support worker for their time at the nursery or group.

Measuring and monitoring progress

The overall aim for the pupils was that they should be able to access mainstream education with a certain amount of support. In the case of one pupil who had classic autism, with no communication, even in the short time since PECS had been introduced, progress had been made towards using sentence strips and to speaking in phrases.

The Portage checklists were not used to measure progress as in more conventional delivery, but there was a weekly report on a child's progress and the stage of PECS they were working on. There were also six-monthly reports. The support workers in the pre-school provision used the children's individual education plans.

Parental views

Parents clearly had a good awareness of the programme as the Portage worker visited the home, although, in most cases, the programme was principally pre-school based, as distinct from home-based.

Parental views varied as to the success of the provision: success was not judged on the Portage input, but on the pre-school provision within which the Portage worker was providing support. In one case, parents described a transformation of their child from one who sat in his own room and would not join the family to one with improved speech, communication and sociability. In another case, while the Portage intervention and use of PECS, and its introduction at playgroup, was viewed positively and as successful, there was some concern that the child was not really being included within the provision. The view was also expressed that, while the LSA was clearly fond of the child, she did not expect the pupil to do a great deal, and that more training for LSAs was needed. In this case, a playgroup with more grounding in special educational needs provision would have been preferred. In the third case, again it was the mainstream provision rather than the Portage intervention which was perceived by the parent to be less than

satisfactory. It was suggested that the child was not being challenged and a more structured approach was needed. The Portage intervention was valued, although initially it was felt that the child found PECS frustrating. Subsequently, he started using PECS purposefully and was independently using sentence strips. Even so, part-time placement in the local special school would have been favoured by the parent.

Professional views

The professional view was that the combination of provision which pupils were receiving was valuable and appropriate to meet the present needs of the children. The LEA promoted the inclusion of children with special educational needs and aimed to offer placement, wherever possible, and as appropriate within the child's local mainstream school. The Portage language project was designed to support children in their mainstream pre-school setting. The role of the Portage worker was to support and develop the expertise of the children's one-to-one workers in the pre-school provision, and liaise between the parents, the pre-school groups and the speech therapists. In the case of the pupil in the mainstream nursery with a shared support worker, it was suggested that if he had not had this provision, he would have been put forward for formal assessment at the age of 2.5. Prior to the appointment of the Portage worker to this project, it had been quite difficult to communicate between the nursery, the child development centre and the parents.

However, while it was felt that this provision was working well, it was also suggested that a specifically tailored programme such as *EarlyBird* might be better for some families, and more input (visits) from the present programme would also be an improvement. However, as things were, with the pupils receiving a variety of provision, there was a need for someone to coordinate provision and take things forward for these pupils: the Portage worker was able to do this and to concentrate on the children's communication difficulties. Overall, the provision was perceived to be working well and to have benefits over specialist provision for children with an ASD, which would provide no 'normal' role models.

Emerging themes and issues

- ◆ The project demonstrated a flexible use of trained Portage workers to deliver a specialist package in a non-specialist setting.
- ◆ Portage workers were able to offer advice and opportunities for development to other staff with less experience and training in supporting children with ASD.
- ◆ Some parents who were very pleased with the progress of their child, nevertheless had reservations about the other provision being made by less well-trained staff.
- ◆ The Portage worker provided some coherence for children and families who were receiving a range of different interventions.

Child Development Centre nursery

Background

The Child Development Centre was part of the local healthcare NHS provision, the funding for the nursery provided jointly by health and education. Children attended on a part-time basis – one day per week, sometimes with an additional afternoon, depending on the groups being held. The children also attended other provision, for example, a pre-school in one case and a private nursery in another, where they had one-to-one assistance funded by the LEA. The pupils had to travel substantial distances to attend the child development centre.

Criteria for access to the provision

Pupils were generally referred for a multi-disciplinary assessment at the centre. For this they attended for one morning per week over a four-week period. For one pupil, however, a fast-track route had been provided and the pupil had been admitted without the assessment procedure. In all cases, the referrals were medical and all three case-study children had additional medical problems.

Description of the provision made

The children had individual education plans, reviewed on a termly basis; none of the children had a statement of special educational needs at the time of the research visit, although one was in progress. The approach used at the centre was described as 'eclectic'. Both the teacher in charge and the speech therapist had undertaken PECS and TEACCH training. The speech therapist worked on communication in general, rather than on speech specifically, depending on the needs of the pupils. Other professionals to whom the children had access, such as Portage workers, were also based at the centre. Areas being worked on with children varied from feeding and toileting to sorting and counting. Respite care was provided for some pupils and a 'skeleton service' operated at the centre during the summer holidays.

Measuring and monitoring progress

The nursery nurses in the centre recorded daily observations of the pupils. Interventions were a response to these, in addition to consultation with other professionals and parents. Individual education plans were reviewed termly at a multi-disciplinary meeting of paediatricians, speech therapists, Portage workers and nursery teachers. Consultation concerning statements took place at these meetings. A review was also undertaken every nine months with a clinical psychologist. There was frequent consultation with a variety of other professionals, such as educational psychologists and Portage workers, who were regularly in the same building; and termly reports were received from the other provisions attended by the children. Some observations were also made of the pupils in their mainstream provision and the pre-school leaders were invited to attend review meetings. At the time of the research, the child development centre staff were looking into video recording as a means of record keeping.

Parental views

Parents were very well-informed about their children and about work being undertaken with them. This was partly the result of specific strategies, and partly because they regularly spent time in the centre with their children. They had a week-by-week guide to the areas which were to be worked on at the centre. Parents were involved and informed from the time of the review following the initial assessment. They also attended TEACCH meetings and the speech therapist worked with them. There was a home-school book for each pupil, and the parents visited the school for an individual meeting about their child at least once a term.

Parents were pleased with the progress made by their children at the child development centre, particularly in the areas of communication and social skills and also in receptive language, which made reasoning with a child more possible. PECS was used at home, as well as in the child development centre. It was also felt that the children responded to the structured setting. However, they also stated that there was no other choice of provision offered to them and that there was little information available concerning other facilities. One mother, in particular, would have liked to have known about Portage provision. It was suggested that if the child development centre had improved funding and accommodation, it would be possible for the children to attend on a daily basis, which would have been welcomed.

Professional views

While professionals felt that the child development centre was meeting children's needs, there would be benefits in having a structured provision for five mornings per week. There were few mainstream places where the level of training and expertise was sufficient to make appropriate provision for these children. Where there were nurseries with particular expertise, there were geographic constraints. It was also felt that pupils could benefit from a nurture class in a mainstream school as a next stage of provision, rather than a separate specialist class for autism or one-to-one assistance which could be viewed as having a 'minder'. One of the great benefits of the child development centre was the ease of communication between professionals using the site and with parents who visited frequently. The outcomes expected for the three pupil case studies varied from placement in the special school local to the pupil's home to attendance at the local mainstream school.

Emerging themes and issues

- ◆ This provision was only a small part of that attended by the pupils, but it was viewed as important in particular in its structured approach, which it was felt could well benefit pupils if available for longer periods of time.
- ◆ Future placement – the issue of mainstream or special school was very much in evidence.
- ◆ The child development centre provided good opportunities for multi-disciplinary work, but was not well-linked to the other settings which the children were attending, so the coherence of approach was an issue.

Assessment class in mainstream school

Background

Pupils attended the assessment class for an average of four terms, although attendance had been as short as two terms and as long as seven terms. It provided for a range of difficulties, not only ASD. There was no comparable alternative provision within the area other than a language unit.

Criteria for access to the provision

Pupils who entered the provision had had an uneven educational profile and their long-term educational needs required further clarification. A decision about the appropriateness of a placement was made by the pre-school advisory teacher, the teacher in charge of the unit, the headteacher of the mainstream school and a number of other LEA personnel after consultation with parents. Most children had a statement of special educational needs.

Description of the provision made

No one particular educational method was employed in the unit. Each pupil had an individual education plan and needs were addressed in a wide variety of ways. The teacher in charge had undertaken PECS and TEACCH training and the LSA, who had trained as a teacher, had some autism training. A nursery nurse was also part of the team.

The pupils each spent some individual time with either the LSA or the teacher in charge, and worked with other children or in a group of four or five if possible. Where possible, the pupils were also integrated into mainstream school with support – perhaps for literacy and numeracy. This indicated how a pupil coped with a change of teacher and was useful in gathering information about the pupil. The pupils also integrated with key stage 1 pupils for physical education and joined with the mainstream schools for assemblies. The main aim was to enable the pupils to cope in a mainstream environment and, to this end, there was a substantial focus on literacy and numeracy. However, fine motor skills and social ability were also attended to extensively.

A speech therapist attended the unit for two mornings a week and two of the case-study pupils worked with her. The speech therapist had known two of the pupils in their pre-school provision. The teacher in charge and speech therapist planned the term's work jointly and also the programme for the mornings when both were present.

Measuring and monitoring progress

Individual education plans were reviewed every term and literacy and numeracy levels recorded in National Curriculum terms. One of the ASD pupils had achieved almost Level 1 in most areas, so it was hoped that he would be assessed at this level in the end of key stage assessment the following year. A comprehensive report was written on each child each term and a review meeting held on a termly basis. Parents were given copies of the records.

Parental views

The parents were very clear about the provision being made for their children. They had copies of the individual education plans and knew the targets. They were also pleased with the progress made in areas such as social understanding and academic skills, and in working in small groups. Improvement in behaviour and concentration were also noted by parents. The parents appreciated the flexibility for regular communication, so that they were able to visit, telephone and record in a home-school book as appropriate. The outcomes sought from the provision by parents were largely to enable the pupil to remain in some sort of mainstream education, but with as much support as possible.

There were some concerns about the pupils' next phase of education and, in some cases, the vulnerability of the pupils. In one case, a pupil was to transfer to the mainstream of the existing school. It was recognised that there was some existing experience within the school which would assist this process, but there was apprehension, nonetheless, about pupils' ability to cope and a preference expressed for a similar sort of unit provision at key stage 2 or a smaller mainstream school.

Professional views

Concern was expressed among the professional group about future provision for the ASD pupils in the unit. Many schools would find that these pupils would stand out, and it was felt that there was a need for some autism-specific mainstream provision at key stage 2. For the time being, it was felt that the present provision was appropriate, although improved staffing would enable greater inclusion with support, as well as more individual work. The staffing ratio was currently 2:10. Difficulties arose if a behavioural incident required the full attention of one member of staff. There were also difficulties associated with liaison with prior and future placements for the unit pupils as the teacher in charge had no non-contact time in which to make visits.

Emerging themes and issues

- ◆ A principal issue was that of future placement for these pupils. They currently were on a mainstream site, were supported when included in mainstream activities and had a secure environment to which they could return. The view was expressed that appropriate key stage 2 provision for these vulnerable pupils did not exist.
- ◆ There needed to be dedicated time for liaison for teachers working in assessment classes to enable adequate links to be made for transition.
- ◆ Staffing levels also needed to be considered, if there were problems of challenging behaviour.

Specialist provision in a school for pupils with severe learning difficulties

Background

The specialist provision was relatively new, having been established for just over two years. The three case-study pupils were to attend for three years only and the teacher in charge did additional outreach work in mainstream schools. The school had some residential places and pupils in the specialist provision could have termly, weekly or part-time, residential placement and respite care.

Criteria for access to the provision

The range of pupils attending the specialist provision was wide. Two of the case-study children had been attending the main school for pupils with severe learning difficulties prior to entering the unit, while one had been attending a mainstream primary school. In the case of these pupils, given the finite period of attendance, pupils were to be between 6 and 7 years of age on admission and having considerable difficulties in their existing educational setting. Headteachers had been made aware of the availability of the provision in order that referrals for placement could be made.

Description of the provision made

The staff-pupil ratio was 1:2, for both the care and the education provision. Every aspect of the pupil's functioning was observed during the first half-term of placement. Residential staff had undertaken training with educational staff to facilitate consistency across settings. There was also close liaison with parents and, in one case, a parent had attended a PECS course. The approach of the unit fell under the umbrella of 'total communication'. PECS had been in use for a year and structured teaching approaches taken from TEACCH were also used. Individual programmes were based on analysis of the child's profile in baseline assessment, and information gained from parents and from other professionals. The teacher in charge drew up 24-hour programmes, ranging from, for example, a behaviour programme for a self-injurious pupil with profound learning difficulties to a literacy and numeracy programme for a pupil with good language skills.

Measuring and monitoring progress

Monitoring was carried out via individual education plans: pupils' performance was recorded daily and detailed personal targets set. Daily conversations took place between residential and educational staff, a communication book was kept and individual programmes were scrutinised termly. The National Curriculum was followed and 'P' levels used where appropriate, although these only informed on the education side.

All three case-study pupils had made progress relative to their starting-point, ranging from the ability to tolerate being in a class setting to making progress with reading. In all cases, social and communication skills and

understanding had improved. Likely future placements for children included schools for pupils with learning difficulties.

Parental views

All parents had a named key worker and written copies of the individual education plans. They were very aware of the programmes their children were following. If used in school, PECS is also used at home; parents found this helpful. A home-school book recorded difficulties as well as successes. Parents were concerned that there had been some difficulty about the provision of speech therapy in the unit, although it had been available in the main school, but the problem had been resolved with the speech therapist working alongside teachers in the class. It was also felt that the highly structured day was beneficial to the pupils and assisted in improving behaviour, although pupils were not always as amenable to trying at home activities undertaken in class.

In some cases, parents would have liked additional interventions – mostly in the area of the sensory curriculum. The view was expressed that it was difficult to predict how a child might have progressed with other interventions, but that there would be a degree of caution about accepting an intervention such as Lovaas as it could be so disruptive to life at home.

Some concern was expressed by these parents about future placements for their children, given the time-limited current provision. However, acknowledgement was given to the work of the teacher in charge in spreading expertise, extending autism-awareness to teachers outside the unit. A particular issue for the three case-study children was that the provision was based outside their own LEA.

Professional views

Professionals considered that critical features of the provision were the consistency in approach between residential and educational elements of the provision, the home-school liaison, and the autism-specific training and experience of the staff. It was felt that it would be important for skills to be transferred to the main special school, and for staff there to be given an understanding of ASD in order to facilitate pupil transfer to the main school. The use of approaches widely used elsewhere was also seen as beneficial and TEACCH, for example, had been introduced on a county-wide basis for pupils with ASD in other settings.

Emerging themes and issues

- ◆ The range of pupils provided for was very wide. This appeared not to present any difficulty as the structure, level of specialist knowledge and adult-pupil ratio were important features.
- ◆ Future placement and the time-limited current provision were causes of concern for parents.
- ◆ The unit had become a centre of expertise and had provided staff development opportunities for those working in other settings.

Inclusion in mainstream primary school

Background

The four pupils in the provision varied in age from 6.11 to 9.5 years, and, because of its denominational status, would have attended this school as a matter of course. The children were, clearly, older than the majority of pupils in the NFER study, but it was significant that the pupils had been in the school since being of statutory school age. A fifth pupil had transferred from this school to a mainstream secondary school. Another ASD pupil, a sibling of one of the existing cohort, was shortly to join the school and the school, was to be designated and funded by the LEA as enhanced provision – like another primary school within the LEA. The LEA was also relatively new, having previously been part of a shire county.

Criteria for access to the provision

Access had not been an issue thus far as the pupils all qualified on the basis of religious denomination and geographic area. However, this was likely to change when the school acquired enhanced provision status.

Description of the provision made

Each of the pupils had a 0.8 LSA, covered at playtimes and lunchtimes. The pupil who transferred to secondary school was also covered for an additional ten minutes to allow for 'handing over' at the beginning of the school day. However, one of the pupils had only been in receipt of 0.5 support in reception. The school was extremely positive about including these pupils and had been proactive in resourcing their needs. A laptop computer, purchased from the school budget, was used by an ASD pupil during the school day and by a teacher thereafter. The school had also received support from other agencies, including twice-termly visits from an educational psychologist.

Interventions were various and included social skills training, encouraging communication with other pupils and developing literacy and numeracy. Attention was also paid to individual difficulties such as poor fine motor skills.

The special educational needs coordinators and LSAs in the school had undertaken TEACCH training. There was contact with other agencies and other elements of education provision, some of which, like the advisory teacher for pupils with physical disabilities worked within the school; a physiotherapist visited and provided a programme of exercises.

Measuring and monitoring progress

Individual education plans were monitored half-termly and a checklist, used with all special educational needs pupils, had been developed. Class teachers formulated weekly plans and LSAs recorded pupil progress with them. Parents had regular contact with the LSAs at the end of the school day, had a home-school diary and received written reports.

Parental views

Parents felt well-informed about work being undertaken and pupil progress and were also actively involved in practice. There was a general feeling that very positive progress had been made with behaviour, communication, the academic curriculum and ability to cope with change. Pupils had become part of a group in this mainstream environment and were happy. However, some concern was expressed about difficulties in obtaining resources and specialist help with areas such as keyboard skills for pupils with fine motor difficulties.

Professional views

At a general level, the professional view was expressed that children had the opportunity to be prepared for life and to be supported in learning to cope in a mainstream school and that, to this end, they were well placed in mainstream school. At a specific and special level, however, concern was expressed at the difficulties associated with the provision of specialist and health-related services in mainstream school.

Emerging themes and issues

The quality and extent of support available to pupils affected the ability of mainstream schools to provide for them effectively:

- ◆ Speech therapy and physiotherapy may have been more difficult to obtain on a regular basis in mainstream school.
- ◆ Future educational placement was as much a concern to pupils as to parents.

Home-based Lovaas provision***Background***

A home-based Lovaas provision was made in a number of the LEAs studied, often as a result of an appeal to the special educational needs tribunal by parents. LEAs had different ways of approaching the funding and management of the provision but, on the whole, left the responsibility for funding Lovaas tutors and supervisors to parents and did not play any great role in monitoring or evaluating the progress of the children involved.

Criteria for access to the provision

There were no clearly defined criteria for access to the provision, since the decision to use these programmes was made by parents, and LEAs would not normally offer such provision unless they were convinced that parents might appeal to a tribunal if the provision were not made, and that the parents would be likely to win such an appeal. In one case study, however, the provision took place at the end of the school day and was being funded by the parents.

Description of the provision made

Lovaas is an intensive programme which is administered by a number of tutors who come to the home and work with the child. The programme is

offered to children upon diagnosis, and could start as early as 18 months of age. Although it is a home-based programme, designed for younger children, some of the children we studied were continuing with Lovaas after the age of five and, in some cases, combining it with part-time attendance at school.

The tutor works with the child on a series of discrete trials which aim to teach specific skills, such as colour matching. The programme is tailored exactly to the needs and skills of the child so that children are not asked to do what is beyond them, but, at the same time, a progression is built in so that the next steps in learning can be planned. It is an intensive programme with daily sessions of up to six hours.

The work of the tutor is monitored by a supervisor who visits regularly (usually every four weeks) to watch sessions and to advise on next steps. A more senior consultant also visits to advise both supervisors (who may be responsible for the programmes of a number of children) and tutors. Training for both supervisors and tutors is an important aspect of the approach.

Measuring and monitoring progress

In the Lovaas approach, children's progress was measured and monitored in minute detail in order for planning sessions to take place; their reactions to the various activities offered were noted and their preferred learning style analysed to enable the programmes to be built around their needs. The tutors and supervisors kept records but they were not routinely shared with LEA professionals, since there was often very little interchange between the Lovaas therapists and LEA-based staff (apart from when schools become involved in part-time placement, in which case professionals from a pupil's school might visit the home in order to see the therapy in practice). In some of the LEAs, the Lovaas supervisor was asked to give a termly report on the child's progress, and there had been some attempts by LEAs to evaluate the outcomes of the Lovaas programmes for the children they were funding.

Parental views

Parents, not surprisingly, were very positive about the impact that Lovaas provision had had on their child, since it had been a positive choice by parents to use the provision. However, they felt, in most cases, that the choice had been forced upon them because the LEA had not been able to provide what their child needed to make progress. Lovaas was often a provision of last resort, when parents had felt that their child's needs were not being met adequately by what the LEA was offering them. The children had often been quite difficult to manage before the start of the Lovaas programme and, because parents were closely involved with the programme in the home, they could see the progress being made and also use the same approaches themselves to help to manage their child's behaviour and communication. Occasionally, when some progress had been made with Lovaas, parents decided that a combination of school and home-based provision would have advantages.

Professional views

Some professionals were more positive than others about the Lovaas approach. They could see the positive impacts it had had on children and their parents. However, there were some reservations about the cost of the provision (because of its intensive nature) and the underlying pedagogy. Some professionals were also concerned that as the provision was home-based, the children rarely came into contact with their peers. This was overcome, in some cases, by part-time placement in school and by school friends coming into the home to work with the children with ASD.

Emerging themes and issues

- ◆ Lovaas was often a 'last resort' for parents who felt that adequate provision was not being made for their child. This might not be necessary if appropriate provision and support were available at an early stage.
- ◆ The intensity of the programme and the fact that it carried on during school holidays was another feature parents liked. It would be useful if LEAs could ensure some provision for children with similar problems during holiday periods.
- ◆ Lovaas tutors kept detailed records of their interventions. LEAs could make good use of these when planning the next stage of provision for a child.
- ◆ Closer involvement by LEA autism service staff with Lovaas tutors and supervisors would have been advisable to ensure that provision was meeting needs.

5.5 Conclusions

Range of provision

As has been seen above, the range and amount of provision available for younger children with autistic spectrum disorders was varied and variable. Some of the arrangements were unsystematic and reactive. It is also clear that placement in a particular provision was related more to local circumstances and availability than to an exact match between children's needs and what was on offer. However, *placement* was less of an issue than *expertise*: children with similar levels of difficulty can thrive and make progress in a range of different provision, both integrated and segregated. One of the key issues for parents was the level of training and experience in autism of the people working with their children; if they felt confident about this, they would be satisfied with the placement.

Intensity of provision

A key issue for parents was the level of provision available. Parents who could see that their children were making progress in their provision were anxious to maximise the gains by ensuring that their children had access to a *sufficient level of intervention*. One of the principal reasons that parents sought Lovaas home-based programmes was their intensity – the fact that 40 hours was recommended, which would be far in excess of what was normally available. Not all parents would want that level of provision, but wanted more than the three or four hours per week that they were currently being offered. Some LEAs were offering a *package of provision* which included home-based, one-to-one programmes and some time in a nursery or playgroup setting with support. The crucial issue here was the welding of the discrete elements into a coherent programme and a key worker to facilitate this.

Tracking progress

In all the provisions studied, children's individual progress was monitored to decide on the next steps of their programme. However, the resultant data were not usually used to evaluate the effectiveness of particular programmes or provision – a crucial exercise to inform strategic planning. As has been demonstrated by the case studies, a range of approaches and interventions is being adopted by providers, and children typically have a number of different strands to their programmes and may also be receiving dietary or pharmacological interventions. However, the research has raised questions about the relative effectiveness of intensive home-based programmes, such as Lovaas, and less intensive and more varied programmes available in nursery schools, Portage programmes or specialist classes.

A tracking document, such as the one devised by the project team (see Appendix 2), would be a useful tool in enabling some longer-term analysis of the outcomes of early interventions.

6. CONCLUSIONS AND RECOMMENDATIONS

6.1 Prevalence

The prevalence of autistic spectrum disorders is currently unclear. Local education and health authorities do not keep adequate records for tracking prevalence and do not always communicate effectively with each other about this issue. Anecdotally, numbers of cases identified are increasing, although whether this is on account of better identification procedures or whether there is a real underlying increase in incidence is unclear. The issue is complicated by the fluid nature of the diagnostic process, and the differences in diagnostic practice and expertise.

Recommendation

Compatible databases to record cases of autistic spectrum disorders should be set up for education and health authorities at a local and national level in order to get reliable estimates of prevalence. This would help local education authorities and health authorities to plan more effectively for this group of children.

6.2 Identification, assessment and diagnosis

There is often confusion around identification, assessment and diagnosis. Not all professionals were using the same terminology to describe autistic spectrum disorders, and some appeared to be reluctant to use the term 'autism' or 'ASD', preferring some looser terminology. This may be understandable, in some cases, but a clear diagnosis can be helpful for parents in accessing support and information. In some cases, there is a lack of agreed protocols between education and health professionals about how parents should be informed of a diagnosis and who should be advising them about possible provision.

Recommendation

There should be protocols common to health and education professionals for diagnosis and subsequent discussions with parents about the range of options available.

6.3 Autism and learning

In most settings for younger children with autistic spectrum disorders, a range of teaching approaches is used, depending on the needs of the child. Each of the main approaches appears to have some positive effects for some areas of the triad of impairments. None of the approaches is likely to be effective for all children with autistic spectrum disorders.

Recommendation

Providers should continue to offer a range of approaches as appropriate to the needs of each child. Continuous monitoring and adaptation of the interventions should be carried out to ensure that the most effective combination of approaches is offered to maximise every child's potential.

6.4 Inclusion and mainstreaming

On the whole, the setting for the provision is less important than the level of expertise and understanding of autism of all those concerned with the child. When there is expertise and understanding, children make good progress in a variety of settings. Where there is less sensitivity to autism, children can be adversely affected and may not make good progress academically or socially.

Recommendation

All staff who are likely to come into contact with children with autistic spectrum disorders need to be adequately trained and updated. A whole-school approach needs to be adopted, and should include peers as well as staff.

6.5 Relationships between education authorities, health authorities and social services departments and the voluntary independent sector

Not all areas of the country have a coordinated approach to identification and provision between the three services, resulting in an unsatisfactory experience for parents and children. Where there is good communication between providers in the three services, parents report much greater satisfaction with both provision and support.

Recommendation

All areas, which have not already done so, should consider establishing a working party that includes representatives from education, health, social services and the voluntary sector, to develop services for children with autistic spectrum disorders and their parents.

6.6 Availability of provision

A key issue for parents was the availability of appropriate provision for their child as soon as a diagnosis of autism had been made. In most cases, there was a gap between diagnosis and the offer of support. New schemes, such as the National Autistic Society's *EarlyBird* scheme, appear to be offering the support and practical help which parents need at this stage. For some parents, a later diagnosis leads to problems with finding appropriate provision and support. Some types of provision can only be accessed if a child has a statement of special educational needs and this sometimes causes delay at a crucial stage of the child's development.

Recommendation

Local education authorities should aim to offer a range of provision to meet local needs in as flexible a way as possible. This will include a combination of home-based, integrated and specialist settings. For younger children, in order to avoid delay, provision should be available on an assessment basis, if a statement is being prepared. Family support offered by education or social services should ideally be available as and when parents need it.

6.7 Staff training and expertise

Staff expertise was found to be a crucial factor in the ability of LEAs and other providers to make satisfactory provision for this group. Many of those involved in making provision had become interested and motivated to develop their expertise as a result of working with children with ASD and had made their own arrangements to take further training. In some LEAs there was a well-developed programme of training for teachers and classroom assistants, but in others parents were concerned that untrained staff were working with their children.

Recommendation

As children with autistic spectrum disorders have a unique set of difficulties which need specialised approaches in order for them to make progress, local education and health authorities should offer awareness training to all those with responsibility for children with autistic spectrum disorders. Staff working closely with children with autistic spectrum disorders should be encouraged to undertake specialist training and to update their skills regularly.

6.8 Parental issues

A theme which ran through the NFER research was the difficulty that some parents have in getting their child's needs recognised and obtaining access to adequate provision. This relates to identification by health professionals and to liaison between health and education professionals. Where there is a seamless service, with good communication, parents feel well-supported. Furthermore, if family support for parents and siblings is available, parents feel better able to cope with the pressures of caring for a child with ASD.

Recommendation

A key worker with knowledge and expertise in autistic spectrum disorders should be assigned to each family to give advice and information, and enable them to access the right programme of support for themselves and their child. The key worker should facilitate communication between the various professionals involved and the family.

6.9 Assessing effectiveness and monitoring progress

In most settings, children's progress was monitored on a regular basis for deciding on the next steps for their learning, but these individual monitoring procedures did not contribute to any more strategic evaluation of the overall effectiveness of provision regarding longer-term outcomes for children. Thus authorities were not in a position to judge the value-for-money or cost-effectiveness of the provision.

Recommendation

LEAs should establish procedures for monitoring children's progress in their various provisions and their response to the interventions offered (see Appendix 2 for an example of a tracking document). Data should be collected over time and analysed to evaluate the effectiveness of provision.

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APPENDICES

Appendix 1: The Skills Checklist

Skills and Behaviour Checklist (Boy)

Glenys Jones, School of Education, University of Birmingham

Name of the child: _____

Gender: _____

Date of birth: _____

Date on which the form was completed: _____

Completed by: _____ Relationship to the child: _____

*Please tick the items or parts of the item which he can do.
You can add further comments if you wish.*

A	<i>Dressing and undressing skills</i>
1	Can take off his shoes
2	Can take off his socks
3	Can take off his coat when undone
4	Can undo easy buttons/zips
5	Can undress himself entirely
6	Can put on his pants/vest/T shirt
7	Can put on his socks/shoes
8	Can put on his coat/do up buttons/zip
9	Recognises his own clothes
10	Dresses appropriately according to the weather
B	<i>Eating skills</i>
1	Eats liquid only / mushy only / solid food and chews it
2	Only uses his fingers to eat
3	Uses a spoon effectively
4	Uses a fork
5	Uses a knife to push his food on fork/ to cut his food
6	Eats a wide/medium/limited/very limited range of foods: <i>(please comment)</i>

C	<i>Toileting skills</i>
1	Wears nappies during the day/ night
2	Uses the potty/ toilet when taken
3	Indicates when needs the potty/ toilet
4	Goes to the toilet himself
5	Tasks with which he still needs help in toileting are:
D	<i>Washing skills</i>
1	Can wash/dry his hands without help
2	Recognises the need to wash his hands
E	<i>Drawing and writing skills</i>
1	Can draw a circle
2	Can draw a person with head/body/arms/legs/clothes
3	Can write over/copy his name
4	Can write his own name from memory
5	Can write other words from memory without help
F	<i>Activities involving another person</i>
1	Enjoys being chased
2	Plays with bubbles/balloons with another person
3	Enjoys rough-and-tumble
4	Plays throw and catch
5	Activities he enjoys in free choice time are:
6	Activities he enjoys with an adult are:
7	Activities he enjoys with another child are:

G	<i>Reading skills</i>
1	Knows which way to hold a book
2	Can select a book of his choice
3	Can point out words when asked
4	Can point to pictures when asked
5	Has a favourite story which is:
6	Can point out letters when asked
7	Can read his own name
8	Can say the letter sounds
9	Can read the words of a story
H	<i>Number skills</i>
1	Can say out loud the numbers from 1 to 10 in order
2	Can count objects to 2/ 5/ 10/ 20
3	Can name number symbols from 1–5/ 5–10/ 11 onwards
4	Can match the number symbol to the number of objects up to 5/ 10/ 15/ 20+
I	<i>Computer work</i>
1	Can switch it on/ use the mouse/ type numbers/ words
2	Enjoys playing the following types of games on the computer:
J	<i>Areas of resistance</i>
1	He insists on the same route/particular item (e.g. cup; chair)/conditions (e.g. lights on)/familiar routines being adhered to: NO/YES (<i>please specify</i>):

K	<i>Behaviours which may disturb others</i>
1	E.g. bites/ kicks/ spits/ swears/ hits/ screams/ pulls hair/destroys things/other NO/YES (<i>please specify</i>):
2	Spinning: spins himself or objects/watches spinning objects
3	Flapping: flaps his hands or objects
4	Rocks his body
5	Other (<i>please specify</i>):
6	Behaviour at school as compared to home is less difficult/similar/more difficult:
7	His general level of activity is very active/ reasonably active/ passive
L	<i>Sensitivity</i>
1	He seems sensitive to some sounds/ sights/ touch/ smell/ taste NO/YES (<i>please specify</i>):
M	<i>Sociability</i>
1	Withdrawn
2	Socially interested
3	Actively avoids others
4	Seems formal or rather indifferent to others

N	<i>Speech and language</i>
1	Makes sounds only, where it is difficult to understand the meaning
2	Makes meaningful sounds
3	Makes word-like sounds
4	Says single words which are echolalic/communicative
5	Speaks in two-word phrases which are communicative (e.g. Ben drink)
6	Can speak in phrases which he has copied/ which are his own
7	Can speak in sentences which he has copied/ which are his own
8	Give 3 examples of the instructions he can understand when you only use words, including the most difficult instruction he can understand (e.g. get your coat; give mummy a sweet)
O	<i>What is <u>your</u> biggest problem in teaching/living with him:</i>
P	<i>What would she say <u>his</u> biggest problem was?:</i>
Q	<i>Areas in which he is most interested:</i>
R	<i>Areas in which he is most skilled are:</i>
S	<i>His most appealing features are:</i>

T	<i>Activities or items which can be used as incentives are:</i>
U	<i>Assessment of his overall ability:</i> Well below average/below average/average/above average for his age
V	<i>Any other comments you would like to make:</i>

Appendix 2: Tracking document

ASD transfer form

Pro forma for tracking the educational provision made for pupils with an ASD

The purpose of this form is to collect information on pupils with an ASD when they transfer out of a school or unit into a different school/unit. This information will be collated by the LEA to use for planning provision for this group of pupils.

This should be completed by staff in the school/unit which the pupil is leaving during the half-term before the child leaves. A copy should then be sent to a named person within the LEA

Name of person completing the form:

Position within the school: _____ **Tel:** _____

Date of completion: _____

1 Name of child: _____

2 Date of birth of child: _____

3 Main diagnosis: _____

4 Any additional diagnoses: (e.g. epilepsy; dyslexia; ADHD; dyspraxia)

5 Name of current school: _____

6 Type of school/unit: *(please circle)*

a Mainstream / MLD / SLD / EBD / specific to autism/

other (please specify) _____

b LEA / independent / other LEA

c Day / residential placement, weekly, termly, 50 weeks a year

7 Date of admission to the school: _____ **Age in years:** _____

- 8 Does the child have a Statement? YES / NO

If YES, which year was this first issued: _____

- 9 Approximate cost of the placement at the school/unit for the pupil during the last financial year (excluding any transport costs):

£ _____ per year Don't know

- 10 Did the child have an assistant allocated specifically to work with them?

YES / NO

If YES:

a For how many hours per week? _____

b To offer support in what type of situation? _____

- 11 Please state briefly why the child is leaving this school/unit:

- 12 Which school/unit is s/he moving on to?

a Name of school/unit: _____

b Type of school/unit: mainstream / MLD / SLD / EBD / specific to autism/ other (*please specify*):

c LEA / independent / other LEA

d Day / residential placement, weekly, termly, 50 weeks a year

- 13 Which factors determined the choice of the next placement and why is it thought suitable for the child?

14 Skills and abilities of the child on leaving your school/unit

Tick all those which apply or write your own description:

Dimension	Skill level	Comments
Expressive language skills	Mainly uses photos / pictures / symbols	
	Mainly uses signs	
	Mainly uses speech	
	Single spoken words / short phrases / full sentences	
Social skills	Prefers to be alone	
	Wants friends	
	Is able to work or play with another child / with children	
Behaviours	Less demanding than ordinary peers / more demanding than ordinary peers / very demanding	
Academic skills	Reading accuracy at his/her age level / below age level / well below age level / not able to read	
	Reading comprehension at his/her age level / below age level / well below age level / not able to read	
	Can write at his/her age level / below age level / well below age level / not able to write	
Overall intellectual ability	Above average / below average / well below average	
Severity of autism as measured on CARS or GARS	Mild / moderate / severe	

Appendix 3: Members of the advisory group

Phase 1

Dr Judith Gould
Director for Social and Communication Disorders
Elliot House

Ms Lorna Selfe
Principal Educational Psychologist
Herefordshire County Council

Ms Caroline Simmonds
Education Officer (Autism)
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