Local Government Association

local authorities' provision for children with autistic spectrum disorders:

some case studies

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INTRODUCTION

This set of case studies of a sample of LEAs' provision for young children with autistic spectrum disorders (ASD) represents work which relates to, and augments, the NFER/LGA broader study of provision for this group of pupils (Evans *et al.*, 2001). The previous study discussed provision for children up to the end of key stage 1 in general terms and presented the national picture, before focusing on individual examples of specific provision in a range of sites.

This present publication fills in the whole authority picture and shows how a sample of authorities are planning to meet the very varied needs of pupils across the authority. An account of this range is important as one of the characteristics of effective provision for this (presently burgeoning) group of young people is diversity – a diversity which has to be met by a range of approaches. There is now sufficient evidence, not least from the increasing number of autobiographies of people with autism, that eclecticism, rather than following a particular line, is what marks effective practice with regard to provision for pupils with ASD. Because this cohort represents a wide range of individual profiles in terms of the severity of their autism, cognitive ability and additional special educational needs and, furthermore, within their autistic profile in terms, for example, of elements such as sensory fragmentation, communication preferences and language needs, the challenge to providers is to offer as great a degree of flexibility as possible so that appropriate responses can be made in a range of settings. As the number of young children diagnosed as having ASD is, for whatever reason, increasing rapidly (as will be evidenced in the following case studies), most authorities across England and Wales are having to review and expand their provision.

The case studies that follow are, it will be seen, identified. It is not normal research practice to do this as, generally, confidentiality is assured and, very often, data are presented thematically in order to preserve anonymity. However, in some cases, anonymous presentation is not always the most helpful approach in moving forward practice. The Local Government Association is keen on sharing practice amongst its members and, thus, being able to name authorities is important in terms of networking and the exchange of information. All the authorities presented in these case studies were involved in the previous NFER/LGA study on ASD; they have approved their respective sections and have expressed a willingness to be identified.

The data set of LEA provision remaining from the previous project was scrutinised and gaps identified. These were then filled in by telephone interviews (autumn 2001) with key personnel in each authority and, at the same time, the position in the authority was updated.

These case studies are not 'stand alone' and readers are advised to go to the full report for explanations of technical terms – in particular, the approaches used. Evans *et al.*, (2000) give information about all the main approaches to teaching pupils with ASD – for example, TEACCH, ABA – and the information is not reproduced here, although a very brief glossary is given as an *aide memoire.*

The provision is not evaluated according to the good practice criteria emerging from the literature. However, it should be pointed out at this stage that the structure of provision in each authority, and the intentions of each authority, accord with these criteria and the structure of the reporting – eg relations with parents, inter-disciplinary collaboration – reflect the issues which are important in relation to provision. This set of authorities was developing provision with sound foundations and is typical of the situation nationally insofar as it will be seen that, in all cases, it was, indeed, a developing situation. There were recognised gaps in provision and most of the authorities had plans for expansion and refinement of provision for the future. Because responses to the education of pupils with ASD are relatively recent as knowledge about the disorder has burgeoned over the past few years, many of the services are relatively young – as compared, for example, with services for pupils with hearing impairment.

In the vignettes that follow, readers will find examples of the following, each of which has been shown to be critical to provision for children with ASD:

- a range of referral paths and good communication between them
- the availability of an expert centre for diagnosis and agreement between experts where there is more than one centre for diagnosis
- a clear relationship between point of diagnosis and relevant services, with speedy follow-up with regard to intervention subsequent to diagnosis
- a range of parental support mechanisms
- positive relations between statutory and voluntary agencies
- the availability of both extensive training (eg higher degree for specialist teachers in units/special schools) and more general training (eg for all teachers and learning support assistants working with a child with ASD)
- a coherent support service offering consistent advice and support for teachers in a range of settings

These are only examples but act as a pointer to some of the interesting facets of the authorities' provision.

One of the things which is not presented here is the hard path to establishing provision: here, readers will have to contact relevant authorities with regard to learning more about developmental processes – a range of authority types, from newly created unitary authorities to 'reduced shires' is represented, each with its different organisational patterns. However, it is clear that in all cases, development was incremental and based on positive experiences of provision that was successful in one location. It is suggested that this is a sound model for development, particularly as the approaches were generally eclectic and flexible: there are, obviously, considerable dangers in developing provision which only acknowledges one approach to intervention (that only uses Applied Behavioural Analysis, for example) or which is tied to a particular environment.

Over the set of case studies as a whole there was a clear commitment to review and evaluation of pupil progress. This is extremely important as, presently, there is a dearth of data which inform about the effectiveness of the application of different approaches for different children with different profiles in different situations (see Jordan *et al.*, 1998). Thus it is particularly welcome to see that authorities are regarding provision for children with autism as an issue to address with neighbouring authorities or within Regional Special Educational Needs Partnerships. We hope that this publication will contribute to the professional dialogue which is already taking place.

References

EVANS, J., CASTLE, F., BARRACLOUGH, S. and JONES, G. (2001). *Making a Difference: Early Interventions for Children with Autistic Spectrum Disorders*. Slough: NFER.

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LONDON BOROUGH OF ENFIELD

Background

The London Borough of Enfield has a population of some 200,000 living in contrasting affluent and deprived areas, coupled with a large refugee population and in some areas, a mobile population. As residents of a London borough, families have access to a range of schools outside the borough. At the time of the research, Enfield itself had 65 primary, 17 secondary, six special school and two pupil referral units. There were good links with health providers.

In a recent audit, there were 162 children identified with serious communication difficulties (including autism) as their primary problem; 76 children were in the age range of two to seven.

Pre-school provision

The borough had a Pre-school Support Service (including a Sure Start programme) for children with special educational needs, of whom an increasing proportion had communication problems and/or autism as their major difficulty. The Service was staffed by 6.2 (fte) staff (teachers and nursery nurses) with administrative support. In additional to a range of support offered, Home Visiting Teachers in the Service visited families fortnightly on average during term time; younger children were seen once a month.

The role of the Service was to work with families and groups of families on programmes to support their children's development. Some of these programmes were structured Portage-type programmes; others were focused around play activities. Teachers were trained on EarlyBird and were planning to deliver the programme during 2001. Home Visiting Teachers also gave advice and support to parents on the kind of education that might meet their child's needs and explained about available resources and facilities. They worked closely with other professionals – speech and language therapists, physiotherapists, occupational therapists and those in Family Centres and nurseries.

Specialist special school

Enfield had a purpose-built school for pupils with autism, with an early years assessment department and a primary department. It also housed the Pre-school Support Service.

The school aimed to be a centre of excellence. It catered for the assessment and training of pre-school children with a range of special needs, some of whom were also autistic. It had 16 part-time places available in two groups for children aged three to four/five, each staffed by a teacher and two nursery nurses. There was also a Reception class which catered for a range of children with special educational needs (not all necessarily with autism). These children would move to other special schools or to mainstream provision for their schooling.

The criteria for admission were that the children had complex special educational needs identified by health professionals and had been assessed by an educational psychologist. In addition, younger children with severe communication disorders were admitted. After assessment, a small number remained in the early years department (six places), others moved to the primary department and yet others were placed elsewhere – in special schools or in mainstream schools with support.

The primary department took children from the age of five to 11, with a range of autistic spectrum disorders. There were 42 full-time places available. Pupils were grouped by key stage and by levels of learning difficulty.

TEACCH was the main approach used in the school. Each child had an individual curriculum linked to his/her Individual Education Plan (IEP). There were opportunities for integration into the local mainstream primary school based on the same site. It was usual for children to be accompanied by a member of the special school staff when they were first integrated. Once a child could manage in the mainstream school for three days a week, the special school support was substituted by LEA-provided support if necessary.

An outreach service to other schools was available. This post (0.6) provided advice and support for teachers in mainstream schools, INSET and other training, occasional observation of children and advice to parents when requested.

A number of children (between 10 and 12) with autism attended specialist special secondary schools outside the borough.

Places in special schools

A number of children (about 20) attended one of the borough's other special schools – for pupils with severe learning difficulties (SLD), moderate learning difficulties (MLD), emotional and behavioural difficulties (EBD) or medical conditions/physical disabilities. The biggest cluster was in the last of these schools.

Places in mainstream schools

Some 48 children were in mainstream schools (41). Of these, 33 had statements for complex communications difficulties and were getting designated support from the outreach service, educational psychologist or the school's SEN department. There were known to be other children (about 18) in mainstream schools who were not statemented but were allocated support.

Experience with Lovaas

The LEA lost a case at tribunal in 1997 and was now funding Lovaas programmes for some five children. Parents found their own therapists and supervisor and the LEA picked up the costs. A specialist educational psychologist was evaluating the programme and a report was being prepared. Initial conclusions were that Lovaas should be more effective as a preparation for the next stage rather than as an end in itself – i.e. total unsupported integration. Much depended on how much parents themselves could do and help.

Staff training

The borough had a central training programme which it offered to all early years providers and as INSET to school staff. More was offered in-borough than externally, although teachers were encouraged to do the professional development programmes offered by Birmingham University or Whitefields School if they so wished. Specialist courses on teaching approaches were available as were workshops run by the specialist special school.

Assessment and diagnosis

The Child Development Team (community paediatrician, specialist health visitor, clinical and educational psychologists and others) based at the local hospital met weekly to discuss referred cases. Decisions were made on which individual professionals should be called upon to assess and report on a child. The borough did not have a Child Development Centre.

Multi-agency working parties/groups

The LEA was represented on a multi-disciplinary Children's Services Planning Team which was looking at overall provision. This group included representatives from health, social services, and education. There were also other, more short-term working groups which met to consider specific issues such as diagnosis.

Enfield representatives had also been involved with five other London local authorities (Haringey, Barnet, Camden, Westminster and Islington) in a collaborative project to develop a protocol and framework for looking at decisions about Lovaas.

A new project, the Early Years Social Intervention (EYSI) Project involved a multi-disciplinary group working with a group of pre-school children and their families to aid entry to school. They were looking at how schools responded to children with an ASD and how autistic children learned and what their learning patterns were. The idea was to get professionals to think about or to re-think how they approached intervention, to help parents gain confidence and ultimately to fill the gap between diagnosis and school entry.

Other support services/parents' groups

There were two psychologists in the borough with a particular interest in, and responsibility for, autism: one was the senior educational psychologist responsible for pre-school children; the other – a clinical psychologist – ran a weekly support group for parents whose children had had a diagnosis of PDD or autism.

There were three Family Centres in the borough, run by Social Services, for children with special needs who were under school-age. In two of the centres, children with autistic-like behaviour although not necessarily diagnosed as on the autistic spectrum, were grouped together. The two groups were staffed by NNEB qualified nursery nurses with an interest and some expertise in autism. The groups were small – eight children with four staff – and each child had a key worker who worked on his/her IEP. There was a range of parent groups here for parents to join.

The children were offered four morning sessions per week. They normally started at two years old and could stay until they were four and a half years old unless they moved to the assessment class in the specialist special school (described above) or to another nursery provision. The children were continually assessed by staff and reviewed every two months. Some of the children at the Family Centres also had a pre-school support teacher who worked with the family.

The Children's Centre was a Social Services provision for children and families who had special needs due to a disability. Some children with an ASD and their families were involved with this service. It offered a range of services including: shared care (respite in families), home-sitting, home care, play schemes, after-school clubs, toddler group, and Saturday drop-in facility. The Centre offered help to families over a long term; it was not an emergency service. As a result, there was a long waiting list and not all who wanted respite care were able to have it.

Issues for parents

Issues raised by parents at the time of the visit included:

- the lack of sufficient specialist educational provision. Even though there was a specialist school in the borough, places were limited.
- some parents wanted more of a home-based programme rather than a pre-school placement.
- concern about the level of training and qualification of classroom assistants who were supporting children with autistic spectrum disorders in mainstream schools.
- the apparent lack of communication between professionals during assessment and the lack of feedback to parents on when key decisions were being made (such as discussion of their child at an SEN panel meeting).
- insufficient respite care when families were under stress.

Future plans and possible developments

The LEA had recently undertaken a Best Value Review and had an LEA OFSTED. The Best Value Review had confirmed the perception that there were increased levels of need in the community. It had encouraged Enfield to look at the pattern of its special school provision and to think about planning centres for children with complex needs. The autism-specific provision will remain and multi-disciplinary early interventions involving parents have been prioritised. The needs of older pupils with autism in the borough will also be addressed.

LONDON BOROUGH OF HACKNEY

Background

Hackney is one of the poorest inner city boroughs in the country, with one of the highest populations of children with special educational needs. It was a small LEA with five special schools, nine secondary schools and 54 primary schools. It serves a largely multi-ethnic, under-privileged population of just under 200,000.

The LEA created the post of Autism Development Officer after the opening of its first resource base in 1998. The officer was responsible for focusing on development provision and policy; setting up a structure for pre-statemented children; keeping an overview of children with ASD in mainstream schools; providing INSET in mainstream and special schools; and providing support, advice and liaison for and between agencies and providers.

The LEA was served by one health authority – the Hackney and City Health Trust.

Pre-school provision

The main provision available for pre-school children with SEN in Hackney was Portage. There were two Portage workers in the borough who, while not ASD specialists, had created close links with the Child Development Centre and had developed some expertise in ASD. A speech and language therapist was involved with the Portage workers when they worked at home with a child. Portage workers used an approach based on Options where the focus was on the child gaining shared attention. They had also used PECS with a number of children although not with huge success, as parents, through no fault of their own, were not always able to co-operate as much as was necessary.

Additional provision for children with ASD was also offered in playgroups or nurseries and in the local all-age school for pupils with severe learning difficulties. Nursery officers did support some children in mainstream nursery provision, occasionally also making home visits.

Specialist provision in special schools

There was no specialist provision for children with ASD in Hackney's special schools. For many years, the LEA had placed children in specialist schools outside the borough and 22 were still so placed at the time of the research.

Places in special schools

Over 50 children with ASD were provided for in the borough's special schools. The two MLD schools (one primary and one secondary) catered for some 25 children (some of whom came from neighbouring boroughs); the SLD school provided places for 18 children; and the two other special schools took at least 10 children with ASD.

There was a specialist teacher for ASD in the SLD school, but none in the other special schools. Speech and language therapy was available – five hours a week in the SLD school and between two and two and a half hours per week in the MLD schools. The Autism Development Officer visited when requested.

The special schools did not have a specific approach for pupils with autistic spectrum disorders. They used a structured approach, symbol systems, objects of reference or sequencing for all children in the school.

Specialist provision in mainstream schools

As more children were diagnosed, the borough needed local school provision. In line with its emphasis on inclusion, the LEA opened two ASD resource bases (in January 1998 and September 1999 respectively) in mainstream primary schools, each with 10 places, for pupils aged three to 11 years. These were rapidly filled. A third base of the same capacity was due to be opened in January 2002. This would start by taking younger children (nursery and Reception).

Each unit had two full-time teachers and either a nursery officer plus five or six LSAs. Specialist speech and language therapy time was available. One of the units included a soft playroom, a sensory room and a smaller room for 1:1 or small group work. The amount of time children spent integrated into the mainstream school differed from 100% with support to less than five per cent of the day. There was also some reverse daily integration when some children from the mainstream school joined their peers in the resource base for some numeracy and literacy work.

Staff in the two bases did not exclusively use one teaching approach: they took what they needed from a variety of approaches depending on the needs of individual children. The approaches used included: elements of TEACCH (such as timetabling or breaking down tasks), intensive interaction, musical interaction, Makaton, visual timetables and physical exercise and movement.

Places in mainstream schools

Hackney estimated that there were approximately 40 children with an ASD in its mainstream primary schools and up to 30 in all placements at secondary level. Primary school-aged children were supported by their schools' learning support assistants (LSAs) who, in turn, were supported by specialist teachers (an ASD specialist and/or teachers with experience of 'complex needs') from the LEA's Learning Support Service, responsible for supporting all children with a statement of special educational needs. The amount of individual support a child received depended upon need. Some were receiving full time support – ie 25 hours per week – while others were receiving considerably less. Specialist speech and language therapy time was available for these children: some received personal therapy from a specialist; others received it from community therapists who were supervised by specialists.

Most of the ten pupils with ASD who were integrated into mainstream secondary schools did not receive specialist support as a result of their autism: their school SEN departments dealt with their needs. A smaller number (five), all in one school, were receiving more specialist support coupled with weekly speech and language therapy.

Staff training

Most teaching staff in the resource bases were qualified special needs teachers and were completing the Whitefields autism course on-the-job. Training for LSAs was most often provided locally. A two-day INSET, run by the Autism Development Officer and the speech and language therapist, was available for LSAs before they started in the bases. External training was also available. Once a term, all base staff also came together for a joint INSET to share experiences and learn about the work of other groups and agencies. Once a year, there was a weekend residential conference for those involved in SEN work. Additional training in ASD was offered to SENCOs and headteachers at these weekends.

Assessment and diagnosis

The Child Development Unit, based in the borough's Child Development Centre, provided services to children with disabilities. A 'complex communications' diagnostic clinic was held weekly by a core team of speech and language therapist, clinical psychologist and paediatrician with involvement from many others (e.g. occupational therapist, physiotherapist, social worker, psychotherapist). The clinic offered assessment over a five-week period, with feedback to the family in the sixth week.

The Child and Family Consultation Service was based in a local hospital. Its role was to help with behaviour support for children with ASD over the age of five.

Multi-agency working parties/groups

After the first resource base was established, a working party made up of representatives from education, health, social services and the voluntary sector worked together to establish baseline assessment across the bases and to consider the use of Lovaas at the time. (Lovaas was no longer an issue at the time of the research). Since then, and as a result of an 'ASD Day' with parents, a new group was formed which included both professionals and parents. Its main focus was to develop a common policy for Hackney. The group met three times a term.

Another working party, including representatives from the education, health and Portage services, was compiling an Autism Awareness Pack that was to be available in all schools by December 2001.

There were other sub-groups in the LEA which met regularly – for example, the base teachers, educational psychologists, the Autism Development Officer and the clinical speech and language therapist. Their remit was to discuss individual cases, do some forward planning of the curriculum and prepare, where necessary, for OFSTED inspections.

There were good links between the Autism Development Officer and the Child Development Centre. There were regular monthly meetings of the diagnostic team which included the speech and language therapist, the paediatric consultant, social workers, the clinical psychologist and a play specialist.

Other support services/parents' groups

There was a parents' group that met twice a term on a Saturday. Professionals such as the clinical speech and language therapist and a social worker attended and looked after the children while parents shared experiences and raised concerns.

Issues for parents

Parents wondered about the precise differences between being at the mild end or on the border of the autistic spectrum. While they understood that their child might always have problems and would remain on the autistic spectrum, they were also able to observe that behaviours which had led to the initial diagnosis were changing as the child grew older.

Another issue for parents was the availability of respite care and holiday provision. Hackney ran a summer school for children with SEN; there was a different focus each year – eg Years 5 and 6 pupils, pre-school children.

Future plans and possible developments

The most critical issue for Hackney was sufficient provision. The existing units were full and had long waiting lists. The third resource base was due to open in January 2002 which, it was hoped, would begin to meet demand for places.

The special schools remained keen to develop their approaches for children with autistic spectrum disorders but continued to be limited by resources and accommodation.

HERTFORDSHIRE

Background

Hertfordshire is a large home county, with a population of just under one million. At the time of the research, it had 19 day special schools, eight residential special schools, 89 secondary and middle schools and 416 primary schools and was served by two health authorities North East Hertfordshire and West Hertfordshire Health Trusts. In 2001, Education and Social Services joined forces and the new, unified service of 'Children, Schools and Families' was formed with the aim of providing a more inclusive service that would be easier for families to understand and access.

Over recent years, there had been a rapid rise in the number of children identified with an ASD. In September 1998, there were 355 children with autism or Asperger Syndrome known to the Advisory Teacher Service. By 1999, the number identified had risen to around 500 and by 2001, that total was over 720.

Specialist Advisory Service

Hertfordshire had a Specialist Advisory Service (SAS) for low – incidence disabilities. The autism team consisted of a senior advisory teacher and three visiting specialist teachers. The role of the senior advisory teacher was to advise on the development of policy and provision for pupils with autistic spectrum disorders. This service helped to establish the specialist resource bases, provided advice, support and training to all school and base staff working with children with ASD and prepared guidelines for schools and support services. The role was primarily one of outreach. The visiting teachers also supported the pre-school home visitors and children with ASD in mainstream schools.

The county had a specialist educational psychologist (part-time) who worked closely with the SAS on developing specialist services.

Pre-school provision

Pre-school children with special educational needs attended a variety of provision: opportunity classes, playgroups, nursery schools or nursery classes. They were supported by the Pre-School Advisory Teacher Service and the Specialist Advisory Service (SAS). An intensive support programme for pre-school children with significant autism and their families was offered from the point of referral to the SAS.

Children under three years were visited weekly or fortnightly in their homes so that the specialist teacher could plan a teaching programme with parents and monitor progress. They could also receive up to 10 hours per week teaching in the home from a specialist (nursery nurse) home visitor and attend an opportunity class or other pre-school setting for five hours a week.

Children of nursery age (three/four) were also entitled to the weekly or fortnightly home visit from the specialist teacher, plus 12.5 hours per week attendance at a mainstream or special school nursery with appropriate support provided through their statement and up to 10 hours per week teaching at home by a specialist (nursery nurse) home visitor. A combination of interactive, cognitive and behavioural approaches were used.

Specialist provision in special schools

Specialist bases

Hertfordshire set up specialist provision for children with an autistic spectrum disorder in each of its four educational areas. This provision consisted of a resource base in a school for pupils with moderate learning difficulties (three primary, two secondary and one all age) or severe learning difficulties (three all-age schools).

Typically, each primary base was staffed by two teachers (one of whom was also the manager/specialist), a nursery nurse, an LSA and a mid-day assistant. Eight places were offered in each, allowing for a staff-pupil ratio of 1:2. The new secondary bases had four and eight places respectively and were staffed by a specialist autism teacher and LSA support. The secondary bases took children from the primary bases or from mainstream schools.

The primary bases in the MLD schools were designed to be bases first and foremost: the aim was eventually for full integration. While each resource base was designed on the same model, each took a slightly different approach to integration. Some children worked entirely within the base to start with and integration was introduced when appropriate. Integration could be functional – i.e. into small groups dealing with a curricular subject; or social – i.e. at playtime. Other children began by joining their age-appropriate class in the main part of the school, with base staff supporting in class or withdrawing children for parts of the day to work on particular areas of need.

Children were accompanied by base staff with whom they were familiar until it was agreed by all staff that pupils could remain in the integrated situation successfully. Sessions were planned with the class teacher involved and parents were kept informed.

Pupils attached to the secondary bases tended to use the base or resource room for one-to-one or small group work and when they needed stress-free time, but they were otherwise supported in their appropriate classes by the specialist teacher and LSAs.

As the LEA recognised that no one teaching approach was likely to meet the needs of all children with ASD, the autism bases used a synthesis of approaches, including: Applied Behaviour Analysis (ABA), Daily Life Therapy, Interactive Play (Options), Intensive Interaction, Musical Interaction, PECS, social skills training and TEACCH.

In all the schools, the base room was designed for flexible use. It allowed for both one-to-one and small group work. There was speech and language therapy available in all the resource bases, funded by the authority.

Places in mainstream schools

There were no specialist bases in mainstream schools for children with ASD. However, there were about 500 pupils on the autistic spectrum fully included in mainstream schools supported by their school's SEN department and the SAS visiting teachers. These visiting specialist teachers mainly advised mainstream school staff, offered help with teaching strategies and IEPs, ran whole-school and area-based workshops and INSET, observed children, talked to staff and parents and occasionally did some small group or individual work (such as social skills) with pupils. Where a child had complex problems, the visiting teacher might work alongside the teacher or the LSA on a more regular basis. If a child's statement recommended it, speech and language therapy, funded by the authority, was provided.

Experience with Lovaas

There were 17 children, aged three to ten, receiving Lovaas in Hertfordshire. Some families were fully funded by the authority; some received some funding and a small number made the financial contribution themselves. Both the visiting specialist teachers and the educational psychology service monitored the home programme and observed and monitored what happened in schools or nurseries. Discussions were held with therapists. The consensus was that the programme was not as effective as promised as none of the children was able to manage full unsupported integration in mainstream school. Some children were developing high level skills but were having difficulties with social understanding, relationships and communication. The view was that the Hertfordshire strategies for children with ASD seemed better than Lovass at enabling them to be socially interactive.

Staff training

Standards Fund money was used for training staff in autistic spectrum disorders. All autism base managers and teachers in the special schools were offered the Birmingham University distance learning course. For LSAs and teachers working in the autism bases and/or in the host schools, a specific module on autism, accredited by the University of Birmingham, was run in-county.

Awareness training was available either in schools or on county courses. Regular support groups, organised by the visiting specialist teachers, were run termly in each area of the county. There were groups for mainstream school staff working with children with autistic spectrum disorders and, separately, for staff working in pre-school settings and those in special schools.

Assessment and diagnosis

There were six multi-disciplinary clinics for communication disorders in Hertfordshire. These were set up by local paediatricians and supported by clinical psychologists, speech and language therapists, visiting teachers, specialist health visitors and social workers. Clinics were run monthly. When a visiting teacher was involved, an immediate follow up visit was made to discuss with parents what educational input was available.

Multi-agency working parties/groups

The LEA had policy co-ordination groups for special educational needs, one of which was specifically for autism. This one was chaired by the Head of SEN and Support Services and had, as its core, a small group of officers and specialists, including the senior advisory teacher for autism and the specialist educational psychologist. The group developed policy, examined maintenance issues, worked on quality assurance and liaised with other groups including parents, providers, elected members and others in the Education department. Within the authority, there was regular consultation and sharing of concerns and developments about autism.
There was also a Liaison Group made up of parents, the NAS, representatives from Education and Social Services which met termly to consult and discuss development of policy.

Other support services/parents' groups

The Hertfordshire Autistic Resource Centre for parents was set up in 1996. Independent and run by volunteers, it supported parents and families through its telephone helpline, newsletter, library, meetings and other social activities. There were monthly meetings and views were fed to the Liaison Group.

A group of parents specifically supporting those doing ABA also existed in the county. Parents of Hertfordshire Early Autism Intervention Today (PHEAT) had representatives on the Liaison Group.

The resource bases in the schools offered support to parents through parent groups, home/school notebooks, making non-contact time available for parents, having an open door policy and arranging review meetings.

Future plans and possible developments

The LEA was:

- re-appraising its provision and support for children with ASD based in mainstream schools. In September 2001, it started two pilot schemes in mainstream secondary schools where extra training and support and advice were invested before pupils transferred into Year 7. The visiting teachers trained the LSAs in advance and were then visiting monthly to evaluate progress and effectiveness.
- evaluating all its services with a view to making access easier for families. There were links with the home visiting service in Essex to try to develop similar evaluation procedures.
- evaluating its specialist provision in special schools.

LEICESTERSHIRE

Background

The new county of Leicestershire, created in 1998, serves a population of over half a million and covers a large rural area with a number of small towns. Even before local government reorganisation when it 'lost' the city of Leicester, it had relied on a considerable amount of peripatetic provision. Within the LEA boundaries, there were 54 secondary, 227 primary and seven special schools and a single health trust.

Pre-school provision

Pre-school Autism Support Project

The Pre-school Autism Support Project – a joint project with the health authority and initially funded for three years – began in 1999. It was created to address the perceived need for more specialised input for pre-schoolers with ASD and their families. An increasing number of children were being diagnosed with an autistic spectrum disorder and the already-existing Autism Outreach Team could only support children who already had statements. As statements were often not issued until the child was four or five years old, many diagnosed children might not have been receiving any specialist support for up to two years.

The Pre-school Autism Support Project employed one teacher who provided early intervention for up to 20 families. Families were offered weekly or fortnightly home visits until the children entered full-time education. In addition, the 12-week NAS EarlyBird programme, with its sequence of workshops and home visits aimed at developing parents' skills and understanding, was offered to all families. The project worker was responsible for ensuring a smooth transition to other services and into school placements. She also provided support and training for staff in any pre-school setting which the children attended.

Nurseries for children with special educational needs

There were two dedicated nurseries for children with special educational needs in Leicestershire (and a third in neighbouring Rutland) which many children with an ASD (even if not formally diagnosed) attended. The staff there had considerable expertise and had had training in catering for the needs of children with autism. If a child who attended one of these SEN nurseries already had a statement, he or she was also supported by the Autism Outreach Team.

There was a strong belief that the teaching approaches should match the needs of the child. One of the SEN nurseries described its approach as eclectic. It included the use of alternative augmentative communication, PECS, interaction work, musical interaction, and elements of TEACCH and Lovaas.

Specialist provision in special schools

The first autism-specific provision in Leicestershire was opened in 1992, largely as a result of parental lobbying through the local autistic society. It was attached to an MLD school. Having begun as a five-place unit, it was later developed to cater for 15 primary-aged pupils up to the age of 11 years.

In 1997, a 10-place specialist unit, attached to another MLD secondary school was also opened. It was thought that this unit would be an extension of the primary unit. However, children placed there have included some with Asperger syndrome who were unable to manage in mainstream secondary schools, while some from the primary unit have continued their secondary education in the SLD school.

While the main teaching approach in both these units was based on TEACCH, other approaches – including intensive interaction, PECS and other forms of augmented communication – were also being used successfully. All staff had been trained on TEACCH. Specialist speech and language therapy was available for one half day per week in each of the special units.

Children in the primary-aged unit were integrated into the MLD school to some extent. There was more inclusion for social than for curricular activities. There was also some integration into a neighbouring mainstream primary school for activities such as art, craft and/or PE.

The amount of integration available to children in the unit for secondary-aged pupils varied according to their individual needs. The geographical isolation of the school made it difficult to arrange a great deal outside although one or two children from the unit had returned full-time to mainstream education.

Places in special schools

Children with an ASD attended the authority's SLD schools (five schools in all dispersed throughout the county) although there was no specialist unit provision per se within these schools. Staff there had all had considerable experience of, and training in, catering for the needs of children with autism. One school had appointed a part-time (0.7) specialist teacher for ASD; the job included supporting children in the classroom, working alongside class teachers, withdrawing children for individual sessions and providing support to staff.

The SLD schools used a range of approaches for their pupils with autism including TEACCH, PECS (and other systems of augmented communication), a stimulus-free room, interactive work and music therapy.

Specialist provision in mainstream schools

A 10-place unit, attached to a mainstream primary school and catering primarily for KS1 pupils and some KS2 pupils, was opened in the west of the county in 2000. This was in response to the growing number of children identified with an ASD and the increased pressure on existing provision. Children in this unit presented much the same broad range of needs as did those in the unit attached to the MLD school.

The unit had two classes of five children, each staffed by a teacher, a nursery nurse and an LSA. Staff were experienced in SLD and ASD work. Teachers were encouraged to complete the Birmingham University Distance Learning course in autism, while NNEBs and LSAs were receiving ongoing training in-county.

The teaching approaches used in this unit were modelled on those being used in the units attached to the MLD schools – ie TEACCH strategies, PECS, signing and interactive work. Specialist speech and language therapy was available for one half day per week. There was limited integration into the mainstream school for curriculum classes, but a considerable amount for social activities.

Places in mainstream schools

Autism Outreach Team (AOT)

This service started in 1992, at the same time as the first unit was set up. Initially, one staff member worked with nine children. The team had subsequently grown to 5.5 FTE staff members working with 183 children with statements, aged 4/5 to 19 (about 105 in mainstream schools and 78 in non-specialist provision including SEN nurseries, SLD and MLD schools).

The focus of the AOT's work was on family and school support, with the main emphasis being on training and individual advice. The team based their advice and input on a detailed assessment of a child's needs in each area of the triad of impairments characteristic of autism. They trained, advised on and used a variety of approaches, including TEACCH, use of structure and visual systems, intensive interaction, some behavioural approaches, Circle of Friends and Social Stories.

It was estimated that there were probably up to another 100 children with ASD attending and integrated into mainstream schools, who were not being support by the AOT, but who were supported as necessary by their school's SEN departments.

Experience with Lovaas

Two children had been receiving Lovaas for about three years. In each case the family was paying for the home-based work, but the LEA subsequently funded the school-based support. Both children were attending mainstream primary schools with full time LSA support. The AOT was also involved in helping the school staff manage. While there was no monitoring of the home-based component, the LEA was reviewing what happened in the schools. The evidence so far suggested that both children continued to need very high levels of support. The extent to which their needs could continue to be met in a mainstream setting remained an open question.

Staff training

The Autism Outreach Team provided a considerable amount of training for teachers, LSAs, NNEBs in both mainstream and special schools and units and for interested others, including parents. The LEA provided funding for AOT and unit staff to complete the Birmingham University distance learning course.

Assessment and diagnosis

There was no Child Development Unit in the county. Assessment and diagnosis were carried out at local level by a range of health and education professionals, with no formal mechanisms for collaboration and co-operation (beyond those required by the process of statutory assessment). Proposals to establish improved levels of co-ordination and collaboration and to set up mechanisms for reaching agreement about the most complex cases were at consultation stage.

In some cases where diagnostic questions were especially complex or where there were substantial management or additional problems, the case might be referred to the Child and Adolescent Mental Health Service. After assessment and diagnosis and if there were significant behaviour difficulties or other mental health problems, this service remained involved with family, either on an outpatient basis or through the more intensive Home Intervention Project.

Multi-agency working parties/groups

The Autism Reference Group included parents, headteachers and teachers from special units, special and mainstream schools, Autism Outreach Team members, educational psychologists, teachers from the specialist nurseries and professionals from health and social services. This group met regularly to exchange information, to share experiences and to take a strategic view of service development and provision.

The Pre-School Autism Support Project was accountable to a steering group which included parents, a paediatrician, a psychiatrist, specialist speech and language therapists and heads of specialist nurseries.

The Leicestershire Autistic Society – a support and information group for parents – had representatives both on the Autism Reference Group and the steering group for the pre-school Autism Project. They met regularly in subgroups around the county and liaised with the LEA.

Other support services/parents' groups

There were several services in the county that provided support for children with learning disabilities. While these were not autism-specific, they did support children with autism, especially those at the more severe end of need.

The Home Intervention Project, jointly funded by Health and Social Services, was a home-based service for parents of children with moderate and severe learning difficulties who were presenting severe problem behaviour. The service was developed especially for families where outpatient treatment alone was not enough. Parents were given the opportunity, through direct support at home, to try new ways of managing their children. A large proportion of families of children with ASD were using this service.

There was support for families from the Children with Disabilities Team in Social Services. They worked with school age children who presented extremely challenging behaviours and whose families were in desperate need of support and respite. A number of children on the caseload had an autistic spectrum disorder. One of the social workers involved was very interested in ASD and had created links with the Autism Outreach Team and become part of the Autism Reference Group.

Issues for parents

During interviews, the following issues were raised:

- A substantial group of families were in need of more support, especially those with children in the middle or at the higher end of the disability spectrum.
- Parents wanted a range of provision and support to meet their needs, especially at the time of diagnosis and immediately afterwards. Many felt that once they were given the diagnosis, they were simply left. The initiative to gather information about autistic spectrum disorders, about where to go and who could help was left very much to them. Often, they felt better supported when their child began attending one of the specialist SEN nurseries, but sufficient support in the home was felt to be lacking. The pre-school project started in 1999 was intended to ease this problem.

Future plans and possible developments

Provision for pupils with a severe learning disability and an autistic spectrum disorder was an issue in the authority. Such children attended SLD schools. Pressure was coming from parents who wanted more dedicated provision – a specialist unit in an SLD school.

OXFORDSHIRE

Background

Oxfordshire is a predominantly rural county with one large city and a number of small/medium-sized market towns. There were 236 primary, 45 secondary and 14 special schools within the LEA, many of which were small village schools. The LEA has a long tradition of integrating pupils with special educational needs into mainstream schools.

There was a large, internationally renowned, teaching hospital in Oxford with a well established paediatric assessment centre.

Service for Autism

Oxfordshire's Service for Autism was well established. The Service provided staff for its autism units and outreach support for all children with an ASD who were attending pre-schools, nurseries, mainstream and/or special primary and secondary schools across the county.

Pre-school provision

Oxfordshire had eight integrated nurseries which children with special needs attended alongside their peers with no such needs. Some of these nurseries were attached to mainstream schools, others to special schools and one was free-standing and fed several primary schools. Typically, in a group of about 24 children in such a nursery, three might have an ASD. The Service for Autism supported these children through outreach – observing the child, talking to the child, staff and parents, offering advice on teaching and therapeutic approaches, offering help with the IEP, attending reviews and so on. They did not provide 'hands-on' support.

All pre-schoolers with an ASD had access to the Service for Autism. If parents wanted their child to attend the local toddler group, additional advice could be provided by the Service. Oxfordshire's comprehensive referral service meant that several practitioners could refer a child to the Service who would then monitor and decide whether this was a child for them or for another service to support.

Pre-school Teacher-Counsellors

This was an education-based home-visiting service offered to families of children with significant developmental delay. Teacher-counsellors usually visited once a fortnight to support parents and to suggest activities for their children. Teacher- counsellor could refer to the service any child whom they considered might have ASD and/or ask for advice. A number of families with children on the autistic spectrum received teacher counsellor support and there were good links between this group and the Service for Autism.

Specialist provision in mainstream schools

Autism Resource Units

This first autism resource unit was set up in Oxfordshire some 20 years ago. Three children with ASD, all located in one area of the LEA, were then receiving home tuition as they were considered too able to be placed in the schools then available to them, i.e. an SLD school or one for 'maladjusted' children as the terminology was at the time. A local headteacher offered a base in his school so as to encourage some inclusion. The autism resource units grew from there.

There were now another five school-based units, catering for pupils aged five to 19 years, in three different towns, plus one based in an FE college for those aged 19+. Teachers and LSAs staffed the units, usually allowing for a ratio of 1:2 adults to children. There were about 91 pupils being supported in the units, many of whom spent some of their time integrated into local mainstream schools – not always only those schools where the units were located.

One of the units had four teachers and 12 LSAs (some full-time and some part-time) for 19 children aged 5 – 11 years. All children spent their lunch and unstructured breaks in mainstream schools with LSA support and up to 90% were also integrated for part of their lesson time. Some staff from this unit also supported children individually placed in mainstream schools.

Teaching was based on a therapeutic approach, although a wide range of techniques was being used, including the Waldon method, intensive interaction, holding, music and art therapy and some elements of TEACCH using visual timetables and individual work stations. There were close links between families of children in the resource units and the staff there.

Several therapists also worked in the unit: a music therapist (two days per week); two speech therapists (two days per week each); an art therapist and a play therapist/counsellor who also worked with families. The speech therapists tended to work with groups of children (up to four) and to set up programmes which the teachers could then carry out themselves.

Admissions to the unit were decided by an admissions panel which met termly and included an education officer, educational psychologist, Head of unit, staff member of unit and a clinical psychologist.

Places in mainstream schools

There were about 250 children in mainstream schools, aged between five and 19, being supported by the Service for Autism outreach team. The outreach team visited the child at least termly, offered advice on his/her IEP and on suitable curriculum differentiation. Other support was available as necessary through the schools' SEN departments. The outreach team also ran INSET sessions, liaised with the child's parents where there was a need and ran awareness-raising sessions for pupils in the host schools.

Places in special schools

A number of children with autism and severe learning difficulties were placed in MLD and SLD special schools where a mix of teaching approaches, similar to those in the units and appropriate to the child, were being used. There was one autism outreach teacher named to link with each special school and to collaborate with the unit staff on approaches and styles. Speech and language therapy was already provided in these schools.

Experience with Lovaas

The LEA had taken on responsibility for the provision and review of Lovaas. Therapists were employed as part of the Service for Autism. The LEA paid for 25 hours per week, plus supervisors' and the consultant's visits up to an agreed annual amount. There were some 14 children, aged between three and five plus, receiving Lovaas.

Supervisors and consultants sent regular reports on their work to the Service for Autism, which in turn sent representatives to the children's termly reviews and to observe children at school or at home. The initial evaluation suggested that parents unequivocally found the process very helpful to them in finding a structure and way of managing their child's development, but what was lacking was enough on the social interaction and emotional side. Several families had opted for a more 50/50 programme where the child spent more time in a social learning environment. The LEA view was that where the Lovaas/ABA was more naturalistic, the outcomes were more transferable. It was felt that the programme should remain a choice for parents. Having it available under the umbrella of the Service for Autism also ensured less fragmentation of support.

Staff training

Oxfordshire LEA provided a considerable amount of in-house training for staff in all its schools. There was input from the Service for Autism, clinical psychologists, speech and language and other therapists as well as from other specialists on teaching approaches such as PECS. It was thought more important that staff working with autistic children be flexible and eclectic than that they have a specialist qualification in one particular method.

Assessment and diagnosis

The Health Trust included two hospitals in the south of the county – one which dealt with acute paediatric cases and the other which housed a purpose-built paediatric centre where children with chronic developmental problems were seen and assessed.

A range of professionals at the paediatric centre assessed children over a one-week period, during which the child, parents and siblings attended daily. Where it was thought preferable and to reduce unnecessary stress, children were also assessed in their own surroundings – at home or in school or nursery. Children could also be seen in their local clinics by a psychologist, a speech and language therapist and a doctor (for hearing and vision checks).

There was also another hospital in the north of the county, where one of the community paediatricians was based. The consultant clinical psychologist at the city hospital NHS, who had a special interest in autism and some time dedicated to autism support as part of the job remit, made regular visits to schools to give advice about individual children.

A good working relationship between the Service for Autism and Health Service practitioners was maintained through formal and informal contact, including liaison meetings, shared workshops and inclusive communication and correspondence. In addition, some community-based speech therapists had become part of the Service for Autism team and were seeing children in their schools rather than in the hospitals.

Multi-agency working parties/groups

There were strong links between the Service for Autism and other agency professionals through Oxfordshire's comprehensive referral system. This allowed different people – GPs, teacher-counsellors, teachers, hospital specialists and many others – to refer directly to the Service.

In addition, there were some multi-agency groups which met regularly. For example, the Advisory Group for Autism was a collective body incorporating representatives from health, education, social services, parents, schools and CFEs which kept people abreast of developments, helped raise awareness and offered some input into strategic planning. The 'Children in Touch' Trust Group, with representatives from parents, professionals in education and interested others, linked in with the units and was a strong supporting factor in developing the Service for Autism. The Service for Autism itself also had a voice on other consultative bodies such as working parties for lifelong learning and meetings of heads of services.

Other support services/ parents' groups

Social Services' support for parents of children with ASD was limited and tended to be restricted to the most severe cases of challenging behaviour. There were four resource centres, offering some respite care (e.g.overnight, weekend, teatime) for children with a range of disabilities, including autism. There was also a childcare scheme which could be accessed on an individual basis and which allowed parents to leave their child with a competent carer for a short time while they went out shopping or for an evening.

A well-established network for families provided information and support. There were two parent-run groups which offered a telephone helpline, playdays in the holidays, monthly meetings with invited speakers, a regular newsletter and networking opportunities for parents and carers. The Service for Autism maintained informal links with these groups through attending their meetings and reading their newsletters.

Future plans and possible developments

The LEA was considering the following:

- gaining approval and funding for resource units in the north of the county
- establishing (perhaps with funding from a charity) a Family Development Officer
- working collaboratively with Health on a project to firm up early identification, more intensive early intervention and family counselling
- looking at providing more/sufficient respite care.

PLYMOUTH

Background

Plymouth was formerly part of the local authority of Devon. As a new unitary authority created in 1998, it now serves a population of about 252,000 and is developing its own distinctive approach to policy across the services – education, health and social services. The authority has qualified for a number of government initiatives – Health Action Zone, Employment Action Zone and Education Action Zone. A jointly-funded post of Integrated Services Coordinator had been created to provide strategic information to facilitate 'joined-up thinking' and development in children's services.

At the time of the research, there were 111 schools in Plymouth – 18 secondary (of which three were grammar schools), 85 primary and eight special schools. Schools in the LEA formed groupings known as 'academic councils', which usually consisted of a secondary school, its feeder primary schools and any special school in its locality. There was also an academic council of Catholic schools. Some funding for special needs was delegated to academic councils to allow the group of schools to make provision for pupils at Stage 3 of the Code of Practice.

The LEA was served by one health authority, which also served parts of the two neighbouring counties of Devon and Cornwall.

Pre-school provision

The Pre-School Advisory and Portage Service was made up of two pre-school advisory teachers for SEN, six full-time Portage workers (jointly funded by education, health and social services), volunteers and an administrator. The pre-school advisory teachers also worked in the Child Development Centre (CDC).

The two advisory teachers were responsible for identifying children with special educational needs in any setting in the community (i.e. at home, in a playgroup or at nursery). They then supported and worked with families and together looked at effective intervention strategies. Of the 130 children on the advisory teachers' caseload, about 30% (and rising) were thought to have an autistic spectrum disorder. Portage workers were used to support parents in their homes where necessary. There were 52 children on Portage programmes.

Places in special schools

While there was no autism-specific provision in the special school sector, there were of course a number of pupils with autism in each of the three MLD, two SLD and three other special schools in Plymouth.

About 30% of the pupils in one of the SLD schools were known to have an ASD. Circle Time was used to great effect with the younger ones. This school was integrating some autistic children into the satellite mainstream class in the neighbouring primary school. The other SLD school had, at one time, created a special 'TEACCH-style' class for a group of KS2 pupils who presented especially challenging behaviour. This had proved very successful, but it was not clear if this was still ongoing.

The MLD school for younger pupils (5-12 years) did not have many pupils on the autistic spectrum. It tried nevertheless to provide an individualised curriculum to meet all pupils' needs. MLD schools in Plymouth were being transformed and one was designated to take on more of a specialist role for children with autism and communication disorders in the future.

Specialist provision in mainstream schools

Enhanced Specialist Provision

The authority had developed what it called Enhanced Specialist Provision (ESP) for autism. The initiative first started in one primary school which took up to five KS1 and KS2 pupils. This was not unit provision but, rather, fully inclusive provision that allowed pupils to be integrated with their peers in the mainstream school for most of their time. The teacher in charge spent about half the week in the school and a day a week providing outreach support. Three special needs assistants supported the children in their classes. There was a room available where small groups or individual children could be withdrawn if necessary, but it was not a unit.

A Roman Catholic primary school in Plymouth provided places for five children with ASD, all of whom were from its catchment area. This provision had originally been created in response to parental requests for local provision. The arrangement was now officially an LEA-funded ESP, with a half time teacher and 2.7 LSAs.

The children were fully integrated with support, but might be withdrawn from time to time for specific work on their IEP. A meal-time assistant gave additional help at lunch-time. The school received support from an outreach teacher and the speech and language therapist. There was some use of intensive interaction and a 'pick and mix' of approaches depending on the pupils' needs.

An ESP for secondary aged pupils was opened in September 1999. It took 10 children across all year groups. Pupils were supported by a teacher in charge and a specialist team of LSAs. The amount of support pupils received in their classes differed from 100% to 'if you need help, come and find me'. Teachers and LSAs made eclectic use of TEACCH; some pupils had their own work stations with visual timetables and work trays within their mainstream classrooms. Older pupils generally needed less support in class. Lunchtime clubs were available.

A second ESP was planned for 2002. This might provide greater opportunities for withdrawal for some adolescents who found it difficult to cope with a busy secondary school environment. The plan was for flexible provision and not unit provision.

A specialist speech and language therapist worked with autistic children in both the special schools and in the ESPs.

Assessment unit in a mainstream school

There was an assessment unit for KS1 pupils based in a mainstream primary school which took pupils with complex communication difficulties who had yet to be given a firm diagnosis. There were places for some 13 children aged five and six. Some of the placements were primarily for assessment and children would move on, after two or three terms, to other provision such an ESP or to their local primary school. Other children remained for slightly longer term 'nurture'. Circle Time, a variety of eclectic approaches and PECS was used in the assessment unit.

The assessment unit was staffed by one teacher and three LSAs. The teacher in charge also spent a small amount of her time providing outreach support for KS1 pupils in mainstream schools and in the primary ESP.

Places in mainstream schools

There were about 80 school-aged children with some form of ASD attending community schools in Plymouth. They were supported by their schools' SEN departments who were, in turn, supported by the outreach service. Outreach teachers (who were also in charge of ESPs) generally advised and trained mainstream school staff, occasionally worked alongside the child and the teacher and provided or advised on materials and approaches.

Staff training

Plymouth had a number of specialist teachers who had completed the Birmingham University distance learning course. Outreach teachers and the educational psychology service provided a considerable amount of internal training for staff in both special and mainstream schools – whole school training, termly support groups and specific sessions on a range of relevant topics.

Assessment and diagnosis

The Child Development Centre (CDC), originally set up in 1978, moved into its present purpose-built accommodation in a local hospital in 1989/90. In addition to all the health professionals based there, there was also a nursery, staffed by NNEB-qualified nursery nurses. Children were assessed over a five-week period. During this time they were seen by the full range of professionals – paediatrician, clinical psychologist, speech and language therapist, physiotherapist and educational psychologist. At the end of five weeks, a multi-disciplinary case conference was held at which an education plan for the child was agreed.

Multi-agency working parties/groups

There were several groups/services which crossed agency and/or local authority boundaries. For example, Devon, Cornwall and Torbay representatives were involved in a regional project looking at achieving a more coordinated approach to assessment and diagnosis. There was constant encouragement to elected members to raise ASD further up the agenda. The Health Action Zone initiative was looking at transition issues for 14-25 years olds, some of whom were autistic. The South West Regional Partnership had a group specifically looking at how best to meet the needs with autism.

Other support services/parents' groups

There was a thriving self-help parents' group in Plymouth that was very supportive of statutory agencies and provision. It held regular meetings and had a number of sub-groups addressing different issues, such as provision for adolescents, social events and so on.

The NAS was represented on some steering groups and had good links with the education service.

Issues for parents

Parents were concerned about diagnosis and on-going support for their children. Some had had difficulty in getting their children's problems recognised and diagnosed. Those interviewed who had children in mainstream schools with support were very happy with their children's placement and felt that the children were making progress and benefiting from inclusion.

There was some feeling that Social Services could provide more support for parents over respite care and claiming the Disability Living Allowance, but resources were limited.

Future plans and possible developments

Plans for the future included:

- plugging the gap between mainstream and SLD provision by creating more provision with the MLD sector
- extending and expanding the outreach service so that outreach could be separate from ESP responsibilities
- creating another secondary ESP in 2002

STOCKPORT

Background

Stockport is a metropolitan borough in the north west of England, with a population of just over a quarter of a million. It had 102 primary, 14 secondary and five day special schools plus nine nurseries. The school age population is about 45,000. Stockport LEA and its health authority (Stockport Health Care Trust) shared the same boundaries.

One of the LEA's educational psychologists had a special interest in autism, was involved in developing coordinated services for children with ASD. This involved compiling a list of all pupils with an autistic spectrum disorder, accumulating a collection of useful materials, tests and resources for schools, facilitating training, liaising with different groups. She also spent some time working in the independent specialist school for children with autism, acting as a consultant to the Portage service, monitoring the progress of children with autism who were placed in residential schools around the country, and disseminating information.

Pre-school provision

Portage started in Stockport in 1987. There were five Portage workers funded by Education – some full-time, some part-time. The service was a home-based teaching one for pre-school children with special educational needs, usually from birth (or diagnosis) to nursery, whose parents wanted it. Referrals to the service were accepted from parents and professionals alike. The Portage staff were trained in different approaches such as interactive and non-directive approaches, PECS and TEACCH.

In addition, the educational psychologist and Portage workers ran a programme specifically aimed at helping parents and adult relatives of pre-nursery children with autism learn more about the disorder and to encourage them to meet other parents. Initially this was an annual four week programme, but it had been replaced by a monthly interest group. Parents and adult carers were encouraged to discuss shared issues and concerns. This contact made it easier for the Portage workers to prioritise the needs of children with an ASD and to smooth their transition to inclusive nurseries.

Inclusive Nurseries

There were three inclusive nurseries (one run by a charitable trust in partnership with the LEA) in Stockport which took children, with a range of disabilities, from the age of two years nine months to be educated alongside their mainstream peers. One of the aims of these nursery placements was to allow for observation and assessment of children with special needs and so help inform their future school placements.

The inclusive nurseries had considerable support from the LEA in terms of access to specialist training for their NNEBs, support of specialists such as the educational psychologist and the inclusion coordinator and the provision of regular speech and language therapy. Nursery staff were well trained about autism spectrum disorders and were familiar with teaching approaches such as PECS, non-directive intensive interaction and structured play.

The opportunity to assess children with an ASD in the inclusive nurseries offered the professionals valuable information about what the child would need at school level and how they might cope. Giving children different opportunities and situations made it easier, during the year, to suggest which type of school placement might be best.

Specialist provision in special schools

Independent special school

There was an independent specialist school, owned by the Boys and Girls Welfare Society, for autistic pupils in Stockport. The school began in the early 1990s as an ASD unit attached to a school for those with physical disabilities and originally catered for four children. At the time of the research, there were 60 children (of whom 27 came from Stockport) aged four to 16 years in the school. There were over 45 staff in total plus 3.5 (fte) speech and language therapists.

The school used several autism-specific approaches to teaching, both structured and interactive as appropriate to individual children, including TEACCH, PECS, signing, intensive interaction and musical interaction. They did not use Lovaas, Options or holding therapy, although some elements of behaviour psychology were present in their work. Training was offered to all teachers and LSAs in the school.

From the outset, the LEA was involved with and supported the development of the school. The first 15 pupils placed there were all from Stockport. The school continued to receive significant educational psychology time from the LEA.

To cope with the increasing need from parents and others for information and support, the school, supported by the LEA, had created a centre for autism which gave access to training and advice, assessment and consultancy mainly in relation to children who were in mainstream schools. The centre ran general and specific courses and workshops on autism and approaches to it. All the LEA's teachers and LSAs had access to these. In addition, the centre had also started the EarlyBird programme to which parents could refer themselves or be referred.

Places in a primary SLD school

One SLD school in Stockport, which catered for a wide range of learning difficulties, had set up two separate classes for those with an ASD – one each for KS1 and KS2 pupils. There were places for six children in each and the provision was always full and in demand.

The school took an eclectic approach to teaching children with ASD depending on what worked best for whom. Strategies included TEACCH (work baskets, symbols, schedules), interactive child-led activities and PECS.

Places in SLD resourced mainstream schools

There were four mainstream schools resourced for children with severe learning difficulties in different areas of Stockport. Each of these had between six and eight children, including some autistic children. In addition to their dedicated staff, they had input from educational psychology, speech and language therapists, occupational and physiotherapists as necessary.

Places in MLD units and resource base

Some pupils with an ASD were placed in the two infant and three junior MLD units within mainstream schools in Stockport. These units had educational psychology support, regular speech and language therapy and could access the INCA consultancy if needed. Staff were not autism specialists but had access to autism-specific training and were very experienced.

Each of the units organised integration differently according to the needs and ability of individual children. In one of the primary MLD units visited, the pupils mainly had severe communication difficulties and autistic tendencies. Children there usually spent their mornings in the unit and then had lunch and afternoon class with their peers in the mainstream school. For some children with a need for a quiet, distraction-free environment, inclusion in mainstream classes was quite challenging.

Typically, teachers in the MLD units used a variety of approaches, not necessarily all specifically for autistic spectrum disorders. These included using a sensory approach, forming social groups for developing turn taking and eye contact, using Makaton, photos, videos, and whole group experiences to draw language and communication from pupils. PECS was also used.

A new MLD resource base, attached to a mainstream primary school, was opened in September 2001. It had 14 places and took children with a range of moderate learning difficulties, some of whom also had an ASD. Children here will be integrated as their ability and needs allowed.

Places in mainstream schools

It was estimated that there were about 150 children with ASD aged five to 16 in the LEA, of whom about two thirds were in mainstream education. Not all were statemented and many had Asperger syndrome. The LEA paid for additional support for these children as necessary. This could include school-based SEN support, educational psychology support, help from the Learning Support Service or Primary Behaviour Support group. INCA could also be accessed.

The LEA had appointed an inclusion coordinator whose role it was to work with schools where children with severe learning difficulties, including ASD, were included. She offered help with programme planning and was particularly involved when children transferred from inclusive nurseries to mainstream schools.

Experience with Lovaas

The LEA has funded four children through a Lovaas programme – a fifth was about to start. The programme had been monitored by the educational psychology service and was thought to have been of some benefit to some children. It had not however resulted in complete inclusion in mainstream schooling for those concerned. Of the four children, one had moved out of borough, one was in an MLD school, a third was in a mainstream school resourced for children with SLD and continuing with Lovaas and the fourth was spending limited time in a mainstream school with a high level of support.

Staff training

The educational psychologist, with a special interest in autism, together with the inclusion coordinator, ran a rolling programme of four-week training for LSAs, both in special schools and units and in mainstream schools. Training was also available for other educational psychologists, Portage workers and others. A range of courses are available at INCA.

Assessment and diagnosis

All children with suspected ASD were referred to the Child Development Team for assessment and diagnosis. The consultant paediatrician, specialising in neuro-developmental disorders then examined the children, obtained their full medical history and undertook an assessment. If a diagnosis of ASD was confirmed, a follow- up visit at home was offered within a week to discuss any concerns and questions that parents had. Parents were directed to local services and the NAS. Referral to the EarlyBird programme and/or to the LEA Portage or other services was arranged. Where a diagnosis was not immediately confirmed, further observations of the child were undertaken in an appropriate developmental group. Assessment would also be carried out by a speech and language therapist and educational psychologist.

A planning meeting between parents and professionals was arranged to draw up an action plan to ensure that the needs of both the child and family were met. This plan was usually reviewed after six months.

Therapy services were managed by the Health Trust. Dedicated occupational therapists, physiotherapists and speech and language therapists were seconded to the Child Development Team. In addition, a specialist speech and language therapist was based at the specialist school. Children and their families had access to a range of other support services offered within the Child Development Team, for example, behavioural support, parental support groups and toy library.

Multi-agency working parties/groups

A joint working group, made up of representatives from both health and education, had been re-established recently to consider assessment, referral and pathways for children, with a view to developing a co-ordinated service for children with complex communication difficulties.

Another group, organised by the NAS and including professionals from various agencies, the voluntary sector and parents, met six times a year to exchange information, raise matters of concern to children and adults with ASD and to address transition issues. Meetings were generally well attended. Stockport also had representation on the North West regional group looking at autism – its services, training needs and provision.

Other support services/parents groups

The NAS was very active in the Greater Manchester area, offering leisure activities and holiday play schemes for young people, and meetings and networking opportunities for parents.

Issues for parents

Some of the issues concerning parents at the time of the NFER visit included:

- the problem of having different escorts and drivers on school transport
- the feeling that there was a shortage of specialist education for children with ASD
- the perceived paucity of information about autism coming from the LEA

Future plans and possible developments

The LEA was planning to do the following:

- continue with LSA training
- evaluate and continue with the monthly interest pre-school Portage groups for parents
- continue developing provision for children with ASD in an MLD school
- continue consultancy for pupils and schools and for training through the specialist school
- offer a range of provision to meet varying needs
- open a fourth inclusive nursery.

TORBAY

Background

Torbay was created as a separate local authority when Devon was divided in the local government reorganisation of 1998. A small new LEA, it serves a population of about 124,000 and has 33 primary schools including three infant and two junior schools. At the time of the research, of its eight secondary schools, three were community colleges, three were grammar schools and one each was bilateral or denominational: in effect, five of the eight were either fully or partly selective so choice of mainstream secondary schooling for all children, including those with SEN, was affected.

The LEA inherited three special schools in the local government reorganisation. At the time of the research, these were being reconfigured to meet local needs. By 2003, it was planned to have three new schools – one each for EBD, SLD and MLD, the latter two with places for pupils with an autistic spectrum disorder.

It was estimated that there were 55 children with autistic spectrum disorders in the LEA, although these figures were thought to be an underestimate. There was as yet no agreed protocol in Torbay for recording the incidence of ASD: discussions across agencies were ongoing.

Pre-school provision

There was no provision exclusively for pre-school children with ASD in Torbay. Instead, such children were supported by the Pre-school Advisory Teaching Service (two half time posts) and the Portage Service which together provided for all children with special educational needs.

Children with special needs (some of whom may have had an ASD) under the age of three years were offered places at the opportunity playgroup; those over three were given support assistants in local playgroups or private nurseries. This support varied but could be one-to-one. The pre-school advisory teachers advised playgroups and nurseries who had children with special educational needs, especially those with severe learning difficulties, physical and medical problems and more marked autism; they also helped to set up individual education plans for children and supervised the Portage Service.

The Portage Service employed three part-time Portage workers (two of whom were funded by Education and the third by Health/Social Services) and four nursery nurses funded by Health. Some 24 families with pre-school aged children with special educational needs, of whom eight had an ASD, were being supported through weekly visits.

There were good personal and professional links between the pre-school advisory teachers and the Child Development Centre staff.

Specialist provision in special schools

There was no autism-specific school-based provision for KS1 children in Torbay at the time of the research. Some children with an ASD attended the new purpose-built unit attached to an SLD school in the adjoining LEA of Devon and others were either in Torbay mainstream or special schools or in independent schools outside the area.

A KS2 autism base was opened at the Torbay MLD school in September 2001. This provided spaces for six children between the ages of seven and 11. The teacher in charge had completed some professional development in autism and the two LSAs had some experience. A visiting speech and language therapist worked at the school, but it was not clear how much of her time was dedicated to the unit. A TEACCH-based approach was being used.

There were opportunities for integration into the MLD school and it was hoped to create some possibilities also for some mainstream experience.

A KS3 unit was to be opened at the MLD school in 2002 with provision for six pupils.

Places in special schools

Some children on the autistic spectrum were attending the special schools in Torbay. A few were in the MLD school itself and about eight were in the all-age SLD school. As there were diverse needs among these children, it was difficult to create an autism-specific environment. The SLD school itself was being reconfigured and it was planned for it to be resited in September 2002.

At the time of this research, the SLD school was using approaches based on TEACCH together with some intensive interaction. Speech and language therapy was available. There were opportunities for integration for some pupils into a nearby mainstream primary school and some secondary-aged pupils had returned to mainstream schooling full-time.

Specialist provision in mainstream schools

There was no specialist provision in mainstream schools for children with autism.

There was an assessment support centre for SEN based in a mainstream primary school which provided for a maximum of ten children at KS1. The children in the centre had a variety of difficulties – moderate learning difficulties, emotional or behavioural problems, language delay and physical disabilities. Some were also on the autistic spectrum, although no more than five at any one time.

The Centre was staffed by one teacher (the school SENCO) and a nursery nurse. The staff used a photo-diary to structure the day and the basic routine remained the same every day. The speech therapy service provided three sessions per week and there was regular support too from a physiotherapist and an occupational therapist. Children moved on from the support centre into the main school or to other mainstream schools, with a statement where necessary.

Places in mainstream schools

Some 17 children with statements for ASD were attending mainstream schools, with varying degrees of individual support. The LEA provided appropriate funding to schools which then decided what support their pupils needed. There was no one person responsible for ASD issues in mainstream schools, no peripatetic or special advisory teacher, although the educational psychology service did advise as necessary.

Experience with Lovaas

There was one child undergoing an ABA programme in Torbay. There was some question about how far this was 'truly Lovaas'. The child had had some ABA while living in Australia and it was being continued so as to enable her to attend school. The LEA was paying for elements of this provision, which was being supervised by an American-based practitioner. The programme was being monitored and its effectiveness with this one child evaluated.

Staff training

Standards Fund money had been used to organise training days for SENCOs in mainstream schools and for staff in the MLD school. Support groups were run termly for teachers and LSAs working with children with ASD.

Assessment and Diagnosis

The Child Development Centre at Torbay hospital carried out assessments of children with developmental problems. The core team consisted of a consultant community paediatrician, senior clinical psychologist, head of the speech and language service, physiotherapists, occupational therapists and nursery nurses. Assessment usually took place over an extended period during which families attended for two mornings a week. There were close links with the education service primarily through the pre-school advisory teachers, who also attended community assessment clinics.

Multi-agency and working parties/groups

A Liaison Group, made up of professionals from different agencies – health, education and social services and the local branch office of the NAS – and run by the educational psychology service met termly.

The educational psychology service in Torbay was also involved in a South West regional group looking specifically at provision for autism with a view to developing an action plan. This involved health, social services and education professionals.

Other support services/parents' groups

The Social Services Children's Disability Team offered support to families, advised on Disability Living Allowance and provided access to child-sitting and other respite services. As with other services, resourcing levels and inter-agency liaison were continuing issues.

The local branch of the NAS ran a parents' group which met quarterly. Its role was to exchange and update information. Any suggestions and issues were fed into the Liaison Group. The LEA's contact with parents tended to be incidental rather than formally organised.

Issues for parents

The parents interviewed as part of the research in 1999 were positive about their child's placement and the support they had received. However, there were concerns then about unmet needs for provision, respite care and other support. Some of these needs had since been addressed.

Future plans and possible developments

A review of special education had been set up soon after the LEA became part of a unitary authority in 1998. As part of this review, a working party – the Autism Working Group – was set up specifically to consider appropriate provision for children and young people in Torbay with autistic spectrum disorders. The group made several recommendations, although not all were included in the LEA's SEN action plan. Their main recommendations *(and progress by 2001)* included:

- creation of a specialist advisory teacher post for autism. *This had not yet happened.*
- establishment of pre-school/primary provision in the form of a unit or support centre. *A KS1 autism base opened at the MLD school in September 2001.*
- development of a protocol for data collection and management which could be used across agencies. *Ongoing.*
- integration of assessment procedures across agencies. *This had not yet happened*
- development of a consistent approach to the management of autistic children and young people across settings. *This was becoming more consistent.*
- access to appropriate equipment (such as IT) mediated by someone with an understanding of the needs of autistic children and young people. *This was yet to happen.*

LEA CASE STUDY CONTACTS

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