A survey of Local Education Authorities on Educational Provision for pupils with Autistic Spectrum Disorders

A report by the All Party Parliamentary Group on Autism

Fiona Loynes
December 2001
With grateful thanks to those LEA’s which set aside time to complete the survey, as the nature of the information requested was such that it was often held by several different departments, and was not easily accessible. The time and effort which people put in amidst already-busy work schedules is very much appreciated.

The All Party Parliamentary Group on Autism is supported by an Advisory Group:
- Allergy Induced Autism (AiA)
- Parents Autism Campaign for Education (PACE)
- The National Autistic Society (NAS)
- University of Cambridge Autism Research Centre
- University of Sunderland Autism Research Unit

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Aims of the study

- To establish numbers of children with autistic spectrum disorders who have statements of special educational needs.

- To learn whether LEA’s believe that there has been an increase in the number of children with autistic spectrum disorders (asd) in the last five years.

- To ascertain whether LEA’s routinely keep records of numbers of children with asd.

- To clarify the profile of educational provision nationally, and examine the balance of provision.

- To identify any shortfalls in provision, in terms not only of physical provision but also in terms of training and awareness raising of autistic spectrum disorders.
The Rising Challenge
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Executive summary

Background to the survey

In 2000, a series of Parliamentary questions were asked of the DfEE about autistic spectrum disorders (“asd”) provision, which it was unable to answer.

This report was commissioned by the members of the All Party Parliamentary Group on Autism (a back-bench group of around 150 MPs and Peers with an interest in the issues facing people on the autistic spectrum), to request information from Local Education Authorities (LEA’s) directly. A survey was carried out of 200 LEA’s in England, Wales and Northern Ireland, which aimed to build up a clearer picture of education for children with asd. The response rate was very high, at 66% (115 LEA’s).

Key findings:

- 87% of respondents (100 returns) perceive an increase in the number of children diagnosed with asd over the last 5 years.
- Only 25% of children with asd have a statement, based on national prevalence estimates. The survey identified 2.1 children in every 1,000 with autistic spectrum disorder and a statement.
- Over 10% of all children with a statement of Special Educational Needs have an autistic spectrum disorder, given that it is estimated that there are 20 children in every 1,000 pupils with a statement.
- Many LEA’s appear unable to measure either training levels or needs, and so there is no coherent authority-wide strategy for pupils with asd.

The survey provided useful initial results, but highlighted an urgent need for consistent data collection across LEA’s for pupils with asd, in order to assist future planning. There is no consistent, accountable system for recording vital data on children with asd at LEA level.

Summary of findings

Autism and increase

| LEA’s reporting increase in last 5 years | 100 |
| LEA’s reporting no increase in last 5 years | 6 |
| LEA’s not answering | 9 |

Some LEA’s reported a small annual increase in autistic spectrum disorder (3%) whilst others reported far higher increases (as high as 77% in one case).

Reasons for the perceived increase in autism

This question was not seeking a scientifically measured response, rather a measure of opinion of educationalists around the country. Most respondents gave more than one reason.

- The overwhelming proportion of reason given for increase, where it was perceived, were around better diagnosis and increased awareness of both parents and professionals.
- However, 20% of LEA’s thought it might be partly real and not just due to increased diagnosis.

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1 “Autistic Spectrum Disorders” or “asd” is used in this report to embrace the whole spectrum, including Asperger syndrome.
2 The author acknowledges the report *Going the Distance* (Booth and Bartley, 1995).
3 Estimate of 2% of children with a statement of special educational needs per general school population provided by Annette English, SEN Regional Coordinator for the West Midlands.
The Rising Challenge

Provision

• An estimated 60% of SEN statemented children with asd need some form of special provision outside the mainstream.\(^4\)

• Of those children educated in the mainstream with asd and a statement, an additional 10% (approx) were in a specialist autism unit attached to the school.

• 13% (approx) were attending schools outside the LEA.

• 17% (approx) were in an autism specific school.

Educational therapies

• The replies to questions on therapy provision showed that TEACCH was used in 77% of LEA’s.\(^5\)

• Lovaas and other ABA approaches were used in 90% of LEA’s.

• Most employed more than one type of therapy, and nine respondents explicitly commented that they use an eclectic approach, “mixing and matching” therapies to suit individual children’s needs.

Problems with provision

Several LEA’s are beginning to recognise autistic spectrum disorders as a distinct educational need and volunteered information about new initiatives. However, some difficulties with provision became apparent:

Tribunals

• Almost half of LEA’s were taken to tribunal about children with autistic spectrum disorders at least once in the academic year 1999/2000, a total of 110 tribunals, with the frequency ranging between 1 to 18 a year.

This can be compared to the SEN Tribunal Annual Report 1999/2000 which cited 319 appeals to the tribunal, of which 183 were resolved in the course of the year (SENT, 2000).

Training

• Many LEA’s do not keep any central record of training, as individual schools have separate training budgets, and manage their training separately.

Given that figures suggest that a considerable number of children might be educated at the school based stages in the mainstream, there would appear to be a lack of strategic LEA-wide planning for pupils with autistic spectrum disorders.

• There is no uniformity of training across the country – examples given were very varied, ranging from single day awareness to longer accredited courses. Autism specialists advocate a range of training to accommodate differing levels of expertise and awareness.

The overall picture of provision suggests a need for greater coordination in training across many LEA’s, and a lack of in-authority facilities in a significant number of cases.

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\(^4\) These provision percentages are estimates owing to some pupils receiving provision covered in multiple categories (see main report for details).

\(^5\) TEACCH is sometimes a classroom-wide approach, and so this percentage may represent a higher number of pupils than Lovaas or ABA, which is most often 1-1.
Recommended strategy

87% of respondents believed that the number of children with a diagnosis of autistic spectrum disorders was increasing in their authority. There is therefore an urgent need for strategic planning of provision.
Recommendations

Prevalence and recording

- Implementation of the Chronically Sick and Disabled Persons Act 1970 s26.6

- Effective multi-agency record sharing.

- Inclusion of an asd category in the annual schools census in the rest of the UK, as is the case in Scotland.

Training

- A dedicated funding stream for training in asd, which could be ringfenced within the Standards Fund and accompany the DfES good practice guide.

- LEA’s could fulfil their new duty to plan for greater access to the curriculum (SEN and Disability Act 2001) by conducting a training audit for asd, and agreeing a programme of action, based on agreed protocols.

- Joint agency training across the whole age range, which would include training in the younger age range, given the importance of early identification and intervention.

- Initial teacher training and continuing professional development should include a section on asd awareness, as is already the case for sensory impairments.

- Families should also be given more support and training, with clear information about what asd are, and advice on working with the child to reinforce what is learnt at school.

- Devolution of budgets to schools will only be effective for children with asd if there is clear central guidance for schools, with a system of accountability.

Inclusion

- In order to boost the numbers of mainstream schools places available, mainstream schools need incentives to take children with asd. The current system of league tables currently does not encourage schools to take children with SEN.

Autism specific speech and language therapy

- Schools to use the dedicated speech and language Standards Fund funding stream to provide autism specific speech and language therapists.

Research into autism specific therapies

- Further research is needed on the efficacy of therapies available, as recommended in a recent DfEE report (Jordan et al 1998).

- There is scope for universities to link with LEA’s to further research, such as the Lovaas research programme initiated by Southampton LEA and coordinated by Southampton University.

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6 “It shall be the duty of every local education authority to provide the Secretary of State at such times as he may direct with information on the provision made by that local education authority of special educational facilities for children who suffer from autism or other forms of early childhood psychosis” Chronically Sick and Disabled Persons Act 1970 s26 (1).
Structure, purpose and methodology

Structure of document

Having presented the executive summary, the main sections of the document are structured as follows:

• A comment on the purpose of the survey, and the methodology and response rate.
• The main body of the report is in two parts, Part A: Findings, and Part B: Comment and Background. Each part has subsections on numbers of children with autistic spectrum disorders; provision, including type of schools, and specialist therapies; problems with provision, including tribunals, exclusions and training.
• Conclusions

Purpose of survey

Following Parliamentary Questions (see Appendix A), it was established that the DfES does not hold figures on how many places there are for children with autistic spectrum disorders in any setting. Members of the All Party Parliamentary Group on Autism (APPGA) sought clarification as to the profile of provision across the country, and the current balance between different types of provision. It was felt that the survey would provide a starting point for the development of a knowledge-base amongst the Members of the current circumstances in three areas. Firstly to gain a clearer picture of numbers of pupils with autistic spectrum disorders with statements; secondly to build up a picture of types of educational provision and thirdly to gain an idea of any shortfalls in provision, either in terms of types of provision or professional awareness.

The premise of the survey was based on prior anecdotal knowledge that many LEA’s are struggling to provide education for children with special educational needs with universally stretched resources. This has been likened to “walking a tightrope in a raging storm” (Sharp, 2001). Hence in some areas of the country children cannot be given the full support that they need, or the educational choices they, and their parents would prefer.

The survey was also prompted by anecdotal evidence from education practitioners that numbers of children with a diagnosis of autistic spectrum disorders were increasing, and parental concerns that some teachers did not know enough about autistic spectrum disorders. Information from parents also indicated that their children were being excluded because their needs could not be met.

The survey follows the work of Hartley Booth (former MP for Finchley). In 1995 he published Going the Distance, a study of 20 LEA’s in North and West London and their autistic spectrum disorders provision. In the years since Going the Distance was written, there has been much more of a move towards inclusion in mainstream schools, therefore this current report takes into account the shift of philosophy.

Methodology and response rate

The questionnaire was designed in consultation with various experts in the field of autistic spectrum disorders education, and piloted with a small sample of LEA’s. All LEA’s were telephoned in advance to establish the best person to send the letter to – in most cases the respondent was the head of the Special Educational Needs department, but in some instances it was directed to specialist autistic spectrum disorders units. Educational psychologists completed some questionnaires. In some LEA’s different people replied to particular questions according to their areas of expertise. Following the pilot, some changes were made to the wording. The questionnaire was posted to every LEA in England, Wales and Northern Ireland. The survey was sent with a brief cover letter explaining the purpose of the survey. The Chair, and
many of the members of the APPGA sent an accompanying letter of support.

Scotland was not surveyed, for two reasons – the first was the significant differences in the education system, and the second was that the Scottish annual schools census records numbers of children with autistic spectrum disorders. There was only a small response from Northern Ireland. However, similar research has been commissioned by the Northern Ireland Education Minister.

The responses from the main survey showed certain ambiguities, and so a clarification sheet was sent out with requests to respondents to double check their responses, which resulted in some revised figures.

**The response rate was 66%: 115 surveys returned from 175.** One LEA explained that they and two or three others had decided not to respond as they had already contributed a good deal of time to other autistic spectrum disorders initiatives, and were too stretched for time. Many LEA’s sent partially completed forms back – some of the answers were either estimated or not answered, because some of the information requested was not always held by LEA’s. It was anticipated that this may be the case, and, paradoxically, blank responses were very useful; they helped to build up a record of what is not known. In other words, although the survey aimed to create a clearer national picture, in fact it was most useful for identifying gaps in knowledge.

Although a pilot survey was conducted, some potentially ambiguous interpretations became apparent; these will be noted in the course of the report. Nevertheless, the survey did produce insights that provide a useful addition to the jigsaw of knowledge that is gradually being put together about autistic spectrum disorders. There remain large black holes in knowledge, and a great deal more research is required.
Part A. Findings of the survey

1 Numbers of children with autistic spectrum disorders who are supported by a statement

1.1 Statement findings

- The survey aimed to form a picture of how many statements are currently being maintained which mention any of the range of autistic spectrum disorders (asd) – autism, Asperger syndrome, autistic traits/features/tendencies and pervasive development disorders. It was hoped that requesting this range of labels would reflect the diversity in diagnostic labels that is known to exist, and so catch as many pupils as possible with a statement.

- It was known that there would be a considerable number of children with autistic spectrum disorders who have their needs met at the schools based stages. However these figures were not requested. We were advised that the LEA’s would be unlikely to keep these figures, whereas they would have a record of statements of special educational need.

- Some LEA’s were unable to give a number of statements for children with autistic spectrum disorders (14 of the respondents). Some made the point that they do not generally record diagnoses on educational statements, because they focus on need rather than labelling. This will be considered further in the Comment section (Part B).

- The returns noted 10,128 statements for children with autistic spectrum disorders. This was between 4.9% and 5.7% of the total number of SEN statements issued by those LEA’s that responded.

- The returns recorded 1,315 pupils under school age.

The numbers of children with asd and a statement gathered by the survey will not, however, be a precise picture of the number of all children with autistic spectrum disorders in the schools of the respondents. The reasons for this are considered in Part B.

1.2 Number of statements and the estimated prevalence rate for the entire spectrum

Whilst acknowledging that the survey will not pick up every student with an autistic spectrum disorder in the LEA, the study has compared the expected prevalence rate of all autistic spectrum disorders in each LEA (9.1 /1,000) with the recorded number of children with autism spectrum disorders and a statement (10, 128 or 2.1/1,000). Whilst the prevalence rates are only estimates, they give a helpful indication as to how many pupils with asd do not have a statement (over 75%).

Table 1.2 demonstrates that the number of children with autistic spectrum disorders with statements (including the estimated prevalence rate of all autistic spectrum disorders):

8 There are three schools based stages in the 1994 SEN Code of Practice, the fourth stage is the stage of LEA involvement, when the LEA considers whether an assessment of need is required, and if so makes a multi disciplinary assessment, which leads on to a statement of need.
9 This range is because some respondents included children under school age in their overall total and some did not.
10 Based on the total school population figures.
11 See Section B for comment on why every child with asd will not have a statement.
The variations between LEA’s reflect both differences in statementing policy (some having an emphasis on meeting needs at the schools based stages) and in the quality of data held by the LEA.

1.3 Has the number of pupils with autistic spectrum disorders increased?

There was a strong response indicating a perceived increase in the last five years.

- Only 44 of the 100 LEA’s reporting an increase were able to supply data to quantify the change. Of the other 56, the LEA’s thought that numbers had increased but did not have the statistics to confirm the impression in the area – they made comments such as “a very considerable increase”.

- Many LEA’s had begun databases in the last two or three years, and some included notes that they were just beginning to set up databases, which would record autism separately.

- Those that were able to calculate increases showed some quite dramatic rises (as high as 400% in the last four years, see Table 1.31 below).

Increases were expressed by LEA’s over a range of time periods, and have therefore been converted to annual figures to provide a meaningful comparison.
1.4 Reasons for Increase, where recorded

- The individuals who completed the survey were asked for a personal view on why autistic spectrum disorder diagnoses had increased in their area, in those cases where it had. It must be emphasised that this was not seeking a scientifically researched response, rather a measure of opinion of educationalists around the country.

The diversity of opinions expressed by LEA’s reflects the need for clear research on increase and reasons for increase.

- Opinions on Reasons for Increase

The results were fascinating, falling broadly into a number of categories:

Some comments did not fit any of the categories above, but provided an interesting reflection of the diversity of theories. These included: “some suggest VDU screens”; “better record keeping and screening”; “service provision is dependent on diagnosis”; “curriculum pressure does not allow for oddness or diversity”; “possibly ultrasound scans in early pregnancy”; “we see increasingly children pathologised as a means of explaining behaviour”. There were views indicating a shift from diagnosis of emotional and behavioural difficulties to autistic spectrum disorders.

2 Provision

2.1 Type of school

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<th>Table 2.1: Type of school</th>
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<tr>
<td>Type of School</td>
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<tr>
<td>Autism Specific**</td>
</tr>
<tr>
<td>Mainstream + Support</td>
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<tr>
<td>Mainstream Special Unit</td>
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<tr>
<td>School for MLD</td>
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<tr>
<td>School for SLD</td>
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<tr>
<td>School for Emotional and Behavioural Difficulties</td>
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<tr>
<td>Home Programme</td>
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<td>Outside Authority</td>
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<tr>
<td>Residential School</td>
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<tr>
<td>Independent/Voluntary</td>
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<tr>
<td>Other***</td>
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</tbody>
</table>

* Numbers are approximate as many of the children’s provision fits more than one category causing double counting.

** “Autism Specific” defined as: where all the students are on the autistic spectrum, and when the school provides teachers with specialist knowledge and understanding of the specific characteristics of autistic spectrum disorders, with training provided by an accredited provider. Information from The National Autistic Society (NAS) information centre is that
there are 17 schools in the UK run by local autistic societies or the NAS, and a further 26 listed by the autism accreditation programme, some of which will also have pupils who do not have autism.

*** Of the “Other” type of provision, these included several special units within a MLD school, specialist nurseries, diagnostic nurseries and a college place.

2.2 Out of authority placements

- 1,294 (13%)\(^{12}\) of pupils with a statement that mentioned autistic spectrum disorders were educated outside their home LEA – this indicates a considerable number of people for whom adequate provision could not be found within their local authority boundaries. In the ten LEA’s with the highest proportion of out of area placements this amounted to a considerable number of pupils, see Table 2.2 below.

Whilst some of these may only be travelling one or two miles across city borough boundaries, a considerable number were in residential schools, which may be a long distance from their families.

The data suggests that, as would be expected, urban LEA’s place out of authority almost 50% more often than rural areas. Further work is needed to establish whether this is just because of shorter travelling distances, or for other reasons.

2.3 Therapies

LEA’s were asked whether they employed or endorsed any of the following specialist autistic spectrum disorders therapies: TEACCH, Lovaas Therapy, Other Applied Behavioural Approaches, Son-Rise/Option, Daily Life Therapy (Higashi), AIT (Auditory Integration Therapy), Autism Specific Speech and Language Therapy. These are briefly described in Part B.

- TEACCH was a popular option. This is because it can be adopted as a classroom-wide or even school wide approach, which is also used for adults in day centres and residential homes. It is relatively cheap to adopt, and presents clear structure for pupils with autistic spectrum disorders.

- Although used in 90% of LEA’s, pupil numbers for Lovaas / Applied Behavioural Approaches were relatively low (approximately 200 pupils). However, they are high cost – averaging between £7,000 and £24,000 per pupil per year. Advocates of such schemes would argue strongly that there is a clear cost benefit, because they argue that many children progress to mainstream schools. Further research is needed.

\(^{12}\) This number will be approximate to allow for double counting of pupils in more than one provision category.

<table>
<thead>
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<th>Table 2.2: The top ten LEA’s for out of area placements</th>
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<td>LEA</td>
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<td>LEA 1</td>
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<td>LEA 9</td>
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<td>LEA 10</td>
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<table>
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<th>Table 2.3: Use of different therapies (% of LEA’s)</th>
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<tr>
<td>TEACCH</td>
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<td>90%</td>
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Although only 17% identified autism specific schools, several commented that they had set up autism specific units attached to MLD schools.\textsuperscript{13}

Only 40% of LEA’s said they provided autism specific Speech and Language Therapy (SLT) services. In some areas SLT will be provided and funded by the Health Authority, hence provision will actually be higher than this.

Nine respondents commented that they use an eclectic approach, picking and choosing from different therapies and programmes.

PECS (Picture Exchange Communication System) was also mentioned by nineteen respondents.

There were a variety of other methods mentioned, for instance: five respondents mentioned The National Autistic Society EarlyBird parent training programme; three mentioned an intensive interaction approach and three mentioned music and art therapy.

### 3 Problems with Provision

#### 3.1 Tribunals

One or more tribunals regarding a child with asd took place during the 1999/2000 academic year in 42% of LEA respondents, a total of 110 tribunals.

In most instances there were only one or two tribunals. There were two notable exceptions, which had eleven and eighteen tribunals respectively.

There were 48 LEA respondents that had no tribunals.

16 respondents did not complete this section.

The numbers of tribunals can be affected by factors such as resource levels and presence of pressure groups.

#### 3.2 Exclusion

There was a total of 61 exclusions across the 116 LEA’s.

Of these there were 17 permanent exclusions, 44 fixed term exclusions (some LEA’s explained that these were during lunch hours, when pupils could not be supervised).

18 respondents did not answer this question, some noting that the LEA data did not distinguish between type of special educational need.

73 LEA respondents reported no exclusions.

Nevertheless 61 exclusions represents a significant number of pupils whose special needs pose challenges which provision cannot meet, either wholly or partially.

### 3.3 Training

The survey found that many LEA’s do not keep any central record of training – individual schools have separate training budgets. In many cases they also do not keep a record of how many teachers there are in the area.

Several gave figures for those specialist autistic spectrum disorders teachers employed specifically by the LEA.

Examples of training were very varied: several LEA’s specifically mentioned the Birmingham University autistic spectrum disorders training course, others mentioned inset days, short diplomas, two week training and training from autistic spectrum disorders outreach teachers. Hence, training varied between a one day awareness course and a fully accredited training course.

Several LEA’s also mentioned training for families of people with autistic spectrum disorders – for example, five mentioned the NAS Early Bird scheme, and one LEA mentioned parents who had attended an Option training day.

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\textsuperscript{13} This percentage is approximate, allowing for double counting of provision.
Part B. Comment and background

1 Numbers of children with autistic spectrum disorders

1.1 Number of statements. Comment.

There are several reasons why the number of statements will not account for all children with autistic spectrum disorders:

- Some LEA’s commented that they do not record the numbers of statements of children with autistic spectrum disorders, as they focus on need and not diagnosis. This approach is understandable, in that it keeps foremost the emphasis on addressing the individual needs of the child, and avoids the temptation of “labelling and boxing”. On the other hand, autistic spectrum disorders experts argue that to have a diagnosis of ASD is vital for understanding what the needs of that individual will be. Although no two people with autistic spectrum disorders are the same, they will share characteristics of learning difficulty, such as for instance they might excel at one subject such as maths, and struggle with another which requires more imaginative thinking, such as English. Thus, far from labelling in a stigmatising way, to know and record that someone has autistic spectrum disorders will actually provide vital clues as to how best meet his or her needs. A diagnosis could be described as a vital pointer, not a label.

- Another factor affecting the reliability of the number of statements recorded by the survey is the fact that many people will not yet have a formal diagnosis, and so may well have been recognised as having special needs, but these may not be specified. The scale of the number of children waiting for a diagnosis, hence not identified in the survey, is indicated by a 1999 survey. This showed that more than 40% of people had to wait over three years to get a diagnosis after their family first had concerns, 15% had between 5 and 9 years, and it took 10% more than 10 years (Opening the Door, NAS 1999).

- Some LEA’s noted in their responses that they do not record autistic spectrum disorders on their databases, rather they record current SEN Code of Practice categories, and “autistic spectrum disorders” or “autism” is not a category. Thus they would have only been able to identify children with autistic spectrum disorders by sifting through their statements by hand. Current categories are: learning difficulties, emotional and behavioural difficulties, physical disabilities, sensory impairments (hearing and visual difficulties), medical conditions. The new Code of Practice (currently draft) will make explicit mention of autistic spectrum disorders.

- Some areas make a determined effort to meet students’ needs at the school stage, and have devised very imaginative and successful ways to do so without the need for a statement. Several LEA’s made this point in their returns, particularly funding provision for children below school age without a statement. It is known anecdotally, however, that this is not always the case; there are some areas of the country where a low number of statements is not paired with a good range of provision at the schools based stages.

- The survey will also not account for those people who are in the process of getting a statement. In 1996 – 1997, 48% of LEA’s reached the 26th week Government time target to make final statements (Audit Commission 1998). This is partly due to pressure of work, and sometimes due to confusion about responsibility for funding, particularly in the case of residential school placements, which are part funded by Social Services Departments.
• Other children who will not be included are those who do not have autistic spectrum disorders as their primary need. For instance six respondents noted that they had only included those pupils with statements of autistic spectrum disorders as a primary need, and knew that there were other children with autistic spectrum disorders who either did not have this as a primary need on their statement, or were older children who had less precise diagnoses.

• It is also recognised that not all children with ASD will require a statement to meet their needs, and will have their needs met at the schools based stages of the Code of Practice.

1.2 Prevalence of autistic spectrum disorders. Comment.

• Prevalence rates of children with autistic spectrum disorders and statements were much lower than the estimates. This raises the question whether there is a huge population of children with autistic spectrum disorders who are not getting their special needs met, or whether they are in fact being listed under more general terms such as attention deficit hyperactivity disorder (ADHD), or learning disability, or helped without a statement.

• At present no attempt to project figures to plan for provision can be done with any certainty, because there is no national recording system for people with a diagnosis of autistic spectrum disorders and LEA’s are not required to keep databases of people with autistic spectrum disorders.

1.3 Increase of autistic spectrum disorders? Comment.

• There is a large amount of anecdotal evidence and a growing number of research papers to suggest that autistic spectrum disorders are increasing, and so the survey sought to gain a clearer picture. LEA’s were asked whether there had been an increase in the number of children diagnosed with autistic spectrum disorders (this is a separate question from whether autistic spectrum disorders are actually increasing in terms of incidence or prevalence).

• The last large-scale prevalence study in the UK was carried out in the 1970s, by Dr. Lorna Wing and Dr. Judith Gould. It looked at a cohort of children born between 1956 and 1970 in the former London Borough of Camberwell (Wing and Gould 1979). Virtually all the children they looked at had IQ levels below 70, or children with “classic autistic spectrum disorders”. They found a rate of 20 per 10,000. A Swedish study in 1993 (Ehlers and Gillberg) looked at children with IQs of 70 or above – the so-called higher end of the spectrum and found a rate of 71 per 10,000.

• The National Autistic Society combines these two studies to make an estimated prevalence across the spectrum of 91 per 10,000. It is this estimate that has been used to compare data.

Recently there have been further smaller scale studies of prevalence:

• In a study of individual schools in Cambridgeshire, Dr. Fiona Scott of the Autism Research Centre at Cambridge University found a rate of 1 in 175 children, across the whole ability range of the spectrum, and 1 in 8 of the special educational needs population as having an autistic spectrum disorder (Scott, 2000).

• Other studies suggest prevalence figures that are much higher. For instance, a ten year Californian study (California Health and Human Services Agency 1999) reported a 273% increase in the incidence of autistic spectrum disorders and Asperger syndrome. A new prevalence study of children between ages 3 and 10 living in Brick Township, New Jersey, found 1 in every 150 children (or 6.7 per 1000) had an autistic spectrum disorder (London, 2000).

• A Boston University study of UK GP figures found a sevenfold increase in diagnoses of autistic spectrum disorders in the past five years (Kaye, Melero-Montes and Jick 2001).

• Evans’ study of autistic spectrum disorders in 3-7 year olds acknowledges: “a general impression that there is an increase in prevalence of autistic spectrum disorders”. From conversations with professionals, she said they were not clear whether they were better at identifying autistic spectrum disorders, or whether it was a real increase. Evans points out that both things might be happening (Evans et al, 2001).
The survey can be compared with the Scottish Schools Census from 1998/99, which found an 18% increase in the number of school pupils under 12 years old with autistic spectrum disorders in one year.

The Regional Coordinator for Six North Wales LEA’s conducted a study that made an interesting comparison between the local Health Authority records and the Education records. There was a difference of 294 health records of autistic spectrum disorders, compared with 285 Education records. The sharing of information between agencies is known to be a problem nationally, and the Health Act 1999 gives the opportunity for greater joint working. The problem of separate record keeping is demonstrated by the fact that one LEA could not answer the question of whether autistic spectrum disorders had increased in their area, because the information was kept by Health, not Education. The current emphasis on streamlined multi-agency working is another argument for recording diagnosis as well as need on statements.

2 Provision

2.1 Type of school. Comment.

Although a relatively small number of pupils were on home programmes (237), the cost for these is considerable, costing between £7000 and £24000 per pupil. Supporters of these approaches argue strongly for long-term cost effectiveness, and there is a great need for further research on the efficacy of programmes to support the anecdotal reports.

PACE and The National Autistic Society’s Education Advocacy line have found that locating the right placement for a child with autistic spectrum disorders, whether in the mainstream or otherwise, can be extremely difficult. One of the London borough respondents echoed this problem: “provision in London is grid-locked”.

There is consensus among autistic spectrum disorders professionals that people with autistic spectrum disorders will need a continuum of educational provision – no one type of educational setting will suit all people with autistic spectrum disorders, due to the range and diversity within the spectrum. This is in line with the DfES recognition that although inclusion in the mainstream is a goal for many people with special educational needs, there will be some for whom mainstream education will not be an option: “for some children, a mainstream placement may not be right, or not right just yet. We will therefore confirm that specialist provision – often, but not always, in special schools – will continue to play a vital role” (DFEE, 1998 p 23).

An NFER study on autistic spectrum disorders provision for children in the early years also reflects the need for this diversity: “The NFER research has demonstrated that it is possible to include some children with autistic spectrum disorders in mainstream settings, but that children in these settings need intensive support from specialist teachers and from support assistants if they are to access the curriculum and overcome their social difficulties. Children whose autism is compounded with severe cognitive impairment present a challenge which is unlikely to be met in mainstream, and which often leads to segregation within a special school setting” (Evans, 2001).

A range of different provision has been seen to be successful for different children:

<table>
<thead>
<tr>
<th>Table 2.1b: Examples of a continuum of provision</th>
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<tbody>
<tr>
<td>Inclusion &amp; the continuum of provision:</td>
</tr>
<tr>
<td>“Inclusive education is a process involving the restructuring of the curriculum and classroom organisation. This distinguishes it from integration which focuses on the placement of an individual or group and that individual or group having to adapt to what the school is able to offer” (Barnard, Prior and Potter, 2000)</td>
</tr>
<tr>
<td>• Emily had a home education programme using an applied behaviour approach (ABA). After significant progress, she now attends a mainstream school with ABA outside of school hours to work on areas of difficulty.</td>
</tr>
<tr>
<td>• Jane has severe autistic spectrum disorders, involving complex and challenging behaviour. She is in a full time, 52 week residential specialist school, and has one to one staff support.</td>
</tr>
</tbody>
</table>
The Rising Challenge

Christopher attends a special day school for children with moderate learning disabilities. Some of his classmates also have autistic spectrum disorders, and others have a range of different learning disabilities. The staff have received autism specific training and they emphasise a calm, clutter free environment in the classroom.

Matthew is in an autistic spectrum disorders unit on the site of a mainstream primary school. He joins his year group for some less academic curriculum subjects such as art, music and drama.

Joe is in a specialist unit within a mainstream school. He started in reception with a learning support assistant, moving later to the specialist unit after greater social difficulties emerged during transition. He integrates within mainstream classes as much as possible and as appropriate. His local health authority provides two hours a week speech and language therapy.

William has Asperger syndrome, and is in a mainstream secondary school. He receives five hours a week of classroom support from a learning support assistant, with additional one to one speech and language therapy. The school has employed a “buddying scheme” with his peers to prevent bullying, and to help him to socialise at lunch and break times.

The parental view, according to a NAS survey, was that the type of provision was less important than the level of autistic spectrum disorders awareness within it. 73% of parents and carers were satisfied with the education their child was receiving (either “quite satisfied” or “very satisfied”) and: “where autism specific support was provided – whether in autism specific units attached to mainstream schools, or special schools, or autism specific schools parents’ satisfaction levels were at their highest”. A parental survey by PACE also reflected this preference – specialist autistic spectrum disorders expertise was felt to be far more important than the type of provision. Of the respondents to the NAS survey, just over half of the children with autistic spectrum disorders were taught in a mainstream setting, and the remainder were in specialist settings.

A 1996 report (Male, Tizard Learning Disability Review) reflected a large difference between LEA’s in attitudes to and implementation of inclusion. For example in 1996 the highest inclusion rate in the mainstream was 89% and the lowest inclusion rate was 28%.

There has been a move towards greater inclusion in mainstream schools across the whole SEN population – The DFEE SEN Report 2000 shows: “The percentage of pupils with statements placed in maintained mainstream schools continued to increase, from 59% in 1999 and 54% in 1995. The percentage placed in special schools (maintained and non-maintained) or PRUs fell from 38% in 1999 and 44% in 1995”.

“Of the children for whom a statement was made for the first time in 1999, 74% were placed in mainstream schools”.

“Between 1995 and 2000 the total number of pupils in maintained or non maintained special schools, including those with and without statements, fell from 98,400 to 96,600”.

2.2 Out of authority placements. Comment.

For many pupils placements outside their local authority mean several hours of travelling a day.

This constitutes a significant cost to LEA’s – one city borough LEA with approximately a third of its pupils with autistic spectrum disorders educated outside the borough put the cost at half a million pounds, acknowledging that this limited the LEA’s potential to develop in-borough, local provision.

However, in some ways the high number of out of area placements is a positive thing, as it reflects the fact that LEA’s are seeking hard to find provision suitable to a pupil and their family.

2.3 Therapies. Comment.

These therapies are described briefly below. Many parents find that they have helped them enormously. However, no one approach has been found to be effective for all children with autistic spectrum disorders (Cumine, Leach and Stevenson, 2000).
• **TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children)**
  A teaching method and “whole life approach” based on an uncluttered “prosthetic” environment and the use of clear routines and visual prompts such as picture timetables.

• **Lovaas (and other applied behavioural analysis)**
  An intensive one to one behavioural modification approach, forty hours a week for up to two years, carried out by a series of therapists coming into the home. It is based on the theory that all behaviour is learned and can be altered by shaping, then rewarding, desired behaviour. It divides the task to be learnt into small steps. A small number of ABA schools have recently opened in this country.

• **Son-Rise Program (Option Approach)**
  A home based intensive approach based on echoing the child’s behaviour and gaining social communication that way, using a positive approach including the three “E’s” – excitement, enthusiasm and energy. It aims to encourage the child to be self-motivating via non-confrontation and unconditional acceptance.

• **Daily Life Therapy (Higashi)**
  Highly structured group teaching, with a great emphasis on physical activity. Based on the theory that routines and patterns of daily living can be taught through the rhythm of life in the group process. There is a Higashi school in Boston, and a school in the UK which has adopted some of its principles (Prior’s Court). Other schools have adopted elements of Higashi methods, such as the emphasis on exercise.

• **Auditory Integration Therapy**
  An intensive treatment involving listening to electronically filtered music through headphones for an hour a day for ten days, based on the theory that this will tackle the sensory impairment experienced by many people with autistic spectrum disorders.

• **Autism Specific Speech and Language Therapy (SLT)**
  Some LEA’s specifically mentioned the Hanen approach. Generally autism specific speech and language therapy targets the environment for the child with autistic spectrum disorders. The therapist may not necessarily work with the child on a one to one basis, but would act as consultant for other professionals, advising on the best communication methods.

  Inequality in SLT between neighbouring LEA’s exists, for example when one pays the local health authority for SLT, and the other does not, hence children sharing the same health authority will get differing service. Anecdotal reports suggest that there is a chronic shortage of Speech and Language Therapists generally, particularly for children for whom English is not their first language.

• **PECS (Picture Exchange Communication System)**
  was also mentioned by a number of respondents. It encourages communication by exchange of picture symbols. It initially requires two adults to teach the idea of exchange, and begins with the main motivator for the child, eg learning the symbol for a favourite food in order to ask for it.

3 Problems with provision

3.1 **Tribunals. Comment.**

- Information from the SEN Tribunal shows that in the past four years there has been a 360% increase in the number of cases related to autistic spectrum disorders which have been taken to SEN tribunal. The Special Educational Needs Tribunal singled out autistic spectrum disorders for comment in its Annual Report (1998 – 1999): “Autism is now unquestionably the second most common disability with which the Tribunal is concerned” (The first disability category, literacy, is a very broad one.) This indicates a marked difficulty in parents and carers achieving the provision which they think is best for their child.

- The numbers of tribunals found by the survey are also not a true reflection of the number of cases in dispute, as they do not reflect the number of ‘eleventh hour’ decisions by LEA’s, meaning that a tribunal is cancelled at the last minute. PACE’s parental survey (soon to be published) showed that a significant number of their returns had a last minute decision from an LEA, before going to tribunal.
• It should also be noted that tribunals are more likely to find on the parent’s side, 78% upheld in 1998 – 1999 (SENT, 2000).

• Although the numbers of tribunals are relatively small compared with the total number of children with SEN statements, they represent a huge cost in time and money – not only educationalists’ time and effort, but high legal fees for both LEA’s and parents.

The National Autistic Society’s Advocacy for Education Service estimates a cost for some families could be between £1,000 and £2,300 in legal costs and expert witnesses, such as private educational psychologists. It is equally costly for the LEA’s.

• For families who feel that a residential school is the right option for their child, there is often a delay of several months whilst Social Services and Education Departments decide what proportion of the overall fees should be paid for by education and social services.

• The scale of the problem is also indicated by the numbers of families calling for help. The NAS Advocacy for Education Service has taken 1070 calls to the line for general advice since its establishment in June 2000. Since November 2000, 134 tribunal cases have been given support.

• The National Autistic Society’s Helpline reported 4 main difficulties with LEA’s:

  i. The LEA in question is unwilling or unable to make funding commitments.

  ii. The LEA is firmly committed to a particular philosophy eg some LEA’s have wholeheartedly embraced the move towards inclusion, interpreted in a way which does not take into account the very different responses of people with autistic spectrum disorders.14

  iii. Some LEA’s have developed a specialist knowledge in other types of disability, and do not have the same knowledge base for autistic spectrum disorders.

  iv. LEA’s try to fit autistic spectrum disorders into the learning disability model of mild, moderate or severe learning disabilities. This is not appropriate for the uneven learning ability which characterises autistic spectrum disorders.15

3.2 Exclusion. Comment.

• The NAS Inclusion and autism report found that: “Children with autistic spectrum disorders and Asperger syndrome are on average twenty times more likely to be excluded from school than their peers… one in five (21%) are excluded at least once, compared with an estimated 1.2% of the total pupil population”.

• Some children could not be supervised during the lunch hour, which explains some of the fixed term exclusions.

• Some children will have behaviour which is so difficult to manage that even a specialist provision may struggle to find the best way to meet the child’s needs.

3.3 Training. Comment.

• Information on training was very difficult to establish. The West Midlands SEN Regional Partnership found a similar problem: “Many LEA’s do not keep central records of staff training and it is therefore often difficult to know which schools or staff have any knowledge or expertise in autistic spectrum disorders” (English and Essex, 2000).

• It should be noted that at present there is no requirement for teachers working with children with autistic spectrum disorders to have training (Helps, S., Newsom-Davis, I.C., and Callias, M., 1999), unlike children with visual or hearing impairments, for whom teachers must be specially qualified.

Powell and Jordan (1993) observe that: “…the normal intuitions of a good teacher are likely to mislead when applied to autistic spectrum disorders.

14 For example, some children with Asperger syndrome may be very able academically, but will only thrive in a special school environment where their social skills difficulties can be catered for.

15 Children with autistic spectrum disorders may excel in certain subjects, and struggle in others, whereas other children with learning disabilities will have universal developmental difficulties.
• Anecdotally, education for children with autistic spectrum disorders in the mainstream can rely heavily on learning support assistants who may not have received much training.

• An NAS report found that the Parental view of training is a clear expression of no confidence: “31% of parents and carers do not think that teachers have received the professional training they need to adapt to the special requirements of pupils with special needs”. This picture is worse at a secondary level (Barnard, Prior and Potter, 2000).

• Interestingly, the West Midlands SEN regional partnership found in a carers’ survey that in fact a large percentage of carers felt there was: “a general awareness of autistic spectrum disorders within their child’s placement” and yet over a third lacked awareness of the level of training and specialist knowledge available in their child’s school. As a result these parents lack confidence in the school’s ability to meet their child’s need. This raises the question of whether the third in the NAS survey and in the West Midlands were simply not informed about the knowledge available in their child’s schools – the problem may then be partly a lack of communication.

• The National Autistic Society recommends that “Local education authorities should develop and make available autism specific expertise for mainstream schools whilst maintaining choice of autism specific schools. This could take the form of autistic spectrum disorders specialist consultant teachers as part of a local education authority’s central teaching support services” (Barnard, Prior and Potter, 2000).

• A study by Helps, Newsom-Davis and Callias (1999) investigated teachers’ views of autistic spectrum disorders and their training needs. The study sample was taken from both mainstream and special schools, all of which were known to have contact with children with autistic spectrum disorders. The findings were as follows:

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<th>Table 3.3b Helps et al findings on training needs</th>
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<tr>
<td>• 70% of mainstream teachers had worked with children with autistic spectrum disorders, but only 5% had specific training in their teacher training, and a further 5% had been on subsequent training days.</td>
</tr>
<tr>
<td>• In Special Schools 50% of teachers and 40% of other staff had received special training. Even the special schools figures reflect a large proportion of people who had worked with people with autistic spectrum disorders without training.</td>
</tr>
<tr>
<td>• 28% of teachers cited a lack of knowledge about autistic spectrum disorders.</td>
</tr>
</tbody>
</table>

• There are some good local examples of training which could be copied nationally. For example: the training course at Birmingham University; in North Somerset all teachers and learning support assistants have the option of a one day awareness course on supporting children with autistic spectrum disorders or Asperger syndrome, and there are also two support groups in the Avon area for teachers working with children within the autistic spectrum; several LEA’s employed autistic spectrum disorders specialist teachers who offer consultancy advice. Others mentioned advice and training days from NAS Development workers.

• Training should not, of course, be limited to professionals. The family is a key component in the education of any child, but perhaps particularly one with autistic spectrum disorders, who will not learn in the same way as others, and may need the lessons they have learnt at school or nursery reinforcing. So whilst it was encouraging that several LEA’s mentioned the Earlybird package for people with disabilities, large parts of the country are left without a system of training for families.
Conclusions

Education for children with autism spectrum disorders is in a period of great change at present. The most significant finding of this survey was highlighting what is not known. LEA’s are not required to collect data specifically on autistic spectrum disorders, and this makes it extremely difficult to plan, either on a local level or a central one. Many LEA’s commented that they are just beginning to set up databases, and various autistic spectrum disorders services are springing up around the country, but there is a need for a national strategy.

Clear information has been difficult to establish, due to the variations in defining autistic spectrum disorders, varying policies on whether to statement or not, the wording of statements and the differences in keeping databases. However, the following conclusions can be made:

1 To seek to establish clearer numbers of children with autistic spectrum disorders nationally, and identify obstacles in this aim.

• The survey highlighted the diversity in statementing practice and recording practice that exists around the country. This is most strongly demonstrated by the fact that 14 of the respondents had no information at all available on the number of children who had autistic spectrum disorders mentioned on their statement, and several others added notes to say that they had estimated the numbers.

• The survey identified 10,128 statements in total.

• The survey found an average rate of children with autistic spectrum disorders and statements of 2.1 per 1,000. The NAS estimated prevalence rate is 9.1 per 1,000 people with autistic spectrum disorders.

• There will be a considerable number of pupils whose needs are met without a statement, including those at the schools based stages, but, as several returns indicated, there will be many more without a precise diagnosis, or without autistic spectrum disorders as the primary need on the statement. There may be a group of pupils with autistic spectrum disorders who remain unidentified, even at the schools based stages, and further research is needed to determine this.

• The numbers of children being diagnosed with autistic spectrum disorders appears to be increasing, as 87% of respondents said that the number of children with diagnoses had increased in the past five years.

• Views from respondents on the reasons for increase were interesting. The most popular responses to this open question were better diagnosis and greater awareness, either of the professionals or parents. There were some interesting other views, including 23% of respondents believing there was a possible actual increase which could not be explained by better diagnosis or awareness. However, 20% of LEA’s thought it might be partly real and not just due to increased diagnosis. 11% of LEA’s thought the increase may be partly due to reasons such allergies, the MMR vaccine or environmental factors.

2 To clarify the profile of educational provision nationally, and examine the balance of provision.

• In terms of type of school, the largest number of pupils was in a mainstream school.

• Around 13% of pupils were educated outside their local authority – a considerable number of pupils when the additional expense is considered.

• Similarly, although only a small number of pupils were on a home programme, their intensive one to
one nature make the costs considerable. Initial research suggests that intensive home programmes can lead to a majority of children going to the mainstream, therefore a cost benefit argument can be made, but much more research needs to be done.

- The therapy provision question showed that TEACCH was a popular approach, used in 77% of responding LEA’s. Lovaas and other ABA methods were also used in 90% of responding LEA’s. Most used more than one type of therapy, and nine respondents explicitly commented that they use an eclectic approach, “mixing and matching” therapies to suit individual children’s needs.

3. The overall aim was to highlight where there are shortfalls in provision, in terms not only of physical provision but also in terms of training and autistic spectrum disorders awareness.

- Tribunals were held in 42% of LEA respondents, a total of 110 tribunals. Reasons for tribunals were not requested, but the number probably reflects two main difficulties: firstly the problem of finding the right provision for children who often have very complex needs; secondly a lack of confidence on the part of parents in the education being offered for their child.

- Training. The survey made clear that many LEA’s do not keep any central record of training. There is a lack of coordination between LEA’s and schools, as individual schools have separate training budgets and in many cases they also do not keep a record of how many teachers there are in the area.

- One area which was not covered in the survey was the number of pupils with autistic spectrum disorders needing additional support because they have English as a second language. There is a great need for research numbers of pupils with asd from minority backgrounds, and their access of services.

- Full recommendations can be found at the front of the report on page 3 and 4 – 87% of respondents believed that the number of children with a diagnosis of autistic spectrum disorders was increasing in their authority. There is therefore an urgent need for national strategic planning of provision.
Appendices

Appendix A. Examples of Parliamentary Questions

House of Commons Hansard Written Answers for 25 May 2000
Mr Boswell: To ask the secretary of State for Education and Employment what studies he has carried out on the incidence of autistic conditions among the school population; and what guidance he has issued to local education authorities in connection with these conditions.

Jacqui Smith [holding answer 24 May 2000] Figures are not collected on the incidence of particular types of special need. Provisions in the Education Act 1981, now consolidated into the Education Act 1996, require schools to submit information on numbers of pupils with special educational needs. In accordance with the recommendation of the Warnock Committee, there is no requirement for them to record the nature of the disability or learning difficulty and we have no current intention to require them to do so.

Guidance on meeting children’s special educational needs is contained in the Code of Practice on the Identification and Assessment of Special Educational Needs. The Department has established an Autism Working Group which is investigating examples of good practice and will be publishing practical advice on early identification and making provision for children with autistic spectrum disorders. In its advice the Group will be taking account of the work of the special educational needs regional coordination projects, one of which, in the West Midlands, has been concentrating on provision for children with autistic spectrum disorders.

House of Commons Hansard Written Answers for 28 Nov 2000
Mrs Ewing: To ask the Secretary of State for Education and Employment (1) when he plans to hold centrally information on the number of children under the age of 10 years, by local authority area, who have been diagnosed with autism in each year since 1990 [140744] (2) what estimate he has made of the number of sufferers of autism a) below and b) over the age of 18 years in (i) 1990 and (ii) 1995 (3) what research his department has carried out in the last 10 years into the principles, methods and effectiveness of the Higashi school for autistic children in Boston, USA 28 Nov 2000 Column 587W

Jacqui Smith: The diagnosis of autism and estimates of the prevalence of the condition are medical matters and questions on these issues should be directed to the Secretary of State for Health. Figures on the numbers of children identified as having special educational needs arising from autism are not held centrally.

My department has not funded any research into the Higashi School in Boston, USA, in the last 10 years, but did publish a research literature review which recorded two studies completed at the Higashi School, Boston. Educational Interventions for Children with Autism: A Literature Review of Recent and Current Research. Jordan, Jones and Murray, 1998.

House of Commons Hansard Written Answers for 20 Dec 2000
Mrs Ewing: To ask the Secretary of State for Education and Employment if he will list the services and provision made available by his department in England for those diagnosed with autistic spectrum disorder.

20 December 2000 Column 228W
Mr Andrew Smith [holding answer 18 December
The Department does not make direct education provision for those with autistic spectrum disorders. It is for local education authorities, schools and other education training providers to arrange suitable provision for all those with learning difficulties and disabilities, including those with autism, in collaboration, where appropriate, with other service providers from the statutory, voluntary and independent sectors. The Employment Service is responsible for helping those looking for work, including jobseekers who are disabled. Although there are no programmes specifically for people with autism, there are a range of mainstream and specialist disability programmes which can help people with the disorder.

Appendix B. Questionnaire

All Party Parliamentary Group on Autism
Local Education Authorities Questionnaire
On Education for Students with Autistic Spectrum Disorders

Name of LEA: __________________________________________

1a. How many statements are you currently maintaining which mention one or more of the following: Autism, Asperger syndrome, autistic traits/features/tendencies, autistic spectrum disorders, pervasive developmental disorder?

1b. How many statements have you issued for children below school age?

1c. How many statements do you issue in total, across the entire SEN population?

1d. What is your overall school population?

2. Of those pupils in 1a and 1b, how many are:

- [ ] in an autism specific school
  (defined as: where all the students are on the autistic spectrum, and when the school provides teachers with specialist knowledge and understanding of the specific characteristics of autistic spectrum disorders, with training provided by an accredited provider)

- [ ] in a mainstream school with support (e.g. from a learning support assistant, speech therapist etc.)

- [ ] in a specialist unit within a mainstream school

- [ ] in a school for children with moderate learning disabilities

- [ ] in a school for children with severe learning disabilities

- [ ] in a school for children with emotional and behavioural difficulties

Continued…
3. Do you offer or fund any specialist education therapies for children with autism, autistic spectrum disorders and Asperger syndrome?

<table>
<thead>
<tr>
<th>Please Tick:</th>
<th>Pupil Numbers:</th>
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<tbody>
<tr>
<td>□ TEACCH</td>
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<td>□ Lovaas therapy</td>
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<tr>
<td>□ Other applied behavioural approaches</td>
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<tr>
<td>□ Son-Rise/Option</td>
<td>□</td>
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<tr>
<td>□ Daily Life Therapy (Higashi)</td>
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<tr>
<td>□ AIT (Auditory Integration Therapy)</td>
<td>□</td>
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<tr>
<td>□ Autism specific speech and language therapy</td>
<td>□</td>
</tr>
<tr>
<td>□ Other (please specify)</td>
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</tbody>
</table>

4. How many tribunals were there in the last academic year (1999 – 2000) for children with autism or autistic spectrum disorders or Asperger syndrome?

5. Regarding training:

- How many teachers (in the mainstream and SEN) have received autism specialist training?
- How many teachers do you employ in total?

Continued…
Appendix C. Definition of autistic spectrum disorders

What are autistic spectrum disorders?

Autistic spectrum disorders are complex developmental neurological disorders. They are generally described in terms of a triad of impairments (Wing and Gould, 1979), of communication (verbal and non verbal), imagination (e.g. finding it hard to imagine how others think and feel, and not understanding the consequences of one’s actions) and social interaction (this can include difficulty knowing what to do when with other people, and understanding social ‘rules’ Powell, 2000). In practical terms this means that:

“People have severe difficulties in communicating and forming relationships with people, in developing language, and in using abstract concepts; characteristics include repetitive and limited patterns of behaviour and obsessive resistance to tiny changes in familiar surroundings” (Treehouse School, 2000).

It is a “spectrum disorder” in that it encompasses people with a variety of abilities, from people with very severe learning disabilities, to people with above average intelligence, all of whom will share difficulties in the triad of impairments. Some more able people will develop very good social fronts, and learn to mask their difficulties, whilst people with very high needs may appear to be completely in their
own world. People with autistic spectrum disorders can be very gifted in some ways, for instance some people have a special interest about which they are extremely knowledgeable.

In the survey, the umbrella term “autistic spectrum disorder” was used because when a division of terms was used in a pilot version it caused confusion. LEA’s were asked to account for people who had been given a whole range of diagnoses, because it is known that people often have vague or unclear diagnostic labels. A National Autistic Society report on diagnosis found that people had as many as 22 different diagnoses (Stirling and Prior, 1999). Parents also mentioned reluctance by professionals to give a specific diagnosis of autistic spectrum disorders or Asperger syndrome, preferring to give a more general definition of learning disability.

In this report “autistic spectrum disorders” is used, along with the abbreviation “asd”, including Asperger syndrome.

Appendix D.
The Advisory Group

Support and consultation was provided by a group of representatives from organisations that work for people with autistic spectrum disorders and their carers. These consisted of two members of PACE (Parents Autistic spectrum disorders Campaign for Education); two members of The National Autistic Society and a member of AiA (Allergy Induced Autism).

Bibliography


