

SCRUTINY OF PROVISION FOR CHILDREN WITH AUTISTIC SPECTRUM DISORDERS

Report of the Director of Children, Schools and Families

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1. Purpose of the report

To provide a summary of the work and recommendations of the Topic Group.

2. Summary

- 2.1 The Topic Group has visited a wide and representative range of mainstream and special school provision in Hertfordshire and other Local Authorities. Members of the group feel that there is some excellent work taking place with autistic children in Hertfordshire but have identified a number of pressure points and areas for further development.
- 2.2 A report to the Scrutiny Committee on 16 October 2002 provided background information and interim proposals for additional provision that might be included in the 2003/04 budget planning progress.
- 2.3 This report summarises further work that has taken place since October 2002 and raises further issues that members of the Topic Group wish to refer to the Scrutiny Committee for its consideration.

3. **Conclusions**

The Topic Group has undertaken a comprehensive review of provision in Hertfordshire and identified many areas of good practice and some areas for further development. The Committee is asked to consider and endorse the recommendations of the Topic Group.

1. Background

1.1 The Scrutiny Committee authorised a scrutiny of provision for Autistic Spectrum Disorders (ASD) at its meeting of 19 June 2002.

1.2 The Topic Group's priorities have been to :-

- examine a representative cross-section of mainstream and special school provision within Hertfordshire
- visit a range of mainstream provision in other Local Authorities
- gather and consider data on exclusions
- examine training and professional development arrangements in Hertfordshire
- examine 16+ provision within and outside Hertfordshire
- consider issues relating to primary-secondary transfer
- gather more information about "Applied Behaviour Analysis" and Lovaas techniques
- observe the work of the specialist pre-school home visiting service
- meet parent representatives, including the National Autistic Society
- meet representatives of the Health sector to clarify arrangements for diagnosis and support for children and families.

A summary of visits is attached as Appendix 1 to this report.

1.3 The Topic Group began its work on 5 July and reported its initial findings and recommendations on 19 October. These were that :-

- (a) Priority should continue to be given to early intervention and parental support by the Specialist Advisory Service.
- (b) Specialist bases in special schools should continue to be funded and developed according to demographic pressures.
- (c) Standards Fund allocations should continue to give priority to the training of teaching and non-teaching support staff in this area of work.
- (d) Subject to availability of resources, a network of mainstream bases should be established over time building on good practice and experience in Hertfordshire and other Local Authorities.
- (e) Parental concerns about exclusions, although not substantiated by analysis of data on fixed term or permanent exclusions over the last 3 years, should be followed up and reported to the Achievement Panel as necessary.
- (f) That a further programme of visits and meetings should be undertaken and recommendations made to the Scrutiny Committee about actions to be taken in the medium term.

- 1.4 As part of the budget building process for 2003/04 it has been possible to fund demographic growth in special and mainstream schools on the following basis:-

SCHOOL	Places	Cost (£000s)
Woolgrove	2	31
Colnbrook	2	32
Middleton	4	64
St Lukes	5 (from 1/9/03)	28 (part year)
The Valley	5 (from 1/9/03)	28 (part year)
Watling View	8	129
Woodfield	5	81
Total		£393

The new autism places at Middleton, Watling View and Woodfield are being created through the conversion of normally funded places to autism provision. There is a saving from discontinuing these normal school places of £190,000 producing a net additional cost of £203,000.

Discussions have also started with the Headteacher of Southfield about the future of specialist ASD provision in that school.

- 1.5 It will be possible to fund 3 mainstream bases in 2003/04. Work is now underway to identify the most appropriate locations and priorities for admission.
- 1.6 The Additional Teaching and Welfare budget has also been increased to take account of the growing number of children being identified with Autistic Spectrum Disorder.
- 1.7 The Teachers Standards Fund has also been used to identify sufficient resource to support a range of training programmes in mainstream and special schools including :-
- (a) University of Birmingham Distance Learning Course for 21 teachers, nursery nurses and learning support assistants
 - (b) Hertfordshire Accredited Module at University of Birmingham for 40 mainstream and special school staff
 - (c) Mainstream 2-day course and twilight support groups for 240 teachers and learning support assistants
 - (d) One day targeted courses for 20 schools with children following behavioural programmes on roll
 - (e) One day awareness raising course for secondary SENCOs
 - (f) Development, training and set up costs for new mainstream Support Bases

- 1.8 Further work has also been commissioned to identify and evaluate evidence of the effectiveness of different types of intervention with autistic children. This includes participation in a research programme led by University College London covering development work in 20 Local Authorities. This will help to ensure that Hertfordshire continues to learn and build further on good practice.

2 Additional work completed during phase two of the scrutiny process

16+ Provision

- 2.1 Parents have repeatedly highlighted their concerns about the lack of any consistent pattern of provision beyond statutory school age. For a number of the students concerned, this could significantly improve their prospects of living independently and finding long-term employment.
- 2.2 Visits took place to the “Stopgap Project” which provides life-skills and preparation for employment in Hemel Hempstead, and to a specialist resource at Harlow College which also offers a range of vocational and life-skills training. Both courses cater for students with a wide range of needs and their effectiveness demonstrates the need to explore the possibility of specialist provision in at least some Hertfordshire FE Colleges.
- 2.3 *It is recommended that further discussion should take place with local colleges and the Learning and Skills Council to explore the possibility of developing further 16+ provision.***

Primary-secondary transfer

- 2.4 This is another area of particular concern for parents, pupils and staff. Pilot projects to support phase transfer have been established in Stevenage at Barclay school and in Watford at Parmiters school. These have demonstrated the importance of careful planning and preparation; of the timely exchange of information, and of appropriate training and advice for receiving staff. Research shows that some ASD pupils find the onset of adolescence unsettling and for many Year 8 can be particularly demanding. Experience to date indicates that a smooth transfer and a good start to secondary education can lessen these problems.

2.5 It is recommended that programmes to support pupils with autism and Asperger Syndrome during secondary transfer be developed. To support the transition process the following need to be developed and shared with schools :-

- (a) transfer protocols covering, for instance, exchange of information, visits, preparatory work with children and families etc.**
- (b) awareness raising courses and good practice guidance for secondary SENCOs and support staff**
- (c) information for parents and pupils**

Meetings with parents and voluntary organisations

2.6 Life with an autistic child can be very stressful and the Topic Group was very aware of the vital role played by parent support groups in this area. The Regional Co-ordinator of the National Autistic Society met the Topic Group on 29 October to explain the work of his organisation and confirm the key issues of concern for parents nationally and locally. These closely reflected the messages already received by the Topic Group and Scrutiny Committee and included: -

- the importance of early intervention
- levels of available funding
- increasing numbers of children being identified
- the value of joint clinics involving education, health and social services
- the key role of Health Visitors in early identification and support
- the enormous variability of provision
- the importance of access to information, telephone help-lines and support groups.

2.7 A follow up meeting with HARC (Hertfordshire Autism Resource Centre) was held on 13 November. Key issues emerging from this included: -

- the importance of establishing specialist mainstream school bases
- the value of the Specialist Autism Advisory Service and particularly its pre-school intervention programme
- the need for an adequate supply of places in special school bases with opportunities, as appropriate, for transition into mainstream bases or ordinary classes
- the importance of awareness raising and staff training
- the need for diversity of provision (“one size doesn’t fit all”)
- concern about the uneven distribution of provision
- continued concern about transition, 16+ provision, respite provision and the need for social work and other staff to work together more closely
- the particular challenges of adolescence for ASD children
- the need for increased family support

- the value of Health Visitors but a generally patchy level of support from health services
- pressures on some parents to keep their children away from school during Ofsted inspections, school trips etc.
- the need for a residential facility within Hertfordshire

2.8 A number of these issues have been addressed as part of the scrutiny process and follow-up activity. However on the basis of the representations of Hertfordshire parents and carers, ***it is recommended that :-***

- (a) work with NHS Trusts should continue to emphasise the importance of early diagnosis and should accelerate the process of establishing contact with parents after a diagnosis has been made.***
- (b) consideration should be given to increasing respite and shared care opportunities for the families of ASD children***
- (c) consideration should be given to developing out-of school activities for ASD children through the Youth Service and voluntary organisations***

Applied Behaviour Analysis (ABA)

2.9 The Specialist Autism Advisory Service offers a home support service which provides up to 10 hours direct teaching per week in conjunction, where appropriate, with part-time attendance at a pre-school, nursery and/or Opportunity Class. Some parents opt instead for an intensive, step-by step behavioural approach based on original work in America by Dr Lovaas. For younger children this is a home-based programme, using individual workers who are specially trained and supervised by one of a number of independent providers. PHEAT (“Parents of Hertfordshire for Early Autism Intervention Today”), which is the main local support group for parents using this approach, has been active in providing information and opportunities for members of the Topic Group to see this teaching model in action.

2.10 The Topic Group met with 16 members of PHEAT on 22 October. The meeting stressed the importance of early and intensive interventions and looked at the benefits of ABA programmes using case studies and personal experiences. Follow-up visits were arranged to two primary schools where successful integration programmes had taken place following home-based ABA programmes. A visit was also arranged to the Treehouse School in London, which successfully uses ABA techniques with 32 pupils aged 4 to 11 years.

2.11 Further evidence was provided on 24 January by the Director of Clinical Services for the London Early Autism Project and an independent educational psychologist specialising in this area of work.

- 2.12 The Topic Group recognises that for some parents, ABA programmes offer the preferred option for helping their children. However it is also recognised that this approach does not suit all children and families.
- 2.13 ***It is recommended that officers continue to work with the Trustees of PHEAT to:-***
- (a) develop a collaborative approach towards planning and monitoring the effectiveness of ABA and other approaches***
 - (b) ensure effective transition from ABA programmes to appropriate longer term school provision***
 - (c) negotiate with providers to maximise value for money for Hertfordshire children***
- 2.14 ***It is also recommended that in appropriate cases, support with ABA programmes is offered as an alternative to the Council's pre-school service. Such arrangements should be closely monitored, time-limited and linked to planned programmes for phasing out the support as the child reaches school age. This work should be linked to the research programme led by University College London (see para 1.8 above).***

Meetings with health personnel

- 2.15 All parents spoken to during the scrutiny process have stressed the importance of early diagnosis. There are 5 multi-disciplinary diagnostic clinics in Hertfordshire and good liaison arrangements between Health professionals and specialist staff in CSF.
- 2.16 On 24 January the Topic Group met with 17 NHS professionals for a wide-ranging discussion about diagnosis and provision issues. The group included paediatricians, health visitors, speech therapists and service managers. Issues emerging from the discussion included :-
- pressure on available resources and concern about the number of referrals for diagnosis (only about 50% of which are positive)
 - the difficulty of diagnosing ASD before 2 years of age, and the fact that the complex combination of difficulties shown by some children can make an early diagnosis difficult or impossible in some cases. In these cases ongoing support to parents is very important.
 - differences in provision in different parts of the county
 - the importance of the health visitor as a front-line worker with the family and the advantages of having specialist workers within health visiting teams
 - the need for more specialist school nurses
 - the role of speech therapists in diagnosis and treatment
 - the importance of joint working with CSF staff and of good liaison links with SENCOs
 - the need for staff training and awareness raising

- the need for sessions from educational psychologists and advisory teachers in Child Development Centres
- the need to increase levels of provision for older children
- the benefits of joint working arrangements.

2.17 *It is recommended that continued liaison takes place with Health Trusts to ensure that :-*

- (a) ***early diagnosis is given priority***
- (b) ***joint or co-ordinated assessments are undertaken as often as possible***
- (c) ***autistic spectrum disorder is regarded as a priority for future planning and provision of medical and therapy services***
- (d) ***awareness raising and training should be made available to health personnel by the Specialist Advisory Service where possible.***

Specialist Advisory and pre-school home-visiting service

2.18 This service has been mentioned positively by almost everyone from Hertfordshire involved in the scrutiny process. It is also commended by the DfES in its good practice guidance produced following the all-party enquiry into autism.

2.19 Staffing was increased by 8 home visiting nursery nurses and one additional visiting teacher in 2002/03. From January the service has been operating at full staffing capacity. This increases the number of home visits that can be made and should also make it possible for contact to be made more quickly with the parents of newly diagnosed children. The requirements for training, advice and support for children and staff in school settings are now growing.

2.20 *It is recommended that the workload and structure of the Specialist Advisory Service, together with the support needs of schools should be reviewed and reported to the Special Needs Panel in the Autumn.*

Training and professional development

2.21 The importance of awareness raising, training and further professional development has been stressed by every group or school contacted during the scrutiny process. The Topic Group wishes to endorse this sentiment and to stress the absolutely critical role that is played by learning support assistants in contributing to the successful education of children with autistic spectrum disorder.

2.22 The Topic Group feels that the training and development programme planned for 2003/04 is appropriate. ***It is recommended that priority should continue to be given to the training of school support staff in subsequent years and that a register of trained staff should be maintained to ensure that their skills are used to maximum effect.***

3 Other issues for further consideration

3.1 Members of the Topic Group were very impressed by the comments made by students at the Stopgap Project about their educational experiences and needs. It was hoped to have first hand discussions with a number of other young people and adults about the life-long implications of autism and Asperger Syndrome for them. This was not possible within the scrutiny timetable and it is recommended that this work should be carried forward by the Special Needs Panel.

3.2 The question of out-county placements for ASD pupils arose on a number of occasions. At present there are 46 children attending independent schools at an annual cost of £2,477,775. It is recommended that the use of out-county provision and the feasibility of developing local alternatives should be considered by the Special Needs Panel.

3.3 Members of the Topic Group would like to formally record their thanks to all the parents, staff and children who have contributed to this scrutiny. Their enthusiasm, commitment and determination have been apparent at all stages in the process. We believe that there is a firm foundation for further work both to improve the life chances of children and adults in Hertfordshire with Autistic Spectrum Disorder. A separate and more detailed report of the findings of the Scrutiny Topic Group will be produced and circulated to Members and those participating in the scrutiny.

4. Financial implications

4.1 The estimated resource implications of the additional provision described in this report for 2003/04 are as follows: -

ACTIVITY	COST (£000)
Additional special school places	203
3 mainstream support bases	163
Additional teaching and welfare for Statements	200
Training and development	65

4.2 These resources are included in the planned 2003/04 revenue budget, bringing the total predicted spend up to :-

PROVISION	COST (£000)
Specialist Support Service	418
Specialist units and bases	1663
Additional teaching and welfare for Statements, including ABA programmes	1929
Out-county provision	2992
Other LEA provision	85
Training (Standards Fund)	65

Background material referred to by the author while compiling this report:

Provision for Pupils with Autism and Asperger Syndrome	SEN Panel	2 Oct 1998
Provision for Pupils with Autistic Spectrum Disorders	SEN Panel	27 Nov 1998
Provision for Autistic Pupils	SEN Panel	1 Oct 1999
Update on Provision for Pupils with Autistic Spectrum Disorder	SEN Panel	16 Feb 2001
Update on Provision for Pupils with Autistic Spectrum Disorder	SN Panel	19 Sept 2001
Update on Provision for Pupils with Autistic Spectrum Disorder	SN Panel	5 Dec 2001
Provision for Children and Young People with Autistic Spectrum Disorder	Scrutiny Committee	19 June 2002
Minutes of Autism Scrutiny Topic Group		5 July 2002
Minutes of Autism Scrutiny Topic Group		26 September 2002
Minutes of Autism Scrutiny Topic Group		24 January 2003
Minutes of Autism Scrutiny Topic Group		19 February 2003

If you require further information about the issues referred to in this report please contact: Alan Sapsford, Telephone: 01992 588500

APPENDIX 1

SCRUTINY VISITS

School	Date	Group Members	Officer
Middleton School	Monday 15th July	Councillors Derek Hills and Moyra O'Neill	Yvonne Morey
Amwell View School	Wednesday 17th July	Councillors Derek Hills, Barbara Lamb, Eleanor Clarke, Lorna Kercher and Mrs Pat Cherry	Alan Sapsford
The Valley School	Wednesday 17th July	Councillors Derek Hills and Lorna Kercher	Angela Dyer
Rye Park Nursery	Monday 9th September	Councillors Derek Hills, Eleanor Clarke and Mrs Pat Cherry	Angela Dyer
Watling View School	Monday 9th September	Councillors Derek Hills, Eleanor Clarke and Mrs Pat Cherry	Alan Sapsford
Samuel Whitbread Upper School	Tuesday 17th September	Councillors Tanis Kent and Derek Hills	Alan Sapsford
Edith Cavell School	Tuesday 17th September	Councillors Tanis Kent and Derek Hills	Alan Sapsford
Ramsey Manor Lower School	Tuesday 17th September	Mrs Pat Cherry	Sue Westgate
Arnold Middle School	Tuesday 17th September	Mrs Pat Cherry	Sue Westgate
New Briars Primary and Nursery School	Monday 23rd September	Councillors Moyra O'Neill, Barbara Lamb and Derek Hills	Angela Dyer
Princes Risborough Primary School	Tuesday 24th September	Councillors Moyra O'Neill, Tanis Kent and Derek Hills	Alan Sapsford
Princes Risborough Secondary School	Tuesday 24th September	Councillors Moyra O'Neill and Derek Hills	Alan Sapsford
The Stopgap Project	Monday 4th November	Councillors Eleanor Clarke, Derek Hills, Mrs. Pat Cherry	Alan Sapsford
The Barclay School	Thursday 7th November	Councillors Eleanor Clarke, Barbara Lamb, Derek Hills and Mrs. Pat Cherry	Angela Dyer
HARC	Wednesday 13th November	Topic Group	Alan Sapsford
Harlow College	Thursday 14th November	Councillors Eleanor Clarke, Barbara Lamb, Derek Hills, and Mrs. Pat Cherry	Angela Dyer
The Tree House School	Friday 29th November	Councillors Eleanor Clarke, Barbara Lamb, Moyra O'Neill, Derek Hills, Mrs. Pat Cherry and Ms Jessica Linskill	Angela Dyer

School	Date	Group Members	Officer
Barkway School	Thursday 5th December	Councillors Derek Hills	Sue Westgate
Bonneygrove School	Thursday 5th December	Councillors Eleanor Clarke, Barbara Lamb, Mrs. Pat Cherry	Angela Dyer
Colnbrook School	Friday 6th December	Councillor Barbara Lamb	unaccompanied
Harper House	Wednesday 18th December	Councillors Eleanor Clarke, Derek Hills, Barbara Lamb, Mrs. Pat Cherry	Angela Dyer
Woodfield School	10th December or	Councillors Derek Hills, and Mrs. Pat Cherry	Angela Dyer
Presentation by Allan Willis and Dr Maggie Anderson (Director of Clinical Services for London Early Autism)	24th January 2003	Eleanor Clarke, Derek Hills, Tanis Kent, Lorna Kercher, Moyra O'Neill	Alan Sapsford
Presentation and discussion with Health Professionals	24th January 2003	Eleanor Clarke, Derek Hills, Tanis Kent, Lorna Kercher	Alan Sapsford
Bonneygrove School	13th January 2003	Derek Hills and Tanis Kent	Angela Dyer
Radlett Lodge	28th January	Eleanor Clarke, Derek Hills, Tanis Kent, and Pat Cherry	Angela Dyer
Parmiters School	28th February	Derek Hills, Eleanor Clark, Barbara Lamb, Pat Cherry	Yvonne Morey t.b.c.
Jigsaw	14th March	Derek Hills and Pat Cherry	Angela Dyer and Yvonne Morey

APPENDIX 2

SUMMARY OF RECOMMENDATIONS

1. Further discussion should take place with local colleges and the Learning and Skills Council to explore the possibility of developing further 16+ provision (para 2.3)
2. Programmes to support pupils with autism and Asperger Syndrome during secondary transfer be developed. To support the transition process the following need to be developed and shared with schools (para 2.5): -
 - a) transfer protocols covering, for instance, exchange of information, visits, preparatory work with children and families etc.
 - b) awareness raising courses and good practice guidance for secondary SENCOs and support staff
 - c) information for parents and pupils
3.
 - a) Work with NHS Trusts should continue to emphasise the importance of early diagnosis and should accelerate the process of establishing contact with parents after a diagnosis has been made.
 - b) Consideration should be given to increasing respite and shared care opportunities for the families of ASD children
 - c) Consideration should be given to developing out-of school activities for ASD children through the Youth Service and voluntary organisations
4. Officers continue to work with the Trustees of PHEAT to (para 2.13): -
 - a) develop a collaborative approach towards planning and monitoring the effectiveness of ABA and other approaches
 - b) ensure effective transition from ABA programmes to appropriate longer term school provision
 - c) negotiate with providers to maximise value for money for Hertfordshire children
5. In appropriate cases, support with ABA programmes is offered as an alternative to the Council's pre-school service. Such arrangements should be closely monitored, time-limited and linked to planned programmes for phasing out the support as the child reaches school age. This work should be linked to the research programme led by University College London (para 2.14)
6. Continued liaison takes place with Health Trusts to ensure that (para 2.17): -
 - a) early diagnosis is given priority
 - b) joint or co-ordinated assessments are undertaken as often as possible
 - c) autistic spectrum disorder is regarded as a priority for future planning and provision of medical and therapy services

- d) awareness raising and training should be made available to health personnel by the Specialist Advisory Service where possible.
- 7. The workload and structure of the Specialist Advisory Service, together with the support needs of schools should be reviewed and reported to the Special Needs Panel in the Autumn (para 2.20).
- 8. Priority should continue to be given to the training of school support staff in subsequent years and that a register of trained staff should be maintained to ensure that their skills are used to maximum effect (para 2.22).