

Report to: **Scrutiny Committee for Children's Services**

Date: **19 September 2007**

Title of Report: **Autistic Spectrum Disorder Policy and Strategy**

By: **Director of Children's Services**

Purpose of Report: **To invite the Committee's comments on the draft Autistic Spectrum Disorder policy and strategy documents**

Recommendations:

The Committee is asked to:

- 1. consider and comment on the draft Autistic Spectrum Disorder (ASD) policy document (Annex 1); and**
 - 2. consider and comment on the Children's Services Authority Autistic Spectrum Disorder (ASD) strategy document (Annex 2)**
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1. Financial Appraisal

1.1 The financial implications of the ASD policy relate to a small amount of printing costs for the document itself and registration costs for schools, services and settings which seek accreditation through the National Autistic Society (NAS), which are around £2,000 per setting/service. These costs can be contained within existing budgets. The financial implications of the ASD strategy relate to the costs of establishing with the Health Service a multi-agency diagnostic service and additional ASD special facilities attached to mainstream schools. These additional revenue costs for the special facilities can be covered through redirection of existing resources in order to achieve best value for money. However, there will be a need to make further 'invest to save' proposals to cover additional revenue and capital costs over the medium term while these savings are achieved.

2. Supporting Information

2.1 The development of the two documents attached as Annexes 1 and 2 arose from the Special Educational Needs (SEN) Review which recommended that the Children's Services Authority should 'review the range and scope of East Sussex maintained specialist provision, with the aim of increasing flexibility and reducing out of county placements, and develop plans for multi-agency co-ordinated services for children with ASD and their families'.

2.2 A number of actions have been undertaken towards achieving this recommendation, including:

- a) A specialist facility has been established by Heathfield Community College. This facility caters for young people with high functioning autism but who require the additional support that a specialist facility can provide.
- b) A specialist unit has been established by New Horizons School, St Leonards, which caters for young people with autism and extremely challenging behaviour.
- c) A specialist facility is under development by Manor Primary School, Uckfield, which will cater for primary aged pupils with ASD who require additional specialist support.
- d) A review of all special facilities attached to mainstream secondary schools has been completed which identifies improvements to the range of facilities in the county, and the establishment of a network of secondary ASD facilities similar to the Heathfield facility.
- e) An ASD Co-ordinator has been appointed.
- f) Three Multi-agency Primary ASD Monitoring and Support Groups have been established to oversee support to children with ASD and their families across the county.

- g) A Multi-agency Secondary ASD Reference Group has been established which is overseeing the development of specialist support for secondary school aged children.
- h) The three Sussex local authorities have received funding through the Department of Children, Schools and Families (DCSF) to establish a regional centre of expertise for ASD involving a secondary specialist provision in each area. In East Sussex the lead for this work is undertaken by Heathfield Community College working in partnership with the Educational Psychology Service. The work has focused on improving transition from primary to secondary schools for children with ASD.
- i) Discussions have begun with Hastings College of Arts and Technology (HCAT) which is the lead college for ASD in the region, as identified by the Learning and Skills Council, to promote the smooth transition of young people with high functioning autism.
- j) Seven special schools, three mainstream schools (Heathfield Community College, Manor Primary School and Bexhill High School) and the two short break services for disabled children are working together to achieve autism friendly accreditation through the National Autistic Society.
- k) The Children's Disability Service is seeking to establish an ASD Service which will work with local providers to increase access to leisure and out of school activities for children and young people with autism.

2.3 To underpin this development work, an ASD strategy for the Children's Service Authority has been produced.

2.4 In addition, a draft ASD policy has been developed. A team of multi-agency professionals from across East Sussex came together to undertake this work. The group, chaired by the newly appointed ASD Co-ordinator, represented the following agencies/services: paediatricians; CAMHS; headteachers; special school outreach services; early years; the Language and Learning Support Service; therapies; voluntary agencies; and parents. Once the outline of the policy had been drafted, a group of young people with ASD were invited to discuss and contribute to the policy in two separate sessions. Their comments and illustrations have been included in the draft document. As a result of the work with the young people, a short DVD has been made that will be used to alert professionals to the needs and hopes of children and young people with ASD.

2.5 The professionals met five times to discuss how the vision for ASD could be met through the policy by a wide range of services/settings. Policies from other authorities were scrutinized, along with current, relevant initiatives, including Every Child Matters (2003), ASD Good Practice Guidance (2002), the Disability Equality Duty (2006), and the SEN Code of Practice (2001). The aim was to produce a document that would be accessible and relevant to all settings and provisions.

2.6 The policy has been circulated to schools, and has been a focus for discussion at the Primary and Secondary Education Strategic Management Board meetings. The Disabled Children's Development Group, which is a specialist group of the Children's Trust, has discussed and agreed the policy. The Group recommended that the policy should be adopted by the Children's Trust Executive Group. The policy and strategy documents will be the subject of consideration by Children's Services Lead Members at their meeting on 12 October 2007.

3. Conclusion and Reason for Recommendations

3.1 Both the policy and strategy documents will provide the underpinning for short and medium term future development work within the county for children with ASD and their families. The Committee is asked to consider the documents and is recommended to support the endorsement of the draft policy and strategy documents by the County Council and its Children's Trust partners.

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Local Members: All
BACKGROUND DOCUMENTS: None



DRAFT

Autistic Spectrum Disorder Policy



My view of Autism

'The rainbow is like a spectrum and we respond best 1:1'
(By Millie aged 13)

East Sussex
Children's Services

Vision:

East Sussex Children's Services believes that all children and young people with an Autistic Spectrum Disorder (ASD) should have access to high quality services and be able to participate in a wide range of everyday and leisure activities as other children do. Their families should have access to effective support from services and staff should have the necessary knowledge and skills to work effectively.

Key Principles: the Policy will

- Provide a framework relating to children and young people with ASD
- Continue to develop and implement a continuum of provision
- Recognise and seek to maximise each child and young person's potential
- Acknowledge the need to work collaboratively with children/young people and their families
- Encourage all schools, settings and services to achieve autism friendly status and/or work towards autism accreditation
- Work towards ensuring that the requirements of the Every Disabled Child Matters Local Authority Charter are met for all children and young people with ASD

Definition:

An autistic spectrum disorder is a lifelong, complex developmental disability that affects the way a person communicates and relates to people around them.

Autistic spectrum disorder is an umbrella term used to describe the subgroups within the spectrum of autism including Asperger Syndrome. The idea of a spectrum is useful because it shows that there is a range of characteristics, indicating that individuals with autistic spectrum disorders differ from each other in terms of the severity of their autism and their intellectual ability. No two individuals are affected in exactly the same way. There are differences between the subgroups within the spectrum but all individuals with ASD share a triad of impairments in their ability to:

- Understand and use non-verbal and verbal communication (for example, not fully understanding the meaning of gestures, facial expressions or tone of voice)
- Understand social behaviour which affects their ability to interact with children, young people and adults
- Think and behave flexibly — which may be shown in restricted, obsessional or repetitive activities, a limited imagination and/or difficulty with change

Some children and young people with ASD have a different perception of sounds, sights, smell, touch and taste, which affects their response to these sensations.

They may also have coordination and planning difficulties and unusual sleep and behaviour patterns.

All the above difficulties mean that the children and young people are often highly anxious from trying to make sense of the world, and this may have an effect on their behaviour.

Children and young people of all levels of ability can have ASD. In recent years there has been an increase in the number of children and young people identified with autistic spectrum disorders.

Roles and responsibilities:


East Sussex Children's Services will seek to

- make sure that the services and provision for children and young people with ASD are further developed as necessary, well publicised and accessible
- provide early support, advice and guidance to families when their child is identified as having an ASD
- ensure that the services work in partnership with parents/carers and the voluntary sector in order to provide an integrated service
- make sure that staff and parents/carers have access to a broad range of training opportunities
- support all provisions, services and settings to become ASD-friendly
- promote the accreditation of our specialist services and schools through the National Autistic Society
- have close links with all relevant agencies to promote successful transitions between stages of education, including to post-16 provision
- support the development of expertise and provision for young people post-16

All provision, including pre-school, schools and other settings, will seek to be ASD friendly by

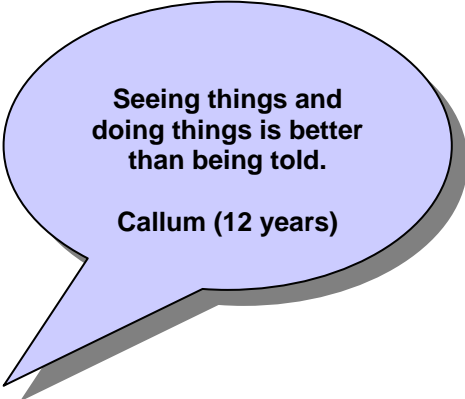
- working closely with parents or carers and their families, consulting them about the child or young person
- including children and young people in planning and decision making
- making sure a named member of staff is available to discuss any concerns the child or young person with ASD may have

- supporting families by ensuring that out of school activities include provision for children and young people with ASD
- ensuring that activities and the curriculum on offer to the child or young person with ASD are tailored to meet their needs
- raising awareness with children and young people of disability, including ASD
- modifying the environment as far as possible to take account of individual difficulties with sensory stimuli experienced by some children and young people with ASD
- providing opportunities for children and young people with ASD to generalise skills learnt in one setting/lesson to other situations/settings
- recognising that Information and Communications Technology can be a particularly effective medium for children and young people with ASD
- making sure all staff are aware of this policy
- making sure all staff are aware of their duties under the SEN Code of Practice and the Disability Equality Duty to identify children and young people's needs, including those with ASD
- having a named person who can provide guidance to staff, ensuring that all who come into contact with a child or young person with ASD are aware of their particular strengths and needs
- encouraging staff with knowledge and experience of children with ASD to share their expertise
- keeping an up-to-date bank of information and resources about ASD for use by staff and parents or carers
- keeping up-to-date records of staff ASD training
- ensuring successful transition between schools/settings by exchanging accurate and up-to-date records and ways of working with the child or young person with ASD
- working closely with post-16 providers to ensure a smooth transition to post-16 provision for young people with ASD



People don't have to be perfect as long as they understand.

Ed (15 years)



Seeing things and doing things is better than being told.

Callum (12 years)

ASD Strategy 2007-2012

Background

This strategy has been developed as a result of the review of SEN provision which was undertaken in East Sussex in 2005. The review identified the increasing population of children and young people with autism and the need to develop a range of support services and provision to meet their needs and those of their families.

More recently, the County Council has established a Children's Services Department to address the key aims of Every Child Matters and to work with other key partners to set up a Children's Trust which will provide integrated services to children.

The National Autistic Society's 'Make School Make Sense' campaign has highlighted the range of issues faced in school by children with ASD.

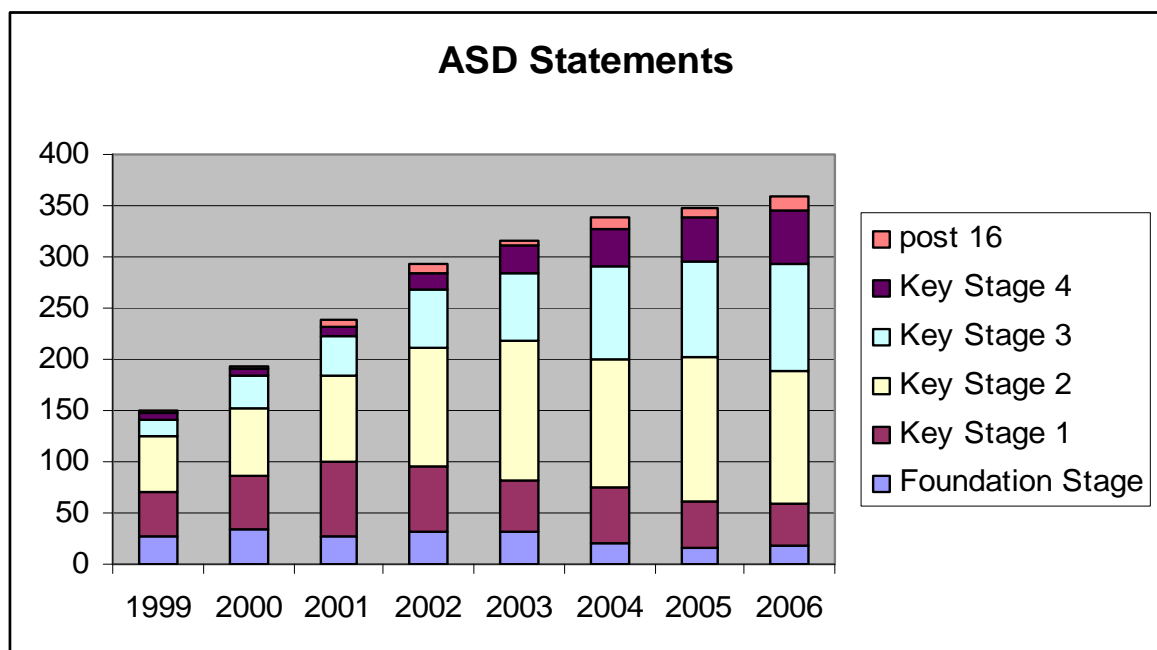
This strategy supports the aim of the East Sussex ASD Policy which sets out the Council's aim that all services and educational settings should become ASD friendly.

The Current Position

a. Data

The National Autistic Society currently believes that about 1 in 100 children have an ASD. This would mean that there could be about 1200 children living in East Sussex who have an ASD.

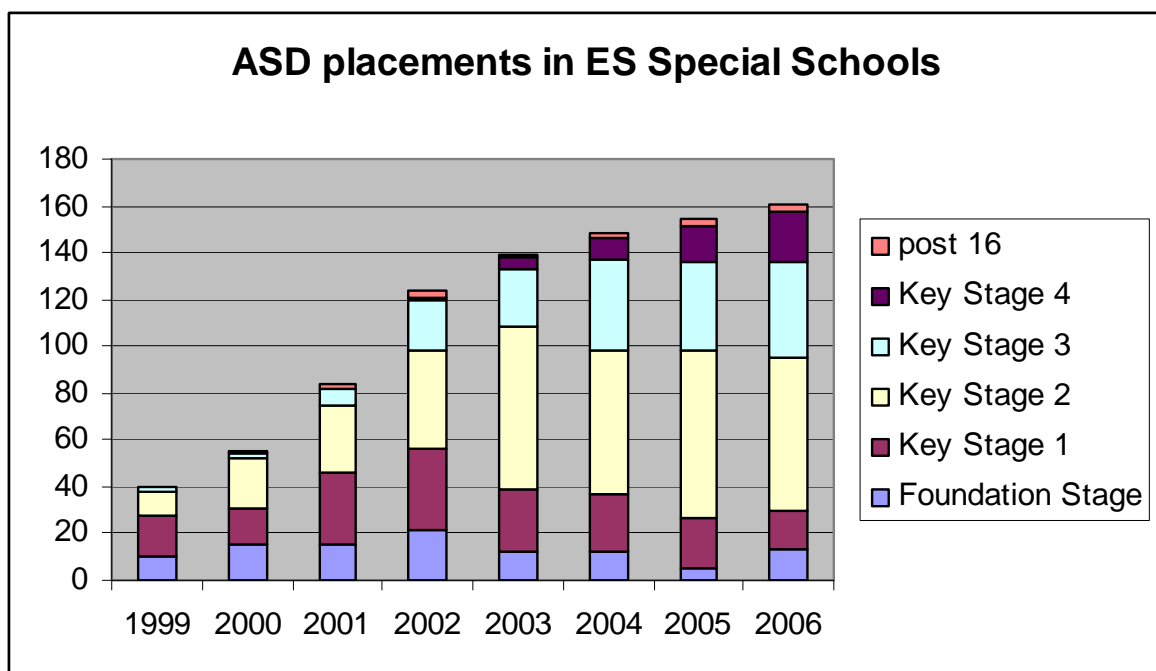
There are 360 children with statements of special educational need for ASD. This figure has more than doubled since 1999.



The number of statements in the 0-11 age range has broadly stabilised since 2002 at around 200. However, the number of statements in the 11-19 age range continues to increase and is likely to be around 230 in the next couple of years. Therefore, it seems likely that the total number of statements for ASD will stabilise at around 430 in the near future.

However, not all children with ASD require a statement of SEN and the number of children supported at school action or school action plus was 142 in January 2006. This has increased from 84 in January 2004. The greatest increase has been in the 11-19 age range. The proportion of children with ASD out of all children supported at school action or school action plus has increased over the last two years.

There are 161 children with ASD attending East Sussex maintained special schools. This has increased more than four fold since 1999.



In a similar way to the overall number of statements, the number of placements in East Sussex special schools in the 0-11 age range has broadly stabilised since 2002 at around 100. However, the number of statements in the 11-19 age range continues to increase and is likely to be around 90 in the next couple of years. Therefore, it seems likely that the total number of East Sussex special school placements for ASD will stabilise at around 190 in the near future.

A similar pattern exists for placements in independent and non-maintained special schools. There has been a steady increase in placements in the secondary age range. It is likely that this is due to the lack of local provision for young people with high functioning autism who require a mainstream curriculum. The data shows that there is likely to be a demand for 40-50 additional local placements that cater for young people with high functioning autism.

The data reveals that the rate of increase in the number of statements for ASD is nearly twice as high in the east of the county as in the west. The greatest increase has been in the Hastings and St Leonards area where the numbers have nearly

doubled since 2001. This rate of increase far outstrips the other areas which have only had about a 50% increase over that period.

b. Issues

- o Early identification, assessment, intervention and support

There are clear benefits to the identification of ASD at an early stage as it allows support to families and educational settings to be provided in a more timely fashion. By the time there is a request for statutory assessment of SEN it is often the case that things have started to go wrong, and it would be more effective for the support to have been provided earlier and more speedily.

The NAS reports that 40% of children wait more than 3 years for a clear diagnosis and that 21% of children with ASD have been excluded from school at least once.

- o Information for families

Parents have indicated that they would welcome opportunities to meet with other parents in a similar situation and have greater access to training, support, advice and guidance.

- o Equality of access

The pattern of specialist educational provision for ASDs in East Sussex and the pattern of outreach support to mainstream schools is not even over the county. It will be important to ensure that there is equality of access to provision as far as possible from all areas of East Sussex.

- o Continuum of provision

The quality of educational provision for children with ASDs and learning difficulties is very high in East Sussex. However, there is a lack of specialist provision for young people with high functioning autism. There is also a need to ensure that there are appropriate post-16 education and training opportunities for young people with ASD and to ensure that the transition at all stages of education is well managed.

- o Increasing skills and expertise

School and service staff require high quality and targeted ongoing training in meeting the needs of children with ASD and their families. There is already a substantial programme of training for school staff, especially in the primary sector, to which parents are also invited but there is a need to extend the availability to other staff groups.

- o Out of School and Leisure Activities

Children and young people with ASDs are often not able to take part in out of school activities and other local leisure opportunities because of their disability. There is a need to develop skills in the sector and to encourage and support local settings to include children with autism. This will support the mental and emotional well-being and development of the children and support their families to have a greater degree of normality in their everyday lives and in the community.

- Supporting Family Life

Families of children with disabilities are much more likely to have low incomes than the general population. They find it difficult to access childcare and to maintain employment. The stresses and strains on families of having a child with ASD are well documented.

Key Priorities

In order to address the issues highlighted above, East Sussex Children's Services Authority, in consultation with key partners and parents of children with ASD, has identified the following key priorities:

- Multi-disciplinary integrated early identification, assessment and support
- Support, training and development
- Developing educational provision
- Co-ordinating specialist services
- Increasing family support
- Increasing opportunities for leisure and out of school activities
- Improving transition – (Regional Centre of Expertise)
- Increasing the consultation and participation of children and young people with ASD and their families – (person centred reviews, parent focus groups, parent participation strategy, children's participation strategy)

We are working together with partners to have:

1. Multi-disciplinary assessment of ASD
2. Clear and effective information for parents from the point of diagnosis
3. An integrated response to early identification, providing a co-ordinated approach to the provision of specialist services through the ASD Monitoring and Support Groups
4. A range of educational provision which provides a wider choice for parents, including developing 7-8 specialist facilities attached to mainstream secondary schools and 10-12 attached to mainstream primary schools, and a wider range of opportunities for post-16 education, training and employment
5. A comprehensive training, support and development programme for professionals and parents, including outreach from specialist provision
6. A network of outreach/partnership support to mainstream services from specialist services
7. All specialist educational provision and central services accredited by the National Autistic Society
8. A range of family support services, including specialist social care teams, parent focus/support groups and improved access to respite, childcare and out of school activities
9. Improved transition pathways at all stages, including to adult services, where appropriate, and involving children and young people in decisions about their future and the services they receive
10. Effective partnerships with parents, including building on the Early Support Programme to have a lead professional where appropriate

Useful Materials:

Inclusion in the secondary school: support materials for children with autistic spectrum disorders by Joy Beaney and Penny Kershaw. £10.99 (NAS 658, ISBN 978 1 905722 02 0)

Copies of the book can be ordered from The National Autistic Society's distributor: Central Books Ltd, Tel 0845 458 9911, fax 0845 458 9912, email nas@centralbooks.com; or order online:

www.autism.org.uk/pubs/recommended

Joy and Penny are authors of Inclusion in the primary classroom: support materials for children with autistic spectrum disorders £8.99, also published by the NAS (NAS 495, ISBN 978 1 899280 95 7)