

# **Review of educational provision in Hertfordshire for children and young people on the autism spectrum**

**Dr Glenys Jones, June 2015**

**Executive Summary**

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## **Acknowledgements**

Very many people have contributed to this review and there are too many to mention them all individually. Special thanks go to Pamela Reitemeier and Leise Cooper who convened and facilitated all the meetings with parents and carers and to all the parents who attended these or sent emails giving their views. Thanks also go to all the teaching staff, parents, support staff and children in DSPLs 4, 7 and 9 who worked very hard on the tasks set for the review. Stuart Bayer assisted with the generation of data on the children with autism and their placements and Peter Gray helped with the analysis and discussion of issues arising. Several members of the Communication Disorders Team and the Educational Psychology Service also spent time exploring issues and giving their views. Debbie Orton, Head of ISL for Hertfordshire County Council, Helen Booth, and others on the Steering Committee also gave a lot of time to this review on top of their usual workload. Finally, many thanks to Sue Westgate and Nicola Coates for their efficiency in arranging and convening meetings and conferences and in producing and circulating the documents needed for the review.

## **Note on terminology and the autism spectrum**

The term autism is used throughout this report to include all those children on the autism spectrum, that is, those with Asperger syndrome\*\*, high functioning autism, autism, semantic pragmatic disorder and pathological demand avoidance syndrome. It is also recognized that some children with autism will have other conditions, the most common being learning disabilities. Some will have medical or genetic conditions such as epilepsy, tuberous sclerosis and Fragile X. Others will have sensory and physical disabilities including cerebral palsy, dyspraxia, visual and hearing impairments. A number of children with autism will also have dyslexia and dyscalculia.

\*\*The use of the term Asperger syndrome has been debated in the UK and the US and the most recent version of the American diagnostic system, DSM – Diagnostic and Statistical Manual (DSM-V) no longer has Asperger syndrome as a diagnostic category, preferring instead to use the umbrella term of autism spectrum for all forms of autism. The rationale for this is that it is very hard to distinguish between those with Asperger syndrome and people with autism who are of average ability or above. However, as there are still many useful books and resources and websites which refer to Asperger syndrome, it is useful for parents and carers and professionals to consult these. Children and young people diagnosed in the past with Asperger syndrome will retain their diagnosis.

## **ASD or ASC or autism?**

There is currently debate in many local authorities, schools and services as to which term to use – Autism Spectrum Disorder (ASD) or Autism Spectrum Condition (ASC) or autism spectrum or just autism. Some local authorities have opted to change to the term ASC. It has been suggested by some that ASC might be best used by those in education and social care and that ASD might be best used by health. There is a need to balance a respect for the wishes of the more able group within the autism spectrum, who do not want to be viewed as disabled or deficient – and argue that if schools and society generally were adjusted to acknowledge the differences in autism, they would not experience significant difficulties. On the other hand, there are some parents and adults with autism and learning disabilities, or whose autism seriously affects their ability to engage with others and to succeed in life, who want to keep the term disorder so that their needs are recognized and taken seriously by health, education and social care.

It would be helpful if Hertfordshire LA could reach a consensus on the terminology and abbreviation they use to refer to children and adults on the autism spectrum across education and social care. It would also be useful to consider a different name for the current Communication Disorders Team. It is likely that health may prefer to use ASD as this is the medical diagnostic label but increasingly in education the term disorder is no longer used and children are referred to having autism or being on the autism spectrum.

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## Glossary

Abbreviation	Stands for
<b>AET</b>	Autism Education Trust
<b>ASC</b>	Autism Spectrum Condition
<b>ASD</b>	Autism Spectrum Disorder
<b>CAMHS</b>	Child and Adolescent Mental Health Services
<b>CD</b>	Communication Disorders
<b>DCSF</b>	Department for Children, Schools and Families
<b>DfE</b>	Department for Education
<b>DoH</b>	Department of Health
<b>DSM</b>	Diagnostic & Statistical Manual of Diseases (American Psychiatric Association)
<b>DSPL</b>	Delivering Special Provision Locally
<b>ENF</b>	Exceptional Needs Funding
<b>EHC</b>	Education and Health Care Plan
<b>EP</b>	Educational Psychologist
<b>EPS</b>	Educational Psychology Service
<b>ESC</b>	Educational Support Centre
<b>FE</b>	Further Education
<b>HFA</b>	High Functioning Autism
<b>LA</b>	Local Authority
<b>LD</b>	Learning Disability
<b>LSA</b>	Learning Support Assistant
<b>NAS</b>	National Autistic Society
<b>NIASA</b>	National Initiative in Autism: Screening and Assessment
<b>OfSTED</b>	Office for Standards in Education
<b>OT</b>	Occupational Therapist
<b>PSB</b>	Primary Support Base
<b>SALT</b>	Speech and Language Therapist
<b>SEN</b>	Special Educational Needs
<b>SENCo</b>	Special Educational Needs Coordinator
<b>SEND</b>	Special Educational Needs and Disability
<b>SEBD</b>	Social emotional and behavioural difficulties
<b>SLD</b>	Severe Learning Disabilities
<b>TA</b>	Teaching Assistant

# Executive Summary

## Contents of the Executive Summary

- 1 Aims of the review
- 2 Methods and timescale of the review
- 3 Main findings of the review
- 4 Recommendations

## 1 Aims of the review

- To identify the key issues and concerns of parents, schools, services, children and young people in relation to the education of children and young people with autism (0 to 25 years) and to identify valuable strategies and sources of support
- To clarify what is on offer by Hertfordshire County Council for pupils with autism
- To consider how to enhance the provision for pupils with autism and to increase a school's capacity to take a wider range of children
- To make recommendations to make the best use of the resources available

## 2 Methods and timescale of the review – four phases

### Phase 1: (March 2014 to May 2014)

Discussions with parents and professionals to identify some of the issues and a survey to schools with key questions. Parents and carers were also invited to complete a brief form to give information on the school experiences with their children with autism.

### Phase 2: (May 2014 to October 2014)

Explore the main issues identified in Phase 1 by asking 3 of the 9 DSPL areas to consider ideas around 4 areas of work, as follows:

#### **Task 1: Evaluating and enhancing whole school practice**

The AET National Autism Standards were piloted in a number of mainstream schools and special provisions and staff were asked to consider the proposal to have a named member of staff who was the lead for autism

#### **Task 2: Parent/carers involvement with schools**

A selection of schools was asked to identify the key methods used to involve and inform parents and carers about their child and to identify the barriers to effective staff-parent engagement

#### **Task 3: Understanding and preventing behavior which challenges staff and identifying children who are vulnerable and very anxious**

A selection of schools was asked to consider how they currently assess a child's behavior and emotional well-being and to identify the key challenges when teaching children with autism and what led to positive outcomes.

#### **Task 4: Placement and funding issues**

Each DSPL was asked to consider its own data on where Statemented and ENF funded children with autism were placed, within and outside the DSPL, and the reasons for these placements and funding.

### Phase 3: (October 2014 to December 2014)

To reflect on the findings of the work by the DSPLs and consider what might be implemented across all 9 DSPLs.

### Phase 4: (January 2015 to May 2015)

Further discussions with parents and professionals to consider the findings and to develop recommendations arising from the review

## 3 Main Findings of The Review

### 3.1 Number of children on the autism spectrum in Hertfordshire

All local authorities in the UK have seen a dramatic rise in the numbers of children diagnosed as having autism. This is thought by most to be due to increased awareness of the condition and the growth in specialist assessment teams.

It is well known that obtaining accurate figures on just how many children with autism there are in any one geographical area or school is very difficult. This is because there is no definitive medical or genetic test that can confirm whether or not a child or adult has or has not got autism. Instead, the diagnosis of autism is made on the basis of observing and assessing the behaviours and skills of an individual and taking a history of their development from birth to the present day. The accuracy of the diagnosis therefore depends on the expertise and experience of the team or person making the assessment. In all local authorities, there are areas that have many more children with autism identified than in other areas within that same authority. The same is true in Hertfordshire (see Figure 1).

Where data are presented in this review, these are based on those children for whom autism has been recorded as the primary need. Hertfordshire does recognize that there will be children with other conditions, particularly learning disabilities, who also have autism, but who are not counted in the figures. There are also children with autism who do not have Statements or EHC plans or ENF funding as they have lower levels of need but where schools make adjustments to help them succeed. These children do not show up in the figures but it is important that their presence and needs in a school are also acknowledged. Both professionals and parents wanted to raise these 'hidden' children as an issue so that it was acknowledged that schools are often teaching a greater number of children with autism than the records indicate. There will also be children in schools who are not diagnosed with autism as some children are not identified until later when the demands made create difficulties at the secondary stage or in adulthood. Some children may also be misdiagnosed as having a different condition. Schools were asked if they thought they had children with autism who were not diagnosed and the estimated figures on these children are given in Tables 14 and 19.

In 2011, the number of children and young people in Hertfordshire aged 0 to 24 years was 343,546 (31% of the population). If the prevalence rate taken for autism is 1%, then there are an estimated 3,435 children and young people with autism living in Hertfordshire (see Table 1). From the Spring School Census data in 2011, there was an average prevalence of 0.7% children with a diagnosis on the autism spectrum but significant variation across different districts (see Figure 1). Whilst this can suggest that given the prevalence rate of 1% (Baird et al., 2006), there is a 0.3% shortfall, not every child with autism will have educational needs that require support that cannot be provided by the ordinary resources available to a mainstream school. However, it may be the case that some children with autism who are in need of support and a correct diagnosis may be missed in some areas of Hertfordshire.

Factors leading to different rates of identification in different parts of Hertfordshire are likely to include differences in the experience, expertise and practice of diagnostic clinicians in the area, the accuracy of the recording systems, the ability of staff in schools and services and parents to identify the signs of autism and their knowledge of how to refer children for diagnostic assessment. A systematic study would need to be done to discover the key reasons for the difference in these figures.

### 3.2 Levels of educational need of children on the autism spectrum

Not every child with a diagnosis on the autism spectrum will have educational needs that require significant adjustments or additional support when at school. The needs of children can and do change over their school career and so the need for help can increase or decrease. It is hard to generate criteria on how to define these different levels of need. It is not determined by the diagnosis – but by the needs arising. One way of defining the different levels of need might be as follows. It is important to note that these levels do not equate to the child's level of intellectual ability.

- Level 1: the child's needs can be met within a mainstream school from within its own resources, without direct support from external agencies



- Level 2 – the child’s needs can be met within a mainstream school with advice and support from external agencies
- Level 3: the child’s needs are greater than most children with autism and the child requires a formal assessment and regular reviews with external agencies. A few of these children may need an alternative type of educational placement to mainstream or special school for some or all of their time at different points in their educational career.
- A child’s level of need is determined by an interaction of factors, mainly:
  - the nature of their autism, their vulnerability and whether they have any other areas of difficulty or disability (eg learning disability; visual or hearing loss; physical impairment)
  - the ability of the school to understand and address their needs
  - the other demands on the family and the family’s ability to support the child
  - the support and advice provided to the family and the schools

If the needs of a child and the family are well met at Level 1, then it is less likely that they will develop greater needs in the future. But, if a child’s needs are not identified and acted upon, there is a danger that their needs will increase and they will then require a greater level of support and resource. So, it is vital that frontline staff in schools act efficiently and appropriately as soon as a child is recognized as having specific needs and action taken to address these.

### **3.3 Number of mainstream schools in Hertfordshire**

The total number of mainstream nursery and primary schools in Hertfordshire is 405, ranging from 23 in DSPL 6 to 68 schools in DSPL9. The total number of mainstream secondary schools in Hertfordshire is 82, ranging from just 5 in DSPLs 5 and 6 to 14 in DSPL 3 (see Table 3). The variation in the numbers of schools across each DSPL has implications for how support services allocate resources to the 9 DSPL areas in a way which is fair and equitable.

### **3.4 Number of children with autism in Hertfordshire with a Statement of Special Educational Needs**

The total number of children with autism with Statements in 2014 was 827, which is 22% of the Statemented population for all SEND and 24% of the predicted number of children with autism in Hertfordshire aged 0 to 24 years. The percentage of children with a Statement varied between the nine DSPLs from 0.16% in DSPL 3 to 0.30% in DSPL 7 (see Tables 4 and 5). If all things were equal, one would expect the percentages to be roughly the same. Factors which affect the Statementing rate include the ability of the schools in the DSPL to meet the needs of children with autism, the differing practices and perspectives of professionals involved with the child and the views and ability of the child’s parents to pursue a Statement (or EHC plan). The total number of pupils with autism with a Statement is 143 in mainstream primary schools, 172 pupils in mainstream secondary schools and 390 pupils in Hertfordshire special school provision. The remaining 102 children with autism with Statements attend other special provision in Hertfordshire or schools outside the authority. In addition to children with autism with a Statement, there was a total of 816 children across the nine DSPLs at School Action Plus (see Table 8), that is a further 24% of the predicted number of children aged 0 to 24 years in Hertfordshire.

There are a number of factors which lead to a school having a larger number of children with autism with a Statement and at School Action and School Action Plus (Categories under the previous Code of Practice). This could indicate that these schools attract more children as they have a good reputation for meeting their needs, or it could be that the staff and parents are more successful in pursuing extra resources for these children or it might mean that the schools are less able to meet the needs of children with autism and so they need additional resources. It could be a combination of these factors. Staff in the schools and the DSPLs could consider which of these factors appear to be the case.

As provision in an authority is enhanced, then the numbers of children with Statements and EHC plans will reduce as a greater number of schools will have the skills and knowledge to address the needs, and the breakdown of school places and the stress on the child and family will also be reduced.



### **3.4.1 Primary school data**

Across the 405 mainstream primary schools there were 143 children with autism with a Statement and 485 at School Action plus (see Table 13). The maximum number of children with autism with a Statement at any one school was 4, with three primary schools having 4 Statemented children on roll. Over half the primary schools had no children with autism with a Statement on roll. As one would expect there were more schools that had children with autism at School Action plus. Thirty two schools had between 4 and 8 children with autism at School Action plus, a quarter of the schools had just one child with autism at School Action plus and there were 168 schools that had no children with autism at School Action plus. So these figures show that some primary schools will have little need for support with identified children with autism, although they may need support in knowing how to identify children who might have autism or Asperger syndrome.

For those children with autism with a Statement, 50 (35%) of the 143 pupils were getting ENF funding. Of the 729 pupils with all types of SEND with a Statement, 247 (34%) were getting ENF funding. In addition, there were 20 (15%) pupils with autism without a Statement who were receiving ENF funding (from a total of 137 ENF funded children without a Statement with all types of SEND).

### **3.4.2 Secondary school data**

The total number of pupils with autism in mainstream secondary schools with a Statement is 172 which makes up almost a third of all the children on roll with a Statement at the secondary stage. Thirty four of the schools have over 1000 children on roll and of these, the number of pupils with a Statement for autism ranges from 1 pupil to 11 pupils. All but 10 of the 82 secondary schools had children with autism with a Statement on roll, and of these 10, all except one school had pupils with autism at School Action Plus.

### **3.4.3 Special school data**

Of the 25 special schools, the overall percentage of children whose primary need was recorded as autism is 19% but this ranges from 0 to 58% of the total (see Table 21). The highest proportion of children with autism is found in schools which specialise in teaching children with learning disabilities but children with autism also form about a sixth of the population in many of the schools for children with social and emotional and behavioural difficulties (SEBD). There are also children with autism on roll in the bases and in the Educational Support Centres.

## **3.5 Gender ratio in the population of children on the autism spectrum**

National and international studies on the gender ratio of males to females with autism suggest a ratio of about 4:1 males to females. However, recent developments suggest that the current diagnostic instruments do not pick up the female presentation of autism and that there may be more females who are missed or misdiagnosed. In Hertfordshire, the figures for Statemented children with autism show that the overall ratio is 7 males to 1 female, ranging from 6:1 to 8:1 (see Table 7). This suggests that some girls with autism or Asperger syndrome in Hertfordshire may be missed (or they may be deemed to have a lower level of need than the boys, as these figures only relate to the children with a Statement). Action is required to enhance the ability of staff in all settings to recognize the signs of autism in girls and to take appropriate action.

## **3.6 Children with autism with a Statement or EHC plan being educated at home or out of school**

Figures were available for children with autism who had a Statement or EHC plan and were being educated at home or who were out of school. No data were available on children with autism who did not have a Statement. There were 7 children with autism with a Statement out of a total of 24 Statemented children being educated at home (see Table 23). There were only three children with autism registered as being out of school with a Statement from a total of 15 Statemented children (see Table 24). On these figures, the number of children with autism out of school or being home educated appear to be relatively low, but parents have argued that the number is higher. Parents maintain that there are children with autism out of school or home educated who have not been diagnosed as such or they have autism but do not have a Statement and so are not recorded in the data. The current system of recording children who are out of school or who are home educated needs to be explored to ensure that the authority is fully aware of the extent and nature of the needs of children out of school or who are home educated.

### **3.7 Good practice in schools in Hertfordshire**

The consensus amongst the support services and school staff was that a growing number of mainstream and special schools in Hertfordshire are working very well with autism. Many parents also mentioned positive aspects of their child's placement in mainstream and special provision. From the three Tasks set in DSPLs 4, 7 and 9, discussions with parents, staff and support services, it is clear that some mainstream primary and secondary schools are working effectively, making adjustments; consulting parents and children regularly; setting up safe havens; and communicating well across the staff group (see Tables 15 and 20). Some schools had shared their ideas and experiences with others, but there was a need to do this more widely.

It is also true from discussions with staff in schools and the support services and from consultation with parents that some primary and secondary schools and some staff in the special school sector lack sufficient knowledge and expertise in understanding or meeting the needs of children with autism. There is then a need to enhance their skills and for input from other schools in their area and external agencies to ensure that staff are knowledgeable about autism and that these children and their families receive appropriate and effective support.

As the staff in mainstream and special provision gain experience in SEND, they often develop their capacity and expertise to take more children and children with greater levels of need. As a result, some mainstream primary and secondary schools and staff in special provision have become experienced and confident in teaching children with autism and have taken children with autism from outside their catchment area. They have become a 'magnet' for children with autism as their reputation has grown. Many of the primary schools reported having done a lot of work on fostering friendships with peers, adjusting their teaching and communicating effectively across the staff group. Fewer schools had worked on providing a space for parents or in setting up a parent support group. This work needs to be enhanced so that parents with children with SEND in mainstream schools particularly do not feel isolated and unsupported.

In the secondary schools, the areas where most work had been done was in communicating the pupils' needs to the staff, creating a safe haven and providing suitable lunchtime activities. Areas where secondary schools reported little work being done included making adjustments to the sensory environment and setting up ways to support parents. In the special schools, bases and ESCs, staff reported having done a lot of work on fostering friendships and communicating effectively with all the staff but less work had been done on the sensory environment of some schools and in having a room for parents to meet (see Table 22).

#### **3.7.1 Challenges for mainstream schools in meeting the needs of children with autism**

Staff were asked to describe the three main challenges in teaching children with autism. The main challenges reported by primary school staff most often were in fostering and managing relationships with peers, managing behaviours which challenge and having the time to produce additional resources (see Table 16). The main challenges reported by secondary school staff fell into two main groups, the first related to understanding the behaviour of the children and the second referred to the level of differentiation needed. Staff found it hard to understand and deal with behaviour which was unpredictable (what were the trigger points?) and in preventing changes to staffing and timetabling which led to difficulties for the children. Respondents felt they needed more time to differentiate materials and to consider how to make group working successful. Other respondents mentioned the need for a safe haven or more quiet times with fewer children and the need to help other pupils be aware of why children with autism were treated differently.

Challenges reported by staff in special provision included the time needed to train up new staff in their knowledge and understanding of autism, addressing the impact that sensory processing and anxiety can have on pupils and the effective and consistent use of communication systems.

### **3.8 Support from external support agencies**

The number of children identified with autism in all local authorities has been growing year on year as a result of better awareness and increased identification rates (see Figure 3). Due to financial constraints, the numbers of external support agencies have stayed the same or been reduced. There are fewer

external staff to support a growing number of children with autism. Despite the pressures on services, the ratings given as to the value of external support from the CD team, the EPS, special school outreach, ADD Vance and Angels were often excellent or good (see Tables 24 to 26). The only service which was given poor ratings by most was CAMHS. It is likely that the children with the greatest difficulties are referred to CAMHS and so perhaps the ratings are an indication that the children's difficulties were not much changed, but further exploration into the expectations of the service and the outcomes for children and families is warranted. There were comments made by staff in external agencies about confusion and overlap between external support services as to what their respective roles were. In addition, there does not appear to be an effective system for sharing information between each agency on their work or involvement with a particular child or school.

### **3.9 Parents' and carers' views of current provision**

In any consultation it is likely that the people who attend the consultation meetings or respond via email are those who have concerns and want provision to be different. Those who feel provision is working well are less likely to make their views known. In addition, there are parents who are not able to attend or reply to emails because they have not got childcare support or transport or the internet or the confidence to attend such forums. This will be true for the parents of children with autism in Hertfordshire and in fact some parents at the review meetings made the point that there were very few parents from black and minority ethnic groups and that other parents would not be able to afford to attend or were not confident or articulate. So it is important to acknowledge that the parents' views collected for the review are not wholly representative of the entire population in Hertfordshire. That said, this does not lessen the contribution and views of the parents and carers who did attend the meetings. Their experiences and suggestions have contributed a great deal to this review.

Parents were asked specific questions on a brief survey form to indicate three positive aspects of their child's current school and three aspects they would like to be different. Almost every parent in the survey identified positive aspects of the school(s) their child attended, across mainstream and special provision (see Section 24.3). The key themes were: being listened to by staff, schools which understood their child and being willing to make adjustments to support their child's needs.

It is also the case that all parents identified aspects of school they would like to be different in both mainstream and special provision and these are presented in Section 24.4. These centred around a lack of staff knowledge about autism, the misunderstanding of their child and the use of sanctions rather than support and a rigidity and an unwillingness to make reasonable adjustments. It appeared that often it was not a change of school but a change of practice within the school that was needed.

### **3.10 Alternative provision**

A significant number of parents have said that what they want to see in Hertfordshire are bases for children with autism attached to mainstream schools and/or a school for children with autism, possibly a school just for girls with autism. It is of note that very few school respondents were asking for this, although there were a number of schools that said they struggled to meet some of the needs of the children and where more support and advice was needed. What most schools wanted was more support to maintain and enhance the child's placement, rather than a change of school.

The main reasons why some parents in Hertfordshire have repeatedly asked the authority (in previous reviews and consultations) to set up provision which specialises in autism are that they feel that their child's current or previous schools have not understood their child and/or have not made adjustments to address their specific needs, despite the fact that parents have expressed serious concerns about their physical and emotional well-being. This is particularly true at the secondary stage but parents have said that some primary schools have not been sympathetic or differentiated what they offer. It is without doubt that these parents and children have at times been let down by some schools and that this has been at a cost to their child's health and well-being. What is also true, however, is that other schools with children with similar types and levels of need have listened to parents and worked very hard to adjust what they do and have supported the child successfully. So, it is not the case that all mainstream schools or generic special schools, bases and ESCs in Hertfordshire fail to meet the needs of children with autism.

The reasons why local authorities including Hertfordshire are often reluctant to set up autism specific provision is that some children who are very distressed or out of school have reached this point because their previous schools have not met their needs. Placements have not broken down because of the nature of their autism. It is well established that the level and nature of a child's needs is very much influenced by the environment they inhabit and the understanding they receive. So, for children with autism, local authorities are working hard to provide the best possible education within mainstream and special provision to enhance current practice, rather than setting up new schools and bases. That said, there will always be a small minority of children with autism whose needs cannot be met by mainstream or generic special schools, ESCs or bases at some point in their school career. What many authorities do for these children is to fund a specialist placement outside the authority in a specialist school. This is a more flexible and cost-effective arrangement as the authority can fund places as and when needed and specialist schools differ so the child's needs can be matched to the school. Some children also need to attend on a residential basis and so a residential placement can be found. At the present time, 62 children with autism from Hertfordshire are funded in independent and non-maintained schools. The number of new placements has fallen year on year - as provision in Hertfordshire for children with autism in mainstream and special provision has developed - and this figure might reduce again. The average costs of these placements is £75,000 per child per year and can be as much as £250,000 per child per year so reducing the numbers means that that money can then be spent instead on schools and support services within Hertfordshire to enhance provision for all children with autism and SEND. Some schools and parents have said that they are not sure whether the savings made on the reduction of the number of children in out of authority schools by Hertfordshire have come back into the SEND budget. The SEND officers at County Hall have said that the money saved has been reinvested into SEND in local schools and also given to the DSPLs for particular pieces of work.

So, the needs of most children with autism in Hertfordshire can and are being met in mainstream schools or generic special provision. When placements break down, this is often because the school has not sufficiently understood the child's needs and has not addressed these appropriately. These breakdowns are therefore preventable – and the solution for the vast majority of children with autism is not to set up bases or schools for autism but to work to enhance practice across all schools so that all children with autism are understood and get a good education, wherever they are. The key ways in which mainstream and special schools, bases and ESCs need to work with children and parents to prevent serious issues developing and placement breakdown are discussed in more detail later in the report, but in summary, these are as follows:

- 1 to identify children with or without a diagnosis who are at risk of not coping at school
- 2 to talk to the children and/or their parents on a regular basis to gain their views on the challenges and potential solutions
- 3 to have a safe haven within the school for the child to go during lessons and breaks, as needed
- 4 to inform all staff about their specific needs
- 5 to foster the child's inclusion with peers in a sensitive way

It will continue to be the case that a small minority of children with autism will find attendance at school very challenging even when much has been put in place. It is therefore important that support services act quickly when there are signs of a decline in attendance, performance, or in their physical and mental health. There may then be a need for the child to be educated out of school for some or all of the week until confidence, trust and well-being are enhanced and a return to their school or a different school is possible. Using a model such as CHOOS (see Figure 12) on a short term basis whilst another school is sought or setting up alternative provision on a longer term basis could be explored by the DSPL areas with input from the CD team and the EPS. If it is thought that there is no provision or school in Hertfordshire that can meet the child's needs, then a placement at a specialist placement outside the authority can be sought.

### **3.10.1 Potential advantages and issues arising in setting up bases and/or an autism specific school**

Many people (parents and professionals alike) assume that a placement in a school or a base for children with autism is an obvious solution to the challenges faced by some children with autism. However, setting up specialist schools and bases within a local authority has its challenges and often takes a large proportion of the SEND budget for a small number of children. Sections B25 and B35 of



this review present some of the potential advantages of such provision along with the issues arising. Specialist schools for autism were first set up in the 1960's by the NAS and then by local autistic societies, there being a total of 14 of these schools in England by the 1990's. One of the early NAS schools was Radlett Lodge which is situated in Hertfordshire and which has some children from Hertfordshire on roll. Most of the children at Radlett Lodge have autism with learning disabilities and the staff have a great deal of expertise in working with this group of children. Some local authorities also set up their own specialist schools for autism and more recently the NAS has partnered with local authorities to set up Free schools for autism. On the face of it, having a school just for children with autism can seem attractive and the expectation would be that the children and parents would be understood and receive a good education. The potential advantages of such provision are that:

- The needs of children with autism may be better understood and addressed by staff
- The children and their families would feel better psychologically and emotionally and therefore be better able to learn
- The curriculum would be broader and include life skills
- Activities out of school in the evenings or weekends could be provided
- Children and families would feel less isolated

However, the quality and effectiveness of this provision can take a long time to develop. It is often hard to attract headteachers and staff who have experience of autism so the assumption that all staff will have expertise and training in autism at the outset is not always the case. It can be a challenge for staff when all the children in the group have autism and particularly when the child finds being with others very difficult. There are often very few girls on roll as autism is still more often identified in boys. There is a school set up just for girls with autism in Surrey (Limpsfield Grange) and this provides a safe haven and a very accepting environment for girls with autism who have experienced real difficulties in other schools. A key question though has to be, Can mainstream secondary schools not adjust their practice to enable these girls to succeed and have friends within their local communities? There are many girls in Hertfordshire mainstream secondary schools who are understood by staff and who are getting their needs met. There are a number of other issues relating to the setting up of alternative provision that mean this is often not a panacea or the best option to pursue for children with autism, for the reasons given in Section 3.10.2 below.

Setting up a base for children with autism can reinforce and create a magnet effect in a school and can make other schools more inclined to believe that there is only one place where children with autism can be educated effectively. There is also evidence that some bases in other local authorities are reluctant to take children who are more challenging.

There are about 3,500 children with autism in Hertfordshire and the needs and resources for all these children have to be considered and addressed in a fair and equitable manner. The costs per child of a place in an autism specific school can range from £45,000 to £75,000 and travel time and costs are high. So, if Hertfordshire funded 30 places, then the total cost would be between £1,350,000 to £2,250,000. For bases, the average cost of a place would be about £16,000 – and if 40 places were available, this would be £640,000.

Given that currently there are about 1600 children with autism in Hertfordshire with a Statement/ EHC plan or at School Action Plus, on whom 12 million is spent (ie average cost of £7500), spending £75,000 on one child has to be justified to other parents whose children receive far less. A better use of the money which would benefit a greater number of pupils with autism would be to give money to the existing schools and/or to the DSPL areas to enhance practice across the mainstream and special sector.

Most specialist schools for autism in other authorities take between 40 and 100 children with autism. Several of these children come from local authorities outside the authority in which the school is sited as there are not sufficient numbers of children deemed to need such a specialist place within the host local authority. Bases or units for children with autism typically have between 10 and 20 children on roll and in a large authority like Hertfordshire, four bases could be set up in the north, south, east and west so that

journey time was not too great for any child. However, children in bases rarely transfer out of the base and so places become filled very quickly and vacancies do not arise very often. This means that children with similar levels of need cannot get a place and parents understandably become very upset.

### **3.10.2 Issues in setting up additional and alternative provision for children with autism**

Creating a new base or a new school can seem attractive but their success is founded on the skills and expertise of the staff within them and their ability to work effectively with the host school or local schools. Allocating pupils to new provision and their gradual admission to that provision is complex and can lead to parents and schools being disappointed and distressed when the hoped for outcomes do not materialize or being told that the child does not meet the criteria for admission. If Hertfordshire did set up bases or a school for autism, then there are issues which arise which include capacity and allocation of children; staffing; peer group, location and travelling time; and academic standards. These are discussed further in Sections 25 and 35.

There is a need to get to a position in Hertfordshire where most schools can teach the majority of children with autism and that it is only a small minority of children with autism who will need something different. At present, it appears to be the secondary sector that struggles most with meeting the needs. Some staff in the early years were also struggling as they had children with autism who were very young developmentally and where resources had not yet been given as their needs had not been assessed. For these staff who are not used to teaching children at such a young developmental level, support is needed from special school outreach teams or the CD team on how to ascertain and meet their needs. Having a diagnosis of autism is not essential to this process. At the secondary stage, problems can occur partly due to the fact that some children find relationships with their peers more demanding and challenging with age, but also due to the fact that far fewer staff attend professional development events on SEND and autism. It is also harder for the DSPL areas to attract representation from the secondary sector. It is important then that Hertfordshire LA does all it can to support secondary placements rather than to set up provision for children whose needs are currently not adequately addressed in mainstream schools.

## **3.11 Findings from Tasks 1 to 4 completed by DSPLs 4, 7 and 9**

### **3.11.1 Auditing whole school practice for pupils with autism**

The main purpose of Task 1 was for schools to pilot the use of the AET National Autism Standards for Schools and to consider whether this would be useful for ALL schools in the DSPL to complete (see the full Task instructions in Appendix 1). Respondents were asked to identify the benefits and any issues which arose when they completed these Standards.

Every school that took part was unanimous in their view that completing and discussing the AET Standards had been a very useful exercise to identify what was working well and which aspects of practice needed to be developed. Only one of the three mainstream secondary schools that took part felt that some of the Standards were not appropriate for their age group. Most schools felt that completing the AET Standards helped to confirm that they had many elements of good autism practice in place and it served to identify aspects of practice that they needed to develop.

A key issue mentioned by many who completed the AET Standards was that it was a time-consuming exercise to do thoroughly. However, the tight timescale was largely due to the fact that the Task set had a deadline. If a school completed the AET Standards as intended, these could be completed gradually over time. In addition, the staff were not familiar with the AET Standards or their format and so had to spend time working out how to complete them. If the AET Standards did become part of a school's everyday practice, then the exercise would be less problematic and staff could complete the four main categories of the Standards at different points to make the audit less intensive. Some staff found it hard to know whether a Standard was developing or established and in working out whether what a school uses is relevant to the Standard or meets the Standard was also difficult for some areas of practice. So, some of the issues would be resolved if the staff engaged in the task had been more familiar with the AET Standards and if these became part of their everyday practice.



### **3.11.2 Obtaining the views of pupils with autism (Task 1)**

Respondents were asked to find out from some of the children with autism what their view of school was. Staff could use the Ideal school template developed by Williams and Hanke which is a resource attached to Standard 3 of the AET National Autism Standards for Schools or use their own method. Feedback from the schools who did this exercise was very positive and many said they had not sought the views of the children in any formalised or systematic way in the past. They recognised the value in asking the children about school but felt that the questions asked and the methods used needed to be carefully considered and selected to match the pupil's understanding and abilities.

### **3.12 Having a lead practitioner for autism who is not the SENCo (Task 1)**

There were mixed views on the potential value of having a person as a Lead Practitioner for Autism in addition to the SENCo. Some thought it was a good idea and would be really useful. Other schools were ambivalent. Their response to this appeared to depend on what their current practice was in terms of sharing responsibility and how many children with autism and SEND there were. There were some schools who already had a number of different people on the staff with responsibility for certain aspects of SEND, such as inclusion or speech and language or autism, so they had already delegated roles. In small schools, the consensus was that it was possible to have just the SENCo as the named person responsible for autism, but for larger schools, some staff thought there was sense in sharing the workload and the responsibility.

### **3.13 Parental engagement with schools (Task 2)**

A short questionnaire entitled Parental Engagement Questionnaire was developed to ascertain the different ways in which staff communicated with parents (see Appendix 2 for a copy of this). The staff in the schools were asked to complete this to indicate the ways in which they engaged and communicated with parents of children with autism (see Table 31).

The most frequent methods used were sharing resources, giving copies of the child's timetable and lunch menu, using home-school books, sending photos home, and emails between staff and parents. The 13 schools involved in Tasks 1 to 3, also asked several parents to complete the AET Parents Guide: Working together with your child's school (which can be accessed at [www.autismeducationtrust.org.uk](http://www.autismeducationtrust.org.uk)). The staff were then asked to comment on how useful they found the Guide to engage parents in conversation about the specific needs of their child. The Guide is not intended as an instrument to judge or challenge a school, but that, together, staff and parents can constructively discuss and agree on the most important elements of practice for their child and to develop these if they are not already in place. Some of the issues raised about the use of the Guide arose from a lack of familiarity with it. Some felt that parents were likely to rank every aspect of practice contained within the Guide as essential. On the basis of the comments from users, there is scope for modifying the instructions but the basic rationale for such a Guide seems clear as what was paramount from the consultations with parents is that they often feel that staff do not listen to their specific concerns about their child. If the Guide became commonplace in all schools in Hertfordshire, this may enable structured and helpful conversations to occur and for appropriate action to be taken.

### **3.14 Understanding and analysing the behaviour of children with autism (Task 3)**

The respondents were asked to list the 3 types of behaviour that challenge staff and to describe the methods used by staff to observe and analyse behaviour that causes concern. They were also asked to give details of their most successful ways of encouraging and developing positive behaviour and to describe how they ascertained the emotional well-being and levels of anxiety in typical children and children with SEND.

None of the respondents said they were using any checklist or method specifically designed for children with autism. They used methods such as the ABC approach to observing and recording behaviour. A potential checklist that could be used in all settings is shown in Figure 10.

The type of behaviours that staff said they found most challenging were refusal, avoidance and a lack of motivation; behaviour which hurt or upset other people; and problems in working in groups. Some of these reflect the issues arising from the child's autism and there is a tension here as staff have to be

seen to be fair to other children when responding to these, and staff who are new to autism may penalize the child for actions which s/he does not realize are inappropriate or challenging. What is needed is explicit teaching of what is expected and support to enable the child to do this.

The most successful ways of encouraging and developing positive behaviour included having consistent boundaries and routines, setting achievable and realistic behavioural expectations, and knowing the children and their needs. One said, 'This is a picture that can only build up over time.' So taking time to observe and get to know the child and what increases and reduces their stress levels and leads to behaviour which challenges others is very important. Having a good relationship with the pupil was mentioned by several respondents.

None of the respondents referred to the use of any formalized method of ascertaining the emotional well-being of their pupils and one said it was an area they needed to develop. As a significant proportion of children with autism do not show their anxiety or distress in conventional ways and may not tell their parents or the teaching staff that they are worried or being teased or finding school difficult, it is vital that other ways are found to identify those children who are 'suffering in silence.'

### **3.15 Analysis of the placements and money spent on children with autism across the 9 DSPL areas (Task 4)**

A total of £12.4 million is spent on 714 pupils with autism who have statements or who are deemed to have exceptional needs. The average spend per pupil is £17,000 per year but the range of costs is wide – with some independent special placements costing between £100,000 and £200,000 per pupil and Hertfordshire special school places costing an average of £16,000 per pupil.

Task 4 showed that some DSPLs place very few children in schools outside of their DSPL and have very few children in Independent and non-maintained schools. Other DSPLs have many more children placed outside their DSPL and in the independent and non-maintained sector. From discussions with representatives from the nine DSPL areas, it was difficult to determine what led to the variation in placements, except when the DSPL had no special provision within its own area. A detailed examination of each of the placements made outside of the child's home area would be useful, particularly for placements in the independent and non-maintained sector.

A third of the money spent on pupils with autism (£4 million) is spent on 62 children educated in independent and non-maintained placements. The placement of 11 of these children was made on the basis of a Tribunal. In the last three years, there have been 25 placements of children with autism in independent and non-maintained schools. Ten of these were as a result of a Tribunal. Four children were under 5; six were aged 5 to 10; 13 were aged 11 to 15 and the remaining two children were over 16 years suggesting that the demand increases with the child's age. A key question is, 'Are the 62 children placed in independent and non-maintained placements very different children from those attending schools within the authority?' A second key question is: 'Are these places effective in enhancing the outcomes for the children and how would we know?' A robust system for decision-making for the allocation of these placements and a method for reviewing the outcomes for children is needed.

### **3.16 Funding for SEND**

Questions asked by parents and some staff included:

- What happens to money given to schools for children who leave and are then home educated – where does the money go?
- Money for SEN children into schools should be ring fenced – how do we know what money our child has and how it is spent in a school?
- Why is SEN funding not scrutinized by Ofsted in the same way as Pupil premium. There is a need for more financial accountability from schools and parents need good information on how much funding is allocated
- What happens to the money saved by reducing the number of Out County placements?
- Parents, carers and staff need good information on the money which is allocated to schools for SEND from Central and Local Government to meet their child's needs and how this is spent. Linked to the questions about funding, parents, carers and staff need good and clear advice on the criteria for formal assessment leading to an EHC plan. They also need to know what benefits the EHC plan has.

### 3.17 Training and professional development in autism

With an estimated prevalence rate for autism of 1% (Baird et al., (2006), almost every mainstream and special school in Hertfordshire will have children with autism on roll at differing levels of need. The data on Statemented children and those at School Action plus showed that 90% of secondary schools had pupils with a Statement or at School Action plus and that 120 primary schools had at least one child with autism with a Statement and 168 primary schools had at least one child with autism at School Action plus. Almost every one of the special schools, bases and ESCs in Hertfordshire has children with autism on roll, with some of those for children with learning difficulties having more than 50% with autism and in the SEBD sector, one sixth of the children on roll are recorded as having autism. As autism affects the way in which children understand other people (adults and children), and their interaction with others, it is vital that all adults working within a school receive awareness training in autism, at a minimum. Teaching assistants and teachers need more than this, particularly those who are working directly with the children in class. SENCOs and staff with management responsibility for children with SEND also need to consider how they can develop practice across the whole staff group.

## 4 Recommendations

Note: Any recommendations made are unlikely to be implemented or to be effective unless they take account of existing structures and working practices of people and settings in the DSPL. Change needs to be introduced and embedded through discussions and decision-making at local authority level, the DSPL level and at the school level and involve key stakeholders such as parents and external support agencies. Although this review focuses on autism, there are many aspects which can apply equally to children with other SEND. Many of the recommendations are relevant to school effectiveness and provision for children with other types of SEND, in particular, those recommendations under Sections 4.3.5 and 4.3.6 and the Conclusions are relevant to ALL types of provision.

### Implications For The Local Authority

The local authority has to make decisions on how the DSPL areas and schools can be supported to do this work. In addition, the authority needs to develop the County Council website to provide clear information on their local offer in relation to autism which has links to all the agencies and services that exist in Hertfordshire to support schools, children and families. Providing clear guidance on the criteria for EHC plans, ENF funding and access to support services is also needed. The local authority has to consider how it will monitor progress towards these recommendations in each DSPL area and how parents will be involved in this process.

#### 4.1 Key Messages

The three key messages arising from the review are that:

##### Key message 1:

There is much good practice in mainstream and special provision in Hertfordshire and a desire amongst staff to do even better. As in all local authorities, the expertise and provision made varies from school to school, so it is essential that all schools continue to develop and enhance their understanding and practice in autism.

##### Key message 2:

There has to be a quick and effective response when a child is at risk of not coping at school and alternative arrangements made in some cases where intensive support is not enough.

##### Key message 3:

All parents need to be listened to and understood and their concerns taken seriously and acted upon.

#### 4.2 Key Recommendations (KR)

The following recommendations are those considered to be the most important to implement:

KR1 That each DSPL appoints an Autism Lead to take responsibility for the implementation of the key recommendations and to take a role in facilitating the exchange of good practice.

- KR2 That every mainstream and special school adopts the use of the AET National Standards for schools as a way of auditing their practice regularly to identify strengths and gaps and to develop an action plan to enhance provision.
- KR3 That every mainstream and special school invites parents and carers of children with autism to use the AET Working Together with your Child's school document to facilitate discussion on what they feel their child needs and to discuss with parents the nature and frequency of contact they would like.
- KR4 That every mainstream and special school develops ways to regularly ascertain the views of children with autism or their response to school and the activities offered and to take action to address any issues arising
- KR5 That each DSPL sets up an early warning system to deliver a quick response in the few cases of children with autism where there is a significant change in circumstances and a danger of placement breakdown, as happens for Looked After Children or children involved in road traffic accidents.
- KR6 That every mainstream and special school has a named lead person for autism. This person could be the SENCo but in schools with many children with SEND, then an experienced staff member such as a teacher or a TA could be the Lead for Autism. This person would take the lead in completing the AET National Standards in Autism to audit whole school practice and be a key person for staff and parents of pupils to contact.
- KR7 For every mainstream primary school to create an area which is quiet and free of distractions to which a pupil can go to work or to relax and reduce the level of social and sensory demands. This might be an area of the classroom or a specific area in the school.
- KR8 For every mainstream secondary school to have a Learning Support Centre for all pupils with SEND, which pupils with autism can access at any point in the school day, as needed, with prior consultation and agreement with staff.
- KR9 That each DSPL explores alternative provision for part or all of the week for pupils with autism where their placement in a mainstream or special school is considered at risk by professionals and parents.

### 4.3 Other Recommendations

Other recommendations have been grouped according to specific elements of practice but there is overlap between these and all recommendations should be read and considered by all professionals involved in the education of children and young people on the autism spectrum. The recommendations are presented under the following headings:

- DSPL Areas
- Parents and carers
- Educational provision made by the local authority
- Children and young people
- Mainstream and special schools, ESCs and bases
- Outreach and support services
- Support from SALTs, OTs and Physiotherapists
- Funding
- Diagnostic issues
- Professional development and training in autism
- Criteria for EHC plans

Whilst these are all important, it is not feasible for the DPSL areas or schools to work on everything. An asterisk has therefore been put against those that are considered to be most important to work on to enhance provision for children with autism.

#### 4.3.1 Recommendations For The Dspl Areas

- D9\* Each DSPL to set up a working group to read the Autism Review Report and consider how the recommendations are to be implemented.



- D10 Each DSPL to appoint a named lead for autism to steer the recommendations of the review and who can be a point of contact for parents and schools.
- D11 There appear to be particular issues in the attendance of staff from secondary schools at meetings of the DSPL and at ENF panels and other forums for the discussion of special needs. Yet, it is known that these schools often have more of a challenge in understanding and meeting the needs of children with SEND and autism than the primary sector. For the DSPL to explore ways to attract secondary staff into DSPL work and to help those staff become advocates and agents for change in other secondary schools in the DSPL.
- D12\* That each DSPL has good and up to date information on the practice within its mainstream and special primary and secondary schools and bases in relation to autism and facilitates the development of good practice in autism across all its schools. This will involve monitoring the use of the AET National Autism Standards for Schools within each school, developing a database of staff who have expertise and experience in autism and proactively recruiting teaching staff who require further training for professional development opportunities. The DSPL will also facilitate the exchange of staff and ideas between the schools.

#### **4.3.2 Recommendations To Support Parents And Carers Of Children And Young People With Autism**

A key finding of the review was that a significant number of parents do not feel listened to by school staff and that their concerns are not taken seriously. That said, some parents have had very good experiences with their children's school and other professionals. What is required are actions to ensure that every parent in Hertfordshire has a positive experience, even when there are disagreements about what should happen. At the current time, many parents consulted for this review have been very distressed and concerned by the response of school staff and other professionals to their requests for support. This then affects their confidence and trust in professionals and their ability to interact effectively with them. Research has shown that bringing up a child with autism is often very demanding and that parents are affected adversely in terms of their physical, emotional and financial well-being. Whatever the local authority and schools can do to support parents is likely to have a positive effect on the outcomes for the child.

- D13\* Teaching staff need to develop the skills to listen to parents' concerns and to ask what would make a difference to their lives and their child at school. The document entitled How helping works is very useful in setting out the key principles of effective engagement and consultation. This is a resource which can be downloaded from the AET National Autism Standards for Schools attached to Standard 15. This makes the point that professionals need to listen more and to talk less about what they feel should happen.
- D14 For parent workshops on understanding autism to continue and for other ways to be explored of providing support on an individual basis to parents of children prior to school age.
- D15 To create a good post diagnostic pack on autism which has up to date information on autism and useful and easily accessible information on the support available in Hertfordshire. There could be a printed and online version.
- D16\* Many parents are isolated and do not access support services or parent groups. Factors which lead to isolation include financial and transport issues, little or no support from family and friends to care for their children, and cultural and language issues which might arise from being part of a black or minority ethnic group. The AET commissioned a Toolkit called Reaching Out which sets out ways in which groups of parents can be accessed and included. This can be downloaded free from the AET website ([www.autismeducationtrust.org.uk](http://www.autismeducationtrust.org.uk)).
- D17 That schools and services consider the factors which affect the ability and willingness of parents and carers to participate in events that are open to them and to take steps to address these.
- D18 This review showed that many parents and schools worked together closely and used a range of methods to share information. This was not consistent across all schools however, and some parents felt rejected and dismissed by school staff when trying to set up a meeting or to voice their concerns. Some schools used email to inform parents but others said they thought there were dangers to this and that it was not legal. Hertfordshire needs to publish clear guidance on the means by which schools can communicate with parents, and staff responsible for SEND need to establish with each parent the frequency and nature of their communication.
- D19 For schools to share ways with each other on how they effectively engage and listen to and act on parents' concerns

- D20\* For schools to help parents to understand what they offer to children with autism and to engage in conversations about what would help their particular child (using the AET Working together with Parents Guide or similar).
- D21\* For schools to discuss and agree with parents the nature and frequency of contact they have to share their views on the child and school
- D22\* For Hertfordshire County Council to enhance the data on children out of school and on children who are home educated and to explore the reasons for this and how the children and families are supported.

#### **4.3.3 Recommendations On Educational Provision For Children And Young People With Autism Made By The Local Authority**

There is a need to reduce the number of pupils whose placements are breaking down or where managed moves or part-time timetables are introduced. Each DSPL should have a system to identify children quickly and then work to support the existing placement. In addition, the DSPL needs to be notified by schools about children who are in danger of being excluded or where the child's attendance is declining or where parents are reporting serious concerns about the placement. Sometimes children in this group are the most challenged children, but sometimes pupils reach this position because the strategies used in school have not been appropriate or effective. There needs to be a consensus on what Hertfordshire would expect all mainstream schools to do. Adopting the use of the AET National Autism Standards for Schools would create a uniform approach where parents wherever they lived would know what schools were expected to do.

- D23 For ENF groups to look at the possibility of more flexible funding for pupils where there is a significant change of circumstance, where short-term funding can help to support the placement.
- D24\* To obtain data on managed moves and part-time attendance and to explore factors which relate to school exclusions, managed moves or part-time attendance of pupils with autism and to consider what can be done to reduce and prevent these.

#### **4.3.4 Recommendations On Alternative Provision**

D25 For a small number of children who do not manage in their mainstream or generic special provision, despite intensive support from the school and external agencies, alternative provision is made where staff work with the child and family to ascertain the most appropriate future placement. This might take the form of:

- A personalized learning programme for that pupil, where the pupil stays on the school roll, but where education is provided elsewhere
- Placement in a Centre off site to build back confidence and trust and to decide on the most appropriate future placement
- Placement in a different mainstream or special school in Hertfordshire
- Placement in an out of county school which may or may not be specific to autism

For all of these options, working closely with the child's family and taking into account the views of the child or young person are vital.

D26 That the system for reviewing out of county placements contains data on the expected outcomes of the placement and the progress towards these.

D27\* That one or two people from the Local Authority are given responsibility for monitoring placements for pupils with autism outside the authority in a way which enables answers to the following questions:

- Are the pupils with autism in the independent and non-maintained sector very different from other children with autism in other types of school?
- Does Hertfordshire get value for money from these placements?
- What impact/benefit are the I/NM placements conferring to the pupils placed within them?
- Which elements of provision in out of authority placements could be incorporated within Hertfordshire provision for children with autism to reduce the number of pupils placed out of county?



D28 There is a need to track pupils more closely in terms of long-term outcomes. Follow-up studies of pupils who take different educational routes are required to explore the value of different types of provision. Using a tracking document such as shown in Appendix 3 could support this.

D29\* To explore the cases which go to Tribunal to ascertain:

- the key reasons for parents going to Tribunal
- the gaps in local authority provision
- the gaps in health and social care services

#### **4.3.5 Recommendations Relating To All Mainstream And Special Schools, Escs And Bases**

Some primary and secondary schools have developed good reputations for their expertise in autism and take children with autism from outside their catchment area. There are both positives and negatives to this. The positives are that staff become knowledgeable and skilled with a diverse range of pupils on the autism spectrum and their confidence is enhanced. On the downside, the level of demand may take up a lot of staff time in discussions on how best to support these pupils and may affect the ability of staff to teach the class where there are 4 or 5 children in a class group. Children are also travelling quite a distance from home, making staff-parent contact more difficult.

Hertfordshire could agree to allow these schools to continue to take children out of their catchment area or the authority can work to continue to develop the practice in all schools to gradually reduce the number of children attending schools outside of their home area.

D30\* As the number of children identified with autism continues to increase each year, the number of children with autism in the school population will increase and so it is preferable to develop the practice across all mainstream primary and special provision. Using the AET National Autism Standards for Schools on an annual basis as an audit tool and continuing the exchange and dissemination of good practice between schools will help to build capacity in mainstream and special provision and in the Educational Support Centres (ESCs) and bases.

#### **4.3.6 Recommendations On The Analysis Of A Child's Performance Or Behaviour**

It is clear from the review speaking to school staff and parents that there are situations where the child's behaviour has not been understood and then sanctions are applied further exacerbating the child's distress and difficulties. Autism is often referred to as a hidden disability – not just because some children are passive and quiet and do not stand out from others, but also because there are often no outward signs that the child has a problem, their behaviour is often misinterpreted as naughty, lazy or defiant when in fact what they say and do is often a direct result of their autism.

D31\* When a child is not performing as school staff expect in terms of their performance on a task or the way in which they act in particular situations, an analysis needs to be made, using a set of key questions, to ascertain what might underlie this (eg speech and language difficulty; specific learning difficulty; literacy problem; emotional concerns; social understanding; visual or hearing problem; physical difficulty; organisational problems). Suggestions for the questions that might be asked are given in Figure 10.

##### **4.3.6.1 Girls with autism and Asperger syndrome**

There is evidence nationally and in Hertfordshire that girls with autism and Asperger syndrome are late to be diagnosed or not diagnosed at all. There can be serious consequences in terms of the development of self harming behaviour, eating disorders, anxiety and depression, which may lead to non school attendance and poor academic achievement, although some girls still do remarkably well in exams despite being very vulnerable (perhaps because they focus on work to the exclusion of other aspects of life). From studies of adults with autism, it is clear that there has to be a focus on the social and emotional well-being of these pupils and not just on their academic attainments otherwise they are not in a position to make use of their exam successes (eg evidence shows that they drop out of College or University or fail to sustain employment).

D32\* All mainstream and special provision, ESCs and bases need to explore the concerns of parents with daughters to ascertain the issues these pupils have about school and how best these can be addressed.

#### **4.3.6.2 Identification of very anxious pupils at risk of developing mental health problems**

It is of paramount importance that all mainstream and special provision in the UK and in Hertfordshire increases their ability to identify passive, quiet children who find school very challenging but who do not tell staff and who are hiding severe anxiety. In addition to the girls with autism who might be missed there are also boys who present as passive and quiet at school but who are highly stressed, have few or no friends and who may develop mental health problems and fail academically. There is strong evidence that pupils with autism can be very different at school and at home so staff need to ask parents on whether the child is showing signs of distress and anxiety at home.

D33\* Staff in all schools need to be vigilant about pupils who are very anxious but who appear on the surface to be fine at school and create time to consider how they might be integrated into their peer group and how their anxiety might be reduced.

#### **4.3.6.3 Working in groups**

As autism seriously affects a pupil's ability to work or play with a partner or in a group, teaching staff have to give careful consideration as to how this is done. As the child has to focus on social interaction which is effortful, their capacity to also do the task successfully is reduced.

D34 To ask the pupil who s/he would prefer to work or be with at break times give a task in the group that the pupil can already do; make it very clear what each pupil is to do as an individual in the group. Randomly allocating pupils to a partner or group or getting other pupils to join the group is likely to be very anxiety-provoking and lead to failure.

#### **4.3.6.4 Effective sharing information on pupils with autism amongst the school staff**

A key issue for secondary schools is the challenge to keep all the many staff informed about the needs of their children with SEND and autism. At a minimum, each child with autism should have a single sheet giving details of their strengths and interests and the areas where they need support. This should be given to all staff who teach the child and a shorter version to be given to other staff whom the children meet (eg midday supervisors, drivers and escorts, office staff). One secondary school holds a surgery every Monday morning where specific children are discussed with the whole staff group and ideas shared. In another school, information on each child with SEND is put on the School's Staff Intranet and updated, when needed, with an alert sent to staff when crucial new information is added.

D35 Every mainstream and special school in Hertfordshire to consider how to create an effective system for sharing key information on a pupil with all staff who need to know

#### **4.3.6.5 Being seen to be fair to other pupils in the school**

Some staff are concerned that when they modify the rules and sanctions for a pupil with autism, then other pupils will view this as unfair. But, treating children equally does not mean treating them the same.' Pupils with autism are at a big disadvantage in school as they find many aspects of school life much more difficult and anxiety provoking than other pupils and behaviour which appears to be defiant is often triggered by anxiety, panic or information overload. Schools could share with each other how they argue the case to other pupils and staff for applying different consequences to seemingly similar behaviour.

D36 Staff need to develop arguments as to why treating pupils with autism differently is sometimes justified.

#### **4.3.6.6 Secondary transfer**

There was evidence from the review that both parents and staff alike experience difficulties and delays with the current system of finding a secondary school place for pupils with autism. This results in pupils and parents feeling unwanted and a lack of time for the primary school staff to work with the secondary school to prepare for transition.

D37\* To explore the current system for decision-making in the allocation of secondary schools for pupils with autism with a Statement or EHC plan and/or ENF funding and refine the process so that ideally, these pupils know which secondary school they are to attend by the start of Year 6.

#### **4.3.6.7 Listening to children and young people with autism**

It was clear from the Task set on asking the children what they thought of school that this was a novel exercise not often done with the children. All staff who engaged in the task had enjoyed the exercise and had learned much from it. As children with autism talk less to adults about their feelings and views, engaging in such work with children at all ages and in different types of provision is recommended. Some schools have set up a School Council which is another means by which children with autism can find a voice and be very effective. It is important also that staff take note of issues raised and act on these where feasible.

- D38 For some schools to create video diaries where children with autism talk about school and their challenges and strategies which have been used to address these. These could then be shared across the 9 DSPL areas (with appropriate permissions and descriptions of the content) for use in professional development.
- D39 For pupils with autism and adults with autism in the DSPL to take part in professional development events
- D40\* For pupils with autism to be asked on a regular basis what school is like for them, identifying successes and areas which they find difficult as was done in Task 1.
- D41\* For a passport or profile of the pupil to be created with every pupil with autism, where possible, and in discussion with the parents and staff which states their strengths and interests as well as their key areas of need and how these can be addressed. This should be reviewed and updated termly. Appendix 4 gives extracts from a passport which is included within the resources attached to the AET National Autism Standards for Schools under Standard 1.

#### **4.3.6.8 Developing social understanding and friendships**

Many children with autism and their parents report that the child has no friends. It has been established that just having one friend at school can enhance self esteem and protect the child from being teased and bullied. There are children who say they do not want a friend, but these children too need to be helped to work or play along with peers. Evidence suggests that engaging the child with autism in an activity s/he enjoys which involves other children is an effective way of developing interaction with peers, rather than setting up a group which purports only to work on social skills. One of the key areas that staff said they struggled with was in helping the child to work in a group.

- D42\* For schools to develop their understanding and enhance the work to foster relationships with peers for all pupils with autism.
- D43 For schools to consider a mentoring system where older pupils support younger pupils with autism

#### **4.3.6.9 Using the child's special interests and activities to best effect**

In this review many staff said their major problem was in motivating the child to work. It is well established that children with autism need more help than others to see the point of some lessons and topics. They need to have evidence that it will help them with a future goal or to make it enjoyable by linking the work to their long and short term aspirations and goals and/or to their special interest (eg Dr Who, gaming, Dinosaurs, Thomas the Tank). Many schools use token systems and other ways to motivate children and sharing ideas on these would be useful.

- D44 That every pupil with autism is enabled to be included in activities they enjoy with other children in his or her class within the school, whilst taking into account the pupil's social preferences and the nature of their social difficulties.
- D45 That whole school work is done on teaching every child about diversity and difference in terms of skills, abilities and preferences which includes information on key developmental and medical conditions such as autism, hearing and visual impairments, physical disabilities and learning disabilities. This should include areas of strength and interests in addition to areas of difficulty. A useful exercise would be for staff to ask all children in a class to develop a profile of themselves using different formats, as appropriate, and for these to be presented to the class by the pupils over a period of a term.

#### **4.6.3.10 Outreach and support services**

It was clear from the review that there were times when two or more agencies were involved with the same child but were not aware of this. In times of financial cuts to services, it is vital that these resources are used efficiently. There needs to be a system where external agencies involved with a child can inform colleagues in other agencies and decisions made on who should be involved. Having termly meetings as a cluster of schools can help to reduce overlap and repetition. Models of working for outreach and support services (eg CD team and Educational Psychologists) (individual versus systemic work and capacity building) need to be explored and determined and the criteria for their involvement needs to be made clear to schools and parents.

- D46\* To create a system where all agencies know which other people are involved with the child and what they are doing at any one time to avoid overlap and confusion. There could be a framework or system established to share data between agencies on their involvement with a school or a family that is easy to access and up date.
- D47 That the ENF groups or representatives from each school within each family of schools meet each term to discuss the children with SEND who are likely to require support from external agencies (eg Educational Psychology service, CD team, special school outreach team). Decisions are made as to which services will be involved to give this support. This also allows for information sharing between schools on professional development, recent Ofsted inspections, and developments within their schools or Hertfordshire generally.
- D48 That each DSPL is given details of the number of days of support from the CD team and the EP team and special school outreach teams and then the DSPL or the cluster of schools decides where these days are best allocated in terms of children, families and schools.
- D49 To consider trialling a telephone helpline set up for parents and for staff in each DSPL one half day a week. A member of the CD team or EPS, for example, could take the calls and give advice.
- D50 To consider the ways in which external agencies provide ideas and strategies to staff in schools and how this can best be done in the future (eg training to staff and parent groups; electronic resources).

#### **4.3.6.11 Support from speech and language therapists, occupational therapists and physiotherapists**

Sensory issues and strategies to address these have emerged relatively recently in the field of autism. As yet, there is not a great deal of evidence to inform work in schools. Some Occupational Therapists are developing expertise in this area and it would be useful if OTs in Hertfordshire with expertise could visit the special and mainstream schools to consult with staff on the methods they use and what might be useful to develop and how to ascertain the value of resources such as weighted vests, sensory rooms for specific children.

- D51 That speech and language therapists, OTs, Physiotherapists and any other staff who work in schools work in ways that share their skills and expertise with the staff and with parents who are in daily or frequent contact with the child.
- D52 That speech and language therapists, OTs, and Physiotherapists spend some of their allocated time observing activities in the classroom and advising staff on activities or equipment and resources which might be useful for individual children or which might have an adverse effect on some children.

#### **4.3.6.12 Professional development and training in autism**

One of the most frequent comments made by staff in schools was the need for more training in autism. Several different courses on autism are run in Hertfordshire every year, some are general and others are specific to interventions such as TEACCH, PECS, Intensive Interaction and SCERTS. It is important to consider the needs of the staff in particular schools and how best their understanding and practice is enhanced. It would be useful for mainstream and special schools, bases and ESCs to be introduced to the AET Competency Framework to audit the skills and understanding of staff and to identify their specific needs for professional development in autism. In addition to providing training in autism, there are other ways to develop staff confidence and skills. Schools within Hertfordshire can share their experiences and ideas of how to work effectively with children with autism. Their experience of Ofsted inspections can also be shared so that they develop a strong rationale as to why staff prioritise some aspects of the curriculum over others (eg life skills, social and emotional understanding, or may reduce the number of subjects taken).



- D53\* For Hertfordshire local authority to consider becoming a sub-hub for the AET training so that Hertfordshire can use its own professionals to put on training using the AET materials combined with their local knowledge of issues and resources and services within Hertfordshire.
- D54 For schools to consider the use of coaching methods within their school to develop the understanding and skills of staff (see Gore, 2013)
- D55 That special schools, ESCs and bases, including Radlett Lodge school, share professional development events and their expertise with others in the authority
- D56 To continue to offer an accredited module in autism for LSAs and teachers across Hertfordshire to encourage collaboration and dissemination of practice between schools.
- D57 To evaluate the impact on practice of the training in autism offered in Hertfordshire
- D58 For schools to share ways in which they adjust the physical, sensory and social environment for pupils with autism.

#### **4.3.6.13 Funding**

Both professionals and parents expressed some confusion and concern about the clarity of SEN funding and how ENF funding and other SEND monies were allocated to pupils and schools and how it was then spent.

- D59 To ensure that schools and parents have access to the criteria for the allocation of ENF funding.
- D60\* That each year, Hertfordshire local authority gives each DSPL the data on the placements of children with autism with a Statement or ENF funding and the costs of this on an ongoing basis each year. For each DSPL then to consider the factors which lead to these placements and with a view to ensuring that money is spent as effectively as possible.

#### **4.3.6.14 Criteria for EHC plans, the protection they afford and the costs of production**

Some parents expressed concern that they have to 'fight' to get a Statement and others were not clear on what protections this or the new EHC plans afforded a child.

- D61\* That Hertfordshire local authority produces a clear set of criteria which is used to determine which pupils are eligible for an EHC plan and to present the potential benefits and the costs of producing these.

#### **4.3.6.15 Diagnostic issues**

Some schools expressed concern that they were not able to access support and advice on children prior to the diagnosis being made. There are free to download resources on how to understand and work with children in the early years and for school-aged children. These were developed with funding from the Department for Education and can be found at [www.aet-idp.org.uk](http://www.aet-idp.org.uk). Working with a child 'as if' they have autism will be helpful and not do harm.

- D62\* That the Lead of Autism in a school supports staff with children who are thought to have autism but who are not yet diagnosed. Their role would be to help ascertain the key areas of need and then to suggest some resources and strategies to address these.
- D63 That each DSPL has information on the diagnostic pathway for the assessment of autism in their area which is shared with the schools and parents. National guidance for how assessments should be conducted is contained within the NICE Guideline 128 and within the National Autism Plan for Children (NIASA, 2003).
- D64 For Hertfordshire local authority to create a leaflet for schools and parents or a section on the Hertfordshire County Council website, on the indicators of autism, the referral routes for a diagnostic assessment and how to support the child PRIOR to the diagnostic assessment.

#### **4.3.6.16 Information at diagnosis**

Comments from parents and professionals alike suggest that the information given to parents when their child is diagnosed is variable across the County and is often not adequate.

- D65\* Hertfordshire County Council should develop its own diagnostic pack for parents (printed and online) which gives basic information on autism and signposts parents to information (eg on services, benefits, courses on autism). Some DSPLs have already been working on this.

D66 It would be helpful if Hertfordshire County Council could reach a consensus on the terminology and abbreviations they use to refer to children and adults on the autism spectrum across education and social care. It is likely that health may prefer to use ASD as this is the medical diagnostic label but increasingly in education the term disorder is no longer used and children are referred as having autism or being on the autism spectrum.