





**Brighton & Hove  
City Council**

# Overview & Scrutiny Commission

Title:	<b>Scrutiny Panel on services for children with autism</b>
Date:	<b>6 November 2013</b>
Time:	<b>1.00pm</b>
Venue	<b>Council Chamber, Hove Town Hall</b>
Members:	<b>Councillors:</b> Jarrett Pissaridou Wealls
Contact:	Rosie Moore – co-optee <a href="mailto:Julia.riches@brighton-hove.gov.uk">Julia.riches@brighton-hove.gov.uk</a> Tel: 01273 290451

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Dr Becky Jarvis, GP

Sue White and Mary Porter, PRESENS

Alison Nuttall, Commissioner for CAMHS, B&HCC

Jenny Brickell, Head of the Integrated Child Development & Disability Service

Education

Amanda Meier, Lead Teacher, Phoenix Centre, Hove Park School

Cath OddHayward, Head of Swann Centre, BACA

Adrian Carver, Headteacher Downs View School and Downs View Link College

- 34.** Any other Business

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290451 – email Julia.riches@brighton-hove.co.uk) or email scrutiny@brighton-hove.gov.uk



## Agenda Item 30

### To consider the following Procedural Business:-

#### A. Declaration of Substitutes

Where a Member of the Committee is unable to attend a meeting for whatever reason, a substitute Member (who is not a Cabinet Member) may attend and speak and vote in their place for that meeting. Substitutes are not allowed on Scrutiny Select Committees or Scrutiny Panels.

The substitute Member shall be a Member of the Council drawn from the same political group as the Member who is unable to attend the meeting, and must not already be a Member of the Committee. The substitute Member must declare themselves as a substitute, and be minuted as such, at the beginning of the meeting or as soon as they arrive.

#### B. Declarations of Interest

- (1) To seek declarations of any personal or personal & prejudicial interests under Part 2 of the Code of Conduct for Members in relation to matters on the Agenda. Members who do declare such interests are required to clearly describe the nature of the interest.
- (2) A Member of the Overview and Scrutiny Committee, an Overview and Scrutiny Committee or a Select Committee has a prejudicial interest in any business at meeting of that Committee where –
  - (a) that business relates to a decision made (whether implemented or not) or action taken by the Executive or another of the Council's committees, sub-committees, joint committees or joint sub-committees; and
  - (b) at the time the decision was made or action was taken the Member was
    - (i) a Member of the Executive or that committee, sub-committee, joint committee or joint sub-committee and
    - (ii) was present when the decision was made or action taken.
- (3) If the interest is a prejudicial interest, the Code requires the Member concerned:-
  - (a) to leave the room or chamber where the meeting takes place while the item in respect of which the declaration is made is under consideration. [There are three exceptions to this rule which are set out at paragraph (4) below].
  - (b) not to exercise executive functions in relation to that business and

(c) not to seek improperly to influence a decision about that business.

(4) The circumstances in which a Member who has declared a prejudicial interest is permitted to remain while the item in respect of which the interest has been declared is under consideration are:-

- (a) for the purpose of making representations, answering questions or giving evidence relating to the item, provided that the public are also allowed to attend the meeting for the same purpose, whether under a statutory right or otherwise, BUT the Member must leave immediately after he/she has made the representations, answered the questions, or given the evidence,
- (b) if the Member has obtained a dispensation from the Standards Committee, or
- (c) if the Member is the Leader or a Cabinet Member and has been required to attend before an Overview and Scrutiny Committee or Sub-Committee to answer questions.

**C. Declaration of Party Whip**

To seek declarations of the existence and nature of any party whip in relation to any matter on the Agenda as set out at paragraph 8 of the Overview and Scrutiny Ways of Working.

**D. Exclusion of Press and Public**

To consider whether, in view of the nature of the business to be transacted, or the nature of the proceedings, the press and public should be excluded from the meeting when any of the following items are under consideration.

*NOTE: Any item appearing in Part 2 of the Agenda states in its heading the category under which the information disclosed in the report is confidential and therefore not available to the public.*

*A list and description of the exempt categories is available for public inspection at Brighton and Hove Town Halls.*

**BRIGHTON & HOVE CITY COUNCIL**

**SCRUTINY PANEL ON SERVICES FOR CHILDREN WITH AUTISM**

**12.30pm 15 OCTOBER 2013**

**COUNCIL CHAMBER, HOVE TOWN HALL**

**DRAFT MINUTES**

**Present:** Councillor Jarrett, Pissaridou and Wealls

**Also in attendance:**

**Other Members present:**

**PART ONE**

**25. PROCEDURAL BUSINESS**

Apologies from Rosie Moore, Co-optee.

There was no reason to exclude the press and public from the meeting.

**26. CHAIR'S COMMUNICATIONS**

Thank you all for attending. Welcome to this information-gathering meeting of the Scrutiny Panel looking at services for children with autism.

As you know, we have had two previous meetings where we heard from support groups and parent/carers. We are now keen to hear your views and experiences. I will ask you each to say who you are and then speak for around 10 minutes and then the Panel will ask any questions.

**27. DRAFT MINUTES FROM THE MEETING ON 17 SEPTEMBER 2013**

The minutes are still in draft as there are still some comments outstanding. There were no amendments from the Panel.

**28. TO HEAR FROM WITNESSES**

There was a change to the published agenda and Jenny Brickell was not present.

**Lalli Howell, SEN Pathfinder (LH)**

LH has been an autism specialist for 30 years. She was invited by the Department of Education to take part in the Pathfinder project. The Government published a Green Paper in 2011 which stated that local authorities needed to work in partnership and LH firmly believes in this. Parents are the experts and to go forward local authorities must work with parents. They are in the second phase of the project and working with 50 families. 60% of these children have autism or significant communication difficulties linked to their disability. What is suggested for children with ASC is valid for most children they work with. LH believes that one of the most effective interventions is working with families. Sometimes you need to look at the school and home environment to see where the key pressure points are. One child described their days as "climbing Everest every day".

They are now looking to work with an additional 115 families – the target the Government has set is 165 by July 2014. They are working with children between 0 and 25 and if any families wish to be involved please contact LH. The new project will involve new Education, Health and Care Plans (EHCP) which views the child in a more holistic way. In the last 18 months, LH has felt that families are getting more choice and control and there is a better way of working in partnership with families.

The SEN pathfinder will be running new surgery drop-ins in King's House once a month for families to talk to the SEN team. This happened in the past for families with ASC but stopped. The local authority has an unfair bad reputation but the goodwill is there and there are some great people.

The SEN pathfinder is also looking at personal budgets which give families choice over how money is spent.

There is a big piece of work going on in working with schools. They are saying to schools let's stop and reflect - not just give the knee-jerk reaction that there is no money. It must be about the needs of the child. It is not all about the curriculum but about giving children the opportunity to feel happy at school. Schools need to be flexible – there are lots of examples of a SENCO who has said yes to small changes and they have made a huge difference. Schools do have resources and we need to work with schools.

Sometimes the problems are not to do with education and you need to sit down and see where the problems are. If someone is too anxious they can't learn. One example was a child who was very anxious and they discovered that the problem they had was in their housing. This can only be identified by sitting down with the family and taking a holistic approach. The housing issue was solved and six months later the child was learning well. Another example was of a child who hated the reading scheme in school but once the books were replaced with books about dinosaurs, the child went up two levels.

They are talking to colleagues about working together – one of the challenges is to sort out the communication channels.

Q – Is the drop in surgery for all parents? Can it be expanded?

LH – It is for all parents and is being advertised in the schools bulletin. It will initially be one and a half hour coffee morning/afternoon but they would like to expand it if there was a need.



Q – What is the background to the pathfinder? What are the resources and how did you recruit people?

LH - The Pathfinder was already established when LH joined. There were initial discussions with SENCOs and Heads of Special Schools who identified families by looking at where the needs were for those schools. LH met with schools and 4 families per school from 16 schools (some have dropped out now). Together with the families and Amaze and health care professionals they designed the EHCP. LH is the lead on the Pathfinder and works with a parent from Amaze one day a week and one parent 4 hours a week. She is scaling up the work. By September 2014 the EHCP will be statutory (statements are still in place now).

Q – Parents need to be seen as part of the solution not part of the problem. How can we change attitudes?

LH – This is a huge culture change (although it shouldn't be). They are currently running one training session a fortnight for colleagues in education, health and social care. Last week they did a training session with CAMHS, transition team, adult social care and the educational psychologists. The SEN team talks regularly to schools.

Q – Are personal budgets seen as part of the solution?

LH – Yes in that it is to do with money but it is also to do with being flexible, looking outside the box. They are looking at children with SEN in the mainstream who have additional funding (around £6,000) that the school receives to cater for that child. Currently the school gets this money but they want it to be used in consultation with the families and not just the schools decision how it is spent.

1-2-1 support is not always beneficial – schools need to be more creative. A social skills deficit is at the core of ASC and 1-2-1 support can isolate a child and create a reliance on that adult. There are more effective ways to help a child than 1-2-1 with a TA.

Q – What about educating children about children with ASC?

LH – The ASCSS is constantly training young people about autism. LH did one powerpoint with a girl with autism and she controlled the slides and put the powerpoint together. As a result the school identified two other children with ASC who had slipped through the net but got flagged up as a result of the presentation. This is a very successful intervention – children explaining to other children - and very effective in tackling bullying. But it needs to be done more often.

Q – It sounds like an excellent project that can change attitudes. Is it an ongoing programme rather than part of the Pathfinder?

LH – It is embedded in the ASCSS practice. You need parental permission and some parents need persuading.

**Mary MacPhail, Interim Head of ASC Support Service (MM)**

MM - The ASCSS offers this to schools – either to specific children or the whole class and it can be used with very small children. It can also be done through story-telling or powerpoints.

This intervention is most successful when it is about one child. They might not use the language of ASC or Aspergers but talk about one particular child and what they do well, what their challenges are and what you can do to help. In some secondary schools they do whole year group awareness of autism and how it impacts on a child. Sometimes an individual child will stand and talk about their lives. This intervention usually comes about if a person is asking a lot of questions about their differences or having difficulties. The parents have to agree. Some parents aren't ready for this.

Q – This is about changing culture. What will bring on this step-change? Will the EHCP help?

LH – What is needed is training in a systematic way. Starting with the SENCOs who feel pressurised. They need to get the message that the focus shouldn't be on league tables. SENCOs are great and we need to use their expertise. The Pathfinder is looking at expanding School Councils because children often have the answers and we need children to be more involved.

Q – Can the ASCSS be more proactive and tell schools they need to co-operate?

MM - The ASCSS would love to be more proactive than we already are, ultimately we cannot make a school do something. Some teachers don't believe in our suggested interventions and see it as pandering to the child, for instance using their special interest or giving them learning breaks. Training is key.

LH – There must be a way of enabling young people themselves to talk to teachers, for example, a child saying I panic every day when I am faced with a blank page, can you put three lines on it please telling me what I need to do.

Q – ASCSS is invited in by the school – how can you increase take up? There needs to be consistently good practice and we need to find ways to get all schools on board to raise standards. Are all schools getting involved? What is the most effective route to getting people involved in the Pathfinder?

LH – You need to start with the Head because they hold all the powerful tools. There are regular Headteachers conferences and the messages need to go there. SENCOs are being trained but it needs to be relentless as people change jobs, move on etc.

Q – Is the training regulated? For child protection training there are registers of who has been trained and when.

MM – The ASCSS usually contact schools when we are made aware of a new diagnosis and arrange an initial observation and meeting. The ASCSS did a questionnaire in September and one of the questions was around training in schools. We have details of who has attended training but schools also keep this information. IDP was set up a few years ago and all schools were offered it but there were some that didn't take it up. We are involved with the team looking at tier training. This is coming out of the SEN partnership strategy and part of the project is to look at what training there is. ASCSS don't offer specific training to Governors but would welcome the chance to do so. They send a leaflet to schools on what training we are providing each term and offer training to TAs on our regular visits to schools. It would be good to see training for the lead SEN Governors.

Q – There are also LA Governors. All nominated SEN and LA Governors could be asked to pursue the option of ASC training.

**Mary MacPhail**

MM - The ASCSS was set up in 1999 as part of Downs Park School and they still operate out of Downs Park, although they are running out of space which is a little unsettling. There have been lots of issues around line-management and who is guiding the service. There is no Service Level Agreement (SLA) but the Head of Downs Park is MM's line manager. The last Head of the ASCSS stepped down in June 2013 and MM has been Interim Head since then.

The service started out as 2 F/T teachers. It is now 4 P/T posts which equates to 3FT. There is also a P/T administrator and P/T parent liaison post. initially it was the ASCSS teachers who identified the need for this parent Liaison post and it was funded by the revenue from courses. More recently, the LA funded this post but this stopped in Dec 2012 and there was no parent liaison for this year but there is someone now in post.

The ASCSS has 238 pupils on its books – a huge number for 3 F/T people. They try to review each pupil every term. The previous Head of service tried to manage the caseload by allocating cases as active or non-active. This needs to be tightened up a little. They are working with 43 primary and 9 secondary schools at the moment. They were working with pre-schools but the funding has been delayed but may yet come through. They do work with PRESENS helping with children who have a diagnosis.

What is working well? The recent questionnaire sent out to 64 schools has only had 31% response rate. The results show that: 95% are satisfied and feel supported by the ASCSS; 81% feel there is a good awareness of ASC among their staff; 85% feel the ASCSS helps them have a good relationship with parents and carers and 95% have received some training from ASCSS in the last two years, Whole staff training is seen to be the most beneficial training. 88% think the ASCSS support inclusion.

It is great to have the parent liaison role (Alicen Haire – AH) and this needs to be developed. The coffee mornings have resumed and it was good to see parents they hadn't seen for a while. AH has been in contacting parents and linking with Amaze and meeting parents in schools. AH has also been to people's homes to help, for example, with a boy struggling with transition.

They are working on a draft development plan and looking at the SEN partnership and then see where the ASCSS's role sits. They are looking at the protocols and procedures and what is driving these.

The challenges include implementing the development plan and ensuring it is embedded into the draft autism plan, Early Help Partnership Strategy and SEN Partnership Strategy; raising parental confidence and looking at why parents have concerns.

Q – Who has overall view of all the strategies and is pulling it all together? Can ASCSS see how they fit in?

MM – ASCSS are working with the SEN team led by Regan Delf. Next week there is a training day looking at working together. They are discussing how the ASCSS fit into the goals and bigger picture – this has been missing previously and it is fantastic it is happening.

LH – The meeting next week is all about how it all makes sense and how to develop good pathways.

MM – Another challenge is how to manage the increasing caseload without compromising the service. How can they broaden their remit? They are a small team but a very effective one. The ASCSS used to work on building schools capability to make sure schools can do it themselves but this has been taking too long. Some schools are good, but not all.

LH – At the start of the ASCSS there were 2 F/T staff with 50 people on the caseload. Now there is 238 caseload and 3 F/T staff!

MM – There are some areas of good practice. Where there is a key worker who oversees what happens and communicates well within the school team, including parents and the ASCSS. A good communication system is very important. On one recent occasion they were asked to help a TA plan a programme of social skills for a child which they did then got an email from the SENCO saying the teacher didn't want to do it. Communication and social skill strategies must be part of good work. Good practice also involves regular target setting evaluating what is working and going forward. Close working with parents is also key.

Q – Can parents go direct to ASCSS?

MM – This hasn't been encouraged in the past because we are often out in schools but it would be great and now we have our Parent liaison that can happen more. In some schools, the Headteacher wouldn't recognise MM although she has been working with the school for years. In others this is far from the case. Some parents do not get the ASCSS reports although they are supposed to be given to them by the schools. There is a SLA with schools which we are revising and this will clarify what schools need to pass on to parents.

The Autism Education Trust is DfE funded and has brought forward tier training. There are also 2 great resources: the Autism Education Trust Standards and Competency Framework for raising competency in schools. It is an audit which will help identify where schools need to improve and what they are doing well; and the NICE guidelines on the management and support of children and young people on the autism spectrum. These are also about the environment and working in partnership.

The ASCSS would like parents to come in and help with training (some parents have found training patronising in the past).

Q – Can you go into the universities teacher training sessions and do a module on ASC?

MM- This has been offered before but the ASCSS hasn't been asked to provide any training.

LH – LH was part of this in 2007. It was only half a day though and felt more like a box-ticking exercise. It is essential that it is part of teacher training courses and should be at least a week long.

Q – Can we look at designing a module? The LA is a huge employer in the city could we put an LA stamp on it?

Q – It has been suggested in the past that the ASCSS was an advocate for schools. Are you an advocate for the child or the school?

MM – ASCSS is an advocate for the child not the school. MM's experience is that they are more likely to be an advocate for the parent, not the school. We are an advocate for the child first and the parent s will help us with this. Often children manage in school but things come out at home.

Q- We need a robust, independent, non-scary complaints process. How can we give families a robust complaints process?

MM – The ASCSS are looking at how to measure their performance and improvements. They will be providing opportunities to feedback – anonymously or not. Parents can really work with the ASCSS.

Q – Do you work with CAMHS?

MM – Not really directly. CAHMS contact ASCSS post-diagnosis and forward paperwork

LH – ASCSS must work with CAMHS especially as children approach secondary school. Of the most successful interventions was a project on social skills run with CAHMS on recreating the home environment.

Q – A recommendation from the Panel may be that there must be a more structured way of working between ASCSS and CAHMS.

Q – Should Ofsted be looking more closely at how schools are dealing with SEN and more specifically ASC?

MM – The Ofsted report on Downs Park did look at the ASC service provided. Ofsted do have a SEN remit.

Q – Could Ofsted be encouraged to look at ASC and SEN in depth? Sometimes this will be a paper exercise.

Q – How are you funded?

MM – The ASCSS has £150,000 from the delegated fund. They charge £75 for schools to go on training and that is used to pay for resources. For instance the ASCSS don't have ipads but it is important for ASC children to have access to computers and the current use of excellent Apps which can help a young person with ASC .We offer a free spaces on our training fpr instance to our host school

Q – Services need to be properly funded. The ASCSS has a limited budget.

MM – Funding is very tight. Realistically the ASCSS can only go into a school 3 times a term and that is for a child who is really struggling. For some children they only go into school once

a term although they would like to go in every 2 or 3 weeks. How the caseloads are allocated and the number of visits per child is carefully planned out.

Q – Who is in charge of exclusions? If schools are excluding children with ASC then they should be challenged on this.

MM – Schools don't have to tell us if they exclude a child with ASC. We have identified that work needs to be done with those who are at risk of exclusion to prevent it. Schools can be a little defensive. One example was a child was excluded but when the details were unpicked, it was the end of term and the TA who was normally there to help the child wasn't there. ASCSS will look to see what information they have on exclusion data.

Q – How is the pathfinder funded?

LH – The SEN pathfinder has £150,000 until 31/8/13 which mainly goes on salaries. They give money to schools if they need it to provide the extra help needed. They also fund the Amaze 'insider' courses. 24 parents were trained last year as part of the pathfinder. The dream is to provide alternative curriculum in schools. Children can't always function if they need to adhere to lots of rules. They need to be educated but schools need to be creative. One example was a child who wasn't accessing learning but loved fishing was given 3 hours fishing a week and then started to learn. Children's needs must be met in a meaningful way.

Q – Are there any secondary schools who have parent liaison roles?

MM – It might be part of the key worker role. Schools with trained key workers are excellent at supporting ASC students. ASCSS will look to see if they have any information on the number of schools who have key workers. Some schools may have resistance to accepting children who have ASC as they are worried they won't be able to meet their needs alongside the needs of others.

Q – We need a more consistent good practice across schools and proper training. There must be good communications.

LH – Training teachers is very important. They must have the ability to differentiate work for children – it makes a huge difference.

Q – We will look at the teacher training courses and ask what they do now about ASC and SEN.

Chair – Thank you very much for coming to the meeting. If there is anything else you feel the panel should consider, please let us know.

## **29. DATE OF NEXT MEETING**

The next meeting is 6 November 2013.

The meeting concluded at

Signed

Chair

Dated this

day of





DRAFT 2

# **Meeting the needs of Children and Young People with Autism in Brighton and Hove 2013-2017**

**‘Better outcomes, better lives’**

**A plan to support the SEN partnership strategy**

# DRAFT 2

## Introduction

The Brighton and Hove Special Educational Needs (SEN) Partnership strategy 2013-2017 set out five key priority areas for children and young people with SEN. The strategy also acknowledged that children and young people with autism are a key vulnerable group and needed a specific focus. This document, therefore, should be read in the context of the overarching SEN strategy. However, this document will also take account of all aspects of the lives of children with autism and their families to ensure the following **outcomes** are met;

- ***Provision of timely interventions which meet the needs of individual children including high quality education provision and support services during and beyond the school day***
- ***Empowering of parent carers – equipping parent carers with information and skills and strengthening families***
- ***Available services that make early intervention a priority***
- ***Ensuring engagement with children and young people and parent carers in the design, delivery and feedback regarding service provision***

**And :To ensure the children’s workforce is competent and equipped to meet the needs of children with autism**

**To ensure that children and young people are effectively protected and safeguarded.**

**To deliver Value for Money (VFM), ensuring that the council is able to provide good outcomes and services whilst demonstrating efficiency and cost effectiveness compared to similar authorities or service providers.**

**To respond to and meet key local and national drivers in both the council, schools and NHS agendas<sup>1</sup>**

The overall objective of a plan for autism is to ensure the right services are identified, commissioned and provided to meet current and future needs. We want children and young people with autism to receive the right assessment and diagnosis as early as possible, to be able to access additional support if they need it and to know that they can depend on professionals and agencies to treat them fairly as individuals.

The plan reflects the parallel strand of work within Adult Services in meeting the requirements of the Autism Strategy ‘Rewarding and Fulfilling Lives’ (March 2012) and related statutory guidance. The two documents and development work will need to dovetail to ensure effective lifelong support for those who need it

We stand a much better chance of succeeding in our ambitions if we work together as agencies, with parents and with the voluntary and community sector, Together, we are determined to improve services for children and young people with autism

## **Scope of the Plan**

This plan is for children and young people with special educational needs and disabilities relating to autism from 0-19 years of age. There is an adult strategy in place in the city and the children’s plan will dovetail with this. We recognise that there is a broad range of the type of need and severity of need. The plan also encompasses the journey through transition to adult services and will take due account of new legislation informing the use of education health and care plans to the age of 25.

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<sup>1</sup> Commissioning strategy children with disabilities and complex needs 2010

# DRAFT 2

The plan does not cover details of interventions for autism. Autism means many different things to each individual child, family and school/setting, and can present very different challenges. Every child is an individual and, as such, pathways and interventions need to be individualised.

## Defining autism

In line with the NICE clinical guideline 2011, we have decided to use the term 'autism' throughout this document to signify children and young people with a diagnosis of autism including, high functioning autism, Asperger syndrome and other autistic conditions as described in ICD 10 (World Health Organization, 1992) - to date the most commonly used diagnostic criteria. In this context the term 'autism' is used as an umbrella term synonymous with all diagnosed autism spectrum disorders.

The National Autism Strategy defines autism as:

*"A lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments'.<sup>2</sup>*

- understand and use non-verbal and verbal communication;
- understand social behaviour which affects their ability to interact with children and adults;
- think and behave flexibly – which may be shown in restricted, obsessional or repetitive activities.

Each person with autism is unique and provision needs to be sensitive, flexible and personalised to meet their needs.

Autism is a lifelong condition that has a great impact on children, young people and their families or carers. It can affect how they make sense of the world around them. Usually, difficulties are present in early childhood although sometimes they are not evident or significant until a time of change or transition. Autism is considered to be a neuro-developmental condition and, as such, health services have a key role in recognising and diagnosing autism.

*"All children with autism are individuals and their areas of strength will vary. Many children with autism will have an ability to focus on detail and they may be able to concentrate for long periods on a single activity if it is of interest to them. They can give their sole attention to a task and therefore can often achieve a high level of skill."*

*Adapted from Autistic Spectrum Disorders – Good Practice Guidance*

There is a wide range of cognitive, social and communicative ability within the autism spectrum which can include children with profound learning difficulties, with little or no verbal communication through to those with average or high levels of functioning. In addition to learning disability, autism often occurs alongside other difficulties or disabilities such as sensory impairment, Down syndrome, gastrointestinal disorders, epilepsy, or other related genetic conditions. Coexisting conditions e.g. specific learning difficulty such as dyslexia may compromise the effectiveness of accepted educational approaches for students with autism, and increase the need for a more personalising teaching and individualised learning strategies.. Some individuals with autism may also go on to develop mental health problems.

Recent research estimates that as many as 70% of individuals with autism may also have other difficulties which impact upon their functioning and wellbeing (NICE Autism: recognition, referral and diagnosis of children and young people on the autism spectrum Clinical Guideline, September 2011).

# DRAFT 2

## **National policy position**

There is no national policy specifically in relation to children and young people. However with regards to adults with autism , in 2009 the Autism Act entered the statute . The Act made two key provisions:

1. that the Government produce an adult autism strategy by 1 April 2010
2. that the Secretary of State for Health issue statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism by 31 December 2010.

The guidance sends a clear message that local councils and local NHS bodies in England must improve:

- training for their staff
- identification and diagnosis of autism in adults
- planning of services for people with autism, including the transition from child services to adult services
- local leadership

The first ever strategy for improving the lives of adults with autism in England was published on 3 March 2010 and is being monitored during 2013.

The elements of the act and autism strategy key to this plan are those related to transition.

For children and young people, there are good practice clinical guidelines produced by NICE and published in August 2013.<sup>2</sup> The guidelines support the implementation of the NICE pathway for autism<sup>3</sup>

## **National context and prevalence**

Autism is much more common than many people think and is recognised as the second most common primary special educational need according to Pupil Level Annual Schools Census (PLASC). The NAS estimates that there are 535,000 people in the UK with autism. If their families are included, autism touches the lives of over two million people every day.

The NAS has reported a 61% increase in autism cases between 2005 and 2010. Recent studies have reported increased prevalence and the condition is now thought to occur in at least 1% of children.

We also know that there is an increase in the numbers of children and young people who have complex learning needs where autism co-exists with another difficulty.

What remains unclear is whether the actual prevalence of autism is on the rise, or whether the increasing numbers of children and young people with autism are the result of the broadening diagnostic concept (Rutter, 2005). What is evident is an increasing demand for diagnostic services for children and young people of all ages in the health services and an increase in the overall volume of referrals to the teams that support these children and young people due to improved recognition. A study by Baird et al (2006) suggested the prevalence of autism may be nearer to 1:86.

More children and young people have autism than ever before and most teachers will teach a pupil with autism at some point during their career. In fact 1 in 3 children in special schools now have an educational need related to autism (Barnard et al, 2002), which highlights the need for an effective educational approach to meet the needs of this complex population of students. It is essential that all staff have an awareness and

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<sup>2</sup> <http://www.nice.org.uk/guidance/index.jsp?action=byID&o=14257>

<sup>3</sup> <http://pathways.nice.org.uk/pathways/autism>

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understanding of autism and how to implement strategies to enable these children and young people to access all aspects of school life and to reach their full potential.

Autism is far more prevalent in boys than in girls (by approximately four to one). Happe (2011) suggests that this may be because of diagnostic practices and that, perhaps, females tend to cope better with their autistic traits.

## Brighton and Hove prevalence

There are 59,500<sup>4</sup> children and young people aged 0-19 in Brighton and Hove including around 35,554 school age children (2012, Schools' Census) across local schools and settings. Taking the national prevalence for autism of about 1 in 100, this suggests that we could expect around 550 children and young people in the city to have a diagnosis of autism. However, some families may choose not to seek a diagnosis or don't wish to access support services. Brighton and Hove has a prevalence rate of 5.9 per 1,000 children with ASC statements in schools.

Nationally, around 19% of statements of SEN are for autism. There are 185 children with ASC with a statement which represents 18% of the total number of statemented children

22% of the pupils statemented with autism are eligible for free school meals

The Autistic Spectrum Condition Support Service (ASCSS) offers support to schools which include one or more pupils with a diagnosis of Autistic Spectrum Condition (ASC). ASC includes pupils who have a diagnosis of Asperger Syndrome. There are currently **242** pupils with ASC on the diagnosed pupil database of the ASCSS: pupils included in pre-school settings, and mainstream Primary and Secondary schools, in Brighton and Hove.<sup>13</sup>

The register of disabled children maintained by Amaze, known as Compass, has 421 children with an ASC registered (348 male and 73 female)

Approximately 60 new diagnoses of ASC are made each year by Seaside View and CAMHS

## 4. Engagement and Consultation

### Joint Engagement in Preparing the Plan

In developing this plan, we have listened to and taken account of feedback from a range of professionals, parents / carers, voluntary sector organisations and young people with autism.

A steering group of professionals and parent carers identified the following areas for development

- Children not meeting criteria for services- social care family support, CAMHS etc
- Support at home with behaviour
- Education health and care plans going to age 25
- Transitions
- Exclusions (particularly informal) and part time timetables
- Information and communication (it was noted that the local offer may help)
- Intensive early intervention (examples given of small pilots at Downsview and SSV)
- Training for parents and professionals
- Keyworker/lead professional
- Support for parents re communication with children at home e.g PECS
- Post 16 provision outside special schools

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<sup>4</sup> ONS census data 2011

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A survey undertaken by a local support group mAScot identified the following themes:

What would improve the quality of life and well-being of your child and your family?

*After school club and social activities*

*More support in school*

*meeting group(s) outside of school, for children from mainstream school,*

*Social skill club or group.*

*Our views to be taken into account by the school*

*Aspirations to be higher for children with autism*

*Less of a need to fight for what our child clearly should receive to address her needs in Education.*

*More support and understanding from school and the public.*

*some ongoing help with anxiety and aggression and social skills*

*An understanding in the Council of ASC. And an LEA not scared of Schools.*

*Better consultation of parents by school*

*Extra help in the home*

*More help and understanding from professionals. I am exhausted and stressed because I have to constantly fight against a system where I feel judged.*

*People having more knowledge on ASC, how it affects the child and family. Most important being listened too - if I say I need help it means I really need help and I am the expert of my child's needs please listen to what I have to say.*

mAScot 19th March 2013

A scrutiny panel was set up with its first meeting in July 2013 with the remit of considering 'what services are currently in place to help children with ASC and their families including: issues around diagnosis, health, education, social care, and home support; to look at areas of best practice; and to make recommendations for action'. The recommendations of the panel will inform the development of this plan

The Autism steering group locally is undertaking an audit of progress against the adult National Autism Strategy and participation in this process has identified risks for young adults with autism presenting within the criminal justice system. The youth offending service does not report corresponding high incidence but this will be an area for further investigation

## Aims and Principles

Our vision for our children and young people with SEN is that they will achieve the very best they can. In implementing this we will

- Work collaboratively across health, education and social care to identify and diagnose children as early as possible
- Demonstrate NICE compliant multi-agency assessment and diagnostic pathways
- Demonstrate our commitment to equality of opportunity, early intervention, preventative action, educational and social inclusion and high achievement for all learners
- Enable access to the curriculum and to the wider activities of our schools and early years providers

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- Place the child or young person at the heart of our plans and service delivery, working in a multidisciplinary way to achieve the best outcomes and shared priorities
- Work in partnership with education providers, parents, carers and communities to ensure that most children are able to be educated in their local area and continue to live with their family. Where this becomes too difficult to sustain we will work with all partners to ensure effective alternative provision is made as locally as possible
- Provide effective information and support to families about autism and strategies to live with and manage presenting behaviours and the impact on the child and family
- Communicate effectively with families about available services and eligibility criteria by publishing a subsection of the Local Offer specific to autism
- Ensure quality evidence-based provision is in place where children and young people have high aspirations and are empowered to achieve them
- Ensure our workforce has appropriate knowledge of autism and that there is access to specialist skilled staff across education, health and social care

## Current provision

### **Autism Diagnosis by Health Services**

It is important that a child's individual needs are identified as soon as possible so that they can be met in the most appropriate way. The assessment over time may indicate autism, but early intervention appropriate to the child's identified needs should not be dependant on a diagnosis of autism. However, it is recognised, that a diagnosis may help to guide families and professionals to the most appropriate source of information and support. A diagnosis can point the way to the type of difficulties that a child may have, but effective support can only be based on identification of the particular profile of individual needs and strengths, working in partnership with other agencies.

Parents/carers who feel that their child may have autistic spectrum condition (ASC) and wish to get a diagnosis or assessment should contact their GP or Health Visitor. If the GP/health visitor thinks a child may have ASC they should refer them for a formal assessment or diagnosis. In Brighton & Hove this is undertaken by **Seaside View Child Development Centre** if they are in primary school (up to Year 6) or **CAHMS** if they are older. In theory, parents can also self-refer. The rationale for having two main pathways to diagnosis (one for primary school children and one for older children and young people) is that for younger children community paediatricians are integral to the assessment of younger children to allow for differential diagnosis of autism, as opposed to other developmental conditions. For older children, the more likely differential is deemed to be between a mental health condition and autistic spectrum condition so a psychiatrist is part of the assessing team.<sup>5</sup>

If a school or nursery feels that a child would benefit from a special educational needs assessment, or if they believe a child may have ASC they must get the consent of the parent/carer first.

National guidance indicates that this formal assessment should lead to a multidisciplinary assessment by a team of professionals including, for example, psychiatrist, clinical psychologist, paediatrician, and possibly a speech and language therapist. NHS protocols suggest certain steps are taken on the procedure for assessment of possible ASC including: collection of information about child's development, health and behaviour from GP or nursery/school such as a series of interviews to gather details of development/history, a series of appointments to observe & assess specific skills and activities, and a physical examination. NICE clinical guidelines for autism diagnosis in children and young children set out very clearly the signs and symptoms of possible autism in children. They note that these signs and symptoms are a combination of delay in expected features of development and the presence of unusual features and are intended to "alert professionals to the possibility of autism in a child or young person about whom concerns have been

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<sup>5</sup> Report to CYPOSC

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raised...to help professionals recognise a pattern of impairments in reciprocal social and communication skills, together with unusual and repetitive behaviours".<sup>6</sup>

## Seaside View<sup>7</sup>

If a GP/Health visitor makes a referral for a *Developmental Assessment* this will be undertaken by a community paediatrician, sometimes jointly with other members of the team. This general developmental assessment (also known as Stage 1) may take various forms and involve various professionals. As a minimum, it will include a community paediatric assessment. Following this, a referral to a Stage 2 assessment will be made if there is a concern that the child may have ASC.

The Stage 2 assessment is an *ASC specific assessment* and it is requested by the community paediatrician at Stage 1 if there is concern about ASC. This is a multi-disciplinary assessment involving ASC-specific history from parents and collating information from other professionals, including information from the school/nursery. The speech and language therapist and clinical psychologist will undertake formal and informal assessments.

In some cases, a diagnosis is not reached at Stage 2. These children may need a period of observation in school and a review appointment. For a very small number of children, there are complex factors preventing a diagnosis and these families may be offered a referral to a tertiary centre which has national expertise in assessment in ASC – usually the Newcomen Centre, Guy's Hospital.

If a child receives a diagnosis of ASC, an action plan and information pack will be offered to the family. The ASC Support Service will be informed if the child attends a state maintained school. Within 6-12 weeks, a multi-disciplinary planning meeting is arranged for all pre-school children (and school age children if appropriate) to formulate the care plan. This meeting will include parents/carers, SENCO, ASC Support Service, School Nurse, and possibly others (eg paediatrician, educational psychologist, speech and language therapist). Specialist HV's are informed of all children diagnosed with ASC and contact parents by letter to offer support.

## Child and Adolescent Mental Health Service (CAMHS)

The CAMHS assessment includes a generic Stage 1 assessment and a multi-disciplinary Stage 2 diagnostic assessment following NICE guidelines. The Stage 2 assessment incorporates a care plan and CAMHS would expect to work closely with schools and other services.

If a child receives a diagnosis of ASC, an action plan and information pack is provided and within 4-6 weeks there is a review meeting for parents/carers with the diagnosing clinician to go through the report. The ASC School Support Service will also be informed if the child is at a state-maintained school. This is followed by a planning meeting arranged by the diagnosing clinician to include parents/carers, SENCo, CAMHS, ASCSS (possibly with educational therapist, speech and learning therapist, school nurse etc). The next stage is back to the referrer within CAMHS. Specialist HV's are informed of all children diagnosed with ASC and contact parents by letter to offer support. Post diagnosis Parent Carers are offered a group

## Other assessment routes

Parents/carers may opt for private assessment in order to reduce waiting times but it is worth noting that local services might not recognise a private assessment. The National Autistic Society recommends that any parents/carers following the private route should also stay on any waiting list for a NHS diagnosis even if a private assessment is undertaken.

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<sup>6</sup> *Autism diagnosis in children and young people. Recognition, referral and diagnosis of children and young people on the autism spectrum.* NHS National Institute for Health and Clinical Excellence. NICE clinical guideline 128

<sup>7</sup> Staff at Seaside View include: Key workers – support for children and families; Nursery Nurses; Occupational therapists; Paediatricians; Physiotherapists; PRESENS; Psychologists/Counsellors; Social Workers; Specialist Health Visitors; Specialist Nurses; Speech and Language Therapist.



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## Intervention

Schools, health and early years' settings have a major role to play in supporting families by expanding opportunities, widening access to education, as well as increasing the opportunities available to, and the achievements of, children and young people with autism.

Schools and settings sometimes work with children using autism friendly approaches prior to diagnosis - perhaps when a process of assessment and diagnosis is underway, or when behaviours strongly suggest that such approaches will be helpful to the individual concerned.

There are different interventions available at different points in the child's life:

### **Pre-school**

Seaside View- diagnostic pathway, post diagnosis support and therapy intervention eg speech and language therapy and small group work . Counselling for parents. Time Out for autism- training programme offered to families with an autistic child of all ages

PRESENS – support within early years child care settings to enable access to early education. Specialist assessment at the Jean Saunders Centre alongside a mainstream early years place where the level of need indicates this would be helpful and appropriate . Access to Educational Psychology

Children's Centres including health visitors and early years visitors – health visitor support in the home. Early years visitors offer some targeted intervention in the home where this is deemed appropriate

### **School age**

Ongoing support from SSV including therapies, community paediatrics, psychology and access to specialist health visitors and nurses . Time Out for autism

CAMHS Tier2 and 3 (Including LD CAMHS) – support for mental health and emotional and challenging behaviour issues associated with and alongside Autism

ASCSS- support to schools to best develop their curriculum and approaches to learning, particularly in mainstream environments. Parent support worker

Disability social work team – including assessment of eligibility for short breaks

Mainstream schools – access to SENCO support and small group and potentially specific additional teaching assistant time or differentiated curriculum depending on need

Units in mainstream- specialist support in a unit and to increase access to inclusion

Special schools – specialist support where the child's needs indicate this would be appropriate- e.g. in instances where autism is associated with challenging behaviour and learning disabilities or a young person is not able to access a mainstream environment for reasons of the curriculum or social interaction difficulties

Specialist provision outside the LA- where the family and LA feel that this is most appropriate to meeting the child's needs.

Educational psychology – assessment of need and ongoing support to schools in managing learning and behaviour needs

Training for staff and parent carers – Time Out for ASC, training offered to schools by ASCSS

Group for parent carers in CAMHS post diagnosis

Transport – offered where a child has a statement of special educational need and accessing school would otherwise prove difficult. Working towards promotion of independence

### **Other**

Community and voluntary sector organisations; eg Amaze can support parents to receive appropriate advice and support, including in thinking about starting school. There are also specific autism focused support

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groups eg Mascot and Autism Sussex. Scope offers Face to Face- a befriending service which links parents with trained volunteers. Not all services are dependant on a diagnosis but may be generic to those families with a child with an additional need, including Autism pre and post diagnosis

## Moving forward – focus areas for development

### Focus Area 1: Early Identification and Awareness Raising

Raising awareness of autism via multi-professional training of the workforce is beneficial to increasing early assessment of need and related diagnosis. Additionally, a workforce that is skilled in autism can help identify particular 'at-risk' groups for which autism is currently under-diagnosed (including individuals who have English as an additional language and those with an intellectual or sensory impairment). Through increasing understanding and awareness of autism it is envisaged that this will help identify children who may potentially have autism at an earlier stage. This should enable early intervention.

#### **Priority Actions:**

- **Increase autism awareness across the workforce through a targeted and tiered programme of competency-based training (universal, targeted and specialist)**
- **Increase the number of professionals able to deliver a range of parent support training courses for autism**
- **build on the current parental support programmes e.g. Time Out for ASC and CAMHS post diagnosis groups**
- **review of the prevalence of young people with autism in the youth offending service and awareness raising in this and other young people's services about the vulnerability of young people with autism**

### Focus Area 2: Integrated Assessment

When autism is suspected the assessment process can be detailed and complex, and usually involves a range of professionals.

*"The identification of autistic spectrum disorders requires expertise, experience and time."*

Wing, 1996 North Yorkshire  
Joint Autism Strategy 27

An accurate diagnosis can often bring clarity of what is needed to help the child or young person progress, and relief to those involved that they now have an explanation for the symptoms they have. We acknowledge that not all parents want to go down the diagnosis route. This may be for a number of reasons; however clinical support will still be available without formal diagnosis.

During the critical period around diagnosis school remains a constant in the child's life, providing regular structure and stability whilst parents and families begin to understand the lifelong implications of such a diagnosis. School provides a sense of structure and stability for the child and family, particularly throughout the diagnostic period. Parents will seek reassurance and evidence that their child's school is, at the very least, autism aware. They may also seek information on the skill level of their child's teacher in relation to autism.

Educational professionals e.g. Educational Psychologist will have been involved with the child and parents during the assessment period, or perhaps been part of the diagnostic process and therefore already have an understanding of the parents and extended family. This relationship can be pivotal in helping parents

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understand how autism affects their child and impacts on their learning as well as developing strategies that will help.

## **Priority Actions:**

- **Ensure the pathway for assessment and diagnosis of autism is consistently applied and that it is NICE compliant**
- **Provide joint health / education / social care plans post diagnosis, for children with autism, linked to the work of the Local Pathfinder**
- **Establish a mechanism for data collection and monitoring of the diagnostic process relating to autism**
- **Ensure that future health commissioning arrangements include full engagement with the plan for autism**

## **Focus Area 3: Give parents greater control and influence**

For partnership working to be effective, sharing and collaboration are essential - between parents, between professionals and between parents and professionals.

We will engage with young people, their parents/carers and those representing support organisations e.g. Amaze, mASCot, in developing the information pack for parents and families. Once the plan is finalised we will work with a group of young people to develop a young-person friendly version.

## **Priority Actions:**

- **Work through Amaze and the Local Offer to ensure comprehensive awareness of local groups that operate for children with autism**
- **Improve signposting to Voluntary Sector organisations that already offer support to children and young people with autism and their families, including opportunities for short breaks and leisure activities**
- **Ensure that families of children 0-5 with a diagnosis of autism are aware of and registered with their local Children's Centre**
- **Increase the number of training events and availability of autism awareness sessions for parents and professionals**
- **Conduct annual service user satisfaction surveys to monitor parental and service user feedback**
- **Ensure information packs are available for families post diagnosis to provide relevant information and support**
- **Ensure autism information is readily available and accessible through Family Information Services and libraries**

## **Focus Area 4: Enhance local provision**

What we hear from parents is that they would like to feel more confident that their child's school understands and knows how to work with their autistic child or young person. This seems to be an area of particular issue where a child attends a mainstream primary or secondary school. We recognise the need to enhance the workforce's understanding and knowledge of autism and also that joint planning and relationships with parent carers is key. The SEN pathfinder team have been developing a new model for a single plan and have been working on information sharing and parental confidence raising. These developments will support the parents of children with autism. We know that parents particularly feel that there is a lack of local secondary provision and we will address this via changes to the facility at Hove Park school. We also need to ensure an integrated approach to supporting children and young people across a range of settings and there will be greater emphasis placed on joint planning across education, health and social care and families to ensure a consistent approach to the needs of the child/young person.

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## **Priority Actions:**

- **Map the autism pathway of services to identify gaps in provision and encourage greater integration of services**
- **Ensure the needs of children with autism are included in the local authority's strategy for "Narrowing the Gap"**
- **Further develop ASCSS and PRESENS to support pre-school children through early intervention**
- **Embed the specialist educational psychology role to increase skills and knowledge in meeting the needs of children with autism and support schools**
- **Ensure that the full range and extent of provision for families of children with autism is identified and included in the published Local Offer**
- **Ensure that older young people with autism engaged with youth services, youth offending etc are well supported**

## **Focus Area 5: support at home**

The vast majority of children and young people live at home with their families and thus families need support and advice about managing the needs of their child/young person and this needs to be consistent across all settings. We are aware that currently parent carers identify this as a real and specific gap and recognise the need to develop greater support in the context of the family home. In some instances children, young people or their families may identify the need for short breaks/respite opportunities. We will seek to enhance the availability of access to support services by developing the Local offer and , where eligibility criteria are met, access to social care resources including direct payments.

Where it is not possible for a child to remain living within their family, careful multi-agency planning will be undertaken to identify the most appropriate placement for a child.

## **Priority actions;**

- **Enhance the autism knowledge of services offering support to families eg health visitors, PRESENS, Community CAMHS**
- **Develop the family support worker role within the ASCSS**
- **Develop the role of special schools and facilities for autism to support the introduction and implementation of particular strategies at home**
- **Make effective use of the Single EHC plan to describe support across all settings and ensure consistent use of agreed behaviour interventions/strategies**
- **Use the Local offer to describe local services, their skills, knowledge and experience to build parental confidence in what they provide**
- **Develop the work of the Behaviour Support Network**

## **Focus Area 6: Transitions**

It is important to ensure that the transition planning and process is well planned and coordinated at every stage for children and young people with autism. All providers and partners must work closely with the child and their family to ensure that these stages of the individual's life are well coordinated. This will ensure that services are tailored to meet the individual needs of the young person.

The goal is to deliver personalised services that give each individual the right support to have more choice and control over their own lives.

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Transition should not be a one off event and preparation should start early and can be supported by a health transition plan. It is important that we improve multi-agency working for young people with autism going through transition.

## Priority Actions:

- **Monitor and track destinations post 16 for young people with autism**
- **Continue to improve local personalised pathways for Post 16 and Post 19 learning opportunities, to enable more young people with autism to be educated and to live locally**
- **Ensure that this plan links with the strategy for young adults with autism and leads to improved pathways and better managed expectations for young people moving from being a child to adulthood**
- **Young people with autism moving into adult services will have an individual assessment of need and transition plan, including plans for education, employment and training**
- **Take a 'One Council' approach to planning for autism, working closely with the Health economy**

## Accountability and governance

The plan will be overseen by the SEN partnership board and agreed at the ASC strategy group- a multi agency group including representation from parent carers . It will be jointly agreed across the Children's Service and sit within the accountability arrangements of the CCG and council structures. The ASC steering group will report performance against the plan, including any areas of concern to both boards. The ASC steering group will link with the adult ASC strategy group through cross over membership and each will take due account of the other

Performance indicators – to be developed

Actions will be drafted in the form of a detailed tabular action plan once principles are agreed. (see appendix 1)

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Appendix 1 Action plan

	How	By whom	when	Resource implications
<p><b><u>Focus Area 1: Early Identification and Awareness Raising</u></b></p> <ul style="list-style-type: none"> <li>• Increase autism awareness across the workforce through a targeted and tiered programme of competency-based training (universal, targeted and specialist)</li> <li>• Increase the number of professionals able to deliver a range of parent support training courses for autism</li> <li>• build on the current parental support programmes e.g. Time Out for ASC and CAMHS post diagnosis groups</li> <li>• review of the prevalence of young people with autism in the youth offending service and awareness raising in this and other young people’s services about the vulnerability of young people with autism</li> </ul>				
<p><b><u>Focus Area 2: Integrated Assessment</u></b></p> <ul style="list-style-type: none"> <li>• Ensure the pathway for assessment and diagnosis of autism is consistently applied and that it is NICE compliant</li> <li>• Provide joint health / education / social care plans post diagnosis, for children with autism, linked to the work of the Local Pathfinder</li> <li>• Establish a mechanism for data collection and monitoring of the diagnostic process relating to autism</li> </ul>				

Appendix 1 Action plan

<ul style="list-style-type: none"> <li>• Ensure that future health commissioning arrangements include full engagement with the plan for autism</li> </ul>				
<p><b><u>Focus Area 3: Give parents greater control and influence</u></b></p> <ul style="list-style-type: none"> <li>• Work through Amaze and the Local Offer to ensure comprehensive awareness of local groups that operate for children with autism</li> <li>• Improve signposting to Voluntary Sector organisations that already offer support to children and young people with autism and their families, including opportunities for short breaks and leisure activities</li> <li>• Ensure that families of children 0-5 with a diagnosis of autism are aware of and registered with their local Children’s Centre</li> <li>• Increase the number of training events and availability of autism awareness sessions for parents and professionals</li> <li>• Conduct annual service user satisfaction surveys to monitor parental and service user feedback</li> <li>• Ensure information packs are available for families post diagnosis to provide relevant information and support</li> <li>• Ensure autism information is readily available accessible through Family Information Service libraries</li> </ul>				
<p><b><u>Focus Area 4: Enhance local provision</u></b></p> <ul style="list-style-type: none"> <li>• Map the autism pathway of services to identify</li> </ul>				



<p>gaps in provision and encourage greater integration of services</p> <ul style="list-style-type: none"> <li>• Ensure the needs of children with autism are included in the local authority’s strategy for “Narrowing the Gap”</li> <li>• Further develop ASCSS and PRESENS to support pre-school children through early intervention</li> <li>• Embed the specialist educational psychology role to increase skills and knowledge in meeting the needs of children with autism and support schools</li> <li>• Ensure that the full range and extent of provision for families of children with autism is identified and included in the published Local Offer</li> <li>• Ensure that older young people with autism engaged with youth services, youth offending etc are well supported</li> </ul>				
<p><u>Focus Area 5: support at home</u></p> <ul style="list-style-type: none"> <li>• Enhance the autism knowledge of services offer support to families eg health visitors, PRESENS, Community CAMHS</li> <li>• Develop the family support worker role within t ASCSS</li> <li>• Develop the role of special schools and facilities autism to support the introduction and implementation of particular strategies at home</li> <li>• Make effective use of the Single EHC plan to des support across all settings and ensure consistent</li> </ul>				

Appendix 1 Action plan

<p>of agreed behaviour interventions/strategies</p> <ul style="list-style-type: none"> <li>• Use the Local offer to describe local services, the skills, knowledge and experience to build parent confidence in what they provide</li> <li>• Develop the work of the Behaviour Support Net</li> </ul>				
<p><b>Focus Area 6: Transitions</b></p> <ul style="list-style-type: none"> <li>• Monitor and track destinations post 16 for young people with autism</li> <li>• Continue to improve local personalised pathways for Post 16 and Post 19 learning opportunities, to enable more young people with autism to be educated and to live locally</li> <li>• Ensure that this plan links with the strategy for young adults with autism and leads to improved pathways and better managed expectations for young people moving from being a child to adulthood</li> <li>• Young people with autism moving into adult services will have an individual assessment of need and transition plan, including plans for education, employment and training</li> <li>• Take a 'One Council' approach to planning for autism, working closely with the Health economy</li> </ul>				

## Pre School Special Needs Service (PRESENS) – AN OVERVIEW 2013

**PRESENS** works collaboratively with Parents, other professionals/other agencies and pre-school settings to ensure that young children's special educational needs are effectively met by promoting good inclusive practice in Pre School settings and nurseries in Brighton and Hove.

The core work of **PRESENS** is two fold :-

1. The PRESENS teams work directly with individual children who are at Early Years Action Plus of the Code of Practice or who have a statement of SEN to provide assessment, intervention and support for children. This is carried out either by the **Offsite team** at the child's mainstream setting or at our **Onsite provision**.
2. PRESENS Offsite team support all Pre-school settings in Brighton and Hove with the provision of high quality inclusive practice; giving them information and advice on Special Needs and disability issues and providing strategies and training to enable them to support children with SEN. This is provided in line with Government/statutory guidance on 'Area Senco' work which is given to LA's.

### How the teams support Children

- The **PRESENS Offsite Team** of nine experienced SEN Teachers (6.5 FTE) and six Specialist Nursery nurses (3.6FTE) support children in their Pre School Setting or at home from 2 years before Reception school age (R-2) through to the end of their first term in school. Children who receive the Early Education Funding for two year olds will receive support the term after they are two. Settings can access general support from our Offsite team for children aged 0 -5 years.
- Home teach may also be offered when a child is not attending a setting.
- The team also provide training on SEN and specialist areas of need e.g. Autism for all Pre School settings.
- The Offsite team supports 180 – 200 children each year.
- Initial referral visit to the home to assess the child's level of development and to draw up an action plan of support with the parents.
- Attending Multi Professional Assessments at Seaside View for children.
- Working with children on a one-to-one basis or in a small group situation to develop skills in areas that are delayed or impaired.
- Managing additional support funding and the inclusion grant to enable children to be fully included into a setting.

**PRESENS Onsite Team** are commissioned to provide a two day placement at The Jeanne Saunders Centre and Easthill Park House for eighteen R-1 children identified as needing a period of in-depth assessment and intervention due to the complex nature of their needs or where their core needs are unclear. On the previous two OFSTED inspections the Onsite provision at JSC and Easthill Park was graded Outstanding in all areas. 4 Teachers (2.2 FTEquiv.) 4 Nursery nurses (2.6 FT equiv.)

### PRESENS Support for Settings

- Each Offsite team is attached to a group of 147 Pre-school settings and mainstream nurseries across Brighton & Hove. Onsite staff also support children who are jointly placed with the JSC and EHP.
- Providing advice and practical support with the identification, assessment and intervention for children within the SEN Code of Practice in settings. Including advice on setting targets for IEPs.
- Providing support for setting based SENCO`s in drawing up and implementing an SEN policy.
- Identifying an area of development for each setting to work on through an agreed yearly target. These are evaluated at the end of each year.
- Developing and sharing good practice. Modelling small group activities for staff to run at the setting with children with additional needs. Opportunities for settings to observe outstanding practice at the Jeanne Saunders Centre and Easthill Park.
- Supporting settings with parent partnership.
- Multi agency working with Child Development Centre – Seaside View.
  - part of Referral panel
  - action planning for children with complex needs
  - coordinating training for staff in PVI settings around children with complex needs including coordinating health care needs
  - attending multi disciplinary assessments
  - part of ASC diagnostic pathway
  - Facilitating links with the settings
- Coordinating provision of specialist equipment and resources for use in PVI settings. (0-5yrs)
- Providing training on
  - Inclusive practice
  - Identification and intervention for children with additional needs
  - Equalities Act
  - The Code of Practice for SEN
  - Practical strategies to support children with additional needs
  - Parent partnership
  - Areas of additional Need including Autism
- This is delivered through 24 days of training per year and in-house training for pre-school settings. The evaluations show that all sessions have received 100% good to very good.
- Developing opportunities for SENCO networking. Each term PRESENS organise a SENCO network meeting to facilitate peer support. Over the past 2 years these have been very well attended and been used as a vehicle to promote new SEN national initiatives and guidance; including the first 2 phases of the Inclusion Development Programme. In addition, an annual SENCO Conference was established last year and is due to take place again in March 2013. This was a highly successful event and extremely well attended with 98% of practitioners finding it.
- Co-ordinating the I CAN Speech, Language and Communication Accreditation for Early Years settings. Working closely with colleagues from the Speech and Language Therapy Service and CEYC to take settings through the process in order to celebrate good practice and develop knowledge and skills. Twenty-two Pre-school settings in Brighton & Hove have achieved accreditation status or are currently working through the process.

PRESENS have also been represented on the 'Every Child a Talker' (ECAT) steering group as these two projects link very well.

- Publishing practical support guides/booklets for Early Years Practitioners, these include:
  - -Small Group Activities
  - -Strategies for Inclusion
  - -Guide to Motor Development
  - -Inclusive Environments.

### **Supporting children with an ASC diagnosis.**

**Offsite team are currently supporting 20 children on the pathway and 6 children with a diagnosis.**

#### **Onsite Team currently**

PRESENS are part of the multi-disciplinary diagnostic pathway and contribute detailed reports for this. PRESENS support children on the diagnostic pathway or with a diagnosis in their Pre School setting and hand over to the ASCSS service in the Autumn term when they start school. In partnership with the ASCSS PRESENS co-ordinate educational support following diagnosis and provide support for the families. PRESENS staff have previously run 'Early Bird' courses and are were involved in provision of Time Out for ASC courses for parents of children with a diagnosis, providing strategies and advice for use in the home facilitating peer support and developing parents confidence and skills in supporting their child. Also see **PRESENS Support for Pre School children with Autism.**

### **Supporting transition to school.**

All children prior to entering reception receive a transition support package. This may include MDR's with SENCOs in the summer term, arranging and supporting visits to the school for the child and parents, writing detailed transition reports, developing support materials and liaising with parents and colleagues to share information. Schools are also offered a maximum of three visits to observe and support the child's progress in the first term.

The transition process has proved to work very well and evaluations by school SENCOs have been positive.

### **Coffee mornings for parents**

To support with Makaton, behaviour, Statutory Assessment process etc. Parent questionnaires have been evaluated and show that 100% of parents are very satisfied/satisfied with the support their child has received.

### **General**

- Keeping abreast of National initiatives by attending regional SENCO networks and SEN Hub meetings and cascading information to staff.
- PRESENS attend ICP Referrals meetings for school age children in order to ensure 'educational' representation.
- Developing the Keyworker system in Brighton & Hove - procedures and forms are now in place. PRESENS are part of the Keyworker Implementation Group that assesses referrals and allocates Keyworkers to families.
- We have an attached Ed Psychologist based with PRESENS offsite service for 2 days a week
- We have an attached Speech and Language Therapist with the on site service 3 days per week.

## **Service Level agreement with Adrian Carver, Head of Downs View School.**

### **What works well**

- Joint working with professionals at Seaside view and joint assessment with Paediatricians.
- Home referral visit with parents.
- Good relationships with settings and focus on targets for support.
- High level of expertise of staff
- Consistently good evaluations for training.
- Transition to school – planned in Summer Term.
- More children being included in mainstream settings.

### **Areas of Best Practice**

- Practitioners in settings being more confident in including children with complex needs due to increased knowledge of strategies to support children with SEN in Pre School settings.
- Direct modelling of strategies through small group work enabling practitioners to improve their practice with individual children with SEN.
- Involvement in the diagnostic pathway and sharing of information leading to possible ASC diagnosis.
- Support to setting with Statutory assessment process.

### **Challenges**

- Settings being able to recruit sufficiently experienced staff.
- Time

**PRESENS Support for Pre school children with Autism including the Diagnostic pathway.**

<b>Stages for intervention</b>	<b>Child support</b>	<b>Parental involvement</b>	<b>Nursery Setting</b>	<b>Other Professionals</b>
Setting has concerns around a child with social communication and interaction.	PRESENS Offsite team observe child and discuss needs with the setting.	Parent's permission needed.	PRESENS Offsite team give the nursery advice and strategies.	Liaise with other professionals who are involved or refer to those that are needed with parental permission. Sign post to AMAZE.
Child identified as having possible social communication difficulties and needing referral to Seaside View Child Development Centre	PRESENS Offsite team take copy of referral to SSV and arrange home referral visit to parents. Additional support funding / Inclusion Grant if needed.	Permission sought for referral to HV, PRESENS and Paed for assessment. PRESENS Offsite team do home referral visit and take child on to caseload with parent permission. Given strategies and explanation of SSV referral pathway.	Advice and strategies and weekly or fortnightly intervention in small groups or 1-1. May be able to access Additional Support funding.	Referral goes through HV to do a CAF and NFER to Seaside View referral panel. PRESENS, Paed, SALT, HV sit on panel and make decision about who the child should be referred to.
Referral seen at SSV panel	Stage 1 assessment	Stage 1 assessment	Information on child passed on by PRESENS	Paed/PRESENS/SALT Stage1
Decided to go forward for stage 2 assessment following further investigation and support	Intervention, observation and assessment at nursery by PRESENS Offsite team weekly or fortnightly visits. Stage 2 report submitted. May be offered Onsite 2 day placement.	Parents kept informed of progress by nursery and PRESENS Offsite team.	Support nursery to gather information for Stage 2 assessment. Stage 2 report submitted.	Information gathered for stage 2 assessment.
Diagnosis of ASC given	PRESENS continue support for child. May initiate statement for school.	PRESENS support parent as appropriate. Explain statementing procedure if appropriate.	Continue support to setting. Support setting with writing advice for statement.	Multi disciplinary meeting arranged for 6 weeks later.

	Transition support into school.	Arrange MDM meeting with school at transition. Information mornings for Onsite and Offsite parents.		PRESENS hand over to ASCSS service in the term that the child starts school.
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PRESENS offer a yearly training course for nursery settings Areas of Need training : Social Communication/ASC –What are Autistic Spectrum Conditions? Triad of impairment. Initial concerns/diagnostic pathway. Understanding key ideas in some intervention approaches. Strategies to support communication, interaction, play and learning in settings. Introduction to Inclusion Development Programme.