

Verview & Scrutiny

Title:	Health Overview & Scrutiny Committee		
Date:	16 November 2011		
Time:	4.00pm		
Venue	Council Chamber, Hove Town Hall		
Members:	<b>Councillors:</b> Rufus (Chair), Barnett, Bennett, Follett, Turton, Marsh, C Theobald (Deputy Chair), Phillips, Brown (Non-Voting Co-Optee) and Hazelgrove (Non-Voting Co-Optee)		
Contact:	Giles Rossington Senior Scrutiny Officer 29-1038 Giles.rossington@brighton-hove.gov.uk		

F	The Town Hall has facilities for wheelchair users, including lifts and toilets
	An Induction loop operates to enhance sound for anyone wearing a hearing aid or using a transmitter and infra red hearing aids are available for use during the meeting. If you require any further information or assistance, please contact the receptionist on arrival.
	FIRE / EMERGENCY EVACUATION PROCEDURE If the fire alarm sounds continuously, or if you are instructed to do so, you must leave the building by the nearest available exit. You will be directed to the nearest exit by council staff. It is vital that you
	<ul> <li>follow their instructions:</li> <li>You should proceed calmly; do not run and do not use the lifts;</li> <li>Do not stop to collect personal belongings;</li> <li>Once you are outside, please do not wait immediately next to the building, but move some distance away and await further instructions; and</li> <li>Do not re-enter the building until told that it is safe to do so.</li> </ul>

# AGENDA

Part	Part One		
40.	PROCEDURAL BUSINESS (copy attached)	1 - 2	
41.	MINUTES OF THE PREVIOUS MEETING	3 - 8	
	Draft minutes of the meeting held on 28 September 2011 (copy attached)		
42.	CHAIR'S COMMUNICATIONS		
43.	PUBLIC QUESTIONS		
	No public questions have been received		
44.	NOTICES OF MOTION REFERRED FROM COUNCIL		
	No Notices of Motion have been received		
45.	WRITTEN QUESTIONS FROM COUNCILLORS		
	No questions have been received		
46.	SCREENING SERVICES	9 - 30	
	Report of the Strategic Director, Resources, on city screening performance (copy attached)		
47.	BRIGHTON & HOVE HEALTH AND WELLBEING BOARD	31 - 40	
	Report of the Strategic Director, Resources, on development of a local Health & Wellbeing Board (copy attached)		
48.	MENTAL HEALTH: ACUTE BEDS		
	Report to follow – this will be a late report as it will be a product of the HOSC MH workshop event taking place on Nov 10		
49.	BRIGHTON & HOVE ADULT AUTISM STRATEGY	41 - 74	
	Report of the Strategic Director, People, on the development of a local Adult Autism strategy (copy attached)		
50.	HOSC WORK PROGRAMME 2011-12	75 - 80	
	(copy attached)		

(copy attached)

## 51. LETTERS TO THE CHAIR

A letter from the Chief Operating Officer, Brighton & Hove Clinical Commissioning Group, and the Brighton & Hove City Council Director of Adult Social Services/Lead Commissioner, People, has been received (copy attached). This letter includes information regarding plans to make changes to:

a) Short Term Services

- b) Community Mental Health services
- c) the Carers' Strategy

Full reports on these issues are included in the papers for the city Joint Commissioning Board meeting on 14 November 2011. The papers for this meeting can be accessed via the council's website or by following this link:

http://present.brightonhove.gov.uk/mgConvert2PDF.aspx?ID=3310&T=10

#### 52. ITEMS TO GO FORWARD TO CABINET OR THE RELEVANT CABINET MEMBER MEETING

To consider items to be submitted to the next available Cabinet or Cabinet Member meeting

#### 53. ITEMS TO GO FORWARD TO COUNCIL

To consider items to be submitted to the next Council meeting for information

The City Council actively welcomes members of the public and the press to attend its meetings and holds as many of its meetings as possible in public. Provision is also made on the agendas for public questions to committees and details of how questions can be raised can be found on the website and/or on agendas for the meetings.

The closing date for receipt of public questions and deputations for the next meeting is 12 noon on the fifth working day before the meeting.

Agendas and minutes are published on the council's website www.brighton-hove.gov.uk. Agendas are available to view five working days prior to the meeting date.

Meeting papers can be provided, on request, in large print, in Braille, on audio tape or on disc, or translated into any other language as requested.

For further details and general enquiries about this meeting contact Giles Rossington, 01273 29-1038, email giles.rossington@brighton-hove.gov.uk) or email <u>scrutiny@brighton-hove.gov.uk</u>

Date of Publication - Tuesday, 8 November 2011

## 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 Commission, an Overview and Scrutiny Committee or a Select Committee has a prejudicial interest in any business at a 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.

# Agenda item 41

# **BRIGHTON & HOVE CITY COUNCIL**

## **HEALTH OVERVIEW & SCRUTINY COMMITTEE**

#### 4.00PM 28 SEPTEMBER 2011

## COUNCIL CHAMBER, HOVE TOWN HALL

#### MINUTES

**Present**: Councillors Rufus (Chair); Barnett, Bennett, Follett, Marsh, C Theobald (Deputy Chair), Phillips and Robins

**Co-opted Members**: Hazelgrove (Older People's Council) (Non-Voting Co-Optee)

# PART ONE

#### 27. PROCEDURAL BUSINESS

#### 27A Declarations of Substitutes

- 27.1 Cllr Robins attended as substitute member for Cllr Turton.
- 27B Declarations of Interest
- 27.2 There were none.
- 27C Declarations of Party Whip
- 27.3 There were none.

#### 27D Exclusion of Press and Public

27.4 In accordance with section 100A(4) of the Local Government Act 1972, it was considered whether the press and public should be excluded from the meeting during the consideration of any items contained in the agenda, having regard to the nature of the business to be transacted and the nature of the proceedings and the likelihood as to whether, if members of the press and public were present, there would be disclosure to them of confidential or exempt information as defined in section 100I (1) of the said Act.

# 27.5 **RESOLVED – That the Press and Public be not excluded from the meeting.**

#### 28. MINUTES OF THE PREVIOUS MEETING

28.1 Cllr Barnett requested clarification regarding point 18.2 of the draft minutes, where the council's Director of Adult Social Services (DASS) had made reference to the suspension of placements at the 'Bon Accord' nursing home. It was agreed that officers would obtain this clarification from the DASS.

# 28.2 RESOLVED – That the minutes of the meeting held on 28 September 2011 be approved and signed by the Chairman.

#### 29. CHAIR'S COMMUNICATIONS

29.1 Mr Robert Brown told members that he had recently been involved in an inspection at Knoll House intermediate care facility. During this inspection, the centre had been 'marked down' because of the poor condition of a service road (meaning patient transport could not always get all the way to the centre). However, this access road is owned by the city council rather than Sussex Community Trust, and Mr Brown felt it unjust that the trust should be penalised for

#### 30. PUBLIC QUESTIONS

30.1 There were none

#### 31. NOTICES OF MOTION REFERRED FROM COUNCIL

31.1 There were none.

#### 32. WRITTEN QUESTIONS FROM COUNCILLORS

32.1 There were none.

#### 33. '3T' DEVELOPMENT OF THE ROYAL SUSSEX COUNTY HOSPITAL

- 33.1 This item was introduced by Mr Duncan Selbie, Chief Executive, and Mr Duane Passman, 3T Programme Director and Director of Facilities and Estates, Brighton & Sussex University Hospital.
- 33.2 In response to questions regarding the suitability of the Brighton General Hospital site for the temporary provision of rheumatology physiotherapy/outpatients services during the 3T rebuild, Mr Passman confirmed that the site would be made fit for purpose before any services were located there. Mr Passman offered to provide members with more detailed information in writing on this matter.
- 33.3 In answer to a question from Cllr Marsh about the proportion of 'single rooms' in the redeveloped hospital accommodation, Mr Passman told members that various specialities

within the Royal Sussex County Hospital (RSCH) and Patient Groups had been canvassed on this issue, but support for 100% single rooms had been limited. In some instances this was because the need to keep higher dependency patients under observation (e.g. on neurosurgical wards) mitigated against the use of single rooms. Mr Passman confirmed that each single room would have its own en-suite sanitary facilities. Where it is not intended to supply single rooms, the 3T plans do specify that beds in four-bedded wards will be very widely spaced, to maximise privacy. It was also confirmed that each 4-bedded bay would have two en-suite WCs.

- 33.4 In response to a query from Cllr Theobald regarding single-sex wards, Mr Passman told members that the hospital was committed to providing gender-appropriate accommodation wherever possible. This might not necessarily be via single-sex 'wards' as wards could quite properly be mixed as long as patients within these wards were accommodated appropriately for instance in single rooms or in single sex bays effectively discrete from other parts of the ward.
- 33.5 In answer to a question from Cllr Robins regarding the use of local workers on the 3T build, Mr Passman told the committee that the hospital wanted to maximise the use of local contractors. However, the specialist nature of some of the build, the sheer size of the project, and the desire to maximise off-site fabrication to reduce waste meant that a good deal of the work would be likely to go to out of city contractors. Mr Passman estimated that it should nonetheless be possible to source at least 30% of the build value locally, but that this would still be subject to confirmation until all the works packages had been tendered.
- 33.6 In response to a query from Mr Robert Brown about the siting of the trauma helipad, Mr Passman told members that it had originally been thought unlikely that the roof of the Thomas Kemp building would be robust enough to site a helipad. However, more detailed investigation had contradicted this initial impression, and it was now planned to use this location..
- 33.7 In answer to questions regarding car parking and access to the RSCH site, Mr Selbie told members that, in addition to the significant increase in car parking space included in the 3T scheme, the hospital was actively pursuing a number of plans to reduce pressure on the RSCH site. These included a desire that the City establish a park and ride for the hospital and purchasing a city car park to use for staff parking. However, successfully implementing these plans depended upon more than the good intentions of the Hospital: the city council was a very significant player here.
- 33.8 The Chair thanked Mr Selbie and Mr Passman for their contributions and welcomed the offer of additional information on plans to make use of the Brighton General Hospital site during the 3T build.

# 34. CARE QUALITY COMMISSION INSPECTION OF THE ROYAL SUSSEX COUNTY HOSPITAL

34.1 This item was presented by Ms Sherree Fagge, Chief Nurse, and Ms Elma Still, Associate Director of Clinical Governance, Brighton & Sussex University Hospitals Trust (BSUH).

3

- 34.2 In response to a question from Cllr Theobald on actions being taken to provide information for relatives of those in hospital, Ms Fagge told members that some matrons at the Royal Sussex County Hospital had set up regular time-slots for relatives to discuss patients' needs and progress with nursing staff. The trust was also committed to using feedback from its patient choice questionnaire to improve services at a ward level.
- 34.3 In answer to questions about how the recent inspection had been triggered, Ms Still explained that the Care Quality Commission (CQC) uses various means to obtain a dynamic 'quality risk profile' for each organisation it assesses. This might include feedback from patients or stakeholders as well as the pro-active volunteering of information from trusts. In this instance, some of the information received by CQC highlighted potential concerns with some of the trust's services and CQC decided that an inspection was appropriate. The trust was happy to have the quality of its services tested in this way by CQC: BSUH considers that it has a very good relationship with the CQC, and views CQC feedback as a key driver to service improvement across the trust.
- 34.4 Mr Brown told members that the LINk was concerned that CQC was intending to discontinue its planned visits to healthcare providers. The LINk have lobbied the Department of Health on this matter.
- 34.5 The Chair thanked Ms Fagge and Ms Still for their contributions and congratulated the trust on having performed so well in its recent CQC inspection.

# 35. CITY GP SERVICES: PERFORMANCE

35.1 This item was introduced by Ms Elizabeth Tinley, Service Lead, Brighton & Hove City Primary Care Contracts and Commissioning Directorate, Sussex Commissioning Support Unit.

35.2 Members agreed that they were disappointed that this report did not include information on the performance of individual GP practices in the city and asked for a paper to be circulated including this material.

35.3 Members also asked for some work to be done mapping the relative performance of city GP practices against areas of deprivation across the city – i.e. to ascertain whether GP practice performance was significantly correlated with derivation etc – and requested that this be circulated alongside information on comparative performance.

35.4 In response to a question from Cllr Robins on the use of locums by individual GP practices, members were told that PCTs had no power to influence the use of locums by GP practices – the practice rather than named GPs is contracted to provide services. However, Ms Tinley agreed to find out whether information on locums was nonetheless collated, and, if so, whether there was any correlation between locum use and performance.

35.5 In answer to a question from Mr Hazelgrove on Patient Groups, members were informed that patients could choose to establish their own groups, although this could cause problems as the groups had to be fully representative of the practice population rather than a self-selecting sample.

35.6 The Chair thanked Ms Tinley for her contribution.

- 35.7 That the committee should receive additional information on:
  - (a) comparative performance of each city GP practice
  - (b) mapping of GP performance against city demographics
  - (c) use of locums and its correlation (if any) with GP practice performance.

#### 36. MENTAL HEALTH ACUTE BEDS IN BRIGHTON & HOVE

- 36.1 This item was introduced by Ms Geraldine Hoban, Chief Operating Officer, Brighton & Hove Emerging Clinical Commissioning Group (CCG); and Dr Richard Ford, Executive Director of Commercial Development; Dr Mandy Assin, Clinical Director for Older People; and Ms Samantha Allen, Service Director, Sussex Partnership NHS Foundation Trust (SPFT).
- 36.2 Dr Ford and Ms Hoban explained to the committee that benchmarking exercises had identified an over-reliance on mental health acute beds in Brighton & Hove, with both above-average admission rates and longer than average bed stays. There is a national consensus that high quality mental health services use acute bed spaces sparingly placing patients in them only when it is really necessary, and keeping people in hospital for as short a time as is commensurate with the best clinical outcomes. For this reason there has been a recent re-design of local mental health services, aiming to reduce reliance on acute beds. By introducing a new community assessment service, by improving pathways for a number of conditions, by commissioning a rapid response service for urgent referrals, by focusing on providing support to facilitate early discharge, and by better liaison with general health services (for people with both mental and physical health problems), SPFT and the CCG are confident that services levels can be maintained or improved with 19 fewer city mental health acute beds. Members were assured that no beds would be cut until it could be proved that the demand for them was no longer there.
- 36.3 Members were told that recent improvements to services had already seen average length of stay in acute beds fall significantly, and that there had been no recent recourse to placing Brighton & Hove patients out of area (although out of area placements had been necessary while the recent refurbishment of Mill View hospital took place).
- 36.4 The committee was told that there had been extensive consultation with stakeholders and service users over these changes, with strong support for the direction of travel. SPFT offered to share this information with the HOSC.
- 36.5 Members agreed that, before they could agree to support the plans, they would need to see more detailed information, particularly in terms of assurances that there would not be a negative impact on local people, and in terms of how impacts would be monitored. It was agreed that a workshop event would be arranged to discuss these issues in greater detail.
- 36.6 RESOLVED That the committee should arrange a workshop session to discuss the accommodation plans in detail before deciding whether to support these plans.

5

# 37. UPDATE ON LOCAL PROGRESS TOWARDS LOCAL IMPLEMENTATION OF ELEMENTS OF THE HEALTH & SOCIAL CARE BILL 2011

37.1 Members received a verbal briefing on recent developments in regard of implementation of the 2011 Health and Social Care Bill.

#### 38. HOSC WORK PROGRAMME 2011-12

38.1 Members discussed the 2011-12 work programme

#### 39. ITEMS TO GO FORWARD TO CABINET OR THE RELEVANT CABINET MEMBER MEETING

39.1 There were none.

#### 40. ITEMS TO GO FORWARD TO COUNCIL

40.1 There were none.

The meeting concluded at Time Not Specified

Signed

Chair

Dated this

day of

6

Subject:	Screening Services		
Date of Meeting:	16 November 2011		
Report of:	The Strategic Director, Resources		
Contact Officer: Name:	Giles Rossington Tel: 29-1038		
E-mail	ail: Giles.rossington@brighton-hove.gov.uk		
Wards Affected: All			

# FOR GENERAL RELEASE

# 1. SUMMARY AND POLICY CONTEXT:

- 1.1 This report presents the Committee with information on NHS health screening services provided to city residents. This information has been submitted by the NHS Sussex Public Health team, and is included as **Appendix 1** to this report.
- 1.2 For the past 2 years, the HOSC has been monitoring city performance in terms of NHS breast-screening services. This followed a sharp downturn in breast screening performance associated with a change of premises, the adoption of digital screening and problems in recruitment to the service. When they examined this issue in 2010, HOSC members were happy to note that performance was improving but requested a further update in a year's time to be sure that the improvements were not temporary. **Appendix 1** to this report contains details on breast screening performance over the past few months.
- 1.3 In addition this report contains general information about a range of screening services offered to city residents.

#### 2. **RECOMMENDATIONS**:

- 2.1 That members:
- (1) Note the content of this report and its appendix;

(2) Agree that recent performance in relation to breast screening demonstrates that the service is now operating effectively and does not require specific monitoring by the HOSC

# 3. BACKGROUND INFORMATION

3.1 See information included as **Appendix 1** to this report.

# 4. CONSULTATION

4.1 The information included in this report has been provided by the city Public Health team.

# 5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

5.1 None to this report for information

Legal Implications:

5.2 None to this report for information

Equalities Implications:

5.3 None to this report for information

Sustainability Implications:

5.4 None to this report for information

Crime & Disorder Implications:

5.5 None to this report for information

# Risk and Opportunity Management Implications:

5.6 None to this report for information

# Corporate / Citywide Implications:

5.7 None to this report for information

# SUPPORTING DOCUMENTATION

# Appendices:

Information supplied by NHS Sussex
 Documents in Members' Rooms:
 None

# Background Documents:

None

# Screening report for the Health Overview and Scrutiny Committee 16<sup>th</sup> November 2011

# 1. PURPOSE OF THIS PAPER

The purpose of this paper is to provide the Health Overview and Scrutiny Committee with background information on national screening policy and programmes, to provide an update on the East Sussex Brighton and Hove breast cancer screening programme, and to highlight some of the other local screening programmes.

## 2. BACKGROUND TO SCREENING AND SCREENING PROGRAMMES

#### 2.1 <u>Definition of screening</u>

The National Screening Committee defines screening as:

"A process of identifying apparently healthy people who may be at increased risk of a disease or condition. Once identified they can then be offered information, further tests and appropriate treatment to reduce their risk, and/or any complications arising from the disease or condition."

#### 2.3 The UK national screening committee (UK NSC)

The UK National Screening Committee (UK NSC), founded in 1996, is funded by the Department of Health to:

- advise Ministers and the NHS in the four UK countries about all aspects of screening;
- assess the evidence for programmes against a set of internationally recognised criteria - covering the condition, the test, the treatment options and the effectiveness and acceptability - to ensure screening does more harm than good at a reasonable cost;
- set up practical mechanisms to oversee the introduction of new programmes in the English NHS;
- monitor the effectiveness and quality of screening programmes;
- regularly review policy on screening for different conditions in the light of new research evidence becoming available;
- make recommendations for screening across all clinical areas, including cancer.

Implementation of cancer programmes is the responsibility of the NHS Cancer Screening Programmes and of non-cancer screening programmes the UK National Screening Committee.

#### 2.4 Limitations of screening

In any screening programme, there are false positive results (people without the target condition identified as having it) and false negative results (people with the target condition identified as not having it); no screening programme is 100% accurate. The UK National Screening Committee (NSC) is increasingly presenting screening as risk reduction to emphasise this point.

2.5

The UK NSC has over one hundred screening policies. A policy review takes between 6 and 24 months, depending on the amount of new evidence to review and the number of stakeholders involved. There are two outcomes of a review: the UK NSC will recommend that screening for a condition should be offered or based on the current available evidence, it should not be.

#### 2.6 <u>Criteria for appraising a screening programme</u>

The UK NSC has developed 22 criteria to assess whether screening should be considered for a certain condition (see Appendix 1). Ideally all of those that are relevant to the condition should be met before a screening programme is initiated.

#### 2.7 National Screening programmes (Appendix 2)

The following national screening programmes are available in England:

Antenatal and newborn

- Fetal anomaly 1<sup>st</sup> and 2<sup>nd</sup> trimester Down's syndrome
- Fetal anomaly 2<sup>nd</sup> trimester anomaly scan
- Infectious diseases in pregnancy
- Antenatal sickle cell and thalassaemia
- Newborn and infant physical examination
- Newborn bloodspot
- Newborn hearing screening

Young person and adult

- Cancer breast
- Cancer cervical
- Cancer bowel
- Abdominal Aortic Aneurysm
- Diabetic retinopathy

<u>Other related/national screening programmes (not discussed in this paper)</u> The following programmes have been introduced although they do not meet the criteria for national screening programmes.

- Chlamydia
- NHS Health checks

#### 2.8 **Quality assurance**

Quality assurance and performance management are an integral part of all national screening programmes. NHS Cancer Screening Programmes oversee the three cancer screening programmes and the UK National Screening Committee the non-cancer programmes. Quality assurance includes supporting regional centres, provision of guidance on good practice, setting and monitoring standards and targets, and organising quality assurance visits.

#### 3. CANCER SCREENING PROGRAMMES

#### 3.1 Breast cancer

#### 3.1.1 Background

The national breast cancer screening programme currently offers women aged 50-70 years screening every three years. The local programme for East Sussex, Brighton and Hove is provided by Brighton and Sussex University Hospitals' Trust and is commissioned by NHS Brighton and Hove (now part of NHS Sussex).

In 2006/7 as a result of the combination of staffing issues, poor facilities and administrative issues the screening round length of the local programme and some of the associated quality indicators began to slip. In 2008 the breast screening unit moved to new premises at "The Park Centre" which has new digital technology. Staff at the unit have worked extremely hard to return their programme to the high standards it was accustomed to delivering. The unit has also been successful in recruiting staff to vacant posts.

#### Current performance

The most recent official breast screening performance statistics are for the year 2009/10 and are summarised below.

Area	Coverage for women aged 53-70 years (women screened within the last 3 years)
Brighton and Hove	71.2%
East Sussex Downs and Weald	62.9%
Hastings and Rother	75.9%
England	76.9%

The unofficial performance for coverage in 11/12 for Brighton and Hove is 71.2%. The minimum standard is 70%. All eligible women in Brighton and Hove have been offered screening within the previous three years. The unit is now also meeting the national standards for the time from screening to results, screening to assessment, and technical recalls and repeats (The percentage of women offered and attending an appointment within 3 weeks did fall in August 2011. This is attributed to the holiday season).

It has taken longer for the unit to recover the 36 month round length than expected. This is for two main reasons:

- Firstly the need to return to a programme of rotating site visits across East Sussex which can be maintained for the future. For example, to try to minimise the impact of the delays in previous years, women from some areas had been invited to different locations for screening compared with previous rounds and this has had a "knock-on" effect to the next round.
- Secondly the need to take into account the age expansion programme.

Since February 2011 the unit has consistently invited over 95% of women within 38 months of their previous screen and in August and September 85% were invited within 36 months. The unit expects to achieve the target of 90% of women across East Sussex being invited within 36 months of their previous screen by the end of October 2011.

Of the women from Brighton Marina area who were invited to attend the Park Centre between February and September 2011, 98% were invited within 36 months.

The table below shows, by the four Brighton and Hove planning areas used by the service, when women were last invited for screening and when they are due to be called for the next round.

Area	Due	Due end	Possible Start Date	Possible End Date	Last invited
Brighton Hollingbury	01/12/2011	14/05/2012	20/09/2011	17/06/2012	02/12/08 – 14/05/09 Currently being invited
Hove & Portslade (BN1)	14/01/2013	03/12/2013	17/06/2012	16/07/2013	15/01/10 – 02/12/10
Brighton Central	29/11/2013	01/02/2014	16/07/2013	14/11/2013	30/11/10 – 02/02/11
Brighton Marina	01/02/2014	19/09/2014	14/11/2013	16/06/2014	02/02/11 – 20/09/11

#### 3.1.2 Age expansion and high risk women.

Nationally the programme is being expanded so that women will now be invited from age 47 to 49 and 71 to 73 years. This is being introduced over six years as a randomised project to establish the benefits and harm of being screened for the two new age groups. To be able to begin the round length, units had to be assessed by the national breast screening programme head office as having the capacity to cope with the introduction without adversely affecting the screening of women aged 50-70 years. The East Sussex, Brighton and Hove programme was granted approval to begin the expansion from April 2011.

From January 2012 the national breast screening programme will have responsibility for the surveillance of high-risk women, such as those with a strong family history of breast cancer associated with a breast cancer gene.

#### 3.1.3 Improving uptake by locality

Since moving to The Park Centre the unit has invited local women to attend The Centre for their mammograms. This has helped the unit to recover the round length. However, for some women the extra distance required to travel to the Centre may have discouraged them from attending for their mammogram. Further analysis of the data is being undertaken to investigate this. To try and mitigate this, the unit is working with the local cancer health promotion team to promote the service and is running additional clinics for those who fail to keep their first appointment.

The programme routinely distributes promotional materials to the GP practices of women it is currently inviting. This is being supplemented by a mail drop in areas where the uptake has been low. This includes information about cervical screening as well.

Promoting the breast screening programme is included in the ongoing work of the local cancer health promotion team. The team promotes the programme either directly to eligible women through educational sessions and attending community events or through key workers and key members of the local community. The local health trainers also support the programme.

#### 3.2 Cervical cancer

#### 3.2.1 Background

The national cervical cancer screening programme offers regular screening to women aged 25 to 64 years of age. Women are invited to attend their GP surgery every three years until age 49 and then every five years. Locally women can also attend the sexual health service at Morley Street. Most local cervical screens are undertaken by practice nurses.

To be routinely invited for their screen women must be on the GP registration system. If a woman does not attend for her screen after two written invitations her GP is advised so that the practice can directly contact her. Women with a result requiring further investigation are referred for colposcopy at BSUHT.

GPs receive payment both for providing the service, and for the coverage they achieve amongst their registered population through the Quality and Outcomes Framework (QOF). Through the QOF practices are able to "exception report" women (exclude them from their figures) who have not attended after being invited three times for their cervical screen. This is not permitted for the national programme. Hence the coverage reported through the QOF is higher than that reported for the national programme.

In recent years in line with national policy the local programme has successfully introduced a new technique for screening (liquid based cytology) and has met the target for 98% of women to receive their results within two weeks. The latter is a great improvement from recent years when women were often waiting over three months for their result.

From 2012 HPV (Human Papillomavirus) testing will also be introduced to the programme. This will eventually reduce the number of referrals of women with screening results requiring further investigation. The HPV

vaccination programme which was introduced in 2008/9, and which is now routinely offered to all year eight schoolgirls, will also help protect against cervical cancer and reduce the need for further investigation. In 2010/11 85% of local year 8 girls completed their three HPV vaccinations.

#### 3.2.2 Current performance

The most recent official coverage information for 2009/10 is shown in the table below:

Area	Coverage for women aged 25- 49 years (women screened within the last three and a half years)	Coverage for women aged 50-64 years (women screened within the last five years)	Coverage for all women aged 25-64 years (women screened within the last five years)
Brighton and Hove	71.9%	74.6%	75.9%
East Sussex Downs and Weald	76.0%	77.8%	79.5%
Hastings and Rother	76.0%	77.3%	79.5%
England	74.0%	78.9%	78.9%

The most recent unpublished data from June 2011 shows the coverage for Brighton and Hove women aged 25-64 years to be 76.4%.

The QOF based coverage data for 2010/11 was 83.1% with 11,546 women being exception reported.

The current programme schedule was introduced in 2004, since when women have received their first invitation at 25 years rather than 20 years of age. The national and local coverage for women aged 25-64 years has fallen from 81.2% and 81.7% respectively since 2003. The most significant fall has been in younger women. The total eligible local population of women aged 25-64 years is approximately 78,000 of whom 26,000 are aged 25 to 34 years of age.

#### 3.2.3 Improving local uptake.

As with most screening programmes the coverage for cervical screening tends to be lower amongst women from more socially disadvantaged groups, such as those living in the more socio-economically deprived parts of the city, women from Black and Minority Ethnic Communities and women with disabilities. In addition the uptake amongst women under 35 years and over 50 years has fallen nationally and locally in recent years.

The cancer health promotion team has worked with key professionals and different partner agencies to promote the programme to various local groups such as the Universities, Bangladeshi women's group, children's centres and travellers.

The PCT makes an annual visit to practices to discuss their overall performance using a "balanced scorecard" of performance relating to

various services. Cervical screening is included in this. Individual poor clinical performance is followed up by the PCT's quality team. The cancer health promotion team has also worked with the ten local practices with the lowest coverage to improve uptake of cervical screening. This has included phoning women who have not attended for their screen. Training for reception staff about screening programmes has also been provided.

Historically the information relating to whether lesbians should be offered cervical screening has not always been consistent. Recent research has made it clear that lesbian women are at risk of cervical cancer and that all women should be offered screening. The cancer health promotion team has run an information campaign aimed at the local lesbian population.

Every opportunity is taken to promote cervical screening through local media. These are often linked to national news items such as the tragic death of Jade Goody and a recent storyline on the Eastenders television programme. These national news items tend to result in a temporary increase in the number women having their cervical screen.

#### 3.3 Bowel cancer

#### 3.3.1 Background

The national bowel cancer screening programme invites men and women\_ aged 60 to 69 to be screened every two years; they are sent a home screening kit and an envelope for test return. People over 70 years of age can request a screening kit via a helpline number. The test looks for Faecal Occult Blood (FOB) ['occult blood' means hidden blood] in stool samples. The FOB test does not diagnose bowel cancer, but the results will identify those who need an examination of the bowel (a colonoscopy).

Results are usually received from the laboratory within two weeks of sending the sample. There are three types of results: normal (no FOB detected); unclear (requires repeat FOB test); abnormal (FOB found) and hence colonoscopy required. About twenty in every thousand who have the test will have an abnormal result.

Of those requiring colonoscopy; about 5 in 10 will have a normal result (they do not have cancer or polyps); about 4 in 10 will be found to have a polyp, which if removed may prevent cancer developing; and about 1 in 10 will be found to have cancer.

#### 3.3.2 Performance

In 2010/11 the average uptake of bowel cancer screening in Brighton and Hove was 53%, compared to 58% across Sussex. However, up-take increased considerably from November 2010 and reached 70.5% in March 2011.

As with breast and cervical cancer screening, the cancer health promotion team have worked across the city to increase up-take with a particular focus on the more deprived areas.

#### 3.3.3 Age expansion

The age range for screening has now been extended to include men and women up to their 75th birthday. Nationally, screening centres are rolling out the extension following their first two-year screening round (subject to meeting criteria and subsequent approval by the national office). By October 2011, 32 of the 58 screening centres had started inviting the extended population. However, there is a delay in introducing the age extension in Brighton and Hove due to the endoscopy waiting list times in East and West Sussex. Plans have been formulated to address this issue and the intention is that the age expansion will be introduced in 2012.

#### 4. NON-CANCER SCREENING PROGRAMMES

#### 4.1 Diabetic retinopathy

Diabetic retinopathy screening is offered annually to people aged 12 or over with diabetes. The aim of the screening programme is to reduce the risk of sight loss amongst people with diabetes by the prompt identification and effective treatment, if necessary, of sight threatening diabetic retinopathy, at the appropriate stage during the disease process. Systematic screening involves digital photography of the retina followed by a two or three stage image grading process to identify the changes of sight-threatening diabetic retinopathy in the retina.

#### 4.2 Abdominal Aortic Aneurysm (AAA) screening for men

The National Screening Committee has introduced a national screening programme for Abdominal Aortic Aneurysms (AAA) in men in their 65th year. Brighton and Hove is part of a successful bid to introduce AAA screening across Sussex from 2012. The programme is already established in West Sussex. The evidence does not support the introduction of screening for women.

Death from a ruptured AAA is more than twice as common in men as in women. About one-third of AAAs will rupture if untreated, with those above 5.5cm in diameter most likely to rupture. Half of those patients with a ruptured AAA will die before they reach hospital and for those who survive to undergo emergency repair the operative mortality is around 40%. Most AAAs are asymptomatic, but they can present with symptoms such as pain, or may be detected incidentally. When repaired electively there is a risk of peri-operative mortality, which can be up to 6%. The current local perioperative performance is below 1%.

For Brighton and Hove the screening programme will invite between 1300 and 1400 men aged 65 for an ultrasound scan at a small number of sites across the city. Most men will have a normal scan and will then be discharged from the programme and not screened again. When an aneurysm is detected, depending on its size, the patient will either be kept under surveillance within the programme or referred to secondary services for possible elective surgical repair. After approximately 10 years, the numbers needing elective surgery will plateau and the number needing emergency repair of ruptured AAA will start to decrease as those who would have needed emergency surgery will already have had their aneurysm repaired electively.

#### 5. ANTENATAL AND NEONATAL SCREENING PROGRAMMES

#### 5.1 Fetal Anomaly Screening Programme (FASP)

Around 700,000 women get pregnant in the UK every year. Over 95% of these pregnancies result in the birth of a healthy baby. However, in a few cases, there are problems affecting the baby's development. Fetal anomaly screening is a way of assessing whether the unborn baby (fetus) could develop or has developed an abnormality or other condition during pregnancy.

Within this programme all women should be offered:

- A screening test for Down's syndrome that meets agreed national standards;
- An ultrasound scan between 18 20 weeks 6 days to check for physical abnormalities in their unborn baby;
- Information to help them decide if they want screening or not.

Combined screening for Downs syndrome was introduced locally in October 2009. Prior to this time women had to be referred by their GP to Kings College Hospital, London; only around 50% took up this opportunity.

#### 5.2 Infectious diseases in pregnancy (IDPS)

The infectious diseases in pregnancy screening programme offers screening to all pregnant women for four conditions: Hepatitis B, HIV, Rubella susceptibility and Syphilis. The tests are performed at one of the first antenatal visits and are usually all done from one blood sample. Results are provided at the next clinic visit.

The new IDPS Programme Standards and Laboratory Handbook, published in September 2010, set out the UK National Screening Committee's expectations around the delivery and quality of the IDPS programme locally. These standards were introduced from April 2011 and are to be fully embedded in practice by April 2012

#### 5.3 Antenatal sickle cell and thalassaemia

Sickle Cell disorders are a group of inheritable genetic conditions in which there is an abnormality of the haemoglobin. Haemoglobin carries oxygen to the various organs of the body and is contained in the red blood cells. In the sickle cell disorders some of the red blood cells assume a sickle shape following the release of oxygen. This abnormal shape causes the cells to clump together making their passage through smaller blood vessels difficult, which may lead to blockage of these small blood vessels and an associated inflammatory reaction. ß Thalassaemia major is a life threatening, genetically inherited, progressive anaemia common in the Mediterranean, Asian, South East Asian and Middle Eastern countries.

The NHS Sickle Cell and Thalassaemia Screening Programme offers a linked programme of:

- Screening during pregnancy for all pregnant women in England
- Screening for sickle cell disease for all newborn babies in England

The NHS Sickle Cell and Thalassaemia Screening Programme is the first service in the world to aim to link antenatal and newborn screening.

The approach in high and low prevalence areas differs; Brighton and Hove is a low prevalence area. From April 2007, all units defined as low prevalence (a fetal prevalence of sickle cell lower than 1.5 per 10,000 pregnancies) were required to offer screening using the recommended family origin question, as well as a formal process of inspection of routine blood indices to screen for thalassaemia.

#### 5.4 <u>Newborn and Infant physical examination (NIPE)</u>

The NHS Newborn and Infant Physical Examination Programme (NIPE) offers parents the opportunity of a head to toe physical examination for their baby to check for problems or abnormalities. The examination is carried out within 72 hours of birth and then again at 6 to 8 weeks of age, as some conditions can develop later. It includes: a general all over physical check, as well as specific examination of the baby's eyes, heart, hips, and testes, in boys. NIPE aims to maintain and improve the standards of care for babies and is part of the Government's Updated Child Health Promotion Programme. Brighton and Sussex University Hospital is one of a number of pilot sites who are piloting the 72 hour examination and the use of webbased software for monitoring and reporting results.

#### 5.5 Newborn bloodspot (See Appendices 3 and 4)

Newborn blood spot screening identifies babies who may have rare but serious conditions. All babies in the UK are offered screening for: phenylketonuria (PKU), congenital hypothyroidism (CHT), sickle cell disease (SCD), cystic fibrosis (CF) and medium-chain acyl-CoA dehydrogenase deficiency (MCADD). For the small number of babies that have one of these conditions early treatment can improve their health and prevent severe disability or even death. It is one of the largest screening programmes in the UK and each year over 700,000 newborns are screened. Uptake of screening tests is high with more than 99% of the babies born each year being screened.

The bloodspot is taken via a heel prick conducted by the midwife between day 5 and day 8 after birth. It is collected on a card which is sent to a London laboratory for analysis.

If a baby is thought to have one of the conditions, he or she will need further tests to confirm the result. The purpose of screening is to identify babies more likely to have these conditions.

#### 5.6 Newborn hearing screening programme

The early identification of hearing loss is known to be important for a child's development. One to two babies in every 1,000 are born with a hearing loss in one or both ears. Most of these babies are born into families with no history of hearing loss. The NHS Newborn Hearing Screening Programme's major aim is to identify all children born with moderate to profound permanent bilateral deafness within 4-5 weeks of birth, and to ensure the provision of safe, high quality age-appropriate assessments and support for deaf children and their families.

#### 6. **RECOMMENDATIONS**

- 6.1 The Health Overview and Scrutiny Committee is asked to note the continued improvement and progress towards recovery of the 36 month screening round length by the East Sussex, Brighton and Hove breast screening programme.
- 6.2 The Health Overview and Scrutiny Committee is asked to note the background information about national screening programmes and the updates on local programmes.

Martina Pickin Public Health Improvement Principal Public Health Directorate NHS Sussex (Brighton and Hove) Peter Wilkinson Consultant in Public Health

# APPENDIX 1

#### Criteria for assessing screening programmes

#### The Condition

- 1. The condition should be an important health problem
- 2. The epidemiology and natural history of the condition, including development from latent to declared disease, should be adequately understood and there should be a detectable risk factor, disease marker, latent period or early symptomatic stage.
- 3. All the cost-effective primary prevention interventions should have been implemented as far as practicable.
- 4. If the carriers of a mutation are identified as a result of screening the natural history of people with this status should be understood, including the psychological implications.

#### The Test

- 5. There should be a simple, safe, precise and validated screening test.
- 6. The distribution of test values in the target population should be known and a suitable cut-off level defined and agreed.
- 7. The test should be acceptable to the population.
- 8. There should be an agreed policy on the further diagnostic investigation of individuals with a positive test result and on the choices available to those individuals.
- 9. If the test is for mutations the criteria used to select the subset of mutations to be covered by screening, if all possible mutations are not being tested, should be clearly set out.

#### The Treatment

- 10. There should be an effective treatment or intervention for patients identified through early detection, with evidence of early treatment leading to better outcomes than late treatment.
- 11. There should be agreed evidence based policies covering which individuals should be offered treatment and the appropriate treatment to be offered.
- 12. Clinical management of the condition and patient outcomes should be optimised in all health care providers prior to participation in a screening programme.

#### The Screening Programme

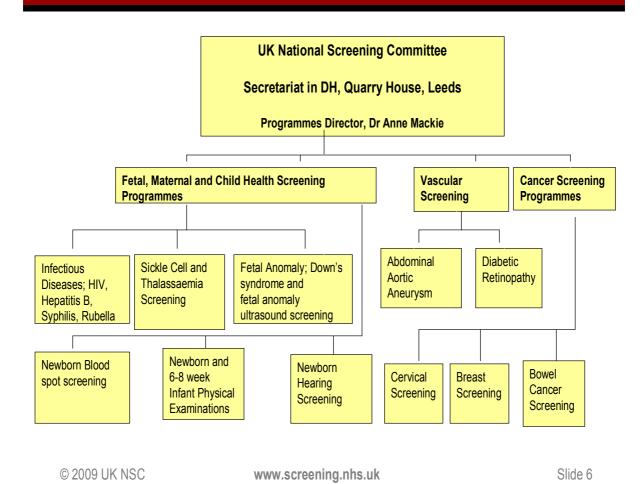
- 13. There should be evidence from high quality Randomised Controlled Trials that the screening programme is effective in reducing mortality or morbidity. Where screening is aimed solely at providing information to allow the person being screened to make an "informed choice" (eg. Down's syndrome, cystic fibrosis carrier screening), there must be evidence from high quality trials that the test accurately measures risk. The information that is provided about the test and its outcome must be of value and readily understood by the individual being screened.
- 14. There should be evidence that the complete screening programme (test, diagnostic procedures, treatment/ intervention) is clinically, socially and ethically acceptable to health professionals and the public.

- 15. The benefit from the screening programme should outweigh the physical and psychological harm (caused by the test, diagnostic procedures and treatment).
- 16. The opportunity cost of the screening programme (including testing, diagnosis and treatment, administration, training and quality assurance) should be economically balanced in relation to expenditure on medical care as a whole (i.e. value for money). Assessment against this criterion should have regard to evidence from cost benefit and/or cost effectiveness analyses and have regard to the effective use of available resource.
- 17. All other options for managing the condition should have been considered (eg. improving treatment, providing other services), to ensure that no more cost effective intervention could be introduced or current interventions increased within the resources available.
- 18. There should be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards.
- 19. Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be available prior to the commencement of the screening programme.
- 20. Evidence-based information, explaining the consequences of testing, investigation and treatment, should be made available to potential participants to assist them in making an informed choice.
- 21. Public pressure for widening the eligibility criteria for reducing the screening interval, and for increasing the sensitivity of the testing process, should be anticipated. Decisions about these parameters should be scientifically justifiable to the public.
- 22. If screening is for a mutation the programme should be acceptable to people identified as carriers and to other family members

#### APPENDIX 2:

#### **Organisational structure of UK National Screening Committee**

# **Organisational Structure of UK NSC**



16

#### **APPENDIX 3:**

#### Conditions screened for by newborn bloodspot

About 1 in 10,000 babies born in the UK has phenylketonuria (PKU). Babies with this inherited condition are unable to process a substance in their food called phenylalanine. If untreated, they will develop serious, irreversible, mental disability.

About 1 in 4,000 babies born in the UK has congenital hypothyroidism (CHT). Babies with CHT do not have enough of the hormone thyroxine. Without this hormone, they do not grow properly and can develop serious, permanent, physical and mental disability.

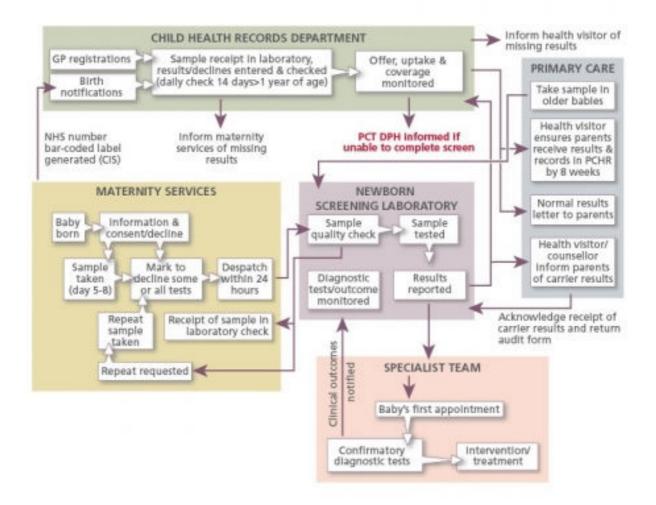
About 1 in 1,900 babies born in the UK has a sickle cell diseases (SCD). These are inherited disorders that affect the red blood cells. If a baby has a sickle cell disease, their red blood cells can change to a sickle shape and become stuck in the small blood vessels. This can cause pain and damage to the baby's body, serious infection, or even death.

About 1 in 2,500 babies born in the UK has cystic fibrosis (CF). This inherited condition can affect the digestion and lungs. Babies with CF may not gain weight well, and have frequent chest infections.

About 1 in 10,000 babies born in the UK has MCADD. Babies with this inherited condition have problems breaking down fats to make energy for the body. This can lead to serious illness, or even death.

#### APPENDIX 4:

#### Newborn Bloodspot screening pathway



Subject:		Brighton & Hove Health & Wellbeing Board		
Date of Meeting:		16 November 2011		
Report of:		The Strategic Director, Resources		
Contact Officer:	Name:	Giles Rossington	Tel:	29-1038
	E-mail:	Giles.rossington@brighton-hove.gov.uk		
Wards Affected:	All			

# FOR GENERAL RELEASE

# 1. SUMMARY AND POLICY CONTEXT:

- 1.1 The 2011 Health & Social Care Bill currently progressing through parliament requires all upper-tier local authorities to establish local 'Health & Wellbeing Boards' (HWB). HWBs are to be partnership boards, bringing together GP commissioners, local authority officers and members and representatives of the public to undertake strategic planning for local health, public health and adult and children's social care services.
- 1.2 An officer-led Public Health & Wellbeing Project Board (PHWB) has been established to develop a draft local HWB model in conjunction with local stakeholders. Details of this draft local model are included as **Appendix 1** to this report. The Health & Social Care Bill requires us to have a shadow HWB in place by April 2012, and a fully operational HWB by April 2013. In order to meet these deadlines, the draft model is currently out for stakeholder and partner consultation. Following appraisal of the comments received during this consultation period, a final draft of the model will then go to Cabinet, Governance Committee and Full Council for decision in early 2012.

# 2. **RECOMMENDATIONS**:

- 2.1 That members:
- (1) Note the content of this report and its appendix;
- (2) Comment on the draft model for a local Health & Wellbeing Board

# 3. BACKGROUND INFORMATION

3.1 More information on HWBs is included in **Appendix 1** to this report.

# 4. CONSULTATION

4.1 **Appendix 1** to this report includes information on the draft HWB model for Brighton & Hove. This model has been prepared by the city Public Health and Wellbeing Project Board, a partnership board bringing together officers from the city council, the PCT and the local transitional Clinical Commissioning Group. The draft model has been informed by consultation with a range of stakeholders, including health and social care providers and commissioners, the voluntary sector, patient and user groups and Councillors.

# 5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

5.1 None directly to this report for information. The draft model for a local HWB (see **Appendix 1**) does not envisage the HWB controlling any specific budgets.

Legal Implications:

5.2 None directly to this report for information. The statutory requirements set out in the Health & Social Care Bill (2011) are addressed in the draft model (**Appendix 1**).

#### Equalities Implications:

5.3 None to this report for information. A primary aim of the HWB will be to reduce health inequalities across the city and this is reflected in the draft model (**Appendix 1**).

Sustainability Implications:

5.4 None to this report for information

#### Crime & Disorder Implications:

5.5 None directly to this report for information. The HWB will consider issues which have crime and disorder implications, such as substance misuse, and the proposed HWB membership and remit reflects this (see **Appendix 1**).

Risk and Opportunity Management Implications:

5.6 None directly to this report for information. HWBs are intended to foster more effective integration of local health and social care services, using budgets effectively, eliminating gaps between services and reducing unnecessary duplication.

Corporate / Citywide Implications:

5.7 None directly to this report for information. For the HWB to be effective it will need to integrate with the city's existing partnership structures.

# SUPPORTING DOCUMENTATION

# Appendices:

1. The draft model for a Brighton & Hove Health & Wellbeing Board **Documents in Members' Rooms:** 

None

# **Background Documents:**

1. The Health & Social Care Bill (2011)

# **Brighton & Hove** Health and Wellbeing Board

# **Summary Transitional Arrangements** November 2011





**Dr. Tom Scanlon Director of Public Health** NHS Sussex (Brighton and Hove)/ Brighton & Hove City Council

**Terry Parkin** Strategic Director People/ Director of Children's Services Brighton & Hove City Council **Brighton & Hove City Council** 

**Denise D'Souza** Director of Adult social Care

# Contents:

# Page Number

Introduction		1	
Process		1	
Scope		1	
Function		2	
Governance		2	
Membership		3	
Supplementar	Supplementary documents		
Annex A:	Lines of accountability for the Health and Wellbeing Board		

Annex B: Process of further engagement in this consultative process

# Introduction

The Health and Social Care Bill will require local authorities to establish a Health and Wellbeing Board by April 2013. This board will be a formal sub-committee of upper tier and unitary local authorities under Section 102 of the Local Government Act.

This paper summarises the proposed approach to establishing a health and wellbeing board during the shadow year of 2012-2013 and follows from two longer discussion papers circulated prior to each of the consultation workshops. The purpose of this paper is to elicit further engagement and feedback prior to the formal establishment of the shadow Health and Wellbeing Board in April 2012.

#### Process

In Brighton and Hove a decision was reached between officers and elected members *not* to become an early implementer of a Health and Wellbeing Board, but rather to engage in a discussion with partners and stakeholders to work at getting the scope, functions, membership and governance of the Brighton and Hove Health and Wellbeing Board right.

Two workshops were held to discuss the establishment of a Brighton and Hove Health and Wellbeing Board. The first on 26<sup>th</sup> July 2011 was used to plan out the scope of the health and wellbeing board. A second workshop on 3<sup>rd</sup> October was held to discuss the likely make up of the board with regard to three key components: function, membership and governance.

In addition, a national pause was announced in the passage of the Health and Social Care Bill and following further national discussion, led by an NHS Futures Forum, a number of small amendments were made to the Bill. With regard to the establishment of a health and wellbeing board, these included stronger public engagement, a stronger role for joint commissioning between health and social care, and powers to the health and wellbeing board to refer to the NHS Commissioning Board the commissioning plans of a clinical commissioning group, if these do not meet the requirement of the health and wellbeing strategy.

The Bill was passed in the House of Commons on 8<sup>th</sup> September 2011, and, despite considerable lobbying from health and nursing groups, in the House of Lords on 14<sup>th</sup> October 2011.

The collective view from the two workshops and consultation to date is summarised in the rest of this document.

#### Scope

The primary purpose of the board will be to oversee the delivery of a joint health and wellbeing strategy which will be based on the local joint strategic needs assessment. The board will monitor the delivery of a series of outcomes covering public health, children and adult social care.

The board will also review and approve the commissioning plans of the clinical commissioning group with regard to how they address the needs identified in the joint strategic needs assessment (JSNA) and written into the health and wellbeing strategy. The joint strategic needs assessment will also inform the work of the partnerships working under the Local Strategic Partnership.

# Function

The remit of the health and wellbeing board will be clearly defined and it will not attempt to assume every function with regard to health and wellbeing, but rather concentrate on the strategic leadership and delivery of a number of key outcomes. The board will be transformational rather than transactional and will be able to influence how budgets are spent, rather than oversee a specific health and wellbeing budget.

The board will have input into wider determinants of health such as housing, economy and education, but this will not be through the board directly overseeing relevant partnerships, but rather having a clear link to groups who led on this work. Key to this is the nature of the relationship with the Local Strategic Partnership and Public Service Board which will emerge in the first shadow year.

The board will be able to hold commissioners, who hold a health and wellbeing remit to account. This will include commissioners delivering children and adults' health and wellbeing services, public health services and the clinical commissioning group.

The board will agree a set of health and wellbeing outcomes; these will be strongly influenced by the national public health outcomes framework but also by the joint strategic needs assessment. The national public health outcomes framework and JSNA will then determine the health and wellbeing strategy that the Health and Wellbeing Board will agree and from which the set of outcomes will be selected and agreed.

The board will also have due regard to the annual report of the Director of Public Health which will be formally presented to the board each year.

The board will not have a formal role in emergency planning but will be part of the assurance process for making sure that processes are in place to protect the public's health in the event of an emergency.

# Governance

The board will report to Full Council. The board will also establish a formal relationship with the Public Service Board and Local Strategic Partnership. There are likely to be some overlaps in remit between the board and these groups. During the first shadow year (2012-13) any overlaps will be identified with the aim of removing these before the formal establishment of the board in April 2013. As part of this shadow year the board will plan in a formal board to board meeting with the Public Service Board.

The board will meet 2 monthly in the first shadow year. A formal 'taking stock' session will take place mid way through the first shadow year. The board will be supported by a key officer from the City Council's Strategy and Governance department.

Key decision-making bodies, such as the Children and Young People's Trust Board, the Local Safeguarding Children's Board and the Joint Commissioning Board will continue, with the same, a reduced or a reformed remit during the shadow year. These groups will discuss their changing role during this first shadow year and report to the Health and Wellbeing Board regarding their remit and any changes in their establishment or role. The shadow year will also be used to 'train up' the members of the Health and Wellbeing Board in their new roles.

As the board comprises both officers and elected members, it shall reach agreement by discussion and not by voting. Where a decision cannot be reached by consensus, Full Council will be asked to consider the matter.

# Membership

The membership shall start small, and during the first shadow year consideration will be formally given to extending the membership as required. The formal membership of the board will be as follows:

- An elected member from the party in office will chair the board;
- The main opposition parties will also select one member to sit on the board;
- The three statutory Directors of Public Health, Children's Services and Adult Social Care;
- One lead clinical and non-clinical member from the Clinical Commissioning Group;
- A member from the Youth Council;
- One member from Healthwatch.

In addition a number of groups will be invited to be in formal attendance at the board. These will include:

- The Older People's Council
- Sussex Partnership Foundation Trust;
- Sussex Community Trust;
- Brighton and Sussex Universities Hospital;
- Community and Voluntary Sector Forum;
- Sussex Probation Trust
- Sussex Police.

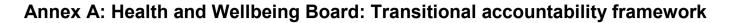
Where a discussion is to be held on a particular subject, for example accident and emergency services, other relevant providers, such as in this case Southeast Coast Ambulance Service (SECAmb) will be invited as is relevant.

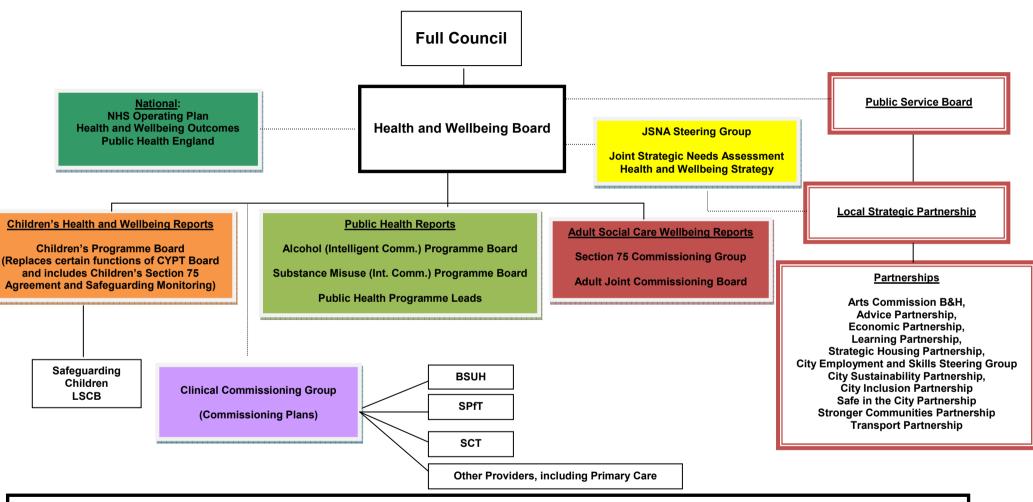
Meetings of the board will be in public and members of the public will have the opportunity to submit questions before the meeting or request, at the discretion of the chair a hearing during a meeting.

#### **Supplementary documents**

Annex 1 summarises the proposed lines of accountability for the Health and Wellbeing Board

Annex 2 summarises the process of further engagement in this consultative process







Health Improvement: Obesity, Nutrition, Physical activity, NHS Health Checks, Smoking cessation, Alcohol and substance misuse, Sexual health and teenage pregnancy, Health inequalities;

Health Protection: Flu (seasonal and pandemic), Immunisations and vaccinations, seasonal mortality;

Health Service Commissioning: Sussex Community Trust, BSUH, Sussex Partnership Foundation Trust, 1ry Care, Other commissioned NHS providers;

Children: Section 75 (children), Dental health, Accidental injury, Health visiting, School health, Children in need, Looked-after children, safeguarding,

Adult Social Care: Section 75 (adults), Quality outcomes;

# HEALTH OVERVIEW AND SCRUTINY COMMITTEE

Subject:		Joint Commissioning Strategy for Adults with Autistic Spectrum Conditions (ASC) 2012- 2015 (DRAFT)		
Date of Meeting:		November 16 2011		
Report of:		Director Adult Social Services/Lead Commissioner People		
Contact Officer:	Name:	Angela Flood Diana Bernhardt	Tel:	29-0790 29-2363
	E-mail:	: angela.flood@brighton-hove.gov.uk diana.bernhardt@brighton-hove.gov.uk		<u>uk</u>
Wards Affected:	All			

# FOR GENERAL RELEASE

# 1. SUMMARY AND POLICY CONTEXT:

- 1.1 The Joint Commissioning Strategy for Adults with Autistic Spectrum Conditions 2012-2015 (DRAFT) (referred to in this document as "the strategy") (Appendix 1), sets out the longer-term direction and scope of how health and social care services and associate organisations can achieve improved outcomes for adults with autism, their families and carers in the City of Brighton & Hove.
- 1.2 The strategy has been developed in response to national level legislation and strategy as well as local level evidence which has raised the profile of autism in adults and shown that adults with autism face significant challenges due to: lack of awareness and understanding of autism amongst frontline staff and the wider public; a complex care pathway that impacts on diagnosis, assessment and support; the transition from childhood to adulthood and accessing services which can lead to other health problems, increasing the emotional cost to the individual and their carers and the financial cost to health and social services.

# 2. **RECOMMENDATIONS**:

- 2.1 That members:
- Note the contents of the strategy (Appendix 1) and its proposed strategic objectives, actions and outcomes (Appendix 1 of the strategy).
- (2) Agree the strategy and proposals.

# 3. BACKGROUND INFORMATION

- 3.1 It is estimated that within Brighton & Hove the numbers of adults with autism will rise by 2020. However, as there is no statutory requirement for services to record or code a diagnosis of autism on databases the number of people recorded as known to services is much lower than the expected prevalence.
- 3.2 Unless diagnosed in childhood, adults with Asperger Syndrome (AS) and High Functioning Autism (HFA) find it difficult to receive the support they need which is easier to access if they are diagnosed with a co-occurring condition such as a learning disability or mental health problem.
- 3.3 The key drivers for change include:
  - The Autism Act 2009<sup>i</sup>
  - Fulfilling and rewarding lives: the national strategy for adults with autism (2010)<sup>ii</sup>
  - Implementing fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy (2010)<sup>iii</sup>
  - Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions Report (March 2011)<sup>iv</sup>
  - Adults with autistic spectrum conditions needs assessment (May 2011) <sup>v</sup>(JSNA) (see Background Documents)
  - Adult Autism Strategy Stakeholder Group.
- 3.4 Local consultative action in particular enabled further evidence to be gathered about the challenges and services for adults with autism in Brighton & Hove as well as informing and shaping future services and support. Evidence shows that adults with autism in the City face difficulties not only due to the condition itself, but also because of the additional challenges associated with: lack of awareness and understanding of autism especially amongst frontline staff; a complex care pathway (diagnosis, assessment, support); transition planning from

childhood to adulthood; planning and commissioning of services and support for adults with autism.

- 3.5 The strategy has been informed and developed in response to national statutory requirements, local level evidence as described in the Scrutiny Panel and JSNA reports and recommendations as well as the ongoing feedback from the cross-sector Stakeholder Group (which continues to meet monthly).
- 3.6 Reflecting national strategy and local evidence, the strategy aims to support adults with autism through improvement of four key areas that will have a positive impact on the quality of care, health and wellbeing and social inclusion of adults with autism:
  - **A.** Increasing awareness and understanding of autism through training of frontline staff and reasonable adjustments
  - **B.** Developing a more joined up care pathway (diagnosis, assessment and support)
  - **C.** Improving the transition process from childhood to adulthood
  - **D.** Ensuring that local planning and leadership underpins and enables the development and commissioning of quality services and support.
- 3.7 The strategy is outcomes focussed and actively promotes a collaborative, partnership approach across all stakeholder groups to support implementation and delivery. It also recognises that public sector finances are already under severe pressure and aims, wherever possible, at *changes or modifications to existing services* through building on existing good practice and via a longer-term integrated, collaborative approach to service planning and delivery that will result in increased efficiency and effectiveness and improved outcomes for service users.
- 3.8 Although focussed on health and social care outcomes, the strategy also incorporates other areas where additional consideration and action would have a positive impact on the health and social wellbeing of adults with autism: housing; employment; education; community safety and social and leisure activities.
- 3.9 Approval of the strategy will:
  - a) Enable actions to be carried out that will move towards achieving the stated objectives under the four key areas of activity (Appendix 1 of the draft strategy).

- b) Serve as a *framework and foundation* for joint development and decision making linked to the development and commissioning of services relevant to adults with autism, their families and carers.
- c) Provide a *basis for more detailed planning* linked to annual operational and work plans that are focused, deliverable and measurable (outcomes and outputs), to enable achievement of the stated objectives.
- d) Assist *benchmarking* and *performance monitoring* linked to the strategy itself and to other related plans, either current or future.
- e) Stimulate *change* and become a *building block* for future plans.

# 4. CONSULTATION

- 4.1 Development of the draft strategy has already involved extensive consultation with key stakeholders including: service users; carers; health and social care professionals; members of the public (Overview & Scrutiny Panel Report; Joint Strategic Needs Assessment; Adult Autism Strategy Stakeholder Group).
- 4.2 In addition, the draft strategy will be submitted to further consultative processes including: 12-week consultation period with the wider public; Health Overview & Scrutiny Committee Chair's and full Meetings (4 November and 16 November 2011 respectively); Learning Disabilities Partnership Board (12 December 2011); Mental Health Commissioning Board (date tbc); Cabinet Members Meeting (16 January 2012); Joint Commissioning Board (20 February 2012); the Brighton & Hove City Council Forward Plan (December 2011 March 2012).

# 5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

5.1 Any financial implications arising from the proposals included in the strategy would need to be met from existing resources and included in the budget strategies, as appropriate.

Legal Implications:

5.2 The statutory guidance for the implementation of the autism strategy (referred to in paragraph 3.3) has been issued under section 2 of the Autism Act 2009. The Council must follow the statutory guidance unless there is a good reason not to do so.

The guidance seeks to make existing policies and public services work better for adults with autism. Each local area should develop its own commissioning plan around services for adults with autism that reflects the output of its Joint Strategic Needs Assessment and all other relevant data around prevalence. The local strategy should reflect local needs.

The Joint Commissioning Strategy for Adults with Autistic Spectrum Conditions (ASC) 2012-2015 (DRAFT) is the local response to the statutory guidance. Local consultation has been done on a regular basis in the development of the local strategy.

Equalities Implications:

5.3 It is believed that adults with Autistic Spectrum Conditions (ASC) face many difficulties in their daily lives including lack of awareness and understanding of the condition, public misconceptions, barriers to accessing services, difficulties linked to post-school education and learning, gaining long-term and meaningful employment as well as having a good quality of life. This also impacts on the families and carers of adults with autism.

The evidence found that people with ASC often do not have equality of access to, and quality of response from, local services and health care. This is a national issue and not just one for Brighton & Hove. However, the development of a local joint commissioning strategy will aim to address many of the issues highlighted. This will help to ensure that people with an ASC have fair and equal access to services.

The draft strategy will undergo an Equality Impact Assessment led by the Equalities Co-ordinator, Communities and Equality Team, together with members of the Adult Autism Strategy Stakeholder Group (11 and 24 November 2011).

Sustainability Implications:

5.4 None identified.

# Crime & Disorder Implications:

5.5 Carrying out of strategic actions outlined under Key Area of Activity C: Planning in relation to the provision of services to people with autism as they move from being children to adults (Community Safety) (page 19 of the draft strategy), would have a positive impact including: autism awareness training for staff working in the Criminal Justice System (CJS), resulting in adults with autism no longer managed inappropriately within the system; conflict minimised in difficult situations.

# Risk and Opportunity Management Implications:

5.6 None identified.

# Corporate / Citywide Implications:

5.7 The Intelligent Commissioning model will provide opportunities to look at how services for people with ASC are provided and commissioned across the authority.

# SUPPORTING DOCUMENTATION

# Appendices:

1. Joint Commissioning Strategy for Adults with Autistic Spectrum Conditions (ASC) 2012-2015 (DRAFT)

# Documents in Members' Rooms: None

# **Background Documents:**

<sup>&</sup>lt;sup>i</sup> The Autism Act 2009. HM Government <u>http://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga\_20090015\_en.pdf</u>

<sup>&</sup>lt;sup>ii</sup> Fulfilling and rewarding lives: the national strategy for adults with autism (2010)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_113369

<sup>&</sup>lt;sup>iii</sup> Implementing fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy (2010)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_122847

<sup>&</sup>lt;sup>iv</sup> Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions Report (March 2011) <u>http://www.brighton-</u>

hove.gov.uk/downloads/bhcc/democracy/FINAL\_REPORT\_18\_MARCH .pdf

<sup>v</sup> Adults with autistic spectrum conditions needs assessment (May 2011)



# Brighton & Hove Joint Commissioning Strategy for Adults with Autistic Spectrum Conditions (ASC) 2012-2015

# CONFIDENTIAL

# CONTENTS

#### **Executive summary**

**Priorities** 

# SECTION 1:

Vision; Mission; Introduction; Background

# **SECTION 2:**

Autism in Brighton & Hove; Finding out more about what is happening locally; Service gaps and implications for commissioning

#### **SECTION 3:**

Delivering the Brighton & Hove strategy:

- A. Training of staff who provide services to adults with autism
- B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- C. Planning in relation to the provision of services to people with autism as they move from being children to adults
- D. Local planning and leadership in relation to the provision of services for adults with autism

Planning other services for adults with autism

#### **SECTION 4:**

Strategic objectives, actions and outcomes; Approach; Structure; Planning and Commissioning; Change; Scope; Evaluating progress

# **APPENDICES**

16

11

14

3

3

5

8

#### EXECUTIVE SUMMARY

The Joint Commissioning Strategy for Adults<sup>1</sup> with Autistic Spectrum Conditions (ASC) 2012-2015 (herewith referred to as the Adult Autism Strategy)<sup>2</sup>, sets out the longer-term direction and scope of how health and social care services and their partners can achieve better outcomes for adults with autism, their families and carers<sup>3</sup>.

National<sup>1</sup> and local<sup>2</sup> level evidence show that adults with autism face significant challenges: lack of awareness and understanding of autism amongst frontline staff and the wider public; a complex care pathway that impacts on diagnosis, assessment and support; the transition from childhood to adulthood and accessing services which can lead to other health problems, increasing the emotional cost to the individual and their carers and the financial cost to health and social services.

Wider issues linked to access to housing, education and employment and safety in the community can also present barriers that impact negatively on adults with autism and prevent them from leading full and rewarding lives and being socially included.

Public sector finances are already under severe pressure and will continue to be so during the period of this strategy. However, despite the significant challenges facing all sectors as a result of the economic environment, advantage can be gained and success achieved through building on existing good practice, clearer care pathways and improved accessibility to mainstream services through reasonable adjustments.

The strategy provides the opportunity to increase cross-sector collaborative approaches to service planning and delivery, to increase efficiency and effectiveness resulting in improved outcomes for adults with autism and their carers, and for services themselves.

The key priorities of the strategy are:

- Increasing awareness and understanding of autism through training of health and social care staff
- Improving access to diagnosis, assessment and support (including assessment and support for carers), through development of a more simple, joined up care pathway

<sup>&</sup>lt;sup>1</sup> People aged over 18 years

<sup>&</sup>lt;sup>2</sup> There are a number of terms that different individuals and groups prefer to use, including autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. This strategy will use the term "autism" for all such conditions, including Asperger Syndrome, in line with good practice.<sup>2</sup>

<sup>&</sup>lt;sup>3</sup> See Appendix 1

- Improving transition from childhood to adulthood through appropriate sharing of information and increased collaborative working between Children's and Adult services and other key agencies
- Strong local leadership to 'champion' and represent the needs of adults with autism at local and regional level
- Planning and commissioning that reflects the evidence base and is integrated with other strategic and commissioning plans
- Involvement of carers of adults with autism in planning and decision making processes that affect the person they care for (with their consent), and their own needs identified and assessed with signposting to relevant support services
- A collaborative approach that values and harnesses the knowledge, skills and views of adults with autism, their families and carers, the Third sector, other professionals and our partner organisations.

# **SECTION 1**

#### VISION

That all adults with autism living in Brighton & Hove are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if needed, can depend on mainstream public services across all functions to treat them fairly, can contribute to society through wider education and employment opportunities and that individuals, their families and carers and professionals are informed, supported and equipped to enable this to be achieved (adapted from the national autism strategy).<sup>3</sup>

#### MISSION

Our mission is to improve health and social outcomes for adults with autism, their families and carers. We will carry this out by increasing awareness and understanding amongst frontline staff, by simplifying the care pathway to improve access to services, by improving transition through better communication, information sharing and joint working, and by strong leadership that takes forward a commissioning approach strengthened by collaborative cross-sector planning and partnerships.

#### INTRODUCTION

The Adult Autism Strategy has been developed in response to the Autism Act 2009, the national strategy for adults with autism (2010) and the statutory guidance (2010).

#### BACKGROUND

#### Challenges and risks

Although many adults with autism do live fulfilling lives and make a successful and positive contribution to society, too many are unemployed, struggle on benefits and rely on the care and support of their families and carers. For those without this support, there are the added risks of severe health and mental health problems, homelessness, addiction and involvement in crime. The costs in emotional terms to adults with autism and their families are overwhelming; the financial costs to public services are huge. Adults with autism can also have other co-occurring conditions such as learning disabilities or mental health problems, adding to the challenges they face in life.

#### 'Hidden disability'

Autism is sometimes described as a 'hidden disability', not only because you cannot always see that someone with autism has a disability, but also because adults with autism are some of the most excluded, and least visible, in the UK. As a result, it has taken a long time for society to understand autism and many lives have not been as fulfilled as they might have been as people have fallen between gaps in services.<sup>4</sup>

# Recording of autism

There is no statutory requirement for services to record or code a diagnosis of autism on databases so the number of people recorded as known to services is much lower than the expected prevalence. Many older people will also be undiagnosed as autism only became formally recognised as a range of conditions in the late 60's. Unless diagnosed in childhood, adults with Asperger Syndrome (AS) and High Functioning Autism (HFA) find it difficult to receive the support they need which is easier to access if they are diagnosed with a co-occurring condition such as a learning disability or mental health problem.<sup>5</sup>

# Government policy

The Government has recognised these many challenges and has put in place a range of key actions<sup>4</sup> linked to equality that not only raise the profile of autism across society and public services, but also to try and make more rapid progress to improving the lives of people with autism and their families and carers. Key amongst these are:

- *The Autism Act 2009<sup>6</sup>* (Legislation)
- Fulfilling and rewarding lives: The strategy for adults with autism in England (2010) (Strategy)
- Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy<sup>7</sup> (Implementation)
- Towards Fulfilling and rewarding lives: The first year delivery plan for adults with autism in England (2010<sup>8</sup>) (Delivery)

# National policy framework

The policy framework aims to address the real needs of adults with autism as well as transforming the way public services are planned, commissioned and delivered. This reflects the current economic climate where all public sector organisations are facing significant budget restrictions and are required to do more with less. It also reflects the Government's policy direction of reducing statutory requirements and placing more responsibility on frontline staff to develop services that meet identified local needs.

# Local policy framework

The strategy is linked to Brighton & Hove City Council and NHS Brighton and Hove (the Primary Care Trust) priorities.

The proposed Council priorities are:

- 1. Tackling inequality
- 2. Creating a more sustainable city
- 3. Engaging people who live and work in the city
- 4. Responsible and empowering employer
- 5. A council the city deserves

<sup>&</sup>lt;sup>4</sup> See Appendix 2

NHS Brighton and Hove priorities include:

The strategy also relates to some of the service transformation intentions set out in the *Annual Operating Plan for NHS Brighton and Hove 2011/2012<sup>9</sup>* including:

- 1. Long Term Conditions and end of life care (equitable care; personalised care for patients and their carers that meets their needs; structured care most appropriate to need)
- 2. Planned Care (Integrated Care Pathways; service user involvement in decisions relating to their care and commissioning decisions)
- 3. Primary Care (*High quality experience for all in GP practices; health improvement; reducing health inequalities*)
- 4. Mental Health (*Promoting Mental Health and Wellbeing; Developing Care Pathways to treatment services*)
- 5. Workforce (Different ways of working; increasing productivity in screening services; increasing flexibility of workforce and roles that work across organisational boundaries)
- 6. information Management and Technology (Good practice and excellence through joint approaches; safe transference of patient information as they progress through the care pathway; work of clinicians is supported and enabled)

The strategy also reflects key priorities in *Creating the City of Opportunities: A Sustainable Community Strategy for the City of Brighton and Hove*<sup>10</sup>: Improving health and well-being; Improving housing and affordability; Promoting enterprise and learning; Reducing crime and improving safety; Strengthening communities and involving people.

# **SECTION 2**

#### Autism in Brighton and Hove

Nationally it is estimated 433,000 adults in the UK have autism. Within Brighton and Hove approximately 1,763 adults aged 18-64 years have autism. It is estimated that this number will rise to 1,854 by 2020. Autism is far more common among men than women with an estimated 1, 589 men and 174 women in Brighton and Hove having this condition. A large proportion of these adults will also have a learning disability.<sup>11</sup>

#### Finding out more about what is happening locally

To find out more about the challenges and services for adults with autism in Brighton & Hove and in order to inform and shape future services and support, three key consultative actions were put in place:

#### 1. Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions

The Panel was set up in 2010 by the Adult Social Care & Housing Overview & Scrutiny Committee<sup>12</sup> (ASCHOC), to examine local services for adults with autism against the national guidelines and policy. The Panel looked at a number of services, within and outside Brighton & Hove City Council, what is currently in place and what might be offered. The Panel acknowledged the impact of the current economic constraints and that long-term changes take time, but it also recommended that local implementation of the national strategy should begin as soon as possible. Meetings were attended by people representing a wide range of sectors, including service users, carers, professionals and members of the public. Information was generously shared and a report with recommendations has been produced.<sup>13</sup>

# Report findings

The report finds that adults with autism, their families and carers face many difficulties in their daily lives. Barriers to accessing services, public lack of awareness and understanding about autism, difficulties in gaining long-term and meaningful employment, all impact on quality of life. The report findings and recommendations<sup>5</sup> reflect the four key areas for action highlighted in the statutory guidance intended to support implementation of the autism strategy. These findings have fed into the development of the strategy.

# 2. Adults with autistic spectrum conditions needs assessment

The Joint Strategic Needs Assessment (JSNA) was commissioned by NHS Brighton and Hove and Brighton & Hove City Council in response to the requirement in *Fulfilling and rewarding lives: The strategy for adults with autism in England (2010),* that every adult autism strategy should be based on a local JSNA. The JSNA was also informed by the Scrutiny Panel report and recommendations.

<sup>&</sup>lt;sup>5</sup> See Appendix 3

#### JSNA findings

The JSNA identified several key issues that impact on the numbers of people with autism known to our services and on access to appropriate services and support, made worse by:

- No statutory requirement for services to record or code a diagnosis of autism on their databases means that numbers known to our services is much lower than the expected prevalence<sup>6</sup>
- Autism masked by other co-occurring conditions such as a learning • disability, mental health problem or attention deficit hyperactivity disorder
- **Risk** of falling into the gap between services for people with learning • disability or mental health conditions, especially if they have not been diagnosed in childhood
- Adults with Asperger Syndrome (AS) or High Functioning Autism • (HFA) in particular struggle to receive the support they need to lead fulfilling and rewarding lives and this, in itself, can lead to development of mental health problems
- Gaps in provision identified at all stages of the care pathway are • linked to:
  - a complex care pathway and long waiting times for diagnosis
  - support for adults with AS or HFA after diagnosis
  - no specialist support to coordinate care between agencies (voluntary sector support for people with AS receives no statutory funding)
  - transition from childhood to adulthood with changes in what and how services are delivered, with parents believing that health services are less than previously received from paediatric services
  - higher eligibility criteria thresholds make it harder to access support from Adult Social Care

These challenges are also compounded by lack of awareness and understanding of autism amongst the public and frontline staff and the adjustments that need to be made to the workplace, living environment, educational and leisure settings to support people with autism to lead more integrated and fulfilling lives in the community. The JSNA recommendations<sup>7</sup> highlight the need for improvements.

# 3. Adult Autism Strategy Stakeholder Group

Membership of the group includes people with autism, carers, representative groups and health and social care professionals<sup>8</sup>. It has been set up to be an active partner in the development of the Brighton & Hove strategy, to share and disseminate information and expertise, to build links across organisations to help future service development and quality

<sup>&</sup>lt;sup>6</sup> The Brighton & Hove Adult Social Care CareFirst database has now begun separate coding of adults with autism and autism with co-occurring conditions

<sup>&</sup>lt;sup>7</sup> See Appendix 4 <sup>8</sup> See Appendix 5

improvement and to develop a work plan that supports the four key areas of action identified in the national autism strategy and guidance.

# Service gaps and implications for commissioning

The Scrutiny Panel Report and Recommendations and the JSNA both highlight service gaps that also have implications for the development or commissioning of services:

- Autism awareness **training** especially for frontline staff including GPs
- A simpler diagnostic, assessment and support pathway
- Post-diagnosis information and support
- Coordinated sharing of information between databases
- **Reasonable adjustments** in services that reflect a greater understanding of need and that prevent the need for increased support later on
- Integrated working between Children's and Adult services, particularly linked to the **transition** from childhood to adulthood
- Harnessing Third sector knowledge and expertise in planning and support
- Education and life long learning opportunities in caring, supportive environments
- Employer awareness of autism and supported work opportunities
- Housing provision taking account of individual and longer-term needs
- Assessment of the needs of carers and their involvement in longerterm planning
- **Information and signposting** regarding relevant support to help with effective management of personalised services

# **SECTION 3**

#### **Delivering the Brighton & Hove strategy**

The statutory guidance identifies four key areas for action with a focus on *outcomes.* Together with the evidence base provided by our local level reports and recommendations it has informed what actions need to be carried out and how we might commission, develop and deliver services in the future.

This strategy aims to support adults with autism to live more fulfilling and rewarding lives through the development and implementation of a range of operational actions and initiatives that will:

- Increase awareness and understanding of autism through training of frontline staff and reasonable adjustments
- Develop a more joined up care pathway (diagnosis, assessment and support)
- Improve the transition process from childhood to adulthood
- Ensure that local planning and leadership underpins and enables the development and commissioning of quality services and support.

#### A. Training of staff who provide services to adults with autism

All staff need better training about autism, to raise awareness and to ensure that reasonable adjustments are made to mainstream services to meet the needs of people with autism. This training would form part of essential equality and diversity training with particular priority for staff working in housing, health and social care and reception staff.

Staff should be trained well enough to do their jobs and there should be more training for staff in key roles that need to know more about autism. It is not always possible to know that someone has autism so staff need to know more about the condition so that they can help people properly. Training will help staff to tell when someone has autism and to communicate and behave appropriately. More specialist training is needed for frontline health and social care staff who provide support to people with autism in their everyday work.

B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services

The national strategy says that every local area should have a service that can diagnose if someone has autism by 2013 with a professional in charge to make that happen. The National Institute for Health and Clinical Excellence (NICE) is also developing a new guide (due to be published in July 2012), that local health services should consult to see how they can make existing services better and to develop a more clear and effective care pathway from referral and diagnosis through to assessment of needs.

When someone is diagnosed with autism they should get good information about what having autism means and the support they might

get. Health services should tell social services quickly (with the permission of the person diagnosed), so that they can have a social care assessment to see if they need any support and, if necessary, help should be provided for the person to say what support they need. Social services should also tell carers that they have a right to a carer's assessment.

All assessments should be done in a person-centred way by staff who have had good training, information should be shared appropriately between agencies and people told quickly about how their support needs can be met.

# C. Planning in relation to the provision of services to people with autism as they move from being children to adults

Transition planning needs to get better for people with autism as they leave school so they get the support they need as they become adults. If there is a statement of autism then planning for the future should begin early in year 9 (age 13-14 years). Services should build on the information already collected by the Connexions service during the Transition Review<sup>9</sup> to further clarify support needs and who will provide this. If there is no statement social services should still carry out an assessment to see what support is needed. Robust plans need to be in place with heads of assessment ensuring that they are followed and that services are good enough.

# D. Local planning and leadership in relation to the provision of services for adults with autism

Having good local leadership is crucial to making sure that adults with autism get the help they need. This means ensuring there is a lead commissioner<sup>10</sup> who will set out how services are commissioned (bought), who will work closely with other local groups and organisations, who will be involved in other planning in the area including the Partnership Board<sup>14</sup> and Valuing People regional work.

Commissioning plans for services for adults with autism should reflect the findings of the JSNA. Consideration should also be given to the needs of carers, to the role of the 'Big Society'<sup>11</sup> in delivering support services, to the benefits of personalised services and to ensuring that the views of adults with autism, their families and carers are taken into account when developing and commissioning services.

# Planning of other services for adults with autism

We have listened to what people with autism and their carers have said and our local plans are based on what local people have told us they need and on other important evidence. The health and social services we commission should reflect this as should those other services, such as housing, education, employment and social and leisure that can have a significant impact on

<sup>&</sup>lt;sup>9</sup>Under section 139A-C Assessments

<sup>&</sup>lt;sup>10</sup> Lead Commissioner for Learning Disabilities appointed

<sup>&</sup>lt;sup>11</sup> Local level problems identified and solved by local level people in a way they have chosen

people's health and wellbeing and on their active participation in the community.

The Equality Act 2010<sup>15</sup> aims to protect disabled people and prevent disability discrimination and this includes people with autism. Commissioning activity should be based on a 'tiered approach' that meets a range of needs. Reasonable adjustments will enable improved access to universal, prevention and early intervention services with specialist commissioning meeting the needs of the most complex and severe cases.

Services have to make changes so that they are accessible and enable people with autism to have more choice and control over their lives with additional support if needed. For example, providing the right information at the right time about available services and support can help people with autism and their carers make informed choices that are right for them.

# **SECTION 4**

#### Strategic objectives, actions and outcomes

This strategy works within a social model of disability which says that disability is created by barriers in society<sup>16</sup>. Changes needed are a long-term goal with the strategy focussing on the local actions for the next 3 years.

The strategic objectives<sup>12</sup> provide guidance on how organisations and services can move towards the 'high goals' of our vision and mission. They clarify what needs to be achieved whilst still being consistent with the plans and priorities of the organisations involved. The more specific strategic actions provide the means for achieving the changes and benefits resulting in the more positive outcomes that we are seeking to achieve for adults with autism, their families and carers in the City of Brighton & Hove.

The strategy promotes changes or modifications that may prove a challenge. However, by making the most of the opportunities presented by current changes in the health and social care sectors, including working collectively towards common goals and using the full spectrum of resources in a more efficient and effective way, they are achievable.

#### Approach

To achieve the vision for adults with autism set out in the national strategy and to successfully deliver the strategy at local level will need a bottom up approach from health and social care services, ownership and decision making by key stakeholders including professionals, service users, carers and service providers, and a focus on outcomes not process targets.

#### Structure

The Brighton & Hove strategy is informed and shaped by the national findings and guidance and, more specifically, by the local level findings and recommendations of the Overview & Scrutiny Panel Report, the JSNA and the contribution and feedback from the cross-sector Stakeholder Group. It covers the four Core Areas of Activity (goals) outlined previously, with a focus on outcomes.

# Planning and Commissioning

Health and social care services can improve the way they identify the needs of adults with autism and can incorporate those needs more effectively into local service planning and commissioning. It is important to reflect local needs and context and build on existing strengths in service provision. We have to fulfil our statutory responsibilities and also recognise that any changes or modifications that need to be made to improve services and support for adults with autism will need to be considered against significant resource challenges.

<sup>&</sup>lt;sup>12</sup> See Appendix 1

# Change

The strategy provides an opportunity to support effective change at local level: better coordination and integrated working; joint planning and commissioning of services; more involvement in decision making for service users and carers and using the knowledge and expertise of the Third sector to help shape and deliver services.

#### Scope

The main focus of the strategy is on health and social care but also includes other key areas which, by improving the way they deliver their services, can have a positive impact on the lives and all-round wellbeing of adults with autism. For example:

- Further and Higher Education and other learning opportunities
- *Employment* (paid or unpaid) contributing to the development of self-confidence, personal growth and contribution to the community
- Housing that takes account of individual needs and longer-term requirements
- Planning around carers that involves them and supports their needs
- Accessing a wider range of *leisure and social activities* increasing social inclusion
- The Criminal Justice System and safety in the community.

# Evaluating progress

A long-term, cultural change is needed to deliver the vision and strategy and this can only be achieved by putting ownership and responsibility into the hands of professionals on the front line. A greater understanding of autism is needed in our services and wider community, services need to be tailored to meet the real needs of adults with autism and genuine partnership working is required to create the right quality frameworks and outcome indicators.

*'Fulfilling and rewarding lives: Evaluating Progress'* identifies seven quality outcomes that can be used to show progress in service development and performance:

- 1. Adults with autism achieve better health outcomes
- 2. Adults with autism are included and economically active
- 3. Adults with autism are living in accommodation that meets their needs
- 4. Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets
- 5. Adults with autism are no longer managed inappropriately in the criminal justice system
- 6. Adults with autism, their families and carers are satisfied with local services
- 7. Adults with autism are involved in service planning

Although these are long-term outcomes they will still have a positive impact on adults with autism, their families and carers. The changes or modifications and ways of working required to achieve them can, in themselves, create service improvements and lead to other opportunities.

# **APPENDIX 1**



A. Training of staff who prov	vide services to adults with autism	
Strategic objective:	Strategic action:	Desired outcome:
1. Increased awareness & understanding of autism amongst health & social care staff	Include autism awareness in general equality & diversity training	<ul> <li>Training available to everyone working in housing, health, social care and reception staff</li> <li>Use of e-learning to increase access and flexibility</li> </ul>
	Provide basic autism awareness training for frontline staff	<ul> <li>Training prioritised for staff in key roles who need to know more about autism</li> <li>Increase in reasonable adjustments in communication, behaviour &amp; services</li> </ul>
	Include autism awareness in other training programmes & evaluate its impact	<ul> <li>Content of management &amp; other development programmes reviewed</li> <li>Autism or potential signs of autism recognised &amp; appropriate support given to staff</li> <li>Staff with autism supported to access opportunities for personal &amp; professional development</li> </ul>
	Support World Autism Awareness Day (WAAD) to raise awareness at organisational & wider level	<ul> <li>WAAD (April 2) highlighted &amp; actively promoted via corporate communication mechanisms</li> <li>Increased knowledge &amp; promotion of a balanced view of autism &amp; associated issues through effective communication channels</li> </ul>
	Identify local experts to help deliver training	<ul> <li>Initial scoping indentifies level of interest, concerns &amp; possible changes in commissioning &amp; delivery</li> <li>Adults with autism, their carers &amp; representative groups involved in training delivery &amp; assessment of current programmes</li> </ul>
	Explore the benefits of combined training programmes	<ul> <li>Cross-sector collaboration &amp; joint working approach; shared knowledge &amp; expertise</li> <li>Financial benefit &amp; value-for-money through co-commissioning &amp; shared resources</li> <li>Comparison of training effectiveness within &amp; across organisations</li> </ul>
2. Provision of specialist training for those in key roles	Develop or provide specialist training for those in key roles that have a direct impact on access to services for adults with autism	<ul> <li>Training prioritised for staff groups most likely to have contact with adults with autism</li> <li>Identified, clear expertise in the local area that colleagues can consult</li> <li>Increased sector capacity to work with adults with autism through specialist knowledge &amp; skills</li> <li>Improved staff retention &amp; career development through workforce development</li> </ul>
	Work with key partners to improve quality of autism training in their curricula	<ul> <li>Review of training curricula supports development of specialist training in health &amp; social care</li> <li>Staff able to develop further knowledge or specialise in autism</li> </ul>
3. Autism awareness included in Primary Care workforce development	Include training in Continuing Professional Development (CPD) & evaluate its impact	<ul> <li>Primary Care health professionals (including GPs &amp; independent contractor partners), able to recognise &amp; refer earlier &amp; appropriately</li> <li>Evaluation &amp; impact analysis measure improvements in awareness, understanding &amp; referral</li> </ul>
	Explore opportunities to deliver training in Primary Care settings following a needs assessment	<ul> <li>Identification of local requirement; barriers; resource needs; potential service improvements</li> <li>Easier, flexible access to learning as part of the Protected Learning Scheme (PLS)</li> <li>Increased opportunities for raising awareness &amp; understanding of autism, shared learning &amp; best practice, multidisciplinary partnership working approach, increased value-for-money</li> </ul>
	Review what is needed in GP practices to enhance services to people with autism	<ul> <li>Better information on health needs to prevent increased needs in the future</li> <li>Better standards in the care &amp; support to adults with autism</li> </ul>
4. Improved services to better	Needs of people with autism included in	EIA undertaken on developing policies, procedures & practices to assess whether they have a positive or negative impact
meet diverse needs	Equality Impact Assessment (EIA)	<ul> <li>End undertaken on developing policies, procedures &amp; practices to assess whether they have a positive of negative impact on people with autism</li> <li>Existing policies, procedures &amp; practices reviewed to address any adverse impact</li> </ul>
	Social & leisure services review barriers to access for adults with autism	<ul> <li>Individuals leading more active &amp; fulfilling lives supported by healthier living &amp; good mental health</li> <li>Reasonable adjustments made by services to increase access to a wider range of pursuits</li> </ul>

B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services			
Strategic objective:	Strategic action:	Desired outcome:	
1. Availability of a clear & trusted diagnostic pathway locally leading to a person- centred assessment of need	Develop the Map of Medicine to include autism	<ul> <li>NHS practitioners can identify potential signs of autism &amp; refer for clinical diagnosis if necessary</li> <li>NHS practitioners able to adapt their behaviour &amp; communication when a patient has been diagnosed with autism or displays these signs</li> <li>Evidence-based clinical knowledge with customised pathways to reflect local care provision &amp; clinical practice</li> <li>Knowledge sharing across care settings with easier access to local &amp; national best practice</li> </ul>	
	Develop a clear pathway to diagnosis & assessment of need	<ul> <li>Existing best practice reviewed <i>now</i> to establish how it might be adopted against the NICE clinical guideline on Autistic Spectrum Disorders in Adults</li> <li>Local commissioners &amp; providers use the NICE model care pathway to form the foundation of local referral &amp; care pathways (due July 2012)</li> <li>Increased access to diagnostic services, more consistent diagnosis, better integration into needs assessment, increased confidence from all stakeholders in the diagnostic process</li> <li>Improved signposting to services for adults <i>without</i> a learning disability or mental health diagnosis</li> <li>Protocol in place for determining the assessment/funding pathway when people with autism (but with no obvious learning disability or mental health need), require social care support</li> </ul>	
	Assessment offered to adults diagnosed with autism who may have an eligible social care need	<ul> <li>Following diagnosis (with consent of the individual), health services promptly inform social services of the need to carry out a community care assessment within a reasonable time period</li> <li>Independence of monitoring, evaluation &amp; review ensured through stakeholder involvement</li> <li>Potential whole system efficiencies identified as a result of service redesign</li> </ul>	
	Identify specific individuals in frontline clinical teams to represent interests of adults with autism	<ul> <li>Identified 'autism champion' &amp; inclusion of autism in the Link Nurse within mental health team</li> <li>Raised awareness within professional teams enable operational services to respond appropriately</li> <li>Capacity of the clinical diagnostic team expanded through development of expertise</li> </ul>	
	Establish arrangements to coordinate health & social care input	<ul> <li>Coordinated, less resource-intensive referral pathway with facilitated liaison between mainstream services</li> <li>Reduced unnecessary functional overlap with sharing of knowledge &amp; best practice</li> <li>Reduced risk &amp; negative impact through earlier intervention or signposting to universal services</li> </ul>	
2. Adults with autism achieve better health & social outcomes	Ensure adults with autism are better able to access health care at an early stage	<ul> <li>Increased accessibility through better service design, management &amp; monitoring systems</li> <li>Reduced need for intensive, expensive interventions at crisis point; retaining independence through a more preventative approach</li> <li>Person-centred assessments by staff who have had good training including autism awareness</li> </ul>	
	Ensure appropriate support is offered following screening or diagnosis, including the needs of carers	<ul> <li>Diagnosis linked to rigorous assessment of individual, personalised need &amp; provision of good information about autism &amp; the support available to enable fully informed decision making</li> <li>Health Action Plan following a learning disability diagnosis; Care Plan following a mental health diagnosis</li> <li>Appropriate signposting by health &amp; social services where the individual does not fulfil the criteria for access to adult learning disabilities or mental health teams</li> <li>Diagnosis linked to assessment of needs an important cultural change reducing emphasis on diagnosis itself</li> </ul>	
	Ensure adults with autism are benefitting from the personalisation agenda in health & social care, & can access personal budgets	<ul> <li>Personalisation offered to adults with autism increasing choice &amp; control over services</li> <li>Reasonable adjustments to the personalisation process by health &amp; social care enables people with autism to understand &amp; exercise choice</li> <li>Number receiving personal budgets/number receiving a personal budget and relevant support for their decision making known year-on-year</li> <li>Availability of relevant services directly linked to take up of personalisation by adults with autism</li> </ul>	
	Develop a locally coordinated & comprehensive data system to inform planning	<ul> <li>Requirement for data collected to be monitored &amp; evaluated</li> <li>Range of evidence gathered to include: numbers diagnosed; numbers in receipt of Adult Social Care services; numbers living in accommodation provided via Housing services; numbers of carers of adults with autism</li> </ul>	
3. Coordinated liaison across agencies	Identified key worker/case manager assigned to adult with autism & their carers	<ul> <li>Where need is identified, provision of a coordinated approach &amp; liaison across key agencies including GP practices, learning disabilities, mental health, social care &amp; health, for adult with autism, their families/carers</li> </ul>	

C. Planning in relation to the provision of services to people with autism as they move from being children to adults			
Strategic objective:	Strategic action:	Desired outcome:	
1. Local Authority & NHS compliance with existing legal obligations under the statutory guidance around transition planning	Review transitions planning process to ensure compliant with best practice	<ul> <li>Director Adult Social Services responsibility for ensuring local area follows its statutory duties &amp; meets at least the minimum standards in transition planning</li> <li>Special Educational Needs team undertake transition planning from age 14 (statutory requirement)<sup>13</sup></li> <li>Transition plans tailored to the needs &amp; wishes of the individual &amp; reviewed &amp; updated annually</li> <li>Delivery of the transition plan overseen by an identified service with transition planning embedded into all key processes across the sector</li> </ul>	
2. Parents & young person informed of their right to a Social Care Assessment & Carers Assessment	Ensure that young person & their carers are informed of their right to assessment as transition approaches	<ul> <li>Professionals, including CAMHS<sup>14</sup>, SENCO's<sup>15</sup> &amp; Social Workers, ensure that the young person &amp; carers are fully informed of their right to assessment &amp; are involved in transition planning</li> <li>Social Services formally notified of possible need for assessment by professionals working with the young person approaching transition</li> <li>Services build on information collected by Connexions during the Transition Review<sup>16</sup> to clarify support needs &amp; providers</li> </ul>	
3. Robust systems & protocols in place to ensure a smooth transition into adulthood	Ensure joint working, planning & robust communication between key services & agencies	<ul> <li>Information shared appropriately between Children's &amp; Adult Service at transition highlights the needs &amp; numbers of children with autism in the local area &amp; improves longer-term planning</li> <li>Local protocols established for transition of clinical mental health care for children with autism in receipt of CAMHS</li> </ul>	
4. Involvement of people with Autism and their families in transition planning & support	Ensure full & appropriate involvement of young person with autism & families in the transition process	People with autism, their family/carers fully aware of the range of support services available to people with autism to enable them to live more fulfilling & independent lives	
Education:			
1. School leaving age determined by individual learning needs	Explore opportunities for changes or modifications to the current criteria based on age limits rather than learning needs	<ul> <li>Person-centred transition plan identifies young person's aspirations with support provided to help them achieve their goals</li> <li>Good, accessible information on available options helps increase choice &amp; control over their future</li> </ul>	
2. Adults with autism actively supported to complete their course of study in Further Education (FE)	Review current support arrangements in FE for students with autism	Reasonable adjustments & support mechanisms help individuals complete their course of study	
Employment:			
1. Adults with autism are included & economically active	Increase awareness & understanding of autism within the employment framework	<ul> <li>Good, accessible information on autism, including within the context of the Council's current review of information &amp; advice services across the City</li> <li>Reduced barriers to finding work &amp; increased access to work experience, paid or unpaid work</li> </ul>	
	Reasonable adjustments in recruitment of staff within the local authority & health providers as responsible & empowering employers	<ul> <li>Increased capacity to employ &amp; retain disabled employees, do business with disabled customers &amp; become disability confident</li> <li>Adults with autism included in the CESP<sup>17</sup> focus on inclusion of vulnerable people in local economic development &amp; growth</li> <li>Legal obligation turned into policy development &amp; culture change through promotion of good practice, addressing disability, engaging colleagues &amp; ensuring barrier-free processes &amp; procedures</li> </ul>	
	Increase engagement with employers through Supported Employment Team	<ul> <li>Employment focus included in the transition from Children's to Adult services</li> <li>Support systems including person-centred plan; selected area of work they want to do on leaving school; job description</li> </ul>	

 <sup>&</sup>lt;sup>13</sup> Special Educational Needs Code of Practice (reference DfES 51/2001)
 <sup>14</sup> Child & Adolescent Mental Health Services
 <sup>15</sup> Special Educational Needs Co-ordinators
 <sup>16</sup> S139 Assessments will continue to be led by the Connexions service
 <sup>17</sup> City Employment & Skills Plan

Strategic objective:	Strategic action:	Desired outcome:
		for a specific job; range of support available to help people into work
		Indication of whether they have recruited adults with autism & have made reasonable adjustments in the workplace
lousing:		
<ol> <li>Adults with autism are living</li> </ol>	Review local housing policy & strategy to	More adults with autism live in accommodation that meets their assessed needs
in accommodation that meets	ensure consideration of needs of people with	• Local Authority equality duty fulfilled by taking account of peoples' needs (not just physical), in housing allocation
their needs	autism	Policy review includes provision of aids & adaptations (including soundproofing)
		Availability of appropriate local housing reduces out-of -area placements for those with complex needs
		Commissioning includes Third sector involvement in delivering support services linked to accommodation
2. Home Move eligibility criteria	Carry out a review of Home Move eligibility	Eligibility criteria reflects the needs of adults with autism
reviewed	criteria	Timely transition planning addresses future accommodation needs of individuals currently living at home & reduces crisis
		intervention for those who can no longer be cared for at home
8. Supporting People Integrated	Review the Integrated Support Pathway to	• Focus includes the needs of people with autism & provides a gateway into housing-related support according to need
Support Pathway reviewed	ensure the needs of people with autism are	• Co-ordinated, structured services promoting independent living for adults with autism & reducing risk & vulnerability
	reflected	Opportunity to explore other support solutions (e.g. East Sussex County Council Homeshare scheme)
<ul> <li>Recording of residents with autism on the City Council</li> </ul>	Begin coding of residents using or applying for housing services on the OHMS database	Adults with autism formerly recorded on the Housing database
Housing database	for housing services on the ORIVIS database	Housing provision reflects internal/external environmental needs, due to sensory & related issues
nousing uatabase		Future planning, strategy & policy development informed by the evidence base
Carers:		
. All carers to receive a Carer's	Carer's Assessment automatically triggered	Carer's needs & support requirements identified
Assessment which is	by diagnosis of autism	Progress or changes to requirements identified through yearly assessment (more often if needed)
reviewed annually		• Following diagnosis, relevant information & signposting to appropriate support & training helps carers to manage the
		challenges of caring
2. Parents & carers included in	Ensure parents & carers are included in	• Active participation & informed decision-making in the planning process as part of an inclusive care pathway approach
discussions & decision-	post-diagnosis discussions (with permission	Rights of people with autism respected in decision-making & planning about their care & support
making	of the individual with autism)	
Community safety: Adults with autism no longer	Explore provision of enhanced autism	
managed inappropriately in	awareness training for key people in the	<ul> <li>Improved communication &amp; behaviours of frontline staff (e.g. custody officers, magistrates, probation officers, lay visitors</li> <li>Reduction in numbers of adults with autism in the criminal justice system &amp; reduced workloads for CJS professionals</li> </ul>
the criminal justice system	police & Criminal Justice System(CJS)	Reduction in numbers of adults with adultsm in the chiminal justice system & reduced workloads for CJS professionals     through inappropriate referrals
and criminal justice system		<ul> <li>Adults with autism &amp; their carers involved in training delivery for police &amp; criminal justice staff</li> </ul>
2. Minimising conflict in difficult	Explore introduction of personal Autism Alert	Person with autism helped to communicate in difficult situations, lowering confusion & stress (e.g. with police officers;
situations	cards to raise awareness of autism amongst	probation officers)
	Criminal Justice staff	Raised awareness minimises risk of misunderstanding, inappropriate communication & responses

D. Local planning and leadership in relation to the provision of services for adults with autism			
Strategic objectives:	Strategic actions:	Desired outcome:	
1. Allocated responsibility for leading the commissioning of community care services for adults with autism at local level	Lead Commissioner for autism identified	<ul> <li>Needs of adults with autism 'championed', addressed at local level, represented at regional level</li> <li>Named local contact for the public, service providers, others working in health &amp; social care as commissioning in health care becomes more distributed</li> <li>Locally level commissioning of community care services for adults with autism</li> <li>Close working &amp; participation in relevant local &amp; regional strategic planning groups &amp; partnership boards (e.g. Valuing People regional delivery boards; proposed Health and Wellbeing Boards)</li> </ul>	
2. Implementation of a local commissioning plan for services for adults with autism	Develop an integrated commissioning plan around services for adults with autism	<ul> <li>Output of JSNA &amp; other relevant data around prevalence<sup>18</sup> reflected in planning, monitoring &amp; review of core services</li> <li>Autism included in key procedures, structures &amp; strategies to ensure needs of adults with autism &amp; their carers are considered</li> <li>A plan or specific structures introduced for involving adults with autism, their carers &amp; representative groups in service design &amp; planning on an on-going basis</li> <li>Commissioning plans subject to same review requirements &amp; processes as other plans</li> <li>Support for the voluntary &amp; community sector &amp; social enterprises (<i>i.e. the Big Society</i>), explored when planning &amp; commissioning local services</li> <li>Adults with autism can depend on mainstream public services to treat them fairly as individuals, develop a more preventative approach &amp; enable them to make choices about the services &amp; support they receive, with additional support provided where necessary</li> </ul>	
	Review contract specifications to ensure inclusion of autism in equality requirements	<ul> <li>Equality requirements aligned to the Equality Act &amp; identified best practice</li> <li>Service providers (including health service providers), aware of &amp; able to satisfy corporate equality &amp; diversity requirements in their service provision</li> </ul>	



<sup>18</sup> Refer Brighton & Hove JSNA and BHCC Overview & Scrutiny Panel Report & Recommendations

## Appendix 2

	Key national documents
Disability Discrimination Act	Promotes civil rights for disabled people and protects disabled people
(2005)	from discrimination
Valuing People Now: a new	Government strategy for people with learning disabilities. Highlights
three-year strategy for people	that adults with autism are some of the most excluded and least
with learning disabilities	heard in society
Better Services for People with	Examines how existing government policy relates to people with an
Autistic Spectrum Disorder	ASC. Identifies that people with ASC can fall between the gap
(2006)	between Mental Health and Learning Disability services
Putting People First (2007)	Sets out a vision for transforming social care to give people more
	independence, choice and control through high-quality, personalised
	services
Independent Living Strategy	Commitment to a shared understanding of the principles and practice
(2008)	of independent living giving greater choice and control over how
	support is provided and greater access to a range of services
The Autism Act 2009	First ever piece of legislation designed to address the needs of one
	specific impairment group demonstrating a new commitment across
	government to transform the way public services support adults with
	autism
Supporting People with Autism	Looked at how the needs of people with an ASC are currently being
through Adulthood (National	met. Found that the effectiveness of existing services can be
Audit Office 2009)	improved by better planning and strategy based on good information,
	raising awareness of autism and the needs of people with autism
Fulfilling and rewarding lives:	A national strategy that sets the direction for long-term change and
The strategy for adults with	meeting the needs of adults in England with autism by improving the
autism in England (2010)	provision of relevant services by local authorities, NHS bodies and
	NHS foundation trusts. It also identifies specific areas for action over
	the next three years. The strategy draws on the findings of the
	National Audit Office (NAO) report Supporting People with Autism
	throughout Adulthood
Implementing Fulfilling and	Aims to empower local areas to develop services and support that
rewarding lives: Statutory	reflect the assessed needs and priorities of the community and
guidance for local authorities	encourage innovation in the way services are delivered
and NHS organisations to	
support implementation of the	
autism strategy	
Towards Fulfilling and	Aims to show how the strategy would be taken forward over the next
rewarding lives: The first year	12 months; priorities for action in the first 12 months; timelines and
delivery plan for adults with	milestones associated with these priorities
autism in England (2010)	
Fulfilling and Rewarding Lives:	Identifies seven tangible quality outcomes – visible and measurable
Evaluating Progress (2011)	indications of whether the vision of improving the lives of adults with
	autism is being realised
	Key local documents
A Business Case For the	Business case for the development of a Sussex-wide ASC service for
Development of Autistic	adults. Highlighted the unmet needs of adults with HFA and AS.
Spectrum Disorder Services for	Recommended the development of an ASC coordination service in
Adults across Sussex (R	each mental health locality to assess and coordinate care for young
Hacket, SPFT 2007)	adults with HFA or AS accessing expertise from a virtual, cross-
	sector team. Business case not implemented
Aspergers Briefing (N Cox,	Outlines the development and work of the Asperger Stakeholder
BHCC Integrated Learning	Group in Brighton & Hove. Supports the development of a pan-
Disability Service 2009)	Sussex specialist ASC Service for adults as described in the SPET
Disability Service 2009)	Sussex specialist ASC Service for adults as described in the SPFT Business Case 2007 Recommends the development of a local
Disability Service 2009)	Business Case 2007. Recommends the development of a local
Disability Service 2009)	

## **APPENDIX 3**

	ts with Autistic Spectrum Conditions h 2011)
Core Area of Activity	Summary of Report Recommendations
A. Training of staff who provide services to adults with autism	<ul> <li>Improve awareness and understanding of autism for frontline staff including GPs</li> <li>Provide specialist training for those in key roles to improve access to services</li> <li>Involve people with autism in delivery of training programmes</li> </ul>
B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services	<ul> <li>Improve earlier identification of people with autism</li> <li>Develop a triage service model to reduce diagnosis waiting times</li> <li>Improve care pathway links between diagnostic, assessment and support services</li> <li>Provide earlier, appropriate services or support interventions</li> <li>Provide appropriate services and support for adults with autism who <i>do not</i> have a learning disability or mental health problem</li> </ul>
C. Planning in relation to the provision of services to people with autism as they move from being children to adults	<ul> <li>Develop an integrated, joint working approach between Children and Adult services to improve the transition process</li> <li>Provide sufficient good information to enable the individual, their family/carers to be fully involved in planning and decision making</li> <li>Review funding to ensure continued involvement of Voluntary sector expertise in planning and decision making</li> <li>Provide more opportunities for adult continuing education and development</li> <li>Provide better information on autism for employers to help increase paid or unpaid work opportunities</li> </ul>
D. Local planning and leadership in relation to the provision of services for adults with autism	<ul> <li>Develop an inclusive, integrated approach to improve service efficiency and effectiveness</li> <li>Develop a virtual, multi-disciplinary team to improve access to appropriate information, services and support</li> <li>Develop a joined up (inter-operable) database so that agencies can share current, accurate information to support effective planning and decision making</li> </ul>

# Appendix 4

Joint Stra	tegic Needs Assessment for Adults with Autistic Spectrum Conditions (May 2011)
Areas	Recommendations
Health	<ul> <li>Simplified, joined up diagnostic, assessment and care pathway</li> <li>Easily accessible information and support for people with autism, their family/carers via a 'virtual' cross-sector, multi-disciplinary team (post-diagnosis)</li> <li>Autism included on the Map of Medicine to assist GPs in identifying potential signs of autism with direct referral to the diagnostic clinic to speed up the process, reduce waiting times and minimise risk of people falling into gaps between services</li> <li>Information on adults diagnosed with autism shared and coordinated across agency databases including data on carers of adults with autism</li> <li>Increased autism awareness training for frontline staff</li> </ul>
Transition	<ul> <li>Integrated, joint working approach between Children and Adult services</li> <li>Identified contact to coordinate and support a more effective transition process</li> <li>Easily accessible information on a range of services and support to inform planning and decision making</li> <li>Third sector expertise commissioned to support effective transition planning</li> </ul>
Education	<ul> <li>Access to further education taking account of individual needs within appropriate, supported settings</li> <li>Opportunities for life long learning enhanced through strengthened employer links and increased work opportunities</li> </ul>
Employment	<ul> <li>Better employer awareness of autism to help increase employment opportunities and understanding of the special skills of people with autism</li> <li>Improved access to Job Centres through reasonable adjustments for people with autism</li> </ul>
Housing	<ul> <li>Local housing provision planned to minimise out of area placements</li> <li>Long term transition planning to reduce crisis situations when living at home is no longer possible</li> <li>Housing provision and environmental issues to reflect individual need</li> <li>Improved access to mainstream housing options and support for people with AS</li> </ul>
Carers	<ul> <li>Carer's assessment carried out with on-going review if necessary (post-diagnosis)</li> <li>Receive or signposted to information and support, including information on managing challenging behaviour, and help for carers themselves</li> <li>Actively involved in planning and decision making</li> <li>Stress minimised through adequate forward planning especially when linked to transition from childhood to adulthood</li> </ul>
Social and leisure	<ul> <li>Increased access to a range of social and leisure pursuits to support living a more fulfilled life</li> </ul>
Workforce	<ul> <li>Increased autism awareness training for frontline staff and involving service users and carers in programme delivery</li> <li>Autism awareness specifically included in equality and diversity programmes</li> </ul>
Community safety	<ul> <li>Enhanced autism awareness training for frontline police officers and criminal justice staff and involving service users and carers in programme delivery</li> <li>Use of Autism Alert card considered to reduce communication difficulties between adults with autism and criminal justice staff in stressful situations</li> </ul>
Personalised budgets	Highlight agencies that can provide support with the different stages of budget management and other official processes

### **APPENDIX 5**

Adult Autism Strategy Stakeholder Group - Membership ORGANISATION:
AMAZE
Aspire
ASSERT
Autism Sussex
 BHCC (Commissioning and Partnerships)
BHCC (Housing Adaptations OT Team)
BHCC (Housing Options Team)
BHCC (Housing, Policy & Performance)
BHCC (Integrated Learning Disability Services)
BHCC (Integrated Services Social/Disability Services)
BHCC (Learning Disabilities)
BHCC (Learning Support)
BHCC (Supported Employment)
BHCC (Supporting People)
BHCC Post-16 Education
Brighton Sussex Medical School
National Autistic Society, SE Region
NHS Brighton and Hove (Commissioning)
NHS Brighton and Hove (Public Health)
Southdown Housing Association
St. Peter's Medical Centre, Brighton; PCT Clinical Lead
Surrey Sussex Probation Service
Sussex Partnership NHS Foundation Trust
The Carers Centre Brighton

#### References

<sup>1</sup> Department of Health (2010), Fulfilling and rewarding lives: The strategy for adults with autism in England (2010). HM Government

<sup>2</sup> Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions Report and Recommendations (March 2011); Adults with autistic spectrum conditions needs assessment (May 2011)

<sup>3</sup> Department of Health (2010), Fulfilling and rewarding lives: the national strategy for adults with autism. HM Government

<sup>4</sup> Department of Health (2010), Fulfilling and rewarding lives: the national strategy for adults with autism. HM Government

<sup>5</sup> NHS Brighton and Hove and Brighton & Hove City Council (2011), Adults with autistic spectrum conditions needs assessment (May 2011)

<sup>6</sup> The Autism Act 2009,

http://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga\_20090015\_en.pdf HM Government

<sup>7</sup> Department of Health (2010), Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy. HM Government

<sup>8</sup> Department of Health (2010), Towards Fulfilling and rewarding lives: The first year delivery plan for adults with autism in England (2010). HM Government

<sup>9</sup> Annual Operating Plan for NHS Brighton and Hove 2011/2012

<sup>10</sup> Creating the City of Opportunities: A Sustainable Community Strategy for the City of Brighton and Hove (updated). Brighton & Hove Local Strategic Partnership. Accessed via <u>http://www.bandshop.co.uk/</u>

<sup>11</sup>) NHS Brighton and Hove and Brighton & Hove City Council (2011), Adults with autistic spectrum conditions needs assessment (May 2011)

<sup>12</sup> Brighton & Hove City Council Adult Social Care & Housing Overview & Scrutiny Committee

<sup>14</sup> The Learning Disability Partnership Board at <u>www.brightpart.org</u>

<sup>15</sup> The Equality Act 2010 accessed at <u>http://www.legislation.gov.uk/ukpga/2010/15/contents</u>

<sup>16</sup> Office for Disability Issues. Accessed at <u>http://odi.dwp.gov.uk/about-the-odi/the-social-model.php</u> HM Government

lssue	Date to be	Referred/Req	Reason for Referral	Progress	Notes
3T development of the	Sep 2011	BSUHT	Ongoing monitoring of major project		Members
Royal Sussex			to re-design RSCH		requested
					additional
					information re
					use of BGH
					during
					construction
					period
GP practice quality	Sep 11	HOSC	Monitoring relative performance of		Members
			city GPs		requested
					information on
					individual
					Practice 'scores'
City MH beds	Sep 11	SPFT/PCT	NHS plans to reconfigure city MH		Workshop
			beds		requested 10
					Nov 2011
PCT annual operating	TBA	PCT	Scrutinise PCT strategic		workshop
plan			commissioning plans for coming		
			year		

HOSC Work Programme 2011/12

Will be addressed as part of 3T update
Ongoing – update on progress of trust FT application
BSUHT
Sep 11
BSUHT Foundation Trust application

Issue	Date to be considered	Referred By?	Reason for Referral	Progress and Date	Notes
Sussex Community Trust - merger	TBA	SCT	Update on progress of trust following merger with WSX community		
MH re-commissioning	TBA	PCT	Update on re-commissioning of MH access services		
Screening	Nov 2011	HOSC	Update on city screening programmes (inc. breast and cervical screening + pilot on co- rectal screening)		
Health & Social Care Bill	Sep 11, Nov 11 and ongoing	HOSC	Ongoing update on progress of Health Bill, focusing on elements requiring local implementation		Nov 11 – HOSC to be consulted on model for local Health and Wellbeing Board
Continuity of care for people with MH problems leaving prison	TBC	Clir Deane	Worries about quality/continuity of care for people leaving prison (esp transfer of information between prison services and GPs)		To be scoped before deciding on course of action
Maternity	TBC	Cllr Buckley	Look at performance of city maternity services – to include info on a city midwife led service		

Issue	Date to be considered	Referred By?	Reason for Referral	Progress and Date	Notes
End of Life Care	TBC	Cllr Wealls	Look at city strategies for EoL care and what providers do to guarantee dignity/quality		Workshop event
Alcohol issues	TBC	Clirs Duncan and Powell	Look at issues re the negative impacts of alcohol on city health		Chair to liaise with executive to identify which aspects of this issue can best be taken forward by HOSC
NHS Provider Quality	TBC	PCT/BSUH	Examine quality of healthcare provision across city inc. annual patient survey		Workshop event
Short term services	Jan 2012	ASC	Look at revised short term services strategy	To include 'delayed discharge	Due to be agreed by JCB Nov 11

Issue	Date to be considered	Referred By?	Referred By? Reason for Referral	Progress Notes and Date	Notes
Air Quality	TBC	Cllr Rufus	Examine health impact of poor air quality		Liaise with ECSOSC to discuss best way to progress this





8<sup>th</sup> November 2011

Dear Cllr Rufus,

As previously discussed, please find links to the three reports that are to be presented at the Joint Commissioning Board on Monday 14<sup>th</sup> November.

- The Reconfiguration of Short Term Services report (often referred to as Intermediate Care) details proposals for changes to the way that Short Term Services are delivered. Part of the programme includes proposing the redesign of these services and the development of an Integrated Rapid Response Service. Part of the review has included consultation with stakeholders, undertaking a needs assessment, information from our Joint Strategic Needs Assessment and evidence based best practice.
- 2. Review of Community Mental Health Support Services. This programme of transformational change follows extensive consultation with service users, GPs, service providers and the public. It has also included a mapping exercise of all contracts to determine strengths of current services and gaps, information from evidence based best practice and our Joint Strategic Needs Assessment. The proposals include proposing the redesign of Community Mental Health services.
- 3. The **Carers Strategy** refresh is a multi-agency strategy and details priorities for the city council and Brighton & Hove Clinical Commissioning Group, NHS Sussex as well as the wider local health economy and voluntary sector. The strategy, which has been developed with carers and organisations providing carers services in the city, details key achievements to date, recommends priorities for the work programme to March 2013 and proposes the development of a universal offer of services which will be available to all carers of adults in the city from April 2012.

If you would like to have further discussion regarding any of these papers we would be happy to discuss at a future HOSC meeting.

Yours sincerely,

Paldine Hovan

Geraldine Hoban Chief Operating Officer Brighton & Hove Clinical Commissioning Group

Denice DSoga

Denise D'Souza Director of Adult Social Services/Lead Commissioner People