Brighton & Hove
City Council

Health & Wellbeing Overview & Scrutiny Committee

Title:	**Health & Wellbeing Overview & Scrutiny Committee**
Date:	**22 April 2014**
Time:	**4.00pm**
Venue	**Council Chamber, Hove Town Hall**
Members:	**Councillors:** Rufus (Chair)C Theobald (Deputy Chair), Buckley, Cox, Marsh, Robins, Sykes and Wealls **Co-optees:** Jack Hazelgrove (OPC), Amanda Mortensen (Parent Governor Representative), Marie Ryan, Youth Council and Healthwatch
Contact:	**Kath Vlcek** 01273 290450 kath.vlcek@brighton-hove.gov.uk

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Part One **Page**

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To consider

(a) Declaration of Substitutes

(b) Declaration of Interest

(c) Declaration of Party Whip, and

(d) Exclusion of Press and Public

116. Minutes of Previous Meeting **3 - 10**

117. Chair's Communications

118. BSUH Reconfiguration of Clinical Services **11 - 24**

Report from Simon Maurice, Programme Director for Major Trauma, BSUH

Contact Officer: *Kath Vlcek, Scrutiny Support Officer* *Tel: 01273 290450*

Ward Affected: *All Wards*

119. Sussex Community Trust Estates Strategy **25 - 32**

Presentation from Gareth Baker – Director of Transformation and Commercial Development and Gillian Wieck - Deputy Chief Operating Officer, Children's and Specialist Services, Sussex Community Trust

Contact Officer: *Kath Vlcek, Scrutiny Support Officer* *Tel: 01273 290450*

Ward Affected: *All Wards*

120. MusculoSkeletal Procurement

Update from the CCG on the outcome of the procurement process – report to follow

121. Scrutiny Panel Report- Services for Children with Autism **33 - 90**

Contact Officer:	*Julia Riches, Scrutiny Support Officer*	*Tel: 01273 29-1084*
Ward Affected:	*All Wards*	

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.

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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 Scrutiny, (01273 290450) or email scrutiny@brighton-hove.gov.uk

Date of Publication 11 April 2014

Agenda Item 1

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.

BRIGHTON & HOVE CITY COUNCIL

HEALTH & WELLBEING OVERVIEW & SCRUTINY COMMITTEE

4.00pm 4 FEBRUARY 2014

COUNCIL CHAMBER, HOVE TOWN HALL

MINUTES

Present: Councillor Rufus (Chair)

Also in attendance: Councillor C Theobald (Deputy Chair), Buckley, Cox, Marsh, Robins, Sykes and Wealls

Healthwatch representative; Youth Council representative

PART ONE

105. PROCEDURAL BUSINESS

105.1 There were no substitutes. Apologies had been received from co-optees Amanda Mortenson and Marie Ryan.

Declarations of Interest – There were none.

Declaration of Party Whip – There was none

Exclusion of press and public was as per the agenda.

106. MINUTES OF PREVIOUS MEETING

106.1 These were approved without amendment.

107. CHAIR'S COMMUNICATIONS

107.1 The Chair welcomed the new Youth Council co-optee Reuben Brett.

107.2 The Chair updated members on the recent regional health scrutiny meeting; it covered a lot of issues that were common to us all including the 111 service, and the proposed reconfiguration of maternity and paediatric services in East Sussex. This is an issue that has been to the East Sussex HOSC before but it has now been determined that the proposals from their three CCGs are substantial variations. This means that there is an extended period of public consultation. East Sussex will keep Brighton & Hove's HWOSC updated with events and have asked if we want to submit a formal consultation statement. The information has been circulated to all members.

107.2 The Chair and Deputy Chair were also due to meet with regional colleagues to talk about mental health service capacity in Sussex. This came about following an article in the Argus late last year where the Chief Executive of Sussex Partnership Trust said that the service was at crisis point. The outcome of the meeting would be shared with HWOSC members in due course.

107.3 The Care Quality Commission was inspecting an out of hours service provider in Woodingdean as part of its standard inspection process. HWOSC members were asked to send any information that they had about the service to Scrutiny.

108. UPDATE ON A& E SERVICE CHANGES AND 3TS DEVELOPMENT

108.1 Agenda items 108 and 109 were heard together so that the Chief Executive of Brighton and Sussex University Hospital Trust, Matthew Kershaw, could contribute to both items.

108.2 Mr Kershaw first updated committee members on the 3T development plans, which was still awaiting confirmation of the capital funding. The hospital trust has weekly conversations with the Treasury; a response was expected by the end of February 2014. Mr Kershaw anticipated a positive response although this was not definite.

The Trust has already started the decant work, moving some of the administrative functions onto the St Mary's Hall site. If the 3T development was not approved for any reason, the Hospital Trust still needs to update buildings and facilities so the decant needs to take place in any circumstance.

108.3 Mr Kershaw then gave an update on the current Emergency Department situation. Members had already had briefings on the action plan, and this remained the action plan. The department was performing much better in comparison to this time last year although there were still days and weeks that were comparatively low-performing. December and January had been particularly pressured months.

108.4 The department's target was 95%; they were regularly hitting 94% so additional work needed to be done. The target figure refers to the four-hour target in emergency departments which was introduced by the Department of Health for National Health Service acute hospitals in England. The target is that at least 95% of patients attending an A&E department must be seen, treated, admitted or discharged in under four hours.

108.5 The Hospital Trust continued to work closely with the CCG and Ambulance Trust amongst other partners. Key issues are the medically fit for discharge patients, ambulance conveyance, time of day of discharge and also flow within the hospitals.

108.6 Positive news was that elderly patients had an average length of stay that was two days less than this time last year.

108.7 Mr Kershaw ended by saying that he visited the Emergency department either in Brighton or in Princess Royal Hospital almost every day, so that he could observe it firsthand.

108.8 The item moved on to the update on the Major Trauma Centre (MTC), presented by Dr Jonathan Andrews, Consultant Anaesthetist, Clinical Lead, Major Trauma Centre.

Dr Andrews gave a presentation on the centre, and explained the reasons that it had been developed. He and Mr Kershaw then answered questions from HWOSC members.

108.9 Members queried the comment in the presentation about 'challenges for rehab' and asked what this meant. Dr Andrews said that the MTC provided very specialist high-end care for patients needing intensive nursing, but that when they no longer needed such intensive care, it was better to move the patients to a more suitable setting. In the case of patients from East and West Sussex, this entailed moving them to the most appropriate local setting.

108.10Members asked about the link between the MTC and the 3T development; was the trauma centre development dependent on the 3T funding being granted?

Mr Kershaw said that even assuming that the funding were to be granted, it is a major redevelopment; some parts of the build are not scheduled for five years. Some of the planned changes cannot wait that long or the hospital trust will not meet the necessary service specifications. The Trust has to make changes to services now to make them compliant, in advance of the 3Ts.

108.11 One member said that he was concerned about the dilution of capacity in neuro-surgery at the PRH site, as it seems to be splitting expert teams. Mr Andrews said that it is true that some services will no longer be at Hurstwood Park, but that the split was a logical one. There are plans for a more coherent pathway for spinal patients. It will also allow for improvements in critical care facilities at Hurstwood Park, which are long overdue.

Mr Andrews said that he wanted to pay tribute to the staff at Hurstwood Park who have been involved in the redevelopment plans for all of their support in the work to date.

108.12 A member said that she had heard several reports about problems with the patient transport service. Mr Kershaw said that the Trust has regular meetings regarding the patient transport service and these would continue to happen.

Mr Kershaw said that the 'medically fit for discharge' list was managed with input from the CCG and social care. This generally worked well but when the list of patients grew, this increased pressure throughout the system; more work needed to be done to address the impact.

108.13 Members asked about the air ambulance, could it be used at PRH? They heard that it was harder to access the site than it had been in the past, due to a new housing development on the edge of the PRH site. In Brighton, the air ambulance currently landed in East Brighton Park, which worked well.

108.14 The report was noted and agreed, with further updates requested when available.

109. BSUH MAJOR TRAUMA CENTRE & HOSPITAL SITE RECONFIGURATION

109.1 Please see 108 above.

110. UPDATE ON 111 SERVICE IN BRIGHTON AND HOVE

110.1 The 111 service went live in March 2013, answering all telephone calls that used to go either to NHS Direct or to out of hours telephone lines. It is for non emergency calls but can also dispatch ambulances if needed. The 111 service can provide a clinical assessment over the telephone and provide appropriate advice.

110.2 They have two main performance indicators; (a) calls answered within 60 seconds and (b) abandoned phone calls. For (a), the target is to answer 95% within 60 seconds; locally the service is exceeding this by answering 98-99% calls within 60 seconds. For (b) the target is for an abandonment rate no higher than 5%; locally only 0.6-0.7% calls are abandoned so the service performs well within the targets.

110.3 The CCG has done some local marketing through a campaign called 'We Could be Heroes' in the local media. NHS England has put a wider campaign on hold until all services are live across the country, which should be in two to three months.

110.4 Ms Hoban said that the launch of the 111 service had not performed as well as it had been hoped, due to a high demand for the service. Unfortunately this had led to negative experiences for some people and they still held negative views of the service. It was important to address those memories and help to show people that the service had moved on.

110.5 The Healthwatch representative said that they had worked with the CCG to involve communities of interest who might not have known as much about the 111 service. Healthwatch had also surveyed young men, only one third of them were aware of the 111 service. Healthwatch agreed that it would be useful to do some more targeted work.

110.6 The Chair said that the issue of local publicity had been raised at the recent regional HOSC meeting, it had been recognised that a national campaign might not be appropriate at present but regional scrutiny colleagues had felt that it would be useful to have a local promotion.

The comments were noted.

111. DIABETIC PROVISION CONSULTATION UPDATE

111.1 Geraldine Hoban, Chief Operating Officer, Brighton and Hove CCG and Nicky Daborn, Clinical Lead, Brighton and Hove CCG presented a report to HWOSC explaining why the CCG was recommending a new model of diabetes care.

The CCG said that there was an increasing number of people presenting with poorly controlled diabetes; only 42% of patients were having the recommended nine checks.

There had been a very extensive consultation exercise, and the suggested model had been agreed by the CCG's clinical reference group.

111.2 The Youth Council representative queried how stakeholders had been involved; with 10,000 diabetes patients in the city, the stakeholder involvement seemed fairly low to him. Ms Daborn said that they sent a lot of publicity to GP practices across the city.

The Youth Council representative said that in his experience, people with Type 1 diabetes did not often need to attend a GP practice. The CCG could be failing to reach a significant percentage of the diabetes population if they were purely focussing consultation publicity on GP practices. Ms Daborn confirmed that she would take this feedback into account when planning further events.

111.3 Members asked about the impact of healthy eating on diabetes management. Ms Daborn confirmed that healthy eating was a key area in preventing diabetes from arising and escalating. The CCG uses the nutritional guidance provided by Diabetes UK, including following a balanced diet. Pre-diabetes work includes exercise targets which can be effective.

111.4 Members asked about work with BME communities. Ms Daborn said that they worked with a number of gateway organisations across the city to improve access to harder to reach groups. This could be more targeted however.

111.5 Members asked about the link between higher rates of diabetes and health inequalities. Ms Hoban said that the CCG planned to introduce a more consistent service across the city. More outreach was needed.

111.6 Members asked why the numbers had escalated to such a level. Ms Daborn said that this was due to a combination of factors including increased obesity, and the fact that there had been under-diagnosis previously.

111.7 Ms Daborn concluded by advising members that the new diabetes provision would go live from April 2015, and plans had come to HWOSC before they had been signed off by the CCG’s own board. There were still areas to be improved, before plans were finally agreed. The CCG could bring finalised plans to HWOSC in due course.

111.8 Members welcomed this and agreed the report.

112. END OF LIFE PATHWAYS

112.1 Geraldine Hoban and Nicky Daborn from the CCG presented on the four workstreams for end of life/ palliative care. These included Sussex End of Life Care and Dementia Project; the Palliative Care Partnership; Primary Care, and the Liverpool Care Pathway (LCP).

112.2 Paul Somerville spoke on behalf of Sussex Community Trust who provide palliative care services in conjunction with Martlets. The service helps avoid unnecessary hospital admissions, and saves many thousands of pounds in doing so, as well as ensuring that 80% of patients had their preferred places of death adhered to. SCT and Martlets had produced literature to help patients and families think about their End of Life care.

112.3 There was a discussion over the merits of the Liverpool Care Pathway; some felt that there were many positive factors but that the lack of communication meant that these had been overlooked. There were concerns about the impact of the backlash on patients who were currently at the end of their lives.

Ms Daborn said that the communication problems meant that people lost confidence in the LCP. The CCG had ensured that all providers followed the principles of good palliative care and emphasised good communication within that. They were waiting for national guidance on what should replace LCP. Ms Hoban commented that there had been positive elements to the LCP and this should not be lost or overlooked.

112.4 Members asked how metrics were measured. Ms Daborn said that Martlets surveyed relatives six weeks after a death had occurred. There was a Gold Standard Framework for the post-death review. Ms Daborn suggested that they could put the results of the publicly available information on the CCG website; this was welcomed.

112.5 The Chair asked the CCG to keep HWOSC members updated with progress as it was known. This was agreed.

113. UPDATES ON SCRUTINY PANELS

113.1 Councillor Lizzie Deane presented the scrutiny panel report on alcohol to HWOSC and summarised the findings and recommendations that the panel had made. Councillor Deane had been Chair of the panel, along with Councillors Mo Marsh and Dee Simson.

113.2 Members queried how much sway scrutiny panels could have over altering licensing definitions. Councillor Deane said that the panel had made their recommendations as they felt that it was an important issue but that they would take guidance from the Licensing Team.

113.3 Members agreed and endorsed the scrutiny panel report without amendments. Councillor Deane thanked everyone who had taken part in the panel.

113.4 Councillor Andrew Wealls then presented the scrutiny panel report on homelessness to HWOSC, summarising the findings and recommendations that were made. Councillor Wealls had been Chair of the panel, along with Councillors Alan Robins and Ollie Sykes.

113.5 Councillor Wealls apologised for the time taken to complete the panel but said that members had wanted to talk to everyone who was involved rather than rushing the process. He paid particular tribute to the homeless service users who had contributed to the panel meetings, as well as the voluntary sector and the council staff.

There was a lot of excellent work taking place in Brighton and Hove regarding homelessness. It was hard to judge whether this made Brighton a more attractive place to be if you were homeless.

113.6 Councillor Robins said that he had found the panel process a very poignant one. He had had personal experiences which had led him close to becoming homelessness in the past; it was just a matter of luck. Councillor Sykes said that he too had gained a lot from the panel.

113.7 Councillor Wealls said that he would be interested to see the administration's response to the report and recommendations.

113.8 Members agreed and endorsed the scrutiny panel report without amendments. Panel members thanked everyone who had taken part in the panel.

114. LETTER RE PROPOSED RE-LOCATION OF SPECIAL CARE DENTAL CLINIC

114.1 Paul Somerville updated HWOSC members on the proposed re-location of specialist dental services provided by SCT. He was seeking comments from HWOSC members; there would also be consultation process with service users and the proposals had been discussed with Healthwatch.

114.2 The Chair asked how many patients used the service currently. SCT said that there had been 56 patients over a twelve month period. Those service users who could not access the proposed new site would also be eligible for home visits.

114.3 HWOSC members agreed to the proposed changes.

The meeting concluded at 6.30pm

Signed Chair

Dated this day of

HEALTH & WELLBEING OVERVIEW & SCRUTINY COMMITTEE	**Agenda Item 118** Brighton & Hove City Council

Appendix 1

Subject:		**BSUH Reconfiguration of Services**	
Date of Meeting:		**22 April 2014**	
Report of:		**Monitoring Officer**	
Contact Officer:	**Name:**	**Kath Vlcek**	**Tel: 29-0450**
	Email:	**Kath.vlcek@brighton-hove.gov.uk**	
Ward(s) affected:		**All**	

FOR GENERAL RELEASE

1. PURPOSE OF REPORT AND POLICY CONTEXT

1.1 This paper is to set out for local authorities, commissioners, partner providers and other key stakeholders (including patient groups and members of the public) further detail on the trust's plans for the reconfiguration of clinical services at Brighton and Sussex University Hospitals (BSUH).

1.2 The purpose of this document is to outline the proposed changes to the fractured neck of femur and urology services, the potential impact upon patients, and the proposed timeframes for the changes

2. RECOMMENDATIONS:

2.1 To note and comment on the reconfiguration arrangements.

3. CONTEXT/ BACKGROUND INFORMATION

3.1 This paper builds on the already consulted and agreed development of a neuro-trauma service as part of the Major Trauma Centre which in turn will ensure compliance with the national service specification for major trauma. It is planned to start the implementation of the reconfiguration of services in 2014 for completion in October 2014. The paper on the Major Trauma Centre came to HWOSC in February 2014; draft minutes are attached as **Appendix One.**

3.2 A programme of work has started to move elective and emergency cranial neurosurgery from Hurstwood Park Neurosurgery Centre (HPNC) to Royal Sussex County Hospital (RSCH) and to establish an integrated spinal service based at the Princess Royal Hospital (PRH) site. It is proposed to move the fractured neck of femur pathway and the inpatient urology service from the Royal Sussex County Hospital site to the Princess Royal Hospital campus. This is in order to create the necessary capacity on the RSCH campus and realise other benefits.

3.3 Considerable work has been undertaken with clinicians to develop proposals; a number of options were considered including the transfer of trauma and orthopaedics and the urology service to PRH. The options were developed using a number of criteria including deliverability, quality and value for money.

Urology Services

3.4 It is proposed to move the inpatient urology service off the RSCH site and establish a single site service at PRH. This will include establishing a urology ward of 18 inpatient beds. Additional critical care capacity is being created by expansion into Cuckfield at PRH in part for the additional urology patient activity.

A daily outpatient session will also be held Monday to Friday at RSCH and outpatients will continue to be seen at RSCH. In 2012/13 a total of 361 patients out of 3678 from the Brighton & Hove catchment area had an in-patient procedure at RSCH which in future will be undertaken at PRH; this cohort represents 10% of all urology patients. Therefore, as it is only the inpatient aspect of the pathway that is changing and outpatients and follow-ups will continue to be undertaken at RSCH, the number of patients affected will be relatively small.

Fractured neck of femur service

3.5 Currently patients with a suspected neck of femur are admitted through the emergency department at RSCH where they have their surgery prior to a transfer to PRH for their rehabilitation; Brighton and Hove patients remain at RSCH for their rehabilitation stay. The trauma service has been working to deliver a more stream lined pathway, to improve patient outcomes and prevent unneccesary delays for patients. This proposed pathway involves fast tracking through the Emergency Department with transfer straight to x-ray, where the fracture neck of femur is confirmed and then admitted directly to the orthopaedic ward. Patients will receive prompt investigation and rapid treatment of co-morbidities, optimising them for surgery. This pathway would remove the need for patients to be transferred from RSCH to PRH for their rehabilition stay.

3.6 The hospital receives approximately 570 fractured neck of femur patients per annum of which 228 patients (40%, mostly from the Brighton & Hove catchment area) do not currently go to PRH and would therefore be affected by this pathway change.

3.7 Treating fracture neck of femur patients in a dedicated unit such as PRH improves the overall level of care they receive and nationally has been shown to reduce length of stay by up to eight days. BSUH has made recent improvements in length of stay and will continue to work on further improvements.

3.8 The next steps are for detailed plans to be developed to enable the proposed service moves to take place by October 2014. The Trust will continue to have discussions with all stakeholders including local authorities, local commissioners and patients and their representative groups to confirm the position.

4. COMMUNITY ENGAGEMENT & CONSULTATION

4.1 Extensive consultation has already been undertaken on the move of neurosurgery to RSCH as part of the 3Ts consultation exercise. This has been undertaken with patients/patient representatives, partner organisations and members of the public across the Trust’s local and regional catchments, and with local residents, statutory consultees and other community and special interest groups. Between 1996 and 2003 three independent reviews were undertaken into the configuration of neurosciences in Sussex.

4.2 A local assessment has been undertaken by BSUH on whether the proposed moves of urology and trauma and orthopaedics from RSCH to PRH constitute "substantial and significant change" for patients in terms of access.

Their analysis shows that:

- 361 patients from the Brighton and Hove catchment area will be affected by the proposed urology move; the total number of elective and day case urology patients in 2012/13 was 3678

- 228 patients from the Brighton and Hove catchment area will be affected by the proposed fractured neck of femur pathway change; the total number of fractured neck of femur patients treated in 2012/13 was approximately 570

- Legal advice has also been taken on whether public consultation is required on the proposed service moves; due to the low number of inpatients affected we do not believe there is a need to undertake a full public consultation exercise. However we want to ensure we are being clear about plans with commissioners and local authorities as well as having a meaningful engagement with service users and patient experience groups. Plans for this are well developed and will be shared in April 2014.

4.3 The proposed changes to the fractured neck of femur pathway and urology moves have recently been introduced to Brighton & Hove HWOSC, West Sussex HASC and to Brighton and Hove CCG.

5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

There are no financial implications for the cover report.

Legal Implications:

There are no legal implications for the cover report.

Equalities Implications:

A public sector equality duty analysis on the impact of the changes has been undertaken on the proposed urology service move and will be undertaken on the fractured neck of femur pathway change. This analyses the effect or potential effect of the site reconfiguration programme on different groups, including patients and staff, who are covered by the protected characteristics described in the Equality Act 2010.

The impact of the service change may be perceived as negative as it is associated with further travel for new patients. In order to mitigate this impact patients and carers need to be advised of the availability of the 40X bus service which is available free of charge for people needing to access either site. Carers and family may require additional support to work out the best transport methods to PRH.

SUPPORTING DOCUMENTATION

Appendices:

1. Draft minutes from February HWOSC

2. BSUH Reconfiguration Report

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108.2 Mr Kershaw first updated committee members on the 3T development plans, which was still awaiting confirmation of the capital funding. The hospital trust has weekly conversations with the Treasury; a response was expected by the end of February 2014. Mr Kershaw anticipated a positive response although this was not definite.

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Mr Kershaw said that the 'medically fit for discharge' list was managed with input from the CCG and social care. This generally worked well but when the list of patients grew, this increased pressure throughout the system; more work needed to be done to address the impact.

108.13 Members asked about the air ambulance, could it be used at PRH? They heard that it was harder to access the site than it had been in the past, due to a new housing development on the edge of the PRH site. In Brighton, the air ambulance currently landed in East Brighton Park, which worked well.

108.14 The report was noted and agreed, with further updates requested when available.

BRIGHTON AND SUSSEX UNIVERSITY HOSPITALS

RECONFIGURATION OF CLINICAL SERVICES TO SUPPORT DEVELOPMENT OF NEURO-TRAUMA SERVICE AT THE MAJOR TRAUMA CENTRE

1. Executive Summary

The purpose of this paper is to set out for local authorities, commissioners, partner providers and other key stakeholders (including patient groups and members of the public) further detail on the trust's plans for the reconfiguration of clinical services at Brighton and Sussex University Hospitals (BSUH).

This builds on the already consulted and agreed development of a neuro-trauma service as part of the Major Trauma Centre which in turn will ensure compliance with the national service specification for major trauma. It is planned to start the implementation of the reconfiguration of services in 2014 for completion in October 2014.

A programme of work has started to move elective and emergency cranial neurosurgery from Hurstwood Park Neurosurgery Centre (HPNC) to Royal Sussex County Hospital (RSCH) and to establish an integrated spinal service based at the Princess Royal Hospital (PRH) site. To create the necessary capacity on the RSCH campus and to realise other benefits it is proposed to move the fractured neck of femur pathway and the inpatient urology service from the Royal Sussex County Hospital site to the Princess Royal Hospital campus.

The purpose of this document is to outline the proposed changes to the fractured neck of femur and urology services, the potential impact upon patients, and the proposed timeframes for the changes.

2. Background

On 1 April 2012 RSCH was designated as the regional Major Trauma Centre for Sussex subject to establishing a neuro-trauma service on the RSCH site. Following publication of the new national service specification for major trauma by NHS England in February 2013 the hospital applied for derogation for neurosurgery (derogation is a time limited agreement that one or more contractual standards or requirements in the national service specification will not be in place during the contractual period and will only be agreed when assurance has been provided that alternative service arrangements are in place).

In August 2013 at the request of the Trust Development Authority (TDA), the national organisation supporting NHS Trusts, and with the support of the Area Team the Clinical Director (Specialised Services) for NHS England visited the hospital. His report (the Palmer report) made a single recommendation on the most appropriate configuration of neurosurgery, specifically the transfer of elective and emergency cranial neurosurgery activity to RSCH and the creation of an integrated spinal service at PRH. This first move is ahead of the full service change when all of neurosciences will transfer into the new 3Ts development and is consistent with the earlier consultation which supported the overall moves.

In December 2013 the Board of Directors approved the investment in clinical infrastructure and workforce to undertake the enabling moves and move the neurosurgery service from HPNC to RSCH by October 2014. Consultation about the plans has started with affected staff and the design processes for the various capital works including bi planer angiography are underway.

3. How the proposals were developed

In 2012 a Site Reconfiguration Programme Board was established to oversee the development of proposals to reconfigure clinical services which would enable sufficient capacity to be created at RSCH for neurosurgery and deliver other clinical benefits associated with moves to single site services, such as an improved pathways, enhanced clinical input and co-location of key care services.

Considerable work was undertaken with clinicians to develop proposals and a number of options were considered including the transfer of trauma and orthopaedics and the urology service to PRH. The options were developed using a number of criteria including:-

- Deliverability - is there sufficient bed, theatre and critical care capacity in the right place to enable the moves to take place?
- Deliverability - are the developments possible within the same timescale required to move neurosurgery to RSCH?
- Deliverability – will key clinical adjacencies and other co-located services be achieved without compromising other clinical services?
- Quality - are the moves and developments supported by clinicians?
- Quality – will the service models comply with any relevant national service specifications published by NHS England?
- Quality – what will be the impact on staff and patients?
- Value for money - what level of capital and revenue investment is required to enable the developments to proceed?

Development of the following service models has therefore been undertaken with the relevant clinical leads. Extensive demand and capacity modelling has been undertaken, using new referral demand for elective activity and current emergency demand, alongside service specific conversion rates and operating times, to ensure that each service has a sustainable model going forward.

4. Proposals

Urology service

The urology service is currently split across two sites, with outpatient and inpatient activity provided at the Royal Sussex County Hospital and the Princess Royal Hospital sites. Outpatient clinics and day case surgery are also provided at Lewes Victoria Hospital. Outpatient one stop diagnostic clinics for haematuria and lower urinary tract symptoms are provided at both PRH and RSCH sites.

It is proposed to move the inpatient urology service off the RSCH site and establish a single site service at PRH. This will include establishing a urology ward of 18 inpatient beds on Ansty ward with 12.5 operating lists in main PRH theatres. Additional critical care capacity (an extra four HDU beds) is being created by expansion into Cuckfield at PRH in part for the additional urology patient activity.

A daily outpatient session will also be held Monday to Friday at RSCH and outpatients will continue to be seen at RSCH. In 2012/13 a total of 361 patients out of 3678 from the Brighton & Hove catchment area had an in-patient procedure at RSCH which in future will be undertaken at PRH; this cohort represents 10% of all urology patients. Therefore, as it is only the inpatient aspect of the pathway that is changing and outpatients and follow-ups will continue to be undertaken at RSCH, the number of patients affected will be relatively small.

Additional bed, theatre and critical care capacity will be also required (and has been quantified) for new urology cancer work if BSUH is successful in bidding for this activity; this is part of a Sussex wide discussion led by the Area Team.

A new centralised service model for urology on the PRH campus will:

- release capacity on the RSCH site
- co-locate RSCH urology services with existing services at PRH, i.e. the lithotripter and stone service
- enable greater efficiency of workforce and increased consultant presence. This has been shown to improve quality of care and patient safety at a time of increasing activity and complexity of work
- provide a consultant led department with 2 ward rounds per day, which should result in bed savings and increased safety
- provide capacity for service expansion and strengthen our bid for the Sussex Urology Cancer and Stone centre, providing a centre of excellence.

Fractured neck of femur service

Currently patients with a suspected neck of femur are admitted through the emergency department at RSCH where they have their surgery prior to a transfer to PRH for their rehabilitation; Brighton and Hove patients remain at RSCH for their rehabilitation stay.

The trauma service has been working to deliver a more stream lined pathway, to improve patient outcomes and prevent unneccesary delays for patients. This proposed pathway involves, in partnership with SECAMB, diagnosis in the ambulance, fast tracking through the Emergency Department with transfer straight to x-ray, where the fracture neck of femur is confirmed and then admitted directly to the orthopaedic ward. Patients will receive prompt investigation and rapid treatment of co-morbidities, optimising them for surgery. Anaesthetic protocols and pre-operative analgesia are optimised including the use of regional anaesthesia in the emergency department and operating theatre. The patient would then remain on the orthopaedic ward for the rehabilitation stage of their pathway, managed by the multi disciplinary team; this programme is referred to as the enhanced recovery project for hip fractures. This pathway would remove the need for patients to be transferred from RSCH to PRH for their rehabilition stay.

The hospital receives approximately 570 fractured neck of femur patients per annum of which 228 patients (40%, mostly from the Brighton & Hove catchment area) do not currently go to PRH and would therefore be affected by this pathway change.

One marker of the quality of care that patients receive is the total length of NHS care following fractured neck of femur. This varies considerably from trust to trust, with the average length of superspell ranging from 17 to 40 days. In the past year, one third of trusts have seen a rise in the superspell of patients with fractured neck of femur of between one and nine days. Treating fracture neck of femur patients in a dedicated unit such as Princess Royal Hospital improves the overall level of care they receive and nationally has been shown to reduce length of stay by up to eight days. BSUH has made recent improvements in length of stay and will continue to work on further improvements.

Fractured neck of femur patients will be cared for on Twineham ward with one theatre staffed Monday to Friday running until 7pm to manage the fluctuations in demand with half-day lists running on the week-end; this is with the move to seven day a week hospital services and consistent medical cover.

5. Timetable

It is planned to move the neurosurgery service to the RSCH by October 2014 when the necessary capital works to create the necessary clinical infrastructure, including neurosurgery theatres and bi planer angiography at RSCH and the expansion of critical care facilities at PRH, have been completed. Detailed plans, including business continuity plans, are currently being developed for the move of the fractured neck of femur pathway and urology service which will move to PRH at the same time as the neurosurgery service moves to RSCH.

6. Public Consultation on Neurosciences

Extensive consultation has already been undertaken on the move of neurosurgery to RSCH as part of the 3Ts consultation exercise. This has been undertaken with patients/patient representatives, partner organisations and members of the public across the Trust's local and regional catchments, and with local residents, statutory consultees and other community and special interest groups. Between 1996 and 2003 three independent reviews were undertaken into the configuration of neurosciences in Sussex; the *Review of Neurosciences Services in Sussex* (1996), commissioned by the then Sussex Health Authorities; a peer review (2001); and a further *Review Of Neurosciences Services in Sussex* (2003) commissioned by Kent, Surrey and Sussex Commissioning Group. The recommendations of the review were encompassed in the *Best Care, Best Place* consultation (2004/5) undertaken by Mid Sussex PCT.

The recommendation that the Regional Centre transfer to the Royal Sussex County Hospital (RSCH) campus was reflected in the *Fit For The Future* consultation (2007/8) undertaken by West Sussex and Brighton & Hove PCTs, which identified RSCH as the 'Critical Care Hospital' (to include neurosciences). It was also reflected in the *Sussex Tertiary Services Commissioning Strategy* (2008) which was prepared by an independent consultancy, 2020 Delivery, for the Sussex PCTs.

The case was further strengthened by the establishment in 2012 of RSCH as the Major Trauma Centre for Sussex which requires a co-located neurosurgery service. A review commissioned by the Trust in 2010 from Society of British Neurological Surgeons (SBNS) into the interim configuration of neurosurgery noted that the planned transfer was " a golden opportunity to expand and secure the neurosciences in modern facilities alongside other specialised services and the Major Trauma Centre.

In addition as part of the planning for 3Ts, extensive consultation and engagement has been undertaken with patients/patient representatives, partner organisations and members of the public across the Trust's local and regional catchments, and with local residents, statutory consultees and other community and special interest groups. This is detailed in the *Consultation Statement** (September 2011) submitted as part of the Trust's application for Full Planning Consent. Full Planning Consent was unanimously awarded by Brighton & Hove City Council in January 2012. No objections were received relating to the plan to transfer the Regional Centre for Neurosciences from Haywards Heath onto the Royal Sussex County Hospital campus.

7. Public Consultation on urology and fractured neck of femur services

A local assessment has been undertaken on whether the proposed moves of urology and trauma and orthopaedics from RSCH to PRH constitute "substantial and significant change" for patients in terms of access.

An analysis shows that:

- 361 patients from the Brighton and Hove catchment area will be affected by the proposed urology move; the total number of elective and day case urology patients in 2012/13 was 3678

- 228 patients from the Brighton and Hove catchment area will be affected by the proposed fractured neck of femur pathway change; the total number of fractured neck of femur patients treated in 2012/13 was approximately 570

- Legal advice has also been taken on whether public consultation is required on the proposed service moves; due to the low number of inpatients affected we do not believe there is a need to undertake a full public consultation exercise. However we want to ensure we are being clear about plans with commissioners and local authorities as well as having a meaningful engagement with service users and patient experience groups. Plans for this are well developed and will be shared in April 2014.

The proposed changes to the fractured neck of femur pathway and urology moves have recently been introduced to Brighton & Hove HOSC, West Sussex HASC and to Brighton and Hove CCG.

8. Public Sector Equality Duty

A public sector equality duty analysis on the impact of the changes has been undertaken on the proposed urology service move and will be undertaken on the fractured neck of femur pathway change. This analyses the effect or potential effect of the site reconfiguration programme on different groups, including patients and staff, who are covered by the protected characteristics described in the Equality Act 2010.

The impact of the service change may be perceived as negative as it is associated with further travel for new patients. In order to mitigate this impact patients and carers need to be advised of the availability of the 40X bus service which is available free of charge for people needing to access either site. Carers and family may require additional support to work out the best transport methods to PRH.

9. Next Steps

Detailed plans are being developed to enable the proposed service moves to take place by October 2014 and the trust will continue to have discussions with all stakeholders including local authorities, local commissioners and patients and their representative groups to confirm the position.

Simon Maurice
Programme Director for Major Trauma
March 2014

HEALTH & WELLBEING OVERVIEW & SCRUTINY COMMITTEE	Agenda Item 119 Brighton & Hove City Council

Subject:		**Sussex Community Trust's Estates Strategy**		
Date of Meeting:		**22 April 2014**		
Report of:		**Monitoring Officer**		
Contact Officer:	**Name:**	**Kath Vlcek**	**Tel:**	**29-0450**
	Email:	**Kath.vlcek@brighton-hove.gov.uk**		
Ward(s) affected:		**All**		

FOR GENERAL RELEASE

1. PURPOSE OF REPORT AND POLICY CONTEXT

1.1 Sussex Community Trust is the main provider of community healthcare in Sussex. They provide the majority of services in people's own homes but also use clinical settings including special dental care at Morley Street and Conway Court, contraception & sexual health services at Morley Street, and children's services at Brighton General Hospital (BGH) and children's centres across the city.

This report gives HWOSC members an overview of how Sussex Community Trust's clinical care strategy and service development plans will impact most directly on service users due to service relocation.

2. RECOMMENDATIONS:

2.1 To note and comment on the strategy.

3. CONTEXT/ BACKGROUND INFORMATION

3.1 Sussex Community Trust's clinical care strategy maps out their commitment to deliver excellent care at the heart of the community; the service development plans are shaped by four main transformational themes:

- **Adult integrated care and support**, for example via co-located, multi-disciplinary teams using risk stratification to wrap care around the patient in their own home.
- **Children and families integrated care and support**, for example by leading the implementation of the Healthy Child Programme.
- **Specialist community care**, for example though our specialist nursing & therapy teams caring for people with long term conditions & complex needs.
- **Organisational design**, for example via our infrastructure strategies – estates, information and technology, human resources and workforce.

3.2 SCT delivers children's services in partnership with Brighton & Hove City Council; staff are seconded into the council and managed as part of an integrated service which includes children's centres and the child development & disability service. Staff are co-located in both council and SCT buildings.

Service development plans

3.3 The vast majority of care is delivered in patients' own homes, and most of the organisational design changes do not directly affect service user access.

3.4 SCT is reviewing its accommodation across the city to ensure it supports service development plans, and is investing to improve the working environment and enhance the delivery of patient care. They have co-located community based staff in community hubs, improved the quality of clinical accommodation; maximised the efficiency of those properties and encouraged flexible working.

3.5 The main hub is at **Brighton General Hospital** (BGH) which is also the SCT HQ. A number of services are co-located there, for example children's services from Morley Street. Further co-locations onto BGH are being implemented for our adult services integrated primary care teams from Hazel Cottage in Woodingdean and from Moulsecoomb and Wellsbourne health centres. Patients do not access these services at the locations: these are staff bases only.

Morley Street will be developed as a mini-hub. A key element is the development of centre of excellence for special care dentistry. SCT will relocate community specialist HIV team there as well.

SCT will continue to invest in other health centres e.g. Moulsecoomb and Portslade, and make use of other accommodation via a lease where appropriate

3.6 Some of the development plans will affect the ways service users access care. Two locations are directly affected in current plans: Hazel Cottage, Woodingdean and Conway Court, Hove.

The Deans children's centre team will move from Hazel Cottage to Roundabout children's centre in Whitehawk in April 2014. This will support joint working and provide better staff cover. SCT has clarified that the Deans children's centre team will continue to deliver the same level of service to families across the Deans community. The speech and language therapy (SLT) clinic at Hazel Cottage will move to General Hospital; this will increase availability of appointments.

3.7 SCT is planning to relocate special care dentistry from Conway Court in Hove to Morley Street to develop a centre of excellence at Morley Street. Members of HWOSC considered SCT's decision to relocate special care dentistry from Moulsecoomb health centre to Morley Street at the last HWOSC..

4. COMMUNITY ENGAGEMENT & CONSULTATION

4.1 SCT has confirmed that it will consult with patients and other stakeholders in due course.

5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

None to this cover report

Legal Implications:

None to this cover report.

Equalities Implications:

None to this cover report.

Sustainability Implications:

None to this cover report.

SUPPORTING DOCUMENTATION

Appendices:

1. Sussex Community Trust , ‘Our Service Development Plans’

Sussex Community NHS
NHS Trust

OUR SERVICE DEVELOPMENT PLANS IN BRIGHTON & HOVE

BRIEFING FOR THE BRIGHTON & HOVE HWOSC, MARCH 2014

Introduction: excellent care at the heart of the community

As the main provider of community healthcare we provide the majority of our health and care services to our patients young and old in their own homes.

However, we also provide care to patients in clinical settings and other locations, including special dental care at Morley Street and Conway Court, contraception & sexual health services at Morley Street, and children's services at Brighton General Hospital (BGH) and children's centres across the city.

This short briefing is designed to give the Brighton & Hove HWOSC an overview of how the organisational design elements of our clinical care strategy and service development plans will impact most directly on our service users in the near future via a number of service relocations.

Our clinical care strategy

Our clinical care strategy maps out our commitment to deliver excellent care at the heart of the community, and our service development plans are shaped by four main transformational themes:

- **Adult integrated care and support**, for example via co-located, multi-disciplinary teams using risk stratification to wrap care around the patient in their own home.
- **Children and families integrated care and support**, for example by leading the implementation of the Healthy Child Programme.
- **Specialist community care**, for example though our specialist nursing & therapy teams caring for people with long term conditions & complex needs.
- **Organisational design**, for example via our infrastructure strategies – estates, information and technology, human resources and workforce.

We deliver children's services in partnership with Brighton & Hove City Council. Our staff are seconded into the council and managed as part of an integrated service which includes children's centres and the child development & disability service. Staff are co-located in both council and SCT buildings.

Service development plans

Again, we must emphasise that the vast majority of our care is delivered in our patients' own homes, and that most of our organisational design changes do not directly affect service user access - though they will enhance our capacity to continually improve the quality of care we deliver.

Getting the best from our accommodation

We are reviewing our accommodation across the city to ensure it more effectively supports our service development plans, and investing to improve the working environment and enhance the delivery of patient care. Our way forward is via a "**Hub and Spoke**" model. This includes:

- Co-locating community based staff in community hubs (hub or spoke).
- Improving the quality of our clinical accommodation for all users.
- Maximising the efficiency and usage of those properties.
- Encouraging more agile and flexible working.

Brighton General Hospital

Our main hub in the city is Brighton General Hospital (BGH) which is also the SCT HQ. We have invested considerably to improve this iconic location, and brought together a number of services, for example children's services from Morley Street.

Further co-locations onto BGH are being implemented for our adult services integrated primary care teams from Hazel Cottage in Woodingdean and from Moulsecoomb and Wellsbourne health centres. Again, it must be stressed that patients do not access these services at the locations: these are staff bases only.

Morley Street

We will develop Morley Street as a thriving mini-hub. We continue to improve the patient environment having already refurbished the main reception. A key element is the development of centre of excellence for special care dentistry involving the expansion of the existing dental clinic from five to seven surgeries.

As the lease has expired at The Old Market, Hove, we will relocate our community specialist HIV team to newly refurbished accommodation at Morley Street.

Other locations

We will continue to invest in other health centres e.g. Moulsecoomb and Portslade, and make use of other accommodation via a lease where appropriate e.g. Hove polyclinic which is owned by Sussex Partnership NHS Foundation NHS Trust.

Forthcoming changes that will directly affect patients and service users

Some of our development plans will affect the ways service users access our care. Two locations are directly affected in current plans: Hazel Cottage, Woddingdean and Conway Court, Hove.

The ***Deans children's centre team*** will move from Hazel Cottage to Roundabout children's centre in Whitehawk in April 2014. Consolidating our teams within the larger centre will support joint working and provide better cover during annual leave, training and sickness.

Members of HWSOC are asked to note that the Deans children's centre team will continue to deliver the same level of service to families across the Deans community. Groups and clinics will continue at the Deans children's centre at Rudyard Kipling school, Boomerang nursery in Saltdean, St Margaret's Cottage, Rottingdean and Rottingdean Library.

We intend to provide health visitor clinics at the new Woodingdean development which will include both a library and a GP surgery, due to open soon.

The ***speech and language therapy (SLT) clinic*** at Hazel Cottage will move to our children & families clinic at Brighton General Hospital - a distance of 1.6 miles. The current service runs two days a week and has a caseload of approximately 50 preschool children who live in Woodingdean, Rottingdean and West Saltdean. Benefits include: a greater choice of appointments over five days, refurbished accommodation, easier access to information and co-location with other specialist children's services. We plan to move the service in the summer term following engagement with parents of children on the caseload.

We are also developing plans to relocate ***special care dentistry from Conway Court in Hove to Morley Street.*** This plan reflects our investment to develop a centre of excellence for our special care dental service at Morley Street. Members of HSWOC may recall recent consideration of our decision to relocate special care dentistry from Moulsecoomb health centre to this new centre of excellence.

We will carry out a full quality impact assessment of the proposal and engage with patients and other stakeholders.

Nick Fairclough
SCT head of marketing & communications
Friday, 21 March 2014

HEALTH & WELLBEING OVERVIEW & SCRUTINY COMMITTEE	Agenda Item 121 Brighton & Hove City Council

Subject:		**Services for Children with Autism Scrutiny Panel Report**		
Date of Meeting:		**22 April 2014**		
Report of:		**The Monitoring Officer**		
Contact Officer:	**Name:**	**Julia Riches**	**Tel:**	**29-0451**
	Email:	**Julia.riches@brighton-hove.gov.uk**		
Ward(s) affected:		**All**		

FOR GENERAL RELEASE

1. PURPOSE OF REPORT AND POLICY CONTEXT

1.1 In December 2012, HWOSC agreed to establish a scrutiny panel to look at services for children with autism in the city. The panel was chaired by Councillor Rob Jarrett, and also included Councillor Anne Pissaridou, Councillor Andrew Wealls and Rosie Moore, Senior Lecturer in the School of Education at the University of Brighton, lead on inclusion and special educational need (co-opted member).

1.2 The scrutiny panel report is attached as **Appendix 1** to this report.

2. RECOMMENDATIONS:

2.1 That HWOSC endorse the scrutiny panel report on services for children with autism (**Appendix 1**) and refer it on for consideration by the appropriate policy committee(s).

3. CONTEXT/ BACKGROUND INFORMATION

3.1 The Panel set out to examine services for children with autism in the city across the board. Services and strategies in this area are evolving, both locally and nationally, and this report should be seen in this light. The Panel was very keen to avoid duplication but to add another dimension to the discussions.

3.2 The Panel held a capacity building meeting on 9 July 2013 to hear from service providers on how the pathways for assessment, diagnosis and support should work. They heard from parents and support groups on 17 and 19 September 2013 – both in public and private. They held three further meetings on 15 October 2013, 6 November 2013 and 19 November 2013 to hear from service providers and schools. They also attended two SENCO Forums on 30 January 2014 and 3 February 2014.

3.3 The Panel’s report sets out key areas of concern and makes a number of recommendations for action around home support, available information, pathways to diagnosis, training and awareness.

4 COMMUNITY ENGAGEMENT & CONSULTATION

4.1 The Panel heard from the support groups in the city and from a number of parents, both in meetings and by email. No formal consultation process was undertaken by the Panel. A number of related consultations were ongoing during the Panel’s inquiry.

5. CONCLUSION

5.1 In line with normal procedure, we are asking that the HWOSC endorses this report and refers it on to the appropriate BHCC Policy Committee(s) for consideration.

6. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

The financial implications of the recommendations from the scrutiny panel will be assessed in the context of the Council’s budget strategy when the recommendations are considered by the policy committees.

Finance Officer Consulted: Anne Silley Date:

Legal Implications:

6.1 Once HWOSC has agreed its recommendations based on the work of the scrutiny panel, it must prepare a formal report and submit it to the council’s Chief Executive for consideration at the relevant decision-making body.

Lawyer Consulted: Oliver Dixon Date: 11 April 2014

Equalities Implications:

6.2 The impact on a family of having a child with autism can be huge. The number of children diagnosed with autism is rising and it is important that services are well positioned to help these families.

Sustainability Implications:

6.3 None identified in this covering report.

SUPPORTING DOCUMENTATION

Appendices:

1. Services for Children with Autism Scrutiny Panel Report

Documents in Members' Rooms

None

Background Documents

Services for Children with Autism Scrutiny Panel report Volume 2 contains the minutes and presentations from the Panel meetings.

Brighton & Hove
City Council

Services for Children with Autism Scrutiny Panel report

April 2014

Contents

Chair's Foreword

Councillor Rob Jarrett, Chair of the Scrutiny Panel

The Scrutiny Panel was set up to examine services for children with autism in the city. [1] Services and strategies are evolving and the Panel hoped to add another dimension to the discussions underway.

During their inquiry, the Panel heard a number of harrowing stories from people who have children with autism who felt they had been failed by the very services supposed to help them, children who had not received a timely diagnosis or support and who had struggled through school. For these families, the experiences they have had must not be underestimated - or replicated.

However, it must be acknowledged that some of these stories have a historical context and things are changing rapidly, both nationally and locally. Nationally, the Children and Families Bill has been going through Parliament and is due to gain Royal Assent in March 2014. Part 3 of the Bill makes new provision for identifying children and young people with special educational needs (SEN), assessing their needs and making provision for them. As part of this, every local authority will be required to publish (in one place) information about provision they expect to be available in their area for children and young people with SEN.

This is known as the 'Local Offer' and Brighton & Hove City Council is part of the SE7 Pathfinder developing it.[2] The Local Offer should be more than a directory of existing services and the process of developing the Local Offer is intended to help local authorities and their partners to improve provision. The Panel trust that when the Local Offer is in place it will help to address some of the issues raised in this report, and provide a further opportunity for parents' voices to be heard.

In addition, an autism steering group has been set up in the city; a draft plan for children with autism is out for consultation; and steps are underway to join-up the mandatory Adults with Autism Strategy with the draft plan for children with autism.

As this report was being finalised, the Health Select Committee in the House of Commons announced an inquiry into children's and adolescent mental

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[1] In this report the term autism is used as an umbrella term for autistic spectrum conditions. The term parent is used for parent/carers.

[2] In 2011 the Government invited bids from local authorities to become Pathfinders to trial potential reforms arising out of the Green Paper on special educational needs and disability. Brighton & Hove put in a bid with six neighbouring local authorities and four PCT clusters, collectively known as the South East 7.

health services.[3] The Panel welcome this investigation and recommend that the pertinent parts of this report are sent to the Select Committee.[4]

Despite the work underway, the Panel's evidence shows there are still areas where more needs to be done as a matter of some urgency. This report makes recommendations for action across a range of areas including training, dissemination of information, governing bodies, home support and performance monitoring.

In should be noted that, in addition to the public evidence-gathering meetings, the Panel received a substantial amount of evidence in confidence. It is inappropriate to disclose the content of this information, but it formed an important part of the whole evidence-base for this report. The Panel would like to thank all those who had the strength and bravery to share their personal experiences with the Panel. The Panel trusts that the recommendations from this inquiry will go some way to ensuring things improve for families of children with autism in the city.

One key message that the Panel have taken away from their inquiry – and hope others will too - is that autism comes with a very complex set of issues and a generic response is not applicable. As a city we need to consider, within our fiscal constraints, how we can best offer as near to a bespoke service as possible for each young person with autism and their families. It is only with this support that children and young people with autism can fulfil their potential.

Rob Jarrett

Councillor Rob Jarrett
Chair of the Scrutiny Panel

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[3] The inquiry is looking both at children and adolescent health services and CAMHS.
[4] http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2010/cmh-2014/

Executive Summary

The Panel set out to examine services for children with autism in the city. Services and strategies in this area are evolving and the Panel was very keen to avoid duplication and to add another dimension to the discussions. Part of the Panel's role was facilitating a dialogue between parents and service providers and providing a vehicle for people to discuss any issues they may have, rather than responding to specific consultations. (The term autism is used throughout this report to refer to autistic spectrum conditions, and the term parent to refer to parent/carers.)

This report sets out key areas of concern and makes a number of recommendations for action around home support, available information, pathways to diagnosis, training, and awareness.

- The Panel recommends that key workers are embedded into Seaside View Child Development Centre and the Child and Adolescent Mental Health Service (CAMHS).

- The Panel was concerned about the monitoring of existing services for children with autism and the apparent paucity of performance indicators. The Panel recommends that steps are taken to ensure that robust and publicly accessible monitoring procedures are put in place alongside a comprehensive feedback system for parents of children with autism.

- The lack of home support for families with children with autism was highlighted to the Panel as a glaring omission. The Panel believe that the area of providing home support needs to be addressed as a matter of some urgency.

- In addition, the Panel recommends that an 'Autism Champion' should be appointed both to ensure that the myriad of strategies and initiatives underway dovetail - rather than duplicate - and to take forward the recommendations from this Panel.

- The Panel heard a lot of praise for the support and training supplied by the Autistic Spectrum Condition School Service (ASCSS). Whilst acknowledging the climate of fiscal constraints, the Panel feels that consideration needs to be given to providing more resourcing to the ASCSS to enable it to provide further support and training, particularly in these changing times. They were delighted to learn that the local authority is taking forward an 'Autism Aware' award for schools in the city.

A full list of the Panel's recommendations can be found at the end of this report (see p50).

Glossary

Clinical Commissioning Group (CCG) – a consortium of GPs with responsibility for the commissioning of local health services.

Common Assessment Framework (CAF) "The CAF is a four-step process whereby practitioners can identify a child's or young person's needs early, assess those needs holistically, deliver coordinated services and review progress."[5]

Child and Adolescent Mental Health services (CAMHS) - is an umbrella term for all levels of support provided to children and young people within a continuum of issues ranging from promotion of emotional wellbeing, support at times of emotional distress through to working with those with a mental health difficulty or disorder. The levels of support are defined as Tiers and there are four Tiers.

Detailed information on the different Tiers is supplied in Volume 2 of this report. Throughout this inquiry the term CAMHS was used by those talking to the Panel, but Tier 3 was the most relevant. Tier 3 was described as: "*This is usually a multi-disciplinary team or service working in a community mental health clinic or child psychiatry outpatient service, providing a specialised service for children and young people with more severe, complex and persistent disorders. Team members are likely to include child and adolescent psychiatrists, social workers, clinical psychologists, community psychiatric nurses, child psychotherapists, occupational therapists, art, music and drama therapists."*

Equality Act 2010

From 1 October 2010, the Equality Act replaced most of the Disability Discrimination Act and introduced the Public Sector Equality Duty which brings together the Disability Equality Duty with other existing duties. The Government Guidance on matters to be taken into account in determining questions relating to the definition of disability gives the example of a six year old child with autism who has difficulty communicating through speech and in recognising when someone is happy or sad. The Guidance states: " *this amounts to a substantial adverse effect on his ability to carry out normal day-to-day activities."*[6]

Local Offer

The draft Code of Practice for SEN (2013) describes the Local Offer: "*Local authorities must publish a local offer, setting out in one place information about provision they expect to be available for children and young people in their area who have SEN including those who do not have Education, Health and Care plans.*

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[5] http://webarchive.nationalarchives.gov.uk/20130903161352/http://www.education.gov.uk/childrenandyoungpeople/strategy/integratedworking/caf/a0068957/the-caf-process

[6] http://www.legislation.gov.uk/ukpga/2010/15/contents

The local offer has two key purposes
- To provide clear, comprehensive and accessible information about the provision available; and
- To make provision more responsive to local needs and aspirations by directly involving children and young people with SEN, parents and carers, and service providers in its development and review."

SEN – definition of special educational needs
"*A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for them. A child of compulsory school age or a young person has a learning difficulty or disability if they (a) have a significantly greater difficulty in learning than the majority of others of the same age; or (b) have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.*" (*Draft Special Educational Needs (SEN) Code of Practice: for 0 to 25 years.* October 2013).[7]

SENCO – Special Educational Needs Co-ordinator. Governing Bodies must ensure that there is a qualified teacher designated as the SENCO for the school. The SENCO has day-to-day responsibility for the operation of SEN policy and coordination of specific provision made to support individual children with SEN. (*Draft Special Educational Needs (SEN) Code of Practice: for 0 to 25 years.* October 2013)

SE7 Pathfinder
In 2011 the Government invited bids from local authorities to become Pathfinders to trial potential reforms arising out of the Green Paper on special educational needs and disability. Brighton & Hove put in a bid with six neighbouring local authorities and four PCT clusters, collectively known as the South East 7 (SE7) consortium. The SE7 is the only consortium and is one of 20 areas in England piloting Pathfinders. The SE7 local authority members are: Brighton & Hove, East Sussex, Hampshire, Kent, Medway, Surrey and West Sussex.[8]

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[7] https://www.gov.uk/government/consultations/special-educational-needs-sen-code-of-practice-and-regulations
[8] Brighton & Hove Special Educational Needs & Disability (SEND) Pathfinder, May 2012 http://www.se7pathfinder.co.uk/

1. Background to the Panel

About this Panel

1.1 A member of the public raised concerns about the assessment and management of children and young people with autism in September 2011. This led to a report that was considered by the Children and Young People's Overview and Scrutiny Committee (CYPOSC).[9] The Committee requested that a user satisfaction survey be carried out by the relevant services.[10] In December 2012, the Health and Wellbeing Overview and Scrutiny Committee (HWOSC) received the report back from the user satisfaction survey. At that point, only 10 surveys had been completed and returned. As a consequence, the decision was taken to set up a Scrutiny Panel looking at services for children with autism.

1.2 The Panel comprised Councillor Rob Jarrett (Chair), Councillor Anne Pissaridou, Councillor Andrew Wealls and Rosie Moore, Senior Lecturer in the School of Education at the University of Brighton, lead on inclusion and special educational need (co-opted member).

The Panel set its terms of reference as:

> "*To consider what services are currently in place to help children with autism and their families including: issues around diagnosis, health, education, social care, and home support; to look at areas of best practice; and to make recommendations for action*."

1.3 The Panel held a capacity building meeting on 9 July 2013 to hear from service providers on how the pathways for assessment, diagnosis and support should work. They heard from parents and support groups on 17 and 19 September 2013 – both in public and private. They held three more meetings on 15 October 2013, 6 November 2013 and 19 November 2013 to hear from service providers and schools. For further information see part 2 of this report.[11]

1.4 The Panel tried to talk to as many people as possible and heard from around 20 parents in meetings and received around 15 emails. The Panel is very aware that those who contacted the Panel were self-selecting. People who are happy with the services they receive tend not to contact support groups. Whilst in no way wishing to downplay the experiences relayed to the Panel, neither do the Panel wish to paint an entirely black picture. It must also be noted that some of the terrible experiences are in past years, rather than in recent months.

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[9] CYPOSC no longer exists

[10] 14 September 2011 CYPOSC

[11] Volume 2 of this report contains the minutes and witness lists.

What is autism (or autistic spectrum condition)?

1.5 Autism can be defined as:

> "*a lifelong developmental disability that affects how a person communicates with, and relates to, other people and the world around them. Autism affects 1 in 100 people. It is a spectrum condition, which means that, although people with autism share certain difficulties, their condition affects them in different ways.*"[12]

1.6 It is important to emphasis the spectrum of autism: one witness told the Panel "*when you have met one autistic person, you have met one autistic person*".[13]

National Institute for Care and Excellence in Health (NICE) guidance states:

> "*The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact. In addition to these features, children and young people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, including: a need for routine; difficulty in understanding other people, including their intentions, feelings and perspectives; sleeping and eating disturbances; and mental health problems such as anxiety, depression, problems with attention, self-injurious behaviour and other challenging, sometimes aggressive behaviour.* ***These features may substantially impact on the quality of life of the individual, and their family or carer, and lead to social vulnerability.***"[14]

1.7 The Panel heard that the number of people diagnosed with autism has risen significantly over the last few years – it is now around 1% of the population. In Brighton & Hove this would equate to around 2,730 people.[15] Often people with autism have high levels of additional needs with 70% of individuals with autism having at least one other mental or behavioural disorder and 40% having at least two disorders, mainly anxiety, Attention Deficit Hyperactivity Disorder (ADHD) and Oppositional Defiant Disorder (ODD).[16] The draft plan to support

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[12] Difference in Mind: Scrutinising Children and Adolescent Mental Health Services for Children with Autism – Centre for Public Scrutiny with the National Autistic Society

[13] 17 Sept 2013 minutes p3

[14] http://www.nice.org.uk/nicemedia/live/14257/64946/64946.pdf (**bold added**) National Institute for Care and Health Excellence (NICE)

[15] mASCot evidence – taken from ONS November 2011

[16] 9 July 2013 minutes (Dr Vicky Slonims)

children with autism suggests that there are around 550 children and young people in the city with a diagnosis of autism.[17]

1.8 Figures supplied by Brenda Davis, Lead Psychologist in the Child and Adolescent Mental Health Service (CAMHS), Brighton & Hove, show that rates of autism among siblings in a family where one child already has autism rises to around 5%. In addition, sometimes siblings may have language related difficulties or delays but not autism.[18]

1.9 The Compass database maintained by Amaze shows that out of 1,563 children and young people up to 19yrs old on the database, 440 have autism. The vast majority of these are male (356) and the ages are: under 5 (19), age 5-10yrs (136), age 11-16yrs (204) and over 16yrs (81).[19]

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[17] Meeting the needs of children and young people with autism in Brighton and Hove 2013-2017 '*Better outcomes, better lives*, A Plan to Support the SEN Partnership Strategy(draft 2)

[18] 9 July 2013 (presentation by Brenda Davis)

[19] Information supplied by Amaze. Amaze is a charity that offers information, advice, and support to parents and carers of children and young people with special needs or disabilities in Brighton & Hove The threshold for the Compass database is claiming DLA or having a SEN Statement.

2. Changing Times

2.1 This report must be seen within the context of a changing landscape, both nationally and locally. From the start of their inquiry, the Panel has been very clear that they do not wish to replicate existing work streams. It is important to see this report and its recommendations in a wider context.

Children and Families Bill (2013)[20]

2.2 The Children and Families Bill currently going through Parliament aims to make life better for children and young people with SEN. The existing system of Educational Statements, School Action and School Action Plus will be replaced by a single Education, Health and Care Plan (EHCP) that will remain in place until a young person is 25 years old (up from 18 years old at the moment). It is intended that this will create more effective ways of linking a young person's education needs with their health and social care needs. Families will also be able to access personal budgets so that they can have more control over the support they need.

2.3 The Panel heard that traditionally, education has tended to fall outside the care package: the new plans will provide a single package of support with all services working together. There will now be one single assessment process where all services will work together to create an individual package tailored to that person's needs.[21]

2.4 The Children and Families Bill also set up a number of 'Pathfinders'. Brighton & Hove City Council is part of the SE7 Pathfinder group. In addition, as part of the Bill, the Code of Practice for SEN is also being revised.[22]

2.5 Dr Vicky Slonims (Consultant Speech and Language Therapist, Honorary Senior Lecturer (Kings College London), Children's Neurosciences Centre, Newcomen Centre at St Thomas' Hospital, London) provided the Panel with background information on what is happening nationally in terms of autism. The National Institute for Care and Health Excellence (NICE) has produced clinical guidance on the management of autism in children and young people.[23] One of the recommendations concerning diagnosis is for the creation of a local autism strategy and a local management group. The aim of this is to

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[20] Royal Assent expected in March 2014

[21] 9 July 2013 minutes

[22] The final Code of Practice is expected in April 2014

[23] National Institute for Care and Health Excellence (NICE). "NICE guidance supports healthcare professionals and others to make sure that the care they provide is of the best possible quality and offers the best value for money."
http://www.nice.org.uk/Search.do?searchText=autism+in+children&newsearch=true&x=8&y=14

improve early recognition of autism and to ensure professionals are aware of the care pathways available.

2.6 In Brighton & Hove there has been a local autism strategy and management group for adults with autism for some time (the multi-agency autism stakeholder group).[24] A separate draft plan for children with autism has recently been developed and a working-group has been set up. As we discuss later in this report, it is imperative that these are closely aligned.

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[24] Adult Autism Strategy – Mark Hendriks. Evidence supplied 19 November 2013.

3. Existing Routes to Diagnosis and Support

3.1 Parents who feel their child may have autism and wish to get a diagnosis or assessment need to contact their GP or Health Visitor who will then refer the child for a formal assessment. In Brighton & Hove this is undertaken by Seaside View Child Development Centre for primary aged children (up to Year 6) and to the Child and Adolescent Mental Health Service (CAMHS) if they are older. The rationale behind this process is that for younger children, paediatricians are integral to the assessment to allow for the differential diagnosis of autism, as opposed to other developmental conditions. For older children, the more likely differential is deemed to be between a mental health condition and autism, so a psychiatrist is part of the assessing team.[25]

3.2 Alison Nuttall, Commissioner for Children and Adolescent Mental Health Service (CAMHS), explained to the Panel the complicated commissioning arrangements in the city. Children's community mental health services are commissioned from a range of CAMHS providers and a tiered structure operates.[26] The diagnostic pathways within Seaside View and CAMHS are part of the commissioned services. Tier 3 CAMHS is delivered by Sussex Partnership Foundation Trust (SPFT) as a part of their block contract to deliver mental health services across Sussex. Monitoring of the contract is at a CAMHS wide level with high level specific performance measures. Local commissioning is based on negotiation of agreements with specific localised but non-contractual performance indicators. **There is no dedicated commissioned arrangement for autism specific services.**

Seaside View Child Development Centre (Seaside View)

3.3 In Brighton & Hove the Seaside View assessment service works with children up to the end of primary school. Children have to be referred from a professional (for example, Health Visitor, GP, pre-school special educational needs service, Educational Psychologist) – they do not accept parental referrals. The process for assessment is two stage: a general developmental assessment at Stage 1 and a more detailed multi-disciplinary autism specific clinic at Stage 2. Between the two stages, there is an intensive information-gathering exercise from as many people as possible.[27]

3.4 The Stage 1 general development assessment will look at:

- standard paediatric and developmental history
- risk factors
- family history
- sight and hearing

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[25] Report to CYPOSC September 2011

[26] See Glossary and Volume 2 of this report for further information

[27] 9 July 2013 minutes (Dr Katharine Anderson, Consultant Community Paediatrician)

- and will include a direct developmental assessment of the child.

If the result of this assessment is that autism is likely or further assessment is required, the child is then referred on to the autism specific Stage 2 assessment. This second assessment will include:

- a paediatrician
- a specialist Speech and Language Therapist
- a clinical Psychologist (for children over 4 years old).

After this assessment the child will either have a confirmed diagnosis of autism or a confirmation that they do not have autism and a description of their needs. In some cases it is recognised that further information may be needed before a decision is made which may include observations over time.[28] Figures supplied to the Panel showed that an estimated 86 children were seen from July 2012 - July 2013 and around 64% of these received a diagnosis of autism. [29]

3.5 NICE guidance recommends an autism-specific key worker, yet there is not an autism key worker at Seaside View.[30] Dr Katharine Anderson, Consultant Community Paediatrician, Seaside View, told the Panel that it would be helpful if there was one person who can say:

> '*this person is struggling and needs to be signposted to different services*".[31]

3.6 Families told the Panel that they often found it difficult to know where to go after a diagnosis. (This report looks further at this issue later on.)

3.7 The Panel is aware that there is a Keyworking scheme in place in the city for those children with complex needs or multiple disabilities. However, there are only a small number of designated Keyworkers and they work with only the most complex children. Keyworkers provide information, co-ordinate multidisciplinary teams, are a key point of contact and often speak on behalf of families. [32]

3.8 The Panel heard that a new role in neuro-developmental psychology had been created within Seaside View. This person would work with children and young people who have complex needs but do not need to access specialist mental health services. It is important to note that this includes children with autism but is not specific to autism.[33]

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[28] Dr Katharine Anderson presentation 9 July 2013
[29] Dr Katharine Anderson presentation 9 July 2013
[30] 9 July 2013 minutes (Dr Katharine Anderson)
[31] 9 July 2013 minutes (Dr Katharine Anderson)
[32] http://amazebrighton.org.uk/wp-content/uploads/2013/03/3891_keyworker_schemeV3_Leaflet.pdf
[33] 6 November 2013 minutes

3.9 The Panel believes that there should be a Keyworker specifically for families of children with autism.[34] A number of the issues parents raised with the Panel may have been avoided if there had been a Keyworker available to help such families deal with the consequences of a diagnosis – or not – of autism.

RECOMMENDATION 1: The Panel recommend that both Seaside View and CAMHS should have a nominated Keyworker specifically to help parents and carers of children and young people with autism. This named person would be the first – and final – point of contact for people using the services of either Seaside View or CAMHS.

Child and Adolescent Mental Health Service (CAMHS) Tier 3

3.10 Tier 3 CAMHS offers assessment and diagnosis for children between 9 and 11 years old, whether they have mental health issues or not. (The Sussex-wide autism care pathway settled on cut off point at over 11 years old for children to access CAMHS but does leave it to individual teams as to the degree of flexibility around children between 9 and 11 years old.) The CAMHS assessment is also a two part process with a generic Stage 1 assessment and a multi-disciplinary Stage 2 assessment. Brenda Davis, Lead for Psychology in CAMHS, told the Panel that this is a time-consuming diagnostic assessment taking a whole morning. It should be noted that others who had less than positive stories about CAMHS stated that this did not reflect their experiences.

3.11 It is worth emphasising that, as the Commissioner for CAMHS explained:

> *"Children and young people with autism don't need or meet criteria for CAMHS **unless** they have a mental health issue."*[35]

3.12 All children, even if they come in with a specific request for a diagnosis of autism, will be screened in a diagnostic clinic prior to a Stage 1 assessment. The Lead Psychologist in CAMHS told the Panel that by secondary school age (11-12 years) CAMHS has become much better than it was at recognising autism as more children are getting diagnosed earlier. She explained that children aged 9-11 years who are coming to CAMHS are often the most complex children with lots of co-morbidity problems. The assessment must then determine whether autism is part of this co-morbidity.[36]

3.13 Figures show that between January and December 2012, there were 26 referrals, 23 of which were accepted and 10 who received a

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[34] See Recommendation 1

[35] 6 November 2013 minutes – additional information

[36] 9 July 2013 minutes (Brenda Davis)

diagnosis of autism. Between January and June 2013, the figures were 12 referrals, 8 accepted and 1 person diagnosed with autism.[37]

3.14 However, some parents felt strongly that one of the issues they faced was their children were not getting diagnosed at Tier 3 CAMHS. They felt they were being ‘batted away’ because they have some ‘traits’ of autism but other traits were masked or not easily visible. There was also a concern that anxiety – a key issue associated with autism – can adversely affect a child or young person’s mental well being, but not result in access to services.

3.15 This situation is not unique to Brighton & Hove. Dr Slonims told the Panel:

> “*Nationally we are not good at responding to need early so when a child is referred in mid childhood problems arise, for example, anxiety may be a core part of ASC but it may not meet the criteria for CAMHS referrals. We are not good at preventing acceleration*.”[38]

3.16 If a child or young person has learning difficulties ***and*** autism, they will be seen by the learning disabilities team in CAMHS. However, if autism is diagnosed but the child or young person does not have learning disabilities or mental health issues, there is a less clear pathway for accessing support and advice around behaviour. The Commissioner for CAMHS agreed with the Panel:

> “*We need to be clearer about the ASC offer and ensure families are clear about what is and isn’t available from who and why.*”[39]

RECOMMENDATION 2: A clear pathway needs to be created for children and young people who have autism but <u>neither learning disabilities nor mental health issues</u>. If there is no clear support in place, children and young people run the risk of returning to CAMHS and other services in crisis.

What services could be provided

3.17 The draft plan for children with autism aims to ensure that the right services are identified, commissioned and provided to meet current and further needs. The plan states:

> *“We want children and young people with autism to receive the right assessment and diagnosis as early as possible, to be able to access additional support if they need it and to know that they*

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[37] 9 July 2013 (Brenda Davis presentation)
[38] 9 July 2013 minutes
[39] 6 November 2013 minutes

> *can depend on professionals and agencies to treat them fairly as individuals."*[40]

3.18 The plan does not cover details of interventions for autism since this means different things to each individual child and their family. In an ideal world, different interventions would be available at different points in the child's life. Examples include: Post-diagnosis support, therapy interventions, counselling for parents, training programmes for families with an autistic child, access to educational psychology, support in the home, and support for challenging behaviour.

Key Issues raised with the Panel

3.19 It is worth reiterating that many parents who contact the support groups in the city are those who have not had positive experiences and are not getting the support they require. Those who are unhappy with services will normally contact support groups like Amaze. Amaze and mASCot, both acknowledged this. mASCot told the Panel that parents join mASCot for support and to contact other families in the same situation as them and to be guided in dealing with issues they are unhappy about.[41]

3.20 Assessment, diagnosis, and available support were all areas highlighted to the Panel by support groups and individuals and through information submitted in confidence.

3.21 The Panel heard from Amaze, a charity offering information, advice and support to parents and carers of children and young people with special needs or disabilities in Brighton & Hove. Figures provided to the Panel showed that Amaze responded to 1,262 calls from parents who had a child with autism. Amaze facilitated a number of parents to talk to the Panel for which the Panel are grateful. The Panel also heard from mASCot, a parent-led support group with more than 160 members who are parents of children with autism living in Brighton & Hove. They are currently the only support group solely for parents of children with autism. They carried out a survey in 2011 and again in late 2012 looking at diagnosis, education, associated difficulties, mental health, and well-being.[42] The key issues reported to the Panel that arose out of this survey were:

> "*Failure to provide timely, diverse, flexible services to meet the needs of ASC children; services provided frequently ineffective, counterproductive, harmful or reactive; families not included at the heart of the process and left without a voice; inconsistency in*

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[40] Meeting the needs of Children and Young People with Autism in Brighton and Hove 2013-2017 'Better outcomes, better lives'. A plan to support the SEN partnership strategy. Draft. P2

[41] 17 September 2013 minutes p4

[42] 17 September 2013 mASCot presentation

> *support provided even by the same service; and failure to proactively commission services*."[43]

3.22 mASCot told the Panel that some parents who spoke to them felt they had been 'blamed' for bad parenting.[44] They explained:

> "*It is important to state that some parents feel the focus is disproportionately placed on their parenting and some feel 'blamed' for their child's behaviour. A huge amount of damage is done by professionals blaming parents*."[45]

3.23 They also described very poor communication between professionals and families which leads to people having to repeat the same information over and over again. In addition, some parents report feeling 'threatened' if they flag up difficulties.[46]

3.24 A couple of people raised the issue of access to Occupational Therapy – both in terms of waiting lists and follow up.

3.25 The information given after a diagnosis was described as a 'factsheet' and people felt they were 'dismissed' from the service.[47] mASCot told the Panel that there was a long-standing issue over support after assessment.[48] In addition, there was very little support for common issues such as eating, sleeping, toileting, and behaviour. The point was made that early intervention was needed to prevent a 'tidal-wave' in a child as they get older. Amaze told the Panel that some parents come to them through their Helpline but most are referred from Tier 3 CAMHS and Seaside View who realise that they can't give emotional support post-diagnosis and so signpost people to Amaze.

3.26 A lack of support was a frequent theme: not only does there appear to be a lack of support post-diagnosis, there is also the issue that children who are not diagnosed with autism but who have 'traits' of autism are equally left adrift.

3.27 Jenny Brickell, Head of Integrated Child Development & Disability Service agreed with the Panel that "*post diagnosis support is an area of concern*". She explained:

> "*The gap is at the moderate end of the spectrum where there is a huge impact on people's lives. Within Seaside View all parents are offered a TimeOut course post-diagnosis but there is often a lack of concrete practical help for children and their families.*"[49]

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[43] 19 September 2013 minutes p2
[44] 17 Sept 2013 minutes p2
[45] 17 Sept 2013 minutes p6
[46] 17 Sept 2013 minutes p2
[47] 17 September 2013 minutes p2
[48] 17 Sept 2013 minutes p4
[49] 6 November 2013 minutes

3.28 One parent told the Panel that after their child was diagnosed at Seaside View:

> "..*there was nothing else forthcoming, it's as if they have the attitude 'oh well it's autism you can't change that so what's the point offering any further help'*."[50]

3.29 Another parent noted that: "*there is a black hole in terms of behavioural support when children are younger – particularly pre-diagnosis… there is a massive gap in the city in terms of behavioural support*."[51] A further parent said: "*parents are ending up with shoddy, sub-standard interventions. Professionals shouldn't blame families nor send families away because there are no resources to help*."[52] This family ended up going privately and now pay themselves for a range of professionals to support them. "*When you go privately you are treated as a partner in your child's care; in the NHS you feel as if you are being treated as the culprit*."

3.30 Parents and service providers both highlighted post-diagnostic support as an area of concern. There is a lack of support for families both in terms of strategies and advice, particularly at the higher functioning end of the spectrum. The Panel hopes that the 'Local Offer' will plug this gap.

Home support

3.31 The specific issue of support and advice for families in the home was highlighted to the Panel as a glaring omission. As mASCot put it:

> " …*there is no home advice - which is a gap in provision. There is nothing in place for when issues arise later*."[53]

3.32 Adrian Carver, Headteacher of Downs View School and Downs Link College, told the Panel about a pathfinder pilot with teachers working with families at home (see p.33). Outside of that pilot scheme, there is CAMHS, some support from the disability social work team, but no other specific home support. He went on to say:

> *"It is crucial that families who struggle to sustain their ability to cope are able to develop targeted systems in the home. Strategies need to function in the home at key pressure points such as bed times or meal times."*[54]

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[50] Email
[51] 19 Sept 2013 minutes p3
[52] 19 Sept 2013 minutes p1
[53] ref
[54] 6 November 2013 minutes

3.33 Suzanne Harmer, Assistant Head and SENCO of Cardinal Newman Catholic School agreed that there was scope for more support for families at home. For example, if a child is not sleeping then this impacts both on the family and on school work.[55]

3.34 Whilst acknowledging that this is a time of immense financial pressure, too many families in the city are struggling without support. Whether that support is someone at the end of the phone to talk to, or expert advice, or a set of clear signposts to help, there is a need for more to be done. It is not inconceivable that children and young people who are not being helped at home, whose families are not able to access support in moments of stress and crisis, will end up re-presenting to CAMHS or using residential respite care. Even if there was not a compelling argument around supporting families of children with autism, there is a financial incentive – preventative care and support is invariably cheaper than high-cost emergency care services.

3.35 The Commissioner for CAMHS told the Panel that there was "*potential for joining up resources to support behavioural issues for children with ASC at home and elsewhere where their needs are not appropriate for CAMHS.*"[56] The Panel welcomes this suggestion and would urge that consideration is given to how resources may be allocated. As part of this, the concept of 'home support' should be discussed with parents and support groups to plan out what may be most effective. The Panel would not presume to suggest what a home support package may include, but suggestions made to the Panel included a crisis helpline that families or young people can call at times of extreme pressure, or a person to contact and receive support from without a lengthy referral process.

RECOMMENDATION 3: The Panel recognises that a key gap in services provided is in the area of home support. The Panel strongly recommends that funding is reconfigured to include home support packages. Parents should be consulted over what they feel would be most beneficial and initiatives put in place to help parents access support at home.

3.36 The parents who told the Panel that their children were now coping well and living successful lives had often used their own money to create the 'bespoke' service that their child needed. One parent explained that they had devised their own respite with a team of carers but many parents don't have this choice.[57] mASCot reiterated that autism comes with a very complex set of issues and a bespoke response is needed for each child not a generic one.

3.37 One key message that the Panel have taken away from their inquiry – and hope others will too - is that autism comes with a

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[55] 19 November 2013 minutes

[56] Presentation 6 November 2013

[57] Mins 7 September p10

very complex set of issues and a generic response is not applicable. As a city we need to consider, within our fiscal constraints, how we can best offer as near to a bespoke service as possible for each individual with autism.

Central role for parents and families

3.38 The Panel strongly believes that parents and families must be central to the assessment, diagnosis and support services offered to children with autism. As parents repeatedly told the Panel, they often feel that they are sidelined in the process yet they are the experts when it comes to their children. As mASCOt pointed out, parents – empowered by training – could be an important asset in times of scarce resources. mASCot noted that they do accept that people are listening to them and they are involved in the autism strategy group. However, the Panel strongly believes that there is more to parent involvement than this. In their opinion, it is important that parent involvement is an integral part of the process.

RECOMMENDATION 4: Current service providers such as Seaside View and CAMHS need to examine the strategies they have in place to ensure parents are at the centre of their services. This should include looking at new ways of getting feedback from service users – particularly parents of children with autism – and reflecting this in their services. This feedback should be open and transparent and externally monitored. (See also Recommendation 5 on monitoring.)

Monitoring performance

3.39 The Commissioner for CAMHS explained that she manages the 'contracts' of CAMHS and Seaside View, not the people. It is a contractual arrangement that involves monitoring the targets that the services must meet. She explained that parents are involved in commissioning reviews, citing the example of the commissioning review on disability services that was done strategically with parents and others.[58] However, she also noted that "*user feedback needs to be embedded more in the commissioning arrangements.*"[59] She explained that this was difficult due to the size of the block contract.

3.40 The Key Performance Indicators for Tier 3 CAMHS are set at a remote level as the contracts are part of a much larger contract that the Sussex Partnership Foundation Trust (SPFT) delivers for mental health services across the whole of Sussex. The Commissioner for CAMHS explained that she meets with CAMHS Tier 2 and 3 together formally on a quarterly basis to look at performance:

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[58] 6 November 2013 minutes
[59] 6 November 2013 minutes

> *"..we discuss referral numbers and patterns, looked after children, A&E presentations with self harm, significant/complex complaints, serious untoward incidents, service pressures, areas of development, user feedback (both surveys and softer intelligence)."*[60]

3.41 Jenny Brickell, Head of Integrated Child Development & Disability Service, told the Panel that she meets with other managers to identify key performance measures and looks at what needs to be monitored across the multi-disciplinary pathway.[61]

3.42 As mentioned earlier in this report, Tier 3 CAMHS and Seaside View carried out a survey of those in the assessment pathways in response to a request for information from the Children and Young People's Overview and Scrutiny Committee. The survey was deemed statistically invalid due to the very small response rate. This Panel was set up as a result. mASCot then undertook a survey of their members to elicit responses to a number of questions. The key issues and concerns expressed in that survey were shared with the Panel.

3.43 The Panel is concerned that the postcard survey used by Tier 3 CAMHS seems to be a blunt instrument to monitor services. In addition, it was not autism specific. The Panel is of the view that if services are to be responsive to their clients, they need to understand the strengths and weaknesses of their provision. This requires effective monitoring and feedback processes. The Panel recommends that Seaside View and Tier 3 CAMHS should revisit the current way of gathering information by use of a postcard. As part of this, the Panel suggests that the service providers should look explicitly at the services provided to families of children with autism and include parents in the creation of new monitoring and feedback processes.

3.44 It must be noted that the Panel heard some stories and "appalling experiences" of people using CAMHS that go back over the years. The Panel does not have the information to judge CAMHS historically – or make a valid statistical judgement now. However, it is imperative that this information is available. The Panel is not clear about the quality of the data held by CAMHS, given the paucity of survey responses and the reliance on the postcard surveys. It is not enough to say things are better now – there must be a robust and publicly accessible evaluation of the quality of services for children with autism.

RECOMMENDATION 5: Monitoring is crucial. CAMHS and Seaside View must have robust and publicly available monitoring procedures. Working with parents and children, CAMHS and Seaside View need to review their monitoring procedures and put

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[60] 6 November 2013 minutes

[61] 6 November 2013 minutes

in place a transparent, comprehensive feedback system for parents of children with autism.

3.45 The Panel recognises that CAMHS locally is to some degree a reflection of a national infrastructure. However, the Panel felt unclear about the ‘ownership’ of CAMHS. The Panel would request further clarity over where the ultimate responsibility locally lies for any systemic problems. Despite the fact that the service is commissioned as part of a large mental health contract, there must be a clear and publicly available statement of who the service is accountable to and how performance is monitored and assessed. Indeed, the argument can be made that there is a greater need for clear local accountability in instances where services are commissioned via big sub-regional block contracts. The Panel were told that anything over and above the agreed key performance indicators is negotiated and delivered locally but there is no contractual obligation on Tier 3 CAMHS to deliver data and information. This raises an important issue around more effective user feedback and data collection around autism diagnosis and treatment in all Tiers of CAMHS.

RECOMMENDATION 6: The Panel recommends that there is a clear and unambiguous statement of where the responsibility lies for the performance of all tiers of CAMHS and the systems in place for addressing any problem areas. In addition, the Director of Children’s Services, after consultation with the CCG who are ultimately accountable for Tier 3 CAMHS, must work to ensure that an Annual Report is produced detailing performance against a clear and relevant set of indicators. Parents and young people should be actively involved in determining key performance indicators and contributing to the assessment and monitoring against them.

Assessments

3.46 Evidence from parents points to insufficient account being taken of the behaviour of children and young people at home (as opposed to in school or assessment centres). The Panel heard from a number of people that behaviour at home is very different to that at school and that the needs of a child or young person can only be fully understood if they are seen at home as well as at school. The Panel attended two SENCO Forum meetings in the city and the issue of assessment and diagnosis was discussed. The point was made by more than one SENCO that they felt that insufficient notice was taken of the views of the school during the assessment process and their input was limited to one space on a standard form.

3.47 Evidence from the pre-school special educational needs service (PRESENS) reflected the fact that some assessments for autism take place at nurseries. Mary Porter, Joint Head of PRESENS told the Panel:

> *"There is a huge challenge when a paediatrician sees a child just with their parents or on their own. So now PRESENS are involved in the Stage 1 assessment to enable professionals to see the child in the social setting of nursery so this has improved…. For a parent, a meeting at home or in a familiar setting might be a better option."*[62]

RECOMMENDATION 7: The Panel recommends that any assessment of a child's needs must not be purely clinic-based but also include assessments in the home and social environments.

3.48 Amaze told the Panel that private Educational Psychologists' reports are no longer "deemed to be acceptable" when a child is on the autism pathway and that families have reported that CAHMS have said that families who get a private assessment are 'over anxious'.[63] mASCot suggested that privately sought opinions and assessments should be "treated by the NHS with the same level of respect an NHS clinician would like to receive."[64] Whilst there are inevitably issues around private assessments and quality control, the services must be flexible enough to use these assessments as a valuable source of information if appropriate.

RECOMMENDATION 8: The Panel believe that, where appropriate, private Educational Psychologists reports should be accepted by CAMHS as a valuable source of information, particularly if services are stretched.

Complaints

3.49 mASCot told the Panel:

> *"We hear of parents who are unsure of how to complain or uncertain what will happen if they rock the boat. One family felt it was made clear to them that complaining would affect their child's access."*[65]

3.50 Whilst this may be an issue of perception, it does raise the wider issue of complaining about a service you still wish to access – be that CAMHS, GPs or schools. The Panel understands that the current situation is that anyone with a complaint directs it to the service provider, for example, SPFT for Tier 3 CAHMS. It can be very difficult for people to complain directly to a service that they need to continue using even if it is clearly the case that such complaints will be dealt with appropriately and professionally. The Panel recommends that consideration is given to allow for the council's Standards and

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[62] 6 November 2013 minutes (PRESENS is the pre-school special educational needs service)

[63] 17 Sep 2013 minutes p6

[64] Submission and Overview, 25 November 2011 (mASCot)

[65] 17 Sept 2013 minutes p8

Complaints to forward complaints on to relevant bodies and mediate between the provider and complainant if appropriate. The team have undergone autism awareness training and are open to exploring how parent carers can use their service to ease any residual worries people may have about complaining.

RECOMMENDATION 9: The Panel recommends that consideration is given to allow for the council's Standards and Complaints team to act as a mediator between service providers such as Seaside View and CAMHS and complainants if appropriate, or refer complainants on to Brighton & Hove Healthwatch who have a statutory role as advocates for those going through the health system.

GPs and Health Visitors

3.51 The Panel heard from Dr Becky Jarvis, a GP in a large practice in mid-Brighton and clinical lead for Mental Health in the Brighton & Hove Clinical Commissioning Group (CCG). In Dr Jarvis's practice, around 1% of patients have autism (21 out of 2,306 patients aged under 16 years). Dr Jarvis told the Panel that the CCG are working to raise awareness of autism and it has been included in one of the protected learning schemes sessions for GPs. Overall, the view is that GPs are more aware of autism than in previous years and most children receive an assessment after parents raise concerns with their GP.

3.52 In discussions over potential areas for improvement, Dr Jarvis remarked that it would be helpful if there were stronger links between GPs and schools/school nurses. School nurses do contact GPs with concerns but there are no clear and defined links in place. However, this can be a difficult issue as there are confidentiality concerns around such issues as communication (for example, the security of email).

3.53 In addition, now with the introduction of Children's Centres in the city, the traditional links with Health Visitors have been eroded – the CCG is looking at different ways to mitigate this. In Dr Jarvis's practice, they work with a link Health Visitor to communicate with a range of Children's Centres.[66] Mary Porter, joint Head of the council's pre-school special educational needs service (PRESENS) also highlighted the issues concerning Health Visitors – in her view it would be helpful if there was a mechanism that enabled Health Visitors to pick up children showing traits of autism. Currently, if a child is at home and not at nursery, PRESENS will not be aware of that child unless the parents go to the GP or a speech and language therapist.[67] Health Visitors are currently commissioned by the NHS England Area Team but are

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[66] 6 November minutes p2

[67] 6 November minutes 2013

shortly to move to be commissioned by the local authority Public Health team.

RECOMMENDATION 10: The Panel recommends that the CCG, Public Health and Children's Services work together to put a strategy in place to ensure there are strong and coherent links between Health Visitors and GPs across the city.

3.54 Dr Jarvis also felt that there was an inconsistency in the information given to parents from GPs: there are 48 GP surgeries in the city and they will not all be providing the same information. Parents need to have consistent advice and support and GPs need to be fully aware of what agencies can deliver what services so that families are fully supported, but without unrealistic expectations.

4. Education and Schools

Current provision in Brighton & Hove

4.1 Brighton & Hove City Council runs two pre-school special educational needs assessment centres – Jeanne Saunders and Easthill Park. There are six schools classified as special schools in the city, five of which offer places to children with autism (alongside a range of other severe and complex needs). There are also special facilities in mainstream schools: West Blatchington ASC Facility (primary), the Swan Centre based at the Brighton Aldridge Community Academy (BACA) and the Phoenix Centre at Hove Park School (both secondary). There are also two residential respite centres in the city for children with disabilities run by the council: Drove Road and Tudor House.

4.2 The Panel approached all the special schools in the city and the mainstream schools with the highest number of children and young people with autism but did not talk to as many of them as they would have wished. However, they did receive valuable input from a number of schools and members of the Panel attended both the primary and secondary SENCO Forums at their meetings on 30 January 2014 and 3 February 2014 to elicit their views. The Panel would like to record their thanks to those who did find the time to share their experiences with them.

Facts and figures

4.3 Figures provided to the Panel show that there are currently 250 pupils with a diagnosis of ASC in *mainstream* schools (Reception to Year 13 of whom 39% have Statements of SEN.[68] Regan Delf, Head of SEN, Brighton & Hove City Council, explained to the Panel that autism now accounts for the biggest category of statements of SEN in the city at 19% (in January 2013). There are:

- 79 children with autism and statements of SEN in mainstream schools
- 7 in Academy schools,
- 2 in mainstream units
- 66 in special schools
- 11 in agencies (that is, independent and non-maintained special schools)
- 1 categorised as ‘other’.[69]

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[68] A Statement is a formal legal document setting out what special needs a child has and how these should be met.

[69] Regan Delf presentation 9 July 2013

4.4 The resource pack for school staff about autistic spectrum conditions produced by the National Autistic Society clearly illustrates the issue facing children with autism in school:

> *"Imagine being suddenly placed in a culture alien to your own, where the people seem different from you, where you are always in danger of breaking social rules you do not understand, and you struggle to keep up with the flow of interaction that comes naturally to those around you. This is what it can feel like for pupils with an ASD in school: constantly bewildering."*[70]

Pre-school special educational needs (PRESENS)

4.5 In addition to running the Jeanne Saunders pre-school assessment centre and Easthill Park, the council PRESENS service works with all 147 early years settings and nurseries in the city. The Panel heard from Sue White and Mary Porter, joint Heads of the PRESENS service. The team consists of 9 teachers (6.5FTE) and 6 specialist nursery nurses (3.6FTE) and there are between 180-200 children on the caseload each year. They will observe a child and determine if there should be a referral to the PRESENS team and then to Seaside View. All 147 nursery settings have a named contact in the team. Part of the role of the PRESENS team is to provide best practice - they visit settings weekly or fortnightly and offer support in small groups or 1-2-1s. Ms Porter noted that there was a lot of good knowledge in nurseries and good awareness of the PRESENS team. However, there was often a challenge around levels of experience and qualifications.[71] Nurseries tend to have high staff turnover and the training modules run by the PRESENS team are always full. It should be noted that the Panel mainly received positive comments on the PRESENS team and the service they provide.

Mainstream schools

4.6 Nationally, 70% of children with autism attend mainstream schools and legislation states that schools must make 'reasonable adjustments' for these children.[72] Most of the evidence that the Panel heard was from parents whose children were in – or had been in - mainstream schools. For this reason, this report concentrates on this area although the Panel did also hear from one special school in the city.

4.7 The mASCot survey reported 67% of those who responded thought the support given in mainstream schools was good or very good. As Janet Poole of Amaze said:

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[70] Autism spectrum disorders - A resource pack for school staff. National Autistic Society

[71] 6 November 2103 minutes

[72] 9 July 2013 minutes

> *"We don't want to paint a bleak picture of Brighton & Hove – it's a pretty good place to have autism".*[73]

4.8 The Panel heard that some teachers are excellent and some children with autism thrive and have supportive peers. However, there is a lack of consistency.[74] One parent made the point that individual teachers are often doing the best they can but the ethos of the school is determined by the Headteacher. Local authorities should ensure Headteachers are delivering the right attitude throughout the schools.[75]

4.9 The Panel agree that Headeachers have a fundamentally important role in ensuring that their schools – and all those in them – are fully aware of autism and how it impacts on children and their lives. Whilst the Panel heard from a range of people including a Deputy Head and an Assistant Head, they did not hear from any Headteachers of mainstream schools in the city. **In light of this, the Panel would request that this report is drawn to the attention of the Headteachers' Forum.**

Parental concerns

4.10 During their inquiry, the Panel heard mainly from parents who felt their children had been failed by their mainstream schools. One parent told the Panel:

> "*at secondary school it all fell apart.. one example was he couldn't use the school toilet but the only suggestion was to go home ….At the end of Y7 he was very anxious, stressed, hitting and breaking things and this got worse and worse…. He was out of school for two years."*[76]

4.11 Another parent told the Panel:

> *"Transition is a nightmare –and starting again after school breaks… He was very distressed and anxious… we requested help and respite via the SENCO who asked for help from the disability social service but were denied twice.."*[77]

4.12 It is indicative of the pressures parents who spoke to the Panel found themselves under, that some did not feel that they could talk to the Panel in public for fear of their child suffering as a consequence. This also applies to some people who sent emails and requested anonymity.

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[73] 17 Sept 2013 minutes p7
[74] 17 Sept 2013 minutes p7
[75] 17 Sept 2013 minutes p9
[76] 19 Sept minutes p6
[77] 19 Sept 2013 minutes p 8

<u>A number of people spoke or emailed the Panel in confidence so whilst their comments remain anonymous, themes included:</u>

Lack of knowledge:

Every start of each academic year followed the same pattern of ignorance (from the class teacher) of the situation despite our efforts to prevent a whole first term of lack of communication within the school

The teacher's ignorance at times left me speechless to the point where I gave up

Lack of support:

Support from teaching assistants was sporadic and often withdrawn without notice

Parents should be aware of the full options available. They should be told which schools have expertise in teaching children with autism and which schools employ teaching assistants with autism expertise and training

Behaviour:

ASC behaviour in mainstream schools is often misunderstood for disruptive, unacceptable behaviour whereas a few minor adjustments could help avoid that

Repeated bullying and exclusions.

4.13 One parent told of their child's terrible experience in a mainstream primary school and made the point that there needs to be greater honesty with parents and schools need to say if they do not have the expertise or resources to meet a child's support needs. A number of parents expressed concern that their child would not fit either in mainstream or special schools. One parent suggested that a small specialist school for high-function ASC children with some academic potential would be the solution for many individuals.

4.14 A number of parents made the point that their child did not get their full amount of Statemented hours and one parent said it can be difficult for parents to know if their children are receiving their full amount.[78] **The Panel believes that it is important that a child receives all the help they need. Schools must find a way to ensure that all children who have a Statement receive the help that best supports them.**

4.15 The Panel heard that "*Statements are seen as currency by schools – schools pressurise parents into getting a Statement because there are*

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[78] An Educational Statement will describe all a child's special educational needs (SEN) and the special help the child should receive.

a number of hours associated with this."[79] The issue of Statements is a complex one with funding arrangements having changed recently. Statements will be replaced by Education, Health and Care Plans (ECHPs) by the end of 2014, as part of the Children and Families Bill. The Panel is not in a position to comment on this, but hopes that clear communication is put in place to ensure that families are fully aware of what the changes mean for them. **However, the Panel does want reassurance that the new ECHPs are strictly adhered to by the relevant agencies and children receive the help they need.**

4.16 One parent contacted the Panel to say they felt lucky that their child was in a good school with help – although they went on to say that it should not be a matter of 'luck'. It is worth reiterating that many who came to the Panel or support groups did not have positive experiences but the Panel do not want to suggest that all parents with children with autism have a terrible story to tell. There is obviously much good practice going on which we hope is also reflected in this report.

Experiences from schools

4.17 The Panel heard from Aaron Sumner, Deputy Headteacher and SENCO at Rudyard Kipling Primary School and Nursery. The school previously had an ASC facility but it closed in 2012. When the unit closed it had 6 pupils, 3 of whom went into specialist provision. The remaining 3 children were supported in mainstream classes and all of them achieved a Level 5 at the end of Key Stage 2. At the moment, there are 4 children with autism and Statements and 2 children with a diagnosis of autism but no Statement (but School Action Plus) at the school. Mr Sumner explained that they overspend on their SEN budget significantly each year but they have high quality staff fully supporting the children. He made the point that children must have on-going assessments as their needs will change. In discussing challenging areas, he expressed concern around the Common Assessment Framework (CAF) process – the school have had to employ additional staff to drive the CAF process which is time consuming and not always relevant.[80] In addition, the school have had issues around continuity from the Educational Psychologists team.

4.18 The Panel also heard from Suzanne Harmer, Assistant Head and SENCO and Jenn Westwood, Senior Teaching Assistant for Learning Support at Cardinal Newman Catholic School. Ms Harmer stressed that the approach the school took towards children with SEN (and specifically children with autism) was very similar to other schools. The school has 456 students on the special needs register. 17 children have autism and 5 of these are Statemented and 7 are on School Action Plus. Suzanne Harmer explained the school has a number of

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[79] 17 Sept 2013 minutes p6

[80] 19 November 2013 minutes. CAF is the Common Assessment Framework used to help families access support and services

strategies to help children, for example, children can leave class early or they may have tailored timetables. She raised the issue that if a student does not have a diagnosis of autism by the time they reach the school, it can be a challenge to get a diagnosis. A student can only access the ASC Support Service when they have a diagnosis so it can be very frustrating.[81]

4.19 Ms Westwood gave the Panel some examples of how they work with students and parents; they work to have children at the core of what they do and the key to this is building trusting relationships. They run a break-time club as a safe place for students to come, and also provide ‘get out of class’ cards so students can leave and find their key worker if they feel too anxious to stay in class.

4.20 The Swan Centre based at Brighton Aldridge Community Academy (BACA) and the Phoenix Centre in Hove Park School offer specialist facilities within a mainstream school. The Panel heard from Cath OddHayward, Head of the Swan Centre and Amanda Meier, Lead Teacher at the Phoenix Centre. The Swan Centre has been open since 2001 and has students from all over Brighton and Hove – with the opening of the Phoenix Centre it is anticipated children from the west and centre of the city will go there. The Swan Centre has 16 places from Year 7 to Year 11 for Statemented children with speech and language needs or autism. Currently 5 students have autism, 4 of whom also have speech and language difficulties. The Phoenix Centre only opened in September 2013 but is modelled on the Swan Centre. It previously was a unit for children with a Statement of dyslexia but in recognition of the rise of children with autism, the SEN team re-designated the facility to take children with autism and speech and language difficulties. They are funded for 13 students and currently have 8 students.

4.21 The special units in mainstream schools are ideally placed to increase awareness in the wider school about young people with autism. Whole school assemblies work with tutor groups, and ‘understanding me’ sessions are all examples of awareness-raising through the school. Ms OddHayward of the Swan Centre told the Panel:

> “*If a child can communicate themselves, they are the best ambassadors”….. Older children can explain themselves that ‘I have different words/think differently’.”*[82]

Special schools

4.22 Five of the six special schools in the city offer places to pupils with autism alongside a range of other severe and complex needs. The

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[81] 19 November 2013 minutes

[82] 6 November 2013 minutes

mASCot survey found satisfaction was high from those whose children were in special schools (86% good or very good).

4.23 The Panel heard from Adrian Carver, Headteacher at Downs View Special School and Downs Link College where they have a high number of children and young people with autism: the proportion of children with autism has risen from 33% to 52% since 2007. Mr Carver told the Panel about the Pathfinder pilot scheme to support children and families which looked at behaviour in the home. Teaching staff worked with four families to look at how to support children better. The teachers would be in children's homes late in the evening for a number of weeks to offer advice and support.[83] The Panel welcomed this initiative.

Training

4.24 The issue of autism awareness training for teachers and teaching assistants (TAs) was raised with the Panel. Autism Sussex felt that there was work to be done to educate teachers further in the nuances of behaviour: a number of other speakers also highlighted training as an issue. Ms OddHayward of the Swan Centre suggested that a basic level of training needs to be rolled out followed by higher level training. Amanda Meier of the Phoenix Centre made the point that there is an issue of allocation of time for teachers to be trained on both SEN and autism – there are many pressures on teachers and time is squeezed.

4.25 The ASC Support Service (ASCSS) detailed the training they have provided. This included:

- An Introduction to ASC
- Understanding ASC plus strategies
- Supporting pupils with ASC
- Social Stories and Comic Strip Conversations
- A Guide to understanding and succeeding with students with ASC.

4.26 Figures showed that 41 different schools received training from the ASCSS on autism in 2012-13.**[84]** The Panel heard that the council is undertaking a scoping exercise around training across health, education and social care early in 2014 with the aim of publishing a clear multi-tiered offer. Mary McPhail of the ASCSS told the Panel "*Training is key*".[85]

Whilst the Panel is pleased to see that schools are undertaking training, there is a concern that these schools are self-selecting. Given staff turnover and changes in legislation, it is of concern if

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[83] 6 November 2013 minutes

[84] Mary MacPhail. 21 schools in the Autumn term of 2013

[85] 19 Sept 2013 minutes p4

not all schools are regularly receiving training in autism awareness.

RECOMMENDATION 11: It is imperative that all schools in the city are fully signed up to being 'autism-aware'. The Panel recommends that steps are taken to ensure that schools are encouraged to take up training, and to make publicly available a list of what training has been undertaken, by whom and how often it is refreshed. This will also aid parents in choosing schools for their children.

Autism Awareness Award

4.27 The Panel understands that the council is exploring the possibility of creating an Autism Awareness Award for schools and discussions are underway with West Sussex ASC team who devised the Award some years ago. Schools who undertake the programme nominate two members of staff to attend training. The Award would be accredited by Sussex University.

4.28 The Panel was told that:

> "*An autism aware school will provide: an environment that accepts and understands pupils with autism spectrum condition and provides opportunities for the whole school community to continue to increase its awareness and develop its understanding of ASC."*[86]

The Panel welcomes the creation of an Autism Awareness Award and looks forward to its implementation.

The role of teachers and teaching assistants (TAs)

4.29 Parents had divided views on TAs and the effectiveness of TAs in relation to children with autism. There were examples of excellent support from TAs but also examples from parents who felt the TA was not giving educational support but '*containment*'. One parent said that their child had not '*learnt how to learn'*.

4.30 One parent told the Panel that they felt TAs were valuable for access (for example, enabling an autistic child to go to the lesson at all) but

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[86] The Autism Aware Award is an award for schools, taking 2 terms to complete. Schools nominate two staff members to attend training (one of these staff members must be the SENCO or on the senior management team of the school). Nominated staff commit to undertaking study and complete 3 tasks during the course. A portfolio of evidence is submitted outlining how the school meets the requirements of the AAA audit tool - AAA School Self Evaluation).

they need to be used judiciously in class. Children need to be taught by teachers not TAs:

> "*Crucial, as was also discussed at the Panel, is that all teachers have knowledge and skills regarding teaching children with ASC, so that children are taught by teachers* …"[87]

4.31 Lalli Howell, local lead on the SEN Pathfinder told the Panel that 1-2-1 support is not always beneficial and schools need to be more creative. A social skills deficit is at the core of autism and 1-2-1 support can isolate a child and create a reliance on that adult.[88] She went on to say that training is needed in a systematic way, starting with the SENCOs who feel pressurised:

> "*the focus should be on social understanding as well as academic achievement. SENCOs are great and we need to use their expertise.*"[89]

4.32 Mary MacPhail of the ASCSS told the Panel that some school staff do not fully understand the reasons for some of the strategies and approaches suggested, thinking that this reinforces behaviours rather than diffusing situations. For example, when a pupil has sensory overload and needs supported 'time out'. Training is key to changing this. Ms Howell told the Panel that children with autism can't always function if they have to adhere to lots of rules. Schools need to be creative at looking at alternative ways of providing education and all children accessing learning. Autism is a spectrum condition and what works for one child may not work for another. Teachers must be able to differentiate work for children.

SENCOs and the SEN Code of Practice

4.33 All maintained schools must appoint a designated teacher as the Special Educational Needs Co-ordinator (SENCO) who is responsible for the day-to-day operation of the school's SEN policy. All SENCOs must have qualified teacher status and all new SENCOs have to undertake a nationally recognised qualification. The Panel heard both positive and negative comments about SENCOs. The Panel appreciated the chance to talk to two SENCO Forums in the city. The comments made by the SENCOs who attended these meetings have been reflected in this report.

4.34 The SEN Code of Practice provides statutory guidance for organisations who work with and support children and young people with SEN. All those covered by the Code of Practice have duties in relation to disabled children and young people under the Equality Act

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[87] Email

[88] 19 Sept 2013 minutes p3

[89] 19 Sept 2013 minutes p 4

2010. They must not discriminate and they must make reasonable adjustments for disabled children and young people. There is a focus in the draft guidance on high expectations and outcomes: parents and children should know how to access support and be instrumental in shaping it. The SEN Code of Practice is out for consultation until April 2014.[90] The Panel does not feel in a position to comment on the draft SEN Code of Practice.

Governors

4.35 All Governing Bodies have specific legal responsibilities in relation to pupils with special educational needs and disabilities. Some Governing Bodies appoint a specific SEN Governor but this is not a legal requirement. One Parent Governor raised the question of how well informed Governors were about SEN funding, how it was allocated and how it was monitored. He explained:

> *"Budgets are controlled by Governors and their knowledge around SEN can be a worry – how much money is put into SEN and from where? Governors are voluntary and many may not understand how the SEN money is spent."*[91]

4.36 The Panel understands that funding to schools for children with Statements has changed. The individual cost basis has been replaced by broad funding streams where the number of hours a child receives falls into 3 bands.[92] It was pointed out to the Panel that this may work against the interest of SEN pupils as any increase per hour will now only come from the local authority if the child moves between the broad funding bands, otherwise the funds come from the school budget. **The Panel would request clarification on this and assurances that this will not adversely affect children with SEN.**

4.37 It is not obligatory for Governing Bodies to be trained in SEN but it is very important. One example cited by mASCot was of a parent going to a Tribunal about exclusions and having to explain autism to the Governors.[93] Whilst it is down to Governing Bodies themselves to ensure they are knowledgeable, the Panel would hope that all Governing Bodies in the city would have a nominated SEN Governor. In addition, the local authority has a role in appointing local authority Governors to schools. As part of this process, the panel that considers applications from people wishing to become local authority Governors should also be given a role in monitoring the training these people have undertaken. **The Panel believes that all Governing Bodies should**

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[90] Draft Special Education Needs (SEN) Code of Practice: for 0 to 25 years. Statutory guidance for organisations who with and support children and young people with SEN. October 2013

[91] 19 November 2013 minutes

[92] £2,250 per pupil for 8 to 17.5hrs; £6,750 per pupil for 17.5 to 27 hours; a variable amount for 27 hours and above.

[93] 17 Sept 2013 minutes p4

ensure that they have the relevant expertise on both SEN budgets, and on autism.

RECOMMENDATION 12: All Governing Bodies of Schools should undergo SEN training - which should include autism awareness training - to ensure they are able to fulfil their role in providing effective challenge to the Headteacher and the Senior Leadership Team and be confident that provision is available for all children, including those with SEN, to learn successfully. In addition, the local authority should use its role in approving local authority Governors to monitor what training these governors have undertaken.

RECOMMENDATION 13: The Panel recommend that the Director of Children's Services ensures that this report is drawn to the attention of all Governing Bodies of schools in the city.

Teacher Training courses offered in Higher Education

4.38 The issue of what is covered in teacher training courses was raised with the Panel. Rosie Moore, a co-opted member of the Panel, is a lecturer in SEN at the University of Brighton and the Panel benefited from her expertise. Trainee teachers are much more likely to be aware of autism today than teachers were in the past and specific modules of courses cover SEN and autism awareness.

4.39 Rosie Moore told the other Panel members that teacher education courses taking place in Higher Education (HE) train teachers to be inclusive practitioners and to have sufficient confidence, knowledge, skills and understanding to become professional teachers. This was a shared endeavour between schools and the university. A key feature of teacher training was ensuring that students become reflective practitioners and understand the importance of lifelong learning. This will mean they are open and flexible and take every opportunity to understand specific needs of children (such as those with ASC) in their work. In addition, there are opportunities within the courses both at university and in schools to learn more about specific needs. These opportunities included practical workshops, case studies in schools, university SEND website, visiting lecturers with ASC specialism etc.

ASC Support Service (ASCSS)

4.40 The ASC Support Service was set up in 1999 and operates out of Downs Park School. It has three FTE posts and 250 children diagnosed with autism between Reception and Year 13 on their caseload. They are currently working with 47 primary and 9 secondary schools in the city.

4.41 The Panel heard a lot of praise for the ASCSS which was described as "brilliant" by mASCot.[94] One parent emailed to "write a message of support for the ASCSS service" and described it as "invaluable". The Deputy Head of Rudyard Kipling School told the Panel they had over 4 years of good consistent support from the ASCSS.[95] Members of the SENCO Forum told the Panel that they had benefited from the advice of the ASCSS. The current parent liaison post with ASCSS (which has recently been re-appointed) was a parent who found it incredibly useful to have the support of the ASCSS.[96] The ASCSS's own survey (although with a low response rate of 31%) had a 95% satisfaction rating.[97]

4.42 The Panel did receive some negative comments, however, with one parent noting that the ASCSS was for schools not parents – this was something the ASCSS did not agree with. Another noted that the ASCSS liaise only with the school not the parents and parents do not know when the ASCSS are observing their child. The Panel trusts that the new post of Parent Liaison will ensure that parents feel closer to the service.

4.43 The ASCSS told the Panel most successful interventions were about looking at the needs of the individual child. One effective method of promoting understanding of autism was when children with autism explained to other children how they experience the world.[98] In some secondary schools they do whole year group awareness of autism and how it impacts on a child. Mary MacPhail, Interim Head of the ASCSS, gave the example of good practice as schools who have a key worker and those who have good communications network.[99]

4.44 The Panel heard that it is only recently that Tier 3 CAMHS have contacted the ASC Support Service post diagnosis. **The Panel would welcome assurances that when a child or young person has a diagnosis of autism, the ASCSS are automatically informed.**

4.45 Regan Delf, Head of SEN, Brighton & Hove City Council, told the Panel that the ASCSS service is very well received by schools but they are "*aware of the need to make signposting in education services clearer."*[100] The figures showing the schools who have taken up ASCSS training and the low response rate to the ASCSS survey show there is more to be done to engage fully with **all** schools in the city.

4.46 However, with the limited resources currently available for ASCSS there are some hard decisions to be made. The Interim Head of the

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[94] 17 Sept 2013 minutes
[95] 19 November 2013 minutes
[96] 19 Sept 2013 minutes
[97] 19 Sept 2013 minutes
[98] 19 Sept 2013 minutes
[99] 15 October 2013 minutes
[100] 9 July 2013 minutes

ASCSS told the Panel that funding for the ASCSS is very tight. Realistically they can only go into a school 3 times a term and that would be to see a child who is really struggling – for some children they only go into the school once a term. Overall, the Panel believes that the ASCSS is a valued service but one that is overstretched. As the emphasis in the city moves more towards supporting and empowering families, consideration should be given to increasing the funding of the ASCSS.

RECOMMENDATION 14: The Panel recommends that the Director of Children's Services considers increasing the funding of the ASC Support Service.

Bullying and exclusions

4.47 The mASCot survey reported that 50% of respondents reported that their child had suffered bullying. Evidence given in private session to the Panel included frequent references to incidents of bullying, many of which were felt to be inappropriately handled. Parents' experiences were that their children can be excluded after reacting to long-term bullying.

4.48 34% of parents in the mASCot survey said their child had been excluded. One parent told the Panel that their son had experienced countless bullying incidents and he was excluded but the children who were bullying him were not. Another reported that her child got sent home regularly and it was exhausting. One parent reported her child being "illegally" excluded (sent home at lunch or unofficially).There are good examples: in comparing a bad experience at a secondary, one parent noted that in the primary school their son attended, bullying was dealt with immediately.

4.49 Information supplied to the Panel by the council's exclusions team stated there were 3 pupils with autism excluded on fixed term exclusions from the special schools in the city for the last academic year, and a further 5 from maintained schools.

The Panel are aware that as they were undertaking their inquiry, another Scrutiny Panel was looking at bullying. This Panel looks forward to the recommendations of the Bullying panel.

Ofsted

4.50 There is no separate judgment for special educational needs (SEN) provision under the Ofsted inspection framework. SEN provision forms part of whole-school inspection. The Framework states that:

> “*Inspectors are required to report on the quality of education provided in the school and must, in particular, cover: the achievement of pupils at the school; the quality of teaching in the school; the behaviour and safety of pupils at the school; the quality of leadership in, and management of, the school.”*

Inspectors must also consider “*the extent to which the education provided by the school meets the needs of the range of pupils at the school, and in particular the needs of disabled pupils and those who have special educational needs*.[101]”

4.50 The Panel understands that Ofsted are currently looking at what role they will play in monitoring the SEN Code of Practice. An Ofsted inspection report could provide a useful source of information on how schools are meeting the needs of children with SEN.

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[101] http://www.flse.org.uk/documents/Special%20educational%20needs%20and%20disability%20report.doc

5.0 Transitions

5.1 The issue around transitions – both between primary and secondary schools and between children's and adults services – was raised frequently with the Panel. This report looks at each issue in turn.

Transitions between schools

5.2 The transition between the relatively small and caring primary school environment to the much larger secondary school environment is often a problematic time for children with autism. One parent told the Panel that her child had a very difficult transition into Year 7 and was home by lunchtime on the first day, despite all their advance warnings to the school. However, eventually a plan was put in place; her child is now in Year 8 and feels like he is in a place where his needs are listened to.[102] Another felt that there was no support over the holidays between primary and secondary school so their child was unable to successfully start secondary school. There was no integrated plan to aid transition from primary to secondary schools. Another parent told the Panel that it all went wrong at secondary school and it took years to sort out. The Panel hopes that the work going into the new Education, Care and Health Plans will take into account the issues around transitions between schools and look at how this process can be improved.

5.3 Currently, when a Statemented child goes to a Further Education (FE) college, they automatically lose their Statement – one example cited to the Panel was that anxiety over transition to FE college and a lack of support was a contributing factor in a breakdown.[103] The Panel were told that FE provision for young people with autism in the city was limited and the application process too lengthy. Another parent told the Panel their real worry was the lack of support given to students when they leave sixth form and if a student is not going on to university, there is no guidance or assistance.

5.4 The area of tertiary education for young people with autism is a difficult but important one. The Panel is not in a position to do more than flag up a concern that young people with autism may struggle to find tertiary education or may find the transition process very stressful and onerous.

Transitions between children's and adult services

5.5 The Panel heard that Autism Sussex received lottery funding to fill gaps in provision in Brighton & Hove, particularly where people don't meet the thresholds to access services. At the time of the Panel's meeting, Autism Sussex had just finished a scoping exercise. The plan was to replicate provision in East and West Sussex and set up family support

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[102] 19 Sept 2013 minutes
[103] 19 Sept 2013 minutes

groups, drop-in clinics and workshops on particular areas.[104] **The Panel welcomes this initiative and look forward to further information on this.**

5.6 As noted earlier in this report, there are issues around provision for children with autism but no learning difficulties. When a child has an identified and significant learning difficulty and autism, they are likely to be known to the children's disability social work team and meet the criteria of the adult community learning disability team. For these children, there is a process and the child will be supported by the transitions team. If a child does not have a significant learning disability, they will not have been identified by the children's disability social team and are unlikely to meet the criteria for either the community learning disability team or adult social care. As the Commissioner for CAMHS noted:

> *"For these children there is less clarity around the process of transition and about the availability of services in adulthood. They may go from having accessed some support to nothing."*[105]

5.8 The Commissioner for CAMHS explained to the Panel that autism is a theme in the SEN strategy. A draft autism plan that supports the focus on autism in the SEN Partnership Strategy (2013-2017) is out for consultation.[106] This is intended to be multi-agency and acknowledge the gaps that are known to exist and address them.

5.9 Dr Becky Jarvis, lead for Mental Health in the CCG, was amongst those who stressed that is was very important to make sure that the strategy for adults with autism and the draft strategy for children with autism dovetail and there are no gaps in provision.[107] The Commissioner for CAMHS explained to the Panel that there would be a 'bridging document' to link the two strategies, particularly in the area of transition between services. Mark Hendriks, Commissioner Learning Disabilities, Brighton & Hove City Council, told the Panel that this year and next year, the work on the Adults with Autism strategy would focus on transition from children to adults.

5.10 The council and its partners carried out a mandatory self-assessment on services for adults with autism which highlighted areas in which they had performed well (for example, nominating a local lead for autism and setting up a multi-agency Autism Stakeholder Group) and areas for improvement (for example, the uptake of training, information, and pathways to assessment and support).[108]

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[104] 17 Sept 2013 minutes

[105] 19 November minutes

[106] "Meeting the needs of Children and Young People with Autism in Brighton and Hove 2013-2017" - Better outcomes, better lives

[107] 6 November 2013 minutes

[108] 19 November 2013 minutes

5.11 The Panel recognises that the whole area of transition from children's services to adult services is a complex one with differing criteria to access help. When Education, Health and Care Plans are in place, young people will be supported for longer (up until they are 25 years old). It is hoped that this will go someway to easing the transition between services. Nonetheless, with the plethora of strategies and potential for people to feel disenfranchised, the Panel would like to ensure that all work on transition is co-ordinated and effectively monitored. In light of this, they recommend that a regular monitoring regime is put in place.

RECOMMENDATION 15: The Panel recommends regular monitoring reports are produced detailing progress on the Transitions Strategy, the Adult ASC Strategy, the Children with Autism Plan, and the work on the Education, Care and Health Plans to ensure there is no duplication or gaps. The committee with responsibility for children's care and health in the city should take an active role in reviewing these reports.

6.0 Linking Together

Pathfinder Project

6.1 Brighton & Hove City Council is part of the SE7 Pathfinder Project, the largest of the Pathfinders in the country set up by the Government after the SEN Green Paper was published. It is due to run until September 2014. In Brighton & Hove they are in the second phase of the project working with 50 families, 60% of whom have children with autism or significant communication difficulties linked to their disability. The team were looking to work with an additional 115 families on the Education, Health and Care Plans (EHCPs). In addition, the Pathfinder Project was working with two schools on how to enhance children's social skills and the use of personal budgets.

6.2 The Panel were told that new drop-in sessions for parents to meet the SEN team would be taking place once a month in King's House in Hove. **This is a welcome initiative and the Panel hopes it will be a successful one. In due course, the Panel would welcome feedback on the progress of these sessions and what action has been taken as a result.**

6.3 Part of the Pathfinder Project is the 'Local Offer'. This will be one place where all information about provision available for children and young people who have special educational needs can be accessed. The SEN Partnership Strategy pledges to:

> *"Publish a Local Offer that provides high quality information about settings, services and provision for SEN in the LA with a route map indicating how to access appropriate support."*[109]

6.4 Brighton and Hove's Local Offer is in phase 1 of development. As part of the SE7 Pathfinder work, Brighton & Hove City Council coproduced (in partnership with parents, pupils and key stakeholders) a set of questions regarding provision made by services for children and young people with SEN. These addressed issues such as what expertise is available and how SEN needs are met. All schools and educational services in the city have provided their responses for publishing on the Local offer. As part of this Phase 1, health and social care information is accessed through links to existing websites. In Phase 2 of the Local Offer development, social care and health services will provide comparable information.

The Panel welcomes all the initiatives underway and hope that the 'Local Offer' will make a real difference to the lives of families with children with autism. There will be clear information on what is available, where and when.

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[109] SEN Partnership Strategy, P11

Existing strategies

6.5 The Panel was pleased to note that “ASC development” is a key priority in the new **SEN Partnership Strategy 2013-17**.[110] As a result of this, a specific strategy for children with autism was drafted.[111] The Children with Autism plan seeks to ensure the following outcomes are met:

> “*Provision of timely interventions which meet the needs of individual children including high quality education provision and support services during and beyond the school day*
>
> *Empowering of parent carers – equipping parent carers with information and skills and strengthening families*
>
> *Available services that make early intervention a priority*
>
> *Ensuring engagement with children and young people and parent carers in the design, delivery and feedback regarding service provision.”*[112]

The recommendations in this report fit closely into the achievement of these outcomes.

6.6 There are a number of strategies that are relevant to the families of children with autism. The Panel heard that the ASCSS are working with the SEN team to see how they fit into the overall SEN strategy – a new development.[113] The Early Help Strategy has been launched recently. The Head of Integrated Child Development and Disability assured the Panel that the ASC Working Group will link into this.[114] The ASC Working Group is a subgroup of the Disability Partnership Board and the SEN Partnership Board. The overall purpose of the ASC Working Group is:

> “*To provide a forum to focus on issues related to the provision of services across health, education and social care to children and young people who are on the autistic spectrum, taking account of the needs of the carers.”*[115]

6.7 The Panel is aware of the range of work going on to try and improve services for children and young people with autism. However, as this report highlights, there is still much to be done and it is important that

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[110] Regan Delf’s presentation Brighton & Hove Special Educational Needs (SEN) Partnership Strategy 2013-2017

[111] Meeting the needs of children and young people with autism in Brighton and Hove 2013-2017 “Better outcomes, better lives”. A plan to support the SEN partnership strategy.

[112] Meeting the needs of children and young people with autism in Brighton and Hove 2013-2017 “Better outcomes, better lives”. A plan to support the SEN partnership strategy. P2

[113] 15 Oct 2013 minutes

[114] 6 November 2013 minutes

[115] Draft terms of reference of ASC Working Group 2013

all the evidence received by this Panel is not ignored. In light of this, the Panel recommends an ‘Autism Champion’ is appointed who can take on the work of this Panel and ensure that there is a genuinely holistic approach to autism. The appointment of a ‘champion’ in other areas (for example, Trans Equality) has had an extremely positive effect in terms of co-ordinating work and driving change.

RECOMMENDATION 16: The Panel recommends an Autism Champion is appointed for the city. This named individual will be tasked with monitoring the agreed recommendations and actions from the Panel’s report and the action plan resulting from the draft Children with Autism Strategy.

In addition, as there are a number of relevant strategies and documents already in place, (e.g. draft Children with Autism Plan, Adults with Autism Strategy, Early Start, B&H SEN Partnership Strategy) it is imperative that there are clear links between them. The ‘Autism Champion’ can ensure a coherent approach is taken with strategies dovetailing and not duplicating.

6.8 The Panel was pleased to learn that an ASC Working Group has been set up and would welcome their response to this report. In addition, it would be helpful if the Working Group were able to take a role in monitoring the implementation of the recommendations in this report.

RECOMMENDATION 17: The Panel recommends that the ASC Working Group takes a proactive role in monitoring the implementation of the recommendations in this report. This would feed into the standard monitoring report to the Overview and Scrutiny Committee (OSC) in 12 months time.

Joint Strategic Needs Assessment

6.9 There is a Joint Strategic Needs Assessment (JSNA) for the city which includes an assessment of needs for adults with autism and a separate assessment for children and young people with disabilities. However, there is no specific section on *children* with autism. Given the move towards joined-up thinking in terms of linkages between services for children and adults, and the increase in numbers of children and young people with autism, it seems logical that the JSNA reflects this.

RECOMMENDATION 18: In order to fully reflect the needs of children with autism in the city, the Panel recommends that the Joint Strategic Needs Assessment (JSNA) is updated to include a section on what services are currently available for children with autism, where the gaps are, and how they can be filled.

7.0 Further Issues raised with the Panel

Leisure activities

7.1 The lack of appropriate facilities for after-school leisure activities was raised with the Panel. Adrian Carver, Headteacher of Downs View School made the point that there is:

> "*an absence of appropriate activities for more able students from Cedar Centre, Downs Park and Patcham House. There is a gap in appropriate leisure activities….. we need to facilitate young people to be an active part of the community."*[116]

7.2 Suzanne Harmer agreed that a youth club for children with autism would be helpful: children with autism often go home and keep to themselves rather than socialise.[117] The Panel were aware of after-school clubs and facilities for children with Aspergers and high functioning autism in Hastings but were not aware of many such facilities in Brighton & Hove although Amaze do run a successful Compass Card scheme which includes the autism-friendly film screenings most months in the Duke of York's cinema. However, after the Panel had finished its hearings, Autism Sussex received Lottery Project funding and are developing new services: a drop-in clinic; a new social group; and workshop space in the Open Market.

7.3 The council's Youth Service states it delivers:

> ".. *programmes of activities to groups of young people with a need, e.g. vulnerability due to exclusion or being marginalised. We also deliver programmes that specifically address a limiting factor in young people's lives, eg racism or sexism. Groups are tailored to age, demand and dynamics."*[118]

RECOMMENDATION 19: The Panel recommends that the Youth Service and/or Youth Collective considers whether it there is enough demand to merit the creation of a youth club aimed at young people with autism, and if so, which organisation might provide this.

Raising wider awareness through wider training

7.4 The draft plan for children with autism makes the very important point that:

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[116] 6 November 2013 minutes

[117] 19 November 2013 minutes

[118] http://www.brighton-hove.gov.uk/content/children-and-education/youth-service/youth-work-group-work

> *"Raising awareness of autism via multi-professional training of the workforce is beneficial to increasing early assessment of need and related diagnosis."*[119]

7.5 A priority action point following on from this is to increase autism awareness across the workforce through a targeted and tiered programme of competency-based training (universal, targeted and specialist). **The Panel welcomes this and looks forward to hearing what progress is made**.

7.6 In addition, two people raised the issue of school transport and a lack of communication when there are last minute changes to escorts and drivers. A late or missed transport appointment is extremely disruptive for children and young people with autism. **Protocols must be developed - and adhered to - that ensure that disruption is kept to an absolute minimum for children and young people with autism.** This may also be an area where further training may be beneficial.

7.7 One specific example given to the Panel was in relation to the Law Courts. Whilst this area was outside of the Panel's remit, it raised an interesting point. The Panel heard that Family Law Courts were missing the more subtle symptoms of autism in girls, resulting in a private diagnosis of autism being overturned by the Court. The Panel were alarmed to hear this and would like to highlight the need for judges and Family Law Courts to be fully cognisant with traits of autism.[120]

RECOMMENDATION 20: The Panel recommends that the Director of Children's Services draws this report to the attention of the head of the Family Law Courts in the city.

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[119] Meeting the needs of Children and Young People with Autism in Brighton and Hove 2013-2017. 'Better outcomes, better lives' Draft 2 January 2014

[120] Mins 19 Sept 2013 p6 anonymous

8.0 Conclusion

8.1 Children with autism form one very specific sub-group of children and young people with special educational needs. The Panel has undertaken its inquiry in time of great change in the services provided for children with SEN. With this, comes the opportunity to really help families of children with autism in the city, to support them, and ensure these children are able to fulfil their potential.

8.2 The Panel has found that there are areas of best practice and examples of innovative working, but also that there is more to be done. In the spirit of openness and clarity, parents and families must be central to all the work currently underway. This, along with clear lines of communication and accountability, further training, and raised awareness will add up to a step-change in the city.

8.3 The Panel wishes to finally record their thanks to all those who contributed to the inquiry and trust that this report and recommendations are taken in the spirit in which they are intended.

Recommendations

Please note that these recommendations are in the order they appear in the report, not in order of importance.

Support and assessment

RECOMMENDATION 1: The Panel recommends that both Seaside View and CAMHS should have a nominated Keyworker specifically to help parents and carers of children and young people with autism. This named person would be the first – and final – point of contact for people using the services of either Seaside View or CAMHS. (p16)

RECOMMENDATION 2: A clear pathway needs to be created for children and young people who have autism but neither learning disabilities nor mental health issues. If there is no clear support in place, children and young people run the risk of returning to CAHMS and other services in crisis. (p17)

RECOMMENDATION 3: The Panel recognises that a key gap in services provided is in the area of home support. The Panel strongly recommends that funding is reconfigured to include home support packages. Parents should be consulted over what they feel would be most beneficial and initiatives put in place to help parents access support at home. (p21)

RECOMMENDATION 4: Current service providers such as Seaside View and CAHMS need to examine the strategies they have in place to ensure parents are at the centre of their services. This should include looking at new ways of getting feedback from service users – particularly parents of children with autism – and reflecting this in their services. *This feedback should be open and transparent and externally monitored. (p22)*

RECOMMENDATION 5: Monitoring is crucial. CAMHS and Seaside View must have robust and publicly available monitoring procedures. Working with parents and children, CAMHS and Seaside View need to review their monitoring procedures and put in place a transparent, comprehensive feedback system for parents of children with autism*.* ***(p24)***

RECOMMENDATION 6: The Panel recommends that there is a clear and unambiguous statement of where the responsibility lies for the performance of all tiers of CAMHS and the systems in place for addressing any problem areas. In addition, the Director of Children's Services, after consultation with the CCG who are ultimately accountable for Tier 3 CAMHS, must work to ensure that an Annual Report is produced detailing performance against a clear and relevant set of indicators. Parents and young people should be actively involved in determining key performance indicators and contributing to the assessment and monitoring against them. (p24)

RECOMMENDATION 7: The Panel recommends that any assessment of a child's needs must not be purely clinic-based but also include assessments in the home and social environments. (p25)

RECOMMENDATION 8: The Panel believe that, where appropriate, private Educational Psychologists reports should be accepted by CAMHS as a valuable source of information, particularly if services are stretched. (p25)

RECOMMENDATION 9: The Panel recommends that consideration is given to allow for the council's Standards and Complaints team to act as a mediator between service providers such as Seaside View and CAMHS and complainants if appropriate, or refer complainants on to Brighton & Hove Healthwatch who have a statutory role as advocates for those going through the health system. (p26)

RECOMMENDATION 10: The Panel recommends that the CCG, Public Health and Children's Services work together to put a strategy in place to ensure there are strong and coherent links between Health Visitors and GPs across the city. (p27)

Education

RECOMMENDATION 11: It is imperative that all schools in the city are fully signed up to being 'autism-aware'. The Panel recommends that steps are taken to ensure that schools are encouraged to take up training, and to make publicly available a list of what training has been undertaken, by whom and how often it is refreshed. This will also aid parents in choosing schools for their children. (p35)

RECOMMENDATION 12: All Governing Bodies of Schools must undergo SEN training - which should include autism awareness training - to ensure they are able to fulfil their role in providing effective challenge to the Headteacher and the Senior Leadership Team and be confident that provision is available for all children, including those with SEN, to learn successfully. In addition, the local authority should use its role in approving local authority governors to monitor what training these governors have undertaken. (p38)

RECOMMENDATION 13: The Panel recommends that the Director of Children's Services ensures that this report is drawn to the attention of all Governing Bodies of schools in the city. (p38)

RECOMMENDATION 14: The Panel recommends that the Director of Children's Services considers increasing the funding of the ASC Support Service. (p40)

RECOMMENDATION 15: The Panel recommends regular monitoring reports are produced detailing progress on the Transitions Strategy, the

Adult ASC Strategy, the Children with Autism Plan, and the work on the Education, Care and Health Plans to ensure there is no duplication or gaps. The committee with responsibility for children's care and health in the city should take an active role in reviewing these reports. (p44)

Linking strategies

RECOMMENDATION 16: The Panel recommends an Autism Champion is appointed for the city. This named individual will be tasked with monitoring the agreed recommendations and actions from the Panel's report and the action plan resulting from the draft Children with Autism Strategy.

In addition, as there are a number of relevant strategies and documents already in place, (e.g. draft Children with Autism Plan, Adults with Autism Strategy, Early Start, B&H SEN Partnership Strategy) it is imperative that there are clear links between them. The 'Autism Champion' can ensure a coherent approach is taken with strategies dovetailing and not duplicating. (p47)

RECOMMENDATION 17: The Panel recommends that the ASC Working Group takes a proactive role in monitoring the implementation of the recommendations in this report. This would feed into the standard monitoring report to the Overview and Scrutiny Committee (OSC) in 12 months time. (p47)

RECOMMENDATION 18: In order to fully reflect the needs of children with autism in the city, the Panel recommends that the Joint Strategic Needs Assessment (JSNA) is updated to include a section on what services are currently available for children with autism, where the gaps are, and how they can be filled. (p48)

Other issues

RECOMMENDATION 19: The Panel recommends that the Director of Children's Services draws this report to the attention of the head of the Family Law Courts in the city. (p49)

RECOMMENDATION 20: The Panel recommends that the Youth Service and/or Youth Collective considers whether it there is enough demand to merit the creation of a youth club aimed at young people with autism, and if so, which organisation may provide this. (p50)