

# HEALTH & WELLBEING OVERVIEW & SCRUTINY COMMITTEE

## Agenda Item 41

Brighton & Hove City Council

<b>Subject:</b>	<b>Services for children with Autistic Spectrum Conditions</b>		
<b>Date of Meeting:</b>	<b>18 December 2012</b>		
<b>Report of:</b>	<b>Heather Tomlinson, Director of Children's Services</b>		
<b>Contact Officer:</b>	<b>Name:</b>	<b>Alison Nuttall</b>	<b>Tel: 29-3736</b>
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<b>Ward(s) affected:</b>	<b>All</b>		

### FOR GENERAL RELEASE/

#### 1. SUMMARY AND POLICY CONTEXT:

- 1.1 This report is produced as an update to HWOSC regarding services for children with autistic spectrum conditions (ASC). It sets out actions and assessment undertaken since this was last discussed.
- 1.2 This report should very much be seen as a discussion piece with Members being asked for a steer as to future scrutiny activity in this area.

#### 2. RECOMMENDATIONS:

- 2.1 That HWOSC note the content of the report.
- 2.2 That HWOSC determines what future scrutiny action is undertaken with regard to services for children with autistic spectrum conditions.

#### 3. RELEVANT BACKGROUND INFORMATION/CHRONOLOGY OF KEY EVENTS:

- 3.1 On 4 July 2011 a member of the public tabled a letter at CYPOSC regarding her experience with her son of accessing diagnostic and intervention services for autistic spectrum condition (ASC). She also asked CYPOSC to respond to guidance produced by the National Autistic Society – Difference in Mind: Scrutinising Child and Adolescent Mental Health Services for Children with Autism.
- 3.2 In September 2011 a report was presented to CYPOSC describing local service provision for ASC. The committee asked a range of questions regarding this including expressing a wish to have greater information about the service user experience.
- 3.3 At the September 2011 meeting of CYPOSC it was agreed to undertake a survey of families who had experienced services for ASC. Following discussion with service providers and scrutiny officers it was agreed that as there is no database of children and young people with ASC it would be difficult to identify all current

ASC children and survey their families. It was therefore agreed that a survey be designed that could be sent or given to families at the point of diagnostic assessment and then followed up to better understand their experience of services.

- 3.4 The primary providers of ASC assessment are Seaside View Child Development Centre and Child and Adolescent Mental Health Services (CAMHS Sussex Partnership Foundation Trust). Seaside View assesses children under 11 and CAMHS sees secondary age young people. This is consistent with NICE /good practice guidance which states that a paediatrician should see younger children and a psychiatrist see older children to enable effective differential diagnosis.
- 3.5 Both providers were consulted as to the best format of the survey and, because Seaside View in particular, wanted the information received to be both satisfy CYPOSC and their own service improvement aspirations the design was developed in conjunction with the service. Due to information sharing constraints the council could not undertake a survey of this nature without the involvement of both service providers.
- 3.6 It was agreed that the survey would be sent out by the provider services prospectively from April 2012 to all those families experiencing an ASC assessment process. In fact CAMHS also sent out the survey retrospectively to all those seen since April 2011.

### **Survey results**

- 3.7 To date ten surveys have been returned. From the small number of responses received to date it isn't possible to provide a comprehensive analysis of user satisfaction however feedback is summarised below: Of the 10 returned forms:
  - 6 children/young people were described as having received services from both Seaside View and CAMHS
  - 4 had been seen at CAMHS
  - 6 children/young people had received other services in addition to Seaside View and/or CAMHS
  - 7 of the children/young people were aged 11 or over at the time of completing the form
  - The age range of the children/young people was between 3 years and 17 years
  - 7 of the children/young people were described as having received a diagnosis of ASC
  - 4 of the forms indicated that children had been first seen during 2012
  - 5 of the children and young people had first been seen before 2012- one in 2010, one at the end of 2011, one first seen in 2008 and 2 since 2003 ( one didn't respond to this question).
  - 9 of the 10 surveys indicated that the respondents had been fairly satisfied or very satisfied with the staff they met during the assessment process

- 3 respondents specifically stated their disappointment that an earlier diagnosis had not been made
- 1 respondent was very satisfied across all areas of the survey and felt that they had been helped to better understand their child's needs.

3.8 Where respondents noted additional comments these included:

- A better understanding of the child and their needs (2)
- Improved access to services and DLA (1)
- concern (1) that there had been a lack of support re behaviour management
- importance of support for siblings and a concern about bullying particularly at secondary age (1)

3.9 5 of the respondents gave satisfaction levels across the survey of either very satisfied or fairly satisfied (with 1 or 2 neutral levels). 5 expressed some degree of dissatisfaction with information provided prior to and after the assessment, support offered and explanations given as to the child/young person's condition.

3.10 When asked to summarise their view of the service as a whole, 8 of the 10 expressed they had been fairly satisfied or very satisfied. One stated they had been fairly dissatisfied and one was very dissatisfied. The two most dissatisfied respondents had been known to services since 2003 and 2008 respectively. One of these children had received an ASC diagnosis, the other had not.

3.11 The total number of surveys returned is small though does reflect a range of experiences. The feedback received will be shared with services in order to inform service improvements. It is suggested that the responsible Commissioners follow up with the services regarding the quality and amount of information provided to families and the waiting times for assessment.

#### 4. CAMHS user satisfaction survey

4.1 CAMHS routinely distributes a postcard survey to those attending appointments. These are placed in collection boxes on site or can be returned by post and are anonymous.

4.2 In year quarter 1 12-13 18 postcards were received and the feedback is summarised below;

##### **New - Brighton & Hove – 18 cards**

Questions/responses	Strongly Agree	Agree	Disagree	Strongly Disagree	Unanswered
(1) Staff were kind and friendly	11	6	1	0	0
(2) Staff listened to me	7	9	2	0	0
(3) I was given the information I needed	5	9	4	0	0
(4) Staff helped me sort out my problems	5	8	5	0	0
(5) I got the help I needed	5	10	2	0	1

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4.3 For the full year 11-12 129 cards were returned in total. There was a change of questions part way through the year so only the data regarding the questions matching the 12/13 questions is included below:

**New - Brighton & Hove – 89 cards**

Questions/responses	Strongly Agree	Agree	Disagree	Strongly Disagree	Unanswered
(1) Staff were kind and friendly	60	28	0	1	0
(2) Staff listened to me	59	28	1	1	0
(3) I was given the information I needed	47	32	7	2	1
(4) Staff helped me sort out my problems	45	29	5	4	6
5) I got the help I needed	43	27	9	3	7

**Other actions and progress**

4.4 The Strategic Commissioner in Children’s Services and the Head of the Integrated Child Development and Disability Service met with parent representatives from mASCot, a parent led ASC support group, in April 2012 to discuss concerns raised and it was agreed that a parent representative would be sought to be part of the ASC Intervention Group ( a multi-professional group considering local service models and pathways ).

4.5 In summer 2012 Amaze, the local parent support organisation, produced a Talk Health report based on feedback from parent carers regarding local health services. Within this CAMHS was highlighted and there has been a meeting between Amaze and the CAMHS services managers to discuss the recommendations. The Talk Health report has been presented to HWOSC who have chosen to champion the recommendations.

4.6 CAMHS has now an established group for parents post ASC diagnosis.

4.7 Within Brighton and Hove City Council Children’s Services there is a Tier 2 Community Mental health and Wellbeing service which had been criticised by parents for lacking any autism specialist knowledge. This service is being funded to attend ASC specific training to enhance the knowledge and understanding of its staff.

4.8 Seaside View has sited within it a mental health service for those children and young people with a learning disability. To enhance this and enable access to psychological support for those children without a learning disability but with a constellation of complex needs additional clinical psychology time is being resourced from the health contribution to the Section 75 in children’s delivery

4.9 Brighton and Hove is part of the SE7 group of local authorities as a pathfinder for the Governments Green paper re Special Educational Needs. Brighton and Hove is leading for the SE7 on parent support and work is being undertaken to better understand how schools communicate with parents and what more could be

done to increase parent confidence in the school's provision for their child. This is not ASC specific but covers the full range of special educational needs. Another strand of the pathfinder work is in the development of a single plan and personalising of support and a third is the development of a local offer. This would set out clearly for parent carers what schools, health and social care offer to pupils and families.

- 4.10 The SEN partnership board launches the city's new SEN strategy on 30<sup>th</sup> November 2012. Enshrined within this is a commitment to undertake further work on educational provision for children and young people with ASC which is welcomed.

## **5. Future scrutiny work**

- 5.1 Members have a number of options open to them at this point. The survey was originally commissioned to inform a decision as to whether a full scrutiny review panel was required.

- 5.2 There is currently a waiting list for scrutiny panels so any further intervention would have to wait until spring 2013 at the earliest unless HWOSC members were to deem it a very urgent matter.

- 5.3 Members can therefore decide:

- To establish a panel now to commence spring/summer 2013
- To establish a panel and request that it commences immediately prioritising it over existing panels
- To allow the survey to continue until later in 2013 and make a decision then
- Decide no further action is required

## **6. COMMUNITY ENGAGEMENT AND CONSULTATION**

- 6.1 Amaze and the local Parent Carer Council are represented on the Disability Partnership board. There is parent representation on the autism steering group

- 6.2 Service providers were consulted on the content of the survey.

## **5. FINANCIAL & OTHER IMPLICATIONS:**

### Financial Implications:

- 5.1 There are no financial implications as a direct result of the recommendations of this report

*Finance Officer Consulted: Name David Ellis Date 05/12/12*

### Legal Implications:

- 5.2 None at present

*Lawyer Consulted: Name Serena Kynaston Date: 11/12/12*

#### Equalities Implications:

- 5.3 Equalities impact assessments would be carried out on any service redesign or development as a result of this report or ongoing work

#### Sustainability Implications:

- 5.4 There are no sustainability implications from this report.

#### 5.5 Crime & Disorder Implications:

Effective diagnosis of mental health and/or developmental conditions leads to increased likelihood of appropriate intervention and support being offered and reducing the risk of antisocial behaviour developing.

#### Risk and Opportunity Management Implications:

- 5.6 This report provides information about the current services. Where services are redesigned or reviewed full risk assessment and management plans would be put into place.

#### Public Health Implications:

- 5.7 The committee is assured that there has been a focus on raising awareness of autistic spectrum conditions to improve diagnosis and interventions.

#### Corporate / Citywide Implications:

- 5.8 The services described in this report support the outcomes of promoting health and wellbeing, inclusion and achievement and reducing health inequality.

### **SUPPORTING DOCUMENTATION**

#### **Appendices:**

1. None
- 2.