Children and Young People Overview & Scrutiny Committee	Agenda Item 15 Brighton & Hove City Council

Subject:		**Services for children with Autistic Spectrum Conditions**	
Date of Meeting:		**14th September 2011**	
Report of:		**Terry Parkin** **Strategic Director People**	
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Ward(s) affected:		**All**	

FOR GENERAL RELEASE

1. SUMMARY AND POLICY CONTEXT:

1.1 This report is produced in response to a letter from the member of the public to the Chair of the Overview and Scrutiny Committee raising concerns about the assessment and management of children and young people with Autistic Spectrum Conditions (ASC) in Brighton and Hove. The parent cited detail of their own experience and case specific information. This report will not respond in detail to the individual case as this has been dealt with via complaints procedures within another organisation. This report will provide the committee with information about the structures and systems in place to assess children presenting with concerns about possible autistic spectrum condition and their ongoing management and support.

1.2 The report provides assurance to the Committee that local services for the assessment and support of children with autistic spectrum disorders are appropriate, follow national guidance and are fit for purpose. Where issues are identified the Committee is advised that these have been recognised and developmental work has been undertaken

1.3 The letter to CYPOSC raised three headlines concerns: appropriate assessment, timely and supportive intervention and access to services for children in private education. This report seeks to address and provide assurance about each of these issues

2 RECOMMENDATIONS:

2.1 That CYPOSC note the content of the report

2.2 That CYPOSC seek further clarification or guidance as required

3 RELEVANT BACKGROUND INFORMATION/CHRONOLOGY OF KEY EVENTS:

3.1 Definition:

Autistic spectrum condition (ASC) is a complex condition with no single diagnostic testing procedure. Diagnosis is based on assessment and observation of a child/young person across what is called the Triad of Impairments (see Appendix 1). In summary these are:

- Qualitative impairment in social interaction
- Qualitative impairments in communication
- Restricted repetitive and stereotyped patterns of behaviour, interests and activities

There are a range of tools used for assessment of each area of the triad whilst other aspects of behaviour are assessed via observation and structured interviewing of those who know the child well. By nature of the condition and its overlap with others and the propensity for ASC to be present alongside other conditions e.g. learning disability, diagnosis can be difficult and sometimes needs to take place over a period of time and in a range of settings.

3.2 Prevalence:

National data cites the prevalence rate of 38.9 in 10,000 for childhood autism, and 77.2 in 10,000 for other autism spectrum disorders, giving an overall figure of 116 in 10,000 for all autism spectrum disorders (Baird et al, 2006).[1]

The authors note that the prevalence estimate found should be regarded as a minimum figure (Baird et al. 2006).

The indication from recent studies is that the figures cannot be precisely fixed, but it appears that a prevalence rate of around 1 in 100 is a best estimate of the prevalence in children. No prevalence studies have ever been carried out on adults. [2]

In Brighton and Hove, the Compass (register of disabled children maintained by Amaze, registration is voluntary and needs/diagnosis self reported) has 388 children [3]who are described as having a diagnosis of ASC. This is from a total child population in Brighton and Hove of approx 55,000 and thus reflects 0.7%.

3.3 Commissioning and service delivery arrangements:

Child and Adolescent Mental Health services (CAMHS) in Brighton and Hove are commissioned and delivered through an integrated care pathway with a single

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[1] Baird, G. et al (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). The Lancet, 368 (9531), pp. 210-215.

[2] National autistic society website- Statistics- how many people have autistic spectrum disorders?

[3] Amaze Annual statistics 10/11

point of referral. There are a number of organisations involved in service delivery across the tiers of provision:

- tier 2 community services are delivered by a partnership arrangement between the council's children's services primary mental health workers and family support workers employed by two voluntary and community sector organisations
- the tier 3 clinical CAMHS service provided by the Sussex Partnership Foundation Trust includes input into a number of multi-agency teams e.g. substance misuse, youth offending, specialist child protection as well as clinic based provision
- tier 4 inpatient and urgent help service and a transitions service for 14–25 year olds are provided by the SPFT.

Commissioning of CAMHS is undertaken by a Strategic Commissioner within the Joint Commissioning Unit based within BHCC and there are regular performance meetings and discussions with managers in SPFT and an agreed performance framework. There is ongoing work to develop detailed service specifications for CAMHS work, including delivery of the ASC pathway, and these will include a set of standards for timeliness of intervention, experience and qualifications of staff involved, reporting and sharing of information and support to families.

There is a multi agency CAMHS Partnership Board in Brighton and Hove with representation from the statutory and community and voluntary sector and parent carers. This allows for sharing of information and identification of needs and areas for development to influence strategic decision making

In 2010 there was a Review of Services for Children and Young People with disabilities and or complex health needs. One of the exercises undertaken was the production of a Joint Strategic Needs Assessment and this included the needs of children with ASC. http://www.bhlis.org/resource/view?resourceId=858

3.4 Performance

SPFT CAMHS in Brighton and Hove in July 2011 reported 100% compliance with the target to see all referrals within 4 weeks. They also achieved 100% compliance with the need to see all children for treatment within 18 weeks.

All urgent cases were assessed in a timely way (100% of urgent referrals responded to in 4 hours) and re-referrals seen within 7 days (100%)

62.9% of CAMHS cases have a completed Strengths and Difficulties Questionnaire (SDQ) allowing for the establishment of effective and appropriate outcomes and their measurement [4].

Within CAMHS, since 2009, there have been 3 complaints made about the assessment and/or diagnosis of ASC with one remaining ongoing.

As the waiting list for assessment is significant at Seaside View, some parents ring to express their anxiety about the length of time they have to wait but there have not been formal complaints made about the assessment process within Seaside View.

[4] SPFT Commissioners report July 11

The views of service users are collected by the provider organisations in a variety of ways including surveys, anonymous postcard reporting and user groups. Amaze provides feedback on parent experience at a strategic level and will also support families in making their concerns heard to service providers and commissioners. This feedback informs both those who provide and commission services and inform service developments.

Ofsted (May 2011) noted that 'Every child and young person has a generic Assessment within 4 weeks and there is a 100% compliance with this timescale, with treatment promptly provided. The CAMHS learning disabilities team provide good direct support to services through pathway plans, providing good advice to schools and carers. They also form an integral part of the multi disciplinary team for looked after children and young people with disabilities and mental health problems'

and that..

…'children and young people with learning difficulties and/or disabilities are provided with outstanding 'wrap around' care from the disabled children's team. This is supported by an effective and very well received key worker system that provides families, including foster families, with advice and support and co-ordinates the care package for individual children and young people. The AMAZE project is an exemplar of good practice for families with children with special needs. Parents who spoke with inspectors at the project reported that there is good take-up of services early, including respite care, by parents who are experiencing isolation, stress and anxiety to prevent family breakdown and the need for children with special needs to enter the care system'

3.5 Assessment and Diagnosis

There are currently two main pathways to diagnosis of an autistic spectrum condition. It should be noted that the age range for the two described pathways has altered since June 2010- prior to that date the pathway at Seaside View applied only to children up to the age of 9 years.

For primary aged children the pathway is as described at 3.6. For older children and young people there is a pathway as defined at 3. 7. The rationale for two pathways, dependant on the age of the child is, following national guidance, that Community Paediatricians are integral to the assessment of younger children to allow for the differential diagnosis of autism vs other developmental conditions. With older children, the more likely differential diagnosis is between a mental health condition and ASC and thus it is considered more appropriate to have a Psychiatrist as part of the assessing team. Both pathways are dependant on professionals working with a child to identify ASC as a possible concern and seek further specialist assessment. Staff in both the child development team, CAMHS and other local services e.g. schools are provided with training in the identification of possible autistic spectrum condition characteristics that would trigger the need for further assessment.

Access to assessment, if needed, is available to all children in Brighton and Hove and is not dependant on their educational setting.

3.6 Autistic Spectrum Condition care pathway primary school aged children:

[5]The current pathway for the assessment and diagnosis of Autistic Spectrum Disorders (ASC) was agreed in 2003 by a steering group led by a consultant community paediatrician and consisting of representatives from PRESENS (Pre School Special Educational Needs Service), ASCSS (Autistic Spectrum Condition Support Services), Educational Psychology, Speech and Language Therapy, Specialist Health Visiting and Senior Management. Its aim was to provide a common and agreed pathway for the identification, assessment and diagnosis for children in Brighton and Hove in whom Autistic Spectrum Disorders are suspected. This process follows the recommendations of *NIASA (National Initiative: Autism Screening and Assessment)* and the current NAPC guidelines.

The pathway has been implemented since 2004 when the first assessments took place at the Children's Development Centre, previously the Mac Keith Centre, and now the Seaside View Child Development Centre situated on the Brighton General Hospital site. The pathway now assesses children up to the end of academic school year 6.

The ASC pathway is monitored by a multi-professional steering group chaired by a Consultant paediatrician. Concerns arising from the group would be taken to the Manager of the Integrated Child Development and Disability service.

See Appendix 2 for details:

3.7 Data:

The detail of children accessing stage 2 appointments at Seaside View is set out in Appendix 3

3.8 Autistic spectrum condition care pathway– CAMHS SPFT – secondary age children

(i) Identification of the need for further assessment

In order for children to be appropriately recognised as needing specialist assessment, Brighton & Hove CAMHS staff have been trained to do a full developmental history/assessment and have also been trained to do a full mental health assessment as part of care planning processes (eCPA).

All Brighton & Hove CAMHS staff have also been given guidance, (in a Service Meeting) as well as written guidance, on how to do a Stage 1 Autistic Spectrum Disorder (ASD) assessment/work up and what to look for as possible signs of a neurodevelopmental disorder.

With the inclusion over the last two years of a wider range of staff/skill mix (e.g. Clinical Psychologists, Nurses and OT's), there are more staff available with training in identification of inherent disorders.

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[5] Dr Sian Bennett **Pathway for the assessment and diagnosis of Autistic Spectrum Disorders: Guidelines for Professionals**

The availability of the Map of Medicine, which is a Nationally developed web site that outlines the identification, assessment and treatment of the whole range of mental health disorders and other disorders, to primary care staff and Tier 2 CAMHS staff, has also aided identification.

(ii)Assessment

The development of Sussex-wide care pathways for ASD (and other disorders) as a Trust initiative, following the Map of Medicine National format outlines the pathway from primary care through to secondary care, and from pre-school through to adulthood. Child and adult ASD services are currently working together on transition issues. The Map of Medicine outlines the evidence base but allows for local variations to also be recorded and available to the public.

The CAMHS assessment incorporates a mental health differential diagnosis, which is necessary when a young person has reached this age without a diagnosis.

The assessment includes a generic Stage 1 assessment/work up and a multi-disciplinary Stage 2 diagnostic assessment following NICE guidelines (June 2011). In CAMHS, there are at least two psychiatrists and two psychologists who have been trained in the formal/standardised ASD assessment in the form of the Autism Diagnostic Interview (ADI) and the Autism Diagnostic Observation Schedule (ADOS) with the other psychiatrists and psychologists currently awaiting training

3.9 Ongoing support for children with ASC

The Stage 2 assessment incorporates a care plan, ensuring follow up from CAMHS (if necessary), Paediatricians, school and the ASC support service, as well as any other services necessary that have been identified (e.g. occupational therapy, speech and language therapy etc). CAMHS would expect to work closely with school and these other services if they are involved in follow up.

A post diagnosis parents' psycho educational group is in the process of being developed by Tier 2 and Tier 3 CAMHS working together in Brighton & Hove, which will be offered to all parents following a diagnosis, either immediately afterwards or when the parents are ready/need it.

Ongoing intervention is provided via a range of services depending on the needs of the child. For children in Brighton and Hove maintained schools there is an ASC support service, operating a service to support schools in the management of children with ASC and advising on curriculum and behaviour issues. CAMHS generic team and /or CAMHS learning disability service, Child Development and Disability Service, Education Special needs services CVS organisations, parent advice and support are all available for families and children with ASC. There is acknowledgement that some families feel they would benefit from more support, particularly related to the child's behaviour at home and there are discussions about how best to take this forward.

Some children may require support in school via an individual education plan or Statement of Special Educational Needs Assessment. Where children require it there are special facilities within the city- units in mainstream and special schools to support children with varying degrees of need and ability to be integrated into mainstream classrooms.

For children attending non-maintained schools, the local authority Autism Support Service is not provided as this is a central support service to LA schools funded by the Direct Schools Grant i.e. a retained amount from the schools budget. Private and Free Schools/Academies can choose how to seek support for children with additional needs. Access to assessment at either Seaside View or CAMHS is not dependant on an educational setting.
CAMHS and other health professionals will produce information and advice to support all schools in managing children and will see children within clinic settings but do not work directly within independent schools. This is acknowledged as an issue and it is currently reliant on the independent setting to secure additional support as required.

4 COMMUNITY ENGAGEMENT AND CONSULTATION

4.1 Service users, parent carers and all stakeholders e.g. CVS organisations are involved in the Partnership Board for CAMHS and service review and redesign is based on both a needs assessment and feedback from consultation.

5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

5.1 There are no direct financial implications arising from the recommendations in this report

Finance Officer Consulted: Andy Moore Date: 02/09/11

Legal Implications:

5.2 This report is for noting only and therefore no specific legal implications arise from it. The report does however demonstrate how the Council meets its statutory obligations to children with Autism Spectrum Conditions, as children in need under S17 of The Children Act 1989 and in compliance with The Autism Act 2010 and The Human Rights Act 1998.

Lawyer Consulted: Hilary Priestley NameDate: 01/09 /2011

Equalities Implications:

5.3.1 Equalities Impact Assessments are undertaken as part of any review or redesign of services described within this report

Sustainability Implications:

5.4

Crime & Disorder Implications:

5.4 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 service level outcomes from the CYPP of promoting health and wellbeing, inclusion and achievement and reducing health inequality

SUPPORTING DOCUMENTATION

Appendices:

1. Diagnostic and statistical manual version IV (DSMIV) description of autism
2. Autistic spectrum condition pathway – primary school age children
3. Data re assessment of primary school aged children

Documents in Members' Rooms

None

Background Documents

None

Appendix 1

The (DSM IV classification)of autism :

A total of six (or more) items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C)

(A) qualitative impairment in social interaction, as manifested by at least two of the following:

1. marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
2. failure to develop peer relationships appropriate to developmental level
3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids)

(B) qualitative impairments in communication as manifested by at least one of the following:

1. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
2. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
3. stereotyped and repetitive use of language or idiosyncratic language
4. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(C) restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

2. apparently inflexible adherence to specific, nonfunctional routines or rituals
3. stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
4. persistent preoccupation with parts of objects

(II) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:
(A)social interaction
(B)language as used in social communication
(C) symbolic or imaginative play
(III) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

In addition there is diagnostic criteria for diagnosis of Aspergers syndrome sometimes described as 'high functioning autism'

There are a range of tools used for assessment of each area of the triad whilst other aspects of behaviour are assessed via observation and structured interviewing of those who know the child well. By nature of the condition and its overlap with others and the propensity for ASC to be present alongside other conditions e.g. learning disability, diagnosis can be difficult and sometimes needs to take place over a period of time and in a range of settings.

Appendix 2:

Staged assessment process

It was agreed that there would be a staged assessment as described below. Currently the pathway based at Seaside View CDC is available for children up to year 6 (prior to 01.06.10 this applied to children up to the age of 9) and a similar process has been and, continues to be, developed for older children in liaison with the CAMHS service.

Referral

Referrals from health and educational professionals are made to the Seaside View Child Development Centre for consideration for a developmental assessment by a community paediatrician, sometimes jointly with other members of the team.

Developmental assessment (known as Stage 1 in retrospect)

This is a general developmental assessment. It may take various forms, and involve various professionals, depending on the age of the child, and the details given by the referrer. It will include a community paediatric assessment as a minimum. It may involve requesting information from other professionals and will always involve requesting information from school/nursery if a referral to stage 2 is made.

ASC specific assessment (Stage 2)

This is requested by the community paediatrician at stage 1, if there is still concern about possible ASC. Stage 2 is a multidisciplinary assessment involving an autism specific history from the parents, and the collation of information from

other professionals, including educational professionals. The speech and language therapist and the clinical psychologist will usually undertake some formal and informal assessments to gain information about the child's language and cognitive profile, alongside some specific observations and assessments of the child's social communication and social interaction skills. There may be some overlap between the assessment at stage 1 and 2. Although the aim is to keep duplication to a minimum, there are a number of reasons why a child may present with certain behaviours, and sometimes detailed discussion with parents, and detailed observations, are necessary to optimise understanding of the child.

The aims of Stage 2 include the identification of a profile of strengths and difficulties for the child, a diagnosis if appropriate, and an initial assessment of unmet need for the family. Details of the assessment process are sent to the family in advance.

Multidisciplinary Planning Meeting (MDPM)

If a diagnosis of ASC is made, and sometimes in other circumstances, the aim is to arrange a Multidisciplinary Planning Meeting for all pre-school children, and school age children if appropriate. It will involve the family, at least one member of the stage 2 team, at least one educational professional, and other professionals as appropriate. The aim is to continue discussion with the family and to formulate a care/intervention plan for the child and family.

Stage 2 Review

In some cases, for a variety of reasons, it is not possible /appropriate to reach a diagnosis at stage 2. (the aim is to keep these cases to a minimum). These children may need a period of observation in school and /or therapy, and a review appointment after a specified time period.

It may or may not be considered necessary to have a planning meeting after this.

Tertiary assessment

For a small number of children it may still not be possible to reach a decision about whether or not to make a diagnosis of ASC, or there may be other complex factors, which require further investigation. In these cases, families will be offered a referral to a tertiary centre which has national expertise in the assessment of ASC. These assessments usually take place at the Newcomen Centre, Guy's Hospital.

Multi-setting assessment

The NAPC recommend assessment of social interaction, which must include focused observations taken across more than one setting, and for primary school children this should include the educational setting.

School/Pre-school

Information from educational professionals in schools and pre-school settings is sought at every stage. Focused observations are requested prior to stage 2 and these are completed either by PRESENS teachers or educational professionals who are most familiar with the child in both the class and playground setting. Referrals to Stage 2 are not accepted until these observations are available.

Sometimes, further observations are undertaken by a member of the diagnostic team in the school or pre-school setting.

Children in special schools and Jeanne Saunders are often assessed in that setting and these assessments involve the speech and language therapist attached to the school or centre who will usually know the child

Home

Information about the child's play and behaviour at home is gathered from parents at all stages.

Sometimes, a home visit may be undertaken particularly if the child is pre-school, or not currently at school. Most often, this is done by an educational professional, specialist health visitor, or nursery nurse.

Clinic

Observations in a clinical setting are provided at all stages. During stage 2 the child is observed engaging in a variety of activities usually by more than one professional.

Other clinic-based observations may be available for example from the local Speech and Language Therapist who has been working with the child in a community clinic or children's centre.

Multidisciplinary assessment and diagnosis

The NAPC advises that *'all the components of a Multi-Agency Assessment should be applied to all children in whom ASC is suspected'*

At Seaside View CDC the stage 2 assessment is coordinated by a multidisciplinary team comprising professionals with expertise in the assessment and management of ASC.

Since some developmental and emotional conditions can resemble ASC, or can co-exist with ASC, a range of professionals is required in order to fully understand a child's profile of strengths and difficulties, and clarify specific diagnoses.

The components of the assessment vary according to the individual child, but the Stage 2 team will consist of at least two of the following professionals:-

- Community Paediatrician (younger children) or Child and Adolescent Psychiatrist (older children/ adolescents).The paediatrician may or may not be the same paediatrician seen at Stage 1.
- Clinical Psychologist
- Specialist Speech and Language Therapist

All the professionals have undertaken additional training and have wide experience in seeing children where there is a concern about their social communication.

Team members are committed to continuing professional development and have regular peer review meetings to consider issues raised by complex presentations and share learning. These meetings are recorded, actions identified and monitored to ensure consistency and address any problems identified in the diagnostic process. The service is registered with the Care Quality Commission (CQC) and licensed to provide multidisciplinary services and is subject to the regulatory requirements laid down by the Commission.

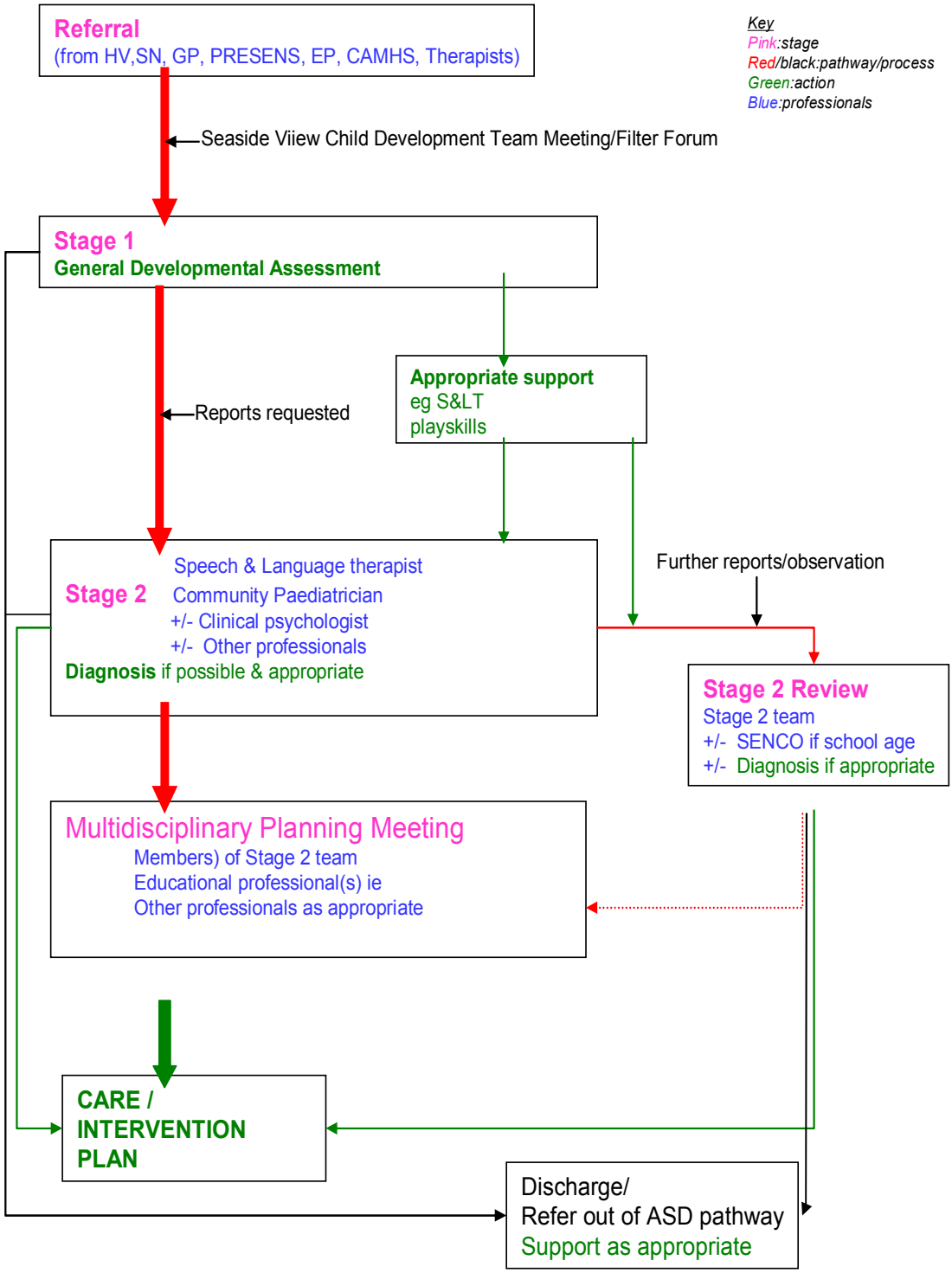
Information and follow-up

The aim is to keep parents informed at all stages. Parents and referrers will receive full written reports after stage 1 and 2 assessments, and after the planning meeting. Permission is obtained prior to requesting information from, and sharing information with, other professionals. If we make a diagnosis of ASC parents are offered a written information pack (in addition to face to face discussion). The nature of this condition and implications for the child and family are discussed with the family. A physical examination will be undertaken at stage 1 or 2 and sometimes medical investigation including genetic testing is discussed.

Appropriate follow-up arrangements are made as necessary, whatever the outcome of the assessment. If a diagnosis of ASC is made , the Special Educational Needs Coordinator at the child's school and the ASCSS (Autistic Spectrum Condition Support Service) are informed; the child's school can make a referral for advice from the Service, but the child and family may need additional referrals. The ASCSS and PRESENS (Pre-school Special Needs Service) will be informed of diagnoses of children in preschool settings so that advice can be offered to the setting. The exceptions to copying in to ASCSS are primary or secondary school age children who attend special schools or independent schools, although parents of children in special schools can still access parent support groups run by the ASCSS.

In addition to the planning meeting, parents are often offered a follow-up visit or phone call from a specialist health visitor, or another key professional, for emotional support, and are encouraged to telephone the team with any concerns or queries.

ASD Assessment Pathway
Children up to Year 6



Appendix 3

Audit ASC of appointments from January to December 2010

	Jan to March	April to June	July to Sept	Sept to Dec	Total
Number of Stage 2 appointments offered	17	15	23	20	75
Number Stage 2 appts DNA or CANC	-	1	5	1	7
Number of Stage 2 review appointments	1	2	-	1	7
Number of Multi disciplinary planning meetings	5	4	-	2	11
Number diagnosed with ASC	9	6	6	7	28
Number NOT diagnosed with ASC	6	5	9	6	26
Inconclusive diagnosis & booked for review	8	3	3	6	20

<u>Referrals received for consideration of Stage 2 assessment</u>

Age at time of referral	Brighton address	Hove address
2	-	-
3	7	2
4	3	2
5	1	3
6	8	2
7	2	1
8	6	1
9	5	5
10	4	-
Total	36	16