

AUTISM SCOPING REPORT DECEMBER 2016

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ACRONYMS

ASD - Autism Spectrum Disorder

SEASIDE VIEW - Seaside View Child Development Centre

T3 –Tier 3

CAMHS - Child and Adolescent Mental Health Service

SPFT- Sussex Partnership Foundation NHS Trust

SCFT- Sussex Community Foundation NHS Trust

ASCSS - Autistic Spectrum Condition Support Service

SCQ - Social Communication Questionnaire

Paed - Paediatrician

MH - Mental health

ADOS - Autism Diagnostic Observation Schedule

ADI - Autism Diagnostic Interview

MDT –Multi disciplinary team

YP - Young person

SEN - Special Educational Needs

EHCP – Education Health and Care Plan

SENCO - Special Educational Needs Co-Ordinator

Disclaimer: The information in this report is based on interviews and information collected during this scoping project. Diagrammatic and narrative information should not be disseminated without permission from Brighton and Hove CCG.

1. INTRODUCTION

Brighton and Hove Clinical Commissioning Group (B&H CCG) Local Transformation Plan (LTP; 2016) set out to improve and access and waiting times for assessment and diagnosis within the autism pathway to align with NICE guidelines, and has set aside investment to achieve this important priority. B&H CCG commissioned this scoping report following The Autism Scrutiny Report¹ and its subsequent action plan (2014) and the Children and Young People's Mental Health and Wellbeing Needs Assessment² (2016).

Brighton and Hove Joint Strategic Needs Assessment³ (JSNA, 2014: 2) CYP with Autistic Spectrum Conditions sets out identified local inequalities as:

Of the 421 children registered with ASC within Brighton and Hove, 390 were male compared to just 91 female... The compass database had lower rates of Black or Minority Ethnic Group (BME) represented in 0-19 year olds than seen in the population of Brighton & Hove as a whole with 17% BME and 83% White British compared to 22% BME and 78% White British in 0-19 years across Brighton and Hove.

Some of the recommended future local priorities identified in the JSNA (3-4) include:

- Nominated key workers for all children with ASC
- A pathway for children with autism but neither learning difficulties for mental health issues
- Improved home support for families
- CAMHS and Seaside View services to put parents at the heart of their provision
- CAMHS and Seaside View to have open and accountable monitoring frameworks
- Clearer accountability lines for all tiers of CAMHS
- Improve links between health visitors and GPs
- All schools take up training to become 'autism aware'
- All Governing Bodies to undergo SEN training and be given copies of Scrutiny Report
- Consideration to be given to increasing funding of ASC support service
- Monitoring of all relevant plans and strategies including those for transition to adulthood
- Appoint an Autism Champion
- ASC working group to oversee Scrutiny Panel Joint Strategic Needs Assessment (JSNA) to include a section on children with autism
- Creation of a youth club for young people with autism

The Adult Autism Strategy for England (2010) and the Brighton & Hove Adults with Autistic Spectrum Conditions needs assessment (2011), identified needs for improvement in the following areas: speeding up the diagnostic process; further education, information and support; training HCPs; transition planning and further awareness and infrastructure improvements.

The children and young people's Autism assessment pathway in B&H is currently split between Sussex Partnership Foundation (CAMHS) and Sussex Community Foundation Trust (Seaside View Child Development Centre).

Autistic Spectrum Conditions (ASC) are developmental disorders causing differences in reciprocal social interaction and social communication, combined with restricted interests and rigid repetitive behaviours, often with lifelong impact. People with Autism also frequently experience a range of

¹ Available at: <https://www.brighton-hove.gov.uk/sites/brighton-hove.gov.uk/files/Draft%20report%20for%20Services%20for%20children%20with%20autism%20final%20April%202014.pdf>

² Available at: <http://www.bhconnected.org.uk/sites/bhconnected/files/Final%20version%20CYPMBW%20Needs%20Assessment%202016.pdf>

cognitive, learning, language, medical, emotional and behavioural problems. These problems can substantially affect a person's quality of life, and that of their families and carers, and lead to social vulnerability (National Institute for Health and Care Excellence. Autism, January 2014).

2. AIMS AND OBJECTIVES

The aim of the scoping was to identify and interview Stakeholders and summarise their views. It was vital that service redesign took a whole system approach, and that steering groups had representatives from stakeholder groups.

Aims:

- Inform future transformation plans
- Identify the interface with other professionals within the pathway
- Highlight current waiting times
- Identify any areas where there are issues in the current pathway
- Consider relevant guidelines (NICE) and National strategy
- Scope other Autism pathways nationally and identify areas of good practice

Objectives:

- To map out the pathway for referral, assessment, diagnosis, and intervention of children's services for Autism for B&H from 0-18 years across the two health trusts; Sussex Partnership Foundation Trust and Sussex Community Foundation Trust
- Make recommendations about future Autism services and transition.
- Provide a solution to monitoring and reporting of the pathway in the future
- Identify appropriate KPIs
- Develop an action plan for further improvements required from December 2016 onwards (ensuring this is programmed for the next 3 years)

3. PREVALENCE⁴

There were 59,000 CYP aged 0-19 resident in B&H, and around 31,550 CYP attending schools in the city (excluding independent schools). Prevalence of ASC in the UK is estimated at between 0.2 and 1%, and the JSNA (2014: 1) estimates between 118 and 590 CYP in B&H have a diagnosis of ASC at any time.

4. METHODOLOGY

Several face-to-face interviews were scheduled with a range of identified participant (see appendix 1). Several parents and carers whose children had recently accessed the service were contacted by telephone to ascertain their views (see Appendix 4-6). Participants were asked semi-structured questions relating to the current provision of service. Interviews took place either in person, or by telephone. Others were conducted with a group of professionals/ parent's carers of children who had accessed services at CAMHS and Seaside View (SSV). A questionnaire was designed to give to parents who were unable to attend the meeting at The Aldrington Centre (see appendix 2). Some feedback from parents was sought by contacting parents of recently diagnosed children/young people.

Participants were recruited through existing services, agencies that interface with the pathway and third sector organisations.

⁴ Brighton and Hove JSNA 2014, CYP with Autistic Spectrum Conditions.

4.1 LIMITATIONS

It would not be possible to capture every opinion through the course of the scoping, and the summaries presented reflect overarching themes.

5. CURRENT PATHWAY PROVISIONS AND PROCESSES

At present, Autism referrals, diagnosis, and interventions are split between two services in Brighton and Hove (B&H). Children who are primary school age (11 years and below) are referred to community child health professionals at SSV Child Development Centre, which is provided by Sussex Community Foundation NHS Trust (SCFT).

Children aged 11 and above are seen by mental health professionals who work as part of Specialist Tier 3 Child and Adolescent Mental Health Service (T3 CAMHS), provided by Sussex Partnership Foundation NHS Trust (SPFT).

Figure 1 is an outline of the pathway for children referred to T3 CAMHS (SPFT) and Figure 3 is an outline of the pathway at SSV (SCFT). Each pathway currently uses different routes to assessment and different professionals at various points in the assessment process.

Post diagnostic support is similarly varied depending on which service assesses the child.

5.1 WAITING TIMES

NICE guidelines state that from autism referral (after preliminary assessment and if autism is suspected) assessment process should start within 12 weeks. B&H CCG Local Transformation Plan (LTP; 2016) sets out an ambition to improve and access and waiting times for assessment and diagnosis within the autism pathway to align with NICE guidelines, and has set aside investment to achieve this important priority.

6. DESCRIPTION OF CAMHS 11+ AUTISM PATHWAY

Children over the age of 11 years can access assessment for Autism through CAMHS. There are two potential routes to the Autism assessment pathway; those who are referred specifically for an Autism diagnostic assessment (via parent or outside agency) and those where a child is already accessing intervention for a mental health difficulty and a CAMHS clinician identifies that the child presents with features consistent with Autism.

6.1 REFERRAL CHILD REFERRED FROM OUTSIDE AGENCY

When a parent has presented to their GP (or other agency) with concerns about Autism, and a referral is received by Specialist T3 CAMHS (SPFT). A Social Communication Questionnaire is sent to the family for completion (SCQs, a validated screening measure for social communication difficulties).

A School comments form is also sent out to the YPs school. If the referral only relates to parental concerns without further clinical information about Autism, the Triage team write back to the parent and request that they contact the child's school to see whether they share similar concerns and request the school contact CAMHS. If the Triage team do not receive the relevant information there is no follow-up response from CAMHS and the case is not opened.

At present, there is no process to follow up cases which have been referred, CAMHS request further information and then this is not received. Of those cases where the relevant information is returned (e.g. school comments form, SCQ and referral information), the Triage team review the

information and decide whether to accept the referral for an initial Choice appointment at CAMHS or signpost them to other relevant services.

From the point at which all the information is received by CAMHS and the referral is accepted, CAMHS have a standard 4-week target for seeing initial Choice appointments.⁵ The parents and child are invited in for a Choice appointment which typically lasts 45 minutes. In order to assess any concerns pertaining to risk, the clinician would normally see the child alone for part of the assessment.

Following this initial Choice appointment, if the family are seeking an assessment and there is some relevant clinical information in the Choice appointment, the child is placed on the waitlist for a Stage 1 Autism assessment.⁶

6.2 STAGE 1 ASSESSMENT

The target for Stage 1 is 12 weeks from Choice appointment at T3 CAMHS in line with NICE guidance. The assessment consists of following clear guidance and a suggested proforma for Autism non-specialists to ask parents about medical history, family background and developmental history. The clinician meets with the child for a clinical interview and clinical observations. The information is collated into a Stage 1 report template including school comments and SCQ. This is submitted for consideration in the specialist Autism panel MDT referrals meeting, which has one Psychologist and one Psychiatrist present. Stage 1 reports are read and a decision is made as to whether to propose the child for a Stage 2 diagnostic assessment.

If the case is not accepted, a letter is written to the referring Stage 1 clinician to inform them (also copying in GP and parents). The Stage 1 clinician then decides as to whether the case should be closed to CAMHS or there are ongoing MH difficulties and an intervention is required. If the case is accepted to Stage 2 the family are informed and they are placed on a Stage 2 waiting list for an assessment.

The alternative route to Stage 1 assessment occurs when a child is referred for to CAMHS and is seen at Choice for a MH difficulty where the Choice clinician identifies a concern around Autism and refers for a Stage 1, or a clinician treating a child for a MH difficulty has concerns about Autism. In this instance the clinician providing the therapeutic intervention is expected to send out the school comments form, SCQ and complete the Stage 1 assessment report alongside the intervention work and refer to Stage 2.

6.3 STAGE 2 ASSESSMENT

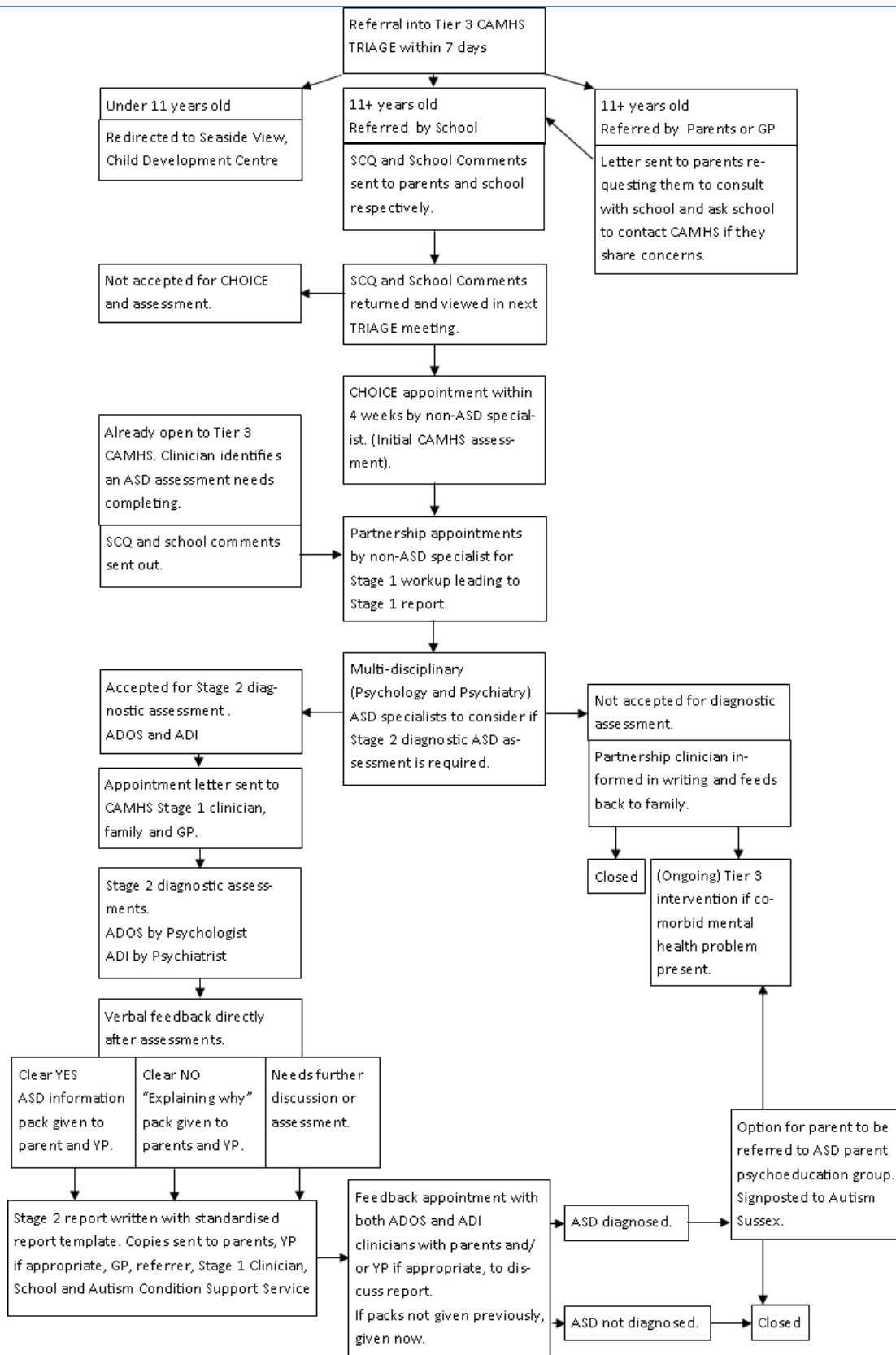
The Stage 2 process consists of diagnostic assessment with standardised tools conducted with parent/carer and child. The child will meet with an Autism specialist to conduct the ADOS and in the parental appointment an Autism specialist conducts the ADI. Ideally these appointments should be conducted jointly by a Psychiatrist and a Psychologist undertaking both of the assessments concurrently with the child or parent at the same time/date. Often however, these two parts of the overall diagnostic assessment are completed in two separate appointments (parental and child). Due to lack of resources, there are also occasions when both parts of the assessment are completed by Psychologists rather than an MDT assessment (including a Psychiatrist and a Psychologist). A joint report is then compiled which includes the results of the two assessments, conclusions and recommendations.

⁵ A Choice appointment is an initial mental health assessment for all referrals entering T3 CAMHS in Brighton. The assessment aims to understand the child's current difficulties, any risk involved, and whether a T3 CAMHS assessment or intervention is required. The Choice clinician would be a non-ASD specialist member of the MDT.

⁶ The 'Choice appointment' explanation is clear but in the appointment letter – this terminology is not adequately explained.

If possible, verbal feedback regarding whether the assessments indicate a diagnosis of Autism is given immediately if the outcome is clear as per Figure 1. However, when the assessment is split, feedback is booked in separately. Parents/carers are sent a copy of the Stage 2 report which summarises the assessment and recommendations and then invited for a feedback session.

FIG 1. SPECIALIST CAMHS 11-18 YEARS CARE PATHWAY FOR AUTISM



7. CAMHS AUTISM 11-18 YEARS INTERFACE WITH WIDER SERVICES

SPFT are responsible for the assessment and diagnosis of 11-18 year olds. The CAMHS care pathway for Autism pathway highlights interfaces with wider service throughout the pathway to gather further information to support the diagnostic process, and to provide post-diagnosis support, including the following:

- Schools including SENCO
- Educational psychologist
- Autistic Spectrum Condition Support Service
- Autism Sussex
- Family Information Service
- AMAZE

8. DESCRIPTION OF SEASIDE VIEW (SSV) CHILD DEVELOPMENT CENTRE AUTISM PATHWAY FOR CHILDREN AGE 11 YEARS AND YOUNGER⁷

8.1 PRE-STAGE 1

- Some children may be open to community health services such Health Visitors and Community Speech and Language Therapist (SALT).
- If a professional in the community is concerned about Autism, they may seek advice and guidance from a health professional based at SSV. Often these are younger children and a speech other developmental difficulty or other neurodevelopmental concern has been identified by community staff.
- The pre-School SALT lead based at SSV child development centre works closely with community SALT professionals, would facilitate a referral to Stage 1 Paediatric appointment if necessary.

8.2 STAGE 1

- Initial referrals come to a central Triage point at SSV child development centre (SCFT) and are discussed at a referrals meeting.
- The referral form for child health services at SSV captures information about social communication.
- If the referrer is a SENCO or Health Visitor, full information tends to be provided.
- If the referral is from a GP, and with minimal information, referrals are redirected to the Health Visitor or education setting as appropriate, and they are asked to complete the relevant referral information forms.
- Once any information is received and discussed an appointment is offered with a Paediatrician within 18 weeks – usually within 12 weeks.⁸

8.3 STAGE 2

- The Paediatrician who saw the child for the initial appointment (now called Stage 1) makes the referral for Stage 2 which includes a letter/ report outlining the information from the Stage 1

⁸ In some cases, appointments are pencilled in when the information is not received but is pending. This is a general developmental appointment, the outcome of which may be to refer onto Stage 2, but it could involve further information gathering and review if there is a lack of clarity at this Stage.

appointment. This is then considered by a multi-disciplinary team (MDT) at an Autism referrals meeting involving a Paediatrician and SALT.⁹

- At the meeting a decision is made as to whether the referral should be a Stage 2 assessment. One possible outcome is that there is a discrepancy between information from home and school is identified. This may result in the clinician completing an observation of the child and it is then it is decided whether to take it forward for a Stage 2.
- The Stage 2 appointment is completed with both child and parent. The parent will spend time with a Paediatrician who will complete a developmental history based on the ADI assessment tool. Depending on the child's age and presenting difficulties, they will either spend time with a SALT clinician (who will conduct a pragmatic assessment of social communication and interaction based on the ADOS) or a Clinical Psychologist (who will complete an ADOS).
- Once both parts of the assessment are complete the parent and child meet the clinicians to discuss the information collected during the assessment. The parent is given feedback and told whether the child meets the diagnostic criteria (based on ICD-10), and given a written copy of any further actions with identified responsibilities.
- If a diagnosis is given the family are automatically offered a follow-up appointment with the Specialist Health Visitor at their home, and are eligible to a post diagnostic support group. A multi-disciplinary meeting (MDM) is organised at the child's education setting, and a clinician from SSV attends this meeting.

9. SEASIDE VIEW AUTISM 11 YEARS OR YOUNGER INTERFACE WITH WIDER SERVICES

Sussex Community NHS Foundation Trust (SCFT) pathway for Autism at Seaside View child development centre highlights several possible interfaces with wider services. SCFT are responsible for the assessment and diagnosis of 11-18 year olds. The pathway highlights interfaces with wider service throughout the pathway to gather further information to support the diagnostic process, and to provide post-diagnosis support. These include:

- SALT Clinicians (community and specialist)
- Pre-school SEN
- Teachers
- Paediatrics
- B&H Inclusion Support Service

⁹ And, in the past a Psychologist, however this does not happen at present as the meeting is on differing times/days to the working hours of the psychologist

FIG 2. SEASIDE VIEW CHILD 11 YEARS OR YOUNGER CARE PATHWAY FOR AUTISM

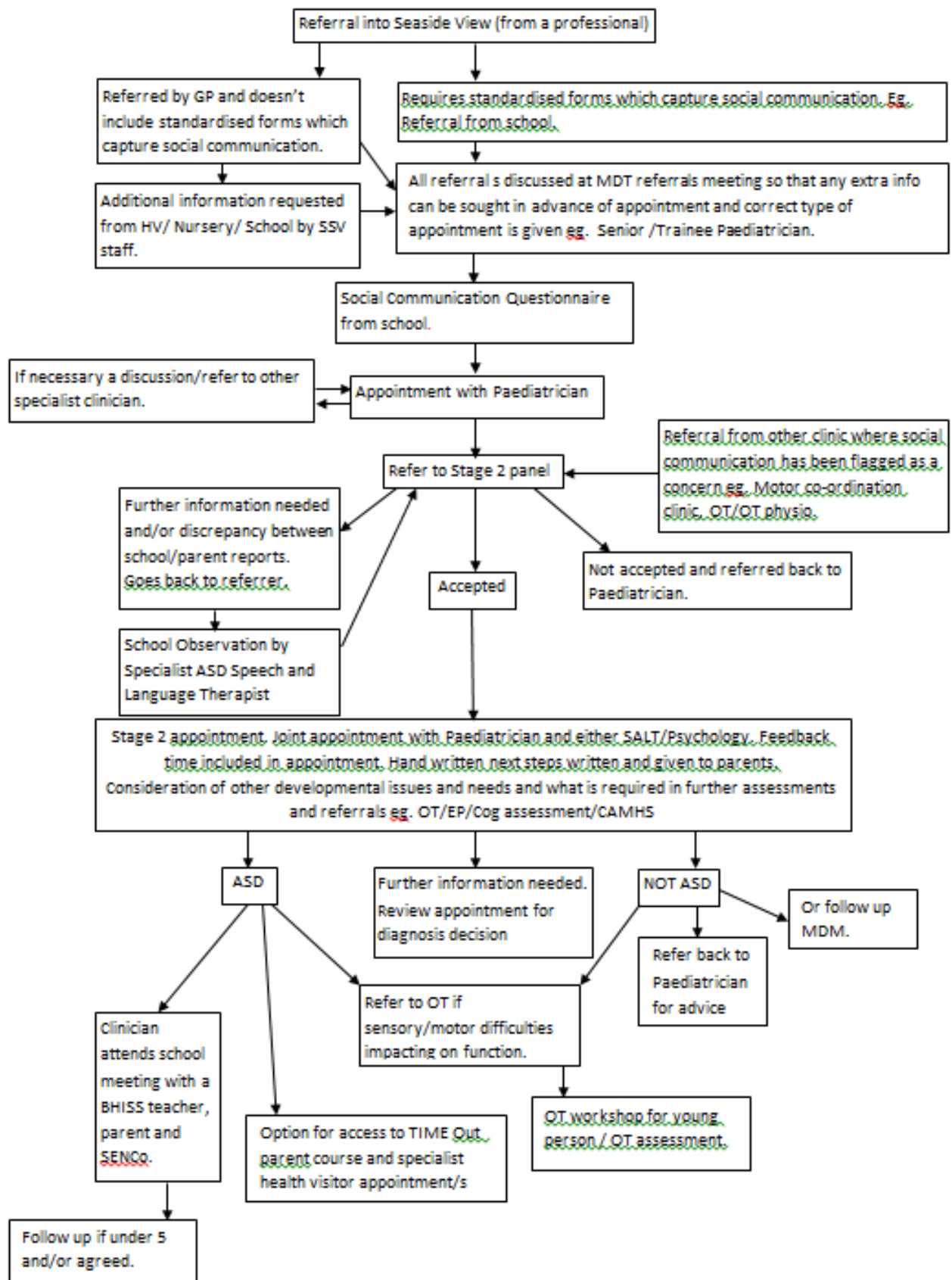
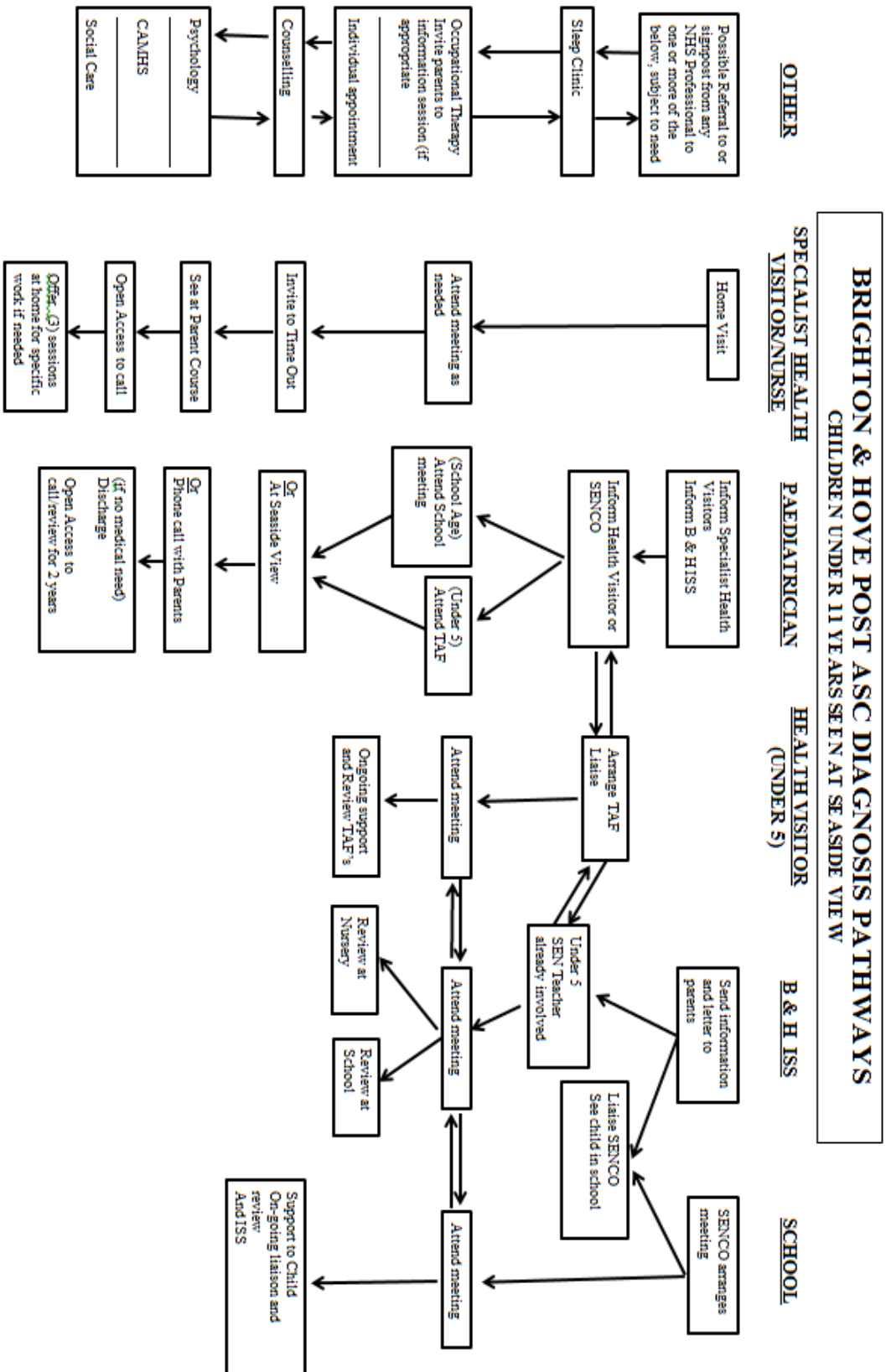


FIGURE 3: SEASIDE VIEW POST DIAGNOSTIC PATHWAY.



10. WHAT IS AVAILABLE POST DIAGNOSIS FOR CHILDREN?

The scoping has highlighted that there are a number of post diagnostic interventions in B&H.

For child year 6 and below (under 11 years old):

- Multi-disciplinary meeting (MDM; including: Nursery, Health Visitor, School Nurse (rarely, Brighton and Hove Inclusion Support Service (BHISS) parents, Paediatrician (where available)¹⁰)
- Parents offered a group (for one parent only due to capacity)
- Appointment at home for parents with Specialist Health Visitor

Courses:

- Time out courses (for children up to and including reception year): facilitated by Specialist HV, SEN Practitioner and B&H Inclusion support service
- Exploring Autism course (for year 5 and upwards): facilitated by T3 CAMHS

11. WHAT IF IT IS NOT AUTISM?

Current access to health service provision for Autism can vary depending on whether the child was assessed at SSV or CAMHS.¹¹ There is limited part time psychology provision at SSV for children with a neuro disability and specific complex psychological or behavioural issues (not just those with ASC) that do not meet CAMHS thresholds.

Psychology provision is employed initially through a professional consultation which may lead to advice or signposting to CAMHS other services, or to direct appointments with or without the paediatrician and/ or short term work. In CAMHS, follow up intervention is for CYP who have comorbid mental health, whether or not there is a diagnosis. Follow up psychology work at SSV is very limited.

Children who do not receive a diagnosis of Autism but require ongoing support due to other neurodevelopmental difficulties may be referred to other specialist clinics/ agencies / followed up and an MDM may be arranged with their school, but these are limited in number because of restrictions on medical time. Those CYPs who do not receive a diagnosis but have possible mental health difficulties can be offered a service from CAMHS tiers 2 or 3 or be signposted to relevant agencies. Anxiety is a common feature in children with ASC and it can be difficult to access specialist mental health advice unless this is extreme and disabling

There is currently a series of parent workshops run by Community CAMHS which are standalone sessions aimed at a wide range of difficulties/issues including:

- Resilience
- Attachment
- Executive Functioning
- Sensory
- Emotions
- Communication
- Behaviour

¹⁰ If paediatrician cannot attend the MDM they offer a follow up appointment to the parents at SSV.

11.1 WIDER SERVICES

There are several statutory and voluntary services in B&H for children and young people with Autism and are detailed below:

- a) **mASCot** is a voluntary organisation with approximately 330 member families. It is a parent led group and provides information and support
- b) **B&H Inclusion Support Service:** is part of a service which support children and families with a range of additional needs including Autism, and offer support services for parents of pupils with an ASC diagnosis. The service includes a Family Worker who organises regular meetings with parents and carers on a range of topics
- c) **Amaze:** work with parents and carers of disabled children and children with special educational needs and disabilities aged 0-25. Amaze offer one point of access for information, advice and support on issues relating to education, social care, leisure, money matters and health care. Amaze supports the PaCC, a city-wide group of local parent carers that provides a voice for parents of children with special needs and works to improve local services
- d) **Autism Sussex:** includes a Sussex wide Family Support Services acknowledges and offers support to family members affected by Autism including parents, carers and siblings
- e) **National Autistic Society:** Are the leading UK charity for autistic people and their families. They provide information, support and pioneering service

11.2 TRANSITION

Transitions for CYP with Autism from primary school to secondary school or transitioning between services can be difficult and anxiety provoking. The adult Neurobehavioral Service recently completed a scoping exercise which examined a range of issues including transition between CAMHS and Adult Mental Health Services.

The adult Neurobehavioral Service has suggested several recommendations¹² including a 'Transitions Pathway' which are summarised below:

- *Regular interface meetings between CAMHS/Wellbeing/ATS/TAPAs to consider the young people who will need a service into adulthood from age 14.*
- *Hold events where services present on services they provide to increase understanding about each other.*
- *Produce clear care plans agreed by professionals in both services in advance, to avoid increasing anxiety, avoid repeated assessments and introduce workers to young person prior to transfer.*
- *Target work with TAPA workers to improve transition to adult services for young people with autism (and no-LD) who are often in the hard to engage group, and most likely to be seen in this service.*
- *Develop a transition pathway of support for young people with autism who will require or want support from adult autism services*

There is opportunity for children's services involved with children and young people with autism Adult Autism Services to work more closely and to share skills and resources. This may also be beneficial in considering how CAMHS and Adult services can work together to consider intervention/courses relating to emotions and life skills.

¹² It would be helpful for a service redesign to consider the findings from the Adult Scoping Report and recommendations.

12. GUIDANCE, AREAS OF GOOD PRACTICE AND BENCHMARKING

B&H Children and Young People Joint Strategic Needs Assessment: CYP with Autistic Spectrum Conditions (2014: 1) estimates between 118 and 590 CYP aged 0-19 in the city to have a diagnosis at any time, with around 65-315 in schools.

12.1 RELEVANT GUIDANCE

A full review of all relevant guidance is outside the parameters of this scoping project however several national guidance and published reports relevant to Autism and service provision are summarised below.

12.2 NATIONAL INSTITUTE OF CLINICAL EXCELLENCE (NICE)

The NICE provides national guidance and advice to improve health and social care. In the UK NICE provides a framework and set of standards for Autism assessment and follow up services for children and young people. The most recent NICE guidance (CG128) released in 2011 titled "Autism spectrum disorder in under 19s: recognition, referral and diagnosis". NICE has identified a number of vital resources that a quality pathway for young people with autism should have:

- A multidisciplinary steering group with representatives from health, social care and education who are able to make decisions and drive change in order to ensure an effective pathway
- A clearly defined autism diagnosis team, with specific professionals as key members and associated professionals identified and to be brought into the team as necessary. This team should be able to assess, diagnose and communicate a diagnosis sensitively and appropriately to families, as well as being a knowledge base for professionals in need of advice.
- Specialists (or links to specialists) in co-existing conditions in order to ensure smooth transitions into other services as appropriate
- Formal links to adult health and social care teams in order to manage transition.
- Clear, standardised assessment protocols in order to diagnose autism
- A case co-ordinator who can act as a single point of contact for families during the diagnosis process
- A clear process for children and young people who require additional tests and diagnostics after an initial autism assessment and formal links with the services who provide these tests.
- An opportunity for families to meet with clinicians at diagnosis, and a protocol for how the diagnosis is communicated and a plan for post diagnosis support as appropriate
- Information, advice and support for young people and families throughout and after the diagnosis process.
- Diagnosis may involve a paediatrician, child psychiatrist, clinical psychologist and SALT

12.3 CYP IAPT¹³

The Children's and Young People Improving Access to Psychological Therapies (CYP IAPT) programme is a whole service transformation model that seeks to improve the quality of CYP mental health services. The principles behind CYP IAPT underpin the development and delivery of the Local Transformation Plan and feature in 'Future in Mind'. As part of the transformation of services a number of training programmes for staff have been developed, including CYP IAPT training for Autism Spectrum Disorders & Learning Disabilities.

12.4 TRANSFORMING CARE AGENDA¹⁴

'Transforming care for People with Learning Disabilities – Next Steps' was published in 2015 and set out recommendations to transform care services in supporting people with a learning disability and/ or autism who display behaviour that challenges (including those with a mental health condition). The plan builds on other transforming care work to strengthen individuals' rights; roll out care and treatment reviews across England, to reduce unnecessary hospital admissions and lengthy hospital stays. The paper explores the following:

- Re-shaping and re-designing services for people with learning disability and/or autism in partnership with people with learning disability and/or autism their families, clinicians, commissioners, providers, other national organisations in the health and care system and other stakeholders.
- To ensure that people with learning disabilities and/or autism experience righteous and lawful treatment and support within services and the community.¹⁵
- Provision of a clear model of care for people with learning disabilities and/or autism.
- To ensure regulation and inspection of care providers.
- Workforce development of those working with people with learning disabilities and/or autism and mental health conditions.

13. AREAS OF GOOD PRACTICE IN BRITAIN

As part of the methodological process of the scoping for this report, several services were identified to explore areas of best practice, and is summarised below,

Assessment:¹⁶

- ADOS assessments do not routinely need to be completed, a diagnosis could be given using ADI/DISCO and ASC specific observations the ADOS should be used to help answer a diagnostic question when it is unclear from 'the developmental assessment tool' i.e. ADI/ DISCO.
- ADOS should always be completed in pairs. Or ideally, one person should always be identified as the lead clinician who will also lead on writing the report.
- The service should operate on a fixed capacity based on prevalence and therefore estimated assessment. Clear databases highlight when capacity is reached and the commissioner is alerted if this happens.
- ADHD should also not be part of CAMHS and is a neurodevelopmental condition but commonly requires on going management advice and assessments of family dimension

Pathway processes¹⁷:

- Referrals via Early Help/ CAF must include all information about what has been provided by other agencies, academic levels and what assessments might have been done e.g. Educational Psychologists and needs to be sufficient evidence of behaviours or difficulties likely to be associated with autism.

¹⁴ More details on Transforming Care Agenda can be found at <https://www.england.nhs.uk/learningdisabilities/care/>

¹⁵ See also: (Sir Stephen Bubb – 'Winterbourne View – Time for change: transforming the commissioning of services for people with learning disabilities and/or autism' (November 2014).

¹⁶ Taken from an interview with: Consultant Clinical Psychologist in Oxleas NHS Foundation Trust Adult Autism Spectrum Disorder Assessment team.

¹⁷ Taken from an interview with: Team Manager, Neurodevelopmental Service, Cambridge and Peterborough NHS Foundation Trust.

- Once a diagnosis is given all families are expected to attend a Cygnet (Barnardo's Autism specific) programme (6 weeks) and psychoeducation group for teenagers on their diagnosis.

Hackney Ark, Homerton Hospital NHS Foundation Trust:

Hackney Ark is a centre for children and young people with disability and special educational needs (SEN). It brings together services from across the fields of health, education and social care to provide an integrated response to the needs of disabled children and their families.

Outlined below are several key areas of good practice:

- Multi-disciplinary team where decisions were always made jointly.
- Strengths focused on feedback.
- Autism specialist clinicians seeing children and parents at first appointment.

13.1 AREAS OF GOOD PRACTICE IDENTIFIED IN B&H

The following section summarises areas of good practice identified in the scoping project, which are of benefit to the development of future service provision.

Sussex wide Autism care pathway meetings.

- Bi-annual meetings with all clinicians from CAMHS and Community Child Health, and more recently widened the invitation to include paediatrics.
- Participants are invited to share ideas, knowledge and areas of good practice and to discuss the latest clinical information and developments as well as reflect on care delivery

Quarterly Seaside View Autism meetings

- Meetings are attended by all professionals in the pathway with the aims to discuss specific individual diagnostic issues or learning other clinical issues, developments, training, report writing and audits. These meetings are attended by a CAMHS representative whenever possible.

Bi-monthly CAMHS Inter-rater reliability meetings

- ADOS trained clinicians who are part of the Autism diagnostic assessments have peer supervision and rate and review videotaped ADOS assessments to ensure that assessors are complying within clinical and governance frameworks, and clinicians are scoring reliably when using the standardised assessment tool (ADOS).

Joint MDT assessments and joint feedback

- Both clinicians are involved in the assessment process and make a joint decision about diagnosis.
- Parents are given immediate feedback and do not have to wait for a further appointment to find out the outcome of their child's assessment.
- Clinicians are given allocated time to discuss the information and give clear feedback to parents.

Outreach/ school observation pre/ post assessment (at Seaside View only)

Clinicians reported the selective use of observations pre-and post-assessment when necessary reduced the likelihood that there would be a lack of clarity of Autism diagnosis at assessment stage.

Post diagnostic multi-disciplinary meeting (Seaside View only)

- A post diagnosis MDM enables family, Health and Education professionals to link together to think about the child's needs and strengths and provide tailored advice and guidance.

This is not a service which CAMHS is currently able to provide and would not be routine practice.

Clinicians

- A key theme identified from a group of parents whose child had recently been assessed at CAMHS/ Seaside View, was that clinicians were helpful and understanding. It should be noted that this was not the experience of all the parents contacted and only those who were part of the telephone interviews.

Post Diagnostic Groups¹⁸

- Clinicians and parents (from two recent evaluations see Appendix 7 and 27) felt that the post diagnostic groups were an area of good practice.
- Although the evaluations contain small number of data, they provide evidence that the post diagnostic groups are valued by the parents that access them.

Specialist Health Visitor for Autism (Seaside View only)¹⁹

- A recent evaluation of the post diagnostic visit offered by the Specialist Health Visitor identified that this was a valued and useful service offered at Seaside View (see Appendix 8).

SALT preschool liaison (Seaside View only)

- The SALT ASC specialist at Seaside View is currently able to liaise with community services and provide consultation/training around Autism and subsequently reported that children are being identified earlier and this is reflected in a list of children identified pre-referral at Seaside View.
- The links with community services means that more children are likely to be identified earlier for diagnosis.

Autism working group –brings together all stakeholders

- There is a working group in B&H for Children's Autism. This group brings together Stakeholders and is an opportunity to work together collaboratively and consider service provision and any concerns.

Voluntary sector support

- Although parents/ carers acknowledged the limited resources as a general ongoing issue across all areas, they (as well as clinicians) commented that there was good voluntary sector support in B&H.

Feedback from YP

- Insights from interviews with CYP and parent who accessed the Autism assessment pathway in CAMHS highlights a key which relates to transparency and the need for timely information as a key area for improvement.
- Patients reported positively about the T3 service because they were allocated a clinician who continued to support her and her family throughout the diagnostic process, stating: *'if it*

¹⁸ For the Exploring Autism group 7 out of 8 parents reported they would 'highly recommend' the group to others. One of the comments was also 'wish there was another one or regular'. Another comment was "Very well run course by facilitators who were knowledgeable and generous". Similar feedback was gathered from the Time Out group for Autism Spectrum Condition evaluation with comments such as "I have found out much more about what is available for children with Autism". A pre-and post-score average was taken for two questions. "How confident do you feel about being a parent of a child with Autism? pre: 5.9 post: 7.7. How much do you understand about Autism? pre-5.8 and post 8.2 scores.

¹⁹ For example, when asked was the visit helpful? 7 out of 7 respondents replied "yes".

wasn't for my CAMHS worker I would not be back in school and doing the things I want to do'.

- Waiting times were an issue for some respondents
- Respondents felt they valued the expertise of CAMHS Clinicians and reported: *'if there are things that have gone on in the week, I know I can talk to him and he will understand'*
- It was reported that it was helpful that felt the diagnosis process was well explained and their CAMHS clinician was open and transparent about the long wait times, and gave immediate feedback

13.2 SECTION SUMMARY

In future service development, it would be prudent to review existing demand and capacity in the system with a view to improve waiting times and demands on resources. It is essential that the service becomes NICE compliant, and that CYP IAPT is embedded into the service as well as fulfilling the recommendations of the 'Transforming Care Agenda'. It will be useful to learn from good practice in the UK around areas of assessment, pathway process, and multi-agency MDT approaches. More locally, best practice in B&H services should be harnessed especially around: effective communication, MDT approaches, involvement and information sharing.

14. SUMMARY OF THEMES FROM SCOPING INTERVIEWS²⁰

Scoping interviews have raised several relevant themes for the purpose of making recommendations for future services. This report also highlights differences across the two services. Themes include:

Identification of Autism

- Parents are not able to clearly identify behaviours associated with Autism, and one parent stated: *"parents don't know what is normal, they need educating before they are put on the pathway"*
- Future pathway development must explore how to support the family in diagnosis
- Schools can and do access support from CAMHS, BHSS, Educational Psychologists and refer to SSV, though it would be useful to clarify a pathway for pre-referral consultation

Referral

- People are confused about the different pathways (and criteria) available resulting in an inconsistent approach
- Support for parents before diagnosis was not adequate
- Concerns about a neurodevelopmental condition is best treated in mental health and one parent stated: *"Autism from a parents point of view is not a mental health condition...this immediately puts barriers up when parents get a letter from a mental health service "*

Assessment

- Once a child is accepted onto the assessment pathway the family will receive different services
- depending on whether the child is over age 11 years or not. This service division, which differentiates young people on age rather than need has been reported as *'arbitrary'* by many of the Stakeholders.
- The Autism care pathway is structured very differently pre-and post 11 years
- Issues of timeliness of the assessment process have been highlighted

²⁰ Please see the recommendations which details suggestions for change given the gaps/areas of review/improvement identified in the scoping project.

- Younger children are seen by a highly specialist Autism clinician much earlier in the assessment process than those children in CAMHS (post 11)

Post-diagnosis

There is a range of post diagnosis support, it was reported that:

- SSV offer additional support including a school network or MDT meeting with BHISS; a follow-up appointment with a health visitor with an option for parents to visit them if required in the future
- Post –diagnosis support exists at SSV for sensory difficulties in children with Autism
- Parents wanted to be able to access services before things got to crisis point and before a mental health service was required and one parent reported:
“We do not want children to need CAMHS, it should never get to the point that a child's self-esteem is so low they are self-harming or feel they no longer want to live in a world that fails to adjust to their processing ability”

Waiting times

- If a child is referred to CAMHS for an assessment wait times are longer and there are an increased number of Stages before a child may be progressed for a Stage 2 assessment.
- Parents/carers consistently report wait times to be an issue and feel that there is a significant period of uncertainty and challenges for which there is very little pre-diagnostic support

Communication and support to parents and carers

- Parents reported that there were difficulties with communication during assessment, that they had to chase information and waiting time details, it was not always clear as to the process they had to follow, and not always knowing who to contact. One parent said *‘I would like to be given information on to ask for another clinician, make a complaint, who to go to during the process.’*
- It was felt that it would be much harder for a young person with Autism to articulate their wishes/needs and information should be given in a written accessible format
- Clearer information on the diagnosis process should be made available to CYP/ Parents and carers
- *One parent said “we need social care, education, health and mental health to work collaboratively and talk”... they don't all need to be involved in the diagnostic pathway but they should be linked in”....at the moment, it's the people in the services who might join things up but the services themselves don't”.*

Resources

- OTs at SSV are working in the pathway but this is not mandated
- Having no administrative support in the CAMHS pathway, or relying on untrained interns can cause issues
- CAMHS strive to conduct joint assessments with psychiatry and psychology, however, this does not always happen due to the competing demands and lack of psychiatry time available in the pathway
- Joint assessments are not always happening
- Waiting times impacted by limited resources where it exists

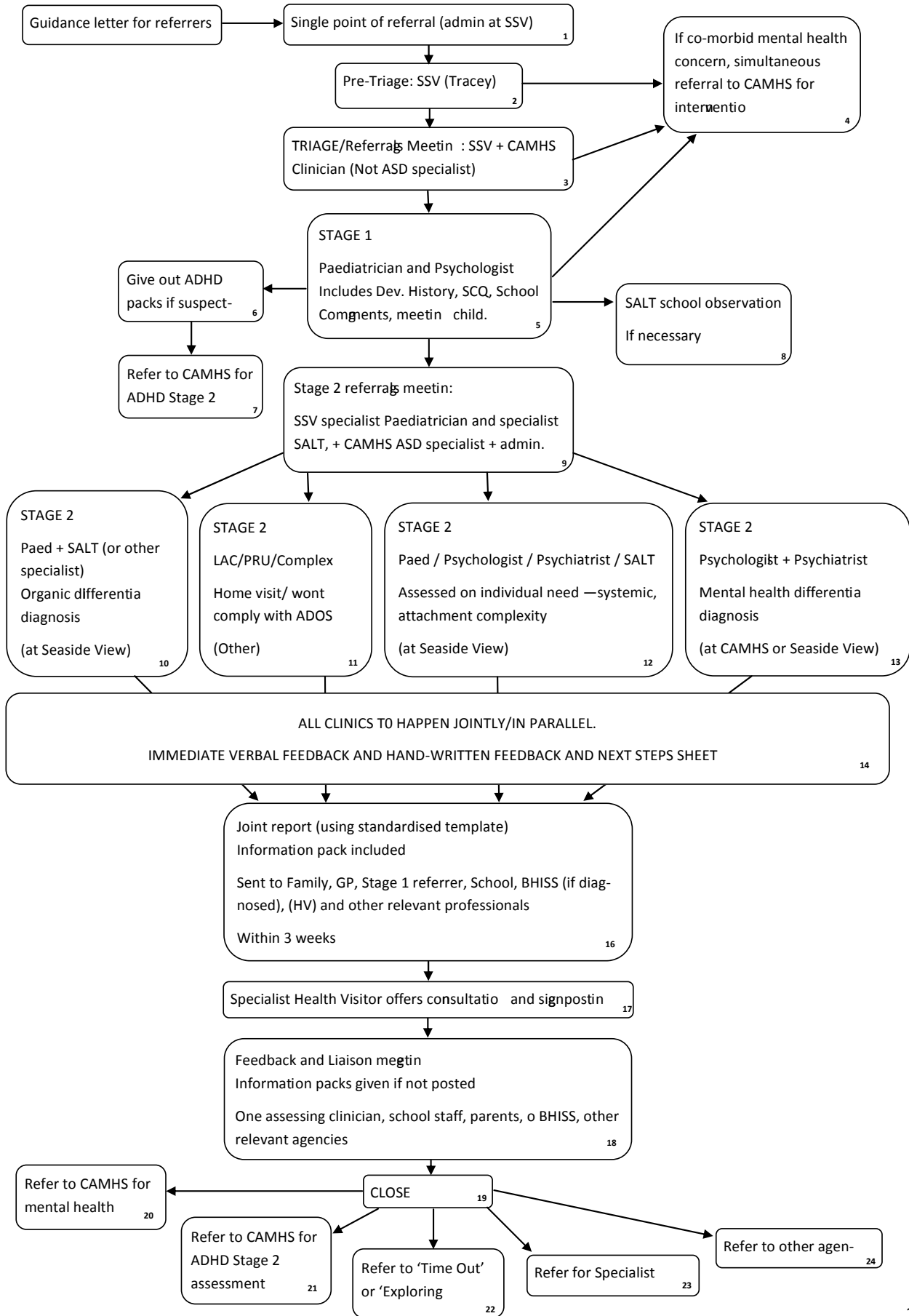
Wider neurodevelopmental issues

- Most stakeholders raised the wish for a neurodevelopmental service which was located away from CAMHS and included exploration of a wider variety of conditions.

- Parents/carers would like a service which is formulation based rather than only diagnosis led with consideration of neurodiversity rather than all support hinging on a diagnosis.
- For suggestions for 0-18 years Neurodevelopmental Service, please refer to Recommendations made at the end of this report.

15. KEY PRINCIPLES OF A NEURODEVELOPMENTAL SERVICE IDENTIFIED AT STAKEHOLDERS MEETING

- **Holistic**
 - Looking at the child holistically, considering neurodiversity and formulation based approach which described child's needs not just as a diagnostic label. A service which conducts holistic assessments for children and flexible and responsive to the needs of the child. Co-morbidity is important to explore in any new service. Consideration of language used. Parent involvement/ consultation at all stages of the process.
- **Linking in with Professionals**
 - For service to always be considering a whole systems approach. Keeping in mind other professionals and linking in/joint working when needed. For a service to ensure a joint 'thinking together approach'.
- **Complexity of Autism being understood**
 - For all services working with Autism to fully understand the complexity of Autism.
 - To move away from a diagnosis model of working and consider support for those children who do not meet a diagnostic criterion. Advice and strategies that are helpful for the child.
 - To work with voluntary sector organisations when planning service development.
 - Resilience model of working which focused on strengths not deficits.
 - *All age service separate from Mental Health*
 - To include a central point of access. Closer working with local authority and education services.



16. CONCLUSION

As part of this scoping, there are three main areas that have been highlighted as requiring improvement: The existing CYP CAMHS and SSV Autism pathways are not consistent with one another and having two separate pathways is not helpful for CYP and their families and impacts on access and waiting times.

Parents and carers have also highlighted that they need more support and advice throughout the pathway. Furthermore, it was identified that transition at 18 years old, to on-going help and support requires a smoother approach and delivery.

17. RECOMMENDATIONS

Issue	Recommendations	When
<p>Access and waiting times:</p> <ul style="list-style-type: none"> • Identification of Autism • Referral • Assessment • Post diagnosis • Waiting times • Demand and capacity • Resources • NICE compliance • CYP IAPT embedded • Transforming Care Agenda fulfilment • Embedding best practice lessons from B&H and nationally • Need for Multi-agency/ MDT approaches 	<ul style="list-style-type: none"> • A service redesign will be triggered, identifying opportunities to set up a Single Point of Access and a single pathway at Seaside View • Additional CCG resources will be made available to the pathway, to ensure NICE compliance in access and waiting times 	<p>By end June 2017</p>
<p>Transition from children's to adult services:</p> <ul style="list-style-type: none"> • From primary or secondary school • Between services • Wider Neurodevelopmental issues 	<ul style="list-style-type: none"> • The Joint Autism Strategy (CYP and Adults) is developing an approach to working towards an all ages service • CCG and local authority are working together to align a vision and a joint commissioning approach for an integrated pathway 	<p>2017/18</p>
<p>Support for parents and carers:</p> <ul style="list-style-type: none"> • Improving communication • Involvement • MDT approach • Information sharing 	<ul style="list-style-type: none"> • The CCG and LA will take the full scope of the issues and concerns raised by parents and carers, and review them with the Autism Working Group to identify gaps and develop a planned way forward to address these, building on good practice locally and nationally, 	<p>By September 2017</p>

Appendix 1. List of Stakeholders and Interviews

Representing	Role	F2F Interview
Young People	YP and Parent <i>Tier 3 CAMHS</i>	19/08/16
	<i>Seaside View</i>	
Parent / carers	PaCC – 8 reps <i>Tier 3 CAMHS + SEASIDE VIEW</i>	21/09/16
	Parent <i>Seaside View</i>	
	Parent <i>Tier 3 CAMHS</i>	04/11/16
	Parent and Carer Service User Representative <i>PaCC</i>	16/12/16
Schools	<i>Lead Autism Educational Psychologist</i>	19/08/2016
	<i>Lead SENCO</i>	
	<i>Homewood College Lead</i>	02/11/16
	<i>West Hove Infant and Junior School Inclusion Team</i>	23/11/16
GPs	<i>GP Lead at B&H CCG</i>	Completed
Sussex Partnership NHS Trust	<i>Tier 3 CAMHS Psychologist</i>	26/10/16
	<i>Tier 3 CAMHS Team Leader</i>	21/07/2016
	<i>Tier 3 CAMHS Nurse</i>	26/10/16
	<i>Tier 3 CAMHS Psychiatrist</i>	10/08/16
	<i>Tier 3 CAMHS therapist</i>	26/10/16
	<i>Tier 3 CAMHS Psychiatrist</i>	19/10/16
	<i>TAPA worker</i>	19/08/16
	<i>Tier 3 CAMHS + SEASIDE VIEW therapist</i>	14/09/2016
	<i>Learning Disability therapist</i>	03/08/2016
	<i>Neurodisability at SEASIDE VIEW therapist</i>	05/08/2016
	<i>SEASIDE VIEW Paediatrician</i>	28/09/16

Sussex Community Health Trust	<i>SEASIDE VIEW Occupational Therapists</i>	28/09/2016
	<i>2 x SEASIDE VIEW Speech & Language Therapists</i>	7/10/16 14/10/16
	Specialist HV	09/11/16
Adult Services	Adult Services manager	Completed
Voluntary Sector	<i>Autistic Spectrum Condition Support Service</i>	21/09/16 21/09/16
	<i>AMAZE</i>	26/10/16
	<i>mASCot</i>	16/11/16
B&H council	<i>Tier 2 CAMHS</i>	07/10/16
Other services	Hackney Ark	Informal discussion
	Peterborough	Email only response
	Oxleas Trust	9/12/16

Appendix 2. Autism Parent Questionnaire

Parent name:					
Child's name:					
Have you completed the assessment process?	Yes	No			
Has your child received a diagnosis of Autism?	Yes	No			
Describe your experience of the diagnostic process.					
Please rate your experience of the diagnostic process.	Very Poor	Poor	Fair	Good	Very Good
What aspects do you think worked well?					
What aspects do you think worked least well?					
What areas do you think could be improved?					
What improvements do you think could be made?					
Any other feedback?					

Appendix 4. CAMHS Autism Pathway Summary Table of feedback

Positive points	Negative points
During session 1 clinicians listened and demonstrated understanding for my concerns – however not sustained.	Parents feel ADI not scientific. Could not remember, then felt it was their fault no diagnosis was received.
Clinicians were helpful and understanding.	Felt left alone when process finished.
Assessment clinician was brilliant.	ADI – remembering historic details.
Clinicians were nice, helpful, friendly and professional.	Process was long, drawn out, not communicated clearly.
	Long process.
	Did not prepare child being seen alone for ADOS.
	Chasing up information.
	Long time for Autism to be recognised when child was in service with ADHD.
	Had to chase up appointments and info.
	Felt that service was overworked and overrun.
	Lack of communication between professionals – no one could provide me with the information I asked for.
	Of five respondents; two rated the service fair; two rated the service poor; and one rated it very poor.

Suggestions

- Better communication further steps + process.
- Help for after positive/negative diagnosis received.
- Call update about stages and timeline.
- One named lead clinician as contact for information.

Appendix 5. Seaside View Autism Pathway Summary

Positive points	Negative points
MDM in school.	Gap between session 1 and 2.
Reflected on strengths of child by clinician.	Chasing up information etc.
Everything explained and easy to understand.	Desire to attend course, but waiting.
Met specialist who could support and answer.	Very long waiting times.
Follow-up was good.	Uncertainty about current happenings.
Clinicians helpful and reassuring if details from early history could not be remembered.	Parent could not say certain things in meetings if child was present.
Once referred process was quick.	Communication of information was lacking.
Staff were supportive, helpful and friendly.	
During feedback child was looked after.	
Of the five respondents interviewed; 3 rated the service very good; and two rated the service good.	

Suggestions

- Parents to be regularly updated with progress and waiting times.
- Paediatrician available via phone if needed for urgent questions – no waiting for extra appointment.
- Emails as well as letters.
- Referral process long
- Child should only be present if necessary or staff present to look after child during questioning.

Appendix 6. Seaside View Evaluation of Post Diagnostic Time Out Group for period September 2015 to July 2016

The course

Time Out for Autism is a course for parents/ carers of children aged up to 10 years with a diagnosis of Autism and comprises 8 x 2 hour sessions over 8-10 weeks. The course is delivered by a Specialist Health Visitor, Specialist Nursery Nurse and Teacher from the Autism Support Service (Education) or PRESENS (from September 2016, renamed as B&H Inclusion Support Service). The course includes opportunities for attendees to learn about: Autism and how it affects their child; practical strategies to help their child and themselves; and get support from fellow parents who may share similar experiences.

Numbers

- 6 courses have been run
- 3 courses being for parents of children up to 5 years of age
- 3 courses for parents of children 6-10 years of age
- 41 parents/carers have attended (from 32 families as some couples, N.B. 10 more than last year)
- 29 of which the child was diagnosed in current year

Evaluation

- On a scale of 1-10, How confident do you feel about being a parent of a child with Autism?
 - The average score pre-course was **5.9** and the average post course was **7.7**
- On a scale of 1-10, How much do you understand about Autism?
 - The average score pre-course was **5.8** and the average score post course was **8.2**

This demonstrates that parents/ carers attending the course perceive significant positive outcomes

The main themes from comments received include:

1. Emotional support, reduced isolation

“Enjoyed the networking with other parents, the most worthwhile and useful part of the course”

“Meeting with other parents makes you feel like you aren’t alone.”

“Really great to share and have an outlet to talk – I didn’t talk with anyone else”

“It really helped me to come to terms with reality and learn to cope and move on with my life”

“I feel more positive about the future, better able to cope thanks to Sheila’s positivity and practical advice

2. Practical tips and information

“Received some very good tips and ideas to help”

“I have found out much more about what is available for children with Autism”

3. Confidence boosting

“My confidence has grown and this course has been a massive part of that”

“My confidence has vastly improved “

4. Suggestions for improvement

“more specific time for everyone to talk”

“10 minutes each ‘diary of the week’?” (check in)
“more structure ‘teaching’ – a little less chat”
“more discussion during info heavy middle sessions”
“more tips i.e. behaviour management earlier in course”
“more about siblings”
“add a bit about home education to offer parents another option”
another option”
“more homework!”/ “longer sessions / course”