

Brighton & Hove CAMHS Autism Spectrum Disorder Care Pathway

Brenda Davis

Consultant Clinical Psychologist,
Lead for Psychology
Brighton & Hove CAMHS

Care Map Information

Information Resources for Parents and Carers

Updates to this Pathway

Clinical Presentation

Children Under 9-11 Years - Stage 1 Initial Assessment

Children Over 9-11 Years

Learning Disability

Stage 2 - Diagnostic Assessment

Stage 1 - Initial Assessment

Generic CAMHS Team or Discharge

Stage 2 - Diagnostic Assessment

Specialist Services

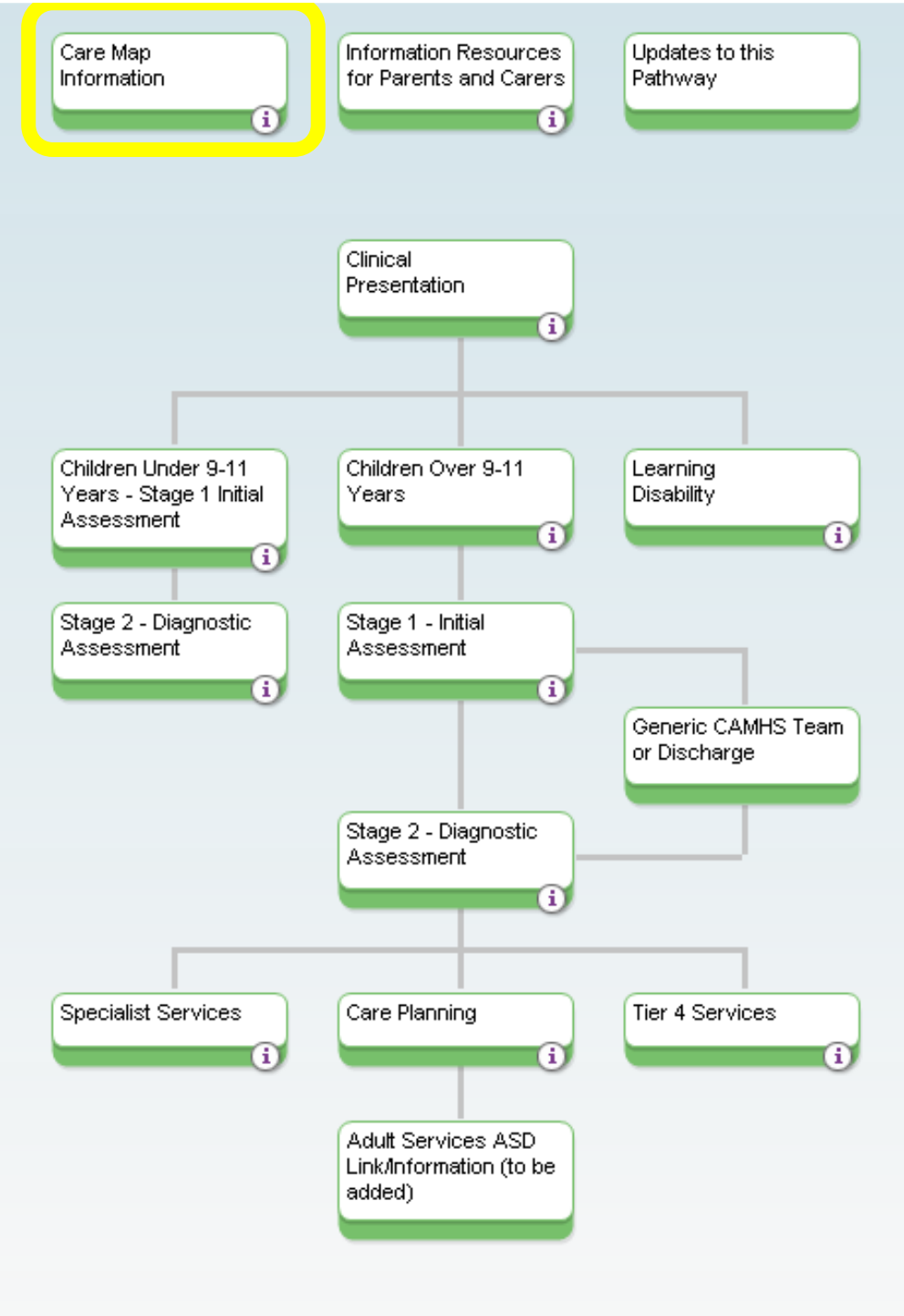
Care Planning

Tier 4 Services

Adult Services ASD Link/Information (to be added)

Map of Medicine Care Pathway

http://localise.mapofmedicine.com/mapmanager/mapmanager.htm?_flowId=login&_flowExecutionKey=e1s1



1. Care Map Information

This care map describes the assessment, diagnosis and management of Autistic spectrum disorders in children and adolescents. It is principally for staff working in Sussex Partnership NHS Foundation Trust Tier 2/3 CAMHS services, including staff in Hampshire and Kent, however it also includes where assessment and diagnosis of children with an Autistic spectrum disorder is carried out by Community Child Health Services.

An expert group of child and adolescent mental health services professionals at Sussex Partnership NHS Foundation Trust have developed this pathway in collaboration with Community Child Health colleagues based on best evidence and staff structures locally. The decision to localise was taken in order to reflect best evidence, including expert opinion and local commissioning arrangements.

The pathway is not intended for use in other LHC's. However, clinicians may use the information to support clinical decision making and commissioners as a useful reference to support future commissioning intentions.

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2. Information Resources for Parents/Carers

Scope:

Diagnosis and management of autism spectrum disorder (ASD) in children up to age 18 years

Out of scope:

ASD in adults & Management of co-morbidities

Definition:

ASD is a collective term that includes:

- Autism
- atypical autism
- Asperger's syndrome

ASD is a purely clinical diagnosis. Diagnostic criteria are specified in the International Classification of Diseases (ICD-10) issued by the World Health Organization (WHO) and also in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), and are based on the following clinical features, which may be present to varying degrees:

- impaired social interaction
- impaired language and communication
- impairments in thoughts and behaviours
- ASD is a lifelong condition

2. Continued

Incidence:

Children with some form of ASD constitute 1% of the child population in the UK
Increased screening and provision of diagnostic centres have resulted in more individuals obtaining a diagnosis of ASD

Prevalence:

The heterogeneous nature of ASD has resulted in different sub-groups, which create great variance in the incidence figures:

- 296,872 children with autism and learning disability in the UK
- 242,894 children with high-functioning autism (HFA) in the UK

ASD can co-occur with other conditions, learning difficulty being the most common

The rate of ASD among siblings in a family, where one child already has ASD is approximately 1 in 20 – sometimes siblings may have language-related difficulties or delays, but not ASD

2. Continued

Factors associated with an increased prevalence of autism:

- A sibling with autism
- Birth defects associated with central nervous system malformation and/or dysfunction, including cerebral palsy
- Gestational age less than 35 weeks
- Parental schizophrenia -like psychosis or affective disorder
- Maternal use of sodium valproate in pregnancy
- Intellectual disability
- Neonatal encephalopathy or epileptic encephalopathy , including infantile spasms
- Chromosomal disorders such as Down's syndrome
- Genetic disorders such as fragile X
- Muscular dystrophy
- Neurofibromatosis
- Tuberous sclerosis

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3. Clinical Presentation

Presentation either in Tier 1 or 2 Services, or emerging during work in Tier 2 or 3 Services. Presentation may be by parents concerned with challenging behaviour and/or hyperactivity, or may present incidentally:

Autism spectrum disorder (ASD) may not be the primary focus of initial referral

ASD symptoms may develop over time, for example a child in an attention deficit hyperactivity disorder (ADHD) clinic who has more clinical features of ASD emerging over time

ASD should be considered as a differential diagnosis in preschool children displaying an absence of normal developmental features as typical ASD behaviours may not yet be obvious in this age group

Referral for diagnosis of an ASD should be considered at any age, regardless of the findings of any earlier assessments

Clinical features that are required for diagnosis of ASD:

- Impaired social interaction
- Impaired non-verbal and verbal communication:
- Speech and language problems range from no speech
- Advanced vocabulary, but pragmatics are always impaired
- Restricted, repetitive and stereotypic patterns of behaviours, interests and activities
- Multiple, rather than specific developmental problems, beginning before age 3 years

3. Continued

Clinical features that may accompany ASD, but are not essential for diagnosis:

- Altered sensory perception
- Unusual sleep patterns
- Unusually long attention span, especially for performing detailed tasks
- Success in academic areas that do not require a high level of social skills
- Seizures
- Intellectual disability
- Dietary/digestive problems

As part of the core programme of child health surveillance, healthcare professionals should be vigilant for features of ASD to aid early detection

If the above are present, referral to Tier 3 CAMHS services if child is 9-11 yrs or above (some flexibility according to commissioning priorities), or to Child Health/Paediatric services if the child is below 9-11 yrs.

If possible, a social communication questionnaire (SCQ) completed by parent/carer should accompany the referral from Tier 1 or 2, as well as information from the school.

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4. Children Under 9-11 Years – Stage 1 Initial Assessment

Following a referral to Child Health/Paediatric Services:

The child is seen by paediatrician and/or child health professional as part of routine paediatric/child health assessment.

If ASD is suspected, a stage 1 work-up would be completed by a relevant professional.

School/pre-school information is collected via school/pre-school information questionnaire

Interview with parent/carer and child, following ASD screening protocol.

Social communication screening would be completed with parent/carer

Other differential diagnosis tools would be used as appropriate, this would include full medical and/or physical examination and genetic testing as, and if, indicated. If a mental health problem/differential diagnosis is suspected, a referral to a CAMHS mental health professional should be involved to contribute to the screening process.

A Stage 1 report is then completed, incorporating the above information.

If, on the basis of the Stage 1 report, an ASD is possible, or the complexity of the problem makes diagnosis unclear, referral is made to a Stage 2 diagnostic clinic.

Depending on the clinical presentation, where stage 1 is an MDA stage 1&2 may be combined to form a diagnostic assessment.

4. Continued

Stage 1 report passed to ASD Stage 2 diagnostic clinic referral meeting, where decision made on the basis of Stage 1 report and any other information available, whether or not to proceed to Stage 2 diagnostic assessment.

If Stage 1 info alone indicates ASD very unlikely to be present, referral back to an appropriate generic team for intervention.

If Stage 1 info indicates possibility of ASD or complexity makes it impossible to decide without full Stage 2 multi-disciplinary diagnostic assessment, pass to Stage 2 multi-disciplinary and possibly multi-agency diagnostic assessment clinic.

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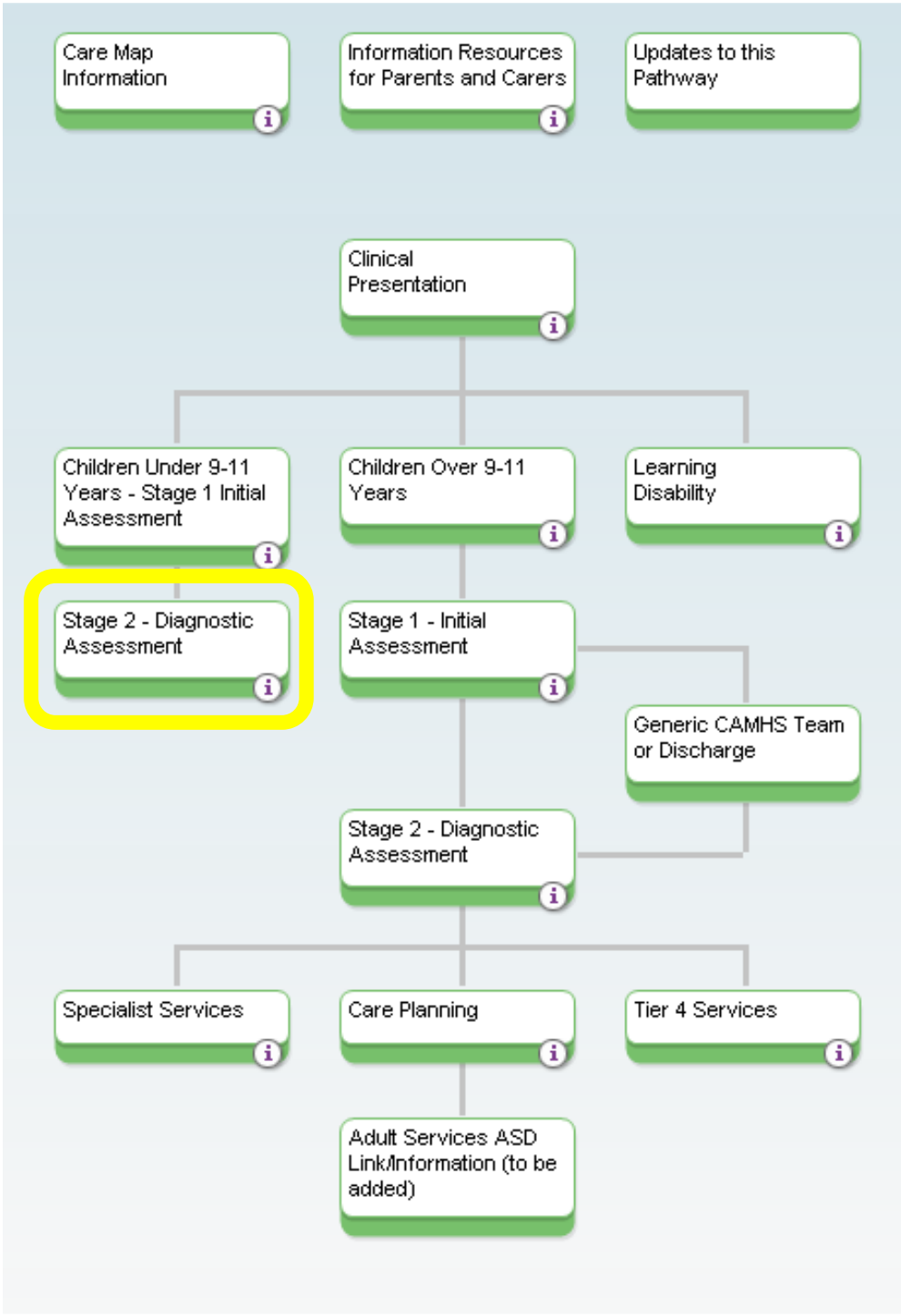
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5. Children under 9-11 – Stage 2 Diagnostic Assessment

Stage 2 ASD diagnostic assessment should be carried out, usually by a paediatrician using a standardised ASD assessment tool for the parental interview, usually expected to be the Autistic Diagnostic Inventory (ADI) or 3DI * and usually by a SLT and/or Psychologist using a standardised ASD tool for the child interview/assessment, expected to be the Autism Diagnostic Observation Schedule (ADOS).

The Stage 2 diagnostic assessment would also be expected to screen for mental health problems, if not already identified.

If necessary, referral will be made for a cognitive assessment, speech and language therapy assessment and/or OT assessment for clarification of diagnosis, as indicated.

If, in exceptional circumstances, due to the complexity of the presentation, an ASD diagnosis is unable to be made/unclear, refer to an ASD Specialist Centre for diagnosis/clarification.

5. Continued

If an ASD diagnosis is not made:

Referral back to generic team for appropriate intervention.

If ASD diagnosis made:

Referral back to ASD specialist within Tier 3 team for appropriate intervention but only if there is an accompanying presenting mental health problem

If not, signposted back to original Tier 1 or 2 referrer and discharged from Tier 3 service

If an ASD diagnosis is able to be made immediately following the assessment clinic, information shared with parents and child/YP as appropriate and following information given then:

- CAMHS ASD info leaflet outlining services available
- Information or booklets advising regards the National Autistic Society
- Information re: availability of input of further counseling from Tier 2 or Child Health (if available according to commissioning)

Standardised report outlining result of diagnostic assessment is also sent to parents/carers, and the child/young person (if appropriate) within 4-6 weeks of assessment

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6. Children over 9-11 Years – Initial Assessment

Stage 1 assessment:

A diagnostic assessment is undertaken (regardless of presence of mental health problem)

Seen as part of Choice/Partnership (CAPA) assessment process/entry to Tier 3 CAMHS service, possibly from Tier 2. Hence referral seen for initial assessment, usually within 4 weeks, in Choice clinic

Passed to appropriate clinician for Stage 1 Uni-disciplinary assessment/work up.

- School Information collected via standard school information form
- Social Communication Questionnaire (SCQ) completed by parent/carer
- Behaviour Rating Inventory of Executive Functioning (BRIEF), completed by parent/carer and teacher
- Clinical interview(s) completed with parent/carer and child, following ASD screening assessment guide/form, which includes family & developmental history and mental health history, attachment history and full mental health assessment as part of eCPA

This leads to a Stage 1 report, which summarises all of the above.

6. Continued

Report passed to ASD Stage 2 diagnostic clinic referral meeting, where decision made on the basis of Stage 1 report and any other information available, whether or not to proceed to Stage 2 diagnostic assessment.

If Stage 1 info alone indicates ASD very unlikely to be present, referral back to generic team for appropriate intervention, if there is a presenting mental health problem. If not, signposted back to original Tier 1 or 2 referrer and discharged from Tier 3 service.

If Stage 1 info indicates possibility of ASD or complexity makes it impossible to decide without full Stage 2 multi-disciplinary diagnostic assessment, pass to Stage 2 multi-disciplinary and possibly multi-agency diagnostic assessment clinic.

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7. Children over 9-11 - Stage 2 Diagnostic Assessment

Stage 2 ASD diagnostic assessment should be carried out, usually by a Psychiatrist, using a standardised ASD assessment tool for the parental interview, usually expected to be the Autistic Diagnostic Inventory (ADI) or 3DI * and usually by a Psychologist using a standardised ASD tool for the child interview/assessment, expected to be the Autism Diagnostic Observation Schedule (ADOS).

The Stage 2 diagnostic assessment would also expect to draw on other mental health differential diagnostic tools as necessary.

If necessary, referral will be made for a cognitive assessment, Speech and Language Therapy assessment and/or an Occupational Therapy assessment for clarification of diagnosis.

If, in exceptional circumstances, due to the complexity of the presentation, an ASD diagnosis is unable to be made/unclear, refer to an ASD Specialist Centre for diagnosis/clarification.

If an ASD diagnosis is not made:

Referral back to generic team for appropriate intervention (if there is a presenting mental health problem)

If not, signposted back to original Tier 1 or 2 referrer and discharged from Tier 3 service

7. Continued

If ASD diagnosis made:

Referral back to ASD specialist within Tier 3 team for appropriate intervention but only if there is an accompanying presenting mental health problem

If not, signposted back to original Tier 1 or 2 referrer and discharged from Tier 3 service

If an ASD diagnosis is able to be made immediately following the assessment clinic, information shared with parents and child/YP as appropriate and following information given then:

- CAMHS ASD info leaflet outlining services available
- Information and/or booklets advising regards the National Autistic Society
- Information re: availability of input of further counseling from Tier 2 or Child Health (if available according to commissioning)

Standardised report outlining result of diagnostic assessment is also sent to parents/carers, and the child/young person (if appropriate) within 4-6 weeks of assessment

Follow-up feedback appointment offered to child/family to discuss assessment and report within 6 weeks of assessment.

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8. Learning Disability

This pathway also applies to children and young people with an existing diagnosis of a Learning Disability, either mild/moderate/severe, who also require an ASD diagnostic assessment.

However in some instances due to the complexity of presentation, the standardised assessment process (e.g division into stage 1 and 2 process) and diagnostic tools may need to be modified or supplemented by other assessments.

In a small number of cases the child or young person may also require a highly specialist neuro-disability assessment and possibly a tertiary referral to clarify their needs.

Where there is also a pre-existing Learning Difficulty, the interventions offered to young people and families e.g. parent/social groups, may need to be adapted or modified.

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9. Tier 4 Services

On occasion, the Urgent Help or Outreach services can offer a second opinion regarding diagnosis, particularly where further observation of a child or young person at home, school or varied community settings is necessary.

Ideally this is done in conjunction with Tier 3 clinicians, but can be carried out separately if this seems more appropriate.

In the case of Tier 4 inpatients, if a possible ASD seems to be emerging, the stage 2 diagnostic assessment could be completed by the appropriate ASD experienced clinicians, using the standardised ASD assessment tools by an experienced Psychiatrist & Psychologist, or in some cases other clinicians, in the Tier 4 setting.

However, if a patient is near the point of discharge, the diagnosis would be assessed when the patient is referred back to Tier 3.

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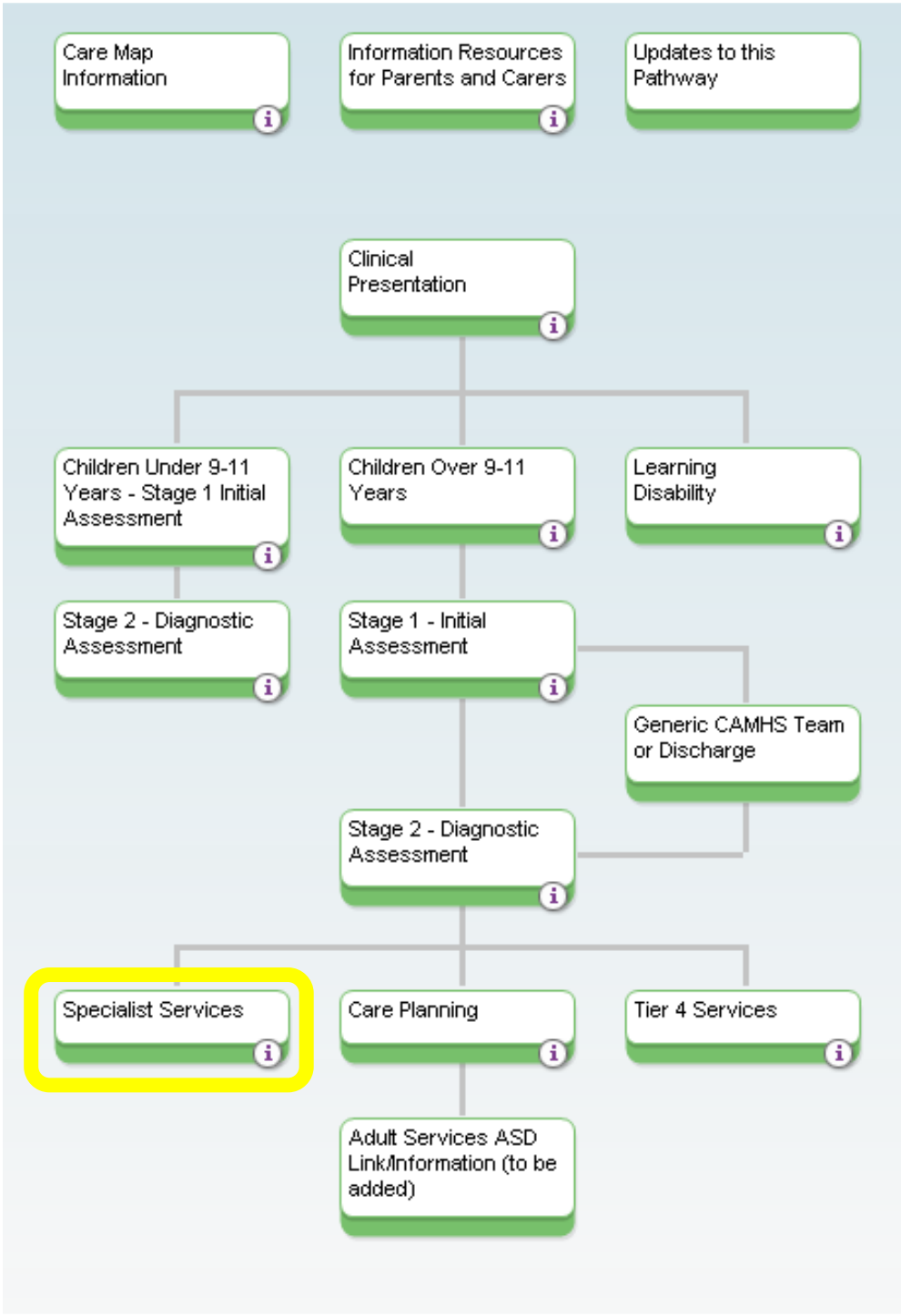
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10. Specialist Services

If, in exceptional circumstances, due to the complexity of the presentation, an ASD diagnosis is unable to be made/unclear, refer to an ASD Specialist Centre for diagnosis/clarification.

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11. Care Planning

As part of Care or Action plan, there should be a meeting at school with the parent/carer, SENCO and the school ASD Outreach Service (if there is one) not more than 4 weeks after the report review meeting, to formulate an education action plan and where necessary, the involvement of other agencies. This action plan may or may not involve CAMHS, depending on the presence of a mental health problem.

Parents of newly diagnosed child or young person would normally be offered a psycho-educational group (typically 6-8 sessions) helping them to know what to expect from a child or young person with ASD, including behaviour management advice. This will be a group for parents of children or young people, 9 years and above and would not necessarily be the remit, or solely the remit, of CAMHS (Tier 2 and/or 3) and this group would normally have multi-agency input.

Ideally, children or young people with ASD should have access to a social group where they can meet others with same diagnosis/problem, particularly to avoid isolation. This sort of group is most likely to be run by third sector/agencies other than CAMHS.

11. Continued

At 18 years, if the child or young person with ASD is still being seen in CAMHS, they would be referred to Adult Services:

There should be a transition meeting with key worker in CAMHS and those working with ASD in Adult Mental Health or Learning Disability services, as appropriate, and also social care services as necessary. This should ideally include an information pack, jointly developed by CAMHS and Adult Services.

If a child or young person is undergoing an assessment for a co-morbid neuro-developmental disorder, most notably ADHD or Tourettes syndrome, then it is good practice for the two assessments/care pathways to cross reference to avoid possible duplication and for the care pathways to mirror each other as much as possible, so the assessments can be completed concurrently.

However, under 9-11 year olds, even with these co-morbid problems, will still need to be seen by child health/paediatric services for their ASD diagnostic assessment.

In the case of a second opinion regarding a Stage 2 ASD diagnostic assessment being required, a referral would usually be made in the first instance to another ASD Stage 2 diagnostic clinic in another area of Sussex, rather than an external referral being made.

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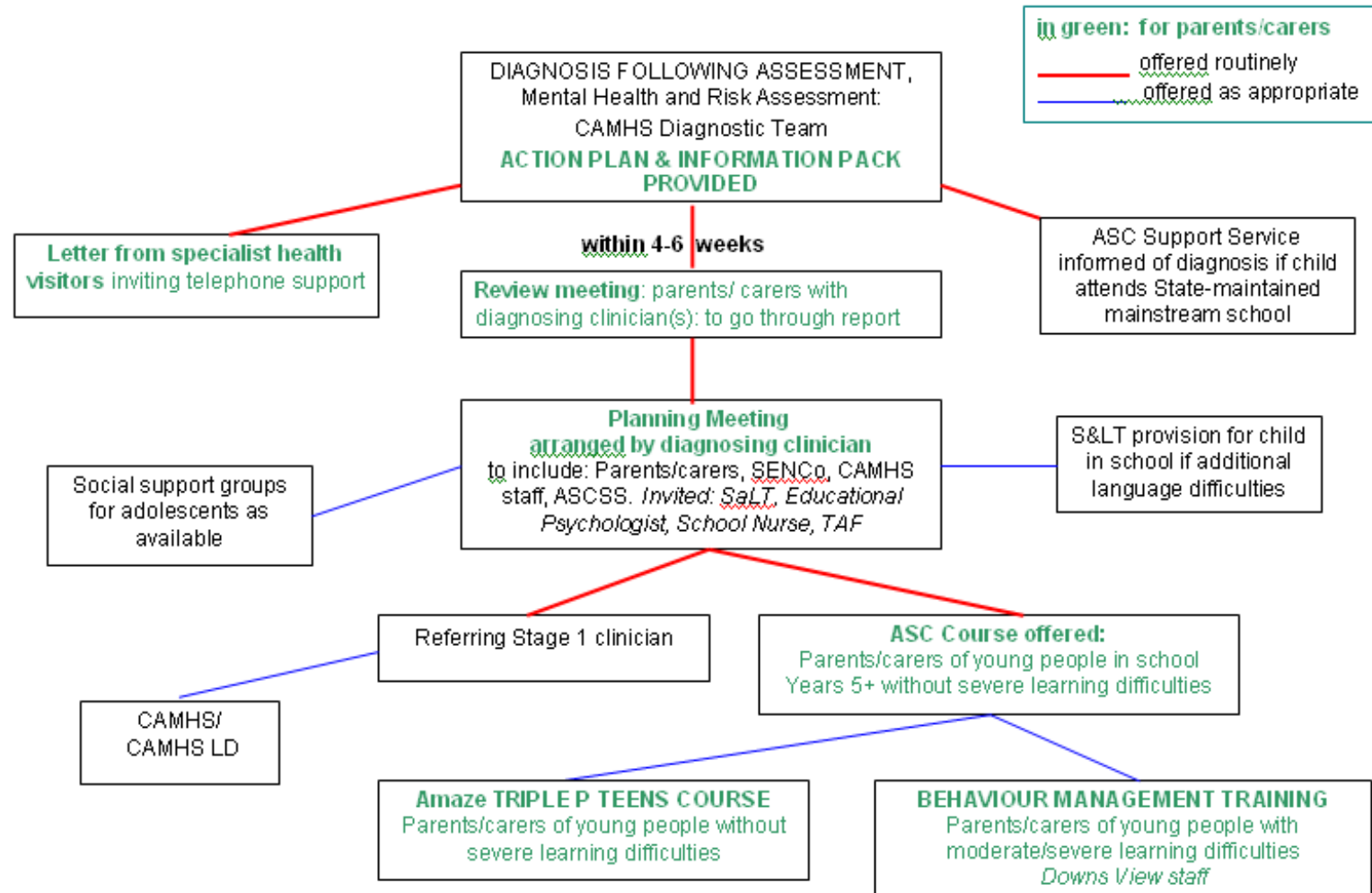
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12. Adult Services ASD Link

At 18 years, if the child or young person with ASD is still being seen in CAMHS, they would be referred to Adult Services:

There should be a transition meeting with key worker in CAMHS and those working with ASD in Adult Mental Health or Learning Disability services, as appropriate, and also social care services as necessary. This should ideally include an information pack, jointly developed by CAMHS and Adult Services.

Secondary Age Post-Diagnostic Care Pathway



Exploring ASD: A Parent's Group

Post-Diagnostic psycho-educational support group for parents/carers of children in school year 5+ with a recent diagnosis of Autism Spectrum Disorder.

The group is run jointly by Brighton & Hove Tier 2 & Tier 3 CAMHS and facilitated by a Clinical Psychologist and a Family Support Worker. There is also specialist involvement from an Occupational Therapist and a Speech & Language Therapist.

It consists of 6 weekly sessions which aim to:

Enhance parent's understanding of how Autism affects thinking, feelings, communication and behaviour

Present useful parenting strategies specific for ASD (e.g. behaviour management strategies)

Provide emotional and social support for parents as they continue to adjust to their child's diagnosis

Outcomes

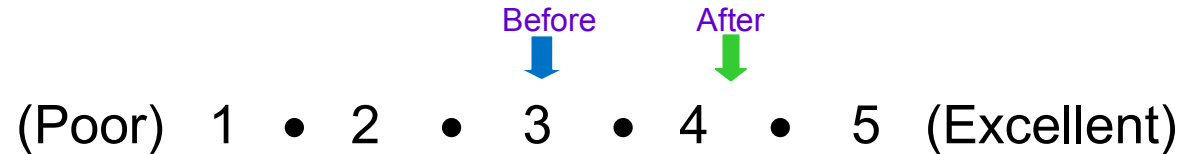
Currently, the group is evaluated with the following questionnaires:

1. Parent-Child Relationship Inventory (PCRI)
2. Depression Anxiety Stress Scale (DASS)
3. As neither of the above are ASD specific, a questionnaire was designed within the service focussing specifically on this course's aims (e.g. confidence and understanding in ASD)

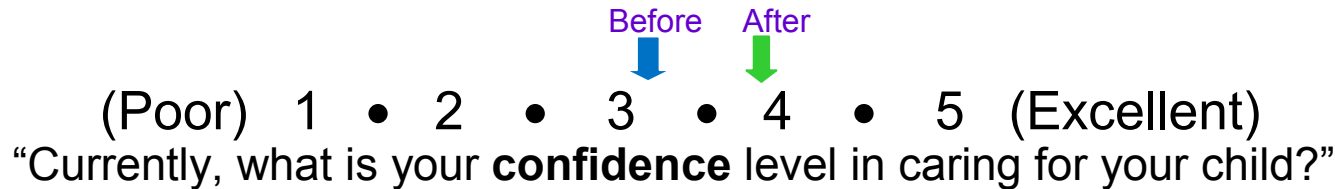
Findings: CAMHS' Questionnaire

Parents from the 4 groups run so far were asked the following questions at the start and at the end of the group:

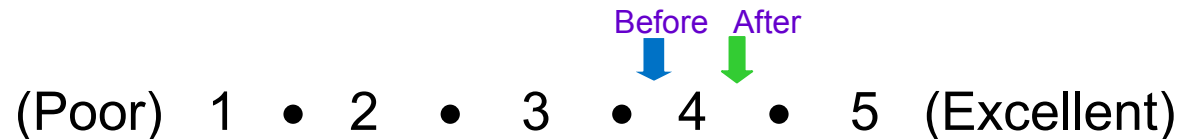
“How would you rate your **understanding** of Autism Spectrum Disorder?”



“In your opinion, what is the quality of **interaction** between yourself and your child?”



“Currently, what is your **confidence** level in caring for your child?”



Parents also reported that the levels of **anxiety and frustration/anger demonstrated by their child** decreased, as did the frequency/severity of **challenging behaviour**.

Findings: DASS

Parents' **stress levels** decreased from 16.54 ("Mild") to 13.49 ("Normal")

Levels of **anxiety** and **depression** also decreased

Findings: PCRI

The parents' perceptions of **parental support** increased from 40 to 45

Their **satisfaction with parenting** increased from 41 to 44

Parent's rating perceptions of **involvement** with their child decreased from 39.60 to 38.43.

Communication ratings decreased from 27.73 to 24.13.

Their ability to **set limits** with their child increased from 41 to 42.

B&H ASD Care Pathway Audit (Dec 09 - Jun 13)

December 2009 - December 2010

How many referrals were there	24
How many referrals were accepted	24
How many of those referrals were not accepted	0
How many were diagnosed with ASD	10
How many had an alternative diagnosis	1
How many received no diagnosis	8
How many will be seen in 2011	5

January - December 2011

How many referrals were there	13
How many referrals were accepted	9
How many of those referrals were not accepted	4
How many were diagnosed with ASD	1
How many had an alternative diagnosis	0
How many received no diagnosis	2
How many will be seen in 2012	0

B&H ASD Care Pathway Audit (Dec 09 – Jun 13)

January - December 2012

How many referrals were there	26
How many of those referrals were accepted	23
How many of those referrals were not accepted	3
How many were diagnosed with ASD	10
How many had an alternative diagnosis	0
How many received no diagnosis	10
How many will be seen in 2013	3

January - June 2013

How many referrals were there	12
How many of those were accepted	8
How many of those referrals were not accepted	0
How many awaiting further info/discussion	4
How many were diagnosed with ASD	1
How many had an alternative diagnosis	0
How many received no diagnosis	0
How many receiving an ongoing assessment	1

B&H ASD Care Pathway Audit (Dec 09 – Jun 13)

Average numbers per 12 months

Number of referrals	21
Number of accepted referrals	18.7
Number not accepted	2.3
How many diagnosed	8
How many not diagnosed	7.7

Referrals with additional mental health problem other than ASD and referred to CAMHS for further work (2012)

Total	13
Received diagnosis of ASD	5
Did not receive diagnosis of ASD	6
Sent to a service other than B&H CAMHS e.g TAPAS, Worthing CAMHS	4

* The mental health issues were frequently anxiety, attachment difficulties or low mood.

