Brighton & Hove
City Council

Overview & Scrutiny Commission

Title:	**Scrutiny Panel on services for children with autism**
Date:	**17 September 2013**
Time:	**2.00pm**
Venue	**Council Chamber, Hove Town Hall**
Members:	**Councillors:** Jarrett (Chair)Rosie Moore Pissaridou Wealls Rosie Moore – co-opted member
Contact:	Julia Riches Email: Julia.riches@brighton-hove.gov.uk Tel: 01273 290451

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16.	Witnesses - Autism Sussex Emily Christie and Samantha Fievez, Autism Sussex	
17.	Witnesses - Amaze Rachel Travers, Chief Executive and Janet Poole, Amaze	
18.	Date of next meeting The next meeting is 19 September from 10-12.30 in Hove Town Hall Council Chamber to hear from parent/carers. Please note that this meeting will start in public then will go into confidential session (Part 2)	

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For further details and general enquiries about this meeting contact Julia Riches (01273 290451 – email Julia.riches@brighton-hove.gov.uk) or email scrutiny@brighton-hove.gov.uk

Date of Publication 11 September 2013

Agenda Item 12

To consider the following Procedural Business:-

A. Declaration of Substitutes

Where a Member of the Committee is unable to attend a meeting for whatever reason, a substitute Member (who is not a Cabinet Member) may attend and speak and vote in their place for that meeting. Substitutes are not allowed on Scrutiny Select Committees or Scrutiny Panels.

The substitute Member shall be a Member of the Council drawn from the same political group as the Member who is unable to attend the meeting, and must not already be a Member of the Committee. The substitute Member must declare themselves as a substitute, and be minuted as such, at the beginning of the meeting or as soon as they arrive.

B. Declarations of Interest

(1) To seek declarations of any personal or personal & prejudicial interests under Part 2 of the Code of Conduct for Members in relation to matters on the Agenda. Members who do declare such interests are required to clearly describe the nature of the interest.

(2) A Member of the Overview and Scrutiny Committee, an Overview and Scrutiny Committee or a Select Committee has a prejudical interest in any business at meeting of that Committee where –
(a) that business relates to a decision made (whether implemented or not) or action taken by the Executive or another of the Council's committees, sub-committees, joint committees or joint sub-committees; and
(b) at the time the decision was made or action was taken the Member was
(i) a Member of the Executive or that committee, sub-committee, joint committee or joint sub-committee and
(ii) was present when the decision was made or action taken.

(3) If the interest is a prejudicial interest, the Code requires the Member concerned:-

(a) to leave the room or chamber where the meeting takes place while the item in respect of which the declaration is made is under consideration. [There are three exceptions to this rule which are set out at paragraph (4) below].
(b) not to exercise executive functions in relation to that business and
(c) not to seek improperly to influence a decision about that business.

(4) The circumstances in which a Member who has declared a prejudicial interest is permitted to remain while the item in respect of which the interest has been declared is under consideration are:-
(a) for the purpose of making representations, answering questions or giving evidence relating to the item, provided that the public are also allowed to attend the meeting for the same purpose, whether under a statutory right or otherwise, BUT the Member must leave immediately after he/she has made the representations, answered the questions, or given the evidence,
(b) if the Member has obtained a dispensation from the Standards Committee, or
(c) if the Member is the Leader or a Cabinet Member and has been required to attend before an Overview and Scrutiny Committee or Sub-Committee to answer questions.

C. Declaration of Party Whip

To seek declarations of the existence and nature of any party whip in relation to any matter on the Agenda as set out at paragraph 8 of the Overview and Scrutiny Ways of Working.

D. Exclusion of Press and Public

To consider whether, in view of the nature of the business to be transacted, or the nature of the proceedings, the press and public should be excluded from the meeting when any of the following items are under consideration.

NOTE: Any item appearing in Part 2 of the Agenda states in its heading the category under which the information disclosed in the report is confidential and therefore not available to the public.

A list and description of the exempt categories is available for public inspection at Brighton and Hove Town Halls.

BRIGHTON & HOVE CITY COUNCIL

SCRUTINY PANEL ON SERVICES FOR CHILDREN WITH AUTISM

12.30pm 9 JULY 2013

COMMITTEE ROOM 1, BRIGHTON TOWN HALL

DRAFT MINUTES

Present: Councillor Jarrett, Pissaridou, and Wealls

Also in attendance: Rosie Moore, co-opted Member

Others present: Alison Nuttall, Commissioner, CAHMS, Julia Riches, Scrutiny Officer

PART ONE

5. PROCEDURAL BUSINESS

No substitutes are allowed on Scrutiny Panels.
There were no declarations of interest?
There were no declarations of party whip?

6. CHAIR'S COMMUNICATIONS

Welcome to everyone to this first public meeting of the Scrutiny Panel looking at services for children with ASC.

The Panel have set their terms of reference as:

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

This meeting is intended to give the Panel up-to-date information on the national and local pathways for assessment, diagnosis and support for children with autistic spectrum conditions and their parents and carers. I will be asking everyone to introduce themselves then speak for 10-15 minutes and then take questions.

PLEASE NOTE THAT THESE MINUTES SHOULD BE READ ALONGSIDE THE PRESENTATIONS – FOR COPY SEE MINUTE BOOK

7. NATIONAL PATHWAY

Dr Vicky Slonims, Consultant Speech and Language Therapist, Honorary Senior Lecturer (Kings College London), Children's Neurosciences Centre, Newcomen Centre at St Thomas' Hospital, London.

(See also powerpoint presentation available on request)

Studies estimate that around 1% of the population have ASC so it is no longer a rare condition. This has been a significant change in the last decade. There are high levels of additional need and 70% of individuals with ASC having one other behavioural or mental health issue and 40% have at least two. Challenging behaviours are very common.

Outcomes for adult life for those with ASC tend to be poor in comparison with others, including those with good intellectual skills – only 25-30% find employment as adults. Having a child with ASC can have a significant – and sometimes negative – impact on family life.

The annual cost of supporting children with ASC is estimated at £2.7b which means the total annual cost per child reaches £25,400 (over and above the cost of a neuro-typical child). A study in 2012 found that over 6 months the cost of parents seeking additional services was on average £2,581 with almost half of the costs for education and childcare and only 12% for hospital services.

There is no screening program for ASC or other neuro-developmental disorders: the approach is of universal surveillance by Health Visitors and other primary health professionals. The National Health service does not recommend screening for neuro-developmental disorders such as autism. There are 4 levels of health provision in the UK from primary care, district and regional services with some specialist national centres and there is guidance on triggers for referral onto the next level. Care pathways across age ranges permit smooth transition across levels.

The National Autism Plan for Children (NAP-C) published in 2003 was influential. There are now more local assessment teams although only 54% have a formal assessment protocol. More services are using multiagency teams and more teams have multi-disciplinary assessment clinics – 57% in 2007 although there is evidence that this is decreasing due to cutbacks. There is still a wide variation on access to, and quality of, diagnostic and intervention services, but there is good awareness and better training in many areas. Nationally, the prevalence of ASC has put huge pressure on services with long waiting lists. In one or two areas, some diagnostic services are being provided by educational professionals and private sector teams not NHS.

Initial provision may be through community health services, e.g. occupational therapy, or speech and language therapy (SLT). Education services are more involved and at an earlier stage from 2-3yrs old. Some services offer home based interventions and placements in mainstream or specialist nursery provision. The Children and Families Bill is extending education to 25yrs old and this will have an interesting effect. In the past, there has been a form of 'postcode lottery' as there has been differing levels of provision hence the drive towards a single package of care. Traditionally, education has tended to fall outside of the care package due to the infrastructure and there is a hope that there will now be one single package of support with all services working together.

70% of children with ASC attend mainstream schools and legislation states that schools must make 'reasonable adjustments'. In 2009 the government set up a resource called the Inclusion Development Programme (IDS) to help teachers address the needs of ASC children. The programme has stopped under this government, although is still available on-line. Vicky was part of developing the IDS and a key aim was to help teachers to understand that children may come in to school with a style of behaviour, not necessarily a label of an autism spectrum disorder.

When children with recognised Special Educational Needs reach 14yrs old there should be a transition plan meeting to provide a benchmark when or current skills and plans for future needs. This has not routinely included Health and Social Services and some professionals feel this may be too early, however the new NICE guidelines have recognised the value of early evaluation of future needs. .

Post 16yrs old, most children are expected to go to college or post 16 provision, There is a broad range of provision on offer ranging from university degrees to vocational training. In spite of this only a very low percentage of individuals with ASC and a typical IQ have a full time job -12%. Across the whole spectrum, this falls even further to 6%. This is lower than for those with other disabilities. There are some examples of success e.g. the NAS Prospectus Employment Consultancy assisted 67% of their clients to find work but this has funding problems at the moment.

The 2010 'Getting it right for children' review of services made key recommendations for the NHS around shared decision making. The Children's National Service Framework states care will be provided in an 'appropriate environment': this is key for people with ASC. For example, bringing ASC people into hospitals and dentists to see what their experience is like would enhance services.

The 2012 report of the Children and Young Peoples Health Outcomes Forum for children and young people included a subgroup for children with disability, SEN and long term conditions such as such as ASC. Some of the main recommendations were: a reduction in time from first presentation to diagnosis/start of treatment; a quality assessment; and a key working approach (families say there is a myriad of people and they would prefer to have one contact person). As soon as and individual that has been identiried as having ASD comes in to the services there should be a rapid response time but this has not been done well in the past.

The NICE guidance covers three key areas: ASC diagnosis in children and young people (published Sept 2011), recognition, referral, diagnosis and management of adults with ASC (June 2012), and management of ASC in children and young people to be published September 2013.

One of the recommendations around diagnosis from NICE is the creation of a local autism strategy and management group. Aims of this include to improve early recognition and make sure professionals are aware of the care pathways.

The core of the diagnostic team will include a paediatrician and/or child psychiatrist; SLT; clinical and/or educational psychologist, and others as required (eg gastro, OT etc). There should be a single point of referral and a care case co-ordinator for every child or young person who is to have an ASC diagnostic assessment.

NICE recommend that there should be a local autism strategy group with responsibility to deliver and co-ordinate interventions across the age range (ie into adulthood). There was a lot of discussion on this but NICE were clear that the autism strategy group doesn't have to *deliver* the intervention but *ensure* the service is delivered and be there as a resource for parents to go back to – a central and single place to go.

Unrestricted access to CAMHS is a big issue.

NICE are aware that implementation could be problematic and are taking a lead on identifying barriers to implementation

A survey by the British Academy for Childhood Disability (BACD) due to be published soon shows a significant decline in services since 2007. It looks across 2 time points. Community Development Teams working together are less and less common.

8. LOCAL PATHWAY - CAHMS

Brenda Davis, Consultant Clinical Psychologist and Lead for Psychology for Brighton & Hove CAHMS, Sussex Partnership NHS Foundation Trust

(See also powerpoint presentation available on request)

Ms Davis is responsible for developing ASC pathways across Sussex (including CAMHS). The care pathway relates to the whole of Sussex (despite differences in commissioning).

The post-diagnostic pathway is Brighton & Hove specific. The Sussex Partnership Trust follows the Map of Medicine pathway. The Map of Medicine is a national pathway initially devised for members of the public to use and follow for physical health problems. The SPT took the national pathway and changed the information boxes.

<u>Children over 9-11years old.</u>

CAHMS service covers 0-18years and offers intervention to any child. If a child has ASC and mental health issues then the service will go right across the age group. Diagnosis is divided so children aged 9-11yrs are seen by child health colleagues. CAHMS see children above 9-11yrs for diagnosis whether they have mental health problems or not. If someone does not get a diagnosis, that can be problematic.

Stage 1 assessments gather information so they have as much information as possible to decide whether or not to go onto Stage 2. Stage 2 is a more time-consuming multi-agency diagnostic assessment using NICE assessment tools and takes a whole morning. As the years go on, the number of children going to Stage 2 has reduced because they are better at doing Stage 1.

All children (even if they come in with a specific request for ASC diagnosis) will get screening in a diagnostic clinic prior to a Stage 1 assessment. The care co-ordinator will be a physician who will get all the information – including a detailed questionnaire for schools, and will talk to tutors and subject heads to get a flavour of how a child behaves in different environments. BRIEF (Behaviour Rating Inventory of Executive Functioning) is used as a screening tool. Clinical interviews take place that follow strict guidelines and provide information over and above the mental health assessment that all Tier 3 children go through. This leads to a detailed Stage 1 report in a standardised format. This report goes to the monthly referral meeting and all those in Stage 1 attend and decide how likely it is this is a child with ASC who needs to go to Stage 2.

By secondary school age, the service is much better than it was at recognising ASC as more people are diagnosed earlier and better. By the age of 9,10,11 CAMHS are getting the most complex children with lots of co-morbidity problems. It is about determining whether ASC is part of a more co-morbid problem in complex children.

At Stage 2 the psychiatrist will use standardised NICE recognised Autism Diagnostic Interview that will be scored at the end with the parent/carer. The Psychologist will use a standardised set of activities and a diagnostic observations schedule which is also scored. The meeting will take a morning. They will meet the parent and child to explain, then the psychologist will meet the child. Following this, they will look at the assessments to see if they can be sure they are talking about ASC as one of the problems. They can call a SLT to explore further or ask for a cognitive assessment from other colleagues. If the assessment is that ASC is possible, there will be a detailed report in a standardised form over the next 4-6 weeks then they will meet with the parent/carer and young person to discuss the report and the action plan.

Some children may have learning difficulties (LD) as well as ASC. It is important to use the same tools so they try and use the same process as much as possible. If LD and ASC are present, the child will automatically fall to the LD team in CAHMS.

Q – What about children with ASC but no LD?

If there is LD and ASC present there is a team for this. If there is a mental health issue and ASC there is another team. If ASC is diagnosed but not LD or mental health issues there can be a lack of clarity. There are services but it is not as clear cut (Alison Nuttall).

If a child has LD then they will see the LD multi-agency team. If they have no LD but a co-morbid mental health issue, they will see that team.

In Tier 4 children need even more specialised intervention and they are at a high level of risk. The assessment may be done in an in-patient setting: there is a process by which these children aren't forgotten and can be part of the pathway.

A well-child with ASC may not need health provision but they are more at risk when a certain point might occur, for example transition (Vicky Slonims).

As the bulk of children are seen early, CAMHS do not have a waiting list. People wait no more than 2 months for an assessment (2nd line) and 4 weeks for a first assessment.

Q – If a child has only ASC with no interventions, can we prevent future problems?

There is no evidence on this. Nationally, we are not good at responding to need early so when a child is referred in mid childhood, problems arise, eg anxiety may be a core part of ASC but it may not meet the criteria for CAMHS referrals. We are not good at preventing acceleration. There are problems around CAMHS accepting children then. A key question is what is the definition of co-morbid presentations with ASC? (Vicky Slonims).

The pathway for post-diagnostic care at secondary age mirrors the primary pathway. CAHMS routinely offer to all parents whose child has been newly diagnosed a group to inform them of the sort of problems/anxieties that may not meet the criteria for anxiety disorder but can typically be expected of child of that age. There will also be planning meetings at the school and they will offer relevant interventions. There can feel like there is a gap, eg my child is anxious but it doesn't meet the criteria of a disorder – it is part of ASC. CAMHS try to cover this in educational psychology groups. A new neuro-disability post (psychologist) to work in Seaside View across the age group to try has just been appointed to try and fill this gap. It is recognition that there is a gap here.

Q – The initial CAMHS survey only went to new parents - this is an issue. How does the caseload information relate to access to services?

**It was agreed to explore the issue of the survey, past users of CAMHS as well as current users and the process around feedback at a future Panel meeting.*

CAHMS now is very different to 10 years ago and parents who used CAHMS then would have a very different experience to parents today.

9. LOCAL PATHWAYS - SEASIDE VIEW CHILD DEVELOPMENT CENTRE

Dr Katharine Anderson, Consultant Community Paediatrician, Seaside View Child Development Centre

(See also powerpoint presentation available on request)

The Seaside View ASC assessment service works with children up to the end of primary school. The service is still a 2 stage process, but is broadly compliant with NICE.easide View accepts referrals from all professionals but no self-referrals. The first stage is a general developmental assessment and the second stage more ASC specific. The general policy at Seaside View is multi-disciplinary assessment from the start for many children, in the form of the Integrated Care Pathway (ICP). ASC is a bit different because we had a pre-existing pathway and also there is limited access to specialist SLT. If the question is 'has this child got ASC' then the ASC pathway is used. If there are wider concerns around the child's development, there will be a wider range of professionals engaged at the start ie the ICP. At the minimum there will be a paediatrician who will take a paediatric/developmental and family history. The majority of children with possible ASC are not already in the ICP, so they will see a paediatrician (only) for a general developmental assessment (stage 1)and if there are still concerns about ASC they will then be referred for a more detailed multidisciplinary ASC-specific clinic (stage 2). Between Stages 1 and 2, they may request a lot of information – particularly from the educational setting to see how children behave in the socially demanding environment of school, and in particular how they interact with their age peers.

Stage 2 lasts around 3 hours. They don't use ADI but a questionnaire based on it. The aim of the assessment is to either make a diagnosis or to reassure, if appropriate, that there is no diagnosis of ASC. They will identify the strengths and difficulties of the child and any possible co-existent or alternative diagnoses.

If there is a diagnosis of ASC they will discuss the needs of the child and support and advice. A focus group found that what parents wanted as they left Stage 2 was support. There is not an ASC key worker although it would be great to have one. They ask the family if they would like us to call anyone specific to support them eg health visitor.

Q – Do you recommend schools?

Not specific schools but may suggest that a child needs a special school or a mainstream school. Age 3-5 will have a planning meeting with the pre-SENs team.

Q - Is there support at that stage?

There should be that support there but can't say categorically that it is always there. (Regan Delf)

The Panel could discuss the issue of advice and where parents get it.

Seaside View is short on SLT time. They follow up all pre-school children but not all older children are followed up – they often aren't ill and therefore do not require routine medical follow-up. There is a need for there to be one person who says this person is struggling and they can be signposted to different services.

They have carried out an ASC peer review service for many years. This involves operational assessment and intervention planning but there is also the opportunity to present (anonymous) information on a child where arriving at the correct diagnosis is difficult for discussion. Seaside View can also refer people on to tertiary services – usually the Newcomen centre in London.

There is a Disability Partnership Board with Jenny Brickell, Head of the Integrated Child Development & Disability Service and Amaze as joint Chair. It is a wide ranging board and includes representatives from SEN, a parent carer (through PaCC), adult commissioning services, schools, educational psychologist and Pre-SEN amongst others. This Board has agreed to take on strategic level planning for services with ASC (as NICE recommends). There is also an ASC group that links in to this – the terms of reference will be circulated.

After the appointment, typed reports are sent to the family, the referrer, and the health, educational and social care professionals involved (with consent). People are referred as appropriate to the ASC Support Service, to a Time Out Course (which is a psycho-educational course that supplies more information about ASC and behaviours).

Q – Is access to services wrapped up with diagnosis?

It shouldn't be but realistically it probably is.
The complaints the Newcomen Centre receives are around indecision and the length of time taken. Waiting for services is a big issue and a 2 tier service can feel like a long time and they may be some issues arising from this but also from shortcutting the process and a diagnosis being made by a paediatrician alone (Vicky Slonim).

There is a care co-ordinator so people do not get left behind and there is not a long waiting list for secondary school age children in CAHMS (Brenda Davis).

An estimated 86 children were seen in the last calendar year through the standard Seaside View pathway (July 2012-June 2013); these numbers have increased to try to minimise the waiting time between Stage 1 and Stage 2. Around 64% receive a diagnosis of ASC through the standard pathway. This is an underestimate of total numbers are some (a minority) are seen through the ICP and special schools systems which involves a similar process but sometimes different professionals. More accurate figures could be provided.

10. SPECIAL EDUCATIONAL NEEDS PROVISION IN BRIGHTON & HOVE

Regan Delf, Head of Special Educational Needs (SEN), Brighton & Hove City Council.

(See also powerpoint presentation available on request)

ASC diagnosis has risen quite steeply over recent years and now ASC makes up the biggest category of statements of SEN (January 2013) at 19%. ASC statements are eligible for 'top-up' funding as they have always been categorised as 'low incidence' and the LA provides additional funding in addition to funding delegated to schools for low incidence categories of need. However as ASC is now the highest incidence category of need for statements, this needs to be re-thought. There are 79 children with ASC in mainstream schools, 7 in academy schools, 12 in mainstream units, 66 in special schools, 11 in agencies (ie independent and non-maintained special schools) and 1 other. (for obvious reasons, numbers vary continuously as pupils move in and out of schools)

Where we need to make provision for pupils with ASC in agency schools, costs can be high – in one case currently heading for the SEN Tribunal, placement cost would be £320,000 per year. These can offer fantastic facilities but the cost is enormous. There is a need to make sure that all our maintained provision is really good so people don't need to seek provision in agency. However all our provision locally is rated good or outstanding by Ofsted and the number of children using agency schools (all categories) is declining.

The Swan Centre at BACA and now Hove Park Special Facility offer specialist facilities within a mainstream school,. These are not specialist ASC units but speech and language as well. Around half of a child's time is spent in the unit and the rest in mainstream classes. The model has been very successful.

All special schools with the exception of ACE offer places to pupils with ASC who need special school provision.

Outreach services from special schools also may offer support to some pupils with ASC and severe learning difficulties.

The Autistic Spectrum Support Service (ASCSS) offers outreach support to mainstream schools but it requires a diagnosis of ASC before you can access the service. There are 3 FT staff.

Q – Does this put pressure on people to provide a diagnosis?

Yes it can do –and it puts pressure on schools as well. There is also the issue that allowances (eg DLA) become accessible with a diagnosis. The team receive a lot of requests for statements – some parents may put pressure for a diagnosis because they see it as a 'passport' to services. This is a change from the past when a diagnosis was seen often seem as more devastating in terms of consequences for a young person. The question is always whether the higher prevalence of ASC diagnosis is about higher prevalence of ASC or a change in classification to include a wider spectrum of need or both.

Speech and language issues are difficult to diagnosis separately to ASC sometimes and sometimes a firm diagnosis means people lose out. It is a very complex area (Vicky Slonims).

Currently there are 250 pupils with a diagnosis of ASC in mainstream schools which represents 0.85% of the mainstream maintained school population. Only 39% of this 250 have statements of SEN so the ASCS service is supporting a lot of children with ASC but no statement.

ASCSS supports schools to understand ASC and supports teachers. There is a need to support families too. The ASCSS has 176 pupils on its active caseload.

In terms of specialist provision, Jeanne Saunders pre-school assessment centre works with children with complex needs, not just ASC. 5 of the 6 special schools offer places to pupils with ASC alongside a range of other complex needs. Downs Park make specific arrangements for pupils with ASC but in Cedar Park pupils are all in the same class. The West Blatchington ASC Facility (primary) only takes children with a diagnosis of ASC. The Hove Park Facility (secondary) is opening in September 2013 – this used to focus on children with dyslexia but that is not such a pressing need so the provision has changed.

There is a big overlap between BESD and deprivation but a very small one with ASC. The overlap between free school meals and ASC is 7%. The overlap with BESD is over 50%.

The ASCSS service is very well received by schools but is aware they need to extend their service to include families more hence recruiting to a vacant family support worker post. The LA is aware of the need to make signposting in education services clearer.

Q – Do you have any influence over independent schools?

It depends if the service are paying the school fees! Generally experience is good – although independent schools are not able to access ASCSS.

There is parent representation on the SEN strategy priority groups and they are currently looking to get better representation of young people.

Young users have been engaged (Aha! Group) via the SE7 pathfinder group (Alison Nuttall).

Q – Why is there not a systematic service user engagement as with adult services?

The focus has been on parents as service users but they need to think more about young people's views. Clearly with children there are issues to consider in terms of age, parental consent for involvement etc . The voice of the young person is a priority area of development for us in our strategy. A lot of work done, but more needs to be done around mapping and collating activity.

Q – Is the ASCSS an advocate for schools rather than parents?

The service has grown hugely and there used to be a bigger focus on children and parents when the service had a family support worker. They still do a lot directly with parents and try to form a 'bridging' role between parents and schools – this will be easier with the agreement to recruit a new family support worker after a period of the post being vacant. (Mary Macphail).

Some parents want private consultants in schools working with their children and this can cause tensions.

Parents can be worried about how disinterested advice on educational provision is when it is provided by the LA. This is an important issue – if you want to make a difference then make this advice independent from the provider concerns (Vicky Slonims).

11. DATE OF NEXT MEETING

The Chair thanked everyone for a very useful and informative session.

The date of the next meeting is 17 September 2013 from 2.00pm in the Council Chamber, Hove Town Hall

The meeting concluded at Time Not Specified

Signed Chair

Dated this day of

ASC assessment pathway Seaside View Child Development Centre

Katharine Anderson

Consultant Community Paediatrician

July 2013

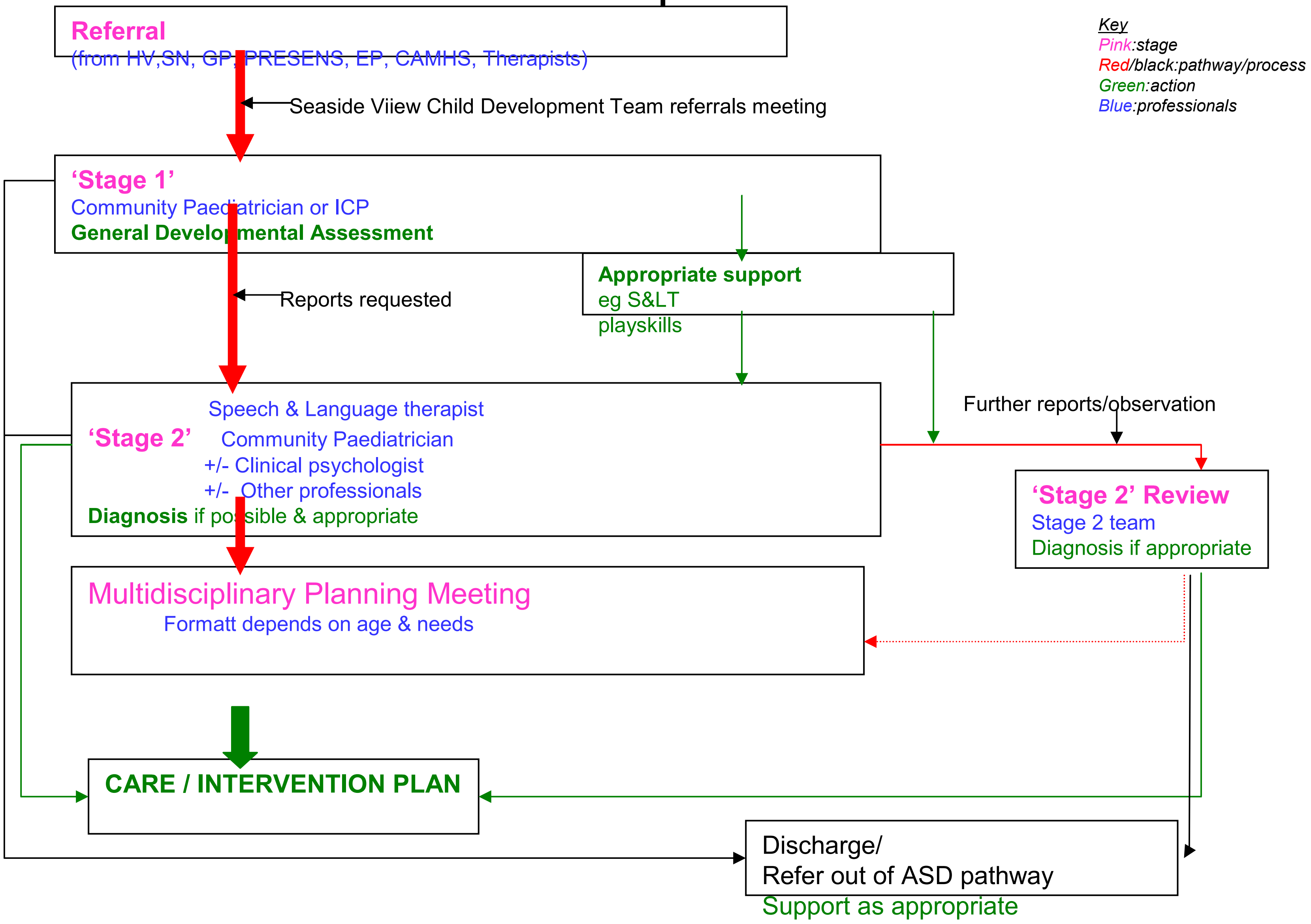
Brighton & Hove ASC assessment service

- Children 0-11 based at Seaside View
- Children & Young People 11+ CAMHS

Seaside View

- Current service based on NAPC (2003)
- For most children a two stage process
- In most respects compliant with NICE guidelines 2011

ASC Assessment Pathway
Children up to Year 6



Key
Pink:stage
Red/black:pathway/process
Green:action
Blue:professionals

Referral
(from HV,SN, GP, PRESENS, EP, CAMHS, Therapists)

Seaside Viiew Child Development Team referrals meeting

'Stage 1'
Community Paediatrician or ICP
General Developmental Assessment

Appropriate support
eg S&LT
playskills

Reports requested

'Stage 2'
Speech & Language therapist
Community Paediatrician
+/- Clinical psychologist
+/- Other professionals
Diagnosis if possible & appropriate

Further reports/observation

'Stage 2' Review
Stage 2 team
Diagnosis if appropriate

Multidisciplinary Planning Meeting
Formatt depends on age & needs

CARE / INTERVENTION PLAN

Discharge/
Refer out of ASD pathway
Support as appropriate

Referral

- All referrals to SVCDC go through single referrals system
- Referrals panel meet fortnightly
- Outcome
    - Concern mainly/specifically ASC: paediatric appt
    - Concern broader &/or child younger multidisciplinary assessment eg paediatrician, S&LT, specialist HV, OT, PT, nursery nurse, PRESENS (ICP assessment)

Initial assessment
‘Stage 1’

- Single/multiple professional
- General developmental/medical assessment
  - Standard paediatric & developmental history
  - Risk factors for developmental conditions
  - Family (genetic & social) history
  - Vision & hearing
  - Direct developmental assessment of child
  - Physical examination

Outcome of Initial assessment

- Reassurance and discharge
- ASC unlikely but other developmental condition identified/suspected; appropriate support
- ASC unlikely but other psychiatric/behavioural condition identified/suspected; referral on as appropriate
- ASC likely &/or needs further assessment

Needs further assessment for ASC

- Most referred on to autism specific assessment ‘Stage 2’

- Some young children have ‘Stage 2’ as part of their ICP assessment ie if already seeing appropriate paediatrician & S&LT

Core members of Autism Specific Team SVCDC

- Paediatrician
- Specialist Speech and Language Therapist
- Clinical Psychologist (most children)

Between Stage 1 & 2

- Referrer (paediatrician) requests
  - written report from school/nursery
  - EP report if available
  - Other information eg Community S&LT reports
- Specific checklist completed by referrer
- Referral discussed at weekly ASC meeting & details of assessment agreed
- If inadequate information to justify Stage 2 further liaison with referrer takes place

Autism specific assessment

- Paediatrician
- Specialist Speech and Language Therapist
- Clinical Psychologist (children age 4+ unless specific request for younger child)

Autism Specific Assessment approx 3 hours

- Detailed autism specific developmental history (paediatrician)
- Direct assessment/observations of child
  - Communication, social interaction & play
  - Cognition (not routine)
  - Behaviour
- Feedback & discussion with parent/s/carer

Autism Specific assessment Aims

- To make a diagnosis of ASC if appropriate
- To reassure child does not have ASC if appropriate
- To identify profile of child’s strengths difficulties and needs & family needs
- To identify possible co-existent or alternative diagnoses
- To identify any underlying medical conditions
- To formulate action plan

Diagnosis of ASC

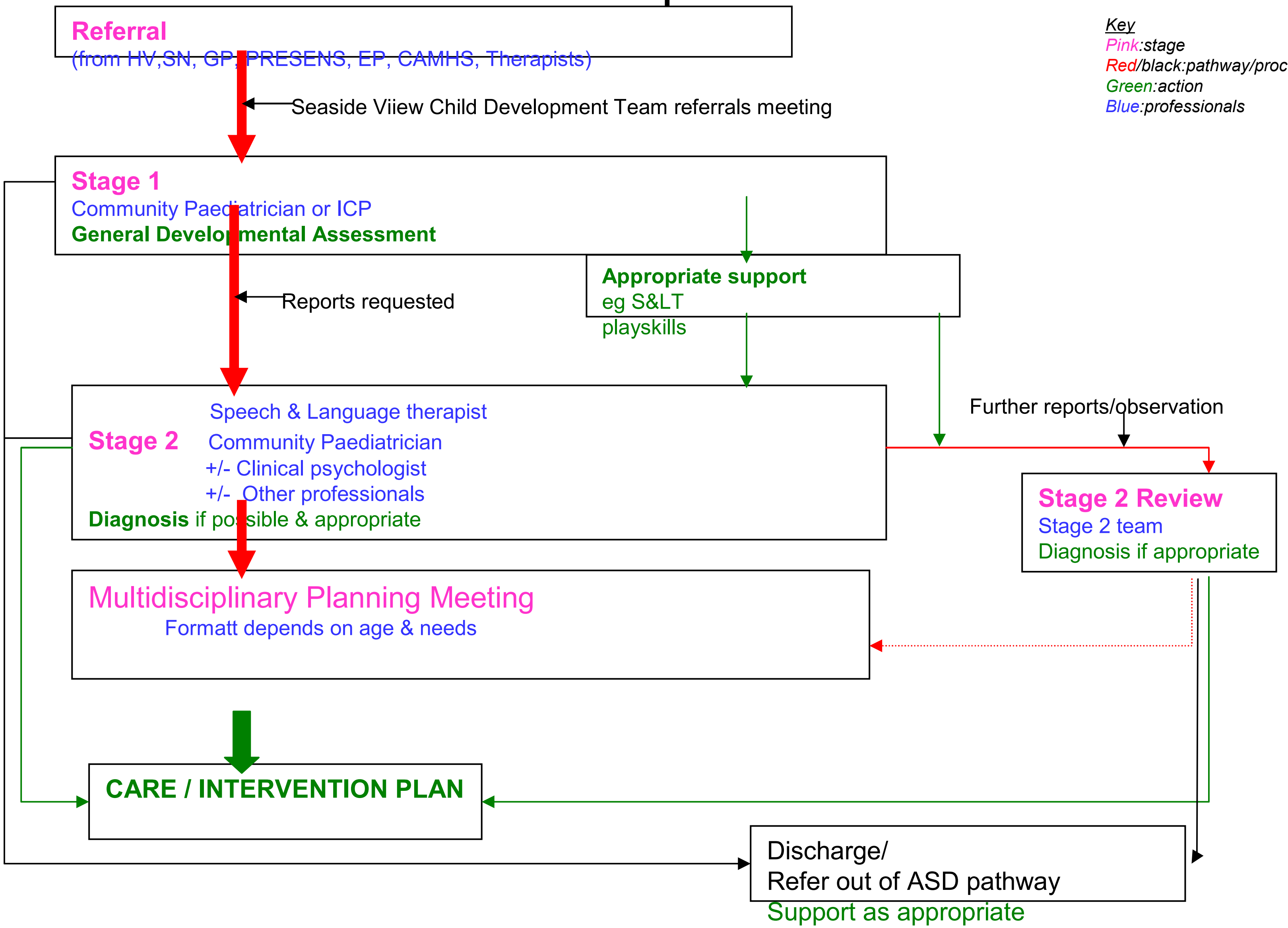
Based on team discussion as to whether the child's profile is consistent with ICD/DSM diagnostic criteria

- Over time (parental history/previous observations)
- Pervasive (information from different settings)

Autism Specific assessment outcome: depends on

- Diagnosis of ASC confirmed
- Child does not have ASC
- Need for more information
  - observation by team in educational setting
  - Observation over time with therapist
  - ‘Stage 2 review’ appt in specified time period

ASC Assessment Pathway
Children up to Year 6



Referral

(from HV,SN, GP, PRESENS, EP, CAMHS, Therapists)

Seaside Viiew Child Development Team referrals meeting

Stage 1

Community Paediatrician or ICP

General Developmental Assessment

Appropriate support

eg S&LT

playskills

Reports requested

Stage 2

Speech & Language therapist

Community Paediatrician

+/- Clinical psychologist

+/- Other professionals

Diagnosis if possible & appropriate

Further reports/observation

Stage 2 Review

Stage 2 team

Diagnosis if appropriate

Multidisciplinary Planning Meeting

Formatt depends on age & needs

CARE / INTERVENTION PLAN

Discharge/

Refer out of ASD pathway

Support as appropriate

Key

Pink:stage

Red/black:pathway/process

Green:action

Blue:professionals

Discussion with family

- At point of diagnosis
- And/or at follow-up appointment

If not ASC

- Explanation of why not
- Alternative explanation of child’s presentation & profile
- Referral on/further assessment/support plan

If ASC

Nature of ASC

Strengths difficulties and needs

Co-existent medical/developmental conditions

? further assessment

- Physical examination
- OT referral
- CAMHS referral

Genetic advice

? medical investigation: underlying medical conditions

ASC: discussion with family

Plan of support for child

- Appropriate educational and behavioural support
- S&LT

Needs of family

- Information (child & services)
- Emotional support
- Financial support

Specific advice

- Eating, sleep, bowels

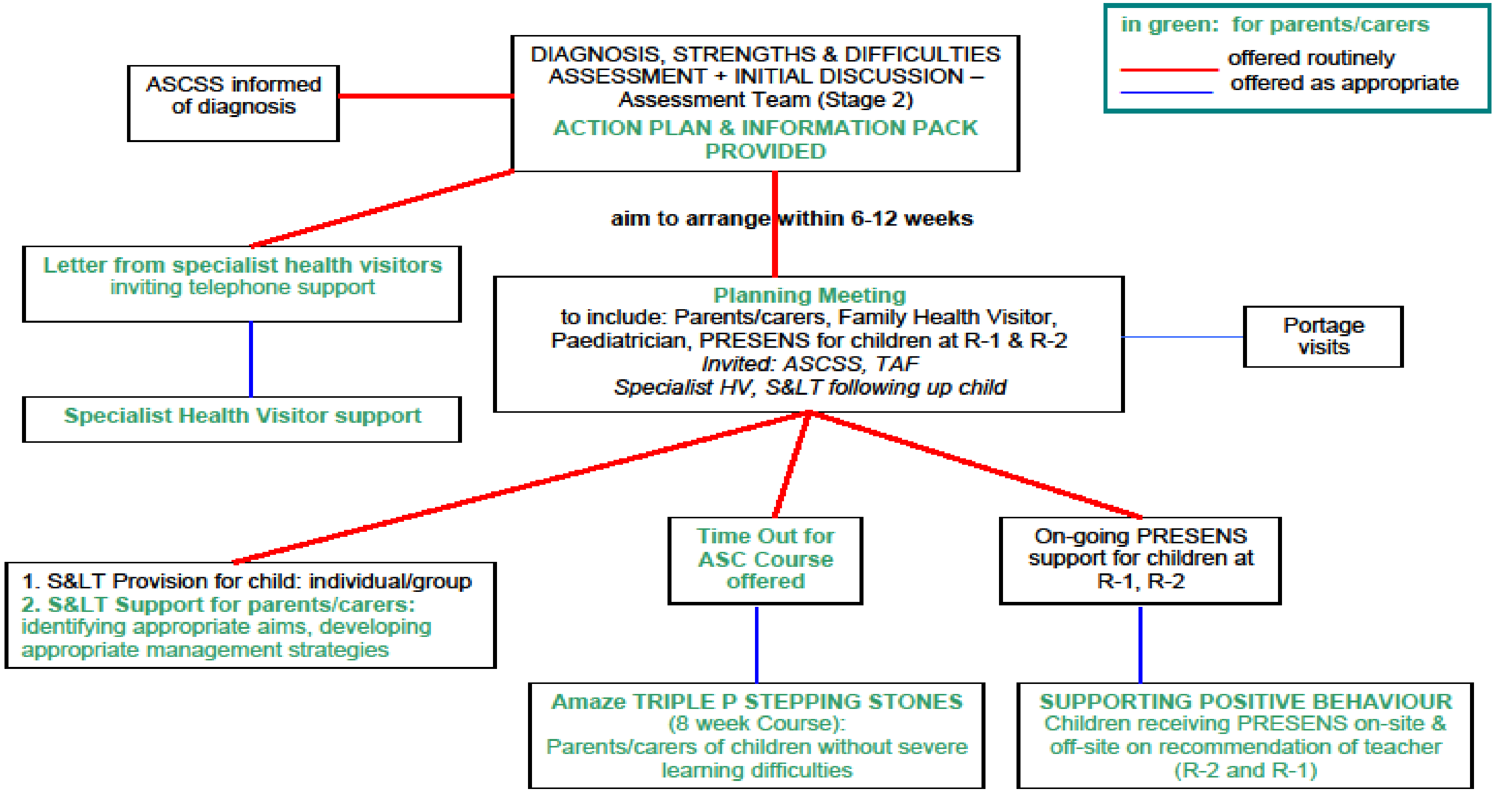
Family leaves appointment (ASC)

- Offer of phone call to professional family see as primary support/sp HV
- Handwritten action plan
- Written information pack including
  - Information about ASC
  - Information about local and national services

After appointment (ASC/Non ASC)

- Typed reports to
  - family
  - Referrer
  - Health, Educational and Social care professionals (consent)
- Referrals as appropriate eg
  - ASC Support Service
  - Time Out Course
  - Genetics, OT,CAMHS etc

ASC Post diagnostic support pathway: PRESCHOOL children



in green: for parents/carers

🟥 offered routinely

🟦 offered as appropriate

ASCSS informed of diagnosis

DIAGNOSIS, STRENGTHS & DIFFICULTIES ASSESSMENT + INITIAL DISCUSSION – Assessment Team (Stage 2)
ACTION PLAN & INFORMATION PACK PROVIDED

aim to arrange within 6-12 weeks

Letter from specialist health visitors inviting telephone support

Specialist Health Visitor support

Planning Meeting
to include: Parents/carers, Family Health Visitor, Paediatrician, PRESENS for children at R-1 & R-2
Invited: ASCSS, TAF
Specialist HV, S&LT following up child

Portage visits

1. S&LT Provision for child: individual/group
2. **S&LT Support for parents/carers:** identifying appropriate aims, developing appropriate management strategies

Time Out for ASC Course offered

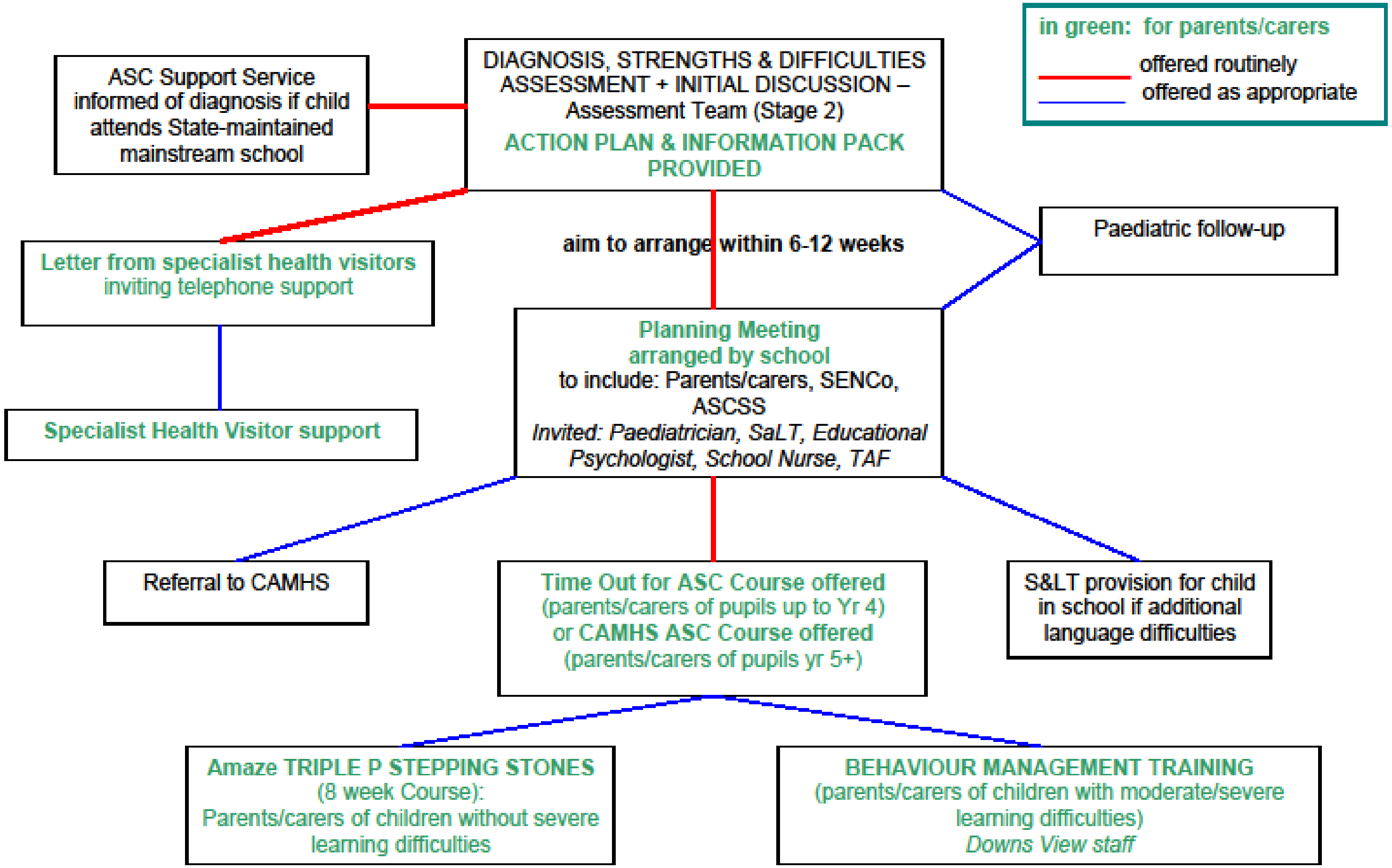
On-going PRESENS support for children at R-1, R-2

Amaze TRIPLE P STEPPING STONES
(8 week Course):
Parents/carers of children without severe learning difficulties

SUPPORTING POSITIVE BEHAVIOUR
Children receiving PRESENS on-site & off-site on recommendation of teacher (R-2 and R-1)

L:\Integrated Child Development and Disability Service\1.Policies, procedures and resources\ASC\ASC Post diagnostic support pathway PRESCHOOL.doc

ASC Post diagnostic support pathway: PRIMARY SCHOOL AGE children



in green: for parents/carers
🟥 offered routinely
🟦 offered as appropriate

ASC Support Service informed of diagnosis if child attends State-maintained mainstream school

DIAGNOSIS, STRENGTHS & DIFFICULTIES ASSESSMENT + INITIAL DISCUSSION – Assessment Team (Stage 2)
ACTION PLAN & INFORMATION PACK PROVIDED

Letter from specialist health visitors inviting telephone support

Specialist Health Visitor support

aim to arrange within 6-12 weeks

Paediatric follow-up

Planning Meeting
arranged by school
to include: Parents/carers, SENCo, ASCSS
Invited: Paediatrician, SaLT, Educational Psychologist, School Nurse, TAF

Referral to CAMHS

Time Out for ASC Course offered
(parents/carers of pupils up to Yr 4)
or CAMHS ASC Course offered
(parents/carers of pupils yr 5+)

S&LT provision for child in school if additional language difficulties

Amaze TRIPLE P STEPPING STONES
(8 week Course):
Parents/carers of children without severe learning difficulties

BEHAVIOUR MANAGEMENT TRAINING
(parents/carers of children with moderate/severe learning difficulties)
Downs View staff

Information available: for parents/carers

- Generic information about service at SV
- Information about autism specific assessments: what to expect
- Information pack given at point of diagnosis (SV + CAMHS)
- NAS information booklet
- Local leaflet re services available for 3 different ages
- Information about national database

Information available: for professionals

- SV diagnostic pathway
- Post-diagnostic support pathways (multiagency)
- ‘Information for referrers’(SV)
- Guidelines/checklists for professionals involved at various stages of ASC assessment (SV)

Audits/evaluation (SV)

- Process audit
- Parent questionnaire (MPOC)
- Focus group
- Current parent survey

Service planning

- ASC peer review
  - Ad hoc eg intervention planning
- CDDS Quality & Standards
- Disability Partnership board

Numbers

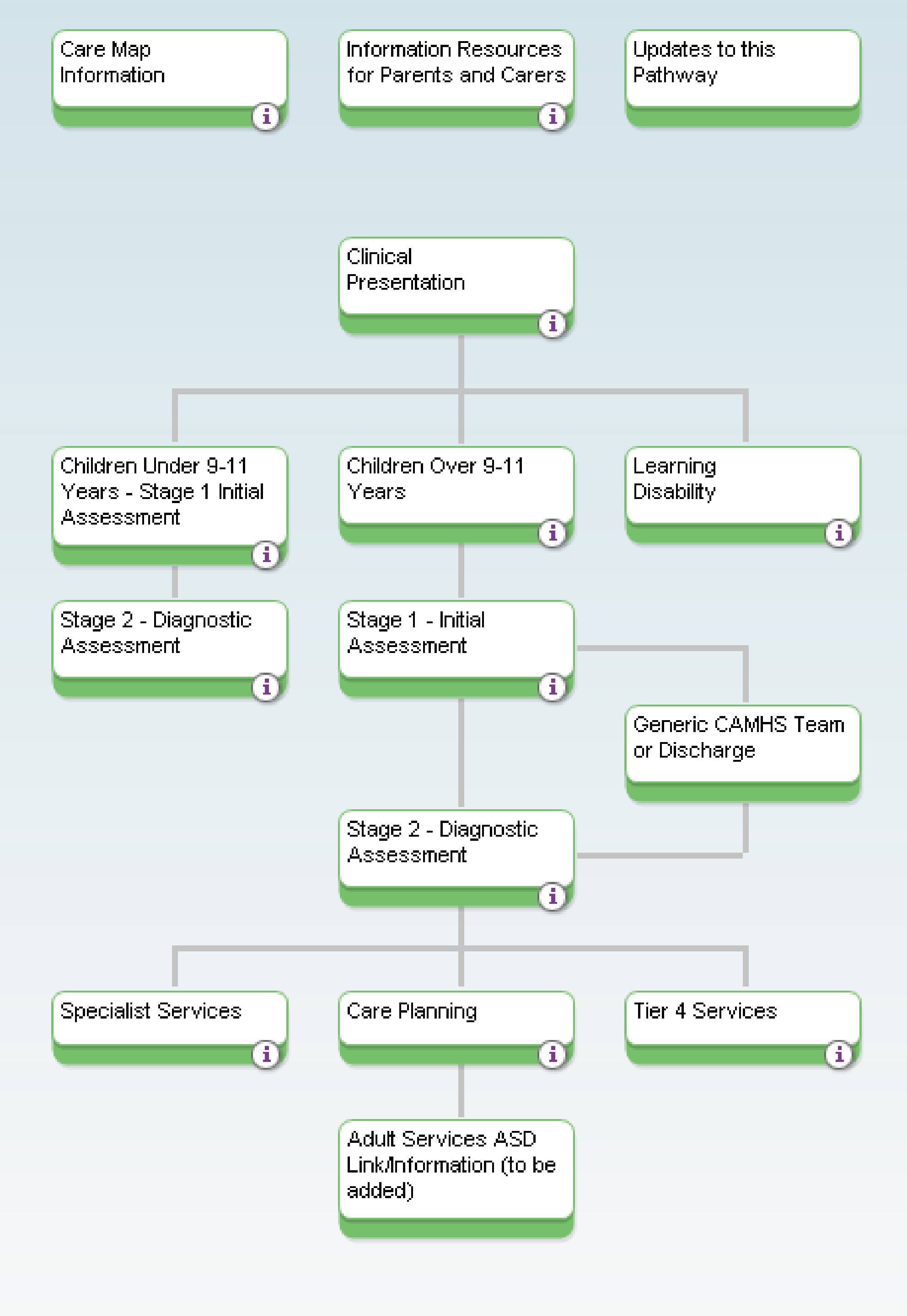
- 2 sessions per week excluding BHs for autism specific assessment
- Most on Mondays: some lost through BHs and AL
- 2 S&LTs, 1 psychologist, 6 paediatricians

Numbers: ESTIMATE

- 63 (48 –74) pa seen through standard pathway
- 86 last calendar year (July 2012-June 2013)
- Additional children seen through ICP or special school process
- 64% diagnosis of ASC made (standard pathway only)

Brighton & Hove CAMHS Autism Spectrum Disorder Care Pathway

Brenda Davis
Consultant Clinical Psychologist,
Lead for Psychology
Brighton & Hove CAMHS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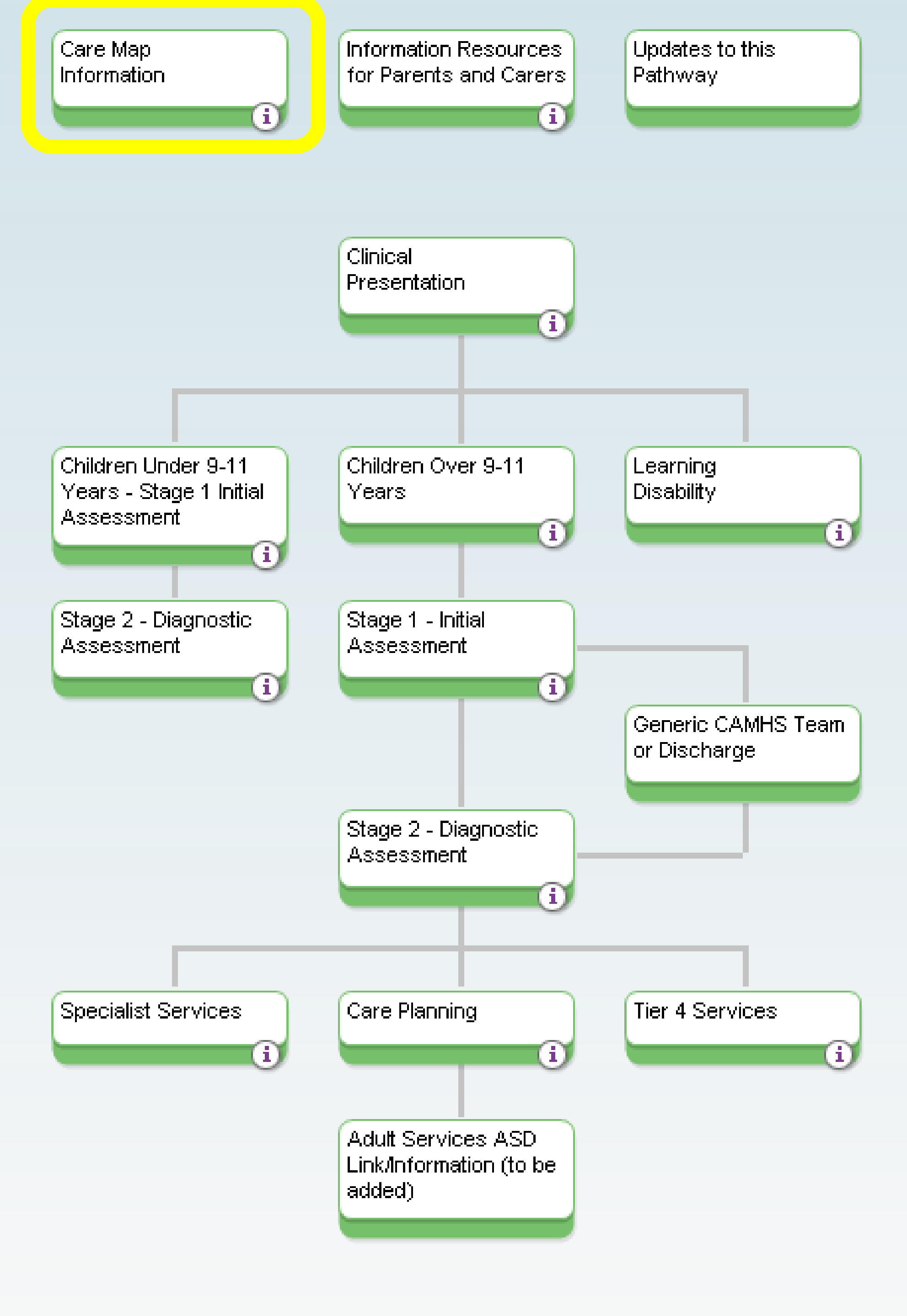
Map of Medicine Care Pathway

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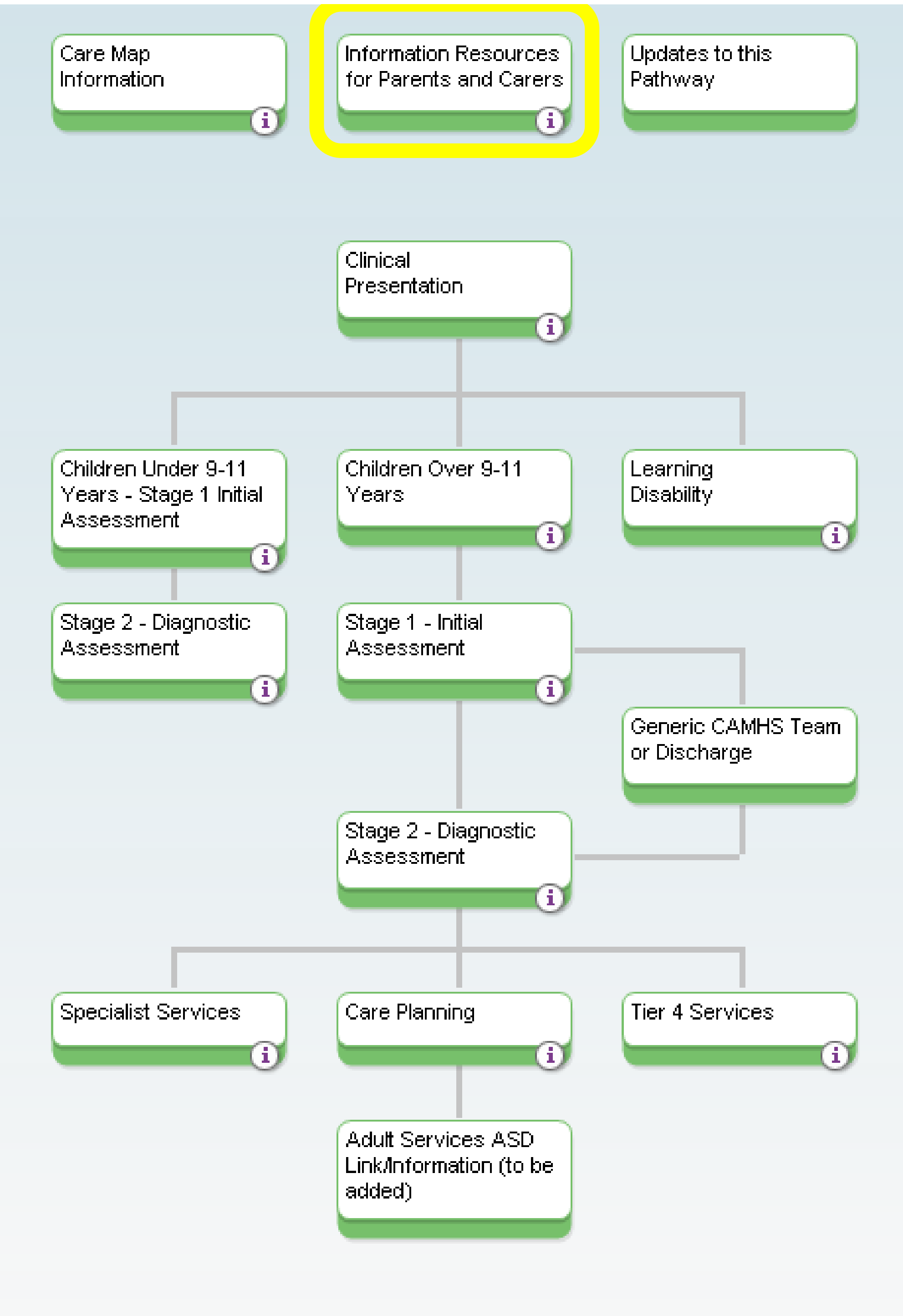
1. Care Map Information

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

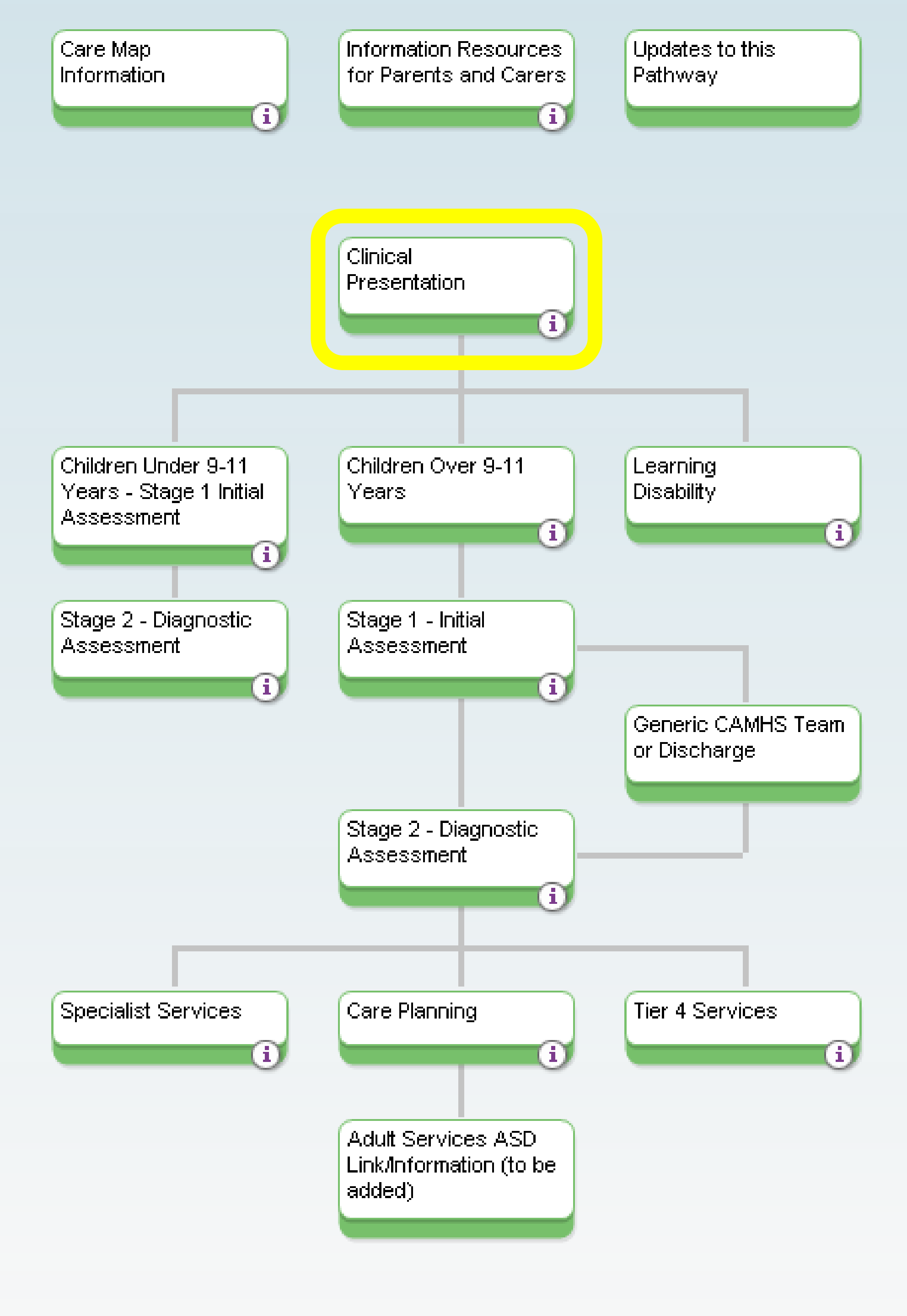
ASD can co-occur with other conditions, learning difficulty being the most common

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

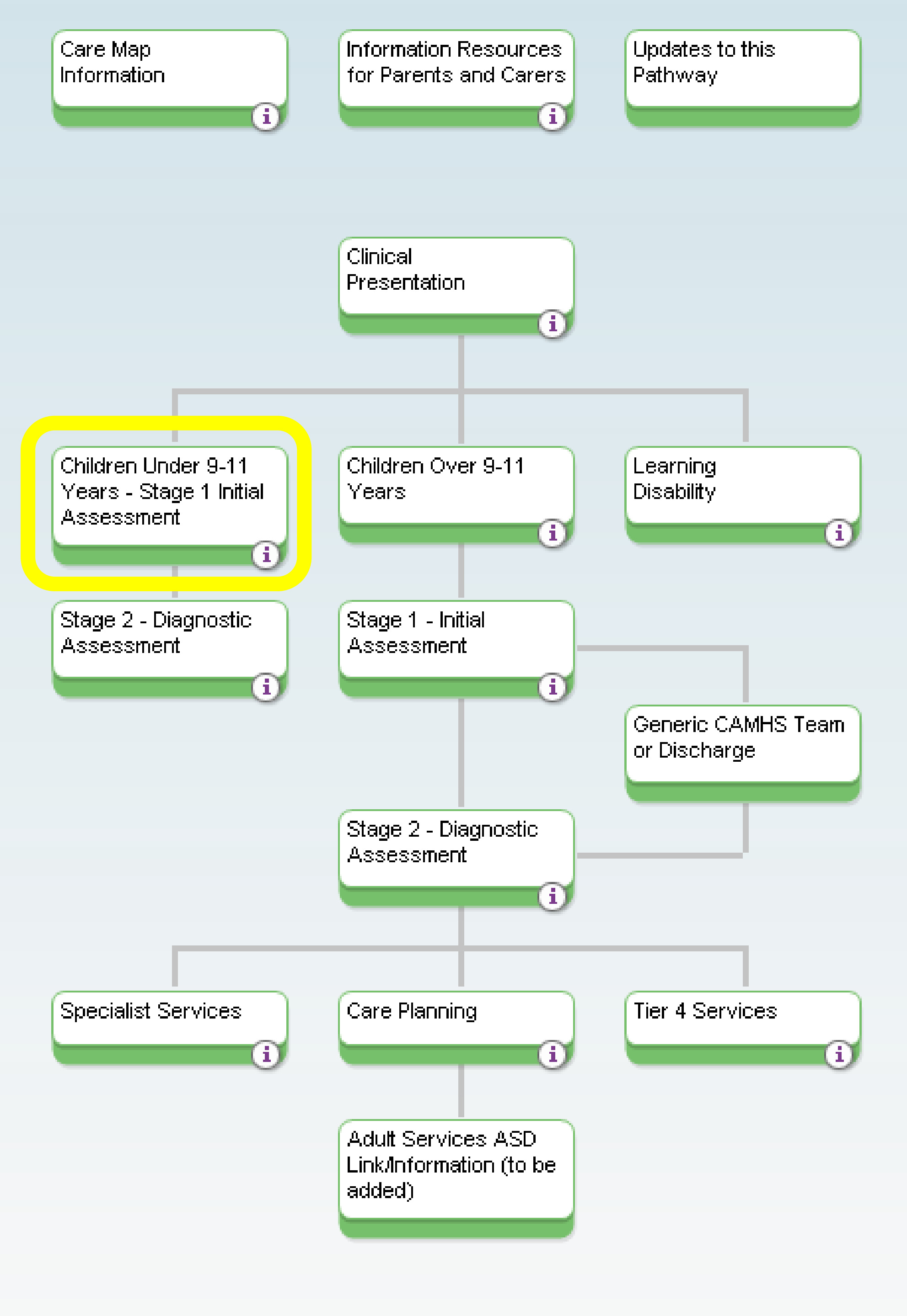
Clinical features that may accompany ASD, but are not essential for diagnosis:

- 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.

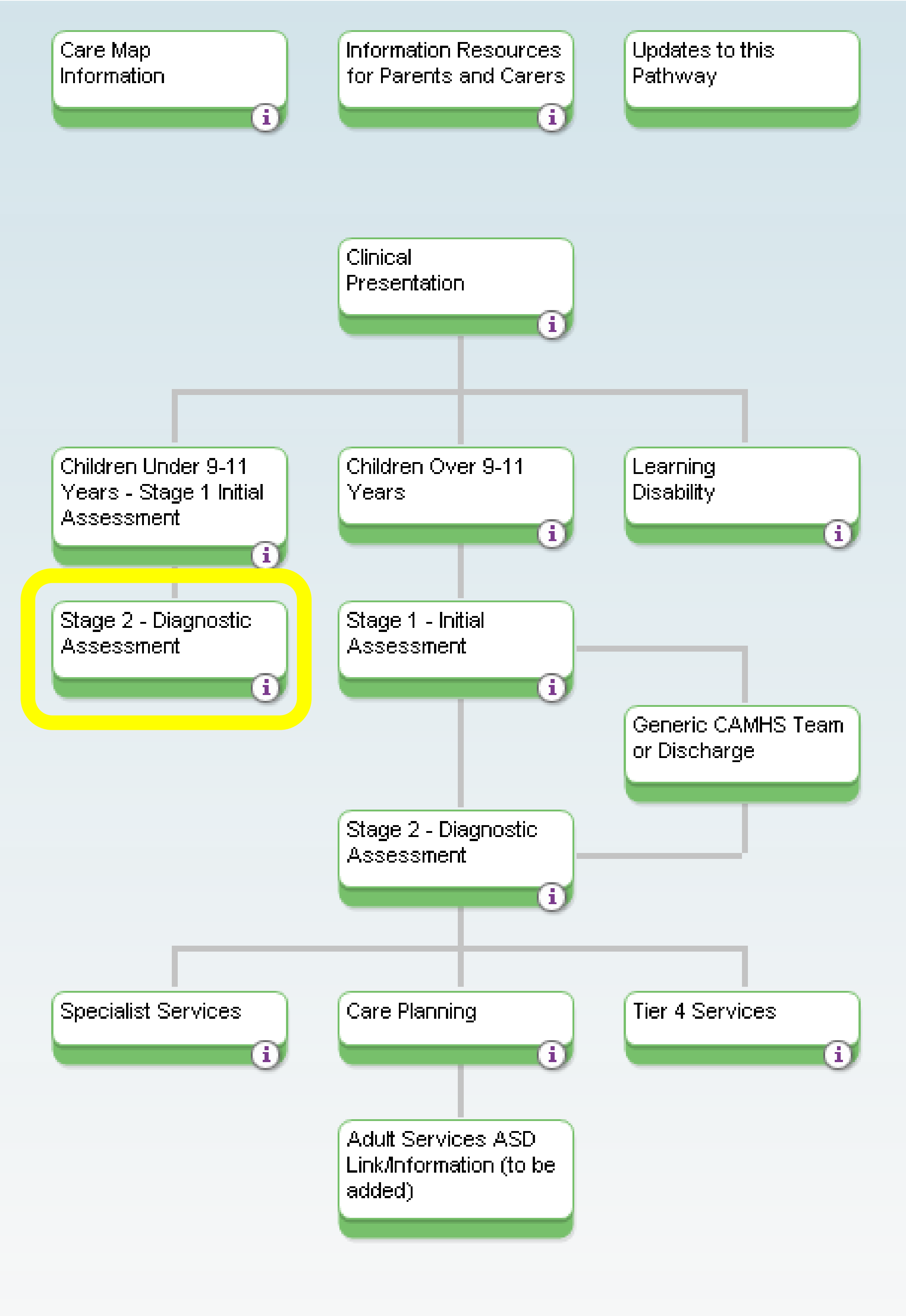
Depending on the clinical presentation, where stage 1 is an MDA stage 1&2 may be combined to form a diagnostic assessment.

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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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:

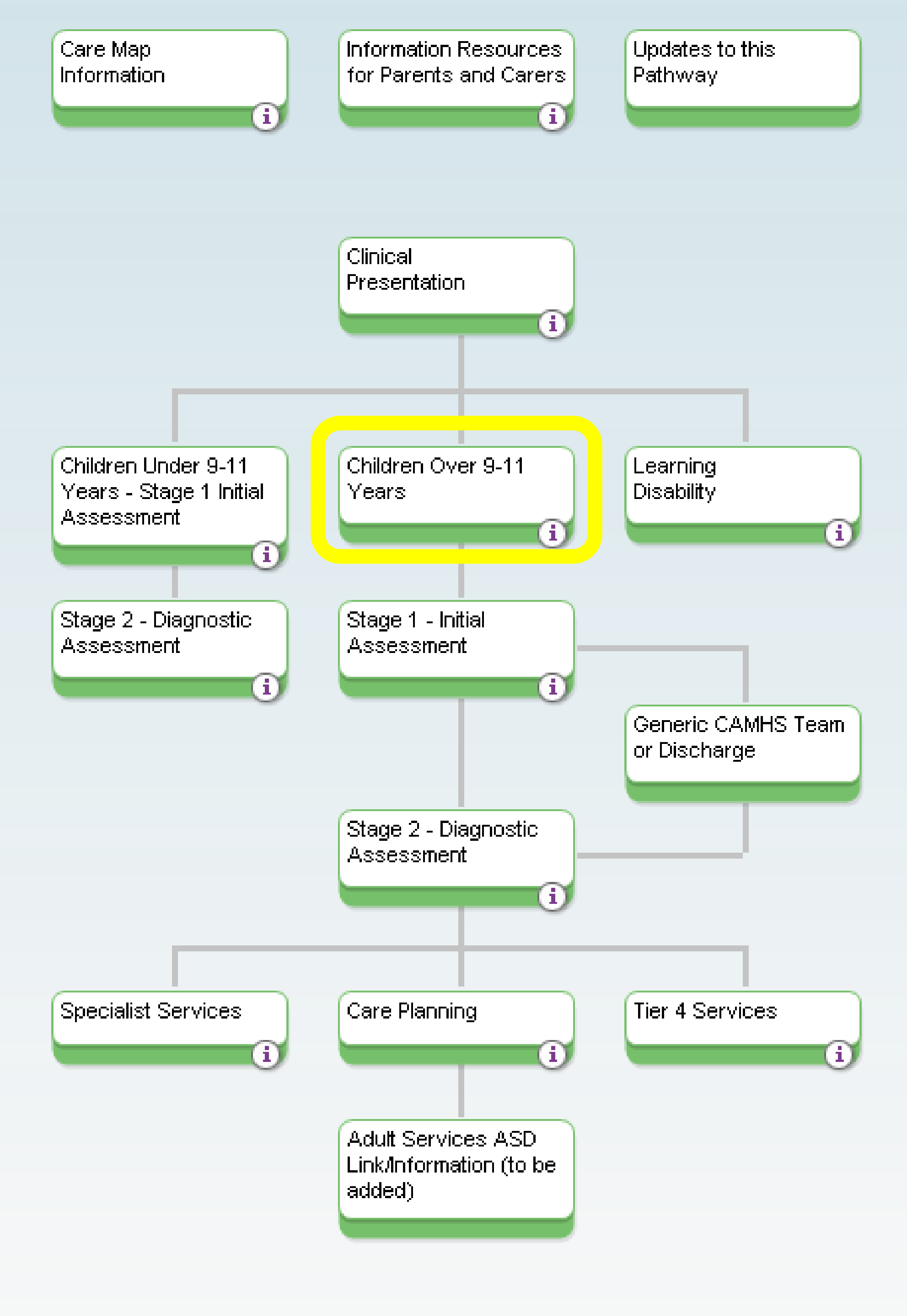
Referral back to ASD specialist within Tier 3 team for appropriate intervention but only if there is an accompanying presenting mental health problem

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 Questionaire (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

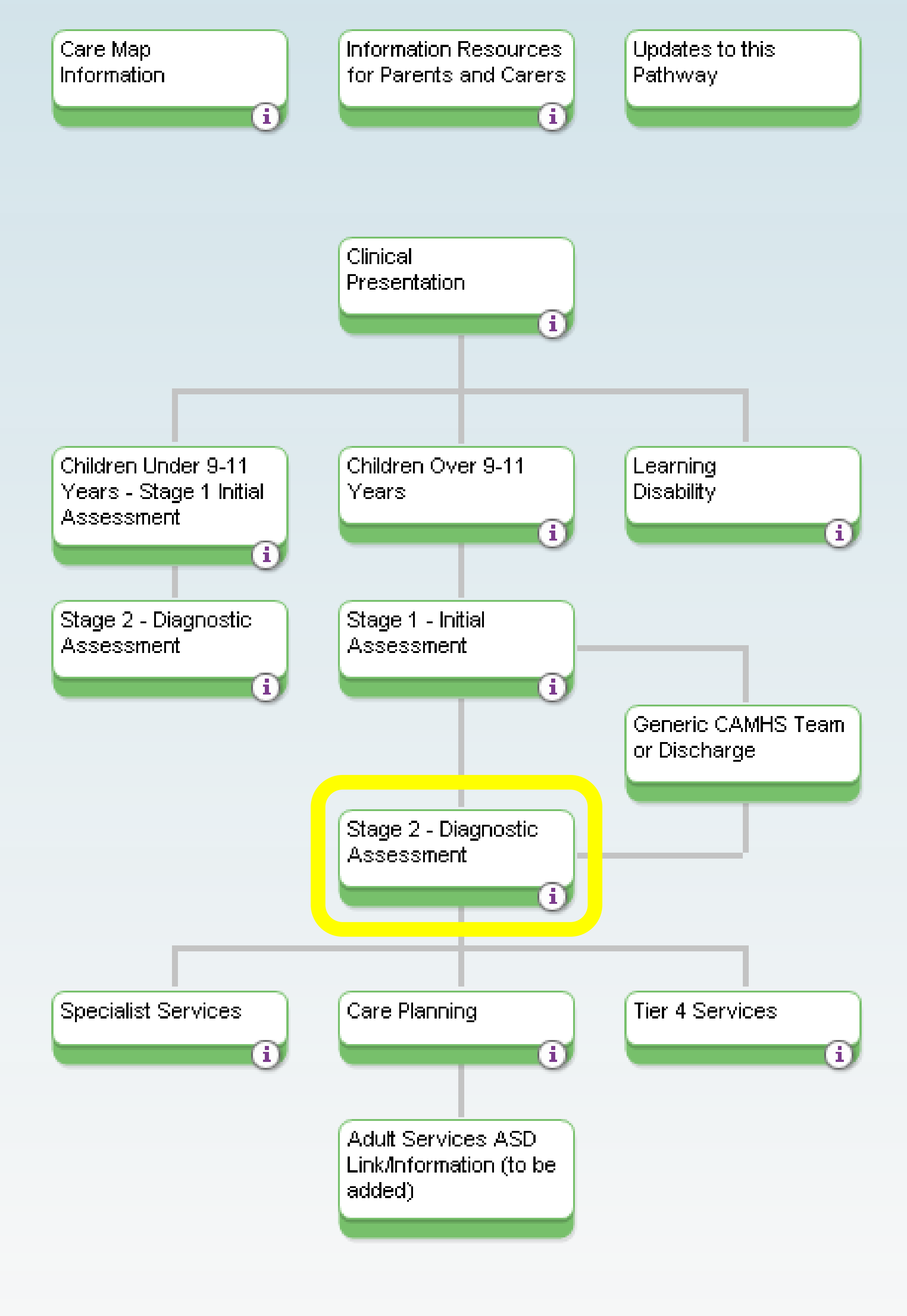
This leads to a Stage 1 report, which summarises all of the above.

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

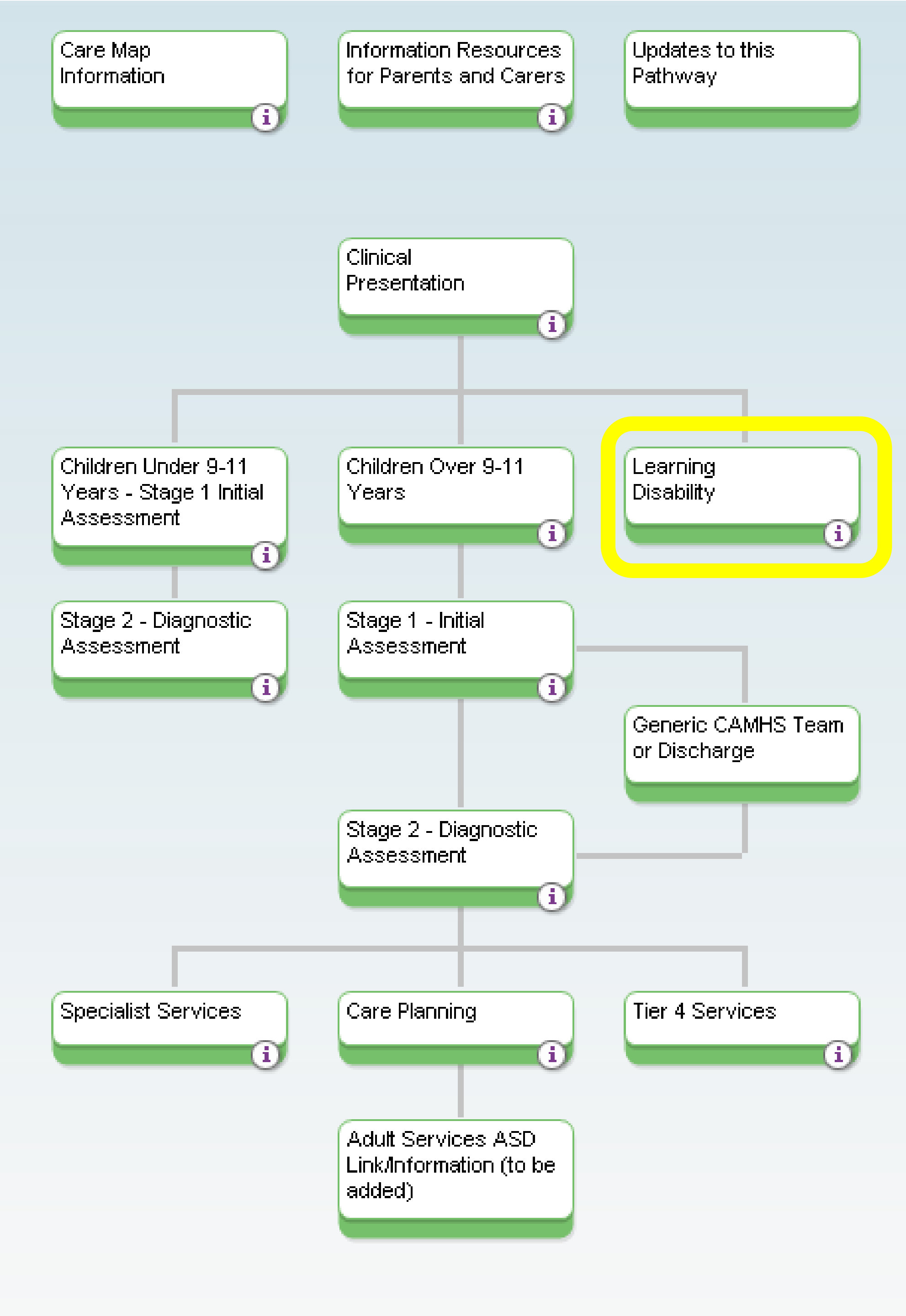
If not, signposted back to original Tier 1 or 2 referrer and discharged from Tier 3 service

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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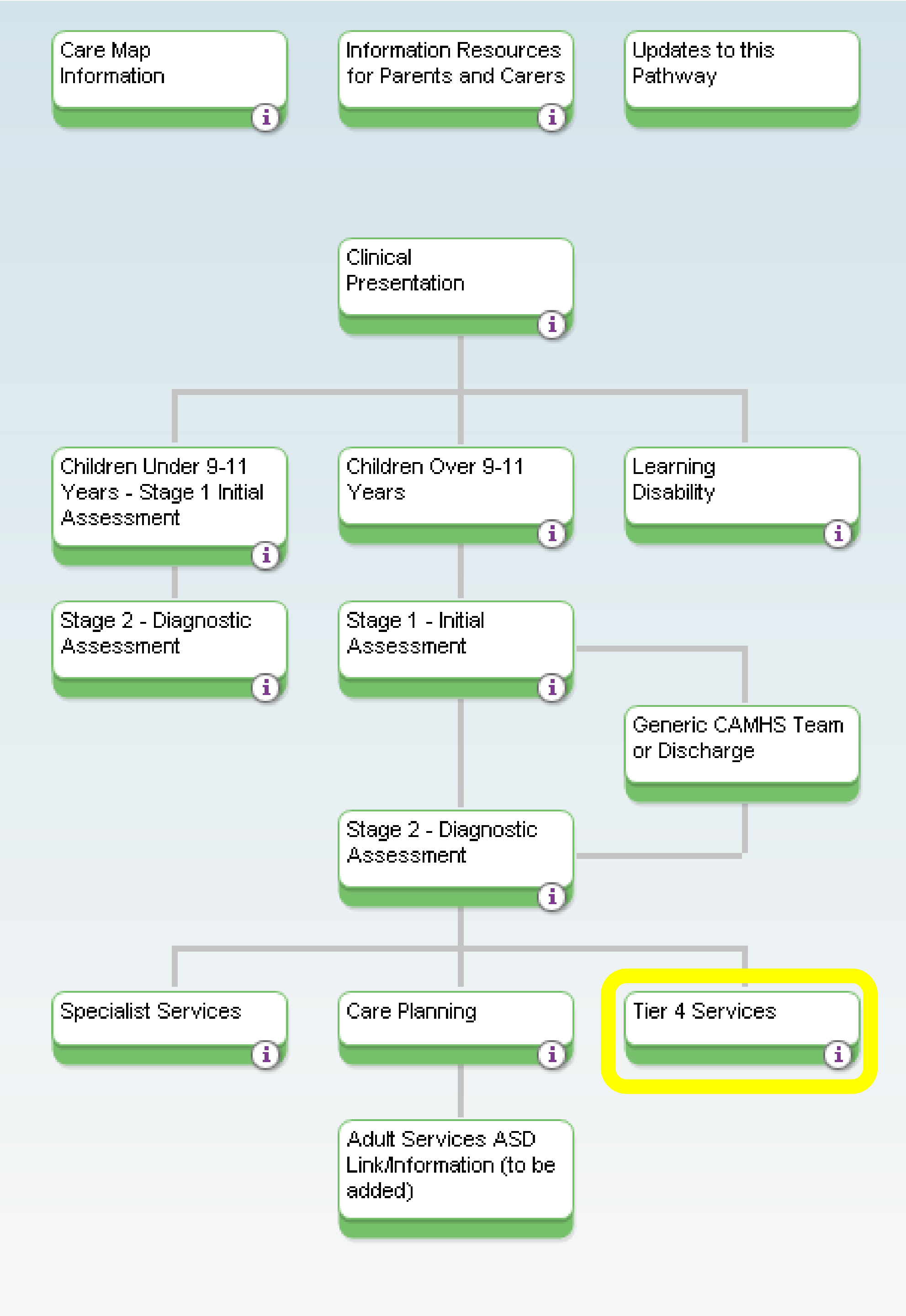
8. Learning Disability

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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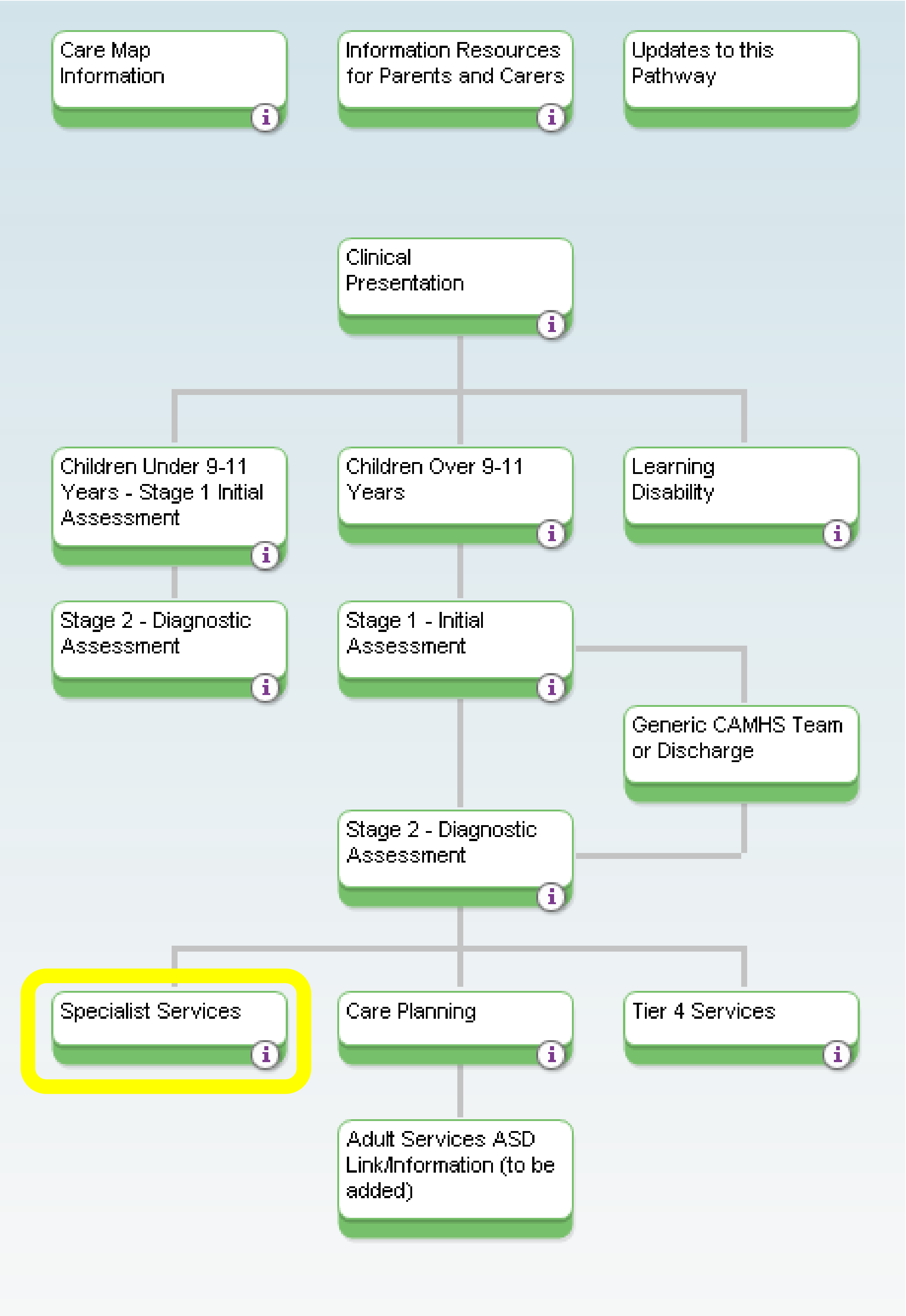
9. Tier 4 Services

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 seperately 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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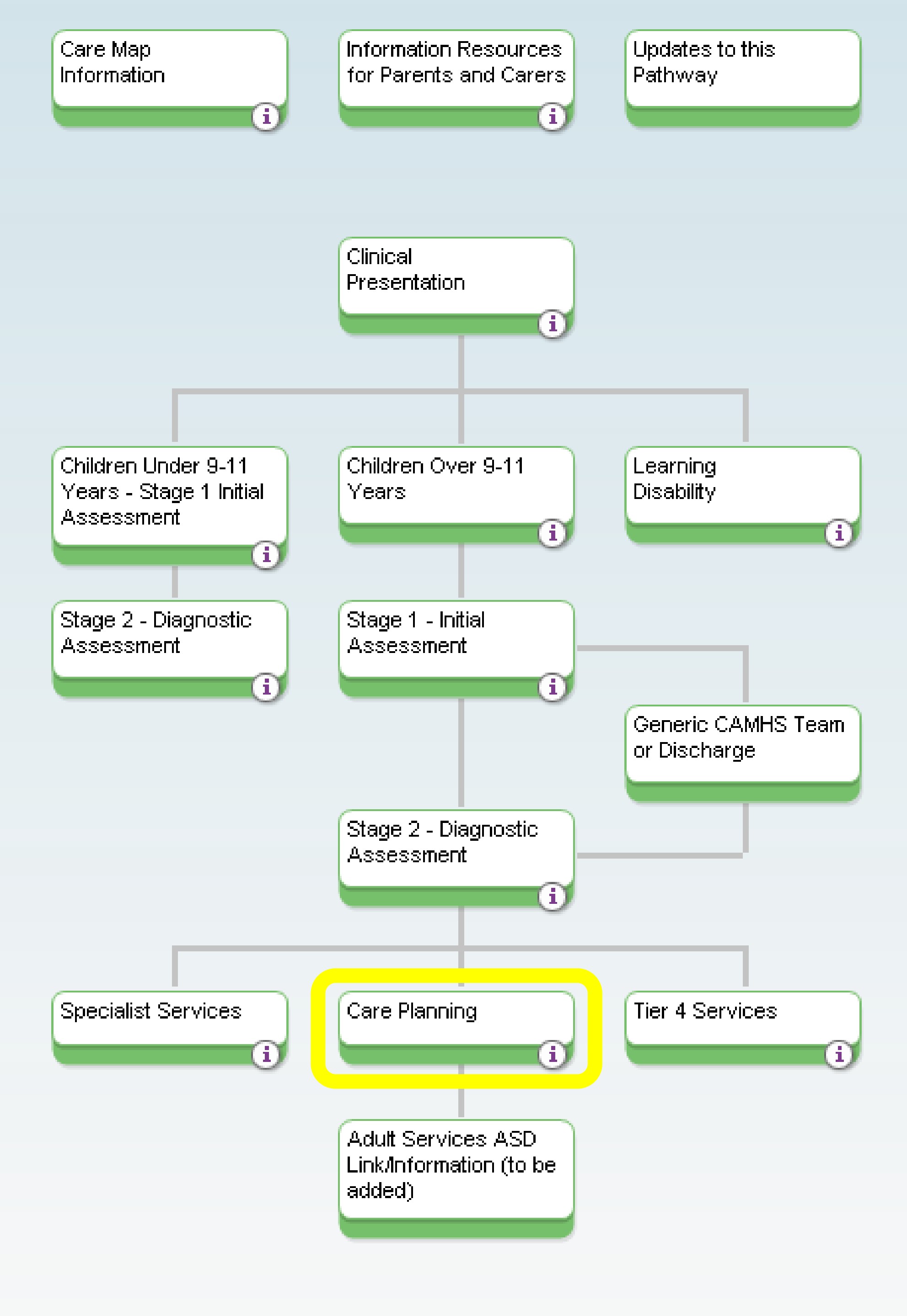
10. Specialist Services

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

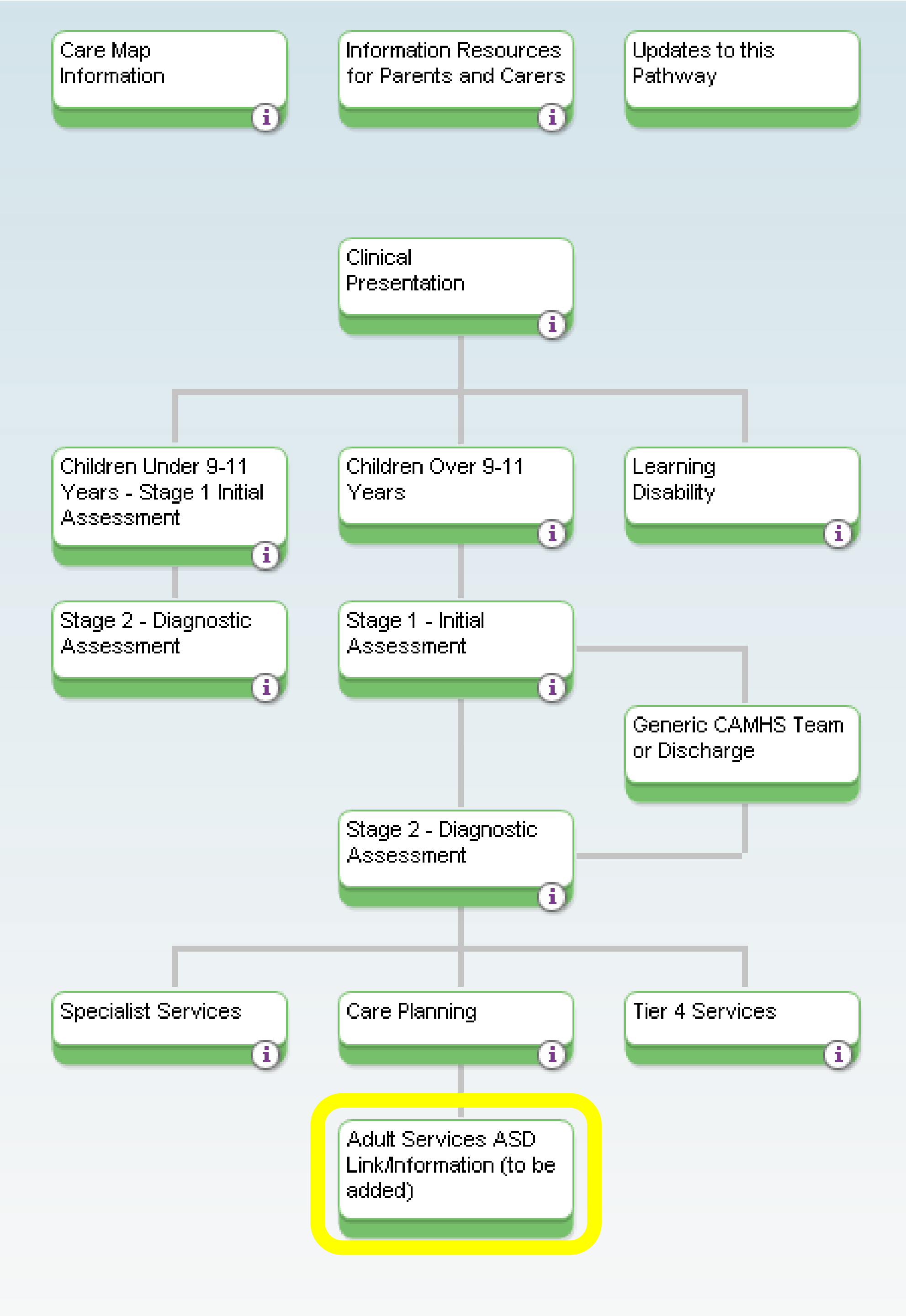
At 18 years, if the child or young person with ASD is still being seen in CAMHS, they would be referred to Adult Services:

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 apprpropriate, 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.


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)

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 apprpropriate, and also social care services as necessary. This should ideally include an information pack, jointly developed by CAMHS and Adult Services.

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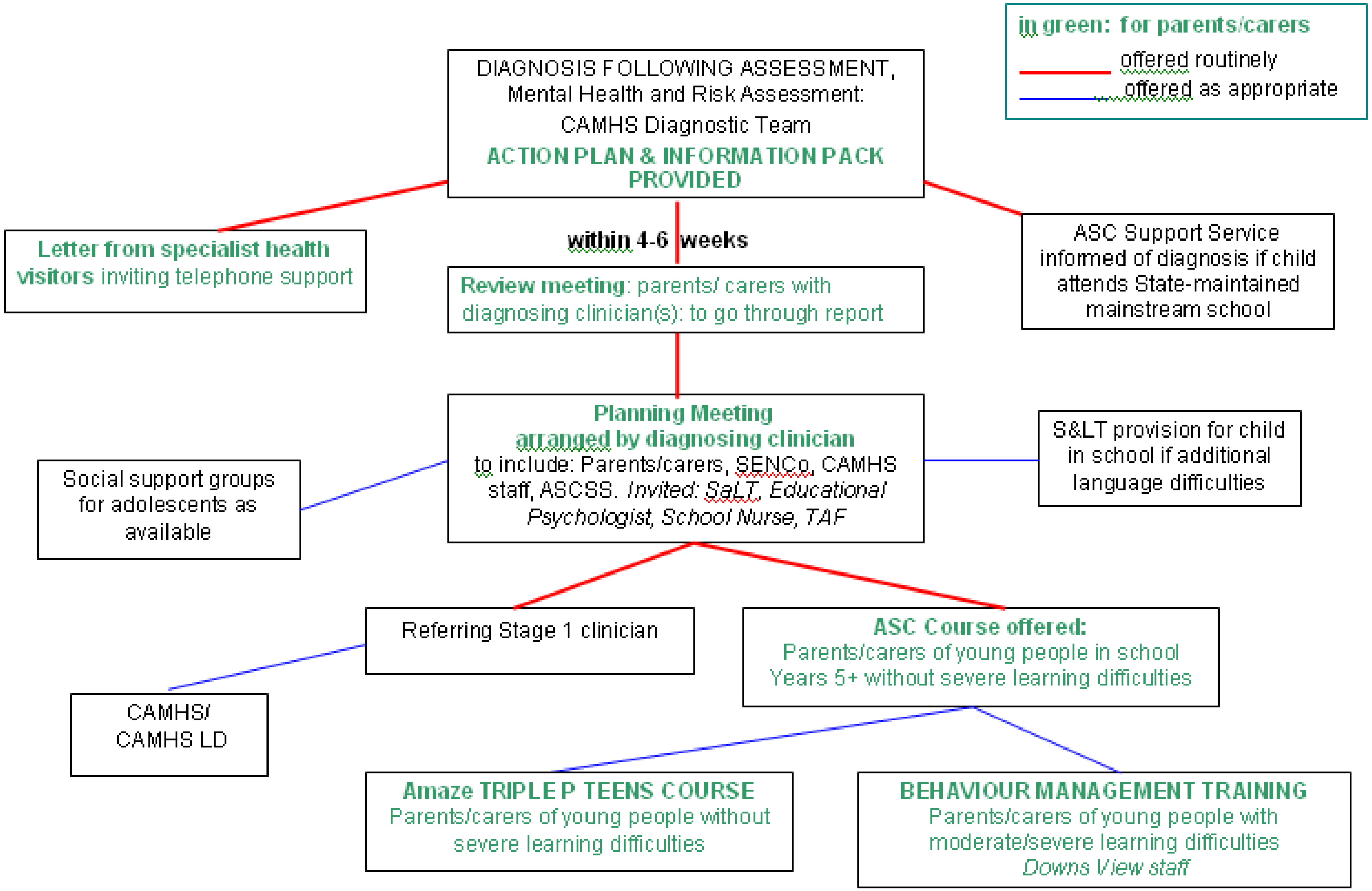
Secondary Age Post-Diagnostic Care Pathway



in green: for parents/carers

offered routinely

offered as appropriate

DIAGNOSIS FOLLOWING ASSESSMENT,
Mental Health and Risk Assessment:
CAMHS Diagnostic Team
ACTION PLAN & INFORMATION PACK PROVIDED

Letter from specialist health visitors inviting telephone support

within 4-6 weeks

ASC Support Service informed of diagnosis if child attends State-maintained mainstream school

Review meeting: parents/ carers with diagnosing clinician(s): to go through report

Planning Meeting
arranged by diagnosing clinician
to include: Parents/carers, SENCo, CAMHS staff, ASCSS. *Invited: SaLT, Educational Psychologist, School Nurse, TAF*

Social support groups for adolescents as available

S&LT provision for child in school if additional language difficulties

Referring Stage 1 clinician

ASC Course offered:
Parents/carers of young people in school Years 5+ without severe learning difficulties

CAMHS/
CAMHS LD

Amaze TRIPLE P TEENS COURSE
Parents/carers of young people without severe learning difficulties

BEHAVIOUR MANAGEMENT TRAINING
Parents/carers of young people with moderate/severe learning difficulties
Downs View staff

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

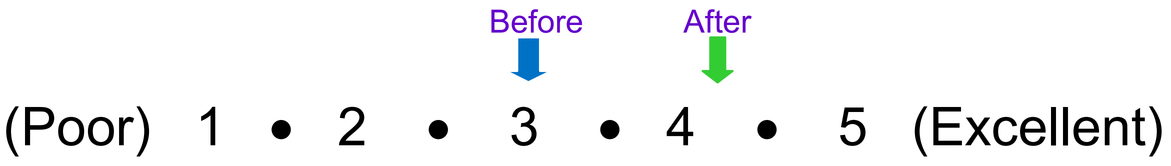
Currently, the group is evaluated with the following questionnaires:

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)

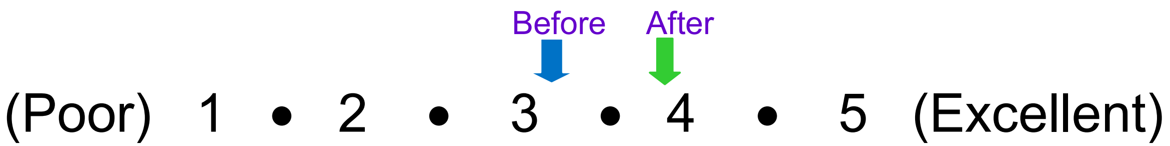
Findings: CAMHS' Questionnaire

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

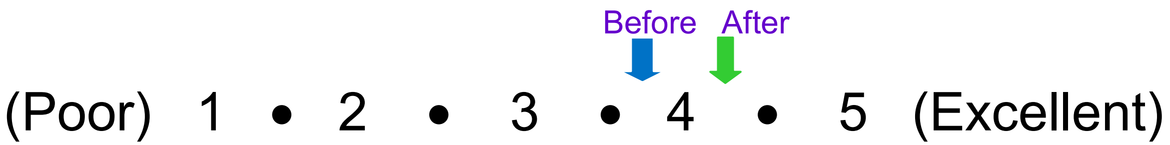
"How would you rate your **understanding** of Autism Spectrum Disorder?"



"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.

Assessment and provision for people with ASD in the UK

Vicky Slonims MRCSLT PhD

Evelina
London
Children's Hospital

KING'S
College
LONDON
University of London

Guy's and St Thomas' NHS
NHS Foundation Trust

Setting the scene

- At least **1% of the population have an autism spectrum condition** (Baird *et al.,* 2006; Baron-Cohen *et al.*, 2009a, Brugha et al 2011)
- High levels of additional needs:
  - **70%** of individuals with autism have at **least one other mental or behavioural disorder,**
  - **40 % have at least two disorders**, mainly anxiety, ADHD and ODD
    - (Hofvander, 2009 Simonoff, 2008).
- **Challenging behaviours are more common** in autism than in other conditions with similar levels of intellectual impairment
  - (McClintock, K., Hall, S. and Oliver, C. 2003).
- **Outcomes in adult life**, i.e. employment, relationships, independent living and community participation, **are often poor** (Eaves, 2008; Howlin, 2004).
- **25 to 30%** of individuals with **good intellectual skills** are able to achieve well academically and **find employment as adults** (Howlin, Rutter et al., submitted).
- **A child or sibling with autism** has a significant, often **deleterious impact on family** members (Davis, 2008; Estes, 2009),

Financial context: children

Knapp and colleagues (2009) based on 1% prevalence of autism estimated **annual** cost of supporting children with autism reaches £2.7 billion

- The mean annual total cost per child with autism in the UK reaches £25,400,

Barrett and colleagues (2012)

- In a study on 152 children (aged 2-5 years) the mean total service cost over 6 months was £2,581 (range £317 to £6,698), equivalent to £450 per month and over £5,000 per year.
    - Almost half the costs (45%) were for education and childcare,
    - 41% were for community health and social services
    - 12% for hospital services.

Financial context: adults

- For adults with autism estimated **annual** costs amounts to £25 billion (2006 prices)
  - costs associated health and social care, respite care, special education and day services, accommodation, voluntary organisation help
  - productivity losses (lost employment) of parents and adults with autism
  - **not including** cost estimates on benefit payments or informal care.

- The annual total cost <u>per adult</u> with autism,
  - £32,500 per person for adults with autism without intellectual disability living in private accommodation,
  - £98,000 for adults with autism with intellectual disability living in hospital.

Context of assessment

- Universal free health service
  - **No screening** program for autism or other neurodevelopmental disorders.
  - Approach is for **universal surveillance** by Health Visitors
    - pick up parental or professional concerns leading to rapid assessment and referral to appropriate assessment pathway.

- 3-4 tiers of health provision
  - Primary – General practitioners, nurses and Health visitors
  - Secondary – local district hospitals, community therapy services
  - Tertiary – regional hospital and specialist services providing second opinion and advanced clincial interventions
  - Fourth tier – national specialist resources

- ‘**Care pathways**’ across age ranges permit smooth transition between levels

Diagnosis

- National Autism Plan for Children (NAP-C) and Scotland (Assessment, Diagnosis and Clinical Interventions for Children and Young People with Autism Spectrum Disorders SIGN) Published by The National Autistic Society (NAS) 2003

- Since NAP-C,
  - increase in the number of **local teams** who have a formal autism assessment protocol: (32% in 2001 rising to 54% in 2007);
  - more services are using a **multidisciplinary/multi agency team approach** (48% in 2001 vs. 93% in 2007),
  - more teams have **joint clinics with child mental health services** (34% in 2001 vs. 57% in 2007).

- Still a **wide variation** in access to and quality of diagnostic and intervention services; **especially poor for adults**
- There is good awareness in many areas of **key diagnostic tools** e.g. autism specific interviews (ADI, 3Di and DISCO) and assessment measures (ADOS, PEP-R etc)
- The current estimated **prevalence rates** of autism have major resource implications and continue to place a **considerable strain on local diagnostic services.**
- Some **diagnostic services** are being provided by **education professionals and private sector teams**

Therapy and teaching

- Early years:
  - **Initially provision** may be through **health services** e.g. speech and language therapy, occupational therapy and psychology
  - **Education** services become involved in provision of **early learning skills** possibly home based visiting e.g. Portage, and providing placements in either **mainstream or specialist nursery provision** that can include therapy input

- School age years 5-19*

New Education and Health care legislation

  - will provide **education to 25yrs** for individuals with special educational needs

  - **One single assessment process** and education, health and care plan to give children all the help they need.
  - Education, health and social **services must work together** to give families **one single package of support**, tailored to their individual needs.

Therapy and teaching

- All children attend either **mainstream (70%) or special school (30%).**
  - In mainstream settings staff are required to make '**reasonable adjustments**' to ensure that a child can achieve their potential (Department for Education, 2006).
  - The government-led **Inclusion Development Programme** (IDP) **helps teachers** address the needs of children with ASD (Department for Children, Schools and Families, 2009a
  - The aim is for **collaboration of universal and specialist services** (health and education)
  - Individuals with statements of SEN are **assessed in school at the age of 14** years to provide a **Transition Plan** aims to collate
    - Information from as many sources as possible to **plan for the young person's transition to adult life.**
    - It is tied in to legislation from education, health and social government departments.

AET programme page

autism education trust
programme

Supported by:
Department for Education

Vision:

The AET believes that all children and young people with autism should receive an education which enables them to reach their individual potential to engage in society as active citizens (and that individuals, families and professionals are informed, supported and equipped to enable this to be achieved).

Therapy and teaching cont

Post 16 years:

- Most young people are expected to go to a college or post 16 provision.
- Depending on intellectual development and degree of autism this can range from a **university degree to skills based or vocational training**.

Adulthood

- Only **12%** of individuals with ASD without intellectual disability have full-time jobs, whilst across the **whole spectrum** the figure is **6%. (**Barnard et al. 2001)
- **Lower** levels of employment than those with **other disabilities**.
- **NAS Prospects Employment Consultancy** assisted **67**% of their clients to **find work** with a job **retention rate of 68%** (Howlin, Alcock & Burkin, 2005).
- For some individuals with learning disabilities and autism the main priorities are access to opportunities for **purposeful occupation and social inclusion** as a priority (Clegg, Murphy, Almack & Harvey, 2008).

Legislation

- **2004 Early Support Programme** (established the DFES/DH) produced **professional and parent *guides on ASD***.

- **2009 Autism Bill** which became the Autism Act - Secretary of State for Health is required to develop a **strategy for adults with autism regardless of their level of intellectual ability or disability.**
  - Set out several legal requirements for local authorities and/or NHS bodies
    - These include specialist training for key professionals
    - A requirement for a clear diagnostic pathway;

- **2010 -** Statutory guidance asserts the requirement for services to recognise that **individuals with autism with an IQ of 70 or over** may **require support**, not just those with intellectual disability .

Legislation

- **2010 ‘Getting it right for Children**’ review of services: Kennedy report.
  - Achieving Equity and Excellence for Children and Young People Government **proposals for the NHS as applied to children**.
    - **Shared decision making** between families, young people and professionals
    - ‘outcomes framework‘ for services emphasising **enhanced quality of life**,
    - ensuring a **positive experience of health care,**
    - **Children’s National Service Framework**, ‘Care will be provided in an **appropriate environment** that is **safe and well suited to the age and development** of the child or young person’.

Legislation cont

- **2012** The Report of the Children and young Peoples Health Outcomes Forum **for children and young people**
- Included a **subgroup for children with disability**, SEN and long term conditions such as autism.

  Main outcomes:

  - Reduction of time from first presentation to diagnosis or the start of treatment;
  - A quality assessment
  - Key working approach
  - Need for integrated care;
  - Effective transition from children's to adult services
  - Age appropriate care.

National Institute for Health and Clinical Excellence

- Management of individuals with Autism is covered by 3 guidelines
  - Autism diagnosis in children and young people
    - Recognition, referral and diagnosis of children and young people on the autism spectrum
      - Published: September 2011
  - Autism: Recognition, referral, diagnosis and management of adults on the autism spectrum
    - Published June 2012
  - Autism - Management of autism in children and young people
    - To be published August 2013

Key recommendations - diagnosis

- Local autism strategy and management groups
- Aims of group
  - **improving early recognition** of autism by raising awareness of the signs and symptoms of autism through multi-agency training
  - making sure the **relevant professionals** (healthcare, social care, education and voluntary sector) are **aware of the local autism pathway** and how to access diagnostic services
  - supporting the **smooth transition to adult services** for young people going through the diagnostic pathway
  - ensuring data collection and audit of the pathway takes place.

Key recommendations - diagnosis

- Team should include
  - paediatrician and/or child and adolescent psychiatrist
  - speech and language therapist
  - clinical and/or educational psychologist
  - and others as necessary e.g. gastro, neurology, OT etc
- Provide a **single point of referral** for access to the autism team.
- A **case coordinator** in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.

Key recommendations - intervention

- **Local autism strategy group** with responsibility to **deliver and coordinate intervention across age range** (i.e. into adulthood)
  - via local MDT teams and services
  - Case coordinator for all families
- Unrestricted **access to** all forms of care including **CAMHS**
- Access to tertiary services if necessary
- Some recommendations for specific treatments

Moving Forward, Supporting Change: for Children & Young People with Autistic Spectrum Conditions in Brighton & Hove

mASCot are a parent-led voluntary group working with families affected by autism in Brighton and Hove.

Following on from our ‘Autistic Spectrum Condition (ASC) Overview’ (November 2011), this document summarises the key issues faced by the families we support and makes recommendations for improving school and community-based services for children with ASC.

mASCot have close to 100 members and have conducted research which reflects findings from the National Autistic Society (NAS)

Autism affects over 1 in 100 people. With a population of 273,000 people in Brighton and Hove (ONS 2011) this equates to **2,730** people in our local area needing access to local, specialised services for autism.

Families in Brighton and Hove recommend:

- improving the quality, quantity, accessibility, and availability of services;
- Improving the education and training of individuals to work more effectively with children with ASC;
- creating appropriate school environments

1) Evaluating: The first step to improving services is to find out what works well and what does not

For the last year we have been actively campaigning for the City Council to undertake their own research to robustly evaluate the quality of existing services for children with ASC, by engaging with the service users themselves.

mASCot are continuing to press for a full and independent review of all ASC services spanning education, health and social care. Education remains the main hub of all the services for children and young people with ASC and must therefore be central to any review.

We recommend the City Council ensure that parents/carers of children and young people with autism are actively involved in designing an open-ended survey. Results should be analysed both quantitatively and qualitatively and findings should be made transparent, accessible and open to scrutiny by all interested parties.

2) Moving forward by ensuring that all interested parties are included and empowered

mASCot are ensuring that the voices of our members are heard by raising awareness nationally, and by supporting parents in improving outcomes for their children. We are also making our voices heard locally in the key areas of education, health and social care and will continue to do so.

We recommend that Brighton and Hove embrace a culture of openness, transparency and inclusion. Parents/carers of children and young people with autism must be included on all Boards that make decisions about autism. In partnership with parents, services can be properly evaluated and re-designed.

3) Supporting change

mASCot are bringing together experts, professionals, therapies and interventions that we, the service-users have evidence are effective for our children and young people.

We recommend that service providers in Brighton and Hove support change by appointing an independent ‘Autism Tsar’ to work with us to pull together all children’s and adult’s services for ASC.

EDUCATION – Our children are the adults of the future

- **SEN Statements**: The law states that SEN **s**tatements should be specified and quantified in setting out provision for a child's individual needs.

mASCot are working with parents regarding the wording of statements and will support them in seeking legal advice to protect the rights of their children.

We recommend the LA ensures that provision is specific to the individual needs of the child regardless of the existing resources available. The Local Authority must make schools accountable for meeting needs.

- **Individual Education Plans (IEPs):** All children with ASC should have an IEP. The provision of an IEP should be on a child's statement. Parental input should be actively sought and targets on an IEP should be SMART, frequently monitored and reviewed to form the basis of a targeted approach of interventions by all involved agencies.

mASCot are helping parents to ensure children have appropriately written, monitored and reviewed IEPs.

We recommend the sharing of good practice across all schools in the writing of IEPs for children with ASC. The LA must ensure that schools are held to account.

- **Exclusions:** Children with ASC are still being excluded from school at a disproportionate rate.

mASCot are continuing to support parents in exclusion meetings and will assist parents in seeking legal advice where appropriate.

We recommend the LA ensure that all exclusion procedures are lawful and that Governors are trained in ASC so that they can come to a fair and non-discriminatory decision.

- **Unlawful Exclusions:** Informal (unlawful) exclusions are still frequent yet go unchallenged.

mASCot are continuing to collect data from parents regarding the use of unlawful exclusions and reduced time-tables in Brighton and Hove schools. We will feedback our findings to the Children's Commissioner.

We recommend a clear procedure for parents to report unlawful exclusions and reduced timetables is urgently put into place. The LA has a responsibility to ensure the law is upheld and that schools are accountable for the safety of children not at school during school hours.

- **Teachers and Teaching Assistants** do not have sufficient training for a full understanding of ASC.

mASCot are supportive of the PaCC recommendations (2010) of an independent review of SEN practice in all schools to look at the nature and effectiveness of the training that teachers, TAs and INAs receive.

We recommend the LA keep records of which schools/staff have undergone training. Records should be available to parents/carers to enable them to make an informed decision about choice of school.

- **Social skills:** School staff are not equipped to plan programmes to help develop the social skills that ASC children find so difficult.

mASCot are working with independent specialists and other agencies who provide social skills interventions. Our members are evaluating the effectiveness of these interventions.

We recommend the LA specify and quantify social skills on a child's statement as appropriate for the individual child and arrange suitable provision to meet the needs of that child.

HEALTH AND WELL-BEING –The right support at the right time

- **Diagnosis:** 34% of parents had to wait three years or more for a diagnosis after first raising concerns (NAS). Some children present with difficulties but without a diagnosis, receive no help.

We recommend ASC specialists are consulted early in the assessment process so that ASC is one of the first possibilities to be considered to enable early intervention**.** If there is no clear 'label' for a child, difficulties should be clearly described so that parents can access the help they need. Privately sought opinions and assessments should be respected.

- **Post-diagnosis:** Our members report being given information leaflets post-diagnosis, but still not knowing what services are available to their families or how to access services.

We recommend providers proactively advertise their services for ASC via schools and health centres and that there is transparency regarding what can and what cannot be provided. Clearer information should be made available about referral procedures, with the option of self-referring.

- **Planning:** Not knowing what to expect is particularly difficult and stressful for a person with ASC.

We recommend practitioners provide a detailed breakdown of what to expect during consultations, appointments and meetings so that parents can help to prepare their child in advance.

- **Needs-led, flexible, diverse services:** Our members are not able to find the right support, at the right time for their children. ASC-specific support in Brighton and Hove is inadequate and limited in scope:

What? - We recommend that commissioning of services is based on identifiable needs. Additional services must be commissioned where there are identifiable gaps in provision. No intervention for ASC should be promoted unless there is robust evidence of its effectiveness. Strategies for overcoming difficulties should be evidence-based and practised in-situ. Consultation time should be spent on actively helping children overcome difficulties, not reviewing and completing paperwork.

Where? – We recommend that practitioners show an understanding of the importance of the child's comfort rather than expecting the child to fit in with the service. In clinic settings it is important that the child's sensory sensitivity is taken into account, and there should be a safe space to release stress in a controlled way. Practitioners should offer home visits or school visits for those children and young people who cannot access clinic settings.

When? - We recommend a drop-in service for urgent cases and crisis support and parents should also be available to be contact practitioners by phone/email. For some services, there are long waiting lists which create further difficulties for families. Appointment times should be flexible because, for some children, missing time from school can be upsetting to their routine. The duration of a course of support must be based on need and identifiable progress, not on completion of an allotted amount of weeks/hours**.**

How? - We recommend practitioners are flexible in both the type of provision and means of delivery – support must meet an individual's needs, be age-suitable and suitable to the child or young person's cognitive and communicative ability. Our children are individuals, and as such there should be some choice for the individual child and family.

SOCIAL CARE - Autism has an impact on the whole family

- **Assessment:** The majority of mASCot families have never had their care needs assessed.

We recommend that any family with a child with autism is given the opportunity to have an assessment, taking into account the needs of the whole family. We support PaCC recommendations that for families who are not necessarily in a critical situation, circumstances can change and needs vary accordingly. Periods of support and assistance should also be made available to such families.

- **Access to services:** 74% of people caring for someone with autism get no support from their local authority (NAS). Our members report not knowing what services are available or how to access them.

We recommend clarity regarding what services are available, who can access these services and that service providers ensure there is consistency in the provision offered to families.

- **The right support:** mASCot members report being unable to get the right support for their family.

We recommend better, faster access to respite care and short breaks. There is a need for more specialist social care services. There needs to be a more personalised, responsive, holistic, consistent approach to provision.

A HOLISTIC APPROACH – Autism affects us every day in every way

- **Communication:**

Health, social and education services must work **together with parents.** There is a need for better communication between practitioners, schools and parents. Practitioners need to work with schools and provide training in how to meet the child’s needs. There must be transparency in correspondence and communication between all parties.

- **Working together:**

mASCot support PaCC findings that parents are still not being acknowledged for their expertise on their children and are not being listened to. Professionals must fully involve those with autism, and their families, in designing the services and the support they need so that services meet locally identified individual needs. Any ASC-specific statutory agency group should actively seek to draw on the expertise of parent/carers and specialist agencies such as Autism Sussex and the NAS.
The child’s needs and views must also be sought and provision considered from the child’s perspective.

- **A wrap-around service**:

Our children's disability does not disappear when they leave the school premises, nor does it fit within the normal working day or week. We recommend a wrap-around service. Children with ASC have difficulty generalisation from one setting to another, therefore, on-going support at home is also essential.

- **Expertise:**

ASC presents in different ways and practitioners need to treat each child or young person as an individual and establish a relationship of trust with the child and family. Anyone who works with a child or young person with ASC should have received high-quality training as part of their equality and diversity training. On-going training should involve parents and professionals working together and sharing expertise.

- **Evaluation:**

Key Area		mASCot Recommendations
All provision must undergo regular monitoring and robust evaluation. Existing data collection models are readily available.		
Education	SEN Statement IEPs	• The LA should ensure that provision is specific to the individual needs of the child. • The LA must make schools accountable for meeting needs • All children with ASC should have an IEP. The provision of an IEP should be on a child's statement • Targets on an IEP should be SMART, frequently monitored and reviewed • Good practice should be shared across all schools in the writing of IEPs • The LA must ensure that schools are held to account
	Exclusions	• The LA must act to stop children with ASC being excluded from school at a disproportionate rate • The LA must ensure that all exclusion procedures are lawful and that Governors are trained in ASC
	Unlawful Exclusions	• The La must have a clear procedure for parents to report unlawful exclusions and reduced timetables • The LA must ensure the law is upheld and that schools are accountable for the safety of children not at school during school hours
	Teachers, TAs and INAs	• The LA should keep records of which schools/staff have undergone training. • Records should be available to parents/carers to enable them to make an informed decision about choice of school
	Social Skills	• The LA should specify and quantify social skills on a child's statement • Provision must meet the needs of the individual child
Health and Well-being	Diagnosis	• ASC specialists should be consulted early in the assessment process to enable early intervention • Difficulties should be clearly described so that parents can access the help the child needs, regardless of diagnosis • Privately sought opinions and assessments should be respected
	Post-Diagnosis	• Services for ASC should be advertised via schools and health centres • Transparency is needed regarding what can and what cannot be provided • Clearer information about referral procedures, with the option of self-referring
	Planning	• Practitioners should provide a detailed breakdown of what to expect during consultations, so parents can prepare their child in advance
	Needs-led, flexible, diverse services	• Commissioning of services should be based on identifiable needs. • Additional services must be commissioned where there are identifiable gaps in provision • No intervention for ASC should be promoted unless there is robust evidence of its effectiveness • Strategies for overcoming difficulties should be evidence-based and practised in-situ • Consultation time should be spent on actively helping children • In clinic settings the child's sensory sensitivity should be taken into account, and there should be a safe space to release stress in a controlled way • Practitioners should offer home visits or school visits for those who cannot access clinic settings • There needs to be a drop-in service for urgent cases and crisis support • Parents should also be able to be contact practitioners by phone/email quickly • Appointment times should be flexible and not only in school hours

		- The duration of a course of support must be based on need and identifiable progress - There should be flexibility in the type of provision and means of delivery to meet an individual's needs: age-suitable and suitable to the child's cognitive and communicative ability
Social Care	**Assessment**	- Any family with a child with autism should have a family assessment - Periods of support and assistance should be made available to families if/when they need them
	Access to services	- There should be clarity regarding what services are available and who can access them - Service providers should ensure there is consistency in the provision offered to families
	The right support	- Better, faster access to respite care and short breaks - More specialist social care services - A more personalised, responsive, holistic, consistent approach to provision

mASCot Contact details:
Sam Bayley (Chair) 01273 414609 or 07943-346055

References:

NAS & Centre for Public Scrutiny 'Difference In Mind' http://www.cfps.org.uk/what-we-do/publications/cfps-health/?id=164
NAS 'Young People's Charter for CAMS' http://www.autism.org.uk/ycgcharter
PaCC SEN Report July 2010
PaCC contribution to the JSNA September 2010

Submission & Overview
25 November 2011

Suggestions by families with Children on the Autistic Spectrum Condition (ASC) regarding the Children & Young People's Overview & Scrutiny Committee's Review of Autistic Spectrum Condition Services in Brighton & Hove

Although recent DfE policy has sought to promote and safeguard the welfare of disabled children and those with SEN, and 'Every Child Matters', it is our experience that in Brighton and Hove, provision and services for children with ASC fall short of statutory guidelines.

Main Areas of Concern – ASC Services in Brighton & Hove (Health, Education, Social Services)

1. Failure to provide timely, diverse and flexible services to meet the needs of children with ASC
2. Services provided being frequently ineffective, counterproductive, harmful or reactive
3. Failure to keep families at the heart of the process, leaving the child and carers without a voice
4. Failing to proactively commission services even where there is an identified need, thus forcing families to find help privately

Autistic Spectrum Disorder Pathways Policy Sussex Partnership Trust

- Concern that the recently introduced 'ASD Pathways Policy' is not being routinely applied

Diagnosis

- No treatment or help offered, ignoring concerns, families 'batted' away
- Long waits for assessments at both Seaside View & CAMHs
- Misdiagnosis (ADHD instead of ASD)
- Missed diagnosis (not picked up at all)

Behaviour Management

- No/very little proactive (or even reactive) management of frequently encountered behavioural difficulties (eating, toileting, sleeping, self-harm, anxiety, aggression, obsessive behaviours)
- Families being left to deal with behaviour issues on their own with little or no support

Mental Health Management

- No immediate, appropriate help for families in crisis
- Inappropriate settings; clinic-based appointments and procedures often intimidating for children who want support in relaxed settings, outside of those times
- Inappropriate treatment offered' ineffective or counterproductive/harmful i.e. CBT delivered with no sensitivity of ASC
- Lack of a comprehensive assessment as to cause of the difficulty; frequently attributing the child's difficulties to poor parenting or suggesting inappropriate therapy without understanding the underlying cause e.g. bullying
- Insufficient treatment; parents given a factsheet and expected to do therapy at home without guidance, structured input or monitoring
- Insufficient treatment; parents forced to re-refer whether there is any evidence of improvement in child or not
- Insufficient expertise; parents advised to seek 'specialist' help
- Insensitivity towards parents; patronising, 'one size fits all' parenting advice in a clinic-based setting

Education

- LA refusing to amend wording on statements in order to allow 'more flexibility' for schools, thus acting in the interests of the school and not the child
- Exclusions; children with ASC are still being excluded at a disproportionate rate. LA do not flag up children with ASC who are at risk of permanent exclusion
- LA still 'turn a blind eye' to informal i.e. unlawful exclusions
- Individual Education Plans are not SMART and the bar is set very low, i.e. teaching staff are not ambitious in terms of the children's potential
- Lack of adequate monitoring of a child's progress against targets set
- Social skills; school staff are not equipped to plan programmes to help develop the social skills that ASC children find so difficult
- Children with ASC are left in the care of Teaching Assistants who have a very superficial understanding of their condition (maybe 1 day of training) and do not fully know what to do
- Continued promotion of 'one size fits all' interventions for ASC even where there is no evidence the interventions work
- School-based advice and support for children with ASC inadequate and limited in scope
- Meetings are often focussed on the outcome for the professionals involved rather than the outcome for the child
- Lack of accountability throughout the education system

Communication

- Communication between practitioners is poor; parents asked to repeat their child's history again and again, particularly in clinic-based settings
- Professionals seem to 'pass the buck' i.e. one might suggest a certain therapy for a child but the relevant agency or service refuses to provide it on the grounds of 'lack of resources'
- Practitioners will often value the school's opinion over the parents' knowledge of their own children and teachers/teaching assistants are often too busy or lack the training to notice nuance behaviour
- Practitioners copy colleagues and other agencies into correspondence but fail to ensure copies are also sent to parents
- Terminology and acronyms used by professionals can be intimidating for parents
- Some professionals are continuing to use entirely inappropriate, discriminatory terms to describe the various presentations of ASC
- Some professionals are continuing to suggest that parents are the cause their child's difficulties either in terms of the family environment or poor parenting skills
- Parents report that they feel their opinions are undervalued or they are under suspicion. This perception comes from direct and indirect comments from practitioners that are intimidating and threatening; some parents fear if they make a complaint their child will be adversely affected

Improving Services: What We Need

1. Diverse and flexible services delivered with ease of access for children – needs-led not resource-led

Services that include choice for the child and the family in terms of intervention, practitioner and style of delivery in a way that works best for them – see National Autistic Society's 'Young People's Charter for CAMS' http://www.autism.org.uk/ycgcharter

Solution

1. Anyone who works with a child or young person with ASC should understand the condition and have received adequate training

2. Anyone who works with a child or young person with ASC should be aware that ASC presents in different ways and treat each child or young person as an individual
3. Anyone who works with a child or young person with ASC should offer different options and be flexible in their approach
4. Professionals should include children in the decision-making process
5. A detailed breakdown of what to expect during consultations and meetings should be provided in advance. Not knowing what to expect is particularly difficult and stressful for a person with ASC
6. Practitioners should give choice about who children and young people work with. Children with ASC have said: “I want to have one person to get to know, not lots of different people”
7. The environment should not disturb the senses. Service providers can help keep sensory sensitivity to a minimum by asking young people if they feel comfortable in the chosen meeting place
8. The environment should have activities suitable for both children and young people
9. The environment should provide a safe space to release stress in a controlled way. Those with ASC sometimes struggle to communicate their feelings verbally so look for other ways to express how they are feeling. It would also be helpful if practitioners could communicate in non verbal ways ie by using anxiety scales, emails, texts, other interventions and therapies
10. Health, social and education services must work together. Practitioners need to tell school what support the child needs and to provide training. Young people need to be able to access support from CAMHs at school rather than travelling to different appointments in unfamiliar settings. With more support in schools children would be less likely to go on to need more intensive support - saving money and improving lives
11. Practitioners should make sure they see a child when they need it (eg a ‘bad day’ drop-in service) or contact them by phone/email. Long waiting times create further difficulties
12. Practitioners should offer home visits or appointments on neutral territory. It’s important to meet where a child feels comfortable
13. Practitioners should be willing to take a child out to help through difficult situations. Owing to difficulties with generalisation it can be difficult for a child or young person to apply techniques learned in one situation to another. They may need to learn those techniques in the situation in which they will have to apply it
14. LA must be an advocate for the children and young people with ASC in their care. They have a responsibility to ensure the law is upheld
15. LA must foster greater accountability in schools, by following up every exclusion of a child with ASC
16. LA must ensure that wording on statements reflect the needs of the child and not the resources available

For parents – needs-led not resource-led

A timely and pro-active response from NHS and Education services working with parents to secure a fast and supportive assessment procedure at a 'one-stop shop' with a holistic approach and not a protracted assessment process by different practitioners at different locations with contradictory responses – see National Autistic Society’s & Centre for Public Scrutiny ‘Difference In Mind’ a tool for Local Authorities to help scrutinise Child & Adolescent Mental Health Service for Children with Autism http://www.cfps.org.uk/what-we-do/publications/cfps-health/?id=164

Solution

1. Services need to proactively advertise their services via schools, health centres etc with a more open approach so parents feel they can discuss issues without having to wait for GP level referrals
2. Once referred correspondence and communication between all parties needs to be transparent with the parents involved at every point
3. Professionals should include families in every step of the decision-making process

4. Does the child need an assessment for ASC? This question needs to be at the forefront, being one of the first things to be considered and not a last option after months or years of a child presenting with difficulties
5. Practitioners need to be trained to spot the initial signs of a child or young person presenting with ASC and to diagnose appropriately
6. Waiting lists are unacceptably long ie child referred by GP April 2010, seen by Occupational Therapist May 2011, OT report finalised August 2011
7. Therapeutic treatments need to be commissioned based on identifiable needs, not on 'what is available' ie it is ineffective and ultimately more costly to give parents information on handouts when structured weekly input by a fully-trained therapist is required
8. All professionals should actively promote 'parents as experts'
9. There must be recourse for parents when things go wrong. Parents should have a voice and be listened to, not passed 'from pillar to post'

2. Needs-based and appropriate services

Services that are individually tailored to the needs of the child including more help in schools/ home rather than clinic-based 'advice' sessions that often lack value, in terms of parents' time off work/care. We need services that parents feel are truly effective, monitored to ensure progress is actually being made and alternatives offered if not. The commissioning of appropriate services is the key to positive outcomes for ASC children in the long term. Questions that need to be asked;

Solution

1. How does an understanding of needs influence commissioning?
2. How can services support better outcomes for children with autism?
3. Are practitioners skilled in autistic spectrum disorders?
4. Is there specialist autism support in the area? How much and is it effective?
5. What support is there to help families in a crisis situation?
6. Are care pathways for mental health support clear and being delivered?
7. Are children, young people and families involved with service planning and delivery?
8. What support is available for children with autism who are inpatients?
9. Do CAMHs services work effectively with parents and schools? What arrangements exist to prevent inappropriate child protection referrals being made in respect of ASC children and their families?
10. Recommendations should be SMART – stretching, measureable, agreed, realistic, time bound.

3. A change in perception & culture of working with families

The promotion of the child's right to be themselves

The new Pathways policy refers to spectrum conditions as 'disorders' rather than conditions of 'difference'. This fails to challenge the prevailing stereotyping of a spectrum child, allowing for children to be marginalised and excluded when health/education workers lack the will to make an effort to understand or accommodate 'difference'. 'We can't accommodate your child because she is 'disordered' instead of asking 'how can we accommodate your child who has some differences'. Ignorance and apathy allow equality, disability and children's rights legislation to be breached by service providers who still promote the use of the word 'disorder'.

Solution

1. Don't label - use the term 'Condition' not 'Disorder'
2. Only refer to the child having a 'disability' if the child themselves describes their condition as a disability or dysfunction for them

3. Proactively promote understanding of extent of the autistic spectrum by raising awareness in venues that children and families use

A recognition that parents must be treated with respect

Practitioners need to provide a supportive culture. However, there appears to be an overt culture of workers often attributing the child's problems to the parents. Mothers are questioned about their mental health background and fathers are deemed as uncaring and 'absent' if not at a session. Parents are repeatedly asked inappropriate questions. This is undermining parents who feel criticised or suspected. Families are then disengaging with services, feeling 'pushed away' by inferences made about their parenting. We want a respectful and knowledgeable response from NHS and Education services and for them to work in partnership by consulting with us and demonstrating 'positive regard' and valuing the family as a whole.

The difference between the customer service culture in the private sector and the NHS is now extreme. We appreciate NHS/Education resources are stretched to breaking point but that does not excuse the disrespectful 'top down' culture that has become entrenched. If you see a clinician privately they will query information to clarify it, in the NHS they query and then make value-based judgements about the parents.

Solution

1. Who supports the parents who support the children? Validate and support - don't undermine.
2. Review prevailing cultural assumptions about parents and parenting and increase training and awareness that ASC is neurodevelopmental not environmentally created
3. Privately sought opinions and assessments must be treated by the NHS with the same level of respect an NHS clinician would like to receive. Disregarding clinician's opinions because they are not in the NHS is both disrespectful to the clinician and to the parents who have chosen, or felt forced, to seek a private route
4. Proactively and consistently seek ongoing customer feedback for satisfaction levels

Written by

Monica Marchi
Lisa Yates
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Endorsed by mASCot -managing Autistic Spectrum condition online together

Key references

National Autistic Society's 'Young People's Charter for Child & Adolescent Mental Health Services' http://www.autism.org.uk/ycgcharter

National Autistic Society's & Centre for Public Scrutiny 'Difference In Mind' a tool for Local Authorities to help scrutinise Child & Adolescent Mental Health Services for Children with Autism http://www.cfps.org.uk/what-we-do/publications/cfps-health/?id=164

National Autistic Society's 'You Need To Know' report detailing upto 70% of ASC children are suffering needlessly from a mental health problem because local services are failing to meet their needs http://www.autism.org.uk/youneedtoknow

Hoyle, David (2008) 'Problematizing Every Child Matters', *the encyclopaedia of informal education* report exploring a culture of blame that has developed post Victoria Climbie
http://www.infed.org/socialwork/every_child_matters_a_critique.htm

mASCot
managing Autistic Spectrum Condition online together
& supporting local families

Survey of services for children with an Autistic Spectrum Condition

In Brighton and Hove

Oct - Dec 2012

mASCot 19th March 2013

mASCot

Who we are

- Parent-led group established 5 years ago.
- More than 130 members- parents of children with an ASC living in B&H.
- Its aim is to create a place that is non-judgemental, supportive and informative.
- Active online forum and support regular coffee mornings, pub meets, activities for the children, talks etc.
- Active links with the National Autistic Society (NAS), Autism Sussex, University of Sussex, Amaze and many other organizations.
- Our ethos is to have a positive regard for all our families. We believe that people thrive with support and understanding and feel diminished without it
- We listen to what our parents say and strive to influence positive change

http://www.asc-mascot.com

Background/ Context

Why a Survey?

- In September 2011 CYPOSC members resolved to request that an **independent user satisfaction survey** (in relation to the overall provision for children with ASC) was to be carried out.
- The Survey was developed by the council.
- mASCot thinks that such survey was limited in scope (only looked at Seasideview and CAMHS), only to newly diagnosed children and that it took a long time to be developed and launched
- mASCot fed back concerns re: approach and scope and that responses may not be meaningful or informative
- mASCot designed and launched a more comprehensive survey.
- It took us about 2 months to develop. We actively worked with the NAS to design the survey and University of Sussex and London South Bank University to validate it.
- Sue Shanks and Andrew Wealls supported its implementation

Survey

When and how

- Oct-Dec 2012
- Funded through mASCot
- Distributed mainly through mASCot, but also Amaze, Pebbles and Link up. It used SurveyMonkey as engine.
- Analysis in progress
- Report to be produced and distributed.

Content

- Diagnosis
- Education
- Associated difficulties and mental health
- Well-being

Questions

- Gender, Age, etc
- Type of diagnosis and any co-morbidity
- Level of satisfaction in relations to services provided by Seaside View, schools, CAMHs, ASCSS, EP, SALT, etc.

Respondents

Numbers

- 80
- 77 B&H

Gender

- Male 75%
- Female 25%

Age

- 0-4 – 2.5%
- 5-9 – 43.8%
- 10-14 – 28.8%
- 15-19 – 25%

Diagnosis

- 74.1% Seaside View

Education

- Mainstream 65.7% : Special 26.9% (Special incl. mainstream with ASC unit)

Key findings

Diagnosis

- L Process of obtaining a diagnosis **Difficult/very difficult – 41%**
- L Support received at time of diagnosis **Bad/very bad/no support- 34%**

“I really struggle with professionals reluctance to acknowledge less severe symptoms early on, if at all. The majority of parents find diagnosis really helpful!”

The diagnosis was straight forward but we had to wait a year for the assessment-far too long

The paediatrician that gave our son his diagnosis was excellent. It is clear, however, that Seaside view only provides a diagnostic service (at least in our case). So you are left completely powerless with the only certainty that your child has a lifelong condition but no one to help you. I feel that Seaside view should be providing a tailored plan of intervention for each child that receives a diagnosis....

“The follow-up was useless. A few speech and language sessions that had no impact apart from stressing my son. Seaside view appointments were few and often cancelled. No practical help and no support for the family.”

“It takes too long from beginning to end.”

I think professionals give a "label" - for example High Functioning Disorder. This condition embraces a range of difficulties, which for my daughter include: difficulties with fine/gross motor skills, Sensory difficulties which lead to ADHD and ADD type behaviours, difficulties in Speech and Language ... I do not feel the HFA diagnosis adequately describes the range of support she needs.

It was the most protracted and painful experience of my life.

Seaside View need to explain better why they are supposedly not diagnosing Aspergers Syndrome. I have informed them of this issue on their own survey.

Key findings

EDUCATION- Overall (mainstream and special)

J Quality of teaching **Good/very good- 72%**

J Teaching stuff **Good/very good- 75%**

L Process of obtaining statement **Difficult/very difficult – 44%**

I have had to write a lot of it myself in order to explain my sons needs accurately. There is a lot of chasing up required by us as parents and we have to coordinate responses of professionals involved with child otherwise their comments wouldn't be considered. Its left to parents to coordinate.

It took too long - it could have been set up so much sooner. Parents should know what options they have - I did not know that I could look at more specialist provision - I feel my child missed out on support available.

The insisted on saying 'moderate' learning difficulty when his condition is obviously NOT moderate. They have finally backed down

Turned down for a statement as the powers that be decided he was not severe enough

L Receiving provisions on statement **All -25%**

Some because we are providing it at home at our own cost.

I say most because I am not there to see what goes on and he is would not always communicate if there was a problem

Difficult to know. Not much communication with school as to whether they are carrying out the interventions in the provision part of Statement or whether Teaching assistant is being supplied. my son just says " I don't know" if I ask him if someone was with him!

Key findings

EDUCATION- Overall (mainstream and special)

- Bullying **50%**

He was being bullied for several years without us and the school knowing because he was being verbally abuse. It only came to light when a major incident happened at school with him and the child who had been bullying him.

I had to pull him from primary school and home educate for 9 months

It wasn't dealt with appropriately by the mainstream school

in primary school not really acknowledged until yr 6 when was dealt with. Continued into secondary school improved since yr 9. Generally due to him being different & not having same social skills

(bullying)...started at Primary school & continued into secondary school. Has improved since year 9.

At Primary school there was a game played in the playground where students followed my son around and tapped him on the back because this would flip him into a rage if they continued to do it.

- Exclusions, part-time schedule **34%**

(exclusion)....due to reacting badly to stressful situations/bullying. Whilst not condoning his actions I do feel if situations dealt with earlier he may not have reacted as he did

At primary he was part time and in yr 7 was excluded from school trip on medical grounds

In the mainstream school which he attended from 2010 Dec-2011April, I was with my child in the classroom, because the school did not have necessary staff to give him 1 on 1. Even with my support, my child was only allowed to stay till lunch time at school.

We have agrees that fixed term exclusions are preferable to internal exclusions, hence they are quite frequent

When the school can't cope with the child they will phone to ask me to pick him up. If I refuse and say he should be at school I am criticised and told that my child is making himself unsafe!

Key findings

EDUCATION- Mainstream Schools

J 1:1 support **Good/very good- 67%**

L Communicating approach and strategies **Bad/ Very bad 49%**

L Professional Expertise available to your school **Unsatisfied/ very unsatisfied 45%**

L IEP and Acquiring social skills **Bad/ Very bad 36%**

Our son's school is excellent for neuro-typical children but fails to meet the needs of children with special needs. They simply do not have the expertise to really maximise potential in children with ASC and the strategies they apply do not take into account that autistic children are actually all different .... In terms of developing social skills I think schools in general unfortunately completely lack the expertise in terms of what approaches to implement and paradoxically they would provide the best setting to address such difficulties.

Staff show v.poor understanding of ASC; communication school and home is not good!!!

....Although the care, provision and support at the school is excellent it is a frustration to not have any protocol for monitoring progress and having strategies communicated or recorded. With no concrete written plan I worry that a change of staff could mean the excellent support he is getting at the moment could completely fall apart. It is down to the quality of the individuals currently working with our son.

The teaching and individual teachers have been very good but not specifically for our child. Teachers do not really know how to include a child with SN and access to the curriculum is inconsistent. The 1-1 support assistant has done her best but is untrained and unqualified and has at times been left to 'do the teaching' or engage our child in alternative activities. SEN support has been appalling. Communication only occurs when we request it or there is a specific problem. The school head has rarely communicated with us about our child's development or lack of.

The feeling of not being listen to by your child's school is the worst thing. Communication is paramount in having a good partnership with the school.

Key findings

EDUCATION- Special Schools

J Relationship with you **Good/very good- 86%**

J Overall satisfaction **Good/very good- 77%**

J Communicating child’s progress **Good/very good- 71%**

J IEP **Good/very good- 64%**

My son's present school is an autism-specific environment. In mainstream school, I was horrified by the lack of awareness and understanding.

I am very happy with my son's school

... everyone who comes into contact with my child has training and expertise in dealing with autism. In the mainstream environment, no-one understood him, and ignored my attempts to explain his needs.

Everyone, from Headmaster to TA to lunchtime assistants are totally committed to supporting the children and a delight to be with. Support is fantastic and the parent support meetings I am sure would be beneficial to any parent/carer with an autistic child.

Key findings

Associated difficulties

- Many families not received help for associated difficulties (eating, sleeping, toileting, attention and concentration etc.) **39%** (or gone private **12%**)

Mental health

For mental health issues, when they did receive help, satisfaction level for the support received is varied

	Good/very good	**Neither good or bad**	**Bad/very bad**
Seaside View (18)	72.2%	11.1%	16.7%
CAMHs (30)	40%	33.3%	26.7%
Private (8)	89.5%	12.5%	0%

I think that services are set up to provide some support only at crisis point. More should be done to prevent children with autism developing mental health issues.

i have asked written and pleaded to have some help with my sons aggression camhs gave one session of family therapy and then referred us to asc support service but i would like some ongoing help for my son to help him manage his anxiety and aggression

When we had a crises when my son had suicidal thoughts and we needed help straightaway I found it very difficult to get support because first I was told he need a social worker but his needs were not sufficient to have one and because nothing had happened. But lucky the National Autistic Society were brilliant and gave me advice and contacts.

Camhs told me there was little their service offered for children with ASC. I was given some generic social story type advice.

Key findings

Well-being

Quality of life and well-being of your child and your family? **Good/very good- 52%**

Our quality of life is very good despite all the battles we have to fight with service providers. It could be even better if there was a culture a true partnership with families!

at the moment things are very calm but we do get to crisis point and have asked for help from camhs on several occasions but to no avail

Our son's quality of life is good but running a home programme and financing it ourselves is hard on family life.

50/50 If our child with Aspergers is coping we cope if not it can bring us to our knees

We are isolated, stressed and dependent on weak resources. We feel we are left to cope alone.

We just about stay above the surface at times with the help of a lot of positivity! Mostly that comes from the help and support of voluntary/ community initiatives such as Mascot and Link- Up.

Generally good but can be like living on a roller coaster not knowing how he will react to situations. However as he has got older & learned strategies to help him manage his condition the bad time are less but when they come can be more intense

(very good) Through our own hard work and building up a good network of support around us.

I am a single parent of 3 young children and my son has challenging behaviour so its not easy.

Key findings

Well-being

L Overall satisfaction with public service provision **Bad/ Very bad 43.5%**

What would improve the quality of life and well-being of your child and your family?

After school club and social activities

More support in school

meeting group(s) outside of school, for children from mainstream school,

Social skill club or group.
Our views to be taken into account by the school
Aspirations to be higher for children with autism

Less of a need to fight for what our child clearly should receive to address her needs in Education.

some ongoing help with anxiety and aggression and social skills

More support and understanding from school and the public.

An understanding in the Council of ASC. And an LEA not scared of Schools.

Better consultation of parents by school

Extra help in the home

More help and understanding from professionals. I am exhausted and stressed because I have to constantly fight against a system where I feel judged.

People having more knowledge on ASC, how it affects the child and family. Most important being listened too - if I say I need help it means I really need help and I am the expert of my child's needs please listen to what I have to say.

Your thoughts?

Thank you

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