GUIDANCE

➢ PRE-REFERRAL

Follow the NICE guidelines for recognition of symptoms that might indicate an Autism Spectrum Disorder (ASD):
http://pathways.nice.org.uk/pathways/autism-spectrum-disorder (Click on identification tab)

(Take account of potential different understanding when English is not the first language, and cultural differences. Offer support as appropriate. This is particularly available for the Somali population)

All referrals should be accompanied by detailed information about the symptoms of concern.

➢ REFERRAL

Refer via the normal SPE referral form to the most appropriate service within CCHP in recognition of the presenting symptoms:

- Primary problem language – refer to SLT
- General concerns about social communication and interaction - refer to Community Paediatrics
- Concerns about mental health as the main presenting feature - refer to CAMHS  (Note that CAMHS will not accept referrals relating to possible ASD UNLESS the associated mental health difficulties meet the CAMHS referral thresholds (see CAMHS referral guidelines) and children or young people have been offered a Tier-1 intervention that has been ineffective).
- Moderate to severe learning disability with complex emotional, behavioural or mental health difficulties - refer to Specialist service for children with LD
Members of each service who may contribute to an autism assessment include:

- All community paediatricians
- Early Years Specialists
- CAMHS team members
- SSCLD team members
- Speech and language therapists
- Occupational therapists
- Clinical psychologists
- Specialist Nurses
- Educational Psychologists
- Specialist teachers

**ASSESSMENT**

**Initial Appointment (or any other appointments gathering and reviewing information) - A1**

The first person to see the child or young person becomes the lead professional for the assessment (see NICE guidelines for definition) unless or until another is identified later in pathway.

NB In CAMHS the first contact is with the CAPA ‘Choice’ clinician **who will not be the lead professional for any subsequent Partnership or specific assessment.** The CAPA ‘Partnership’ professional will assess the mental health difficulties and if there are complex ASD assessment concerns these are likely to be referred onto ASD specialist clinic/professionals within the team.

If more information is needed – gather this.
Consider using standardised questionnaires for preschool, school aged children; school information
Other team members needed—make referrals and share information already received.

Possible outcomes:

- **Not autism spectrum disorder** - Refer to appropriate pathway or service or discharge.
- **Watchful waiting** – sometimes symptoms will either reduce or become more obvious over time, particularly if a referral is received during a transition point, e.g. starting school, or changing from primary to secondary. Sometimes symptoms are a result of developmental immaturity, and the situation will become clearer with time.
- **Decision to undertake Autism Diagnostic Assessment** – with informed consent from parents / carers/ child/young person as appropriate.

Discuss and agree the timescale of assessment with the family.
Involve appropriate community support e.g. Autism Independence, or Somali link workers.

**Decision to undertake Autism Diagnostic Assessment - A2**

The decision to undertake a diagnostic assessment should be made jointly with the family and young person (where appropriate). It should be clearly documented in the clinical records, and any accompanying letter. Bear in mind that some families might want an assessment of need but not want to specifically consider a ‘label’. This does not preclude them from an assessment, but all involved need to be aware of the situation. Sometimes there will be clear information that would suggest a diagnostic assessment would be appropriate but if the family is not ready it may be better to wait, but make sure that support to meet the child’s needs is in place in the meantime.
To make a decision, the following advice can be helpful:


NICE guidelines state “Start the autism diagnostic assessment within 3 months of the referral to the autism team”

WHAT TO DO WHILST WAITING

Consider sending an update letter to parents at intervals whilst they are on the waiting list to confirm they are still in the system (particularly if you have a long waiting list)

You may wish to consider whether they are likely to need a standard or complex assessment

Complete Autism Diagnostic Assessment - A3

Diagnostic assessments should gather as much information as needed in any particular case, from more than one setting, and involve at least 2 different professionals from the autism team. The range of professionals involved should reflect the particular presenting difficulties in the child or young person.

Please use:


Standard assessment:
This should include

- Developmental, medical, social and family history and current functioning information from parent or carer, and physical examination
- Gather information from educational setting
- Observation at educational setting, clinic or home

Suitably experienced and qualified clinicians should be able to complete with this with at least some consultation with one other suitably experienced professional (i.e. not a uniprofessional assessment).

Complex assessment:
In more complex presentations, further assessments may be necessary to clarify the diagnosis and needs of the child or young person. On occasion this may require cross-area working. Consider the following on an individualised basis:

- Structured observation e.g. ADOS, CARS
- Additional observations in different settings
- Language assessment
- Psychological assessment
- Mental health assessment
- Structured standardised developmental interview, e.g. 3Di, DISCO or ADI
- OT assessment
- Cognitive assessment
- Other specialist assessment e.g. attachment assessment
- Assessment of family circumstances, e.g. child protection issues
Diagnostic meeting and feedback meetings - A4

Possible outcomes:
- Diagnosis of an Autistic Spectrum Disorder (and profiling of comorbidities, strengths and needs)
- Alternative Diagnosis (not ASD)
- Alternative formulation of presenting difficulties (not ASD or no diagnosis of ASD is given at this time due to other explanations for the difficulties, or limited functional impact, or need for time to be allowed for child’s developmental pattern to be clear).

Action plan identifying appropriate support to meet needs (consider cultural and language support needs where English is not the first language, especially when sharing the outcome with the family).

a) The diagnostic meeting
   - This meeting between involved professionals should review all the information gathered during the diagnostic assessment.
   - ICD 10 or DSM 5 should be used to determine whether the threshold has been reached to make a diagnosis on the autism spectrum.
   - Consider holding this professionals meeting in the child or young person’s educational setting, and/or with staff who know the child well, to enhance the observational information available and enable education-based actions to be taken forward afterwards.
   - Parents should be involved in decisions around diagnosis, but it is often useful for this to be a professionals-only meeting to collate information and decide about thresholds for diagnosis and alternative formulations.

b) Feedback Meeting with Parents and YP (if appropriate)
   - Share the outcome of the assessment with parents (and child/young person where appropriate) and agree with them whether a diagnosis (if meets diagnostic threshold) is helpful to be made at this time. Also agree the best way to describe their child/young person’s presentation.
   - The parents/young person should know the outcome of the assessment before it is shared more widely.
   - Feedback should be to both parents together, where possible, in a quiet, undisturbed environment.
   - Feedback to young people should be discussed with the parents.
   - Action plan should be agreed with the parents.

c) If a diagnosis is given:
   - Parents should receive basic information about autism spectrum disorder and local support groups. Parents should be offered access to specific courses to learn about autism spectrum disorder e.g. EarlyBird, EarlyBird Plus, Cygnet, Teenage Life, as appropriate.
   - In Bristol, schools can be directed to approach the Bristol Autism Team (BAT) for further advice.

d) If a diagnosis of autism is not given:
   - Ensure that the alternative formulation is clear and that the parents have been guided towards the appropriate support services to meet the child’s needs, including parenting courses and universal services for emotional/mental health, or specialist CAMHS (if meets criteria).

e) Assessment report
   - The assessment report should include an executive summary listing the people involved in the assessment, the individual elements of assessment carried out, the outcome, including profiling strengths and needs, and an action plan.
   - A copy of an annotated ICD 10 or DSM 5 template is recommended where a diagnosis is made.
   - Detailed assessment reports can be added as appendices where appropriate.
INTERVENTION

Management and support following diagnosis - A5
(including all follow up appointments in children or young people with an autism spectrum diagnosis)

Offer a 6-8 week post-diagnosis appointment to parents/carers/ young people where a diagnosis has been made, with one of the diagnostic team. Consider medical investigations as appropriate.

If a diagnosis is made during an episode of CAMHS care the presenting mental health difficulties will be driving a care plan that will have additional issues to address stemming from the ASD diagnosis. Appropriate follow-up appointments will be driven by this care plan.

Many children and young people with an autism spectrum diagnosis do not need routine follow up appointments with community paediatricians or therapists, and follow up will be agreed with families on an individual basis.

Much of the support, signposting and intervention will occur in the educational environment, or through parent and community support groups.

There are some specific health issues associated with autism spectrum disorder which may need additional assessment and management. These include sleep difficulties, coexistent ADHD, language disorder, sensory processing difficulties and emotional / mental health difficulties. The arrangements for this should be agreed with families on an individual basis.

Consider using an open appointment with planned transition reviews with telephone clinic access to be responsive to crises.

Interventions from other health services will be tailored to the child’s needs

WHAT NEXT

Transition to adult services (also see transition care pathway)

Consider transition arrangements from age 17years onwards.

If a parent recognises they may have an ASD themselves, they should be signposted to GP for referral to BASS for assessment if they wish.

Young people over the age of 18 needing a diagnostic assessment can also be signposted to BASS.

Specific transition to relevant adult specialist services should be arranged as appropriate. Consider Adult ADHD service, Adult learning disability service, Adult mental health service, Adult community therapy service.
APPENDIX

To follow

OTHER RELATED DOCUMENTS

To follow

REFERENCES

NICE. Autism spectrum disorder in under 19s: recognition, referral and diagnosis, Clinical guideline [CG128], Published date: September 2011. https://www.nice.org.uk/guidance/cg128

AUDIT TOOL

Adapted NICE Guidance Audit Tool