

## SCHEDULE 2 – THE SERVICES

### A. Service Specifications

<b>Service Specification No.</b>	ASD CYP 01
<b>Service</b>	Autistic Spectrum Condition- Children and Young People (CYP) Diagnosis and Intervention Service
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#### 1. Population Needs

##### 1.1 National context

Throughout this specification, unless otherwise specified, the term 'autism' is used to refer to all diagnoses on the autism spectrum, including Asperger Syndrome, high-functioning autism, Kanner (1) syndrome or classic autism. Autism symptoms are present in the early developmental period but may not become fully manifest until social demands exceed limited capacities or may be masked by learnt strategies in later life. Someone with autism will typically have persistent difficulties with social communication and social interaction across multiple contexts. They will also have restricted, repetitive patterns of behaviour, interests or activities. These may be evident in their preoccupation with a particular subject or interest. Autism is developmental in nature and is not a mental illnesses or a learning disability but can co-exist with other neurodevelopmental conditions or mental health conditions including anxiety. These may be related to social factors associated with frustration or communication problems or to patterns of thought and behaviour that are inflexible or literal in nature.

A person with autism may also have sensory and motor difficulties, including sensitivity to light, sound, touch and balance. These difficulties may result in a range of regulatory behaviours, including rocking, self-injury, and avoidance such as running away. Often these are coping mechanisms. There can also be a repetitive or compulsive element to much of the behaviour of people with autism. The person may appear to be choosing to act in a particular way, but their behaviour may be distressing even to themselves. However, these behaviours can also be an important self-calming mechanism and should not be stopped or discouraged or seen as a deficit.

**1.2** Autism is known as a spectrum condition, both because of the range of difficulties that affect children and adults with autism, and the way that these present in different people. For example, Asperger syndrome is a form of autism. People with Asperger Syndrome typically have well-developed functional language, but they have significant difficulties with the pragmatic aspects of communication that can be masked by their verbal abilities. They are also often of average or above average intelligence.

**1.3** Autism Spectrum Condition is a common, lifelong neurodevelopmental disorders affecting at least 1% of the population with considerable financial and psychosocial burden on the affected individuals, their families and society. Children and young people with ASC are characterised by a broad range of impairments across three main areas of functioning: social communication, social interaction and rigid stereotyped repetitive behaviours and interests that have a pervasive impact on all aspects of functioning. Other related characteristics include communication and language impairments, additional learning and intellectual impairments, sensory sensitivities and difficulties, rigid and inflexible thinking and limited creative and imaginative play skills.

**1.4** These disorders are increasingly being recognised and diagnosed in childhood thus increasing demand for local diagnostic and intervention services. Levels of understanding of ASC among healthcare and mental healthcare services and availability of services vary greatly from one area to another leading to inequalities

**1.5** It is increasingly recognised that children and young people with ASC often have additional co-occurring mental health, developmental and other disorders: approximately 10-15% will have an identified medical disorder, 70% have at least one psychiatric disorder that further impairs psychosocial functioning, and 40% two or more mental health disorders. One in ten children currently attending general Tier 3 CAMHS will have a recognised diagnosis of ASC and a higher proportion in Tier 3 CAMHS Learning Disability services.

**1.6** Intellectual disability (IQ below 70) coexists in approximately 50% of children and young people with autism. It is therefore fundamental that the provider works effectively with agencies involved in the diagnosis and support of children and young people with (or suspected as having) these conditions.

**1.7** NICE have issued guidelines in relation to the recognition, referral and diagnosis of autism in children and young people (2011) and the management and support of children and young people on the autistic spectrum (2013). The provider shall comply with the prevailing guidance in relation to the delivery of services.

### **1.8 Special educational needs and disability (SEND)**

A child or young person has special educational needs and disabilities if they have a learning difficulty and/or a disability that means they need special health and education support, we shorten this to SEND.

The SEND Code of Practice 2014 and the Children and Families Act 2014 gives guidance to health and social care, education and local authorities to make sure that children and young people with SEND are properly supported. It stresses the importance of early identification, use of best practice in meeting needs, partnership working between parents/carers and professionals, multidisciplinary approaches to service provision and timely intervention. Although these principles apply specifically to educational needs, the overarching themes are replicated in the broader 'Keeping Children Safe in Education 2018' agenda. 'Keeping Children Safe in Education 2018' recognises the need to bring services together, work in a multidisciplinary 'team around the child' and to focus on the needs of the child in the home, community and education settings.

The provider is expected to support all children with SEND eligible to receive this service in line with the Code of Practice 2014 and support the delivery of Education Health Care Plans (EHCP).

### **1.9 Transforming Care and Building the Right Support 2015**

Nationally, the Transforming Care programme aims to improve services and support for children, young people and adults with autism, learning disabilities or both to have the right to the same opportunities as anyone else. The focus of Transforming Care is to reduce the use and length of stay in hospitals for this group.

This will be achieved by: improving services available within the community, offering more innovative care options from multidisciplinary teams; empowering people and their families to have more say in their care, strengthening individuals' rights; providing personal budgets to help people select the right, personalised care and support to meet their needs; discharging individuals from hospitals to more appropriate community-based settings; providing intensive support earlier for those who need it, to prevent new unnecessary hospital admissions and help people stay in the community close to home; ensuring that appropriate hospital care is available closer to home for those who need it but only for as long as they need it.

### **1.10 Stopping over medication of people with a learning disability, autism or both (STOMP) & Supporting Treatment and Appropriate Medication in Paediatrics (STAMP)**

It is a national project involving many different organisations which are helping to stop the over use of these medicines. STOMP is about helping people to stay well and have a good quality of life.

Psychotropic medicines affect how the brain works and include medicines for psychosis, depression, anxiety, sleep problems and epilepsy. Sometimes they are also given to people because their behaviour is seen as challenging. People with a learning disability, autism or both are more likely to be given these medicines than other people.

These medicines are right for some people. They can help people stay safe and well. Sometimes there are other ways of helping people so they need less medicine or none at all.

It is not safe to change the dose of these medicines or stop taking them without help from a doctor.

Public Health England says that every day about 30,000 to 35,000 adults with a learning disability are taking psychotropic medicines, when they do not have the health conditions the medicines are for. Children and young people are also prescribed them.

Psychotropic medicines can cause problems if people take them for too long. Or take too high a dose. Or take them for the wrong reason. This can cause side effects like: putting on weight; feeling tired or 'drugged up'; serious problems with physical health.

### **1.11 Care and Treatment Reviews**

Care and Treatment Reviews (CTRs) are part of NHS England's commitment to transforming services for people with learning disabilities, autism or both. CTRs are for people whose behaviour is seen as challenging and/or for people with a mental health condition. They are used by commissioners for people living in the community and in learning disability and mental health hospitals.

Since 2015, thousands of CTRs have been carried out. They are helping to reduce the number of people going into these hospitals.

CTRs also help to improve the quality of care people receive in hospital by asking key questions and making recommendations that lead to improvements in safety, care and treatment. They reduce the amount of time

people spend in hospital and bring people together to help to sort out any problems which can keep people in hospital longer than necessary. They do this by helping to improve current and future care planning, including plans for leaving hospital.

CTRs are carried out by an independent panel of people. This includes an expert by experience, who is a person with a learning disability or autism or a family carer with lived experience of services. The panel also includes a clinical expert who is qualified to work in healthcare and the commissioner who pays for the person's care.

Care, Education and Treatment Reviews (CETRs) enable the specific needs of children and young people to be met, of over 350 children and young people who have had a community CETR since 2016, 79% resulted in a recommendation not to admit the child to hospital.

The provider will be expected to fully participate in CETR's for children eligible to access the service.

**1.12 Dynamic Risk Registers**

Local health and care services will develop a dynamic register based on sophisticated risk stratification of their local populations to enable local services to anticipate and meet the needs of those people with a learning disability and/or autism who display behaviour that challenges, or who are at risk of developing behaviour that challenges ensuring local services plan appropriately and provide early interventions, including preventative support. Commissioners and providers will risk-stratify their local population of people with a learning disability and/or autism to enable them to put in place appropriate anticipatory support

**1.13 Local Context**

The area covered by this specification is that of South Staffordshire within which there are four clinical commissioning groups: East Staffordshire CCG, South East Staffordshire and Seisdon Peninsular CCG, Cannock Chase CCG and Stafford and Surrounds CCG. Staffordshire County Council is our local authority partner and it should be noted that the boundaries of the county council extended beyond the area of South Staffordshire to include an area in North Staffordshire covered by North Staffordshire CCG. CCG commissioners are increasingly seeking to work in an integrated fashion with Staffordshire County Council to ensure the most cost-effective use of resources and to identify opportunities for delivering integrated services to simplify the experience of service users and carers. Commissioners will continue to consider the advantages of greater integration between the commissioned ASC service and other services providing support to this client group.

1.5 In Staffordshire, the system of support for children with special educational needs and disabilities (SEND) is under significant pressure. There has been a 44.5% increase in EHC plans in the last four years.

In November 2018, Ofsted and the Care Quality Commission conducted a Local Area Inspection of the way professionals at the county council, in local health services and education providers work with families to support children with SEND. The inspection report was published on the Ofsted website in January 2019. It highlights some strengths but there are many areas which need significant improvement.

**Working together to improve support for children with special education needs and disabilities**, we have big ambitions for children with special education needs and disabilities and want to see them thrive.

Together with our partners in education, health and social care as well as with local parents, we have now developed a formal Written Statement of Action to drive the improvements we all want to see.

**1.15** Prevalence rates for ASC are subject to significant debates both nationally and internationally as generally there has been a major increase in the numbers of children who have received a diagnosis. The rates can vary significantly depending on diagnostic criteria. The key research is that of Baird et al (2006) indicating a total prevalence of ASC as 116.1 per 10,000 and Baron-Cohen et al (2009) suggests 157 per 10,000.

The Table below shows:

Children with Autism known to schools  
 15.26394584 per 1,000 pupils  
 122,904 Population (Staffordshire)  
 1876 Count  
 1.5%

	March 18 CCG populations			Rate per 1,000 pupils		
	Males	Females	Persons	Males	Females	Persons
Under 18s (based on those known to schools)						15.26395

Cannock Chase	13,246	12,680	25,926	n/a	n/a	396	
East Staffordshire	15,080	14,449	29,529	n/a	n/a	451	
South East Staffordshire and Seisdon Peninsula	21,709	20,684	42,393	n/a	n/a	647	
Stafford and Surrounds	14,011	13,489	27,500	n/a	n/a	420	
<b>South Staffordshire CCGs</b>	<b>64,046</b>	<b>61,302</b>	<b>125,348</b>			<b>1,913</b>	
18 plus				% prevalence			
				1.80%	0.20%		
	Males	Females	Persons	Males	Females	Persons	
Cannock Chase	53,022	54,063	107,085	954	108	1,063	
East Staffordshire	56,023	56,197	112,220	1,008	112	1,121	
South East Staffordshire and Seisdon Peninsula	86,409	88,923	175,332	1,555	178	1,733	
Stafford and Surrounds	60,686	60,811	121,497	1,092	122	1,214	
South Staffordshire CCGs	256,140	259,994	516,134	4,611	520	5,131	
				% prevalence			
All ages (based on estimates)				1.80%	0.20%		
	Males	Females	Persons	Males	Females	Persons	
Cannock Chase	66268	66743	133011	1,193	133	1,326	
East Staffordshire	71103	70646	141749	1,280	141	1,421	
South East Staffordshire and Seisdon Peninsula	108118	109607	217725	1,946	219	2,165	
Stafford and Surrounds	74697	74300	148997	1,345	149	1,493	
South Staffordshire CCGs	320,186	321,296	641,482	5,763	643	6,406	

<https://fingertips.phe.org.uk/profile/learning-disabilities/data#page/6/gid/1938132702/pat/6/par/E12000005/ati/102/are/E10000028/iid/92133/age/217/sex/4>  
 J:\Research\Disabilities\LearningDisabilityProfiles-CountyUA.data Feb 2019.xlsx

POPPI and PANSI: The prevalence of ASC was found to be 1.0% of the adult population in England, using the threshold of a score of 10 on the Autism Diagnostic Observation Schedule to indicate a positive case. The rate among men (1.8%) was higher than that among women (0.2%), which fits with the profile found in childhood population studies.

Additional information regarding local health needs are available in the Staffordshire JSNA:

<https://www.staffordshireobservatory.org.uk/documents/Health-and-Wellbeing/Staffordshire-Joint-Strategic-Needs-Assessment-Annual-Update-2019.pdf>

<https://www.staffordshireobservatory.org.uk/documents/Health-and-Wellbeing/Emotional-wellbeing-JSNA-July-2018-FINAL.pdf>

<https://www.staffordshireobservatory.org.uk/documents/Health/JSNA/2017/Childrens-Joint-Strategic-Needs-Assessment-April-2017.pdf>

## 2. Outcomes

### 2.1 NHS Outcomes Framework Domains & Indicators

<b>Domain 1</b>	<b>Preventing people from dying prematurely</b>	✓
<b>Domain 2</b>	<b>Enhancing quality of life for people with long-term conditions</b>	✓
<b>Domain 3</b>	<b>Helping people to recover from episodes of ill-health or following injury</b>	✓
<b>Domain 4</b>	<b>Ensuring people have a positive experience of care</b>	✓
<b>Domain 5</b>	<b>Treating and caring for people in safe environment and protecting them from avoidable harm</b>	✓

## 2.2 Local defined outcomes

2.3 To provide a NICE compliant assessment and diagnostic service to children and young people in South Staffordshire who meet the acceptance criteria defined below. The provider shall ensure that the service user and family/carers of the children and young people are satisfied with the assessment/diagnostic process via a formal process to establish user satisfaction. This process should include capturing the views of all that are using the service.

2.4 To provide a positive/negative diagnosis to the service user and their family/carers following the completion of the assessment (In accordance with NICE guidance, where appropriate, the Provider shall provide a working diagnosis in some cases and observe periods of watchful waiting where the evidence base for diagnosis is unclear). Where a watchful waiting is determined, it should be communicated to the family the timescale for this and when a review will take place.

2.5 To provide a range of NICE compliant, evidence based interventions to children and young people who have received a positive diagnosis of autism.

2.6 The needs of children and young people with Autism with sensory needs will be met through the provision of a range of strategies and not a stand-alone intervention.

2.7 To promote the involvement of users and carers in the delivery and development of ASC (assessment and intervention services) as evidenced by the development of user and carer groups within the service. Ensure that all service developments and / or redesigns are undertaken using co-production.

2.8 To ensure there is close link with the SEND parent/carer forum

## 3. Scope

### 3.1 Service description

#### The specification has two elements:

- The delivery of a NICE compliant assessment and diagnostic service to all eligible children and young people
- The delivery of a range of interventions to children and young people. The interventions shall be delivered to children and young people with a diagnosis of ASC and will be in line with NICE guidelines

3.2 A CYP Autism service will be multidisciplinary (including but not limited to: Paediatrician and/or child and adolescent psychiatrist; Speech and language therapist; Clinical and/or educational psychologist; Occupational Therapist) and play a key role in the delivery and coordination of autism services. The autism service will have the skills to carry out a diagnostic assessment, and to offer information about appropriate services and support. The service will provide (or organise) the interventions and care recommended in the NICE guidelines. The service will have the skills to carry out diagnostic assessments for all presentations or profiles of autism across the spectrum with varying levels of complexity.

3.3 For children and young people, autism service will have a key role in:

- Providing a specialist assessment and diagnostic service
- Overseeing specialist care and interventions for children and young people with autism, including those living in specialist residential accommodation

- Providing advice, training and support for other health and social care professionals, educational provider staff and staff (including in residential and community settings) who may be involved in the care of children and young people with autism
- Advising on interventions to promote functional adaptive skills, including communication and daily living skills
- Assessing and supporting the management of behaviour that challenges
- Assessing and advising on the management of coexisting conditions
- Facilitating access to leisure and recreational activities
- Facilitating access to and maintaining contact with educational, housing and employment services
- Providing comprehensive ongoing support for CYP's with complex support needs that make it difficult for them to access mainstream services
- Providing support for families (including siblings) and carers, including ensuring that short breaks and other respite care is offered and provided
- Producing and implementing local protocols (agreed with and by the CCG) for information sharing, communication and collaborative working among healthcare, education and social care services, including arrangements and a plan for transition to adult services
- Producing and implementing local protocols (agreed with and by the CCG) for shared care arrangements with primary care providers (and alternative arrangements when not agreed by primary care) and ensuring that clear lines of communication between primary and secondary care are maintained.
- Produce joint working protocols with Staffordshire County Councils Autism Outreach Team (agreed with and by the CCG and Local Authority)
- Re-assessing needs throughout childhood and adolescence, taking particular account of transition points, including but not limited to adult services.
- Attend, advise and participate as appropriate in the development and delivery of SEND and EHCP's and support all Educational Providers/educational establishments regarding how CYP's may present differently as they try to come to terms with their conditions working in partnership but not duplicating or replacing the role of the Autism Outreach Service provided by Staffordshire County Council. This will include attendance and participation at Tribunals in line with the First Tier Tribunal Trial and Disagreement, Resolution and Mediation meetings.
- Participate as appropriate in Care and Education Treatment Reviews
- Comply with the recommendations of STOMP and STAMP.
- Comply with requirements around the 'Local Offer'

**3.4** CYP with autism will have a designated professional suitably qualified key worker from the service to oversee and coordinate their care and support requirements. A designated professional must be identified and the professional's role will include ensuring that an individualised and person centred care plan is developed for the person covering all the care, support and adjustments they need. The designated professional will also help them gain access to the services; including education they need and support transitions between services. In services for children and young people, the longer-term designated professional is likely to be described as a case manager or key worker. Where a CYP has multiple needs this professional may be a member of the CYP autism service or someone from local community services who is identified by the autism service as suitable for the needs of the child or young person. It will be assumed that the Autism professional is the Key worker until is agreed and documented that another professional assumes this role.

**3.5** The autism service will have either the skills (or have access to professionals that have the skills) needed to carry out an autism diagnostic assessment, for children and young people with special circumstances including:

- coexisting conditions such as severe visual and hearing impairments, motor disorders including cerebral palsy, severe intellectual disability, complex language disorders or complex mental health disorders
- Looked-after children and young people.

If young people present at the time of transition to adult services, the autism service will carry out the autism diagnostic assessment jointly with the adult autism service, regardless of the young person's intellectual ability.

### **3.6 Clinical Risk Assessment**

There will be a clinical risk assessment and management policy that provides:

Standardised Recording of Risk Assessment; Standardised Recording of Risk Management Plans; Standardised Recording of Crisis Contingency Plans; Regular reviews and recordings of the aforementioned. The service will provide relevant Continuing Professional Development (CPD), appropriate supervision to support risk management delivering best outcomes.

### 3.7 Client Record Management System

There will be an Electronic Clinical Recording System to ensure accessibility to all clinicians within the provider and support appropriate joint working protocols with other providers.

The provider will Maintain an accurate data set and provide accurate and timely reporting to commissioners (local, regional and national) and national organisations).

The provider will ensure that the technology in place includes effective integrated embedded technology to support and underpin practice in a clinically meaningful way and ensure that management information is readily accessible and regularly used for service improvement.

The service will comply with new Staffordshire and Stoke on Trent Electronic Integrated Care Record

### 3.8 Crisis Contingency planning

The provider will have in place joint working protocols (agreed with and by the CCG) in relation to children with Autism and their families 'in crisis' and providers of emergency or out of hours care including adult services from the age of 16 when support or consultation be required urgently.

This will include the development of an agreed joint approach agreed by the CCG, that includes:  
Regular (at least weekly) meeting between clinical leads from providers (via face to face / teleconference) to identify children 'at risk' and agreement of joint contingency plans.

The protocol will adhere to CCG guidance and practice in relation to CCG CTR/CETR and Dynamic Risk Register Guidance and processes.

Develop a risk management plan, if required, in collaboration with the child / young person and their parents / carers. When appropriate develop shared risk management plans in addition with key agencies involved in holding the risk, in particular the voluntary sector and social care.

### 3.9 The Assessment and Diagnostic Service

- The provider shall deliver an assessment & diagnostic service for ASC to any child suspected as having autism within the qualifying area. The service will be fully compliant with NICE guidelines and related guidance.
- The provider will have diagnosticians that understand autistic female characteristics.
- The provider shall provide advice and guidance to all potential referrers regarding eligibility for the assessment and diagnostic process including written advice to referrers.
- For all children/young people accepted for assessment, the provider shall appoint a Key worker to lead on the completion of the assessment.
- The provider shall acknowledge receipt of the referral within 10 calendar days.
- The provider shall offer a first appointment to initiate the assessment process within 12 weeks of the referral being accepted by the provider. This appointment is the beginning of the formal assessment process and not an initial contact appointment.
- An initial contact appointment could be an opportunity to screen referrals.
- If autism is diagnosed, this will be communicated to the parent/carer during a face to face meeting (unless explicitly otherwise requested by the parent/carer) by a professionally qualified, appropriate member of the autism service.
- If autism is diagnosed, then the Key worker shall lead in providing information to the family regarding the implications of the diagnosis and liaise with health, education and social care agencies. The timing for this will be based on need but shall take place within 4 weeks of the diagnosis being made and shall include discussion of available options for post-diagnostic interventions. Written information shall be provided to the family regarding the outcome of the assessment, this report will be individualised and person centred and written in a way that they are easy to understand and jargon free; any technical terms in these assessments / care plans will be defined.
- The provider shall provide adequate translation of the information to any family if the family's first language is not English and ensure that the family understands the meaning of the assessment if they have intellectual or sensory disabilities. This shall be provided at the provider's expense). The provider will meet the accessibility the NHS England Accessible Information Standard<sup>1</sup>

<sup>2</sup> <https://www.england.nhs.uk/ourwork/accessibleinfo/>

- If autism is not diagnosed, the provider shall provide the outcome of the diagnosis face to face, they will also provide a written report with the assessment findings. The provider shall provide advice and guidance to the family regarding other services that might be able to assist with the child/young person's condition. With the permission of the family, make referrals to appropriate agencies.
- The outcome of the assessment (with parent or carer consent) shall be provided in a written form to all agencies involved in the health, education and social care of the child/young person and to the child/young person's GP. This could include setting up of a school visit. This report will be individualised and person centred.
- The provider shall discuss any concerns from the family/child/young person regarding the outcome of the diagnostic assessment including the appropriateness of obtaining a second opinion from another provider and information on the complaints process.
- The provider shall contribute towards any special educational needs (SEND) assessment and care planning processes including any changes resulting from legislative change.
- The aforementioned written information and reports could be one combined or dual purpose report; for example reporting on outcomes and the CYP's profile of autism with a set of recommendations provided.

### 3.10 The Intervention Service

- The provider shall deliver a range of evidence-based interventions to children/young people diagnosed with ASC in settings across South Staffordshire. These interventions shall include both individual and group interventions.
- The settings for delivery will be determined by the needs of the child and can include educational provider settings.
- Interventions shall be provided in line with NICE guidelines.
- Individual interventions (one to one) will include a range of individual psychological interventions to children and young people with complex presentations of ASC.
- The provider shall deliver a range of group-based interventions that are evidence based to support children/young people and their families in understanding and addressing the challenges associated with ASC.
- Seek and use feedback in a range of settings, including the use of routine outcome monitoring in therapy, positive feedback regarding service delivery, and complaints.
- Ensure that children, young people and their parents / carers are offered a choice of interventions appropriate to their needs.
- Ensure the impact of trauma, abuse or neglect in the lives of children and young people is properly considered when identifying and developing appropriate interventions.
- Ensure that any additional vulnerability or inequality suffered by children and young people (e.g. learning disability, victim of child sexual exploitation, homelessness) is properly considered when identifying appropriate interventions.
- Agree the aim and goal/outcome of interventions with the child / young person or parent / carer, monitor the changes to agreed and shared goals as well as symptoms and amend therapeutic interactions as a result of these changes, to deliver the best possible outcome.
- Provide information at all stages of the pathway about interventions or treatment options to enable children, young people and parents / carers to make informed decisions about their care appropriate to their competence and capacity; this information needs to be clear, easy to understand and jargon free.
- Include discussion of use of social media/digital technology within assessment and explore constructive use of social media/digital technology during therapy.
- Prescribe medication and appropriate reviews when necessary in line with STOMP and STAMP.
- Provide care / interventions that will prevent unnecessary admission to an inpatient bed and promote safe discharge and recovery.
- Ensure that initial and continuous care planning involves all members of the multi-disciplinary team providing care, the child / young person and their parents / carers.
- Where the consequences of not immediately meeting clinical need are assessed to be similar, services will prioritise children and young people who are likely to have the poorest long term life outcomes. Breakdown of their school, home or care situation has the highest priority.
- The provider shall offer a telephone advice and consultation service during all working hours to other professionals (including Educational Providers) and parents/carers regarding the management of ASC.
- Ensure that clear communication pathways and information sharing mechanisms are in place so that children, young people and, where appropriate, their parents / carers experience a smooth journey through the care pathway. Ensure that informed consent issues around both sharing of information within the family and with other agencies and around treatment are clearly explained and documented. Work

together in a collaborative way with relevant agencies in health, social services and education to ensure that children and young people have appropriate advice and support throughout their care: Including using locally agreed systems to support joint agency working (including in-reaching into Early Help, using Single Assessment. Framework, Team Around the Family), meeting safeguarding standards and providing clear protocols on information sharing.

- The service will work with other services including voluntary sector and local authority services to improve accurate identification of need and swift and flexible access to services to the services an individual needs through direct and indirect working flexibly across services.
- Contribute to other parts of agreed multi-agency care pathways.
- Contribute to Local Area Reviews

### **3.11 Population covered, acceptance, exclusion criteria and referral source**

#### **Population Covered**

- The Provider shall provide services to all Children and young people from birth up to their 19th birthday (unless they have an EHCP in place in which case it will be up to their 25<sup>th</sup> birthday) registered with a General Practitioner in Cannock Chase Clinical Commissioning Group (CCG), Stafford and Surrounds CCG, East Staffordshire CCG and South East Staffordshire and Seisdon Peninsula CCG areas. Where the aforementioned CCG's are recognised as the Responsible Commissioner under the Guidance that eligibility will apply. A child or young person with an existing diagnosis from that has moved from another area that the aforementioned CCG's become the responsible commissioner for.

### **3.12**

#### **Acceptance Criteria**

### **3.13**

- The CCG will agree a purpose built referral form with the provider and/or a face to face triage.
- The acceptance criteria will be in line with NICE guidance. The referrer will provide evidence of the Triad of Impairment in their own assessment, provide information about how the child responds in a nursery or school setting (if they attend) thus demonstrating that the problem is occurring in the community and not just the home setting and summarise parental information about home based concerns. Avoid repeated information gathering and assessments by efficient communication between professionals and agencies.
- Referrals can only be made with the fully informed consent of the child/young person's parents/carers and where possible with the child themselves.
- Children younger than 3 years if there is regression in language or social skills.

#### **Refusal Criteria**

### **3.14**

- The provider shall not accept any referral for diagnostic assessments that does not provide evidence of the signs and symptoms of autism as described in NICE guidelines. If there is insufficient information to decide whether an autism diagnostic assessment is needed, the provider must gather any available information from health or social care professionals or directly from the parent/carer. With consent from parents or carers and, if appropriate, the child or young person, seek information from Educational Providers and/or other agencies. If there is uncertainty about whether an autism diagnostic assessment is needed after information has been gathered, offer a consultation to gather information directly from the child or young person and their family or carers. Parent/carer and referrer are to be kept informed throughout.
- The provider will understand the subtle presentation of autism is also a major barrier to clinicians and other professionals recognising autism and understanding the experiences of autistic women and girls.
- If a referral following the aforementioned process is refused, there should be a clear written explanation provided to the parent/carer and referrer and sign-posting and referral to alternative provision.
- Service Users registered with a General Practitioner outside of the Cannock Chase CCG, Stafford & Surrounds CCG, South East Staffordshire and Seisdon Peninsula CCG and East Staffordshire CCG.
- Anybody over the age of 19 unless they have an EHCP in place
- Responsible Commissioner guidelines shall be adhered to particularly in respect of looked after children placed within the geographical region of South Staffordshire even if the child/young person is registered with a GP in South Staffordshire.
- Referrals for the intervention service shall only be accepted for children and young people who have a formal diagnosis of ASC.
- Refer first to a paediatrician or paediatric neurologist (who can refer to the autism service if necessary) children and young people: older than 3 years with regression in language; of any age with regression in motor skills.

**Referral Source**

3.15 Shall include but not limited to:

- Educational Providers (Educational Psychologists, School Teachers, SENCOs)
- Health Services (Paediatricians, General Practitioners, Health Visitors, Speech and Language Therapists, School Nurses, CAMHS)
- Staffordshire County Council Children's Disability (Social Care) Service
- Staffordshire SEND Information Advice and Support Service (SEND IASS)
- Staffordshire Youth Offending Service

The provider will provide referring agencies with information about the service, including how to refer, at regular intervals and produce targeted communications during the mobilisation phase.

It is an aspiration to allow for self-referral, please see SDIP.

**3.16 Accessibility**

- The Service shall provide a range of service outlets within the geographical area of South Staffordshire.
- Ensure that the service is accessible and provided in an appropriate setting that creates a safe and secure physical environment. This will take into account issues such as stigma and sensory needs.
- Ensure that services have age-appropriate physical settings.
- The provider will address health inequalities, by providing a service acceptable to vulnerable groups. Young people who are offered appointments at stigmatising bases are less likely to take these up if they are from low income groups for example, which disproportionately affect young people from Black and Minority Ethnic (BAME) groups, disabled young people, and those with little family support. Offering follow up in community settings, and working with voluntary/ community sector organisations delivering in an integrated way will help facilitate take up of services for disadvantaged young people.
- Vulnerable groups will be targeted with the aim of equity of outcome through flexible, intense, strength based joint working
- Ensure services are available to all children and young people without regard to disability, gender, sexuality, religion, ethnicity, social, or cultural determinants.
- The provider will operate provision in line with the Equality Act 2010 and any subsequent legislation.
- However, where it is deemed clinically appropriate, alternative services may be established that meet the specific needs of one or more groups within a community. Such services will enhance rather than detract from the existing provision
- Offer children, young people and parents / carers age and format-appropriate information about their condition and care.
- The Provider shall ensure that the full multi-disciplinary Service is available for 52 weeks per year. The Service shall be available a minimum of 5 days per week, excluding public holidays, between 9 am-5pm. The provider will also offer availability during evenings and weekends as appropriate to need.
- The service shall provide a single point of access for service users and referrers via telephone, and email from 9-5pm Monday-Friday as a minimum. Additional hours shall be provided by the service should resource be available.
- The service shall be respond in a timely manner to requests for support/intervention from parents/carers when their child's needs have changed. These requests shall be documented in clinical records with timescales for response.

**3.17 Discharge, Transfer of Care and Communication****Children/Young People Diagnosed with ASC**

- The provider shall communicate the results of the diagnostic assessment, provide a follow up appointment and share information with other professionals in line with NICE guidance.

**Children/Young People Not Diagnosed with ASC**

- The Provider shall discuss the outcome of the assessment with the parents/carers (and the child/young person if appropriate) and provide a written individualised and person centred report on the findings. This

shall include advice (including referral on to other services with parental/carer consent) regarding other assessment and support services appropriate to the needs of the child/young person.

- The parents/carers (and child/young person if appropriate) will be informed of their right to access a second opinion from a specialist autism service if they are dissatisfied or disagree with the outcome of the assessment.
- The provider shall provide written information to the GP regarding the outcome of the assessment.
- With the consent of the parent/carer (and child/young person if appropriate), the Provider shall share the outcome of the assessment with other professionals including education provider staff involved in the care of the child/young person.

### **Intervention Service**

- Children and young people who have completed an episode of care (either group or individual interventions) can be discharged from the service and (subject to the appropriate consent of parents/carers/child/young person) relevant information shall be shared with other agencies.
- The provider will ensure that children and young people leaving the service have an agreed and documented discharge plan that supports self-management where possible and explains how to access help if this becomes necessary. Where a young person is moving to another service, whether to adult services or to a different service, the Provider will ensure that the agreed transition protocol is followed. As a minimum this will involve: a joint meeting between the Provider and the new service that includes the child / young person and / or parent / carer, and a written discharge summary, followed up after 6 months to check that the transition has proceeded smoothly.
- A child or young person will have open or continued access without the requirement for a new referral in line with 3.11

### **3.18 Interdependence with other services/providers**

The Provider shall ensure that interdependencies and relationships are built with other service providers. These are essential and shall include, but not limited to:

- Staffordshire County Council (SCC) Autism Outreach Service
- Educational Psychologists
- General Practitioners
- Secondary Care Providers
- Social care providers and commissioners
- Safeguarding professionals
- Education providers
- Community health providers
- CAMHS
- Adult Mental Health Services
- Acute Providers
- Housing
- Youth Offending Services/Forensic Services
- SCC Children's Disability Service (within Families First)
- Adult Learning Disability Services
- Voluntary/Third Sector
- NHS Continuing Care Assessment Services
- Transforming Care Team
- Children & Young People's Advocacy Service (commissioned by Staffordshire County Council)

### **3.19 Complaints Processes & Policy**

The provider shall operate a Complaints policy and process that meets the requirements of the Local Authority Social Services and National Health Service Complaints [England] Regulations (2009), and conforms to the NHS Constitution and reflects the recommendations from the Francis report (2013).

The provider will treat complaints seriously and ensure that complaints, concerns and issues raised by patients, relatives and carers are properly investigated in an unbiased, non-judgmental, transparent, timely and appropriate manner. They will be investigated without any conflicts of interest. The outcome of any investigation, along with any resulting actions will be explained to the complainant by the investigating organisation.

The key issues taken into consideration when formulating this policy are that all Parents/carer and children and young people needs to:

- Know how to complain to the provider; the CCG and the ombudsman;
- Feel confident that their complaint will be dealt with seriously.
- Understand that their concerns will be investigated and they will be informed of the findings of that investigation.
- Trust that provider will learn from complaints, feedback and praise and apply those lessons whilst also learning from and sharing best practice.

#### **4. Applicable Service Standards**

##### **4.1 Applicable national standards (e.g. NICE)**

- Autism spectrum disorder in under 19s: recognition, referral and diagnosis (2011 updated 2017) NICE guideline CG128
- Autism Quality standard [QS51] Published date: January 2014
- NICE guidance: Management of Autism in Children and Young People CG170 28<sup>th</sup> August 2013
- NICE guideline [NG11] (May 2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges
- Stopping The Over-Medication of children and young People with a learning disability, autism or both (STOMP) and Supporting Treatment and Appropriate Medication in Paediatrics (STAMP)

<https://www.england.nhs.uk/wp-content/uploads/2019/02/STOMP-STAMP-principles.pdf>

- Care and Treatment Review Policy: <https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf>
- The learning disability improvement standards for NHS trusts NHSI June 2018

#### **5. Applicable quality requirements and CQUIN goals**

##### **5.1 Applicable quality requirements (See Schedule 4 Parts A-D)**

##### **5.2 Applicable CQUIN goals (See Schedule 4 Part E)**

#### **6. Location of Provider Premises**

The Provider shall provide a central access centre for referrals but deliver services in various locations across South Staffordshire that are accessible to local communities.

The Provider premises and reception facilities shall be child/young person friendly and easily accessible from main transport links. Services will comply with You're Welcome Standards.

##### **The Provider's Premises are located at:**

- The Bridge Children's Centre, Midlands Partnership NHS Foundation Trust. St George's Parkway, off Crooked Bridge Road, Stafford ST16 3NE.
- 113 Eccleshall Road, Stafford, ST16 1PD
- Cross Street Clinic, Crosstreet, Burton-On-Trent, Staffordshire, DE14 1EG

