

**Pathway for Recognition, Referral, Assessment Management and Support of possible  
Autism in Children and Young People  
North, South, Norwich & West Norfolk  
(C&YP ASD Pathway)  
2016**

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## 1 Introduction

The concept of a pathway means the right people, doing the right things, in the right order at the right time to achieve **the right outcomes** for the child or young person. This should also be **resource effective** in terms of avoiding duplication and role confusion.

This model seeks to ensure that highly skilled specialist professionals focus on the key tasks that require their level of expertise and provide appropriate support across the professional network to skill up others to fulfil their roles more effectively.

To receive a formal diagnosis of Autistic Spectrum Disorder a child must have significant difficulties in ALL areas of the “triad of impairment”:

- social interaction
- social communication and
- rigidity in thinking with difficulty in social imagination.

Because ASD is a spectrum some children will meet all the criteria for a diagnosis but others, who do not reach the threshold for a diagnosis, may still have significant problems in some of these areas. These children will also require additional support. Whilst this pathway focuses on those with a diagnosis of ASD it acknowledges that the needs of children who do not receive an ASD diagnosis should also be addressed. Signposting to the locality early Help teams and The Family Support Plan should always be considered in these cases.

Many parents of children who have been diagnosed report that initially professionals did not listen to and analyse their concerns properly. Some reported that professionals dismissed concerns as “the terrible twos” or made the parents feel they were being over anxious. This is clearly unhelpful and undermines the achievement of positive outcomes for these children. It is important that ASD is recognised at an early stage and professionals have reference to this pathway even if the child is coping well at that point.

Some children who have ASD manage well at primary school stage if that environment is favourable. This can mean that the full extent of their needs may not be formally recognised. As a result problems may emerge post transition to high school because their support needs are not anticipated.

The NICE Guidance on recognition is appended to this pathway and all relevant organisations should ensure that key professionals are familiar with them and that they have access to consultation from someone with expertise in this area to support them.

### Key Priorities

- Access to health & social care  
All children and Young people with autism have full access to health & social care services, regardless of their intellectual ability or any coexisting diagnosis.
- Knowledge and competence of health & social care professionals  
All professionals working with children and young people in should receive training in autism awareness and skills in managing autism.

## 1.2 Key Principles

The Norfolk pathway is underpinned by clear principles to shape its direction:

- It is accessible
- It is delivered in partnership with parents/carers
- Early recognition and intervention are key to improving outcomes for the child and family and are cost effective
- There is a holistic approach to meeting the needs of children
- It is multi-disciplinary with joined up working across disciplines/organisations
- It is characterised by evidence based practice, informed by NICE Guidelines
- It focuses on supporting the following agreed outcomes.

## 1.3 Desired Outcomes

- More children/families feel their needs are supported
- Children with needs are identified early and responded to in a timely manner
- Improved access to and engagement with education
- Children with ASD feel safe and secure at their school
- Reduction in the number of children with ASD who develop secondary mental health problems
- Reduction in the number of children with ASD whose problems disrupt their education
- Reduction in number of children with ASD who develop such problems that they need specialist placements away from home.

These outcomes for children and young people will be supported by achieving an increase in the following **outcomes for parents/carers** of children with ASD. An increase in the number of parents and carers who:

1. Have greater understanding of factors affecting their child's emotional and mental well being
2. Feel well supported and confident to meet their child's needs and deal with their child's behaviours

### **The pathway should also impact on the following:**

- Reduction in number of C&YP in the criminal justice system
- Reduction in school exclusions and part time school timetables
- Efficient use of scarce resources
- Improved quality assurance
- Duplication avoided

## 1.4 Assessment of need

The latest national guidance indicates that amongst the under 18 population, 1:100 will have an autistic spectrum disorder. (Office of National Statistics (2005) Mental health of children and young people in Great Britain, London: Palgrave Macmillan) This equates to approximately 1,800 children for Norfolk. Of these approximately 50% will have a learning disability. There are also a number of other co-morbidities typically associated with ASD, these include ADHD, epilepsy and a range of medical and genetic problems and disorders,

which may result in digestive and feeding and sleep problems. Children with ASD are at high risk of developing secondary mental health disorders, particularly anxiety and conduct disorders.

The NHS does not currently collect data on the number diagnosed and at present Norfolk does not capture local prevalence data for Autism.

### **1.5 Governance**

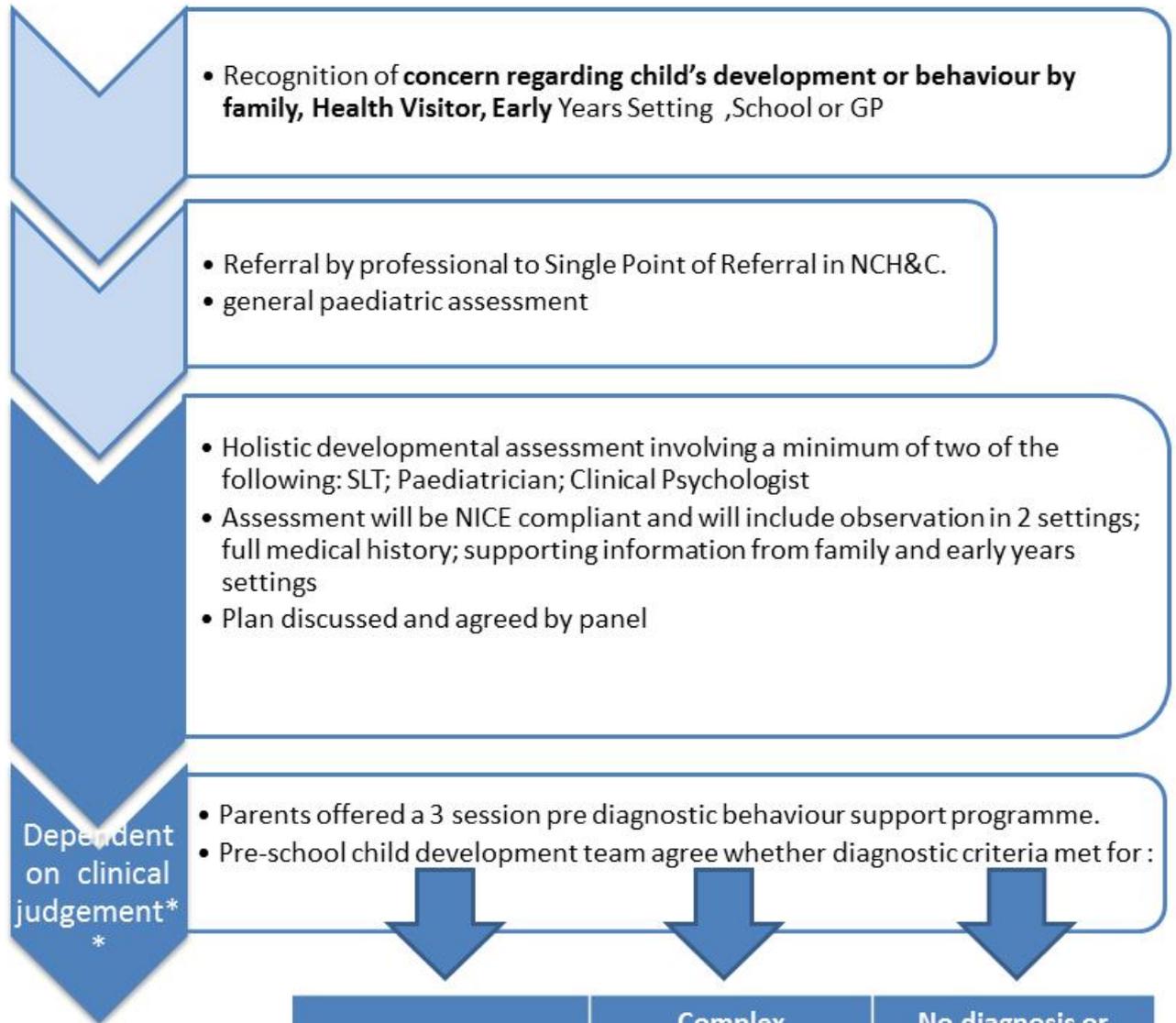
The overall strategic responsibility for the delivery of the agreed pathway will sit with Norfolk Health & Wellbeing Board . The Norfolk All Age Autism Strategic Partnership will take an overview of the operational delivery of the pathway, including the delivery of appropriate information and education for parents, training for professionals and, in particular, it will ensure that the views and experiences of parents and children are represented.

### **1.6 The ASD Panel**

All ASD assessments will be led by a core ASD team / panel including CAMHS & CFYPS which will ensure that the assessment is compliant with the standards within this pathway. The assessment team will include input from a minimum of 2 of the following:

- A Paediatrician
- A Specialist Speech & language therapist
- A Clinical psychologist
- A Child Psychiatrist
- Nurse with specialist ASD Training
  
- Where appropriate the panel will have access to: Social worker, Specialist teacher, any other appropriate professional .

## ASD Diagnostic Pathway : Age 1- 6

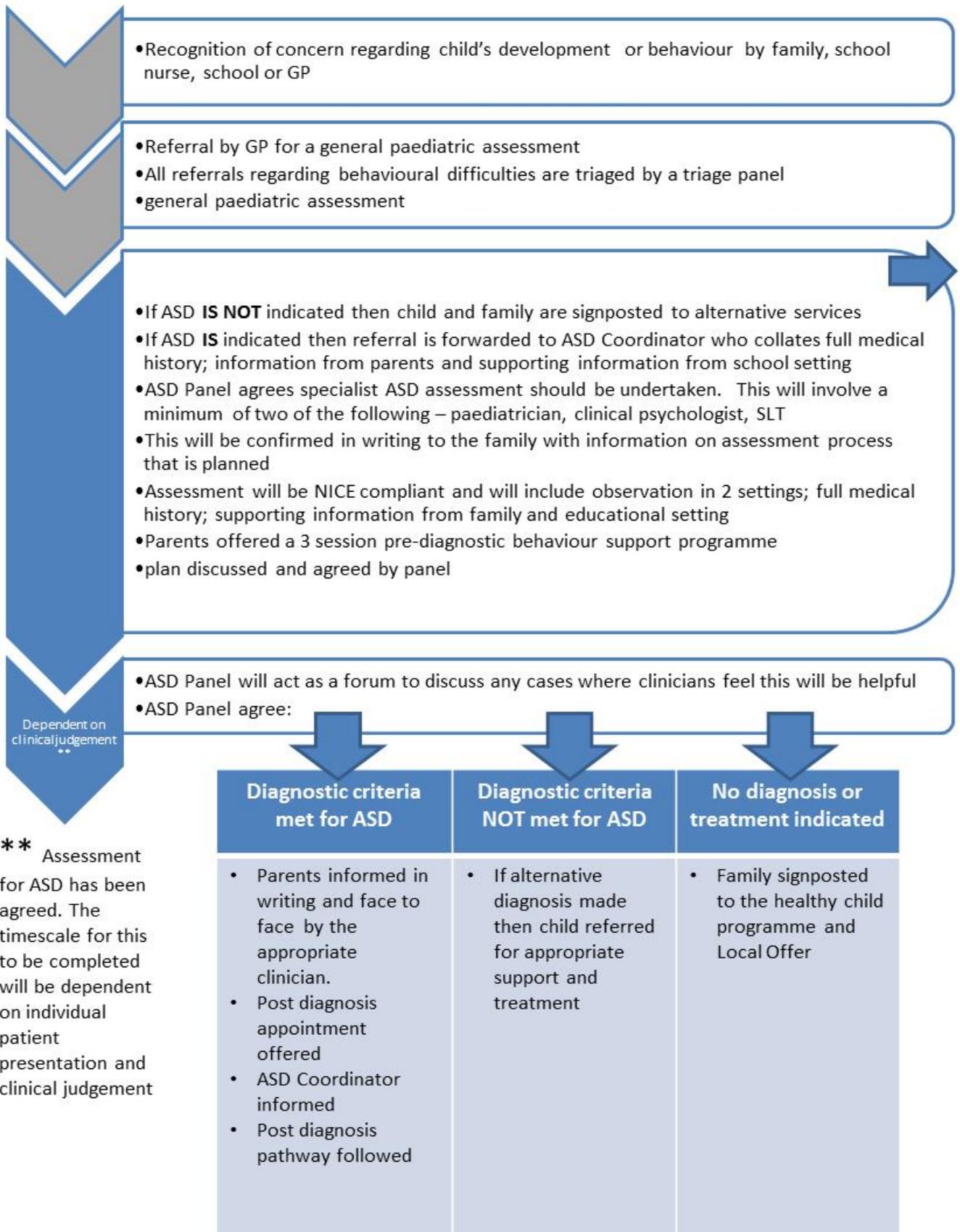


ASD	Complex Developmental Disorder	No diagnosis or treatment indicated
<ul style="list-style-type: none"> <li>• Parents informed in writing and face to face</li> <li>• Post diagnosis appointment offered</li> <li>• ASD Coordinator informed</li> <li>• Post diagnosis pathway followed</li> </ul>	<ul style="list-style-type: none"> <li>• Referred for appropriate support and treatment</li> </ul>	<ul style="list-style-type: none"> <li>• Family signposted to the Healthy Child Programme and Local Offer</li> </ul>

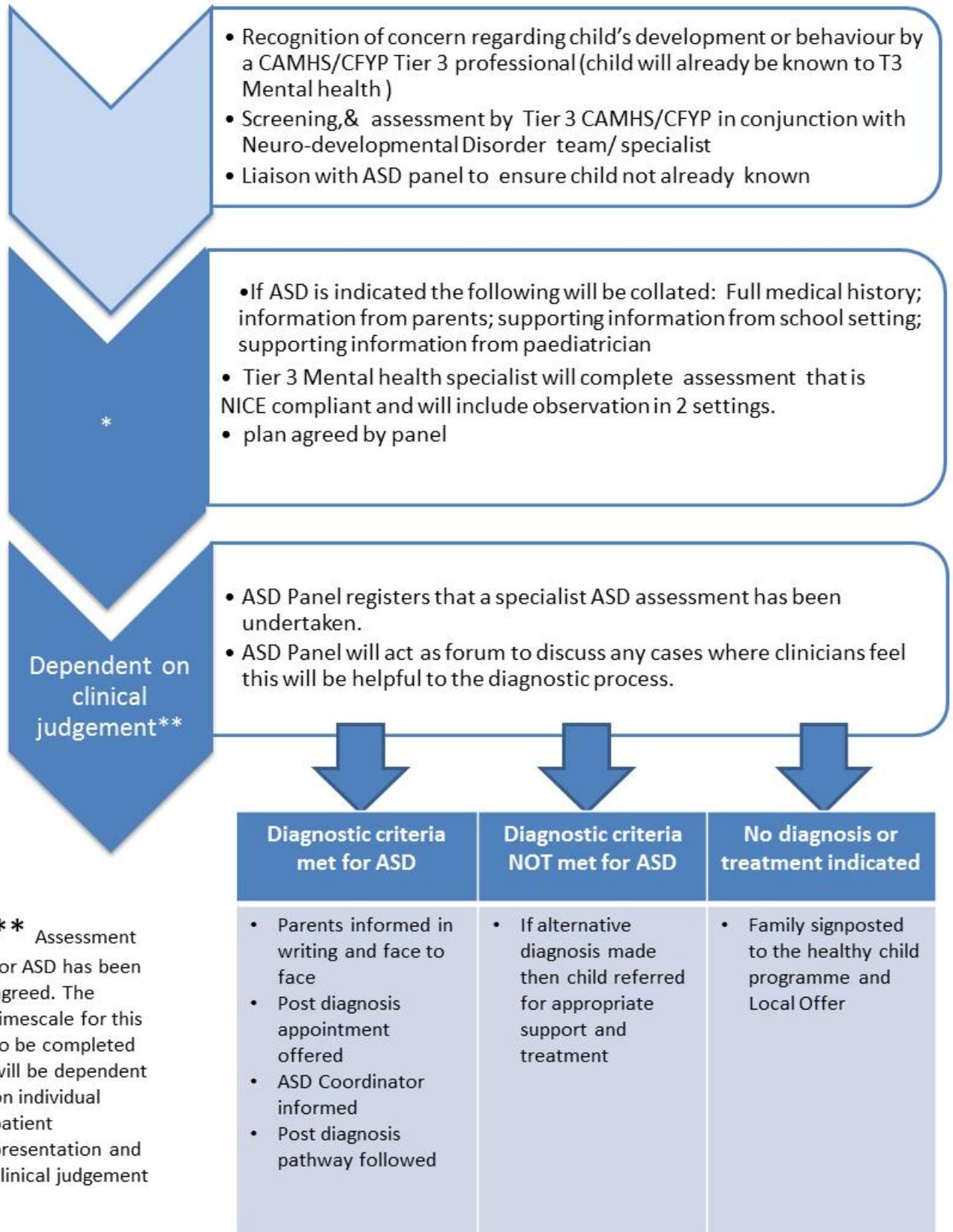
**\*\*** Assessment for ASD has been agreed. The timescale for this to be completed will be dependent on individual patient presentation and clinical judgement

pathway v4

## ASD Diagnostic Pathway : Age 6 - 18



## ASD Pathway : CAMHS for Children with a Mental Health disorder



\*\* Assessment for ASD has been agreed. The timescale for this to be completed will be dependent on individual patient presentation and clinical judgement

pathway v4

## 2 Detailed Pathway

### 2.1 Recognition Stage

Where a teacher or early years worker, health visitor or other professional becomes aware that a child may have ASD they should consult with the family and advise a referral to the community paediatrician via the GP.

There will be some cases when the parent/carers and, if appropriate, the child do not want a referral for ASD assessment at this stage. In such circumstances there should be a period of watchful waiting and follow up consultation if concerns remain. A Family Support Plan should also be considered.

### 2.2 Referral for Initial Paediatric Assessment /Screening of Referrals

Referral details **must** include:

- Reported information from parents, carers and professionals about signs and/or symptoms of concern
- Observations of the signs and /or symptoms
- If school age full details of approaches tried by school (Individual Education Plan (IEP) /Assess, Plan, Do, Review Cycle ).

Include if available:

- antenatal and peri-natal history
- developmental milestones
- relevant medical history and investigations
- Information from previous assessments ( e.g. completed Strengths and Difficulties Questionnaire (SDQ)

Any factors associated with an increased prevalence of autism should also be identified. These include:

- 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

All referrals for an ASD assessment should have an initial general paediatric assessment. The following should be taken into account:

- Regression in language, social skills and motor skills.
- The severity and duration of the signs and/or symptoms.
- The extent to which the signs and/or symptoms are present across different settings.
- The impact of the signs and/or symptoms on the child or young person and on their family or carer.
- The level of parental or carer concern.
- The concerns of the child or young person if appropriate.
- Factors associated with an increased prevalence of autism
- The likelihood of an alternative diagnosis including:
  - Neurodevelopmental disorders
  - Mental and behavioural disorders
  - Conditions in which there is developmental regression.
  - Severe hearing impairment.
  - Severe visual impairment.
  - Maltreatment.
  - Selective mutism.

The initial paediatric assessment will determine whether to either carry out a full autism diagnostic assessment and /or an alternative assessment. Where there is insufficient information the ASD Co-ordinator will, with consent, seek further information from schools or other services.

### **2.3 The following standards will apply to every Autism Diagnostic Assessment:**

- The assessment will always involve more than one discipline from the core team.
- Details of parent/carers concerns
- Child /young person's concerns
- Details of home & social care
- Education report from school A developmental history.
- Medical history
- Physical examination
- Observation of child in 2 different environments i.e. clinic/home, clinic/school (the school observation may be completed by a member of staff from the school/early years setting, but will be interpreted by the ASD Panel)
- Access to child psychiatry if appropriate.
- ASD specific tool can be used. This will be at the discretion of the panel ASD diagnostic assessments will be completed and families informed of the outcome as swiftly as clinically possible but within a **maximum** time frame of 24 months from a specialist request being made.

### **2.4 Assessments by the ASD Panel.**

The ASD Coordinator will register the request for an ASD assessment. The ASD panel will discuss & plan the assessment.

Parents will be advised that they are able to bring a support person with them.

Whilst families are waiting for a diagnostic assessment it is acknowledged that they may need help and advice on managing aspects of life that their children are finding difficult.

Getting or not getting a diagnosis will not change the child's behaviour or how they feel or interact with those around them. However we need to ensure that our diagnostic process is of high quality, valid and individual for each child. This necessarily will take time and so may lead to families waiting. It is therefore planned to offer parents/carers waiting for a diagnostic assessment, practical support through setting up Positive Behaviour Support Workshops across Norfolk. These are planned to be a partnership between specialist ASD professionals and the Norfolk Early Help services including children's centres and early Help teams.

## **2.5 ASD assessments by Tier 3 Mental Health Teams**

Where children and young people are already receiving treatment from the Specialist Mental Health Teams and there are concerns raised regarding ASD they will coordinate and plan the assessment. There will be liaison with the ASD panel to ensure there is no duplication. The ASD coordinator will register the request for assessment so that adequate data is collected.

## **2.6 ASD assessment outcome**

The assessment outcome will be either:

1. A diagnosis of ASD
2. A diagnosis of an alternative condition with referral to appropriate services
3. Diagnosis of ASD and a co-existing condition.
4. Further specific specialist assessment needed.
5. Where there is uncertainty regarding a diagnosis consideration needs to be given to whether to have a period of watchful waiting and/ or planned review.
6. The ASD panel will offer a forum to clinicians where this will assist in the diagnostic process.
7. ASD not indicated signposting to the Healthy Child Programme and Local Offer.

## **2.7 Communicating the outcome of the assessment**

Parents /carers must be informed in person at the conclusion of the assessment and in writing of the assessment outcome. The child or young person should be also informed as appropriate. Parents /carers /young people should be able to bring a supporter to any meetings if they wish.

It is important to find the right balance regarding the amount of information shared with the parents/carers at this point. This will vary between families. The 'Right from the Start' guidance should be applied. The agreed **information pack** that has been developed should be given out.

Education should generally be engaged in the assessment process, as should social care in some instances. However where this is not the case, consent should be sought to make the assessment outcome available to education and if appropriate social care.

## **2.8 ASD assessments by Private Providers**

The ASD Coordinator will register all assessments by private providers once the ASD panel has confirmed they are NICE compliant. If the evidence for compliance is not available the private provider will be informed with a request for further evidence.

## **2.9 Quality Assurance**

Providers of ASD Diagnostic processes must have quality assurance systems in place to ensure they are completed as per NICE guidance.

The ASD panel will quality assure all private diagnoses that they are informed off. They will also quality assure any incoming diagnostic assessments for children moving into Norfolk.

## **2.10 Second opinions**

A second opinion may be considered:

- Where there is disagreement within the ASD team or with parents and young person that cannot be resolved.
- Where there is a lack of progress /response to the care plan and interventions put in place.

This should be accommodated within local Child Health Specialist Teams and NSFT. Referral to any specialist unit should only be considered with prior approval from commissioners

### 3 Management & Support Post Diagnosis

In August 2013 NICE, in association with the Social Care Institute for Excellence (SCIE) issued guidance on post diagnostic support “Autism: the management and support of children and young people of the autistic spectrum.”

<https://www.nice.org.uk/guidance/cg170/chapter/recommendations>

The guidance states that

“There are many claims of a 'cure' for autism, all of which are without foundation. However, there are interventions that can help some of the core features of autism, some of the symptoms, behaviours and problems commonly associated with autism, and support families and carers. There is also evidence for treatment strategies to reduce behaviour that challenges.”

And identifies the following as a key priority for implementation:

“Ensure that all children and young people with autism have full access to health & social care services, regardless of their intellectual ability or any coexisting diagnosis”

The following local pathway focuses on local service provision across health, education and social care, against the interventions recommended in the NICE clinical guideline 170. It does not describe the wider range of services available from the voluntary sector as these are subject to change, depending on grants and local initiatives. However the Local Offer will have comprehensive information on local services available to help families.

It should be recognised that ASD is a disability and the main evidence based intervention is education for parents/carers to support them in their understanding of how to best support a child with ASD. Adjusting the environment in early year's settings and schools to have regard for the needs of children with ASD is also crucial to support their outcomes.

**All children** diagnosed with ASD will receive:

- An invitation to attend a Post Diagnosis Follow Up (PDFU) Information Session with a health professional, as agreed by the assessment team The agreed parent / carer information pack including:
  - Information on The Early Support Programme
  - Information on local support services
  - Information on the disability register
  - Information on the Family Support Plans and Early help Hubs
- Access to Early Bird/ Early Bird plus or Cygnet
- Additional health visiting support for children under 5 years.
- The offer of contact to the relevant educational support service.

## Additional Services Available in Norfolk

NICE recommended intervention	Delivery model	Provider	Access
<p>Psycho Social Interventions.</p> <p>A range of social-communication interventions that include play based strategies for parents, carers and teachers focused on increasing attention, engagement and reciprocal communication.</p>	<p>Home-visiting educational service for pre-school children with additional support needs and their families including those with Autism.</p> <p>Early education entitlement (15 hours) per week</p> <p>Tiered training approach specifically around social communication difficulties and ASD to support early years practitioners to promote the development of social communication and interaction in individual children.</p>	<p>NCC - Norfolk Portage Service</p> <p>All Ofsted registered early years providers within the private voluntary and independent sector</p> <p>School 2 School offers direct support to registered early years providers, which includes strategies to promote social communication and engagement using play based strategies</p> <p>NCC approved training providers</p>	<p>Both professional or parental referral via form or telephone call to office</p> <p>Via individual early years providers. Information available via NCC Family Information Service or local offer</p> <p>Early years providers are able to access this support via their Advisor early years-inclusion</p> <p>Training accessed via NCC early years training team</p>
	<p>One to one sessions with parents and children to improve communication and interaction.</p>	<p>Starfish provides a range of ASD specific Clinical Psychology and family support interventions for children with Learning Disability.</p>	<p>Referral is via NCH&amp;C's Single Point of Referral (SPOR)</p>



	<p>Promoting Alternative thinking Strategies (PATHS) programme.</p> <p>(Not ASD specific but is designed to aid development of self-control, emotional awareness and interpersonal problem-solving skills.</p>	<p>Schools can access this programme through the Healthy Schools Team. There is a charge.</p> <p>(Non ASD specific )</p>	<p>Access is via Healthy Schools</p>
	<p>Early Bird, Early Bird plus and cygnet are ASD specific</p> <p>Programmes to provide support for the parents foster their child's social communication and appropriate behaviour in the day to day environment; and to support parents.</p>	<p>There is a trained multi agency, multi-disciplinary team of workers from NCC &amp; NCH&amp;C who provide this training across the county.</p> <p>(In April 2016 ECCH will also be a provider.)</p>	<p>All parents whose child is diagnosed with Autism are offered a place on the appropriate programme. (there is however a waiting list)</p>
	<p>Generic Parenting Programmes</p>	<p>Point 1 offers a range of generic parenting programmes including Triple P which has evidence for successful outcomes for parents and families with ASD members.</p>	<p>Referral via telephone, letter or fax to the Point1 (SPOC) team, A specific section which relates to parenting is included on the standard referral form</p>
<p>Interventions for Behaviour that challenges.</p> <p>Anticipating and preventing behaviour through assessment and care plans.</p>	<ul style="list-style-type: none"> <li>• Treatment for physical disorders or coexisting mental health problems</li> <li>• Making adjustments to physical and social environments</li> <li>• Advice to families and carers.</li> <li>• Psycho social goal based behaviour plans.</li> <li>• Pharmacological interventions</li> </ul>	<p>Starfish provides a holistic service that meets all the recommendations for the management &amp; treatment for children with Autism and learning disability.</p>	<p>Access is via NCH&amp;C's SPOR</p> <p>BUT</p> <p>There is no similar commissioned holistic service for children without a learning disability</p>

		<p>Children and young people open to Starfish have access to psychiatric and pharmacological interventions if needed.</p> <p>Point 1 offers generic assessment and care plans for children and families where behaviour is an issue. They offer generic advice and support to families and carers</p> <p>NSFT Specialist Mental Health Teams assesses and treats co-existing mental health disorders for children with Autism who do not have a Learning Disability.</p> <p>For children with co-existing ADHD there is access to specialist intervention via NCH&amp;C (Central &amp; West ) or NSFT Specialist Mental Health Teams (West )</p>	<p>Access is via the Starfish team</p> <p>Via telephone, letter or fax to the Point1 Single Point of Contact (SPOC) team, or through a weekly triage function</p> <p>Via telephone, letter, fax or email to the Mental Health Access Hub</p> <p>Via NCH&amp;C single point of referral (SPOR)</p>
Interventions for life skills.	Support to children in developing coping strategies and enabling access to community services.	<p>TITAN (Travel Independence Training Across the Nation) Provided by NCC.</p> <p>Point 1 support children in developing coping strategies to enable access to community services.</p> <p>High schools and colleges provide life skills training. (Non ASD Specific)</p>	<p>Available through schools &amp; Colleges</p> <p>Via telephone, letter or fax to the Point1 Single Point of Contact (SPOC) team, or through a weekly triage function</p> <p>Contact Individual Schools &amp; Colleges</p>

Interventions for sleep problems	<p>Assessment of :</p> <ul style="list-style-type: none"> <li>• sleep patterns</li> <li>• Sleep environment. physical or emotional cause</li> <li>• Development of a sleep plan.</li> <li>• Access to sleep specialist</li> <li>• Medication</li> </ul>	<p>Starfish provide assessment and sleep hygiene input for children with Autism &amp; a learning disability.</p> <p>Paediatricians will prescribe medication to support sleep if needed. The child may or may not be open to Starfish. This is not specific to children with a learning disability.</p> <p>Point 1 offer interventions for sleep problems caused by emotional difficulties.</p>	<p>There is no longer any specialist Sleep Counselling service commissioned in Norfolk.</p> <p>Via NCHC</p> <p>Via telephone, letter or fax to the Point1 Single Point of Contact (SPOC) team, or through a weekly triage function</p>
	Short breaks or respite care	<p>NCC provides a range of short break provision for children with disabilities who meet the criteria for specialist services, advice &amp; support. Children who do not meet these criteria can access services through the Early help hubs.</p> <p>( short breaks provision is currently under review )</p> <p>For children with autism who do not need specialist short breaks, but may need some assistance with accessing local play and leisure activities best place for advice and guidance is the local offer and discussion with early help localities</p>	<p>Parents refer themselves through MASH. A Social work assessment will identify which provision best meets needs.</p> <p>Via local offer and early help hubs</p>

Interventions for Autism and Anxiety	<p>Group CBT adjusted to the needs of children with Autism</p> <p>Individual CBT adjusted for children with autism</p>	<p>Starfish provides specialist individual CBT to meet the needs of children with a learning disability <b>and</b> Autism.</p> <p>Point 1 provide individual CBT but not by ASD specialists.</p> <p>Specialist Mental Health Teams provide a full range of interventions for children with anxiety disorders including CBT</p>	<p>Access is via the Starfish team</p> <p>There is no adjusted CBT for Autism commissioned in Norfolk</p> <p>Via telephone, letter, fax or email to the Mental Health Access Hub</p>
	School based anxiety	<p>Point 1 offer school based anxiety work.</p> <p>NCC ASD support team provide individual and small group work in school on managing anxiety</p>	<p>This is accessed through schools.</p>
Information & support	<p>Parents and children to receive information on Autism and its management.</p> <p>Contact details of local &amp; national organisations who offer specific support on Autism.</p> <p>Information on short breaks/respite and access to leisure activities.</p>	<p>Following diagnosis all parents receive a pack of information on Autism and local support. All parents are offered a post diagnostic meeting within 6 weeks of diagnosis with an autism specialist.</p> <p>NCC Local Offer signposts parents to the range of local support available including short break provision</p>	<p>Sent out by NCHC's ASD Coordinator</p> <p>CAMHS have their own pack, which contains the same shared information.</p> <p>Local Offer website</p>

	<p>Rights to parent/carer /young carer assessment</p> <p>NCC ASD support team</p>	<p>Under the Care Act 2015 parents /carers can request a parent carer needs assessment.</p> <p>Young Carer's assessments.</p> <p>Information &amp; support to school &amp; early years setting to enable children to access education</p>	<p>Referrals can be made directly to NCC via the MASH. They will triage all referrals and arrange assessment through the early help Hubs or the Social work teams.</p> <p>Referral via MASH or early help hubs</p> <p>Access is through schools and early years settings.</p>
Interventions that should <b>NOT</b> be used	<p>Neuro feedback.</p> <p>Auditory integration training.</p> <p>Omega -3 fatty acids for sleep.</p> <p>Secretin</p> <p>Chelation</p> <p>Hyperbaric oxygen therapy</p>		

## **Appendix 1**

### **Definitions**

#### **a) Learning Disability**

The Department of Health define a Learning Disability as:

1. A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence, an IQ below 70), with;
2. A reduced ability to cope independently (impaired social functioning);
3. Which started before adulthood, with a lasting effect on development

(Valuing People: A New Strategy for Learning Disability for the 21st Century. DH, 2001).

When a child is younger than school age, these difficulties are likely to be called a Global Developmental Delay.

A more detailed description is:

A Learning Disability will be diagnosed if a child or young person meets all of the following criteria: The child:

1. Has significant difficulty in 'intellectual functioning', such as reasoning, problem solving, abstract thinking, and academic learning or learning from experience compared to the expectations for their age. An intelligence quotient of below 70.
2. Has significant difficulty with 'adaptive functioning'. This means that the child will not meet the expected standards of independence and responsibility for his or her age. This might include difficulties in being able to feed or dress themselves, or not being able to manage money independently when they get older. Without on-going support, the difficulties are likely to affect their activities of daily life, such as being able to communicate with others, participate in social events or gain independence. These difficulties occur in different environments, such as at home, school and during leisure time.
3. These difficulties began during the developmental period.

#### **b) Learning Difficulty**

In UK education services, the term 'learning difficulty' includes children and young people who have 'specific learning difficulties', for example dyslexia or dyspraxia but who do not have a significant general impairment of intelligence (British Institute of Learning Disabilities, BILD) as described above.

An Autism Spectrum Disorder is not a Learning Disability, because intellectual functioning is not always impaired in individuals with ASD; however some children with ASD also have a Learning Disability.

## **NICE Guidance**

The Norfolk pathway has been developed in accordance with the following NICE guidance:

### **Autism in under 19s: recognition, referral and diagnosis**

NICE guidelines [CG128] Published date: September 2011

<https://www.nice.org.uk/guidance/cg128>

### **Autism in under 19s: support and management**

NICE guidelines [CG170] Published date: August 2013

<https://www.nice.org.uk/guidance/cg170>