



## **Briefing for Norfolk Health Overview and Scrutiny Committee**

**7 September 2017**

### **Children's Autism and Sensory Processing Assessment / Therapy**

#### **1. Introduction**

1.1 The Norfolk Health Overview and Scrutiny Committee (NHOSC) have requested a briefing on a number of key issues related to the provision of services for Autistic Spectrum Disorder (ASD) service for children across Norfolk and Waveney. This paper provides a response to each of the specific queries raised.

#### **2. Background**

2.1 The five Clinical Commissioning Groups across Norfolk and Waveney have recently agreed to collaborate with a single leadership team for children's, young peoples and maternity services. This work is being led by the Great Yarmouth and Waveney Clinical Commissioning Group across all five CCGs, and will ensure improved integrated working across all sectors for the benefit of the children that we all serve. It will have the added benefit for ensuring key priorities for services are agreed, with the delivery of integrated commissioning for health, education and social care, plus strong leadership. Whilst this is a work in progress, it will mean a much improved and joined up approach, which has been widely welcomed.

2.2 At the recommendation of Norfolk HOSC in October 2012, Great Yarmouth and Waveney Joint Health Scrutiny Committee (GY&W JHSC) continued to receive reports from Great Yarmouth and Waveney (GY&W) CCG and Norfolk and Suffolk Children's Services about the progress of children's autism services in its area. The last report was on 6 July 2017, when the Joint Committee received an update on progress made by Great Yarmouth and Waveney CCG working together with Children's Services in Norfolk and Suffolk County Councils to support children's needs. For this reason, the rest of this report relates to services for children and young people in Norwich, West Norfolk, North Norfolk and South Norfolk.

The next sections of this report address the specific queries raised by HOSC.

**3. Q: A description of the current commissioned autism services (i.e. when did the current contract start and when does it finish; who commissioned it and the proportion of funding from each party; the commissioned capacity (i.e. how many children is it expected to see); who is the provider; description of the service and the type and numbers of staff involved; what is the geographic spread of the service and where are the location bases?**

### **3.1 Current commissioned service**

A new Norfolk ASD pathway for the assessment and diagnosis of autism for children and young people was commissioned in 2012. This was following the publication of new NICE guidance on recognition, referral and diagnosis of autism in children and young people (2011).

This new pathway was developed collaboratively by health, social care and education providers and commissioners. It was acknowledged that no single service can meet the needs of this group of children who have a diverse level of needs and presentations.

This Norfolk ASD pathway was updated in 2016 to a 'pathway for referral assessment and support of possible autism in children and young people'. This was to take account of the major restructuring of services locally and publication of new NICE guidance on the management and support of children and young people on the autism spectrum (2013).

There are three current autism pathways for the recognition and diagnosis of autism in children and young people. These are:

- ASD Diagnostic Pathway: Age 1-5
- ASD Diagnostic Pathway: Age 6-18
- ASD Diagnostic Pathway: CAMHS for children with a mental health disorder.

All ASD three diagnostic pathways are commissioned by Norfolk CCGs. The contracts run to March 2019.

### **3.2 Proportion of funding from each commissioner**

The ASD service is commissioned as part of a block contract with providers and we are now in the process of understanding the detail of that. This is a high priority for the commissioners so that we have a better understanding of the funding provided for the service and that it is being used to best effect.

### **3.3 Provider of the service**

The pathways for children aged 1-18 are provided by Norfolk Community Health and Care (NCH&C), with support from other providers.

The CAMHS pathway is provided by Norfolk & Suffolk Foundation Trust (NSFT).

### **3.4 Geographic spread of the service**

The service provided by NCHC is for children aged 1 to 18 years who are registered with a GP in Norwich CCG, West Norfolk CCG, North Norfolk CCG and South Norfolk CCG (with the exception of Thetford where services are commissioned from Suffolk Community Healthcare).

### **3.5 Staff delivering the service**

The NCHC ASD diagnostic pathway is a multi-disciplinary pathway delivered by paediatricians, clinical psychologists, specialist nurses and family support workers, supported by speech and language therapy, psychology, therapy and teacher resource from other agencies and health/care providers such as East Coast Community Healthcare (ECCH), Norfolk County Council and Norfolk and Suffolk Foundation Trust (NSFT).

### **3.6 Description of the service**

A referral is made into NCHC, the child will then be reviewed by a community paediatrician, clinical psychologist or nurse and this is aimed to be within the 18 week wait timeline.

If there is a likelihood of ASD the referral is then passed to the multi-disciplinary team who will gather and evaluate clinical information from referrer, parents, early years setting, school and any other relevant agencies.

Acceptance of referral for a full ASD assessment is based on this information. Children who do not reach the criteria for assessment for ASD will be referred on to alternative appropriate pathways / services such as mental health.

A diagnosis of ASD is made using holistic developmental assessments, with standardised tools and school observations.

Each child is seen by a minimum of two professionals in two different environments. All commissioned diagnostic assessments must be NICE compliant.

There is face to face feedback with the parent(s) or carer(s) about the outcome of the assessment. Each family is offered a post diagnosis appointment within six weeks to offer advice and information.

The CAMHS pathway is provided by Norfolk and Suffolk Foundation Trust (NSFT).

Autism is not a mental health diagnosis, although a significant number of children with autism also present with mental health needs. Mental health services are commissioned to provide targeted and specialist mental health support for the whole population, including those with additional or particular needs, like autism). The specifications for mental health services make it clear that reasonable adjustments need to be made to the standard treatment offer to accommodate the particular needs that autism can bring. Because some children with a complex or hard to assess set of symptoms are referred first to the main specialist mental health provider (NSFT), they complete diagnostic work for some cases.

### **3.7 Post Diagnostic Support**

The Norfolk ASD Pathway identifies a range of services across health, education and social care that provide interventions as recommended by NICE guidance. It does not describe the wider range of services available from the voluntary sector because 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.

### **3.8 Other health commissioned ASD specific services.**

There are a range of other services commissioned to support ASD which include:

- ASD specific parent support programmes commissioned following diagnosis; groups for parents of school age children
- Early bird support for parents of pre-school children
- A holistic service to children with co-morbid learning disability and autism

## **4. Q: Details of the sensory processing assessment provided and the sensory integration therapy service offered, or service, or acknowledgement / explanation if such as service is not commissioned.**

### **4.1 Sensory Processing**

The ASD diagnostic assessment undertaken by NCH&C includes a generic assessment of children's sensory sensitivities.

Sensory Integration Therapy has been the subject of controversy. In 2014, the Norfolk Public Health department were asked to review sensory integration therapy (SIT) and present a series of recommendations to inform the evidence base for SIT and future funding.

A report was produced for Norfolk Commissioners, Sensory Integrated Therapy Policy (February 2015). It concluded that there is no national guidance relating to the prescribing, deployment or monitoring of SIT. There is little robust scientific evidence to support the use of SIT. As a result of this lack of strong evidence and cost effectiveness, the recommendation was that SIT should not be routinely funded.

This position is kept under review in the light of any future national guidance.

## **5. Q: Workload – what is the current workload; the trend; comparison between commissioned capacity and actual number of referrals?**

Demand for ASD assessments by NCHC has increased over the last five years since the establishment of the ASD Pathway. Reasons for this increase are as follows:

- Greater awareness by families and referrers of the condition of ASD
- Belief by parents in the value of a diagnosis as a means to leverage disability benefits as well as further educational and social care
- Parental expectations for post-diagnostic support have been increasing

NCHC's most recent figures from the years 2015-16 and 2016-17 show no significant change in the overall number of referrals to the pathway, leading NCHC to believe that demand has now plateaued and should not significantly increase further. Effective triage is in place; therefore of those referred over 80% are accepted for assessment.

Almost 300 cases are still waiting to begin their assessment (August 2017). The Pathway's capacity can accommodate approx. 150 assessments at any one time. Therefore many families are experiencing a wait of at least two years from acceptance for assessment to completion of the process.

## **6. Q: Staffing – number and types of vacancies**

NCHC staffing resource for the pathway comprises:

Clinical Psychologist – Pre school	0.8 WTE
Clinical Psychologist –School age	1.0 WTE
Children's Nurse	0.6 WTE
Family Support Worker	1.0 WTE
Nursery Nurse	1.0 WTE
Path Way Administrator	0.88 WTE
Assistant Psychologist	0.5 WTE

There are no current staff vacancies. Input by speech and language therapy is provided by East Coast Community Health (ECCH). This is jointly commissioned by the CCGs and Norfolk County Council and managed by NCC.

## **7. Q: Waiting times – from referral to assessment; from assessment to start of therapy; numbers on the waiting list.**

The current waiting times from first GP referral to a generic assessment by a paediatrician, nurse or clinical psychologist are aiming to meet the 18 weeks target within the next two to three months.

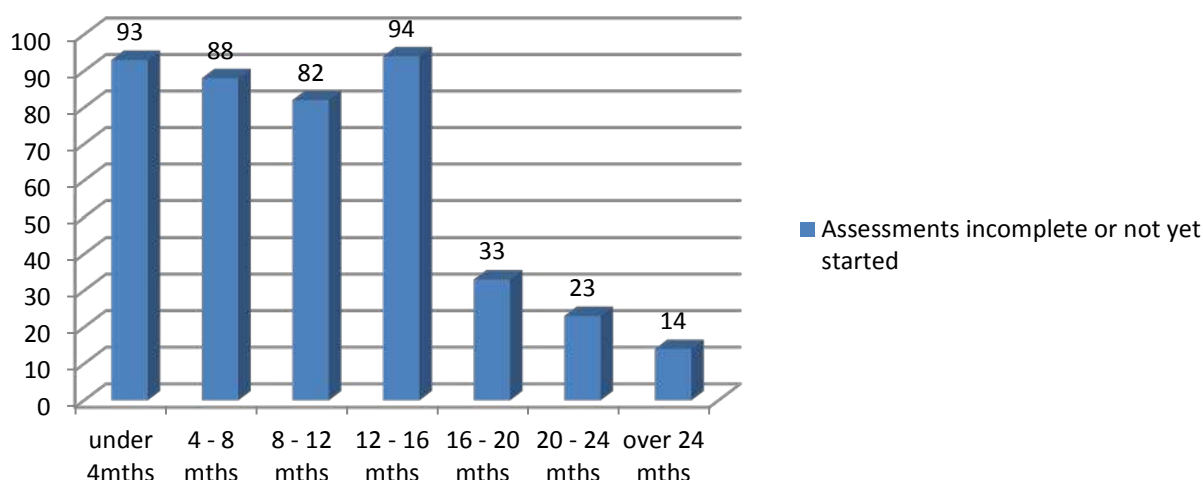
The length of time for assessment may be variable depending on the age of the child. The timescale for an ASD assessment to be completed is dependent on each patient, currently this can be a maximum of 24 months. The diagnosis of autism will have a lifetime impact so commissioners have focused on quality and timeliness of the service.

### **7.1 Numbers of children on the waiting list as of 8 August 2017:**

	Referred in - awaiting discussion and decision by team to accept for full assessment	Accepted for full assessment – awaiting start of first assessment	Assessment started (= accepted onto pathway and first assessment underway)
Preschool - West 1- 4yrs	1	18	8
Preschool – Central 1 – 4yrs	1	20	35
School age – West 4 – 18yrs	19	186	53
School age – Central 4 – 18yrs	54	192	52
<b>Total</b>	<b>75</b>	<b>416</b>	<b>148</b>

This shows a total of 639 children that are awaiting discussion or assessment.

## Wait by length of time since acceptance onto pathway



A significant number of those cases waiting more than eight months are waiting for their first or second assessment to complete their diagnosis. Of assessments currently in progress, approximately 90% are waiting for specialist ADOS or equivalent assessments to be completed. The issue of waiting times and availability of support to families is under active consideration by the CCGs.

A positive behaviour support programme was trialled in 2016-17, and well received by families. Since April 2017 there has been no programme of support available to families while their child is waiting for their diagnostic assessment to complete and this is currently under review by the CCGs.

### 8. Q: KPIs – current performance against key performance indicators (KPIs) and trends in performance

We are working as part of a new leadership arrangement with NHS Great Yarmouth and Waveney CCG as the lead for children and young people to put in place more robust monitoring of the service. We are introducing a weekly overview and regular management of waiting times.

We are aware that currently there are no performance indicators in place or analysis of trends in performance to enable us to monitor performance.

### 9. Q: Complaints / user feedback – numbers of complaints; complaint themes; user satisfaction survey feedback

There have been 53 complaints recorded since 2014 by NCH&C and North East London Commissioning support unit. We are planning to work on capturing complaints that may be directed through a number of different systems such as individual CCGs, Norfolk Children's Services, CAMHS or MPs.

Of those 53 complaints the themes include: length of wait (largest number), support for emotional/behavioural difficulties associated with autism (second largest number) and non-

confirmation of independent assessments. There are rarely any complaints about the quality of the current service provided.

## **10. Conclusion**

We recognise this is an area where services have not kept up with local need. The current service is NICE compliant. The CCGs are now working alongside NCHC to address this so that we have greater oversight, capacity and scrutiny.

We are actively looking at the options available to us to ensure that parents and families are better supported whilst they wait and that waiting lists are addressed and that the time to wait is far shorter.

Tracy McLean:	Head of Children Young People and Maternity Norfolk and Waveney
Alan Hunter:	Head of Service (Children) Norfolk Community Health and Care Trust (NCH&C)