

Children's autism and sensory processing assessment / sensory integration therapy

Suggested approach by Maureen Orr, Democratic Support and Scrutiny Team Manager

A report from commissioners on access to autism services and sensory processing assessment / sensory integration therapy in central and west Norfolk.

1. Introduction

- 1.1 Norfolk Health Overview and Scrutiny Committee (NHOSC) added 'Children's autism and sensory processing assessment / therapy' to its forward work programme in February 2017, following concerns raised by a Member about waiting times for assessment and diagnosis and the availability of treatments.
- 1.2 NHOSC last looked at services for children with autism in October 2012, following up on a scrutiny review which had been completed October 2011. The initial concerns, which were brought to NHOSC's attention by Autism Anglia in 2011, had been about:-
 - Lack of a funded diagnostic service for school age children
 - Under-resourcing of the pre-school paediatric diagnostic services to meet the demand for assessments
 - Variation in diagnostic methods across Norfolk
 - Inability of the Child and Adolescent Mental Health Service to meet the needs of children with autism.

In 2012 progress had been made in relation to pathways for diagnosis of children. There was a more joined up approach between the NHS, education, parents and other services involved with the child to gain a fuller picture and make more accurate diagnosis within reasonable timescales. Post diagnosis support for families was expected to improve under the post diagnostic pathway.

- 1.3 2012-13 saw a major reorganisation of NHS commissioning with the formation of 5 Clinical Commissioning Groups (CCGs) in Norfolk, which took over commissioning responsibility for autism services from the 2 former Primary Care Trusts on 1 April 2013.
- 1.4 At the recommendation of NHOSC 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. The report is available via the Norfolk County Council website (Great Yarmouth & Waveney Joint Health Scrutiny Committee, 6 July 2017, item 6, page 17):- <http://norfolkcc.cmis.uk.com/norfolkcc/Meetings>

The Joint Committee commended the considerable collective work that had been done in 2016-17 to improve the service and recommended:-

1. That Norfolk and Suffolk County Councils should encourage Ofsted, in their regular inspections of schools, to strengthen the focus on assessing how schools manage children with ASD.
2. That Norfolk and Suffolk County Councils and the Great Yarmouth and Waveney CCG should seek to provide more support to, and contact with, parents and carers of children with ASD, with more information and signposting of where and how they can get help.
3. That Norfolk and Suffolk County Councils and the GY&W CCG should continue to improve the feedback given to referrers, to ensure that children are placed on the correct assessment pathway at an early stage.
4. That Norfolk and Suffolk County Councils and the GY&W CCG should keep encouraging schools to play a greater part in identifying and supporting children with ASD, and recognising the link between academic success and children's emotional wellbeing.
5. That Norfolk and Suffolk County Councils should continue to share knowledge and good practice between each other.

The Joint Committee also asked to receive an information bulletin in February 2018 with updated data showing the numbers of children in Great Yarmouth and Waveney with Autistic Spectrum Disorders, data on time-to-assessment and time-to-treatment, and any data on the reasons why children haven't attended their appointments.

- 1.5 In October 2016 the Norfolk Autism Partnership Board (APB) consulted on a draft Norfolk All Age Autism Strategy 2016-2019 in response to the National Autism Strategy. The consultation documents are available on the Norfolk County Council Consultation Hub
<https://norfolk.citizenspace.com/consultation/draft-autism-strategy/>

The final strategy was to be launched in 2017. Part of the vision for the future set out in the consultation document was for an Autism Partnership Board to be set up that included autistic people and family representatives as well as statutory services.

- 1.6 NICE Clinical Guideline CG128 (Sept 2011) 'Autism spectrum disorder in under 19s: recognition, referral and diagnosis' recommends that consideration should be given to whether 'sensory sensitivities' assessment is needed when constructing a profile for each child or young person'.

In February 2015 Norfolk Public Health produced a report for the Norfolk commissioners on Sensory Integration Therapy Policy, which concluded that due to the lack of strong evidence and cost effectiveness sensory integration therapy should not be routinely funded. A copy of the Policy report is available on West Norfolk CCG's website:-

<http://www.westnorfolkccg.nhs.uk/individual-funding-requests-nhs-treatment/clinical-policies>

2. Purpose of today's meeting

2.1 As GY&W JHSC is already looking at children's autism services in its area, the information presented for **today's meeting focuses on the central and west Norfolk areas**. Norwich, North Norfolk, South Norfolk and West Norfolk CCGs hold a single contract with Norfolk Community Health and Care NHS Trust (NCH&C), which provides community services for children with autism. The CCGs have been asked to report to NHOSC with the following information:-

- (a) A description of the current commissioned autism services (i.e. when did the current contract start and when does it finish; who commissioned it & 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.
- (b) Details of the sensory processing assessment provided and the sensory integration therapy service offered, or acknowledgement / explanation if such a service is not commissioned.
- (c) Workload – what is the current workload; the trend; comparison between commissioned capacity and actual number of referrals for autism diagnosis / services
- (d) Staffing – number and types of vacancies
- (e) Waiting times – from referral to assessment; from assessment to start of therapy; numbers on the waiting list
- (f) Key Performance Indicators (KPIs) – current performance against KPIs and trends in performance
- (g) Complaints / user feedback – numbers of complaints; complaint themes; user satisfaction survey feedback

The CCGs' report is at **Appendix A** and representatives will be in attendance to answer Members' questions.

Great Yarmouth and Waveney CCG has recently taken the lead for Child Health and Maternity for all five of the Norfolk and Waveney CCGs, so the CCG representatives come from that area and will be able to answer questions for the whole county.

- 2.2 Representatives of the NHS provider of services for children with autism in central and west Norfolk, Norfolk Community Health and Care NHS Trust (NCH&C), have also been invited to attend to answer questions which may arise about the delivery of commissioned services in their area.

3. **Suggested approach**

- 3.1 After the CCGs' representatives have presented their report, Members may wish to discuss the following areas:-
- (a) The commissioners' report (Appendix A) says that almost 300 cases are still awaiting to begin their assessment for autism and the service pathway's capacity can accommodate approximately 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. The CCGs have this issue under active consideration. Are there plans to increase capacity?
 - (b) The CCGs are currently reviewing the results of a positive behaviour programme that was trialled in 2016-17 to support families while their child is waiting for their diagnostic assessment to be completed. When is there likely to be a decision about whether such a service should be commissioned on an on-going basis?
 - (c) There are currently no performance indicators in place for the children's autism services and the CCGs are working to introduce more robust monitoring of the service through a weekly overview and more robust management of waiting times. When do the new monitoring arrangements start?
 - (d) Has there been continued progress in liaison between health, education and social care in the diagnosis and care and development of children with Autistic Spectrum Disorders?
 - (e) Are parents sufficiently and appropriately involved?
 - (f) What was the response to the draft Norfolk All Age Autism strategy in December 2016 and when will the strategy, including an appropriate Autism Partnership Board, be in place?

4. **Action**

- 4.1 Following the discussions with representatives at today's meeting, Members may wish to consider whether:-
- (a) There is further information or progress updates that the committee wishes to receive at a future meeting.

- (b) There are comments or recommendations that the committee wishes to make as a result of today's discussions.



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