



Hampshire and Isle of Wight
Sustainability and Transformation Partnership

Hampshire Autism Update

September 2020



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Autism Pathway – key issues and challenges

There is currently a significant delay for children being referred for autism assessments.

- Currently there is a waiting list of circa 1,750 assessments outstanding in Hampshire with a mean average waiting time of 35 months
- Waiting lists are significantly outside of the current National Institute of Clinical Excellence (NICE) guidance of an assessment commencing within 13 weeks of referral
- On top of this growing waiting list an average of 90 children are referred to services for assessment each month in Hampshire and 30 on the Isle of Wight which equates to 1,068 children referred per year
- In Hampshire, piecemeal investment over the last 2 years has poorly managed this waiting list with a total of circa 50 assessments per month currently commissioned (602 per annum)
- There is no recognised treatment pathway following a diagnosis of Autism in the NHS. However early identification of needs and corresponding support not only provides richer evidence towards a diagnosis but also rules out other ‘treatable’ conditions before a lifelong diagnosis of Autism is obtained
- There needs to be a culture shift in schools, that moves away from being diagnosis reliant and focuses much on interventions such as sensory support, emotional regulation and anxiety management at the earliest stage possible in order for children to receive the greatest gains. Once these interventions have been provided a diagnosis can be sought if necessary, helpful and useful to families and individuals

A brief history of Autism assessment diagnosis in Hampshire

- In 2018 a decision was made by the then 5 Hampshire CCGs to transfer a cohort of 824 children waiting for an Autism assessment from Hampshire Child and Adolescent Mental Health Services (CAMHS) to an interim service in order to clear the backlog. £989k was identified over a 10 month contract
- The decision was taken as part of a wider CAMHS improvement plan, however it was acknowledged that the removal of these children would not generate additional capacity within Hampshire CAMHS. Instead it would guarantee that this cohort of children (who were not deemed as a priority in terms of risk) would at least be seen after waiting a number of years at the bottom of the CAMHS waiting list
- In late 2019 a deep dive was performed by the then Deputy Director and the CAMHS Associate Director and presented for investment. This investment was not agreed due to competing demands at that time, then Purdah relating to the General Election and subsequently the impact of COVID-19 further disrupted commissioning plans. In consequence Autism Spectrum Conditions (ASC) diagnosis commissioning has been maintained at similar levels to 2019-20 during this year. A plan to address longer term needs is under development.
- Due to interim solutions to the commissioning of ASC assessments, plans for a longer term procurement of ASC assessments have been delayed.

Progress since November 2019

- Changes in senior management leadership during November and December 2019 interrupted procurement planning in relation to Autism assessments meaning that short term commissioning arrangements for Autism Assessments needed to be extended into 2020-21
- The lockdown associated with COVID-19 further introduced a level of complexity to the model for delivery of Autism Assessments using non-face to face methodologies that needed to be tested before they could be incorporated into service specifications as part of future proof commissioning intentions
- With this in mind NHS commissioners directly awarded Autism Assessment activity for Hampshire CCGs to two providers of such service for twelve months, with the option of a further twelve month exemption should this prove necessary
- The HIOW CCG partnership Maternity and Child Health SEND team took over commissioning of Paediatric Autism in July 2020 and performed a rapid deep dive and diagnostic to assess the need and size of the waiting list so options could be worked through with CCGs to find a longer term system that would offer timely assessment whilst tackling the historic waiting lists.
- Additional funding to complete 250 assessments over a 2 month period was agreed in July 2020 and commenced in August 2020 due to the National uncertainty of NHS CCG budgets. This work is due to complete at the end of September 2020 and commissioners are working with CCG finance colleagues and providers to re-profile activity for the second half of 2020-21
- Commissioners are also nearing completion of an options paper to scope and clarify CCG commissioning intentions and budgets for 2021-22 and beyond

Next steps in addressing this ‘wicked’ issue

Having assessed various different models as part of the ‘deep dive’ performed by the CCG Special Educational Needs and Disabilities (SEND) team, most are prohibitively expensive and require a significant lead time to impact upon the waiting list; we have considered that the solution to this ‘wicked’ issue is to:

- Reduce and eliminate the growing autism assessment waiting list through enhanced levels of commissioned autism assessment activity for a defined period of time following agreement of funding regime
- Engage the current provider to perform a rapid assessment and triage of the existing waiting list for harm and escalate those cases accordingly
- Clarify support and referral pathways to ensure the right-sizing of commissioning arrangements for Autism Assessments as part of a more joined up pathway to prevent recurrence of a waiting list in future
- In order to reduce the waiting list rapidly a multi-faceted phased approach focussing on early intervention and prevention is recommended that will:
 - To keep the child or young person central in the process appropriate support mechanisms need to be commissioned including Sensory support, Emotional regulation and Anxiety management
 - Explore, utilise and develop the support of other services such as the Hampshire County Council Primary Behaviour Service to provide behavioural support and identify other conditions such as attachment disorder.
 - Explore need for (and where necessary commission) other support to help those with autism and other neurodevelopmental diversity understand their differences, the impact of them on their lives and approaches.

The above phased approach proved hugely successful on the Isle of Wight in improving the timeliness of assessment and reducing new assessment referrals.

Current scope of addressing Waiting Lists for ASC assessment

1. To reduce the waiting list by:

- Agreeing the funding regime for an ‘investment to save’ by commissioning 1,600 assessments in Hampshire to be completed in 2021-22, followed by the commissioning of approximately 708 ASC assessments per annum) from 2022-23 until 2024-25.

2. To significantly raise awareness and develop cultural change through working on preventative strategies. Professionals working with children and young people (CYP) should be supported in developing an improved knowledge and understanding of Autism and how it impacts on the lives of CYP and their families using their services:

- To enhance the commissioned offer of a range of support services to all children including those on the waiting list so that interventions can be **accessed prior** to assessment. This will in turn reduce the current cultural emphasis on diagnosis and also provide support to families and CYP whilst awaiting a diagnostic and may also eliminate the need for diagnostic testing

3. To resolve the longer term funding for and future proof the service:

- Long term funding arrangements should be agreed in order to inform and underpin the procurement of a long term service in order to significantly reduce waiting lists whilst demonstrating value for money for CCGs and the public. A longer term procurement will also allow the provider to invest in correct levels of staffing and appropriate premises for provision of service in and across Hampshire.

“Appropriate intervention as early as possible”

Commissioners manage the process of securing the provision of diagnostic services for Autism Spectrum Conditions (ASCs) for children and young people in Hampshire on behalf of NHS Clinical Commissioning Groups (CCGs) according to approved NHS budgets. They also commission other services to support people with ASCs. Where appropriate intervention services are commissioned, referral numbers should start to reduce and/or be staggered over longer timeframes which will in turn reduce overall waiting times for others that need them.



Continuing to invest into an assessment only services will continue to promote a culture of parent's seeking 'diagnosis' rather than support. Due to the similarities between ASC conditions and other disorders there is also a risk that some children may be being misdiagnosed as having an ASC. To address this, commissioners are recommending an investment by CCGs in diagnostics with a larger percentage dedicated to delivering intervention services. This will help to start the shift away from the current 'diagnosis only' model to better support CYP with ASC and their families.

The services we intend to commission

Prevention and early intervention are key in managing Autism and as such Commissioners are recommending the development and implementation of the following services in Hampshire, replicating the model recently commissioned on the Isle of Wight which has seen waiting times fall from 4 years to 18 months (and which continue to fall):

- CYP Wellbeing Social and Emotional Mental Health (SEMH) service – HCC Primary Behaviour Service (also meets CCG actions in the recent CQC/Ofsted Inspection and Designated Clinical Officer (DCO) workplan)
- Therapeutic Intervention – including Emotional Regulation workshops and training in schools – to be included in the upcoming procurement project
- Family Support – removing the need for a diagnosis and focusing on need
- Diagnostic Peer support – supporting those undergoing diagnosis peer to peer
- Working with education to shift school and parental culture – understanding that a diagnosis is not required in order to receive SEND support or an Education, Health and Care Plan (EHCP) – this will be carried out through the DCO work plan



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**Thank you for your time
Questions?**



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