

Update on Adult Autism and ADHD Pathway Development and Procurement

Report from: Marie Hackshall, System Programme Lead Kent and Medway – Learning Disability, Autism and ADHD

1. Update on Adult Autism and ADHD Pathway - Development and Procurement

Introduction and Background

- 1.1. The committee requested a report from the Kent and Medway Learning Disability and Autism Delivery Partnership to provide an update on its programme of work being undertaken on the adult autism and ADHD pathway development and procurement.
- 1.2. This paper provides Members with information on the work progressed following an initial paper presented in October 2024 outlining the proposals and reason for change.

Outline of proposal with reasons

- 1.3. In summary, there has been a rapid increase in demand for adult neurodevelopmental (autism and ADHD) services nationally since 2022 (post Covid-19 pandemic) and this has also occurred in Medway. While demand for adult autism and ADHD assessments was expected to grow based on activity levels increasing between 2019 -2021 the increase seen from 2022 was unexpected and accelerated by the pandemic. The most significant increase in demand is related to ADHD assessment and medication initiation and reviews. This has resulted in significant waiting times within the current commissioned pathway for ADHD assessment (up to 7 years) and medication reviews (up to 2 years). This demand coupled with workforce pressures and NHS financial constraints has placed significant demand on the service.
- 1.4. The drivers of demand for autism and ADHD services are multifaceted and complex, spanning wider societal and environmental factors. We know in Medway that demand has followed the national trend and is strongly influenced by increased public awareness of ADHD along with social and environmental changes that have impacted on people's lives following the pandemic. Demand for ADHD assessments has risen at such speed that current service models and the ability to keep pace with demand is recognised by NHS England as a significant challenge for all ICBs. This change was not predictable in terms of the speed in which this has happened.
- 1.5. The number of private providers undertaking autism and ADHD assessment and prescribing privately or through right to choose (RTC) has also increased significantly in recent times in response to the increased demand in this clinical area. The NHS Choice Framework gives patients the legal right to choose where they have their NHS treatment. These choices



apply to both physical and mental health but only apply at the point of referral (from a GP) to providers that have an NHS contract with an ICB in England to provide the service the patient needs. The virtual (online) nature of many ADHD services allows patients to choose to be referred and accepted from any geographical location in the UK. RTC applies for autism and ADHD assessment and treatment and many patients in Medway have taken this option

- 1.6. The challenges for autism services, whilst seeing a less significant increase in referrals by comparison with ADHD, include insufficient capacity to meet demand for intensive multidisciplinary team support, high numbers of autistic people seeking support from other parts of the healthcare system, e.g. mental health services and/or A&E, due to unmet psycho-social needs related to autism and a limited range of support 'in the right place at the right time' to prevent needs escalating.
- 1.7. Services for neurodivergent (autistic and ADHD) adults are limited when compared with services for other population groups e.g., mental health, learning disability. It is important to achieve maximum efficiency from the comparatively limited funding available for autism and ADHD services through the development of a streamlined, seamless care pathways that address the needs of this population at several levels.
- 1.8. The proposed new adult autism and ADHD care pathway aimed to bring all elements of the existing provision together and to progress the development of a community autism and ADHD support pathway at different levels to work with existing provision within health and social care to meet gaps in current services.

Update on the redevelopment of adult Autism and ADHD pathways

a. Procurement process and timelines

- 1.9. Under the current procurement legislation commissioners must use Direct Award Process B of the Provider Selection Regime (PSR) to contract for all services where patients have a legal right to choose their provider. This applied to the diagnostic assessment and follow up treatment for autism and ADHD and means these parts of the clinical pathway are now commissioned under right to choose (RTC).
- 1.10. A contract accreditation process for NHS Kent & Medway is in place and the service specification, standardised tariffs and accreditation process for autism assessment diagnosis and ADHD assessment diagnosis, prescribing and titration went live in February 2025. This will be the process through which diagnostic and post diagnostic pharmaceutical (ADHD prescribing) will be undertaken for new patients referred from 1 April 2025 onwards and should enable patients to access assessment in a timelier manner, although as demand continues to be very high for these services, waiting times are expected to be long via right to choose. A clear process for referral management and clinical triage through primary care is in place locally to ensure referrals under RTC are appropriate and meet agreed clinical thresholds.
- 1.11. Providers can apply for accreditation at any time, so regular communication will be maintained with GPs to ensure they have an update list of accredited providers to choose from.

- 1.12. Patients currently on the NHS commissioned service waiting list for assessment will be held by Kent Community Health NHS Foundation Trust (KCHFT) and then transferred to accredited providers over the course of the next 12 months. Patients will be transferred based on clinical need, with those identified as priority being transferred first, e.g. patients waiting for medication reviews. Patients transferring from a children's ADHD service will be prioritised and should be seen by the accredited provider for a medication review within 12 weeks of their 18th birthday.
- 1.13. Provision has also been made for people with a complex mental health comorbidity and/or learning (intellectual) disability, alongside ADHD, where the needs of the individual might be better supported by specialist NHS services commissioned locally. These services will be in place from April 2025 onwards.
- 1.14. Procurement of the other parts of the autism pathway (the community support and intensive support offer) has been progressed through direct award with existing providers as per the current procurement regulations. KCHFT will expand the current post diagnostic support offer for autistic adults to include additional keyworker capacity which will provide support to more people and Sinclair Strong will continue to deliver intensive support to autistic adults via Kent and Medway Complex Autism Service.
- 1.15. The requirement to procure the different elements of the autism pathway under different procurement arrangements has meant that the desired outcome to have a more streamlined service provision for neurodivergent people has not been realised. However, there is commitment from all parties to work together, in partnership with people with lived experience, alongside their families to work in new and different ways to build sustainable models of delivery which enables different levels of support to be available, including self-management approaches, peer networks, community support and specialist services.
- 1.16. The need to procure under right to choose legislation will create a significant financial pressure for the ICB as the demand for ADHD assessments and medication remains high. To mitigate this risk, we
- i. are continuing to work with KCHFT to cleanse the current waiting list and ensure only referrals who meet the clinical triage criteria are progressed for assessment
 - ii. Are ensuring there are locally clinical triage processes in place prior to referrals being made through RTC to ensure only appropriate referrals are made
 - iii. have agreed local tariffs for RTC activity in place
 - iv. are continuing work to scope and develop a community hub with skilled staff in each locality in Kent and Medway to provide more local expertise increasing skills and expertise within primary care to increase and improve the delivery of ADHD assessment, medication reviews and prescribing so people do not need to be referred to a specialist service if not required, thus reducing demand for RTC
- b. Engagement with people with lived experience of ADHD
- 1.17. Between November 2024 and February 2025, 1,157 people took part in a survey carried out online to gather people's views on the existing adult ADHD pathway. We also held events, two in-person and two online discussions which 42 people attended.
- 1.18. Prior to starting this engagement, NHS Kent and Medway commissioners and the Communications and Engagement Team worked with the Adult ADHD Patient Reference

Group (PRG) to develop a proposed model with the view to inform a procurement for ADHD assessment and support. While going through this engagement process, updated legislation meant that ADHD assessments and follow up would become a right to choose service and no procurement was needed for that aspect. Therefore, although we began by looking at a model it became apparent that the model wouldn't change significantly and that the impact patient experience could have, was around the commissioning of support.

- 1.19. What we have heard highlights significant challenges in accessing assessments and treatment as well as support pre and post diagnosis. People said that they would like tailored support such as coaching, therapy, crisis services, financial and employment guidance. Other suggestions to help improve services include awareness and training for healthcare staff and GPs, better communication during the process, self-referral options, crisis escalation pathways, and a central directory for ADHD-friendly services. We also heard practical solutions such as introducing a post-diagnosis welcome pack, text or WhatsApp reminders, and a visible NHS waiting list system.
- 1.20. We are using this feedback to inform our plans as we look to commission extended support for people with ADHD aligned to the areas people have identified as having the greatest impact. These services will start to come online from April 2025 onwards.
- 1.21. We are also working with colleagues in primary care and the specialist ADHD services to try address some of the immediate concerns raised, in particular around shared care arrangements for ADHD prescribing.
- 1.22. The full report from these engagement events can be found in **Appendix 1**

Next Steps and Improvements

- 1.23. Accredited list of providers for people to access right to choose pathways via GP referral goes live from 1 April (currently GP referral only goes to KCHFT unless the patient requests right to choose)
- 1.24. Webpages pulling together local and national support offers for people with ADHD and autism are currently in development and will launch from 1 April. They will be reviewed and updated regularly, with the support of people with lived experience
- 1.25. Working with partners to address issues and provided contingencies around shared care where GPs have opted out of shared care or choose not to offer it as an enhanced service
- 1.26. Working with primary care to progress development of community ADHD hubs with skilled staff in each locality in Kent and Medway thus reducing demand for RTC and improving patient experience

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