### **MEDWAY COUNCIL**

Gun Wharf Dock Road



### **Health Overview and Scrutiny**

# Assessment of whether or not a proposal for the development of the health service or a variation in the provision of the health service in Medway is substantial

### 1. A brief outline of the proposal with reasons for the change

Background to the redevelopment of adult Autism and ADHD pathway 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.

NHS Kent and Medway commission specialist diagnostic and post-diagnostic services for autism and ADHD for adults over 18 years from Kent Community Health NHS Foundation Trust (KCHFT). KCHFT subcontract Psicon and Sinclair Strong to provide autism assessments, and Psicon and Psychiatry UK to undertake ADHD assessments and initial prescribing of ADHD medication where clinically appropriate for patients.

Referrals to this commissioned specialist service have increased by 600% against contracted activity in the last 2 ½ years (a total of 31,314 referrals received since April 2022 against contracted activity of 2,131 annually).

### Medway referrals 2022 - 2024 (Quarter 1)

No. Referrals by Locality (Referral Received Date)	2022/23	2023/24	Apr-24	May-24	Jun-24	Q1 24/25	2024/25
Medway	1830	2206	125	97	86	308	308
Referrals by Type (Referral received date)	2022/23	2023/24	Apr-24	May-24	Jun-24	Q1 24/25	2024/25
- ASD Assessment	275	475	44	36	34	114	114
- ADHD Assessment	599	992	57	45	34	136	136
- Dual ASD + ADHD Assessment	487	408	0	0	0	0	0
- ADHD Medicines Review	219	326	24	16	18	58	58
- Unknown	250	5	0	0	0	0	0
Referrals by Gender (Referral received date)	2022/23	2023/24	Apr-24	May-24	Jun-24	Q1 24/25	2024/25
- Female	1045	1304	69	52	56	177	177
- Male	781	901	56	45	30	131	131
- Not Specified	0	1	0	0	0	0	0

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. 71% of this 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). National prescribing data shows that there has been a significant growth between 2019/20 and 2022/23 for adult prescriptions with the 25-44 age groups seeing the biggest increases in patients being prescribed ADHD medication, with a 146% increase in the 30-34 age group. This demand coupled with workforce pressures and NHS financial constraints has placed significant demand on the service.

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.

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. Judgement on the clinical appropriateness of the referral is for the referring clinician, i.e. GP, to make. The patient's GP must be satisfied that the patient's chosen provider can provide safe, effective, and evidence-based care in accordance with standard quality and patient outcomes before making the referral. However, not all services offer the same level of assessment and treatment. For example, some services might provide a diagnostic service but may not initiate prescribing or support shared care with the patients GP. This means that patients who have gone through 'right to choose' and then wish to have their medication prescribed by their GP may be unable to do so because the ADHD service they went to does not support shared care for prescribing.

NHS Kent and Medway did not have clinical or commissioning oversight of non-NHS providers who see patients privately or through RTC (though is working to change this). This means the quality of assessment provided to patients can vary considerably, the number of people diagnosed by some providers is much higher

than others and shared care arrangements with patients GPs for prescribing are difficult.

In December 2023, NHS England undertook a rapid review of the ADHD service provision within the NHS and identified challenges with:

- a) current service models (how services are delivered) and the ability to keep pace with demand
- b) lack of reliable data to fully understand the size of the challenge
- c) the rate of growth within the independent sector and the potential variation in the service models and thresholds for diagnosis being used
- d) the balance between use of medication and therapeutic treatment options, e.g. non-medication support such as ADHD coaching
- e) variation in access, experience and outcomes for different groups of patients
- the join-up across ADHD services and interrelated policies across health, care, education and the justice system

NHS England has established a taskforce, with experts from within the NHS and wider system partners, supported by public and patient engagement to identify potential actions to address the challenges in the complex ADHD landscape. The taskforce is looking at the following areas and expected to report on their findings later in 2024.

- a) develop a national ADHD data improvement plan so more information is available on numbers of people seeking assessment, being diagnosed etc.
- b) carry out more detailed work to understand the service provider and commissioning landscape across England. This includes mapping all the service providers (NHS and private), speaking to service providers, and analysing provider outcomes (patient satisfaction, diagnostic rates etc)
- c) capture examples from ICBs who are trialling innovative ways of delivering ADHD services, to ensure best practice is captured and shared across the system

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.

In response, Kent and Medway Integrated Care Board (ICB) has undertaken a review of the existing pathways between June 2023 and May 2024 (in partnership with people with lived experience of autism and ADHD and those awaiting assessment, the current service provider and system partners) to:

a) map out why and how patients are referred to the service and change the service provided to give people access to support while they wait for assessment or instead of needing an assessment. This included online

- workshops and facilitated peer support sessions being offered to those on the waiting list for assessment. Changing the service offered by the local NHS provider to a need led and support first service, i.e. prioritising referrals based on need, with those with the highest clinical need being seen.
- developing a new care pathway for autism and ADHD that includes early intervention and support through social prescribing outside of the diagnostic pathway and offering non-medication treatment options, e.g. ADHD coaching.
- c) reviewing the referral process and support offer to individuals and GPs to complete all relevant paperwork prior to the referral being made to the specialist service so all the information needed to make a clinical decision is available when the patient is due to be seen and their care is not delayed
- d) put in place in partnership with KCHFT an electronic system to improve clinical triage processes as part of waiting list management and prioritisation approaches to ensure patients with the greatest clinical need are seen first. This is being tested in September 2024 and will be in place by mid October 2024.
- e) Over 4,100 people on the waiting list for the specialist service have accessed app-based support, online workshops and facilitated peer support sessions Feedback has been positive about this support offer, but this is unlikely to reduce the demand on the pathway in the short term as people continue to seek an assessment.
- f) improve the referral process from GPs to the specialist service by using electronic referral tools being developed. This will be in place by April 2025. Increase the information, advise and support available to people so they don't have to go through the specialist autism and ADHD service to get this. The ICB in partnership with Kent County Council have funded a social prescribing platform (Joy) which will enable people to access to support and information directly or through their GP. This will be available from late September 2024.
- g) review and improve the shared care arrangements for ADHD prescribing so that patients can access medication and/or have their medication reviewed via their GP (or alternative GP when their GP is not signed up to shared care) rather than needing to be seen by the specialist service. This will reduce the waits patients have for medication reviews and free up capacity in the specialist service.
- h) Look at new ways to manage prescribing and shared care for ADHD, e.g. develop a community hub with skilled staff in each locality in Kent and Medway to provide more local expertise so GPs have access to better support and patients can be seen more quickly when needing a medication review or changes to prescribing. This model is still being developed and will take time to implement as will require staff to be trained and services to set up.

 i) develop a revised service specification and business case to support the commissioning of a new model and pathway for adult autism and ADHD services from April 2025 onwards

### Commissioning Body and contact details:

NHS Kent and Medway Integrated Care Board Learning Disability and Autism Programme Team kmicb.km-icb-neuro-diversity-pdu@nhs.net

### **Current Provider(s):**

Currently NHS Kent & Medway commission the following services for autism and ADHD

- Specialist diagnostic and post-diagnostic services for autism and ADHD 3-year lead provider contract (April 2022 March 2025) awarded to Kent Community Health NHS Foundation Trust.
   KCHFT subcontract Psicon and Sinclair Strong to provide autism assessments, and Psicon and Psychiatry UK to undertake ADHD assessments and initial prescribing of ADHD medication KCHFT
- Intensive support for autistic people Kent and Medway Complex Autism Service (KAMCAS) – contract with Sinclair Strong Ltd. extended to March 2025
- Community support for autistic people Touch Base Project & All Together Autistic – Initial contract to March 2023 awarded under the mental health transformation programme and local authority grant funding. Contract extension awarded to the provider Advocacy for All to March 2025 funded through the Learning Disability and Autism programme.

Under the national policy drivers for the transformation of adult autism services NHSE has made £1.3 million additional investment available to enable us to enhance the support available in the community for autistic people and to meet the needs of those with more complex needs alongside the existing funding in place for diagnostic and post diagnostic services. The ICB worked with NHS England, local autistic people and health and social care providers to agree how this funding will be used.

At this time no additional funding has been provided by NHSE specifically for adult ADHD pathways and so the challenge of demand verses capacity remains. NHS Kent and Medway is working with the current providers of the adult autism and ADHD service and other stakeholders to take actions to mitigate the risks associated with the continued high demand in this clinical area, including prioritising referrals based on clinical need and risk factors, offering support to people while they wait and increasing skills and expertise within primary care to increase and improve the delivery of ADHD medication reviews and prescribing so people do not need to referred to the specialist service if not required. Additional funding is being made available by NHS Kent and Medway for this financial year (2024-25) to address the waiting times for medication reviews and ensure those who have been prioritised are seen in a timely manner.

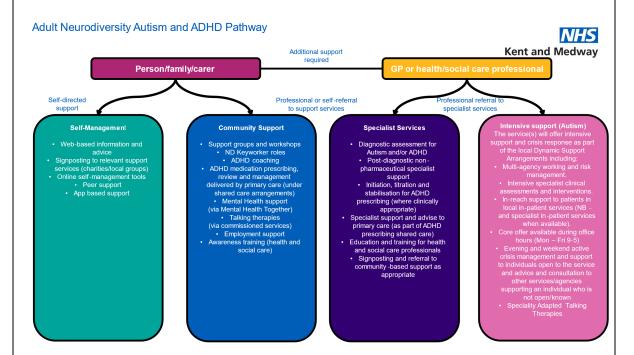
### Outline of proposal with reasons:

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 pathway that addresses the needs of this population at several levels.

The proposed new adult autism and ADHD care pathway aims to bring all elements of the existing provision together and to progress the development of a community autism support pathway at different levels to work with existing provision within health and social care to meet gaps in current services.

The proposed pathway comprises four pillars spanning early and proactive support (both self-directed and expert by experience lead) to specialist diagnostic, post diagnostic and intensive support services.

The proposed model for service delivery is described in the following diagram:



As part of the work undertaken, we have coproduced with autistic people and people with ADHD several community-based support offers which aim to:

- Improve the range and reach of community-based resources to reduce demand for post diagnostic interventions under specialist support from April 2025 onwards
- Establish a new advocacy key worker service as part of community support will reduce demand for specialist and intensive support from April 2025 onwards

 Set us a Community Developments Committee – The committee will be made up of autistic adults, those with ADHD and carers and will be responsible for developing the range and reach of community support across Kent and Medway according to the expressed preferences of people. The committee will have access to an identified budget for this purpose. Information about new developments and support will be available to the public via local platforms

### **Financial Modelling**

Services for autistic people are subject to particular focus in national policy and programmes of work and dedicated funding has been ringfenced for autism services. The indicative annual budget for each pillar of the care pathway for autism and ADHD is set out below.

	Pillar	Description	Indicative Unit Cost	Indicative budget £
1.	Self-Management	Information, advice and signposting to local support groups via Joy (social prescribing platform)  App based support (e.g. COGS-AI)	N/A £1 per license (15,000 already purchased)	440,000
2.	Community Support	Community Support Committee (responsible for developing the range and reach of community support across Kent and Medway according to the expressed preferences of autistic people and those with ADHD)	N/A	
		ND Keyworker Service	N/A	840,000
		ADHD Group Coaching	£100 per person	200,000
3.	Specialist Support	Diagnostic Assessments (Autism/ADHD) Prescribing (initiation & titration) and shared care arrangements ADHD	This pillar is subject to Right to Choose and a separate provider accreditation process (current spend approx. £4.8 million including commissioned service and current RTC activity)	
4.	Intensive Support	Core offer	N/A	843,000
	(Autism)	Specially adapted talking therapy – average 20 sessions per person	£120 per session	200,000
		Out of hours support	N/A	100,000
Subtotal (pillar 1, 2 & 4)				£2,623,000
S	Subtotal (pillar 3)	Commissioned services		£2,800,000

Ī		Right To Choose expenditure	£2,000,000
	Total		£7,423,000

2. Intended decision date and deadline for comments (The Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 require the local authority to be notified of the date when it is intended to make a decision as to whether to proceed with any proposal for a substantial service development or variation and the deadline for Overview and Scrutiny comments to be submitted. These dates should be published.

### **Procurement process and timelines**

Work commenced on the redesign of adult autism and ADHD pathways in September 2023. The plan was to have a new combined pathway in place from April 2025. KCHFT issued notice on the adult ND diagnostic and post-diagnostic service in November 2023 indicating that they would hand the service contract back early. KCHFT and the ICB have worked together since then to take actions to mitigate the risks associated with the continued high demand in this clinical area. KCHFT has agreed in principle to withdrawing the notice and to continue with the contract until the original end date of 31 March 2025.

Several workshops and meetings were held in January, February and March 2024 with key stakeholders including people with lived experience, providers and health and social care colleagues to develop the draft service specification. The procurement group established in March 2024 includes officers from Medway Council, Kent County Council, people with lived experience and ICB commissioning and procurement leads.

An options appraisal on the procurement approach and contractual model was develop by the procurement group in April 2024. The original procurement timeline was impacted by the pre-election period in May and June 2024. The revised timeline was set to issue the Prior Information Notice (PIN) at the end of August and Invitation to Tender (ITT) at the end of October 2024.

The issuing of the PIN was paused while further clarity was obtained on the route to market that needs to be taken given the ruling by the Independent Patient Choice and Procurement Panel in May 2024 of a proposed contract award: online ADHD assessment, diagnostic and management services for North Cumbria. This ruling found that 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. The areas of this care pathway that are eligible under right to choose are those that are mental health services and must be led by a consultant or mental health professional (i.e. diagnostic and some post diagnostic support including pharmaceutical interventions).

Legal advice received in early September 2024 has clarified that the parts of the adult Autism and ADHD pathway that are subject to right to choose (RTC) under NHSE guidelines will need to be procured under the Direct Award Process B. A contract accreditation process for NHS Kent & Medway was agreed by the ICB board in July 2024. This process will be implemented for the areas of the adult Autism and ADHD pathway that align to patient choice. The service specification, standardised tariffs and accreditation process for this clinical area will be complete by early 2025 so that eligible providers will be in place by 1 April 2025 when the current contract with Kent Community Health NHS Foundation Trust (KCHFT) will terminate. This will be the process through which diagnostic and post diagnostic pharmaceutical (ADHD prescribing) will be undertaken for new patients referred and accepted to the pathway from April 2025 onwards. A clear process for referral management and clinical triage through primary care will be in place locally to ensure referrals under RTC are appropriate and meet agreed clinical thresholds.

### Procurement of other parts of the pathway (community and intensive support)

Given the requirement to direct award parts of the pathway this means the remaining parts of the service specification (namely the community support and intensive support offer) will need to be procured separately to the diagnostic and post diagnostic support offer. In relation to these areas the following options appraisal has been carried out:

### Option 1 – Do nothing

It is not a viable option to maintain the status quo as this is not meeting patient needs due to gaps in service provision and current contractual arrangements come to an end on 31 March 2025

## Option 2 – ICB to procure the remaining service elements from a lead provider via competitive tender PROS

- Potentially introduces new entrants into the local provider market
- Potentially introduces new expertise and innovation to the pathway through new providers

#### CONS

- Community support is a psychosocial (lived experience led) model
  whereas intensive support is a clinical model and may result in the
  psycho-social model being heavily influenced by the clinical model. This
  possibly contravenes the strategic aims of the pathway to move need and
  demand from the clinical end to the social end of the pathway.
- The differing models are also likely to result in subcontracting by the lead provider and will compound the fragmentation that will ensue from Direct Award Process B particularly if the lead provider (and subcontracted provider) are new entrants and therefore unfamiliar with to the K&M market, population needs and caseload.
- New entrants to market will be unfamiliar with the system, population needs, service gaps etc

 Many current issues (e.g. capacity, funding) will remain as legacy issues in the new pathway and will be a significant challenge for new providers.

Option 3 – Commission community support as an expansion of the existing Dynamic Support Service (DSS) under the Partnership for Neurodiversity Agreement (Section 75 between ICB and KCC) and award the intensive support contract to the incumbent provider under Direct Award Process C.

#### **PROS**

- Will effectively counterbalance the fragmentation of Direct Award Process B by having the remaining services in the pathway provided by local partners/providers with established local infrastructure, system knowledge, relationships and knowledge of local need.
- Will effectively expand the offer of the existing DSS (current scope to age 26) to an all-age service which removes the transition issues that currently occur at age 26.
- Ensure continuity and consistency in clinical support and risk
  management for autistic people with the most complex needs through the
  incumbent provider of intensive support working in partnership to deliver
  an expanded and improved overall pathway.
- Allows for the following service gaps and inefficiencies to be addressed with existing providers within the current contract term (to 31 March 2025) rather than with a new provider from October 2025 following tender and mobilisation
  - duplication of role and function (mission creep) of existing services in the pathway due to service gaps and variations in provision for children and young people (to age 26) and adults
  - unmet need and waiting lists for priority referrals in existing services due to gaps in the current pathway
  - pressures on capacity of services in the wider system (e.g. A&E, mental health) due to gaps in the ND care pathway
- Allows for all elements of the new care pathway to be operational from April 2025 rather than October 2025 timeframe under a competitive tender.
- Allows for the benefits of integrated commissioning and integrated care under the Partnership for Neurodiversity Agreement to be realised
- Aligns with the expressed preferences of people with lived experience in Kent and Medway for local and familiar services and providers
- Achievable within the new PSR regulations (Jan 2024)

#### CONS

 Requires approval and sign off through an increased number of governance forums

Option 3 is the preferred procurement approach which has been recommended to the ICB Executive Management Team for consideration and approval.

### 3. Alignment with the Medway Joint Health and Wellbeing Strategy (JHWBS).

Please explain below how the proposal will contribute to delivery of the priority themes and actions set out in Medway's JHWBS and:

- how the proposed reconfiguration will reduce health inequalities and
- promote new or enhanced integrated working between health and social care and/or other health related services

The proposal will contribute to the following priorities within the JHWBS:

- 1. Healthier, longer lives for everyone promote mental health, emotional wellbeing and resilience, by encouraging community-based initiatives and facilitating social connections whilst recognising the importance of a robust support network for people's resilience
- 2. Connected communities and cohesive services
  - a) Ensure easy access to service information and actively promote digital inclusion. This will enhance equality, promote inclusivity, and empower residents through better access to the information they need to make informed decisions about their health and wellbeing
  - b) Work together so that when people move between services, their journey is seamless. We will work with system partners to improve the coordination of services
  - c) Champion a focus on trust and respect between services, organisations, and users. We will recognise and embrace diversity and embed equity within our communities and service provision

We will do this through the provision of greater and more accessible information and advice for autistic people and people with ADHD so they have access to self-management options, e.g. app based support for mental health (COGS-AI) and peer support groups, and community based support, e.g. ADHD group coaching and ND Keyworker service. By establishing a lived experience led committee to develop community support offers we will foster greater trust and respect in the skills, expertise and knowledge users of services bring to the development of local services and enable more diverse approaches to supporting others.

### 4. Alignment with Kent and Medway Sustainability and Transformation Plans.

Since its establishment in January 2022 the Learning Disability and Autism Delivery Partnership Board has recognised the need to work across the system, acknowledging the scale of the challenge for the NHS and local government in responding to their collective responsibility for the health and wellbeing of people and communities. There is commitment from all parties to work together, in partnership with people with lived experience, alongside their families, carers and communities, to work in new and different ways to ensure that people with learning disability and autistic people live good lives as part of their community with the right support. There is a need for a system-level approach to improve outcomes and reduce inequalities for this population in Kent and Medway by building sustainable models of delivery which enables different levels of support to be available, including self- management approaches, peer networks, community support and specialist services

This aligns with the Integrated Care Strategy shared outcomes and areas of priority.

5. Please provide evidence that the proposal meets the Government's five tests for service charge:

### Test 1 - Strong public and patient engagement

- (i) Have patients and the public been involved in planning and developing the proposal?
- (ii) List the groups and stakeholders that have been consulted
- (iii) Has there been engagement with Medway Healthwatch?
- (iv) What has been the outcome of the consultation?
- (v) Weight given to patient, public and stakeholder views

Several events were held between January – April 2024 with key stakeholders including existing service providers, 35 autistic people and others with lived experience (in group and 1:1 sessions) to inform the development of the service specification and to gather their views, feedback and suggestions about the proposed model of service delivery.

A monthly ADHD lived experience reference group with representation from 9 Medway citizens (who have a diagnosis of ADHD or are waiting for assessment was set up in April 2024. Officers from Medway Council are also members of this group. This group was established to

- bring people with lived experience and key stakeholders together to coproduce a new pathway for ADHD
- review the work undertaken to date and consider how it can be applied in a new pathway
- identify any gaps and challenges in delivering a new pathway from April 2025 and possible solutions to address these

Further communication and engagement are planned to take place between September and December 2024 with wider stakeholders, relevant patient groups and support organisations and people on waiting lists to

- Gather known views and opinions of current services using current data
- Inform relevant patient groups and support organisations of the proposed pathway
- Ask people on waiting lists/ how they feel the change should be implemented and what support they might need

### Test 2 - Consistency with current and prospective need for patient choice

NHS Patient Choice Guidance states that "for mental health referrals, where a patient requires an elective referral, for a first outpatient appointment including

any subsequent treatment if required, with a consultant or a health care professional or their team, the patient can choose any clinically appropriate provider that holds a qualifying NHS Standard Contract with any ICB or NHS England for the service which the patient needs as a result of the referral".

This right is given legal effect by Part 8 of the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012.

The areas of this care pathway that are eligible under right to choose are those that are mental health services and must be led by a consultant or mental health professional (i.e. diagnostic and some post diagnostic support including pharmaceutical interventions).

#### Test 3 - A clear clinical evidence base

- (i) Is there evidence to show the change will deliver the same or better clinical outcomes for patients?
- (ii) Will any groups be less well off?
- (iii) Will the proposal contribute to achievement of national and local priorities/targets?

Activity levels in current services are impacted by existing service gaps that this pathway will aim to address. For example, non-urgent referrals for intensive support and referrals for post-diagnostic support will have needs that will be met with a new and enhanced community support offer. A key objective for the provider(s) is to deliver early intervention and preventative support (in conjunction with other agencies/services e.g. mental health) to reduce demand for higher intensity support. Resource allocation across the pathway should be commensurate with the achievement of this objective. In practice this should mean that, over time, the greater allocation of resources should be targeted at community support and specialist support i.e. pillars 2 and 3. Levels of activity across the pathway should also reflect this objective over the term of the service(s) contract with a move most of the activity at pillars 1 and 2. It is recognised that even with the changes in service provision implemented through this revised pathway that demand will exceed capacity, especially within the ADHD pathway. Therefore, locally agreed clinical triaging criteria (currently being tested) will be implemented as part of waiting list management and prioritisation approaches to ensure those with the greatest clinical need and higher risk factors are prioritised by services. Provider(s) will be required to implement referral and waiting list management approaches as part of service delivery and to work with commissioners to review and refine the implementation and use of these based on clinical impact and patient experience.

This proposal contributes to the following priorities for autistic people in the NHS Long Term Plan (2019)

- Continue investment in community support, including 7-day specialist services and crisis care in every area by 2023/24, reducing the number of people needing hospital care to less than half of 2015 levels.
- Test the most effective ways to bring down waiting times for autism diagnoses.

The NHS Long Term Plan acknowledges that most people with a learning disability, autism or both rely on universal primary, community, and secondary health care services to keep them well. Therefore, equitable access to universal health and care services, coupled with appropriate specialist services, will have a significant impact on reducing health inequalities for this group.

### Test 4 - Evidence of support for proposals from clinical commissioners – please include commentary specifically on patient safety

Information on the proposals have been submitted and noted by the Kent and Medway Improving Outcomes and Experiences Committee in July 2024.

## Test 5 – Does the proposal include plans to significantly reduce hospital bed numbers? If so please provide evidence that one of the following three conditions set by NHS England can be met:

- (i) Demonstrate that sufficient provision, such as increased GP or community services, is being put in place alongside or ahead of bed closures, and that the new workforce will be there to deliver it; and / or
- (ii) Show that specific new treatments or therapies, such as new anticoagulation drugs used to treat strokes, will reduce specific categories of admissions; or
- (iii) Where a hospital has been using beds less efficiently than the national average, that it has a credible plan to improve performance without affecting patient care (for example in line with the Getting it Right First Time programme).

Not applicable

#### 6. Effect on access to services

- (a) The number of patients likely to be affected
- (b) Will a service be withdrawn from any patients?
- (c) Will new services be available to patients?
- (d) Will patients and carers experience a change in the way they access services (ie changes to travel or times of the day)?

In Medway the number of patients likely to be affected is approx. 7,000. This is around 3.27% of the adult population.

Services will not be withdrawn from any patients. Those who do not meet the agreed clinical criteria for referral to the specialist services will be offered support thought self-management and community support offer which will be needs led rather than diagnosis led.

New self-management and community support services will be available to patients

Access to specialist services will be through revised referral management processes, e.g. electronic self-assessment tools for people seeking an

understanding of ADHD and whether they meet the criteria for onward referral to a diagnostic service are being developed. If a person meets the criteria for assessment then referral will be via their GP.

All providers must have local infrastructure (IT and Estate) to enable a range of individual, group, in person and online support to be offered according to the preferences of each individual. Services must offer parity of access across the geographical area of Medway

Core services will be available throughout standard working times (Monday to Friday, 9am-5pm).

### 7. Demographic assumptions

- (a) What demographic projections have been taken into account in formulating the proposals?
- (b) What are the implications for future patient flows and catchment areas for the service?

The National Institute for Health and Care Excellence (NICE) estimates

- the prevalence of autism in adults in the UK is about 1.1%\*, with relative consistency across studies. The proportion of males to females diagnosed with autism varies across studies but always shows a greater proportion of males to females, mostly ranging from 3:1 to 5:1
- the global prevalence of ADHD in children is estimated to be around 5%, and in adults in the UK at 3% to 4%. Data for other countries show a rate of diagnosis of ADHD between 10.2% and 10.5% in children in the USA, and 3.4% in children and 1.4% of adults in Sweden.

\*It should be noted that it is likely the prevalence of autism is higher as the 1.1% came from epidemiological research published in 2011, before changes to the diagnostic criteria for autism that made them more inclusive. Some estimates place the prevalence at double this and a higher ratio of females to males as they are underdiagnosed due to the assessment tools often used

In Medway this would equate to 8,500 adults (3% - 4%). Not all individuals would require support and most individuals will benefit from community and specialist support with small numbers requiring intensive support.

It is difficult to obtain data on the current number of people using services due to data being held in different places, e.g. primary care for ongoing prescribing, specialist services for assessment, and due to gaps in provision but we have estimated that annually approx. 1000 people will seek assessment and 250 will seek medication reviews from the specialist service based on current activity.

### 8. Diversity Impact

Please set out details of your diversity impact assessment for the proposal and any action proposed to mitigate negative impact on any specific groups of people in Medway?

An Equality, Diversity and Inclusion Impact Assessment was initially undertaken in March 2024 and is being reviewed as part of the revised procurement process to ensure any additional areas of impact are considered. The actions identified to mitigate any potential negative impact are:

- the need for tailored intervention and observation of cultural sensitivity when working with neurodivergent people due to a potential stigma and lack of acceptance for seeking support
- the need to provide access to written materials in those whose first language is not English so they can engage with online tools within the social prescribing platform
- to ensure service providers to recruit a mix of male and female employees to give fair consideration to people's needs where they may require a person of a specific gender to support them due to past trauma, cultural or religious considerations
- to adopt a positive action recruitment approach to encourage people with lived experience to apply for roles within the pathway.

### 9. Financial Sustainability

- (a) Will the change generate a significant increase or decrease in demand for a service?
- (b) To what extent is this proposal driven by financial implications? (For example the need to make efficiency savings)
- (c) Is there assurance that the proposal does not require unsustainable level of capital expenditure?
- (d) Will it be affordable in revenue terms?
- (e) What would be the impact of 'no change'?

It is likely that the change will generate some increase in demand for services within the community support offer as people become aware of this. This should be off set over time with a reduction in the demand for specialist and intensive services but not initially. Careful monitoring of existing waiting lists and future demand will be maintained by the ICB to determine where financial spend should be prioritised within the pathway and/or additional investment if made available should be targeted.

Finaical efficiencies are required across health and social care provision, but the proposal is not looking to make savings. We are looking to increase the support offer made to residents at the lees intensive end of the pathway which over time should reduce cost at the specialist and intensive end. We will also continue to scope more financial sustainable models of service delivery to manage the demand and capacity issues within the assessment / diagnostic parts of the pathway.

Capital expenditure is not required.

The need to procure under right to choose legislation is likely to create significant financial pressure for the ICB as the demand for ADHD assessments and medication remains high. To mitigate this risk, we will

- a) continue to work with KCHFT to cleanse the current waiting list and ensure only referrals who meet the clinical triage criteria are progressed for assessment
- b) ensure there are locally clinical triage processes in place prior to referrals being made through RTC to ensure only appropriate referrals are made
- c) agree local tariffs for RTC activity
- d) continue 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

### 10. Wider Infrastructure

- (a) What infrastructure will be available to support the redesigned or reconfigured service?
- (b) Please comment on transport implications in the context of sustainability and access

To support people to access an assessment and support in a timelier manner there is a need to look at alternative ways of meeting people's needs and undertaking assessment consistent with NICE guidelines, including growing the number of health care professionals with training and expertise in the diagnosis and management of autism and ADHD within primary care.

Commissioners are working to develop and improve the interface between primary care and the ND specialist service(s) to achieve the following

- a) Consistency of shared care arrangements for ADHD prescribing between primary and secondary care across Medway
- Improved referral pathway including triage, clarity of roles and responsibilities and improved quality of supporting information or documentation
- Seamless shared care arrangements and improved liaison, consultation and advice between primary care and specialist provider(s) for all patients on the care pathway
- d) Development of a streamlined digital referral pathway

The use of technology such as Apps and on-line interactive interventions provides numerous opportunities to create more efficient and cost-effective ways to deliver care and support at the front end of the care pathway.

At this time app-based support, online workshops and facilitated peer support sessions are being trialled with people waiting for assessment with feedback on the impact of this support being positive.

However, the use of such technology will not work for all neurodivergent people and so consideration will be given to ways that digital and online support can be interwoven with in person or other types of remote access, e.g. telephone support when required.

Autistic people and people with ADHD who use services have advised us that their needs are often better or more easily understood by other neurodivergent people and that they would relate much better to staff that are neurodivergent. There is an opportunity for provider(s) to grow and develop an expert workforce, achieve greater cost effectiveness and offer support to a greater number of people through employing both neurodivergent and neurotypical people across a diverse range of roles in the delivery of the whole pathway.

There should be no transport implications as existing infrastructure will be utilised and where people require in person support this will be made available within Medway.

### 11. Is there any other information you feel the Committee should consider?

None currently.

## 12. Please state whether or not you consider this proposal to be substantial, thereby generating a statutory requirement to consult with Overview and Scrutiny

We do not feel this is a substantial change in provision to the current services commissioned for autistic people and those with ADHD living in Medway. It does not remove access to services and will enhance the offer of support to people at a self-management and community level, so they have direct access to services rather than having to go via specialist services to gain access to support.

The bringing together of existing provision with additional community support and intensive support will improve the patient flow through these services and enable those with the greatest need and higher levels of risk to be seen and supported by the specialist services in a timelier manner.

Further opportunities for greater integration between health and social care exist for this population and this is an area of development which will be progressed through the Learning Disability and Autism Delivery Partnership Board and other joint commissioning and operational delivery groups.