

**Health, Housing and Adult Social Care
Scrutiny Committee**

15 May 2024

Report of the Director of Nursing, Humber and North Yorkshire Integrated Care Board and the Place Director for York, Humber and North Yorkshire Integrated Care Board

Briefing on Adult Autism and ADHD Assessment services

1. Summary

1.1 The purpose of this briefing is to seek input and views from Committee members about Adult Autism and ADHD Assessment services, and in particular:

- The commissioned service, pressures and risks.
- The pilot phase (April 2023 – June 2024), initiated in response to the service pressures and risks, during which time a series of service developments and engagement events have taken place with professionals and people with lived experience.
- The proposed solutions under consideration, which reflect the learning from the pilot phase, including actions to be undertaken between now and the conclusion of the pilot.
- What happens next, including the work being undertaken by the Humber and North Yorkshire Mental Health, Learning Disabilities and Autism Collaborative

2. Background

2.1 Adult ADHD and Autism services are commissioned for the following populations:

North Yorkshire – 615,491 people
City of York – 202,821 people (including Pocklington - 250,800)
Total – 866,291 people

The National Institute for Health and Care Excellence estimate the prevalence of ADHD in the UK at 3% – 4%. The estimated prevalence of autism in adults is about 1.1%.

2.2 The commissioned service and pressures:

The adult ADHD and autism assessment service was commissioned from The Retreat in 2016, with a capacity of 10 referrals per month. The contract was reprocured and commissioned in 2021 to manage 60 referrals per month and conduct 40 assessments per month.

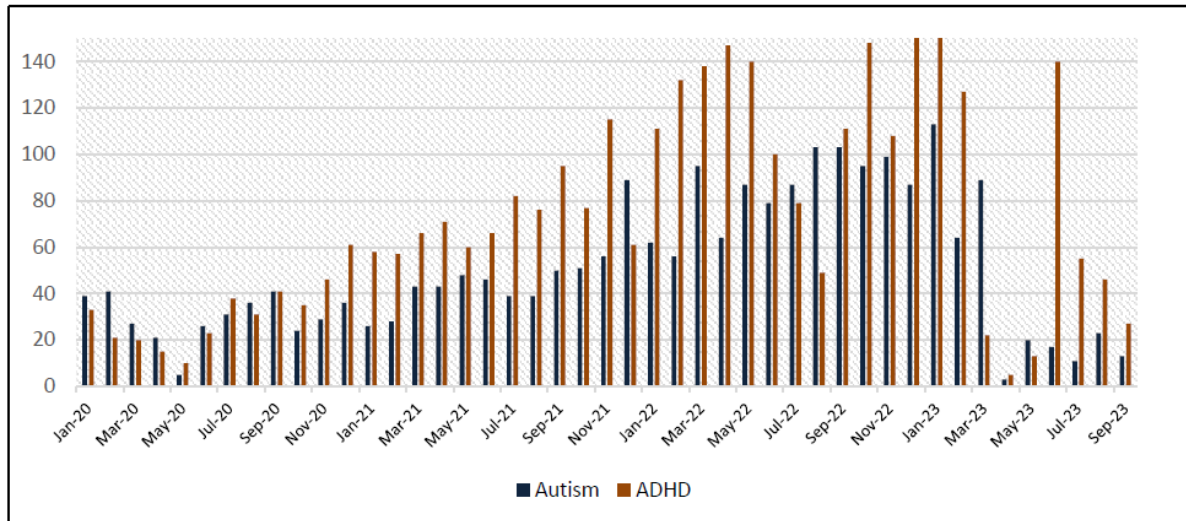
2.3 Demand:

Referrals increased from 60 per month in November 2020 to 200 per month in March 2022, leading to projections of a five-year waiting list.

In April 2023 there were 1500 people waiting for assessment following triage, and 2000 people waiting for triage.

In that time ADHD assessment has increased as a proportion of total demand. This has generated additional pressures for ADHD medication follow ups and annual reviews. 47.9% of appointments of the total service are now taken up with ADHD medication follow up, and 13.6% with annual/medication reviews.

Changing demand is illustrated in figure 1 (Q3 2023/24 Report from the Commissioned Provider, The Retreat):



2.4 Workforce and Assessment:

Demand side pressures are compounded by supply side pressures, namely the ability to recruit and the lengthy assessment process which requires multiple appointments with a multi-disciplinary team. Additional funding to address the waiting list is not fully utilised due to workforce constraints.

As a provider of NHS services regulated by the Care Quality Commission, The Retreat must continue to meet its regulatory requirements around quality and safety. As a result, the provider raised significant concerns about the continuation of the service.

2.5 Comparisons:

There is a lack of robust comparative data for adult ADHD and assessment services. This is because data collection is inconsistent and there is not a commissioned service available in all places. The Humber and North Yorkshire Mental Health, Learning Disabilities and Autism Collaborative is led by the providers of NHS services and is working to clarify this position as the increase in demand is seen as a collective challenge, for all age groups and all providers.

Nationally the pressures are:

1. A significant increase in referral numbers
2. Lack of national recurrent funding streams to support expansion of services
3. Long waits for assessment and diagnosis
4. Lack of pre and post-diagnostic support
5. Clinical pathway for assessments sits predominantly in secondary care with limited capacity

3. The Pilot Phase, April 23-June 24

- 3.1 The pilot phase represents a time during which a series of service developments and engagement events have taken place with professionals and people with lived experience.
- 3.2 In response to the pressures described in section 2, the ICB in North Yorkshire and York introduced a pilot project to test a new referral process. The pilot shifted the service from a demand-led service to a needs-led service.

Demand-Led	Needs-Led
Waiting list in time order	Prioritised referrals and clinically triaged waiting list
No prioritisation at point of referral	Clear prioritisation criteria for referrers
No restrictions on who can be referred	Clear pathway eligibility/prioritisation criteria
Little pre-assessment support	Functional support while waiting for assessment
Safety risks around managing increasing demand vs provider capacity	Clearer understanding of which people are at higher risk when managing increasing demand

- 3.3 In practice this introduced two elements to the pathway.

Firstly, specific acceptance criteria to enable those most at risk to be prioritised for assessment rather than referrals being managed in chronological order.

Secondly, an online screening and support tool to receive and prioritise referrals based on the criteria and enabling all adults to access support more quickly in the form of bespoke modules, functional guidance and a personal portrait based on strengths, challenges and skill development.

- 3.4 Both elements of the pathway attracted significant criticism, from people with lived experience, groups representing people with lived experience, and attracted the attention of the local and national media.
- 3.5 In hindsight communication and involvement during the initiation phase could have addressed many of the issues raised.
- 3.6 Healthwatch York's report, 'ADHD and Autism Pilot Pathway: An independent assessment', found significant issues with the piloted approach. We took significant learning from the Healthwatch report, and our response signalled a different approach from this point forward. The project expanded to include ICB engagement expertise and community involvement in the development of a formal engagement plan. The Healthwatch report can be found here:
<https://www.healthwatchyork.co.uk/wp-content/uploads/2023/08/Independent-evaluation-pilot-pathway.pdf>
- 3.7 From that point on, the pilot evolved beyond testing how best to respond to the pressures, and to a phase of doing, listening, learning, and developing. Engagement plans and a summary of feedback/learning for Autumn 2023 events can be found here:
[York and North Yorkshire Adult ADHD and Autism Assessment Service - Humber and North Yorkshire Health and Care Partnership](#)
Spring 2024 engagement plans and feedback are included in Annexe 2a and Annexe 2b.
- 3.8 Engagement with professionals and people with lived experience has driven learning and development, and we thank all of our stakeholders for taking the time – often in emotive circumstances – to share their stories and give their feedback and suggestions for how we improve the local offer and continue to work with them in the future.
- 3.9 Developments during the pilot phase include an expansion to the pathway acceptance criteria initiated at the start, trying different approaches to waiting list management, and supporting the University of York and York St. John on how to use the personalised reports created by people in the online tool to support academic adjustments and student support plans.

- 3.10 The pilot phase was introduced by necessity in response to unprecedented demand and supply challenges and risk of service closure due to concerns raised by the provider. The pilot phase enabled a service to be maintained, with a shift from seeing people in chronological order to seeing people in priority order using an online tool. This approach protected available capacity whilst testing and evaluating potential changes that could support a solution in whole or in part to the challenges faced.
- 3.11 The pilot was extended beyond the initial 3-month initiation (April-June 2023) to collect and analyse feedback, evaluate, and give time for potential solutions to emerge. The final stage of the pilot focused on involvement with professionals and people with lived experience through a series of focus groups to test and build up a set of proposed solutions for the commissioned service.

4. Proposed Solutions for the Commissioned Service

- 4.1 The Healthwatch evaluation, together with feedback and insights gained from people with lived experience via the engagement events in December 2023 and April/May 2024, have informed all of our proposed solutions.

The commissioned service has been maintained and the intention is to involve the community in future decisions which could divert a proportion of the funding available to the commissioned service towards community-led pre diagnosis support.

- 4.2 The criteria introduced in the pilot phase will be removed from the pathway and prioritisation will be based on clinical professional judgement by GPs and Community Mental Health Teams. This is similar in practice to how demand for clinical/specialist treatment is managed across many health conditions, where clinicians are empowered to take different action if a person is 'urgent' or 'routine'.
- 4.3 Priority referrals will go directly to The Retreat. Routine referrals will be triaged for an assessment. Steps are being taken to maximise capacity available for triage and assessment to bring down waiting times – see section 4.5.

- 4.4 The online tool is an additional offer to the commissioned service, rather than a necessary step to access the commissioned service.

Criticism of the online platform focused largely on the platform being used as a screening tool and the potential to digitally exclude people.

The screening function will be removed from the online tool. GPs will provide the link to the online platform to people wishing to seek an assessment to register their referral. People can opt to register their referral via telephone or email and consent to information being entered on their behalf to enable equal access to the online tool early help and support.

The Online Platform will be improved in the following ways:

- Making it clearer for users to understand how to access a waiting list for assessment, how to create a 'personal portrait' and how to access functional support.
- Comprehensive information/history from users to streamline the referral process.
- For students choosing to use the online tool, the University of York and York St. John will adopt the online personalised reports to support academic adjustments and student support plans.

- 4.5. Developments have been undertaken with local providers to maximise the availability of triage and assessment capacity within the commissioned service.

1. Shared Care Agreements:

Developed by York general practices working in collaboration with The Retreat and the Local Medical Committee to help safely manage some of the workload for medication reviews so that the specialist provider can focus resource on delivering assessments and reduce waiting times for people.

Under this agreement, The Retreat will take on the shared care of patients prior to seeing them, while GP's continue to prescribe ADHD medication. Specialist oversight, advice and guidance will be provided

by The Retreat when needed. Depending on the individual circumstances, a person's medication review will now take place bi-annually.

The LMC and ICB Medicines Management Team agree to the Improvised Shared Care process. It is important to note that the Shared Care Agreement differs from NICE Guidance and safeguards are in place should patients require fast-tracking and input from the specialist provider.

2. Autism Assessment:

Developments to the autism assessment process means that time per patient has reduced from 12 hours to 4 hours, representing a three-fold increase in capacity for assessment independent of any other improvement.

4.6 Actions to be undertaken between now and the conclusion of the pilot:

- Seek views on the proposed solutions from Health Overview and Scrutiny Committee
- Finalise the proposed solutions under consideration (one remaining focus group from this round of engagement is planned in Catterick)
- Finalise Equalities and Quality Impact Assessment (continually updated throughout the pilot) and Data Protection Impact Assessment seeking ICB specialist input as required (as has been the case throughout the pilot)
- Develop the communication of the pathway (to patients, public and professionals) using the outputs from focus groups with the neurodivergent community and learning lunches with GPs.

5. Assessment

- 5.1 At the core of the proposal is the balance between the rights of patients and the duties in managing scarce health resources in a just manner.

- 5.2 The right to an assessment and importance of a diagnosis is stated in the NHS National Framework. The Equality and Disability Acts identify Neurodiversity as a disability but state that reasonable adjustments should be made based on need, and not necessarily on diagnosis. A full Equalities and Quality Impact Assessment (EQIA) has been developed and signed off through the appropriate process (by an ICB Director of Nursing and the Deputy Director of Legal and Regulatory functions). A revised EQIA reflecting the proposed solutions under consideration is in draft and awaiting approval – this is attached in Annexe 3.
- 5.3 The proposed pathway mitigates the clinical risk from increased demand by identifying those with the greatest clinical need and prioritising them for intervention.
- 5.4 Increasing demand has placed significant operational and workforce pressures on The Retreat, who as a Provider that is regulated by the Care Quality Commission, must continue to meet its regulatory requirements around quality and safety. Long waiting lists raise the risk of a regulatory breach of the specialist provider with the Care Quality Commission. The provider's response to service challenges has developed clinical practice to optimise the productivity of the workforce given the challenges in recruitment of skilled professionals to address the increase in demand.
- 5.5 The proposed solutions under consideration aim to improve quality and sustainability by identifying people with the greatest need while ensuring that everyone receives support/functional guidance, in the context of unprecedented demand and pressure on the specialist provider and responsibility to make best use of the workforce available to triage, assess, and diagnose.
- 5.6 The ICB has sought advice from NHS England about the proposed pathway and compliance with Patient Choice. Our understanding is that priority referrals from a GP or CMHT are eligible for choice at the point of referral. Routine referrals are eligible for choice at the point when the referral is triaged and deemed clinically appropriate for an assessment by the provider.

- 5.7 There are quality implications in increasing waiting times for assessments which is compounded by the variable offer to the neurodivergent community across Health, Local Authority and VCSE for pre and post diagnostic support. One of the ongoing actions is to explore a community-led approach to pre-diagnosis support. The neurodivergent community can shape, participate in and take ownership of their health and wellbeing in a holistic approach. The intention is to involve the community in future decisions which could divert a proportion of the funding available to the commissioned service towards community-led pre diagnosis support.
- 5.8 The advantages of maintaining a safe commissioned service with a local specialist Provider cannot be under-estimated. Many areas nationally are now realising the challenges where diagnosis and prescribing is initiated through alternative Providers (many operating online from other areas of the country) and the issues that this presents around longer-term safe management of ADHD medications, when a person's GP is under no contractual obligation to take on continued prescribing after the Right to Choose Provider's titration period ends. The Shared Care Arrangement aims to address this.
- 5.9 The ICB has a statutory duty to involve patients and their representatives on changes to services. The pilot was initiated in response to an immediate risk of closing the service to new referrals and/or the provider giving notice. The ICB took urgent action to prioritise the safe continuation of services. The initiation of a pilot has enabled the ICB to test, evaluate and refine the model, with the involvement of people with lived experience and time to seek views from those affected by any proposed changes to the commissioned service.

6. Involvement

- 6.1 An engagement plan was developed to initiate an appropriate period of engagement with people with lived experience. Engagement plans for Autumn 2023 and Spring 2024 sessions are referenced in Section 3.7 above.

Planning was initiated in September 2023, formal engagement commenced in December 2023 and will conclude in May 2024.

- 6.2 Engagement events held 12 and 14 December 2023

To help transform and develop a sustainable adult autism and ADHD assessment service in York and North Yorkshire members of the neurodiverse community were invited to take part in public events to share experiences and learn more about service developments.

- Tuesday 12 December 2023, 1pm – 4pm at LNER Lounge, LNER Community Stadium - A total of 72 members signed up to attend the event and 60 attended on the day.
- Thursday 14 December 2023, 6pm – 8pm via MS Teams – In total 83 people registered to be involved and on the night 35 took part.

Significant dissatisfaction was expressed during the sessions about the lack of support pre and post diagnosis, the online tool in terms of the outputs and how it was implemented, and the lack of understanding, education and empathy in all services about neurodiversity.

The full report is on the ICB website:

[York and North Yorkshire Adult ADHD and Autism Assessment Service - Humber and North Yorkshire Health and Care Partnership](#)

6.3 ICB hosted Focus groups, April/May 2024

The ICB hosted three focus groups across North Yorkshire following the same format.

- Harrogate – St Roberts Centre, 2 April 2024, 10am to 12pm – A total of five signed up to attend the event and four attended on the day including a GP.
- Virtual, 3 April 2024 – In total ten registered to attend and seven attended on the night, including representation from Spectrum First
- Scarborough – Falsgrave Community Centre, 8 April 2024, 1pm to 3pm: In total five signed up and 4 attended on the day including Autism Plus.

6.4 Community partner hosted groups March-May 2024

- Neurodiverse York focus group took place Saturday 22 March 2024, with thirteen members involved.
- York Disability Rights Forum focus group was held 28 March 2024, a total of twelve participants attended.

- Catterick Neurodiverse Group – due to take place in May – Date TBC

Focus groups enabled participants to be involved, contribute to active conversations and share experiences. Those present welcomed having the proposals explained in detail and the opportunity to share their views.

The key themes raised from participants through the focus groups were:

- To be open and honest with people from the outset and manage peoples' expectations
- To improve communications - explain the referral process and the waiting times
- For there to be greater awareness of autism and ADHD

6.5 We heard a lot from people about how best to conduct engagement events with the neurodiversity community. For example, share information in advance of photos of all the staff so that people are familiar with faces, share a video of the venue and access points, dedicate a staff member responsible for health and wellbeing and provide a separate quiet room available.

6.6 Relationships have been forged and mutual understanding has developed. The ICB has learned about how neurodivergence is experienced and what is important in how we design services.

6.7 On-going engagement will communicate the pathway to referrers and patients and support the development of wrap-around services and therapeutic alternatives.

6.8 Professional engagement

Pathway solutions have been discussed with the LMC (representing the wider GP body), clinicians and operational managers from The Retreat, clinical staff from Tees Esk & Wear Valleys NHS Trust, representatives from the ICB Medicines Management Team (with respect to shared care agreements), and NHS England patient choice leads.

All professional groups have been supportive in the context of working to find solutions to address increasing demand for Autism and ADHD services, but it is recognised that wider peer-led and community-based

support is equal in value alongside healthcare services.

- 6.9 The Humber and North Yorkshire System Ethics Panel has provided support and advice around the ethical aspects of running the pilot programme (to test approaches to managing increasing demand within finite resources) before and during the pilot. The panel is chaired by a qualified ethicist, with membership from a wide range of professionals and lay members.

7. Future Work of the ICB

7.1 Future work across North Yorkshire and York will include:

- On-going engagement with the neurodivergent community and system partners across health, Local Authorities, and VCSE will be key to the success of this pathway.
- Consider re-procuring the online platform to ensure best value and involve the neurodivergent community in provider selection.
- Involve the neurodivergent community in the development of pre and post diagnostic support services, potentially diverting a proportion of funding from assessment towards peer-led / VCSE led support.
- Continue work with the provider to preserve and grow workforce capacity for triage and assessment. Consider allocation of a proportion of waiting list funding to support pre and post diagnostic support, in discussion with the neurodivergent community.

7.2 The Humber and North Yorkshire Mental Health, Learning Disabilities and Autism Collaborative will, over the next 12 months, finalise a system wide approach to pathways and criteria, and build a robust data source for these services. The Collaborative will also spend this time reviewing our local work to inform future proposals.

Work is overseen by an Autism and ADHD All-Age Assessment Pathway Steering group and split into four phases:

1. Obtain accurate, up to date data, to fully understand the situation across all six Places and the current assessment protocols.
2. Assessment of challenges and opportunities
3. Improvements in processes, use of technology and workforce
4. Assessment of impact on assessment wait times for Autism and ADHD assessments.

7.3 The challenges are impacting children and adults, and the solutions go beyond assessment services – including pre and post diagnostic support and addressing social and wider determinants reflecting societal shifts and the role of educators and employers.

7.4 The learning from the pilot phase with respect to service development, professional and user insight, and views from people affected by local services has been incredibly valuable. This learning is helping to inform the HNY approach, now led by the Humber and North Yorkshire Mental Health, Learning Disabilities and Autism Collaborative, and can help inform work led by our Council partners.

8. Recommendations

8.1 Members are asked to consider and comment on the proposed solutions under consideration for the commissioned service and approach taken to involve patients and their representatives on changes to services.

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Wards Affected:

All

For further information please contact the author of the report

Background Papers:

Healthwatch York, 'ADHD and Autism Pilot Pathway: An independent assessment', <https://www.healthwatchyork.co.uk/wp-content/uploads/2023/08/Independent-evaluation-pilot-pathway.pdf>

Engagement Plan – York and North Yorkshire Adult ADHD and Autism Services (Autumn 2023), <https://humberandnorthyorkshire.org.uk/wp-content/uploads/2024/02/Engagement-Plan-Autumn-2023-adult-autism-and-ADHD-Services-plan-on-a-page-002.pdf>

Summary from Engagement events held 12 and 14 December 2023, <https://humberandnorthyorkshire.org.uk/wp-content/uploads/2024/02/Summary-of-December-engagement-York-and-NY-adult-autism-and-ADHD.pdf>

Annexes

Annexe 1: NHS Humber and North Yorkshire Integrated Care Board response to Healthwatch York draft report on Pilot pathway for Autism and ADHD, July 2023.

Annexe 2a: Engagement Plan Summary - York and NY Adult Autism and ADHD, May 2024.

Annexe 2b: Engagement Feedback - York and NY Adult Autism and ADHD, May 2024.

Annexe 3: Equalities and Quality Impact Assessment (EQIA).

Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
ICB	Integrated Care Board
LMC	Local Medical Committee