## **Update on York and North Yorkshire Adult Autism and ADHD Assessments**

In April 2023, we started to test out a new way of assessing adults for Autism and ADHD. This pilot program ended in June 2024. Here are the key changes:

**Why We Had to Make Changes**

* Because of the significant increase in demand for assessments, the service was at risk of closing to new referrals, or the Provider stopping their contract.
* The ICB (Integrated Care Board) had to act quickly to keep the service open and running safely.
* The pilot allowed the ICB to test, evaluate, and improve the assessment process so that it prioritised access for those people with the greatest need, whilst also providing access to a waiting list and support for everybody who wants to access an assessment.
* Feedback from people who use the service and from clinical professionals made it clear that the service needed to change in order to manage increasing demand.

**The Feedback and Insights that Helped us to Develop the Pathway**

* Healthwatch York evaluated the pilot in August 2023.
* People with lived experience shared their feedback during a programme of engagement events in December 2023 and April/May 2024.
* This feedback directly helped to create the final solutions for the new assessment process.

*Engagement with professionals and people with lived experience has driven our learning and the development of the pilot project, and we thank all 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 how we can continue to work with them in the future.*

The table below shows how feedback influenced the design of the pathway:

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| You said! | We did! |
| The referral acceptance criteria on introduction of the pilot barred access to an assessment. | The referral acceptance criteria has now been removed from the pathway, meaning that any person who wishes to be referred can access a waiting list to be clinically triaged for assessment.  The online platform will no longer be used as a screening tool to check referral acceptance criteria. |
| The ‘RAG rating’ approach is confusing. | The screening tool and Red/Amber/Green rating of referrals has been removed from the Online Platform. |
| The referral process is confusing. | Prioritisation of referrals according to need has been simplified and will now be based on clinical professional judgement by GP's and Community Mental Health Teams at the start of the pathway, with clear guidelines re. prioritisation.  This is similar in practice to how demand for clinical/specialist treatment is managed across most health conditions, where clinicians are empowered to take different action if a person's needs are ‘urgent’ vs. ‘routine’.  All clinically prioritised referrals will go directly to The Retreat via referral forms which have been developed by The Retreat's clinicians. |
| How will my routine referral be managed? | Routine referrals will be managed via the Online Platform. Any person who wishes to access an Autism or ADHD assessment whose needs are not considered to be time sensitive will have the option to complete The Retreat's standard referral form on the Online Platform, where they will join the 'routine' waiting list and be able to access pre-diagnosis functional support while they wait for their referral to be triaged when capacity becomes available. |
| Waiting lists are too long. | It is acknowledged that 'routine' wait times are currently much longer than we would normally aim to achieve, and steps that are being taken to maximise the capacity available for triage and assessment include:  i) Streamlining The Retreat's Autism assessment process to make this significantly quicker – reducing the number of appointments needed.  ii) Use of additional 'waiting list initiative' funding from the ICB for additional triage and assessment capacity and addressing pressure points in the service. |
| The online platform is badly organised and does not provide truly unique or personalised advice. | The Online Platform is now an additional offer to the commissioned service, rather than a mandatory step to access the commissioned service.  The online platform has continued to be adapted and revised based on feedback received through the platform itself, and from what we've heard during the engagement sessions.  i) We have made it clearer for users of the Online Platform to understand how to access its different functions - the waiting list for assessment, how to create their 'personal portrait', and how to access functional support.  ii) The Retreat's standard referral form is included on the Online Platform to enable (with consent) comprehensive 'patient history' to be entered by users to streamline The Retreat's triage/referral process.  iii) We will continue to develop, for students choosing to use the Online Platform, the personalised reports which the University of York and York St. John have agreed to accept in reviewing neurodivergent students' requests for academic adjustments and student support plans. |
| The online approach disadvantages people who are digitally excluded. | For those without digital access, or who struggle with forms, people are able to join the routine waiting list for assessment by telephoning the York Place Referral Support Service (RSS) team who, with appropriate consent, will add a person's details to the Online Platform where the routine waiting list is held.  It should be noted that The Retreat will still require a 'patient history' in order to clinically triage these referrals and will invariably have to contact the person for further information at some point.  We are also exploring options to support neurodivergent people who may struggle to complete forms to provide their 'patient history' – potentially with help from General Practice based Mental Health Practitioners or community-based services.  Again, this is similar to how referrals for Hospital elective planned treatment is managed. |
| For patients who have been diagnosed with ADHD outside the NHS, shared care arrangements for access to medication do not always work. | A revised shared care agreement is now in place, which means that people who are stable on medication, or diagnosed elsewhere can receive ongoing prescriptions from their GP with specialist oversight by The Retreat. |
| There is not enough support both pre and post diagnosis. | Joint working continues across the NHS, Local Authority, neurodivergent communities and other service Providers to co-produce solutions to meet peoples' needs as effectively as possible within our collective abilities. |

**What is Different?**

The assessment pathway is now a needs-led model. The table below compares the old pathway to the new model.

|  |  |
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| **Old pathway** | **New needs-led model** |
| No restrictions on who can be referred | Clear pathway eligibility/prioritisation guidelines for referrers (clinically agreed) |
| No prioritisation of patients based on their need at the point of referral | Clear guidelines for referrers to ensure that clinical need is prioritised |
| Waiting list is triaged in chronological order | Prioritised referrals are clinically triaged by The Retreat to understand any time sensitive needs for assessment |
| Little pre-assessment support for people while they wait for an assessment | Functional support available for people via the Online Platform while waiting for triage/assessment – and we're facilitating co-creation of support services |
| Safety risks around managing increasing service demand versus Provider capacity | Clearer understanding of which people are at higher need/risk |

**York Plans for Developing Support Services for Neurodivergent People**

Alongside the Autism and ADHD assessment pathway, a group in York called the Connecting our City Working Group is planning to lead the co-creation of community-based support that anyone can access. They have secured £15,000 with an opportunity to have this match funded by York Together, working with the York Disability Rights Forum. They are working on deciding how to use this money and want to hear from the community through a survey. Here are the priorities they have identified so far:

1. **Voluntary Peer Support**
   * Informal and unpaid support within community settings.
2. **Formal Peer Support**
   * Peer supporters are employed by a group or organisation.
3. **Mentoring/Coaching Services for Neurodivergent People**
   * A mentor offers advice, shares insights, and provides encouragement to help someone overcome challenges and achieve their goals.
4. **Training and Advice for Local Organisations**
   * Training developed and led by neurodivergent people to educate local organizations, community groups, and businesses on increasing accessibility for neurodivergent individuals.
5. **Community Outreach and Engagement Work**
   * Working with local GP's, hospitals, businesses, and community centres to host inclusive events and activities that increase understanding and awareness of neurodivergence.

If the group secures additional funding, they plan to hire a facilitator/coordinator who will:

* Support and advise groups that receive funding for neurodivergent support services.
* Organise regular meetings for these groups to share experiences and learn from each other.
* Coordinate training across the funded groups and organisations.
* Be the main contact point for funded neurodivergent service support.
* Provide advice and support for peer support services.
* Manage training activities for the funded groups.
* Help groups with development support, like governance, policies, and structure.

**Plans to Improve Autism and ADHD Services in York and North Yorkshire, and the Wider ICB Include**

1. **Engaging with the Community**
   * We will keep talking with neurodivergent people and our partners in Health, Local Authorities, and VCSE (Voluntary, Community, and Social Enterprise) to improve our services.
2. **Improving the Online Platform**
   * We are updating our Online Platform based on user feedback to make it better.
3. **Co-Designing Support Services**
   * We want neurodivergent people to help us design and develop support services for before and after diagnosis.
4. **Working with The Retreat**
   * We are working with The Retreat to explore opportunities to increase the number of triage and assessment slots available.
5. **Improving Access and Support**
   * The ICB's Mental Health, Learning Disability, and Autism Collaborative is working with partners to improve:
     + Access to Autism and ADHD assessments for all ages.
     + The assessment process.
     + Support for individuals before and after diagnosis.
   * Their goal is to have a consistent assessment criteria and support across Humber and North Yorkshire, but flexible enough to meet local needs.
   * This will be supported by a 5-year Strategy, co-created with people who have lived experience.