



Adult Autism and ADHD York and North Yorkshire – Next wave of engagement May 2024

Feedback which emerged through the focus groups based on some of the proposed adaptations shared in the discussion guide

The online platform

1. Proposed adaptations - For those without digital access it is proposed telephone support will be available via the Referral Support team who will help people to register their referrals on the online platform.

Feedback:

- *As phones can be a problem for the neurodiverse community suggest various options are also available ie: email/text service/drop-in sessions.*
 - *Make it clear that the Referral Support Team is not an automated service, and you will speak to someone.*
2. Proposed adaptation - The online platform will be retained as a support tool to assist people waiting for an assessment with practical advice and guidance and continues to be adapted and revised based on feedback we receive.

Feedback:

- *To reduce the fear for some people to use the online platform to offer human support and guidance ie: signpost to GP Practice/neighbourhood hubs/social prescribers/First Contact Mental Health Practitioners - who can support those to complete the online platform.*
- *The functional guidance available on the online platform is telling autistic people to mask more.*

The adult autism and ADHD referral pathway (waiting list)

3. Proposed adaptations - It is proposed that referrals which are clinically considered to be a priority are referred directly through primary or secondary care. Referrals considered to be routine will be via the online platform for triage.

Feedback:

- *Concerned for those on the online platform waiting list who are waiting to be triaged and may not meet the criteria to go on The Retreat waiting list – need to see clearer communication on the referral pathway.*
- *It would be helpful to see the triage criteria.*
- *It was suggested the online platform provide patients with formal acceptance and communication is clear advising you are on a waiting list awaiting triage.*



- *It would be helpful if The Retreat communicate with patients after triage, so they know they are on The Retreat waiting list and to receive regular communications advising of timescales.*

There is a lack of understanding, education and empathy in the NHS and other service providers about neurodiversity

4. Proposed adaptations - The ICB continue to work with GPs and health professionals to ensure that there is greater understanding on the approach that is developing and raise awareness of neurodivergent.

Feedback:

- *GPs and health professionals need to be upskilled in neurodivergence.*
- *To create neurodiverse champions in the community.*
- *If there are learning sessions with GPs and health professionals, suggest the training is coproduced with the neurodiverse community.*
- *Education is key – the level of acceptance of neurodivergent varies so much.*

General questions:

Q: Is "Right to Choose" available to people?

A: *Right to Choose is a national policy, giving people the option to choose a provider for their assessment when referred by a GP.*

Q: Disabled Student Allowance (DSA) - Students on the waiting list are being denied access to DSA and the learning support available because a diagnosis is needed and the GP has to complete the Disability Evidence Form.

A: *The ICB are looking at ways this can be evidenced either by GP or The Retreat.*

Mixed views

There were mixed views from participants on the importance of a diagnosis.

- Having a diagnosis is important to some people, to allow people to apply for "Access to Work".
- Suggestion to move away from diagnosis and accepting people as they are.
- To some people the support was key rather than the diagnosis ensuring different approaches are available as everyone has different needs.

Looking forward

- Strong endorsement on the proposals and how these were based on the feedback received from people who are neurodivergent had been acted on.
- Participants welcomed the opportunity for further involvement on a smaller scale, allowing constructive open conversations to take place.



- Strong plea for continued involvement and communication as the model develops and progress on improving the support available to people.

Next steps

- To continue to maintain and strengthen the relationships with the neurodiverse community
- On-going engagement will communicate the pathway to referrers and patients and support the development of wrap-around services and therapeutic alternatives.
- To continue to work with voluntary sector how we increase support
- To come together as a system with the work of the North Yorkshire Council led public engagement on the North Yorkshire All Age Autism Strategy and the Community Mental Health Transformation.

What would good pre and post support look like going forward and how do we support people?

Examples shared of how people would like to be supported:

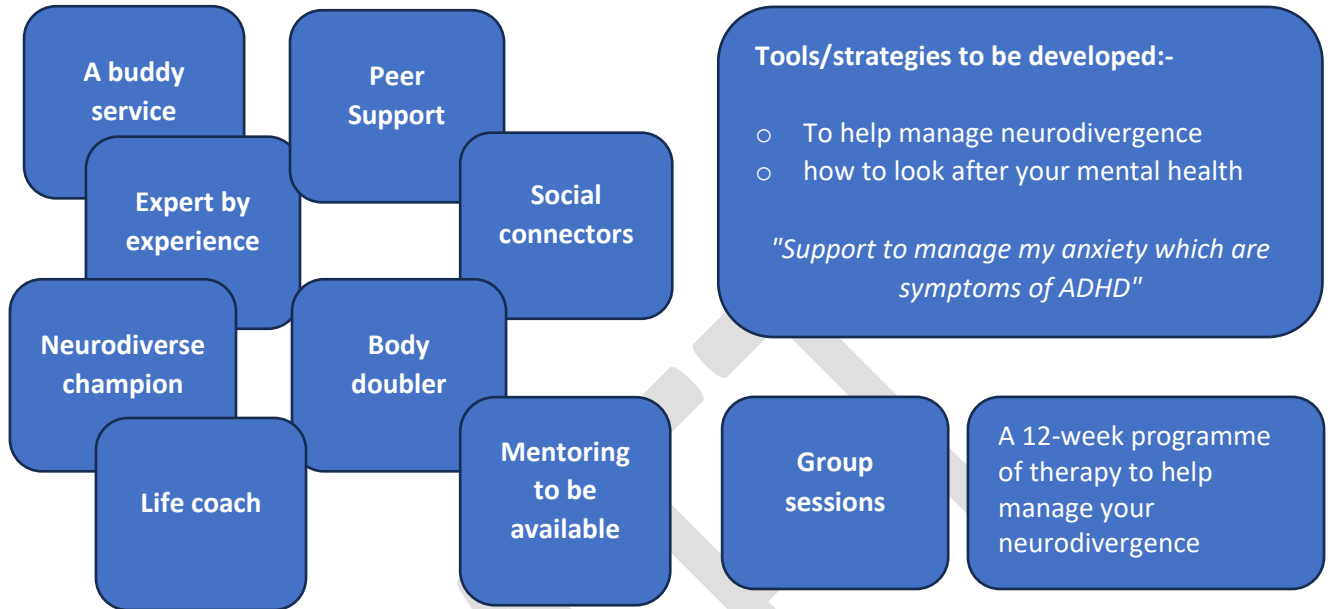
- A patient leaflet - explaining the pathway and support available – giving people a greater understanding of the adult autism and ADHD pathway
- GPs and health professionals, Social Prescribers, First Contact Mental Health Practitioners to connect/signpost people to support networks
- To have confidence your GP/health professional will give you the answers
- To know you are not alone
- Someone is available when I am overwhelmed
- To learn from other people's experience
- To have a key point of contact

The project team has learned much more about how neurodivergence is experienced and what is important in how we design services. As illustrated by the following quotes from participants

"I know I have ADHD, I don't need a diagnosis, I need support to help manage by anxiety which is a symptom of my ADHD".

"If appropriate support was available to people at the point of contact, this may filter people out of the waiting list"

Suggested formats of what pre and post support could look like:



Participants shared their own knowledge and experience of support networks available

- The post support provided by The Retreat following assessment was good and very helpful
- When you are on The Retreat waiting list you receive a monthly newsletter – which is good as you have validation you are on their waiting list.
- "Access to work" – gives you access to a mentor or coach who can support people. The support available explores neurodivergent from a lived experience -
- Support does exist through Disabled Students Access but you need a diagnosis.
- North Yorkshire Council – Education, Health and Care Plans
- Better Connect – Rise 2 Thrive / Multiply /
- Autism Plus

A leaflet was shared with participants providing helpful details of local support networks across York and North Yorkshire. The ICB continues to keep the website updated with further support networks for people to access, "Where can I access additional support."¹

¹ <https://northyorkshireccg.nhs.uk/your-health-and-local-services/adult-adhd-and-autism-assesment/>



Feedback from participants

It was really helpful to have this conversation and have everything explained
It was a pleasure to take part in the focus group
I felt I was listened to

Event evaluation

A digital event evaluation was shared with all attendees the day after the events.

Questions

1. Which event did you attend? Harrogate/virtual/Scarborough/Catterick
2. Was the information you received prior to attending the event helpful?
 - Discussion guide (presentation)
 - Photographs and details of staff present at the event
 - For face to face groups only - details and graphics about the venue
3. Is there other information that would be helpful to receive before attending an event? please detail
4. During the event, do you feel you had the opportunity to get involved and share your feedback?
5. Were you aware that health and wellbeing support was available to you, if required at the events? Yes/No
6. If you received health and wellbeing support at the event, was this helpful to you? Yes/No
7. The focus groups were an opportunity to share everything we had done based on what we have heard in earlier engagement and to capture the views from people with lived experience on the draft proposals to inform final recommendations as we exit the pilot in summer 2024. Based on what you heard at the event, do you think we are on the right track? Yes/No/Not sure
8. Do you have any suggestions that were overlooked to improve the adult autism and ADHD pathway? Please explain your answer
9. After the event, do you feel you have a better understanding of the proposals for the adult autism and ADHD services in York and North Yorkshire? 1 being a little and 5 being a lot? (slide scale to the right to adjust)
10.
 1. Is there anything else you would have liked to know not covered at the focus groups?
 2. Is there anything else you would like to share with us?