



## **Adult Autism and ADHD York and North Yorkshire – Next wave of engagement May 2024 (version 1)**

### **Summary of focus groups**

Continuing our engagement to help transform and develop a sustainable adult autism and ADHD assessment service in York and North Yorkshire the next wave of engagement consisted of a blend of Humber and North Yorkshire Integrated Care Board (ICB) focus groups and hosted with the help of community partners across York and North Yorkshire (Neurodiverse York, York Disability Rights Forum (YDRF), Neurodiverse Catterick).

The focus groups were an opportunity to share everything we had done based on what we heard; to get the views from people with lived experience on the draft proposals and to check we are on the right track<sup>1</sup>. As well as gather insight on what good pre and post assessment support would look like, a concern dominated throughout the earlier engagement. The feedback will inform the final recommendations as we exit the pilot in summer 2024.

To enable us to learn from previous events, the focus groups were shaped with the involvement of the neurodivergent community to maximise opportunities for those with lived experience. For example: materials shared in advance included a discussion guide (presentation) so those attending were familiar with the format, photos of all the staff to be present at events so people are familiar with faces and a video of the venue and access points. A dedicated staff member responsible for health and wellbeing was available throughout the session and at the end for ICB focus groups; as well as there being a separate quiet room available, and this was explained during the welcome and introduction. When entering the venue, a staff member welcomed members and signposting was on display to the meeting room. Each focus group to have no more than twelve participants to allow constructive conversation and participation.

### **Community partner hosted groups:**

The community partner hosted groups took place before the discussion guide (presentation) was agreed, which detailed the changes to the pathway that had been implemented based on what we heard in earlier engagement and the proposed adaptations to be introduced as we exit the pilot. Therefore, these sessions did take a different approach, allowing members the opportunity to have an open and honest conversation in a safe space sharing their experiences and challenges.

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<sup>1</sup> Discussion guide [Presentation\Adult Autism ADHD Focus Group March 24.pdf](#)



- Neurodiverse York - focus group took place Saturday 22 March 2024, with thirteen members involved. (Feedback from the event is included in Annex 2).
- York Disability Rights Forum (YDRF) - York Disability Rights Forum focus group was held 28 March 2024, a total of twelve participants attended. (Feedback from the event is included in Annex 3). An artwork reflecting current emotions and hopeful aspirations of service users from YDRF focus group is included in Annex 4).

### **ICB hosted focus groups**

The ICB hosted four focus groups across North Yorkshire, sharing everything we had done based on what we heard; to get the views from people with lived experience on the draft proposals and to check we are on the right track.

- The first focus group was held in Harrogate, on 2 April 2024. A total of five signed up to attend the event and four attended on the day.
- The second event was held virtually on 3 April 2024. In total ten registered to attend and seven attended on the night.
- The third event took place in Scarborough, on 8 April 2024. In total five signed up and four attended on the day.
- The fourth focus group was held in Catterick, on 13 May 2024, hosted by Neurodiverse Community Catterick. Six members of the group attended the event.

All ICB focus groups, proved successful in that they 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.

All the focus groups held agreed on the following points:

- Strong endorsement on the proposals and recognition that we had based them on the feedback received from neurodivergent people. (ICB only focus groups).
- Participants welcomed the opportunity for further involvement on a smaller scale, allowing constructive open conversations to take place. (ICB only focus groups).
- Participants want to see shorter waiting times and good communication while waiting.
- To have more health professionals available to diagnose and prescribe.
- Strong plea for continued involvement and communication as the model develops and progress on improving the support available to people.
- Community groups happy to co-produce when developing modules for the online platform.
- To link community groups with Community Mental Health Transformation.

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

- To be open and honest and transparent with people from the outset and manage peoples' expectations.
- To improve communications, to listen, to explain the referral process and the waiting times.

- Support to be available pre and post diagnosis.
- For there to be greater awareness and acceptance of autism and ADHD.

### **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.

(Feedback from the ICB hosted focus groups is included in Annex 1)



## Annex 1

### **Feedback which emerged through the ICB hosted 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 system to be more user friendly, it was very difficult to use.*

#### **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.*
- *If you are supported by members of the Community Mental Health Team, would like to see this continue regardless of your autism and/or ADHD.*

**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 neurodivergence.

*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 neurodivergence varies so much.*

**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" and for reasonable adjustments to be put in place.
- My life fell into place following a diagnosis, it allowed me to understand me.
- Suggestion to move away from diagnosis and accepting people as they are.
- To some people the support was key rather than the diagnosis, so ensuring different approaches are available as everyone has different needs.

**General questions:**

**Question:** Is "Right to Choose" available to people?

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

**Question:** 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.

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



**During the December engagement, a key point raised was the lack of pre and post support. Each of the focus groups had an open discussion with participant to understand – "What would good pre and post support look like going forward and how do we support people?"**

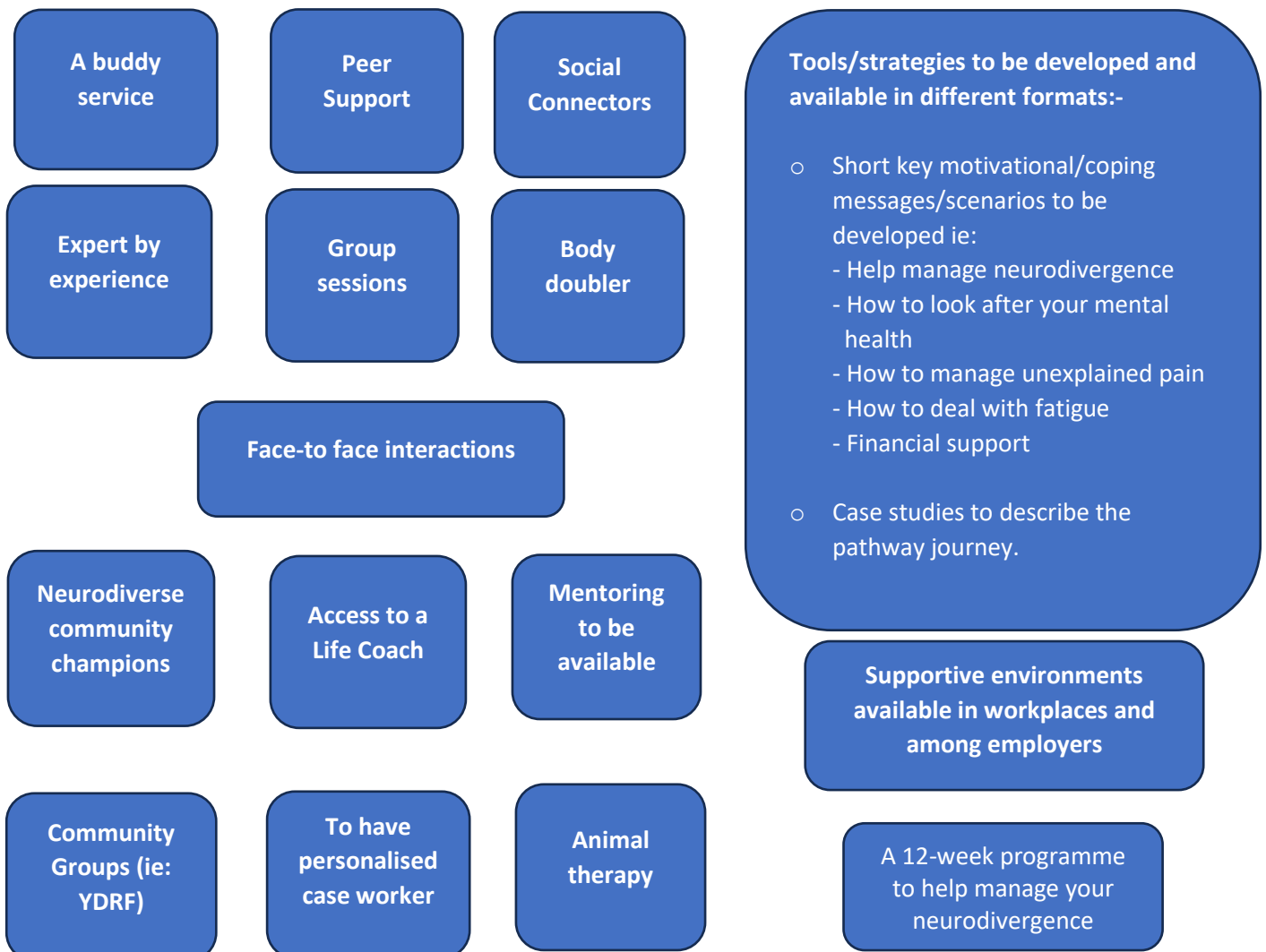
Examples of how people would like to be supported:

- **Improved communications**
  - A patient leaflet/newsletter - explaining the referral pathway and support available – giving people a greater understanding of the adult autism and ADHD pathway.
  - Patients to be kept updated whilst on the waiting list.
  - GPs to be kept updated of the patient's journey from point of referral to diagnosis.
  - Detailed reports to be shared with patients.
  - More positive media involvement to prevent people going into crisis and raise awareness and understanding of the service.
- **GPs and health professionals**
  - To have confidence your GP/health professional will give you the answers.
  - To have the respect and understanding from my GP.
  - More training for GPs to avoid prejudice.
  - GPs and health professionals, Social Prescribers, First Contact Mental Health Practitioners to connect/signpost people to support networks in the community.
  - Full recognition of diagnosis irrespective of NHS or private in-order to access support.
  - The Retreat and GP to communicate.
  - Mental health support to be tailored to autism and ADHD.
- **Key point of contact to be available**
  - To have access to face to face, one to one coaching.
  - Someone is available I can contact if I am overwhelmed.
  - To have regular face to face check ins.
  - Could someone from the GP practice occasionally phone you to check to see how you are?
- **Dream pathway**
  - To have an ADHD and Autism contact line you can contact when you think you have ADHD or autism. They can then contact and triage and decide whether or not you are put forward for an assessment and offer coaching in the meantime. After the initial conversation if you are triaged they put you forward for a diagnostic test to find out what type of ADHD or autism. Then provide the relevant advice and support including crisis management.
  - Assessment of ADHD and Autism to be done at the same time.
  - Providing access to health and wellbeing workers, involving Primary Care Networks in supporting the entire assessment pathway, and recognising the validity of self-diagnosis within organisations.



- **General support**
  - To learn from other people’s experience.
  - To have someone to listen to me/to offload/ to talk to people/someone to take me seriously before reaching crisis.
  - Just to know support is available whilst I am waiting for an assessment.
  - Signposting alone does not constitute support.
- **Pre support**
  - To have access to local support whilst waiting for an assessment, to help me during times of meltdown.
  - To receive supportive information relevant to my struggles and useful for use in the workplace. Information available in visual format and in layman's terms.
- **Post support**
  - To be available following assessment whether you are diagnosed or not.
  - Post diagnostic support that encourages empowerment and self-care.

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





**Participants shared their own knowledge and experience of support network they have accessed:**

- The post support provided by The Retreat following assessment was good and very helpful, but I had to wait for this.
- 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 you. The support available explores neurodivergence from lived experience.
- Support does exist through Disabled Students Access but you need a diagnosis.
- North Yorkshire Council – support available via Education, Health and Care Plans ie: Better Connect, Rise 2 Thrive and Multiply.
- National organisations - Autism Plus, ADHD UK.
- Community groups - York Disability Rights Forum (YDRF), ND Community York, ND Community Catterick, Quakers York.
- Brain in Hand – a helpful app available on your smart phone to help you organise and manage your daily appointments.
- Role models positive influencers Chris Packham, Christine McGuinness.
- Social media – people posting on social media sharing their experiences.
- Me – helping others.

The ICB has produced a leaflet providing details of local support networks across York and North Yorkshire<sup>2</sup>. The ICB continues to keep the website updated with further support networks for people to access, "Where can I access additional support."<sup>3</sup>

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<sup>2</sup> [..\..\ADHD and Autism signposts \(7\).pdf](#)

<sup>3</sup> <https://northyorkshireccg.nhs.uk/your-health-and-local-services/adult-adhd-and-autism-asesment/>





**A snapshot of personal quotes captured throughout this wave of engagement from participants:**

*I want to be listened to!*

*Please tell me what is happening – am I on a waiting list?*

*The needs of the service should not to be prioritised over the needs of individuals!*

*Help me, to help myself!*

*I want to talk through my symptoms with people face to face!*

*To deliver a consistent service for all!*

*I don't want to be punished for symptomatic behaviour (swearing)!*

*Staff within the Emergency Department need to be trained in autism and ADHD – PEACE pathway and trauma informed!*

*I want to know I am not alone!*

*ICB, please take responsibility don't blame the people and make excuses!*

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" - "Treat symptoms over problems"*

*"If appropriate support was available to people at the point of contact, this may filter people out of the waiting list" - "Lack of support can lead to mental health problems"*

*"I am told to minimise time of my mobile phone, but short reels feel good"*

*"So many people are left to have "half a life" or die rather than be supported to live their best life and get the support to thrive"*



## Annex 2

### Feedback from Neurodiverse York Community focus group held 22 March 2024

#### A total of 13 members were in attendance

This event took place before the discussion guide (presentation) was agreed, which detailed the changes to the pathway that had been implemented based on what we heard in earlier engagement and the proposed adaptations to be introduced as we exit the pilot.

Members of the Neurodiverse York Community came together to have an open and honest conversation, sharing their experiences and challenges.

The key themes which emerged through the focus group:

- **The online platform (Do IT profiler - as adapted locally in York and North Yorkshire)**
- **Top tips for running neurodiverse engagement events**
- **Cases studies**
- **Emotions expressed in creativity**

#### The online platform

- The whole process is confusing.
- The information is overwhelming for those with poor focus and short attention span.
- Everything it tells me, I am doing – some of the information can be seen as patronising and triggering.
- The contents/support within the online platform does not constitute support and signposting.
- Criticism included concerns that the support provided was too general and not adequately generalised or customised.
- Concerns about whether there was adequate distinction between support for people with autism and ADHD and for different genders.

**Top tips for running neurodiverse engagement events** - to help with people's sensory anxiety and trauma.

- Greater communication advising of engagement events.
- Venue – to consider lighting, lights off, use natural lighting, fresh air, in a no echo environment.
- Meeting size – smaller groups work well.
- Staff to wear name labels and offer to attendees.
- Improved signage at venue - when arriving at the venue clear signage on display and to be greeted by a staff member and direct people to the meeting area.
- Format - Agenda to be shared in advance or upon arrival – so you understand the format of the event.
- Instructions at event - When entering the meeting room, to be provided with clear instructions ie: where to sit, to be given a choice to sit alone or take part in the main



event. To understand you can take a break or walk around at any time during the event or ask a question at any stage.

- Health and wellbeing support - In advance or during the welcome and introduction advise the audience a quiet room and health and wellbeing support is available throughout and after the event.

## Case studies

### Patient A

*"My care package has broken down nine times in 10 years because my neurodiversity is not understood. Care packages for physical health keep falling apart because of the lack of diagnosis, support and awareness amongst the staff for autism. I am on a waiting list, there is no time frame "When will I hear from the Retreat?". There is no support whilst I wait. I am fortunate to have an amazing GP and mental health nurse but what I need is a diagnosis with tailored support. An autism diagnosis would open more doors, change how care providers see me and my needs. It will improve the quality of my care and potentially allow increased amount of care/funding to meet my needs. This would make an enormous difference to my daily life. All I need is consistency, clarity and routine."*

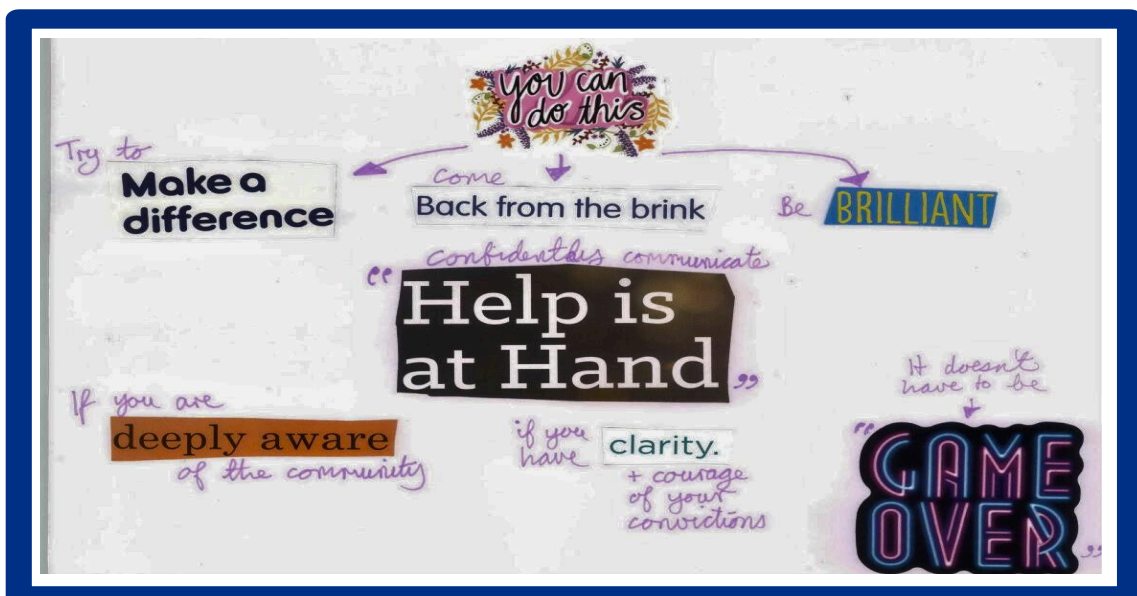
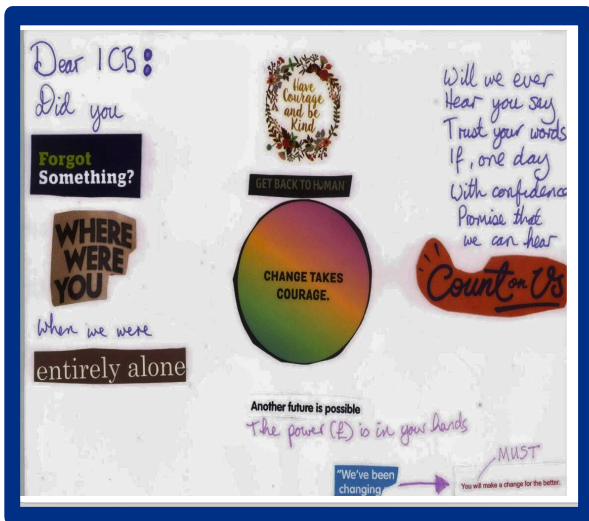
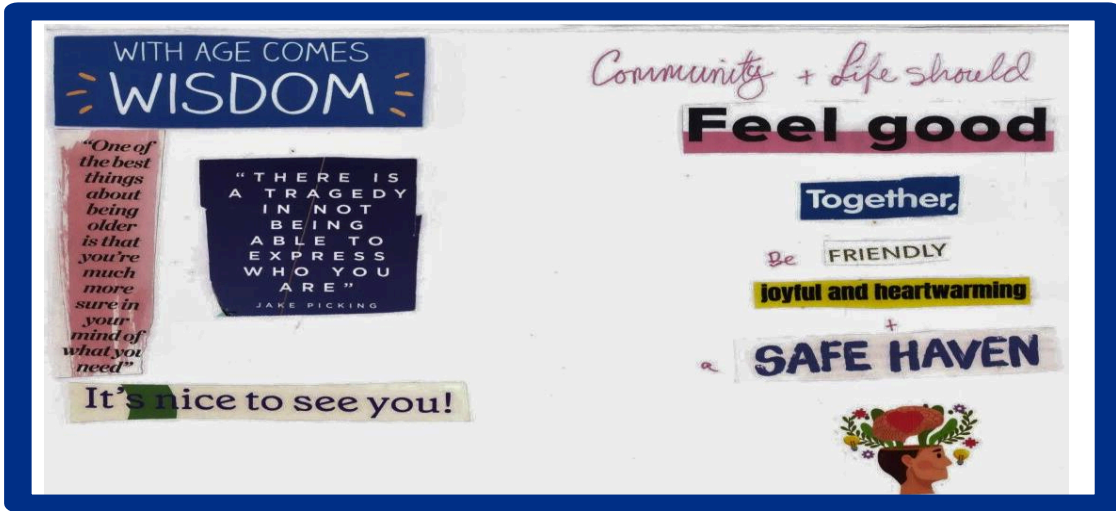
### Patient B

*"I have had care my whole life, I always thought I was autistic from a young age. I spent 10+ years in a psychiatry hospital, mis labelled borderline personality disorder and this stuck. My autism spectrum disorder (ASD) traits were seen as symptoms they tried to force out of me. This made me feel more like a faulty human. They used sensory difficulties against me. The specialist unit suggested an ASD assessment four years ago, but the consultant at the unit did not agree. The assessment took place and confirmed ASD. The consultant from the unit was not in agreement and tried to remove it. I was removed from their care, then fast tracked for another assessment and was diagnosed again. Despite this I still can't get a dissociative identity disorder (DID) diagnosis recognised or any therapy treatment in the community. My care has been appalling at times, left to die many times. I woke up out of a coma having spent five weeks sectioned and discharged with no care for the first time in my life. Section 117 was removed because I had "no social care needs" and only mental health needs. This had a great impact on my life, unable to eat and drink nowhere to live, leading to sensory meltdown and trauma, essentially left to die or become a revolving door patient. Please, listen to the people, they know best. If I had been listened to at an early age, I may not have grown up feeling like a faulty human, difficult, not engaging and misdiagnosed."*

During the session, service users from Neurodiverse Community expressed their feelings through artwork, examples displayed below:



Artwork from a service user of Neurodiverse Community





### Annex 3

#### **Feedback from York Disability Rights Forum (YDRF) – focus group held 28 March 2024 A total of 12 members were in attendance**

This event took place before the discussion guide (presentation) was agreed, which detailed the changes to the pathway that had been implemented based on what we heard in earlier engagement and the proposed adaptations to be introduced as we exit the pilot.

Members of YDRF came together to have an open and honest conversation, sharing their experiences and challenges and suggestions on future developments to the adult autism and ADHD pathway. The discussion topics included:

- **The online platform (The Do IT profiler - as adapted locally in York and North Yorkshire)**
- **Waiting lists**
- **Assessment process - criteria**
- **Shared care agreements**
- **Lack of support both pre and post diagnosis – (Detailed in main report)**
- **The lack of understanding, education and empathy in the NHS and other service providers about neurodiversity.**
- **Necessity for incorporating the voices of lived experience in decision making process**

#### **The online platform - The online platform is badly organised and does not provide truly unique or personalised advice:**

- Use of the online platform – while there was a large number of voices which articulated limitations with the online tool, some people said this format was useful and appreciate the information it provides.
  - *Adaptations: The online platform is not mandatory to complete in order to register for a referral. People can self-refer on to the waiting list by providing their basic details, (name, address, contact details).*
- The present system does not allow sections of the platform to be skipped ie: Work and Education for those who are not currently engaged in either work or education.
- Feedback on the online platform was critical regarding dissatisfaction with the questionnaire citing misleading questions and does not provide truly unique or personalised advice.
- Concerns about whether there was adequate distinction between support for people with autism and ADHD and for different genders.
  - *Adaptations: Feedback on the online platform has been co-produced by people with lived experience and continues to be adapted and revised based on feedback we receive.*
- There continues to be substantial criticism of the way the pilot was introduced and the lack of communication surrounding it.



- *Adaptations: On-going engagement incorporating the voices of lived experience will continue and feedback from the focus groups will be used to help transform and develop a sustainable adult autism and ADHD assessment service in York and North Yorkshire.*
- Concern that the online platform was only available in digital format and not accessible for all neurodiverse people who often have comorbidities with written comprehension.
  - *Adaptations: It is proposed telephone support will also be available via the Referral Support team who will help people to register their referrals on the online platform.*
- The group felt the online platform was irrelevant when no support is available or follow up after completion.
- It was suggested the online platform needs more videos or practical examples of conversations or scenarios to assist people in social situations.
  - *Update: The ICB to collaborate with YDRF to create more videos.*
- The group still believed more engagement needs to be done before the implementation of this as the overarching consensus is that they do not find the advice useful, and it made them feel angry.

#### **Waiting lists are too long and people are left without any support while they wait:**

- Strong concern over the long waiting lists and people desperate for support.
- It was suggested if mental health support could be offered whilst waiting.
- The group concerned about those who are not seeking a referral because of the time it takes.
- The group felt there was insufficient service capacity and more staff was required to meet the high demands of the service.
- Personal experiences were shared of people having to pay for a private assessment and not being able to get prescribed medication.

#### **Assessment process**

- Concern the original criteria barred access to an assessment and encouraged risky behaviour
  - *Adaptation: It is proposed the online platform will no longer be used as a screening tool to check referral acceptance criteria and the criteria no longer refers to self-harm and crisis.*

#### **Shared care agreements - For patients diagnosed with ADHD outside the NHS, shared care arrangements for access to medication do not always work**

- The group expressed concern on the inconsistency of shared care agreements, with some GPs referring you to shared care and some not recognising a private diagnosis.
- A strong plea for all systems to work collaboratively.



- *Adaptation: A revised shared care agreement is now in place, which means that people stable on medication, or diagnosed elsewhere can receive ongoing prescription from their GP with specialist oversight by The Retreat under the revised shared care agreement.*

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

- There continues to be concern raised around how more is needed to educate people about autism and ADHD, particularly in healthcare and for to help employers understand neurodiversity, so reasonable adjustments can be made.
- Suggestion to have safety procedures for suspected meltdown in place in healthcare settings.

**GPs are unsure what to do and give misinformation:**

- Feedback from the group suggests that GPs continue to be unsure of the referral process
- Request that more needs to be done to ensure GPs understand the conditions and the current pathway.
  - *Adaptations: The ICB continue to work with GPs and the Local Medical Council to ensure that there is greater understanding on the approach that is developing. This will be supported through communication with clinical colleagues and development of documentation coproduced with lived experience groups.*

**The community want more opportunities for input and influence as the pathway is developed and decisions are made:**

- Strong plea from the group for there to be greater opportunity to input and influence from people who are neurodivergent. "Nothing about us without us"
- Ask for improved communication.
- The service meets the Autism Act.
- Suggestions the ICB take inspiration from different systems inside or outside the UK – it can work.
- The ICB Board to have representation from an neurodiverse individual.
  - *Update: Ongoing engagement will continue, involving people who are neurodivergent to help transform and develop a sustainable adult autism and ADHD assessment service in York and North Yorkshire.*
  - *The project team continues to meet with members of YDRF on a regular basis. All participants are committed to addressing challenges and improving service delivery for individuals with neurodiverse conditions.*





### **General questions:**

**Question:** Has anyone done the profiler and got a clinical diagnosis?

Answer: There has been around 70 people, however the assessment process is taking longer than expected as the information provided in the referral is lacking evidence and The Retreat are taking time to ask about this additional information.

**Question:** I have a diagnosis; would the profiler pick up my traits?

Answer: If you have a diagnosis and want to use the platform as a support mechanic then the platform will be able to pick up your traits as long as you provide the correct information.

**Question:** What is the NHS 'right to choose' advice/referral?

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

**Question:** Where are social care and the police in these discussions? Can we also include the prison and prohibition services?

Answer: Both the police and social care are involved in the All-Age Autism Strategy work, led by North Yorkshire Council. Health service for prisoners is the responsibility of NHS England not the local Integrated Care Board.

**Question:** Uncertainty about how decisions are made and where the York place board fits in all of this?

Answer: Decisions are made at both North Yorkshire Place Operational Delivery Group and York Senior Leadership Team.

### **Summary**

Participants of the focus group expressed their aspirations for the assessment pathway to prioritise feelings heard, having their perspectives acknowledged, and fostering a more personalised approach. An artwork reflecting current emotions and hopeful aspirations of service users is included in annex 4.

Annex 4 – An artwork reflecting current emotions and hopeful aspirations of service users from YDRF focus group.

