



Adult Autism and ADHD York and North Yorkshire - Autumn engagement 2023

Summary From 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.

The first event took place in person on 12 December 2023 at York Community Stadium. This included a marketplace event with information about services and with health care professionals on hand to speak to participants. A brief presentation was delivered by NHS colleagues followed by group discussions and closing with an open Q&A session. A total of 72 members signed up to attend the event and 60 attended on the day.

The second event was held virtually, on Thursday 14 December 2023. In total 83 people registered to be involved and on the night 35 took part (we sought feedback on why some registrants did not attend. Reasons cited were work commitments and anxiety. Many registrants had also already attended the session on Tuesday. Those who were uncomfortable with this format were given alternative ways to share their views.)

Both events, proved successful in that they enabled participants to be involved, share experiences and contribute to active and robust conversations.

However there as significant anger expressed during the sessions about:

- Lack of support both pre and post diagnosis.
- The profiler – it's implementation and outputs.
- The lack of understanding, education and empathy in the NHS and other service providers about neurodiversity.

This was also reflected in the feedback on the events (feedback on the event is included in the annex 1).



Key themes which emerged through the engagement sessions

The most dominant concerns which emerged through our engagement were:

- **Lack of support both pre and post diagnosis**
- **The profiler – its implementation and outputs**
- **Skills, knowledge and capacity in the healthcare system to implement improvements and meet the needs of the neurodivergent community**

The adult autism and ADHD pathway

(waiting times and support)

- Waiting times are too long and people are left without any support while they wait.
- Lack of support continues after a diagnosis.
- Signposting which does happen is often to services which are themselves oversubscribe and cannot help, e.g., mental health services.
- Significant endorsement for increased support to local groups who are active in this space to provide support for neurodivergent individuals and for funding and coordinating additional opportunities such as peer support groups.
- Ask that the Do IT Profiler be made available to those already on the waiting list prior to implementation of the pilot in March 2023.

(role of GPs)

- Many shared instances of lack of empathy or support from GPs. Request that more be done to ensure that GPs understand the conditions and the current pathway.
- Strong message that GPs are unsure what to do and giving misinformation (e.g., message reaching patients that they must go into crisis before being eligible for an assessment).
- Ask if the profiler could be made available to everyone, without the need to go through a GP practice.



(diagnosis)

- While people wanted support before and after diagnosis, there was still a strong need for a diagnosis.
- Importance of a diagnosis linked to: being about to secure reasonable adjustments at work and education, legal protection under the equalities act, self-awareness and self-understanding, and mental health (such as feelings of 'imposter syndrome').

The Do IT profiler (as adapted locally in York and North Yorkshire)

- Feedback on the profiler was largely critical (note that not everyone who shared a view had used the profiler but examples of how it works and the outputs were available on the day).
- Criticism included concerns that the support provided was too general and not adequately generalised or customised. It was characterised as 'abilist' directing people to be neuronormative, which in itself could be triggering. Concerns about whether there was adequate distinction between support for people with autism and ADHD and for different genders.
- There were also concerns raised about the functionality of the profiler including: to clunky, no way to go back, no way to skip sections that are irrelevant (e.g., employment), too long to work through.
- There were significant concerns about potential barriers to access as a result of introduction of the profiler. Suggestions that paper copies or supported access be made available to as not to exclude people who were unable or unwilling to use an on online platform.
- There were questions about whether people with neurodivergence were involved in developing the profiler and whether its outputs had been tested with users.
- There was strong support for interventions or adaptations which could provide more personal support and connect people with people rather than a digital approach (this should be balanced with some expressions of support for online tools).
- There was concern that the do it profiler and RAG rating system may be pushing people to undertake risky acts in order to increase their RAG rating and make them a priority. This was seen as dangerous.

NHS skills and capacity

- There were a number of questions raised about the depth and breadth of autism and ADHD knowledge and training at both the ICB and Tees, Esk and Wear Valleys NHS Foundation Trust.
- Concerns raised that the lack of trained specialists in the system would make it difficult to ever improve diagnosis times.
- Views expressed that neurodiversity should sit separately from mental health.

Societal context and partnership working

- There were discussions around how more was needed to educate people about autism and ADHD, particularly in schools and healthcare.
- Views that more needed to be done to help employers understand neurodiversity so they can make reasonable adjustments and develop neurodiversity welcoming environments.
- Calls to involve the volunteer and community sector in developing future models and to focus on looking forward.
- Strong support for the view that each neurodiverse person is unique and customisation is important.

Implementation and current pilot

- There was substantial criticism of the way that the pilot was introduced and the lack of communication surrounding it (discussion on the day hoped to explain that the pilot was introduced to address a rapid and sustained increase in referrals to help manage the service while a sustainable future approach was explored).
- While in the minority, some voices supported the current implementation in their feedback.

Looking forward

- Strong endorsement for proposals that there is greater opportunity for input and influence from people who are neurodivergent as the pathway develops.



- Strong plea that services work together to lead to better connectivity – e.g., between diagnosis and support both pre and post diagnosis.
- Ask for greater involvement of existing groups and the volunteer and community services sector in developing a future model and for improving support currently available.

Mixed views

There were a few areas where there were mixed views from participants.

- Use of digital platform – while there was a large number of voices which articulated limitations with an online tool there were some people who said that this format was very useful for some people who are neurodiverse.
- Whether autism and ADHD should be separate – equally strong views on whether autism and ADHD should be looked at together or separately.
- Role of mental health services – some criticism of signposting to mental health services when neurodiversity is something different, however many participants also felt that mental health and crisis support was important.



Event evaluation

A digital event evaluation was shared with all attendees the day after the events. For the Thursday 14 virtual event at which there were substantially more registrants than attendees we also asked why people did not attend on the day.

Questions

1. Which event did you attend?
2. After the event, do you feel that you have a better understanding of 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)
3. Is there anything else you would have liked to know not covered at the event?
4. What are your thoughts on the direction of travel for adult autism and ADHD services in York and North Yorkshire?
5. Do you have any feedback on the venue (if you attended on 12 December) or the online meeting space (if you attended on 14 December)?
6. Is there anything else you would like to share with us?

Responses

25 people shared their views. This is what we heard.

1. **Which event did you attend?**
 - In person event York 12 December – 71%
 - Virtual event 14 December – 29%
2. **After the event, do you feel that you have a better understanding of 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)**

The data captured for this answer is incomplete as we are unable to separate out those who did not answer the question to create an average. We can tell that of the 25 people who answered the survey the maximum score out of 5 was 3, with no one who attended the event rating the event as improving their knowledge as 4 or 5. A number of people in the comments said that they would have rated the

improvement in their understanding a '0' if that had been an option on the scale.

3. Is there anything else you would have liked to know not covered at the event?

Many people who answered this question wanted to know more about the services which are available to support people both before and after a diagnosis. People also wanted to know what we were going to do to help bridge the apparent gaps in support and how we are going to ensure how we do this with the help of people with neurodiversities.

Some said that there was too heavy a focus on the Do IT Profiler, but others wanted to know more about why it was introduced and what it cost, as well as why it wasn't available without GP referral.

A number of respondents also said they would have liked to have heard more about the right to choose and clarity on when it could be exercised. In addition, there were question about knowing when people had been referred and when they would receive an assessment.

4. What are your thoughts on the direction of travel for adult autism and ADHD services in York and North Yorkshire?

There were calls for better communication, better inclusivity, more effective working with existing groups and a focus on support.

Concern was the dominant response, although there were one or two voices which support some elements of the direction of travel. There was a strong sentiment that we should look to see what is working elsewhere and increase our involvement with the neurodivergent community.

There was also a call that the work to find solutions should be done in a wider collaborative partnership to include local authority, schools, people with lived experience and health professionals, particularly experts in neurodiversity.

A few responses expressed significant concern about the current pathway, direction of travel and the impact on people who are neurodivergent, including words like 'disastrous', 'disgraceful' and 'dangerous'.



5. Do you have any feedback on the venue (if you attended on 12 December) or the online meeting space (if you attended on 14 December)?

Views on the venue were mixed. Many said that the lighting was too harsh for people who are neurodivergent. The decision to include a 'marketplace' was questioned as multiple start times caused some people anxiety. It was also agreed that signage was very poor in the venue and the event itself was hard to find.

People wanted more visibility of the reasonable adjustments being made to support people with neurodiversity, as well support available on the day for those who might be triggered by the conversation (e.g., quiet room, mental health practitioners or first aiders).

A number of people said they would have found it useful to have seen the presentations and break out discussion questions in advance so that they could have had time to prepare.

6. Is there anything else you would like to share with us?

Additional views were shared about ways to make events more accessible to people who are neurodivergent including dimming the lights, visible support, chairs against the wall and permission to move around the room if and when needed.

There was the view that not much has changed over the last few years. That something needs to be done to give people who are neurodivergent hope. It was noted that there is a long way to go and there was a call on the ICB to be more inclusive.

The expertise and knowledge of the ICB was queried, and the need to get people who have the right experience and knowledge involved in developing solutions emphasised. Some found the event patronising and uninformative.

Thursday 14 December virtual event only: If you were registered and did not attend the event would you mind telling us why?

There were a number of reasons cited including: competing commitments, unable to access event on the day and anxiety. A number of people were also registered for both events and attended only the in person event on 12 December.