

York Disability Rights Forum (YDRF) & NHS Humber and North Yorkshire Integrated Care Board (ICB) Meeting re adult autism and ADHD 7 December 2023

SUMMARY OF MEETING

Members of the York Disability Rights Forum (YDRF) met with representatives of the NHS Humber and North Yorkshire Integrated Care Board (ICB) for an hour and a half on 7 December to discuss adult autism and ADHD services in York and the pilot approach to assessments implemented in March 2023.

YDRF shared voices and feedback from the neurodivergent community. This included issues with the current Do It Profiler, the fact that some people are feeling abandoned by the current process and the need for a diagnosis. The ICB welcomed this feedback which will become part of the input which will shape decisions about the future approach.

There were also specific questions and answers about the current approach, and the Do It Profiler specifically, which can be found in the full note below.

The final part of the meeting included a discussion of some of the issues which need to be overcome including the volume of referrals for assessment, lack of clinical capacity and lack of transparency around what the ICB is trying to achieve.

It was agreed that YDRF would continue to be an active part of the conversation as the ICB continues to find ways to address some of the current issues and develop a sustainable approach to adult autism and ADHD assessments. Further meetings of this group were agreed.

A full note of the meeting can be read below.

FULL MEETING NOTE

Welcome

Chair Helen Jones, Chair, YDRF (HJ)

Attendees Hilary Conroy, YDRF (HC)
Hazel Kerrison, YDRF (HK)
Michelle Carrington, ICB, Director Quality and Nursing (MC)
Peter Billingsley, ICB, Clinical lead (PB)
Kirsty Kitching, ICB, Assistant Director for the North Yorkshire Mental Health, Learning Disabilities and Autism Partnership (KK)
Angie Walker, ICB, Senior Contract Manager (AW)

Note taker Rachael Durrett, ICB, Head of Communications, Marketing and Engagement – York and North Yorkshire (RD)

- The meeting started with welcome and introductions. The chair confirmed that everyone had completed the prereading prior to the meeting (links to pre-reading included at the end of this note). The group also discussed and agreed to meeting etiquette.
 - Pre reading will be completed by everyone prior to the meetings
 - Attendees' neurodivergence is recognised
 - Behave in a professional manner
 - Communication should be clear, honest and direct
 - Communicate openly, critiquing ideas rather than individuals
 - Respect the privacy, rights, safety and dignity of all
 - Treat each other with respect and consideration, valuing a diversity of views and opinions

Voices from the neurodivergent community

- YDRF has been gathering input since the ICB launched the adult autism and ADHD assessment pilot in March 2023. It has also specifically asked the neurodivergent community what it would like YDRF to raise with the ICB prior to this meeting. YDRF is acting as advocate for a diverse community that cannot always advocate for itself, for example, by attending engagement events.
- YDRF shared an email from a York resident:

The email shared that the process is confusing, their GP had no empathy and a lack of knowledge on the correct way forward. The on-line profiler is difficult to use – some boxes are not present and there is no going back to fill in extra information. There was no meaningful advice provided on how to use the profiler. The advice provided by the profiler was not new or helpful.

Once completed it was unclear on whether there had been a referral to The Retreat. In following this up neither the GP nor The Retreat would provide clarity on whether there had been a referral. In getting in touch with The

Retreat there were time lags in receiving any response to queries. Lack of clarity on next steps remain and it is not clear where to go for answers.

- YDRF has had over 160 responses through its online form since the pilot was launched in March 2023. YDRF stated that it is clear from these responses that the current situation is affecting real people and having a significant negative impact.
- Feedback on the pilot from respondents includes:
 - The output of the profiler is not adequate to support disabled student allowance (DSA) or any other benefits claims.
 - the output of the Do It Profiler is not useful in discussions about reasonable adjustments with employers or educational institutions.
 - There is a real lack of clarity on what next after completing the profiler.
 - People who have not been referred for an assessment feel abandoned and don't know where they should go next.
 - The current approach feels like there is a missed opportunity for early intervention.
 - The current approach does not reflect the reasons people seek assessment and diagnosis – issues with education, employment and relationships.
- YDRF continued that there is a strong concern that the lack of clarity and feeling of invalidation is pushing people into crisis.
- They also said that a minority of people have found some use in the profiler but say it does not go far enough. YDRF also made clear that people want an assessment because they want to be able to access support and to understand themselves, and in the case of ADHD, access the medication that significantly changes the lives of the majority of people diagnosed with ADHD.
- YDRF also shared concerns from the National Autism Society which said:

“We are hugely concerned about the impact that this will have on people seeking an autism assessment in the area. The assessment process is frequently life-changing for those receiving a diagnosis, enabling them to make sense of the world, and is a vital gateway to accessing services, care and support. Without access to appropriate support, today's new referral can become tomorrow's person in crisis.”

The briefing from the National Autism Society is attached as Annex 1 to this email.

- YDRF concluded that there is a real appetite to work together to create change and all sides welcomed the meeting today.

Questions arising from the pre-reading.

Q: What is the difference between red and amber and green on the profiler?

A: The NHS use a RAG (red, amber, green) rating system for prioritisation. Those who meet the eligibility criteria are RAG-rated 'red' and a referral is sent to The Retreat for triage. The responses people give as they progress through the profiler

are given scores from 1 to 4. People are currently separated into 'red, 'amber' and 'green' based on this score. Their written narrative will also be taken into account when this is reviewed. The more information people put in the long text boxes the more helpful for these eventual evaluations.

Discussion followed: HK commented that the long box format can be difficult to complete for some of the people who fill out the profiler alone, without support and online. This was noted, and PB said that the ICB has also received feedback that some people find them useful.

It was also confirmed that the detail provided in the long box will be considered during the triage process. People with an amber and green RAG rating stay on the waiting list and have not met the criteria for triage'. People who have met the criteria and rated red have been added to the triage list.

Q: How do people move from the amber and green waiting list to the triage list?

A: People can move to the triage list if their circumstances change and they meet the eligibility criteria. If this happens people should speak with their GP.

It was discussed that this is not likely to happen for the vast majority of people on the amber and green waiting list.

There is an ambition to be able to consider the amber and green waiting list in the future when we move beyond the current situation of long waiting lists and times for referrals. This could be accomplished as the number of people seeking a referral starts to fall (it was noted that we likely have not seen the peak in people seeking referrals yet because of historic unrealised demand).

There are changes being made to implement rapid or condensed assessments which would reduce the clinical time required to complete an assessment. It is hoped that with this change, The Retreat will be able to reach a target of 80¹ assessments a month.

Q: The numbers are huge – about 22 years by YDRF calculations from ICB figures. Much of the discussion does not reflect the scale of the issue. Would it have been more honest to close the waiting list?

A: All agreed that the length of both waiting times and waiting lists are not where we would want them to be. The suggestion that the list could be closed was acknowledged by ICB members, but they were concerned that then those people who were seeking help might be lost into the system and not identified.

PB explained that by keeping the lists open, it has provided the opportunity to better demonstrate the scale of the issue to encourage people to focus on solutions.

There are plans to undertake intensive work to reduce the triage backlog and The Retreat staff will be focusing on this in January 2024 which will slow the rate of assessments during that month. There is an ambition to get to the end of the red referrals by the end of the current contract which is based on the rapid assessments

¹ It was noted after the meeting that this figure does not reflect that fact that The Retreat contract also includes provision for medicine reviews.

and 80² assessments a month target. This would dramatically reduce the waiting time calculations but are not in place yet and could take up to 12 months to achieve.

Q: It appears that there is a desire to restrict people's right to chose which is guaranteed under the NHS constitution.

A: KK said that the ICB fully supports people's right to choose and is trying to establish equitable access. The current approach anticipates that people will follow the criteria and the pathway.

In the current model, people with a red RAG-rating **are** able to exercise the right to choose. HC noted that communication to ensure that everyone is aware of this, including GPs, would be helpful.

Q: What does criteria two actually mean? Could we have an example?

A: This criteria is largely about patients who already have complex mental health co-morbidities and where a diagnosis of neurodiversity would help with future case management, capacity assessments, surgery and secure more appropriate placements. PB clarified that criteria two was developed with community mental health teams (CMHT) colleagues to help facilitate securing people appropriate care and residency. PB and AW met with The Retreat last week and they are developing definitions for their clinicians that will be share publicly.

Discussion

- There was detailed discussion about the five-year contract for The Retreat to provide specialist services. The contract includes assessments, medication reviews and post referral support. The current contract reflects the volume of activity at the time it was procured but there has since been a sharp and step increase in demand for services. The Retreat were concerned about Care Quality Commission (CQC) scrutiny of the length of the waiting list if nothing changed and the ICB were concerned that The Retreat would serve notice on the contract.

There have been some additional changes which have had an impact on The Retreat's balance of activities:

1. There has been a significant number of ADHD transitions from children and adolescent mental health services which require medication reviews.
2. There has been an increase in medication reviews generated by people who have sought private assessments through the right to choose pathway.

There is also a lack of clinical capacity and The Retreat has been unsuccessful in attempts to recruit additional staff.

The ICB is working to identify solutions to some of these issues. For instance, using clinical pharmacists, supported by The Retreat, to conduct medication reviews. There are also some mitigations that have been put in place for early

² It was noted after the meeting that this figure does not reflect that fact that The Retreat contract also includes provision for medicine reviews.

January to get the triage waiting lists down to six weeks with the view to a greater focus on assessments after this.

We would also like to see more assessments done. PB stated that The Retreat has assured him that they can develop and implement effective two-hour assessments (previously significantly longer). If two teams are running this could be eight assessments a day rather than as little as one. We are along this journey at the moment. This can be implemented after the triage backlog is addressed.
(PB)

- There was discussion about the need for assessment. PB said that not everyone needs a formal full assessment as some people are seeking functional support to help with specific elements of their lives, and the Do It Profiler is enough.

HC countered that people **do** need an assessment and would not start this journey without seeking a diagnosis. This is reflected in law with the Care Act and Equality Act requiring an assessment for legal protection of protected characteristics. YDRF do not agree with the proposition that any of the people on the waiting list do not want a formal diagnosis.

- There was an extended conversation about people's experiences. HC reminded the meeting that some people who are undiagnosed and neurodivergent are not as confident as others and do not necessarily have the self-advocacy skills implied in accessing provision like access to work, even though you do not need a diagnosis to apply. The chair also said that it is important to recognise that GPs are different and some can be more supportive than others on any medical issue.

PB said that we are trying to get clinicians to think differently so that we can ensure that money is used where it is needed. The ICB would like to bring down the cost of diagnosis so there is more money available for therapy and support. The ICB is trying to make change happen while working collaboratively with The Retreat, adapt the clinical pathway, and keep costs within budget.

- HC strongly encourages ICB to not use the Do It Profiler. Expert observations, and views heard from others in the community, are:
 - It feels outdated, not intuitive, and reflects older, gendered ideas on autism.
 - It is not possible to skip areas that are irrelevant to the person filling out the profiler such as education and employment.
 - It has never been used in this way before and is not fit for purpose.
 - Sending people a library of .pdfs is not meaningful support. The .pdfs provided are not screen reader compatible and so inaccessible to some. PB stated his belief that people completed the profiler on their phones. HK was not aware of anyone who did this, or any screen reading technology accessible to the majority via phones (mostly on laptops).
 - Some of the content is inappropriate: the empathy section reads like 'ableism 101', trying to train people who are neurodivergent to be neurotypical.

- Many people feel insulted by the 'information' provided by this profiler. It is generic and often suggests seeking a diagnosis, which patients cannot actually do.
- There is concern that AI might be involved in using the data provided to develop extra support (the ICB confirmed that this is not the case). Patient data is being used on an aggregate level by Do It Solutions to improve their system. YDRF do not believe this is ethical and question the consent process provided as there is no option to opt out.

HC said that Portsmouth has an interesting model which trains people in the community to support people to fill in a different screening tool. It embeds a strong ethos of connecting people to support, rather than connecting people to an anonymous tool without appropriate support. Importantly, this does not prevent patients from seeking a formal diagnosis but is useful to people while they are waiting.

KK thanked HC for these observations and reiterated that the ICB is keen to listen and learn both today and through our current broader engagement to make sure that any screening tool does what it needs to do.

- There was a discussion of some of the current complexities and challenges in this area:
 - Looking to ensure that the money available is spent in the best possible way. MC welcomed advocacy to help the ICB understand what the needs are.
 - HC said that greater honesty, clarity and transparency is needed which the ICB acknowledged. HC relayed that there has been missed opportunities and ineffective use of previously available platforms, such as Connecting our City in York.
 - HK commented that there is a broad lack of understanding of neurodivergent conditions in the NHS and that the change to CMHT being referral gatekeepers is a concern. The ICB acknowledged this and identified that training is happening.
 - HC commented that neurodivergent social groups, and other groups in the community, are picking up the tab for free. How can the ICB sustain, maintain and actively involve the groups that have the knowledge, insight and community trust? The ICB acknowledged this challenge.
 - The chair asked that the ICB also acknowledge the good work and input from the community.
 - There was a discussion of the relative value of quantitative and qualitative data. MC recognised that things are changing within NHS funding where more notice is being taken of qualitative data and case study style reporting now.

Where we are now and next steps

- It was agreed that the ICB could get better through greater transparency, clearer communications, the use of plain English and being more accessible. HC noted

that different people in the ICB give different answers to the same question which can be confusing and undermine confidence. The ICB seems faceless. Is there a way to make our work more about real people?

- There was further encouragement that the ICB work with trusted voices in the community.
- The ICB was also encouraged to make clear it is hearing what people are saying. It will be impossible to retain people's interest in sharing their views if they feel like what they say is going into a void.
- There was discussion about the December 12 & 14 engagement events and some ways they could be made better. This included concerns about parking, location, the fact that the two events are different lengths and some lack of understanding of the purpose of the events. It was also noted that there is no telephone number available so the event is inaccessible to people who are not able to register digitally or email the ICB.

The ICB welcomed contributions on information that it would be useful to incorporate into the event: you said we did, greater understanding of The Retreat's priorities and feedback on how to make some of the content more accessible (post meeting note: these have been actioned)

- RD drew attention to the alternate opportunities to get involved in the conversation about adult autism and ADHD services including participation in focus groups and 1-2-1 discussion (details are available here: <https://www.valeofyorkccg.nhs.uk/get-involved/lets-get-talking-about-adult-autism-and-adhd-services-in-york-and-north-yorkshire/>).
- The meeting was concluded with the commitment to keep talking.

PRE READING:

1. four legal letters
 - a. YDRF letter 19 September 2023 <https://ydrf.org.uk/legal-letter-1/>
 - b. ICB letter 3 October 2023 <https://ydrf.org.uk/icb-response/>
 - c. YDRF letter 20 October 2023 <https://ydrf.org.uk/legal-letter-2/>
 - d. ICB letter 13 November 2023 <https://ydrf.org.uk/icb-response-2-13-11-23/>
2. YDRF waiting list flowchart <https://ydrf.org.uk/waiting-list/>
3. ICB pathway flowchart <https://northyorkshireccg.nhs.uk/wp-content/uploads/2023/11/North-Yorkshire-and-York-Adult-Autism-and-ADHD-Assessment-and-Diagnosis-Service-Pathway.pdf>
4. ICB integrated impact assessment (link from page below)
5. ICB webpage <https://www.valeofyorkccg.nhs.uk/adult-adhd-and-autism-assessment/>
6. ICB Q&A page <https://www.valeofyorkccg.nhs.uk/adult-adhd-and-autism-assessment/>

Rachael Durrett
11 December 2023

Annex 1 – briefing from National Autism Society

Top line from the National Autistic Society:

“We are hugely concerned about the impact that this will have on people seeking an autism assessment in the area. The assessment process is frequently life-changing for those receiving a diagnosis, enabling them to make sense of the world, and is a vital gateway to accessing services, care and support. Without access to appropriate support, today’s new referral can become tomorrow’s person in crisis.”

Latest Autism Waiting Lists Statistics

- As of June 2023, 143,119 people were waiting for an autism assessment in England, new NHS data has revealed. This is a 47% increase in the number of people waiting in just one year.
- NICE (National Institute for Health and Care Excellence) guidance states that no-one should wait longer than three months between being referred and first being seen. But this data shows that the vast majority of people 83% (118,000 people) have been waiting longer than 13 weeks.
- Within the Humber and North Yorkshire ICB the NHS data shows that 4680 people are waiting for an autism assessment and 3340 (71% of people) have been waiting longer than 13 weeks. The total number of those waiting and those waiting longer than the 13 weeks is lower we see in many other ICBs across the country who have not imposed such strict restrictions on assessment access.

The National/Legal Requirements

- However, restricting access to assessments as the North Yorkshire and Humber ICB have done is not the answer and has serious system-level implications.
- NHS England’s new autism assessment framework has just been published. It should finally help embed consistency across the country and set clear expectations for what assessment pathways should look like.
- The *National framework to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care systems* makes clear that, “It is important that **ICBs do not restrict or withhold access to an autism diagnosis, for example, because locally a decision has been taken by health to conduct only a needs-based assessment.** Barriers to a diagnosis increase a person’s risk for poor outcomes in life, for example, late diagnosed autistic adults commonly experience multiple forms of abuse and can experience poorer mental health, suicidality or hospital admission. As a result, autistic people, and especially people without an intellectual disability, represent a significant proportion of the mental health inpatient population in England.”
- The accompanying draft *Operational Guidance* also makes clear that screening and triage should be subject to clinical decision making.

- Bristol, North Somerset and South Gloucestershire Integrated Care Board introduced similar restrictions but since acknowledged that the need to revisit this decision in light of the new NHSE Assessment Framework. It is very disappointing that NHS Humber and North Yorkshire Integrated Care Board have not done the same and have instead extended the pilot.

What the Government needs to do

- We know that localities are not making these choices lightly. They are struggling with challenging budgets and a workforce under considerable pressure. However, assessment is critical to achieving the aims of the national all-age autism strategy, and improving autistic people's lives.
- The Government needs to urgently address the growing autism diagnosis crisis and to immediately invest in rolling out diagnosis services to solve the waiting times crisis. The NAS are calling at a national level for the Government to provide funding to the NHS to roll out and fully embed NHS England's new assessment framework.

Justifications for the Pilot made by the ICB

Documents were published in response to FOIs on the decision to extend the piloted pathway with regards to adult access to autism and ADHD assessment. I have summarised the main arguments some of the main justifications and issues with these below:

Other areas have developed or are talking about developing similar criteria.

- Not aware of anywhere that has imposed such strict criteria (at least publicly) as this pilot. Other areas e.g. Bristol have backtracked when the new framework has been published.

Unable to follow legal/national requirements due to lack of workforce

- While this is understandable, it is not clear whether the ICB have made this case to NHS England or DHSC. It is unclear whether the ICB have asked for any help from outside the ICB or considered other ways to manage the workforce issues. The answer to a lack of workforce simply can't be to restrict patient rights.

The profiler tool provides an indication of whether a person has neurodiverse traits along with further information to help people.

- An indication of neurodiverse traits is in no way equivalent to an autism assessment. Support simply on just neurodiversity is in no way equivalent to support for autism. Neurodiverse traits can cover such a wide range and information based on potential neurodiverse traits is far from suitable for someone who may be autistic.
- Of the 1250 people who used the profiler in the first three months only 126 met the acceptance criteria. Meaning around 90% of people using the profiler are missing out on an assessment despite the fact many of them likely will be autistic.

The Equality and Disability Acts identify neurodiversity as a disability but state that reasonable adjustments should be made on need and not necessarily on diagnosis.

- This is one of the main arguments made throughout to justify the do-it profiler as an alternative to the assessment but does not consider the reality that in many cases people aren't able to get adjustments without a diagnosis. If people don't have a diagnosis they are much less likely to be able to access adjustments.

Prior to the pilot, the use of non-routinely commissioned private providers used for assessment and diagnosis through patient choice was significant. These come with an additional cost pressure to the ICB and create a disparity for patients across the region

- This suggests an intention of the pilot is to restrict a patient's right to choose.
- Advantages/Disadvantages for reverting to the original pathway.**

Options	Advantages	Disadvantages
Option 1- Revert to original pathway	<ul style="list-style-type: none"> • Satisfies patients wishing to remain on a waiting list/wanting diagnosis • Meets legal /national requirements 	<ul style="list-style-type: none"> • Unsustainable service • Risk of destabilising provider • Risk of provider terminating contract • Future procurement risk • Staff retention • Workforce issues (availability etc) • CQC pressures- long waits deemed a risk • Demand outstrips capacity • Cost pressures • Medication review/medication costs • Increased private provider spend through right to choose • Increased disparity in waits for those seeking a diagnosis with a private provider • No shared care agreement with private providers • No system for identifying people needing help more urgently • Failure to identify and direct adults with autism and ADHD to an appropriate support service may result in harm occurring to those individuals • May attract backlogged increase in referrals from those not meeting the criteria during the 3 months • Waiting list will continue to grow – predicted 5 years • No immediate support or functional guidance for patients • Tirage time/resource pressures for the Retreat

- The advantages and disadvantages for reverting to the original pathway don't consider the effect using the alternative pathway will have on autistic people and their families themselves.
- It is not simply 'patients wishes' to remain on a waiting list that needs to be satisfied. This is reductive language. Patients need to be on waiting lists to eventually get a full diagnosis to be able to access the proper support they need. It is an issue of what patients need not what they want.

The Do-IT Profiler is one element of work to develop an enduring model to support adults seeking neurodiversity support.

- Again, general neurodiversity support is not equivalent for specific ADHD or Autism support.

Currently if a patient is on the waiting list for more than six months, they are entitled to obtain a private assessment, which will be paid for by the NHS. It transpires that 90% of those who obtain a private referral obtain a positive diagnosis. This highlights issues of possible medicalisation of normal traits and over-diagnosis of neurodiversity conditions. The latter has been documented in The Sunday Times May 23, 2023, and by the BBC Panorama investigation into neurodiversity diagnosis.

- The Panorama investigation was into ADHD diagnoses specifically so shouldn't be applied to autism diagnoses. The tone here and throughout is dismissive and

patronising towards people seeking a diagnosis. Stats on ADHD and autism are mixed to suit their argument and claims high numbers getting a positive diagnosis suggests an over-diagnosis of neurodiversity conditions and doesn't consider other reasons why this may be the case.

- As long as the NHS makes sure that the referrals go to private providers who follow NICE guidelines it shouldn't be concerned about over-diagnosis through private providers.
- It is also simply not appropriate to be drawing such wide assumptions about people seeking diagnosis from one documentary especially one which as ADHD UK say has "done serious damage to our community and real harm to individuals with ADHD. Our research, from over 1,500 people, evidences that the Panorama show's presentation was misleading and harmful to people with a disability."