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Humber and North Yorkshire Integrated
Care Board

Our Ref: 290750/1.JEBR

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Date: 19 September 2023

Dear Madam/Sir

ADHD and Autism Pilot Pathway

1. We are instructed by Hilary Conroy as a representative of York Disability Rights Forum ("YDRF"), which is an unincorporated association.
2. YDRF is led by disabled people and works to promote equal access to human rights for all those with disabilities who live or work in York. YDRF aims to be a collective voice, to raise awareness of issues affecting disabled people in York and create positive changes.
3. YDRF are very concerned at the restriction of access to diagnosis and support for the vast majority of neurodivergent adults in York and North Yorkshire, and YDRF has not been permitted to feed into the decision making of the ICB. YDRF are acting on behalf of a vulnerable community, with many unable to advocate for themselves. The wider community also has not been consulted or allowed to participate in the decision making which has resulted in almost all adults in York and North Yorkshire being unable to access assessment and personalised treatment for ADHD and Autism.
4. York Executive Committee and North Yorkshire Place Operational Delivery Group which are both part of the Humber and North Yorkshire Health and Care Partnership¹ and Humber and North Yorkshire Integrated Care Board², implemented a three month pilot pathway which it then decided to extend in June 2023 for a further nine months – until March 2024.
5. The Humber and North Yorkshire Integrated Care Board has commissioning responsibility in these areas so we are addressing this letter to the ICB.

Factual background

ADHD and Autism

6. Autism and Attention-deficit/hyperactivity disorder (ADHD) are both examples of neurodivergence, which means having a mind that functions in ways which are different

¹ <https://humberandnorthyorkshire.org.uk/>

² <https://humberandnorthyorkshire.icb.nhs.uk/>

to typical and dominant societal standards (i.e. neurotypical standards). The social model of disability perspective is that the neurotypical society we live in is disabling for neurodivergent people.

7. Autism is lifelong and shapes how people communicate and interact with the world. Autism is not a learning disability. Whilst autistic people share certain characteristics, they do not all present in the same way. Common ways of experiencing the world that many autistic people share include: enhanced sensory perception, a preference for honesty and clarity in communication, a preference for agency, predictability and control, self-expressive body language and a passionate enjoyment of interests and hobbies.
8. As of April 2022, 1% of the population are autistic and an estimated 5,727 autistic adults live within the boundaries of City of York Council and North Yorkshire County Council.³
9. ADHD is a neurological condition that affects people's concentration, activity levels and impulses. The impact this has on people's lives is significant with symptoms varying for each individual. The UK NICE guidelines reports the adult ADHD incidence rate as between 3% and 4%⁴. ADHD is not a mental health condition although it often occurs alongside or is mistaken for other conditions.
10. As of April 2022, it is recorded that between 2.3% and 4.5% of the population have ADHD, in North Yorkshire and City of York Council areas this is an estimated 19,218 people⁵.
11. It has only been possible to diagnose adults with ADHD since 2008⁶, and only available as a co-occurring diagnosis to autism since 2013. The differing presentations in girls and women were only made clear in 2018⁷, highlighting previous under- and mis-diagnoses in the mental health system.
12. Neurodivergent people are at a higher risk of suicide. Henry Shelford, Chairperson and co-founder of ADHD UK said: "*Recent research shows adults with ADHD are 5 times more likely than those without to have attempted suicide (14% vs 2.7%). That rises to one in four for women with ADHD*".⁸
13. Research conducted by the University of Cambridge and the University of Nottingham has found that "*10% of those who died by suicide had evidence of elevated autistic traits, indicating likely undiagnosed autism. This is 11 times higher than the rate of autism in the UK*". Dr Sarah Cassidy commented: "*Many adults in the UK find it very difficult to*

³ 'Adult autism spectrum disorders (ASD) and Attention deficit hyperactivity disorder (ADHD) service', Service Specification, April 2022 – March 2027.

⁴ NICE, 'Attention deficit hyperactivity disorder: How common is it?', August 2023: <https://cks.nice.org.uk/topics/attention-deficit-hyperactivity-disorder/background-information/prevalence/>

⁵ Service Specification, April 2022 – March 2027

⁶ 'Attention Deficit Hyperactivity Disorder: The NICE Guidelines on diagnosis and management of ADHD in children, young people and adults', National Collaborating Centre for Mental Health, 2009.

⁷ 'Attention deficit hyperactivity disorder: diagnosis and management', NICE guideline [NG87], March 2018

⁸ 'New study to understand the relationship Between ADHD and suicide risk', 27 September 2022 [https://www.gla.ac.uk/news/headline_881944_en.html#:~:text=Henry%20Shelford%2C%20Chairpers on%20and%20co.\(14%25%20vs%202.7%25\).](https://www.gla.ac.uk/news/headline_881944_en.html#:~:text=Henry%20Shelford%2C%20Chairpers on%20and%20co.(14%25%20vs%202.7%25).)

obtain an autism diagnosis and appropriate support post-diagnosis. Our study shows that undiagnosed autistic people could be at increased risk of dying by suicide".⁹ A BBC News investigation also recently found that autistic people continue to die after serious failings in their care, despite repeated warnings from coroners¹⁰.

14. Neurodivergent people also face higher mortality risks than does the general population, according to a meta-analysis published in the journal JAMA Paediatrics. The study found that death in childhood or midlife from natural or unnatural causes was twice as likely for neurodivergent people, compared to the general population.¹¹
15. These statistics evidence the extreme vulnerability of this section of the population, their need for proper specialised support and the risk of leaving people unable to access diagnosis under the Pilot Pathway.

Importance of a diagnosis

16. The importance of timely diagnosis, in particular for autism, has been recognised by the Secretary of State for Health consistently over the last 13 years (see: the Autism Strategies from 2010 to date and the NHS Long Term Plan from 2019).
17. 'Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy' (March 2015), also confirms the importance of a diagnosis for adults:

*"Diagnosis can be particularly important for adults who did not have their condition or sensory issues recognised as children. Their life to date may have been affected by a sense of not fitting in, of not understanding the way they respond to situations or why they find social settings difficult"*¹²; and

"A diagnosis can be an important step in ensuring that support takes account of how a person's autism affects them and their whole family, as well as their participation in learning, employment or other activities. Some people with suspected autism may not need further support. However, this does not mean that they should not have access to a diagnosis. For some people, simply having a diagnosis of autism confirmed can be incredibly important, and can help them avoid needing more intensive support at a later stage for example, if they hit a crisis point".

18. NHS England's Guidance, 'A national framework to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards', states:

⁹ 'Study reveals high rate of possible undiagnosed autism in people who died by suicide', University of Cambridge', February 2022: <https://www.cam.ac.uk/research/news/study-reveals-high-rate-of-possible-undiagnosed-autism-in-people-who-died-by-suicide>

¹⁰ 'Young autistic people still dying despite coroner warnings over care', BBC News, 7 September 2023: <https://www.bbc.co.uk/news/uk-66731265>

¹¹ 'ADHD Life Expectancy Study Shows Increased Risk of Early Death', Attitude, 17 February 2022: <https://www.additudemag.com/adhd-life-expectancy-news/>

¹² Section 2.1

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf

“an autism diagnosis can serve several important purposes as set out below. This is why universal, equitable and timely access to autism assessment in every ICB is important”.

19. The reasons provided in that NHS England Guidance are:
- a. A diagnosis enables clinicians to recommend interventions that have been tested for safety, acceptability, efficacy and effectiveness with people meeting the same diagnostic criteria as the person they are supporting; a critical tenet of evidence-based care;
 - b. an autism diagnosis is a mechanism to ensure reasonable adjustments are made in general physical health or mental health services, including for example cognitive behavioural therapy for anxiety or depression;
 - c. the clarity of an autism diagnosis can be validating for many people in their day-to-day lives; and
 - d. an autism diagnosis can help facilitate access to some forms of statutory protection beyond the healthcare context, including an EHCP, Care Act assessment and protection under the Equality Act 2010.

20. NHS England expressly warns ICBs not to restrict or withhold assessment¹³:

“For an undiagnosed autistic person access to personal understanding, healthcare, education, social care, reasonable adjustments in the workplace, statutory protection from discrimination, or benefits may be withheld. For these reasons, 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”.

21. These same reasons also apply for ADHD, and in addition, a diagnosis for ADHD is required before medication can be prescribed. NICE Guidance, ‘Attention deficit hyperactivity disorder: diagnosis and management’ states that before starting medication for ADHD, people should have a full assessment, which should include a review to confirm they continue to meet the criteria for ADHD and need treatment. It is not possible to be prescribed ADHD medication without having a diagnosis¹⁴, and restricting access to assessment prevents people from accessing appropriate evidenced based treatment options.

Adult ADHD & Autism assessments in York and North Yorkshire

22. In September 2021, The Retreat¹⁵ were awarded a new five year contract to provide Autism and ADHD assessments for Vale of York and North Yorkshire Place following a competitive tendering process. A new contract was started on 1 April 2022.

¹³ NHS England – “A national framework to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards” <https://www.england.nhs.uk/publication/autism-diagnosis-and-operational-guidance/>

¹⁴ <https://www.nice.org.uk/guidance/ng87>

¹⁵ <https://theretreatclinics.org.uk/>

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23. The service specification for the April 2022 contract stated: *“The service will provide a person-centered diagnostic and assessment service for adults referred with potential Autism and ADHD in line with NICE guidance”*.¹⁶
 24. For Autism the pathway under the April 2022 Contract was a referral by GP, Social Care or Secondary Care to the Retreat. The Retreat would then issue a questionnaire on acceptance of the referral to determine if the patient is suitable for assessment. If suitable, an assessment would be conducted and post diagnostic support would be provided, such as group sessions on understanding Autism and group and individual learning programmes. Self-referrals were not permitted.¹⁷
 25. For ADHD referrals for diagnostic assessment were made by the GP, Social Care or Secondary Care, and the referral should include completion of the Wender Utah rating scale, which is an aid for diagnosing ADHD.
 26. Once the referral was accepted by the Retreat, the patient was to be issued with a pre-assessment guide which included a dedicated named contact, practical support guides and signposting to online support. The patient would then receive assessment and post diagnosis support, including a treatment plan, from the Retreat.
 27. The April 2022 Contract states that patients with identified complex needs, high risk and vulnerability and those who present frequently in Community Mental Health Teams will be triaged by the clinical team and discussions will take place with the commissioner concerning their treatment.
 28. A Key Performance Indicator was that 90% of people referred for an assessment were to start their diagnostic assessment within 13 weeks of the referral¹⁸.
 29. The exclusion criteria¹⁹ under the April 2022 Contract were:
 - a. Where the person’s primary needs are mental health conditions, the Specialist Autism and ADHD team would be expected to support colleagues in secondary mental health services to manage the person with autism/ADHD effectively, taking into account both conditions together, and offering appropriate consultancy;
 - b. If a patient is suffering from memory problems or is otherwise without capacity to consent to undergo the assessment process, the service will not be able to complete the assessment and will refer the patient to appropriate memory assessment services locally;
 - c. Anyone with a BMI of 15 or less will not be seen by the service until physically well enough to undergo the assessment process; and
 - d. If a patient’s substances and/or alcohol use is at a level that may interfere with observational assessments/ability to engage in assessment process.
 30. The April 2022 contract estimated 60 referrals per month²⁰.

¹⁶ Service Specification, April 2022 – March 2027

¹⁷ Service Specification, April 2022 – March 2027

¹⁸ Service Specification, April 2022 – March 2027

¹⁹ Service Specification, April 2022 – March 2027

²⁰ ‘Adult Autism and ADHD Assessment and Diagnosis Service Referral Criteria’, the Care Partnership, November 2022 Report

Pilot Pathway

31. The Humber and North Yorkshire Health and Care Partnership (the “Care Partnership”) stated in March 2023 that it estimated that the number of referrals currently on the waiting list, along with those yet to be triaged, will use 90% of the contract value and take the remaining 4.5 years of the contract.
32. Discussions regarding a change to the assessment criteria took place at the York HCP Executive Meeting in October 2022 and the North Yorkshire HCP Operational Delivery Group in November 2022. No minutes were taken of these meetings, which is highly irregular. However, we do know that a report dated 8 November 2022 (the “November 2022 Report”) was discussed and accepted with a recommendation for an Equality Impact Assessment to be developed.²¹
33. The November 2022 Report proposed that the 3-month pilot be used to work through the 1,500 referrals that had not been triaged and prior to the end of the three months a paper would be brought back with recommendations for a more sustainable long-term solution.
34. The Retreat had been commissioned for approximately 60 referrals per month but was receiving 180 per month. It noted that the diagnosis rate has remained consistent at around 85%, suggesting these were appropriate referrals.
35. The criteria proposed by the Retreat in the November 2022 Report were:
 - a. Immediate harm to themselves or others is likely and due to possible Autism / ADHD excluding Mental Health deterioration. MH assessment completed;
 - b. Imminent risk (in next 3 months) of person having a criminal record e.g., court case pending;
 - c. Imminent risk (in next 3 months) of person losing place in education or employment e.g., tribunal, final warnings etc;
 - d. Imminent risk of distress due to access to major healthcare treatment e.g., hospital treatment ,operations etc, care homes;
 - e. Imminent risk of family court decisions being determinant on diagnosis e. g family breakdown, custody hearing; and
 - f. Other factors on an individual basis maybe due to vulnerability and lack of support.
36. It is unknown and undocumented when or why these six criteria were reduced to only three. The ICB have shown a significant lack of transparency of decision making throughout this process.
37. On 28 February 2023 a letter was sent to GPs in the local area to advise them of the changes to the referral pathway for adult Autism and ADHD. That letter explained²²:

“Following discussions with Commissioners, the Clinical Lead for The Humber and North Yorkshire, The LMC and The Retreat, there is agreement by The Humber

²¹ FOIA Response, 2 May 2023

²² North Yorkshire and York Adult Autism and ADHD Assessment and Diagnosis Service Letter to GPs, 28 February 2023.

and North Yorkshire Health and Care Partnership to pilot the introduction of the following criteria for referral to assessment:

1. *Immediate self- harm or harm to others. A mental health assessment must have been undertaken and a crisis management plan in place;*
2. *Risk of being unable to have planned life-saving hospital treatment, operations, or care placement;*
3. *Imminent risk of family court decisions determined on diagnosis e. g family breakdown, custody hearing.*

The means that only people who meet one or more of these criteria will receive an assessment.

The pilot is intended to test the new referral process and the Do-it Profiler approach over the next three months. Evaluation of the pilot is expected to involve consultation with neurodiverse groups, statutory health and social care partners and Third Sector support groups.”

38. That letter also explained that the wait for referrals with The Retreat was currently approximately 20 months and that the piloted change would also apply to private providers who hold the NHS Standard Contract. This removed the patient’s Right to Choose, which is contrary to the NHS Constitution.
39. YDRF were informed of this decision on 16 March 2023, when the notes for a Neurodiversity & Mental Health Working Group Meeting on 20 March 2023 were circulated. During the meeting on 20 March 2023 concerns were raised about the proposed pilot, including: the lack of consultation and coproduction; the very restrictive criteria (especially in connection to the definition of harm being self-injury or threat to others *and* requiring a mental health assessment and a crisis plan in place. We are aware of people who have attempted suicide who have not been placed on a crisis plan due to existing failings within the mental health support in the local area); the lack of information or knowledge of the online profiler; and the importance of having a diagnosis in order to receive certain support. No changes were made due to the concerns of the members of the Working Group.
40. On 27 March 2023 the ADHD and Autism Pilot Pathway started. Under the pilot all new referrals for Autism and ADHD assessment would be directed through a web-based screening tool called the Do-It Profiler. The Vale of York CCG webpage explained:

“Commissioners in North Yorkshire and York have designed additional specific modules within the Do-IT Profiler system which are the ones determining eligibility for referral based on three assessment criteria. Commissioners have developed a mechanism for scoring the patient's response to the three eligibility criteria, and those who meet one or more of these directly to The Retreat for assessment.

(Note: The Do-IT Profiler itself does not make decisions on who is accepted or not for referral.)

All those who complete the profiler will receive immediate functional guidance and a unique profile describing strengths, challenges, and the skills to develop at home, socially and in the workplace.”²³

41. The effect of the Pilot Pathway is that only those people who meet the very strict criteria are able to access assessment and obtain a diagnosis. Everyone else is prevented from obtaining an assessment via the NHS, either locally or by patient’s exercising their Right to Choose in accordance with the NHS Constitution.
42. This is a serious degradation of duty by the ICB and one that must be remedied immediately.
43. On 9 May 2023, the ADHD and Autism Pilot Pathway was discussed again at the Neurodiversity & Mental Health Working Group Meeting. It was stated that when the pilot ended “[t]he experiences of people who have used the Do It Profiler firsthand will be important in helping to determine what a future referral pathway might look like. Healthwatch York is conducting an independent assessment when this pilot is concluded. Informed by this and our evaluation of the piloted approach, we intend to co-design the future pathway together with clinicians and other healthcare professionals – and people with lived experience of seeking a diagnosis for ADHD or autism who have either used the Do-It Profiler already or are likely to access the service in the future” and that “an Equality Impact Assessment was being undertaken in tandem with the pilot”.
44. In May 2023 Humber and North Yorkshire System Ethics Panel prepared a report entitled ‘Ethical considerations around North Yorkshire and York Adult Autism and ADHD Assessment and Diagnostic Service’ (the “Ethics Report”).
45. The Ethics Report included the following ethical concerns:
 - a. Failure to identify adults with autism and ADHD and direct them to an appropriate support service will result in harm occurring to those individuals; and
 - b. That label of a diagnosis may entitle the patient to certain benefits – financial, educational, social - which otherwise they would not receive.
46. However, the Ethics report concluded that:

“This proposal now satisfies the principles that make up distributive justice, in that;

 - it follows need principles, for those with the greatest need by addressing the degree of ill health and the time scale involved;*
 - it follows maximising principles by aiming to achieve maximum benefit to the greatest number;*
 - it follows egalitarian principles by equalising the opportunity for all to benefit”.*
47. As of 9 June 2023, the ICB did not hold a fully completed Equality Impact Assessment. It stated, in a FOIA Response, that an Integrated Impact Assessment, which includes an Equality Impact Assessment, was initiated as part of the project but that the Integrated Impact Assessment continues to be developed as the pilot progresses.

²³ <https://www.valeofyorkccg.nhs.uk/north-yorkshire-and-york-adult-adhd-and-autism-assessment-and-diagnostic-service1/>

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48. Unless and until the ICB has assessed the impact of the Pilot Pathway it must not continue to operate the pilot, as it is in breach of its duties under the Equality Act 2010 (see further below).
 49. An extension of the pilot was discussed at North Yorkshire Place Operational Delivery Group (PODG) on 13 June 2023 and York Place Senior Leadership Team on 14 June 2023.
 50. There are no minutes of 13 June 2023 meeting of North Yorkshire Place Operational Delivery Group, a further example of a breach of the ICB's transparency policy. A report entitled 'Adult Autism and ADHD Assessment and Diagnosis Service Referral Criteria and Alternative Web Based pathway' (the "June 2022 Report") was discussed and recommended an extension of the pilot.
 51. The updated figures reported 1600 referrals on the standard triage lists (an increase of 100 since November 2022). It is a concern that the movement of people from the triage list to the waiting list for assessments appears to have stalled entirely in this time.
 52. The June 2023 Report states that "*[p]reviously there was no system within the service for determining who has the most severe or complex needs, and referrals were assessed in chronological date order. Across healthcare the NHS has mechanisms in place to 'triage' services seeing those with the greatest clinical need first*". This is misleading, as the April 2022 Contract Specification provides for high-risk cases to be specially discussed with the commissioner and for mental health teams to be in charge of care for those with mental illness.
 53. An enhanced use of the Do-IT Profiler as a Red-Amber-Green (RAG) rating scale that can be used for people requesting assessment and support has been included in the proposal. There is a distinct lack of clarity concerning exactly what support would be offered to those remaining on the 'register', and no evidence has been presented for the benefit of this use. It is understood from implications cited in the June 2023 Report that the aim is for programmes and workshops to be developed using the data gathered from people completing the Do-It-Profiler. This change does not permit people who do not meet the strict assessment criteria to gain access to the waiting list for an assessment which is what the patients are seeking.
 54. Another proposed amendment was to include direct referrals from secondary mental health services, which would enable a 'fast-track' assessment for people with the greatest clinical need – and if applicable, also support a mental health diagnosis.
 55. The June 2023 Report also states, like the November 2022 Report, that alongside the introduction of a stricter referral criteria, Commissioners in Vale of York and North Yorkshire are currently working with TEWV to introduce a new model that will improve core Mental Health support for neurodivergent patients regardless of a diagnosis. However, no progress has been reported on the development of new models and a Healthwatch York report in June 2023 stated that people found "it hard, sometimes impossible, to access help when it is most needed" and that "there is no doubt that [York's] current system is letting people down to the point where some have died"²⁴. In

²⁴ 'Breaking Point', Healthwatch York June 2023

fact, at least two reports to Prevent Future Deaths from 2022 criticised TEWV for its lack of understanding of autistic people²⁵. It is perverse to suggest that already inadequate services can be improved sufficiently to eradicate the need for specialist assessment and diagnosis for autism and ADHD.

56. The June 2023 Report also states that the ICB would not be an 'outlier' as other areas are taking similar steps. No evidence has been supplied to support this assertion, and we have been unable to locate any ICB that operates such strict criteria to access assessment and support. Also, this Pilot Pathway only impacts two out of the six 'places' under the ICB which creates a postcode lottery for adequate healthcare.
57. The concerns cited in the Care Partnership's June 2023 Report include:
 - a. The right to an assessment and importance of a diagnosis is stated in the NHS National Framework to ensure people have access to reasonable adjustments and to provide clarity and validation;
 - b. Using data about individuals for a purpose it is not currently used for or in a new way, for example for profiling and service evaluation; and
 - c. The new criteria will mean that some individuals who would have previously received a referral for assessment and diagnosis will no longer be offered a diagnosis.
58. These are serious concerns, which show the recommendations to be unlawful, and the board should not have been asked to consider approval, much less action them.
59. It states that a full Equality Impact Assessment will be developed in consultation with people with lived experience and that a full Data Protection Impact Assessment will be completed with advice from the ICB Information Governance specialist. Despite the ongoing Pilot Pathway, these assessments have not been completed and published online by the Care Partnership as required by its statutory duties.
60. The timeline presented in the June 2023 Report provided that in September 2023 there would be an update on:
 - Healthwatch evaluation;
 - Three-month pilot evaluation;
 - Expanded criteria/direct referrals;
 - Development of support groups; and
 - Co-production and engagement.
61. The options presented to the North Yorkshire Place Operational Delivery Group and York Place Senior Leadership Team were:
 - Option 1: Revert to the original pathway;
 - Option 2: Fund the assessment and diagnostic service (original pathway) based on the level of demand (including the waiting list);
 - Option 3: Evaluate pilot after 3 months; and
 - Option 4: Extend pilot for a further 9 months.

²⁵ https://www.judiciary.uk/wp-content/uploads/2022/04/Zoe-Zaremba-Prevention-of-future-deaths-report-2022-0117_Published.pdf; https://www.judiciary.uk/wp-content/uploads/2022/09/Antony-McLellan-prevention-of-future-deaths-report-2022-0207_Published.pdf

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62. On 13 June 2023, North Yorkshire Place Operational Delivery Group (PODG):
- a. Considered and agreed the proposal to extend the pilot for nine months until March 2024;
 - b. Considered and agreed proposals to expand the acceptance criteria throughout the remaining pilot (subject to learning from the pilot);
 - c. Considered and agreed proposals to maintain a register of referrals on the Do-IT Profiler; and
 - d. Considered and agreed proposals for enhanced use of the Do-IT Profiler as a Red-Amber-Green (RAG) rating scale that can be used for people requesting assessment and support (including clear definitions of RAG statuses).
63. On 14 June 2023 the York Place Senior Leadership Team, met and:
- a. Members approved a proposal to extend the pilot for nine months until March 2024; however, the SLT requested that some of the features of the current extension be discussed in greater depth and rearticulated to reflect the discussion.
 - b. Supported proposals to expand the acceptance criteria throughout the remaining pilot.
 - c. Agreed to reconsider proposals to maintain a register of referrals on the Do-IT Profiler subject to discussion and rearticulation of options.
 - d. Supported proposals for enhanced use of the Do-IT Profiler as a Red-Amber-Green (RAG) rating scale that can be used for people requesting assessment and support.
64. A further meeting took place on 15 June 2023, but we do not have a record of what was discussed or agreed.
65. On 14 July 2023 the Vale of York CCG and North Yorkshire CCG²⁶ updated its website to announce that: *“Approval has been given to extend the pilot for a further nine months to 31 March 2024 to enable us to further improve our approach to assessment with the benefit of feedback from users and an independent review by Healthwatch York, an independent voice for patients”*.
66. The website states that during the pilot *“[the ICB] will also be working further with clinicians”* in order to develop an assessment pathway.
67. On 3 August 2023 Healthwatch York published its evaluation of the pilot²⁷. Concerns included:
- a. Lack of engagement with the neurodivergent community prior to the pilot being implemented;
 - b. The narrow referral criteria, especially the reliance on a crisis plan;
 - c. Whether HNYHCP considered the patient’s Right to Choose;
 - d. Whether the Digital Health Technology (DHT) used within the pathway meets the scientific rigour required for its use within a diagnostic pathway;
 - e. Whether the DHT used within the pathway meets the requirements for clinical risk management;

²⁶ <https://www.valeofyorkccg.nhs.uk/adult-autism-and-adhd-assessments-york-and-north-yorkshire/>

²⁷ <https://www.healthwatchyork.co.uk/our-work/hw-york-publications/>

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- f. Lack of consideration for wider NICE guidelines for the use of DHT to assist and inform patients;
 - g. Lack of consideration of NICE guidelines on the use of DHT to direct treatment and collect data to make service delivery decisions;
 - h. Lack of consideration made to the Public Sector Equality Duty;
 - i. Lack of consideration of data protection principles and legislation; and
 - j. Lack of consideration made to legal requirements of the 2016 Accessible Information Standard.
68. Healthwatch York and YDRF surveyed affected individuals and it was reported that the new approach was inaccessible for many who weren't online or needed help to fill in forms. Individuals reported that no help was provided when it was sought to complete the profiler. Many people who did not meet the criteria for further assessment felt abandoned and believed they must be in crisis or a risk to others to warrant support from the NHS.
69. The advice provided by the Do-It-Profiler was also reported to be "completely useless". It only offered generic advice, not access to treatment and additional support which is required by the NICE Guidelines.
70. One responder encapsulated the issue when stating: "*It is incredibly daunting to find out I am likely to have a condition that has caused me immense difficulty and distress throughout my life, and yet I have no viable or credible avenue open to me to access appropriate support to navigate this or access specialist treatment. I understand that those in urgent crisis need to be prioritised but I don't accept that the rest of us should be left by the wayside without access to explore a diagnosis and then specialist support or medication*".²⁸
71. Another reported that the Do-It-Profiler had not been accepted by their employer as evidence to make reasonable adjustments, and another stated that their employer required a diagnosis to make more than very basic adjustments. The Pilot Pathway therefore offered neither of these people any assistance in accessing the support they require.
72. The Response from the Care Partnership, included in the Healthwatch Report states "*Since the start of the pilot in March 2023 we have identified a number of adjustments based on user and clinical feedback including expanding the triage criteria. Everyone registered with the platform will be offered the opportunity to remain on a triage waiting list and, based on their needs, will be referred for an assessment or offered/signposted to appropriate relevant support*".
73. This is a grossly insufficient response to the serious problems with the pilot identified in the report and the statement is very misleading. It suggests that those on the 'triage waiting list' can access support and assessment when they cannot unless they meet the very strict eligibility criteria. There is no timescale for this waiting list, so people could be waiting for an indefinite amount of time and never actually access assessment. There has not been a significant expansion of the criteria, they are simply now allowing referrals from secondary mental health services.

²⁸ 'Pilot pathway for Autism and ADHD: Independent evaluation August 2023', Healthwatch York

74. Further, YDRF are aware that even those people who meet the very strict criteria (so are by definition 'in urgent need of assessment'), and have been referred for assessment have not yet received one. Some patients have reported that they have been waiting for the entire five months the pilot has been operating for any contact or clarity on next steps. The Pilot Pathway is therefore not even achieving its aim of prioritising those most in need.
75. We write at this juncture to alert the ICB to the serious legal deficiencies in their actions to date and to ensure that the ICB commits to pausing the pilot and to take the required action to ensure the new pathway is lawful. Should the ICB not take these steps it is likely that we will be instructed to bring legal proceedings against the ICB.

Public law grounds

Unlawful failure to adhere to statutory duties under NHS Act 2006 and NHS Constitution

76. Section 3 of the NHS Act 2006 which sets out the services that an ICB "*must*" provide, includes diagnosis and treatment services.
77. Section 1 of the NHS Constitution provides that the NHS is: "*available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status. The service is designed to improve, prevent, diagnose and treat both physical and mental health problems with equal regard. It has a duty to each and every individual that it serves and must respect their human rights. At the same time, it has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements and life expectancy are not keeping pace with the rest of the population*".
78. Section 14z32 of the NHS Act 2006 creates a duty to "*act with a view to securing that health services are provided in a way which promotes the NHS Constitution*".
79. Section 14z43 of the NHS Act 2006 provides that in making a decision about the exercise of its functions, an Integrated Care Board must have regard to all likely effects of the decision in relation to the quality of services for or in connection with the prevention, diagnosis or treatment of illness, as part of the health service in England.
80. In restricting access to assessment, diagnosis and specialised treatment for all but those in crisis, the ICB is acting contrary to its obligation to provide diagnostic and treatment services for Autism and ADHD, and is not treating physical and mental health problems with equal regard. The ICB has restricted healthcare for the neurodivergent community to generic online information.
81. This decision is a financial one. The ICB accepts that funding the assessment and diagnostic service (original pathway) based on the level of demand (including the waiting list) would "*meet legal/national requirements*", but decided not to do this. It has placed financial resource above its statutory duties to provide health care services.
82. The pilot is also directly contrary to the Right to Choose principle. The NHS constitution makes clear that "*you have the right to make choices about the services commissioned by NHS bodies and to information to support these choices*". This right includes choosing

which provider you would like to receive treatment from as an outpatient, provided they have the requisite NHS Contact, and allows a person to ask to be referred to a different provider if they have to wait longer than the maximum waiting times.

83. The ICB has applied this pilot to private providers who hold the NHS Standard Contract. This prevents individuals from exercising their Right to Choose and seek treatment from an alternative provider, and is a further breach of the NHS Constitution.

Unlawful failure to follow statutory guidance / NICE Guidelines

84. Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (March 2015) states that *“each local authority area should have an easily accessible autism diagnostic service”*. NHS bodies and NHS Foundation Trusts should provide access to services that can diagnose autism, and its frequently associated medical and mental health conditions. CCGs and NHS England should: *“Establish, maintain and promote autism diagnostic pathways, working with partners in local authorities. This includes giving appropriate post diagnostic advice and support; promote NICE best practice (e.g. where people seeking an autism diagnosis have a first appointment within 3 months of their referral) as set out in the NICE Quality Standard on autism [QS51]. GPs have an important role to play in recognising autism and knowing where to refer locally for a diagnosis and other support”*.
85. NICE Quality standard [QS51] provides *“People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral”*.
86. NICE guideline [NG87] ‘Attention deficit hyperactivity disorder: diagnosis and management’, states that formal intervention and guidance should only come following a formal diagnosis.
87. NHS England’s Guidance, ‘A national framework to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards’, expressly warns against this type of needs based assessment criteria and stresses the importance of a diagnosis (see paragraphs 16 to 21 above).
88. The ICB’s restriction of Autism diagnosis is also directly contradictory to Department of Health’s Autism Strategy 2021 – 2026 which states *“[r]eceiving a timely autism diagnosis is vital in getting the right support and helping autistic people and those supporting them to better understand their needs”*, and aims that by 2026 it *“will have made demonstrable progress on reducing diagnosis waiting times and improving diagnostic pathways for children, young people and adults across the country. Autistic people will be able to access a high quality and timely diagnosis, as well as the support they need following diagnosis”*.
89. NHS England’s Guidance, ‘A national framework to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards’ also sets out further duties which have been breached in this case, including ensuring that assessments are accessible, having transparent decision making procedures, and involving local communities in decision making.

90. The Framework goes on to explain how autism assessments should be available to all where clinically indicated; there is no suggestion whatsoever that assessments/diagnoses should be restricted to a limited group of people.
91. The Framework also sets out principles of autism assessment, which include that autism assessments are available to all, irrespective of gender, ethnicity and culture, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status and that the universal precautions approach to health literacy should be adopted within Autism assessment pathways. This approach calls for health care services and professionals to assume that all patients and family/carers can have difficulty understanding information and accessing services.
92. The universal precautions approach is to help address the negative impact of low health literacy on people and the health system. The Framework states that in England, 43% of adults do not have adequate literacy skills to routinely understand health information and 61% of adults do not have adequate numeracy skills in this regard. Variation in health literacy plays a powerful role in many health inequalities.
93. The Do-It-Profiler is only available online and requires a high level of literacy and IT skills and resources to access. No support is available to users, including interpreters or IT support. It is not a service accessible to all, and therefore many people are left with no way in which to access even this very low level guidance. In the March 2023 Working Group meeting, the commissioner stated that support would be available to help complete the profiler from primary healthcare services, but no support has been arranged. YDRF understood that social prescribers would be available but such support has not been available upon request, and individual social prescribers in the local area have reported to YDRF to be unaware of the expectation.
94. Transparency is a core principle of the ICB's Constitution²⁹ which states that it will:
 - a. provide information that is clear and easy to understand, free of jargon and in plain language;
 - b. be timely, targeted and proportionate in how we communicate and engage;
 - c. foster good relationships and trust by being open, honest and accountable;
 - d. ask people what they think and listen to their views;
 - e. talk to our communities including those most likely to be affected by any change;
 - f. provide feedback about decisions and explain how public and stakeholder views have had an impact;
 - g. work in partnership with other organisations in Humber and North Yorkshire;
 - h. use resources well to make sure we get the most out of what we have;
 - i. review and evaluate our work, using learning to make improvements.
95. The decision-making outlined above has only been discovered due to YDRF making FOIA requests. The ICB has been incredibly opaque concerning its decision making, by announcing the pilot only a week before it started in March 2023 to a group specifically designed to work on neurodivergence and mental health in York. The ICB then only announced the extension to the public on the defunct CCG website in July 2023, three weeks after the initial timeframe for the pilot ended.

²⁹ <https://www.england.nhs.uk/wp-content/uploads/2022/06/23-nhs-humber-and-north-yorkshire-icb-constitution-010722.pdf>

96. The local community cannot understand their own access to healthcare when limited information is only published on outdated websites in vague terms.
97. It is the ICB's duty to assess, plan and develop services in its area. NHS England's Guidance states that *"each ICB will need to establish how many people from the population it covers are likely to need an autism assessment during each commissioning cycle"* and that *"Autism assessment capacity modelling should recognise that autism assessment, by its nature, is time intensive. When planning capacity to meet predicted demand for an autism assessment offer, attention must be given to historical diagnostic rates of specific groups in each area to correct for historical inequalities"*.
98. The ICB did not correctly assess need as it only commissioned for 60 referrals per month when 180 were then being received within a few months. In this case 85% of referrals resulted in a diagnosis, which the ICB accepts indicates that these are appropriate referrals. The current situation is the result of the ICB's mismanagement and poor assessment of need when commissioning services. The result should be better investment, not a restriction of access.

Duty to consult

99. Under section 14Z45 of the NHS Act 2006, an ICB: *"must make arrangements to secure that individuals to whom services are being or may be provided, and their carers and representatives (if any) are involved (whether by being consulted or provided with information or in other ways):*
- a. In the planning of the commissioning arrangements by the integrated care board;*
 - b. In the development and consideration of proposals by the integrated care board for changes in the commissioning arrangements where the implementation of the proposals would have an impact on:*
 - (i) The manner in which the services are delivered to the individuals...or*
 - (ii) The range of health services available to them.*
 - c. In decisions of the integrated care board affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact"*.
100. The circumstances in which a duty to consult arises were summarised by the Divisional Court in *R (Plantagenet Alliance Ltd) v Secretary of State for Justice* [2014] EWHC 1662 Admin at [98]: *"First, where there is a statutory duty to consult. Second, where there has been a promise to consult. Third, where there has been an established practice of consultation. Fourth, where, in exceptional circumstances, a failure to consult would lead to conspicuous unfairness"*
101. The common law principles of fair consultation (commonly known as the *Gunning* principles) were set out in *Coughlan* (at [108]) and have since been endorsed by the Supreme Court in *R (Moseley) v LB Haringey* [2014] UKSC 56 (at [25]): *"First, that consultation must be at a time when proposals are still at a formative stage. Second, that the proposer must give sufficient reasons for any proposal to permit of intelligent consideration and response. Third ... that adequate time must be given for consideration and response and, finally, fourth, that the product of consultation must be conscientiously taken into account in finalising any statutory proposals"*.

102. The decision in question has made a significant impact to the range of services available. Therefore, a statutory duty to consult arises; this has not been carried out.
103. The ICB appears to accept that this is necessary. For example, on 9 June 2023 they state that *“we intend to co-design the future pathway together with clinicians and other healthcare professionals – and people with lived experience of seeking a diagnosis for ADHD or autism who have either used the Do-It Profiler already or are likely to access the service in the future”*. On 14 July 2023 the CCG website made clear that they would be seeking feedback from patients.
104. Despite this, YDRF is not aware of any attempt by the ICB to engage in consultation up to this point, nor any plans for a future formal consultation. This reflects further public law breaches, particularly because it has failed to consult with those affected by the decision.
105. The ICB has failed to consult to date, and continues to act unlawfully by failing to consult on the planned future changes.

Public Sector Equality Duty

106. Section 149 of the Equality Act 2010 provides:

“(1) A public authority must, in the exercise of its functions, have due regard to the need to—

(a) eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act;

(b) advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it

[...]

(3) Having due regard to the need to advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it involves having due regard, in particular, to the need to—

(a) remove or minimise disadvantages suffered by persons who share a relevant protected characteristic that are connected to that characteristic;

(b) take steps to meet the needs of persons who share a relevant protected characteristic that are different from the needs of persons who do not share it”.

107. A comprehensive outline of the relevant principles was given by the Court of Appeal in *Bracking v SSWP* [2013] EWCA Civ 1345 at [25] (approved at least provisionally by the Supreme Court (see Lord Neuberger in *Hotak v Southwark London Borough Council* [2016] AC 811 at [73] and [75]). In so doing, the Court of Appeal endorsed the following observation (from *R (Hurley & Moore) v Secretary of State for Business, Innovation and Skills* [2012] EWHC 201 (Admin)): *“In short, the decision maker must be clear precisely what the equality implications are when he puts them in the balance, and he must recognise the desirability of achieving them, but ultimately it is for him to decide what weight they should be given in the light of all relevant factors”*
108. The need for an Equality Impact Assessment has been recognised a number of times by the ICB but this has not been published, yet the Pilot Pathway is ongoing. People are being impacted – they are not being referred for assessment – but the ICB has not

properly considered the impact of what, by the end of the extended pilot, will be a year of its service.

109. Until the ICB has assessed the impact of the Pilot Pathway it cannot lawfully be in operation as the ICB has not fulfilled its statutory duty under s.149 of the Equality Act 2010. It is not sufficient to say that this assessment is underway, when the amended service is in force.
110. The Pilot Pathway must be stopped until a proper assessment has been completed to establish what the equality implications are.

Human Rights Act

111. It is unlawful for a public authority, like the ICB, to act in a way that is incompatible with the European Convention on Human Rights, as per section 6 of the Human Rights Act 1998.
112. Article 8 of the Convention provides that:
 - a. Everyone has the right to respect for their private and family life, their home and their correspondence.
 - b. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.
113. The concept of "*private life*" is broad, and is not susceptible to exhaustive definition. States are under a positive obligation to take appropriate measures to protect the life and health of those within their jurisdiction.
114. Article 14 requires that all of the rights and freedoms set out in the Act must be protected and applied without discrimination.
115. The current pilot, and potential future pathway, to the extent that it continues to limit access to assessment, may breach the rights of neurodivergent adults under Article 8 & 14 of the European Convention of Human Rights.
116. The ICB must act in accordance with the Convention and stop the pilot now, and consider its human rights obligations prior to taking any further steps.

Data protection

117. The Do-It-Profiler seeks the following limited consent from users:
 - a. *"I consent to this referral and to use and access the Do-It-Profiler and I understand that the information I enter may be seen by Do-It Solutions Ltd;*
 - b. *I consent to profile information I give being shared with The Retreat Clinics and my GP (typical membership of the clinical team includes psychologist, psychotherapists, psychiatrist, speech and language therapist, occupational therapist, counsellor);*

- c. *I consent for my information/data to be stored by NHS Humber & North Yorkshire Integrated Care Board on the North Yorkshire and York Platform for Autism/ADHD Referral;*
- d. *I consent to my data being used for the purposes of triaging my referral for referral and appropriate support”.*
118. Without providing consent to all four of these statements, the patient is told they will not be given access to the Do It Profiler and thus this is not genuine consent.
119. The user is not asked for consent to process their data for research and development. Without that consent the ICB is acting in breach of UK data protection legislation and must cease all processing immediately.
120. The ICB has recognised that the retention and use of the data obtained via the Do-It-Profiler may give rise to breaches of UK data protection legislation, but has continued to act in breach.
121. Again, it is not sufficient to say that an assessment is underway, when the amended service is in force and people’s data is being unlawfully processed.

Required Action

122. For the reasons set out above, the ICB is acting unlawfully in continuing with the Pilot Pathway and must immediately cease its operation.
123. If the ICB stops the Pilot Pathway and agrees to coproduce a solution, YDRF will support them in this process.
124. We consider the following steps to be the minimum necessary in order to properly consult and coproduce a solution to the long waits for ADHD and Autism assessments in York and North Yorkshire:
- a. Set up a specific webpage for updates and publications concerning the development of the new pathway and to provide regular public updates, including notes, minutes and reports from relevant meetings;
 - b. Publish all the Equality Impact Assessments and Integrated Impact Assessments connected to the Adult ADHD and Autism Pathway over the last 5 years;
 - c. Publish a detailed response to Healthwatch York’s Evaluation of the Pilot and other concerns raised in this letter and by other experts, including risk management and data protection concerns;
 - d. Request relevant details form providers and publish a comparison of the Adult ADHD and Autism Pathways in all six areas under the ICB including waiting timescales, assessment providers, numbers of Right to Choose referrals, and pre- and post-diagnostic support available;
 - e. Publish the research/evidence the ICB relies upon to assert that their actions are similar to those of other NHS authorities;
 - f. Specifically and meaningfully consult with interested groups including YDRF, Healthwatch York and other neurodivergent community groups on any options for any future Pilot Pathway; and
 - g. Open a public consultation to gather the views of those affected on any options for any future Pilot Pathway and evidence how these are taken into account.

125. Should the ICB not take these steps it is likely that we will be instructed to bring legal proceedings against the ICB.

Conclusion

126. Please provide a response within 14 days, i.e. by 3 October 2023.

127. If you wish to discuss this matter further, please contact Jessie Brennan using the information provided in the letterhead.

Yours faithfully

Bindmans LLP

Bindmans LLP