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3 October 2023

Your ref: 290750/1.JEBR  
Our ref: VOYY/SCL/AC-2009

Dear Ms Brennan,

### **ADHD and Autism Pilot Pathway**

I am writing to you further to my acknowledgement on 20 September 2023.

The ICB is grateful to you and your client's for taking the time to write such a detailed and comprehensive letter to us and offering us an opportunity to respond to this prior to engaging in any specific legal proceedings. It is fair to say that the ICB does not accept the totality of your correspondence however there are a number of matters within the correspondence which the ICB acknowledge and would welcome the opportunity to discuss with you further. I will return to these.

Paragraph 122 onwards of your letter relates to what you have termed 'required action'. I will address these matters before returning to other points raised within the correspondence.

### **Summary of Required Action**

#### 1. Cease the Pilot Pathway

The ICB is not in a position to cease the pilot pathway at this stage. There are a number of reasons for this not least the fact that the ICB was in the position that the provider of services was no longer able to meet demand and assess the referrals that had been made to clarify whether the individuals were eligible for assessment and diagnosis. The provider sought support from the ICB to find a way in which those waiting would receive some support and guidance whilst they waited and enable them to review the most at risk individuals first for the purposes of assessment and diagnosis.

It is within this context and a significant increase in referrals that the ICB has had to take the steps which it has taken. None of these steps prevent someone from remaining on the waiting list for assessment and diagnosis provided that they meet the NICE eligibility for an assessment however this does ensure

that those who are not regarded as the highest risk individuals will also be able to access advice and guidance from the online platform to stay well whilst they wait and some may choose to come off the waiting list at that point.

The ICB has determined that it was appropriate to undertake a pilot to allow the ICB to test different pathways and engage with those affected by the change. Ideally the ICB would have planned a programme of engagement before commencing the pilot pathway; for example where an existing contract is coming to an end and the ICB wishes to consider different ways of delivering the service before procuring it would engage with those affected and take that information into consideration when developing and commissioning the service provider. That has not been possible in this case and the ICB legacy organisations had already commissioned a 5 year contracted service based on projected activity levels which were established on the basis of known previous activity levels and prevalence. Within the term of the contract the provider raised concerns during contract management meetings that the activity was far higher than had previously been the case and based on the activity anticipated within the contract effectively the provider would have used the value of the contract long before the end of the five year term. On top of that the provider did not have the capacity to assess the referrals to see which of those met the criteria for assessment; and this may in effect mean that the waiting list is longer than it ought to be if there are individuals on the list who do not meet the criteria for an assessment. Both the provider and the ICB agreed to jointly consider the options to keep the service operating at the commissioned level as a priority.

Instead, the ICB has had to undertake the pilot to ensure that the contracted service for the provision of ADHD and Autism assessment could continue to assess patients based on eligibility and risk. If the ICB had not taken these steps, the waiting list would have had to close and it is likely that there would have been no provision available for those awaiting assessment. This was in part due to the waiting list having reached a time of 5 years and the provider being concerned about holding this risk and CQC concerns raised about the length of the waiting list.

The ICB was also concerned that even if the provider did not close the list or serve notice on the contract, it was now aware that due to a significant increase in referrals, those patients who were waiting on the list were not in receipt of clinical triage and risk assessment or any advice and support whilst they waited. The online platform was a remedy to this risk but does not remove anyone from the waiting list for a formal assessment.

The ICB also does not shy away from the fact that there is a financial element to the decision which has been reached. This is not based upon the additional cost of a number of patients utilising private providers for assessments but was based on an unexpected increase in referrals. The ICB however, has had to increase the spend on the service provision to some degree to allow for the on line platform to be made available to patients. The ICB did discuss with the incumbent provider whether there was scope to recruit additional staff to provide more capacity and it was advised that due to a national shortage in the specialist skill set this would not be possible.

The ICB was committed to making sure that everyone had access to support whilst they waited and is also mindful of the fact that financially a provision had been commissioned which had used the financial envelope available. That financial envelope was based on good data on previous referral rates and known prevalence however there has since been an unexpected surge in demand for the service with no additional funding or workforce available to meet that demand. It is important to note that historically the ICB had funded referrals to private providers individually however even those private providers had developed waiting lists of up to 2 years for patients to be seen.

## 2. Coproduction of a solution to the long waiting list for ADHD and Autism

The ICB recognises that it has a statutory duty to involve patients and the public in decisions about the planning and provision of health and care services and undertakes this way in a number of ways. The ICB is required to make commissioning decisions and would not coproduce commissioned services but would welcome a discussion with YDRF and others as part of the engagement work which it has planned and would welcome alternative thoughts and ideas as to how this might be delivered.

### 3. Specific steps requested by YDRF:

- a. Set up a specific webpage for updates and publications concerning the development of the new pathway.

The ICB is committed to providing a specific webpage for updates and publications concerning the development of the new pathway. This is intended to be on the ICB website however it may be that the former CCG websites are also utilised if these remain the live 'Place' websites for the ICB at the time.

- b. Publish all the Equality Impact Assessments and Integrated Impact Assessments connected to the Adult ADHD and Autism Pathway over the last 5 year.

The ICB is committed to providing the IIA that has been undertaken in respect of the decision made to continue the pilot for 9 months. This will be available on the website along with the paper and the notes of the meeting where decisions have been taken.

- c. Publish a detailed response to the 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.

The ICB is developing an engagement plan which will cover these matters. This engagement plan is being developed with the input of Healthwatch following their initial report. The first meetings are planned for November 2023 and the ICB will ensure that the engagement plan, once finalised, is made available. The purpose of the Pilot however is in part to enable the ICB to gather information and make adjustments to the service provision throughout the life span of the pilot and see whether that results in more positive experiences. For that reason the ICB has to prioritise its staff and services into developing the pathway rather than providing detailed responses to concerns raised on the website. That does not mean the ICB disregards the concerns raised but that the concerns are used as part of the development of the service.

- d. Request relevant details from providers and publish a comparison of the Adult ADHD and Autism Pathways in all six areas under the ICB.

The ICB has started to request this information and can confirm initially that one of the six places have closed the waiting list for ADHD and autism assessments due to demand and another has commenced a similar triage process to the one in North Yorkshire and York.

- e. Publish the research/evidence the ICB relies upon to assert that their actions are similar to those of other NHS authorities.

Again, the ICB would intend to discuss this with stakeholders as part of the engagement throughout the lifespan of the pilot.

- f. Specifically and meaningfully consult with interested groups

As stated above, the ICB is developing an engagement plan to ensure that its statutory duty to consult is discharged throughout the life of the pilot.

- g. Open a public consultation to gather the views of those affected

As stated above, the ICB is developing an engagement plan to ensure that its statutory duty to consult is discharged throughout the life of the pilot.

#### **Other matters raised in your letter**

The ICB acknowledges that it could have approached the launch of the pilot more openly with service users and organisations supporting them. This would not have changed the fact that the pilot was

necessary however it would have ensured that those affected by it understood the proposed pilot and how they could influence the future of the service and indeed the pilot as it progressed.

Acknowledging that the ICB would welcome the opportunity to meet with your clients and understand from them the feedback that they have received and the impact that this has had on service users to date. The ICB would also welcome YDRFs involvement in the engagement work which is being undertaken including suggestions and observations about how the service may be commissioned differently in the future. The ICB is not offering coproduction but meaningful engagement and consultation on the future of this service.

I look forward to hearing from you in relation to the request to meet with your clients and unless you feel it is necessary I do not propose to have the lawyer present for that meeting. If you feel it would assist to discuss this response or next steps with me any further I am of course happy to do so.

Yours sincerely

A handwritten signature in black ink, appearing to read 'A Combes', written in a cursive style.

Abigail Combes  
Deputy Director of Legal and Regulatory Functions  
NHS Humber and North Yorkshire ICB