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NHS Humber and North Yorkshire ICB  
Legal Services

Our Ref: 290750/1.JEBR

**By email only:**  
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Date: 20 October 2023

Dear Sirs

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

1. We write in response to the ICB's letter of 3 October 2023 ("the Response").
2. York Disability Rights Forum ("YDRF") welcomes the ICB's acceptance that could have approached the launch of the Pilot Pathway more openly with service users and organisations supporting them and the ICB's commitment to consultation on the future of the service.
3. However, the ICB's response fails to engage with the risks that arise when an individual is refused access to assessment and support and that limiting funding in this way will have a detrimental impact on the health of many adults under its care.
4. The ICB also fails to address the legal arguments presented, offering no reassurance to YDRF or the wider community that the current pilot is lawful.
5. We maintain that the Pilot Pathway is unlawful for the reasons outlined in our letter of 19 September 2023 (the "September Letter"), but at this time YDRF is willing to engage with the ICB to find a suitable solution to the ICB's previous failure to adequately fund this care.
6. YDRF is also very discouraged that the ICB is not willing to coproduce a solution to this issue. The ICB's refusal evidences a dismissal of people with lived experience of Autism and ADHD, who are often best placed to advise on what support and services will make a positive difference to their lives. YDRF are willing to offer the ICB their expertise and time free of charge in order to improve services, but in order for this to be successful the ICB must approach this issue openly, and be willing to listen and change its course as required. The ICB must enter into this consultation with an open mind.

### **Consultation**

7. In the Response the ICB commits to consultation on the future of the service. As the ICB will be aware, consultation must be carried out in accordance with the *Gunning* principles:

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- a. Consultation must be at a time when proposals are still at a formative stage, i.e. a decision must not have been made;
  - b. The proposer must give sufficient reasons for any proposal to permit of intelligent consideration and response;
  - c. Adequate time must be given for consideration and response; and
  - d. The product of consultation must be conscientiously taken into account in finalising any statutory proposals.
8. Consultation is not a “*discussion*” as the ICB appears to conflate it with in the Response.
9. With these principles in mind we make the following requests, some of which were also requested in the September Letter:
- a. Publication of the engagement plan within 14 days.

It has been seven months since the Pilot Pathway started, and four months since the extension, and this document should have been completed. The ICB heavily relies on actions which will be set out in this plan in the Response and therefore it is essential that we see the proposed steps in order to establish whether adequate consultation is being undertaken.

- b. Publication of all the Equality Impact Assessments and Integrated Impact Assessments connected to the Adult ADHD and Autism Pathway over the last 5 years.

In the Response the ICB agrees to publish the Integrated Impact Assessments for extending the pilot for 9 months only. The ICB provides no justification for its refusal to publish the other assessments. We submit that there is no justification for its position. Without these assessments responders to the consultation do not have sufficient understanding of the ICB’s reasons to permit an intelligent consideration and response.

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

Again this information is required to understand the ICB’s reasons and not providing it reflects a breach of the *Gunning* principles. The Response states that the “*ICB would intend to discuss this with stakeholders as part of the engagement*”, which is vague and insufficient.

In relation to the other six areas of the ICB the Response states “*the ICB has started to request this information*”, and provides initial information concerning two unidentified areas. The June 2023 Report, which approval for the extension of the Pilot Pathway was based on, stated the ICB “*would not be an outlier as other areas were taking similar steps*”. Either the ICB has this evidence, and must publish it as part of the consultation, or it does not and so inaccurately presented information to the decision makers. Clarification from the ICB as to which of these options is correct is required by way of response.

- d. Provide the details of the webpage for updates on the pilot.

Again, we are seven months into the Pilot Pathway and this webpage should have already been set up. If it has not been set up yet please provide a date for completion.

#### *Proposed Meeting*

10. We can confirm YDRF wish to accept the invitation to a meeting with the ICB. YDRF is agreeable to not have legal representatives attend and requests that the meeting takes place in person.
11. Members of YDRF are not able to take detailed notes during meetings and ask that the meeting is recorded so an accurate record is held.
12. Please provide some proposed dates/times over the next 6 weeks.

#### **Other issues**

13. We also take this opportunity to raise some additional issues from the Response.
14. First, the Response states "*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*". That statement is incredibly misleading. A person being referred under the Pilot Pathway cannot access assessment or diagnosis unless they meet the three criteria set out in the Pilot Pathway and are then triaged for assessment. Any list of people who completed the Do-It Profiler but did not meet the pilot criteria is a list of people who cannot access assessment, this is not a waiting list. These people receive poor quality general advice from the Do-It Profiler and then remain on a list for no known purpose. The ICB must publicly confirm this, that anyone who does not meet the pilot criteria will not be able to access assessment or diagnosis unless or until the ICB's commissioning arrangements are amended.
15. Second, the Response also misrepresents the NHS Right to Choose as mandated by the NHS Constitution, by stating "historically the ICB had funded referrals to private providers". As the ICB is aware, and explained in 19 September 2023 letter, the Right to Choose 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. Again on this issue the ICB states that waiting lists for private providers are up to 2 years without providing any evidence or names of these private providers.
16. Third, the ICB wrote to GPs in the relevant areas on 26 September 2023 to notify GPs of the extension to the pilot and another change to the acceptance criteria. The reference to risk of imminent self-harm has been removed and now one of the Pilot Pathway criteria is receipt of a direct referral from the Community Mental Health Teams. This change was not mentioned in the Response, which highlights the lack of

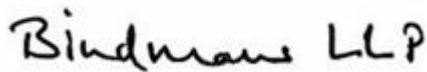
transparency and openness shown by the ICB and is in breach of the ICB's duty of candour.

17. This change was also made without any consultation with the community or notification to the public. The original changes presented to the North Yorkshire Place Operational Delivery Group and York Place Senior Leadership Team in June 2023 was for an expansion of the direct referrals, there was no mention of the removal of the self-harm requirement in the papers we have seen. This is a significant change to the criteria and a change which removes people under the care of the Community Mental Health Team to use the Do-It Profiler, so should have been consulted on. Please explain how the decision further amend the criteria was taken and provide the underlying records.
18. For the avoidance of doubt this amendment does not expand access to assessment for many people as access to Community Mental Health support is very difficult to obtain due to these services being very over prescribed in the area.
19. Finally, YDRF submitted a FOIA request on 16 September (copy **enclosed**). A response was due on 13 October 2023 but has not been received. Please provide a response for this request with the reply to this letter.

#### **Conclusion**

20. Please respond with propose dates within 7 days and the requested information within 14 days.

Yours faithfully



**Bindmans LLP**