



Meeting Minutes

Meeting with York Disability Rights Forum, ICB and The Retreat

Thursday, 4th April 2023

12:30 pm – 2:00 pm

West Offices

Attendees:

Dr. Peter Billingsley (ICB)

Guy Richardson (The Retreat)

Hazel Kerrison (YDRF)

Helen Jones – Chair (YDRF)

Hilary Conroy (YDRF)

Jacob Gilson (ICB)

Kirsty Kitching (ICB)

Michelle Carrington (ICB)

Rick Taylor (YDRF)

Ruth Dixon (The Retreat)

Stephen Simpson (The Retreat)

Apologies:

Liam Goodwin (The Retreat)

1. Declaration of Interests

1.1. There were no declarations of interests stated during the meeting.

2. Update from The Retreat

2.1. Stephen provided an update on the current capacity at The Retreat. It was highlighted that there is a significant demand for autism and ADHD assessments, surpassing the available capacity. Specific numbers shared by Stephen can be referenced in **Appendix 1**.

2.2. The actual assessment appointment is relatively quick, lasting approximately 3 – 5 hours. However, a substantial amount of time is allocated to gather necessary information prior to the assessment appointment, this requires time for the client to complete forms to provide the information and for clinicians to review the returned information. In response to this challenge, The Retreat has introduced a new assessment process aimed at better meeting the needs of service users and enhancing efficiency. While this new process is more effective in terms of minimising the number of visits required for assessment appointments, it does not necessarily increase the overall capacity for assessments. It was also acknowledged for clients whose assessments are more complex this further appointments will be needed, something that The Retreat have factored in within their pathways.

2.3. Regarding the ADHD assessment process, Stephen noted that it remains unchanged. He also posed a question to YDRF regarding potential strategies to streamline the data collection stage of the assessment process. In addressing this, The Retreat is exploring the possibility of utilising online forms.

2.4. It was highlighted that approximately two-thirds of referrals were accepted at triage. This data is specifically from the 'triage month' and is variable for 'standard' referrals. The



remaining one-third of referrals were rejected in the triage month for various reasons, i.e. not suitable, too complex, not enough information etc. However, service users have the opportunity to resubmit their referral with the required information, and in such cases, their original referral will be backdated only in the circumstance that information was originally missing

3. Voices from the Neurodivergent Community

- 3.1.** Hilary began the discussion on the next agenda item, reporting that 12 individuals participated in the focus group. Several key outcomes emerged from the discussions, including the necessity for incorporating the voices of lived experience in decision-making processes. Additionally, concerns were raised regarding the legality of certain aspects of the assessment process, the burden of excessive paperwork, and the tendency to overlook women.
- 3.2.** Participants of the focus group expressed their aspirations for the assessment pathway to prioritise feeling heard, having their perspectives acknowledged, and fostering a more personalised approach. An artwork reflecting current emotions and hopeful aspirations of service users is included in **Appendix 2**.
- 3.3.** One prevalent theme highlighted was the challenges posed by General Practitioners (GPs) and the Do It Platform. Participants expressed dissatisfaction with the Do It Platform's questionnaire, citing misleading questions and poorly formatted PDFs. Suggestions for improvement included transitioning towards more face-to-face interactions, providing coaching, and fostering supportive environments in workplaces and among employers while awaiting assessment.
- 3.4.** Additional recommendations included providing access to health and wellbeing workers, involving Primary Care Networks in supporting the entire assessment pathway, and recognising the validity of self-diagnosis within organisations.
- 3.5.** Rick then shared his personal experience with the Do It Platform. He noted encountering broken links and redundant information in his report, which posed challenges when sharing the report with his employer. Rick raised concerns about the impact of such errors on individuals and questioned the security measures of the platform, particularly regarding staff logins and authentication methods.
- 3.6.** Dr. Billingsley clarified that the Do It Platform is currently password-protected and assured compliance with all GDPR laws and regulations.

4. Do It Platform

- 4.1.** During the meeting, Kirsty began a discussion on leveraging online tools and resources to support individuals. In response, Hilary expressed concerns about the continued use of the Do It Platform by the ICB. She emphasised the need for functional support to be provided face-to-face by local groups, highlighting limitations and accessibility issues associated with the platform.



- 4.2. Hazel echoed Hilary's opinions, noting that screen readers do not function effectively with the Do It Platform, rendering it inaccessible to certain users. Additionally, she raised concerns about the platform's section on Work and Education, which is not skippable. This lack of flexibility can be problematic for individuals who are not currently engaged in either work or education.
- 4.3. The consensus among the group was that reliance on the Do It Platform support may not be contributing to meeting the diverse needs of individuals, particularly those with accessibility requirements or unique circumstances. Moving forward, the group agreed to explore the idea on the importance of exploring alternative methods of providing support, such as face-to-face interactions and local support groups, to ensure inclusivity and accessibility for all.

5. Proposal for Exiting Pilot

- 5.1. In the next stage of the pilot, TEWV and General Practitioners (GPs) will be empowered to make direct referrals for service users who meet the national criteria. This shift aims to streamline the referral process for those who meet national criteria, providing more direct access to assessment and support services. While individuals referred through this channel will bypass the Do It Platform, they will still have the option to create an account, granting them access to a range of available support resources tailored to their needs.
- 5.2. To ensure a seamless transition and to provide support to individuals navigating the referral process, the Referral Support Team will be readily available to assist anyone with their referrals. This dedicated team will serve as a valuable resource, offering guidance and assistance to service users and professionals alike, thereby fostering a more supportive and efficient pathway.
- 5.3. Furthermore, as we embark on this new phase, the ICB will take on the responsibility of developing autism and ADHD services for the North Yorkshire and York regions. It is imperative to recognise that the challenges and needs faced within our areas are not isolated incidents; rather, they reflect broader trends observed nationally. With this understanding, the ICB is committed to addressing autism and ADHD concerns comprehensively across the entire ICB footprint. By adopting a holistic approach, we aim to ensure consistency and effectiveness in our service delivery, thereby enhancing outcomes for individuals across the region.
- 5.4. In addition to developing services within our designated regions, the ICB is actively exploring avenues to address autism and ADHD concerns across the entire footprint, recognising the interconnectedness of communities and the importance of collaboration in driving meaningful change.

6. Next Steps

- 6.1. Recent developments within NHS England have seen the establishment of an ADHD Task Force, aimed at gaining a deeper understanding of the challenges faced by individuals with ADHD and implementing a coordinated approach to address concerns surrounding rising demand for services. This initiative reflects a commitment to better support individuals with ADHD and underscores the importance of collaboration in developing effective solutions.



- 6.2. During the meeting, Hilary proposed a change in terminology from 'waiting list' to 'holding list', emphasising that individuals awaiting assessment are not merely waiting but rather being held on a list. This shift in terminology aims to accurately reflect the status of individuals within the system.
 - 6.3. Dr. Billingsley provided insights into the current demand for assessments, noting that saturation point has not yet been reached. However, Ruth highlighted the continuing challenges faced by The Retreat in scaling up assessments, citing workforce and recruitment issues as significant barriers.
 - 6.4. In response to these challenges, YDRF expressed a desire to reconvene with the ICB in a month to further discuss strategies for addressing concerns and improving service delivery.
 - 6.5. The discussion then turned to Right to Choose, with Kirsty informing the group that none of the Right to Choose requests had been rejected thus far. A Shared Care Agreement has been established to address the increasing number of individuals receiving ADHD diagnoses outside of the NHS but seeking medication through NHS services. This development has placed additional pressure on The Retreat.
 - 6.6. Hazel raised questions regarding the prescription of ADHD medication by GPs, prompting Dr. Billingsley to clarify that ADHD medication is considered specialist medication and therefore requires prescription by specialist care providers. Ruth suggested transitioning to online referral forms to streamline the process and improve efficiency. Additionally, she emphasised the importance of ensuring the accuracy and accessibility of referral forms, with YDRF offering their support in this regard to ensure questions are worded correctly and forms are accessible to all individuals.
7. **Meeting Concluded:**
 - 7.1. The meeting concluded with participants expressing their commitment to addressing challenges and improving service delivery for individuals with neurodiverse conditions.
8. **Next Meeting:**
 - 8.1. **Date:** Thursday, 2nd 9th May 2024
 - 8.2. **Time:** 12:30 pm – 2:00 pm
 - 8.3. **Location:** West Offices



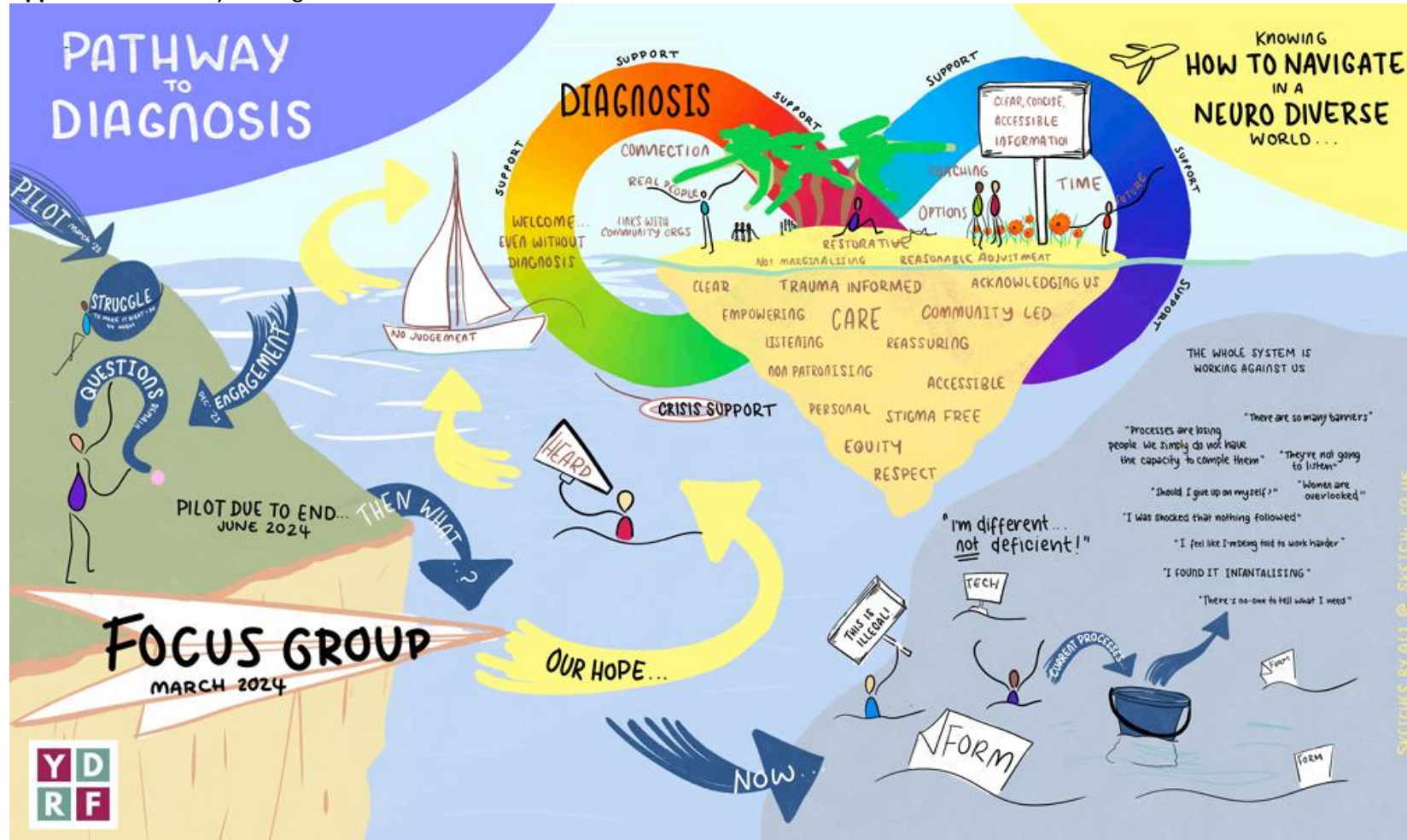
9. Appendices:

9.1. Appendix 1: Assessment Service Data

Autism & ADHD Service Numbers	
<u>Referrals</u>	
Commissioned in April 2022 – expected referral numbers = 60 per month covering both Autism & ADHD (720 per annum) Capacity and cost based on these including Triage of all new referrals	
April 2022 – March 2024 expected referrals = 1440 (2x 720) per annum	
April 2022 – March 2024 Actual referrals = 3750 (160% more than expected) excludes DIP refs.	
Expedite Triage – was not considered in early contract but now and added capacity issue 2023-24 = 251	
<u>Commissioned assessment numbers</u>	
Year 1 	
179 Autism Assessments	
242 ADHD Assessments	
Of the ADHD Assessments it was estimated that approximately 142 med reviews	
Year 2/3/4/5/6/7	
214 Autism Assessments	
297 ADHD Assessments	
Of the ADHD Assessments it was estimated that approximately 166 med reviews	
<u>Current waiting lists</u>	
ADHD Assessment Expedite - Accepted	22
ADHD Contract - Expedite Requests Triage	34
Autism Contract - Expedite Requests Triage	12
ADHD Adult Contract - Assessment	1609
ADHD Adult Contract - CAMHS Transfer Med Review/Annual	65
ADHD Adult Contract - Expedite Med Review	2
ADHD Adult Contract – Annual Med Review	314
ADHD Adult Contract – Single Med Review	471
ADHD Adult Contract - Med Review Triage	11
ADHD Adult Contract – Med’s titration	178
Adult Autism - Diagnostic assessment waiting list	1091
Adult Autism & ADHD - Awaiting 1:1 THERAPY	59
Adult Autism & ADHD - Current Therapeutic Work	44
Adult Autism & ADHD - Therapy Referral Triage	7
Adult Autism Contract - P-D Group - F2F	27
Adult Autism Contract - P-D Group - Online	45
Adult Autism Contract - P-D Individual - F2F	25
Adult Autism Contract - P-D Individual - Online	21
ASD-ADHD Adult - Diagnostic Assessment Triage	1063
DIP referrals	471
Total	5756
DIP referral waiting list =471	
Additional 180 not uploaded without information.	



9.2. Appendix 2: Pathway to Diagnosis Artwork





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