NHS Humber North Yorkshire Integrated Care Board response to draft report:
Pilot pathway for Autism and ADHD: Independent (Healthwatch York)

July 2023

We acknowledge receipt of the report and thank Healthwatch York for sharing this insight from users with us. The experience of our patients is our priority, and we actively review our approach based on the feedback we receive.

This report will become part of the body of evidence that helps us improve our approach to adult autism and ADHD assessment, and continue conversions with people with lived experience, clinicians and partners in the months ahead.

We would also like to acknowledge that the pilot aims to identify those most at risk and channel them towards a face-to-face intervention with the specialist provider while allowing others, who might have had to wait years for a diagnosis, to access help online at a much earlier stage. Previously, all referrals were assessed in chronological date order and there was no system for identifying those people who needed help more urgently. The changes are in the context of growing demand for adult autism and ADHD assessments resulting in unacceptable wait times and the need to prioritise resources towards most at-risk adults.

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.

Data from the Profiler can help us understand where the greatest need is to develop the most relevant programmes and workshops for people needing support. This enables us to provide targeted information about functional skills such as time management, organisation, dealing with anxiety and low mood and understanding local pathways to services.

<u>Points of factual accuracy</u>

- The pilot is across both North Yorkshire and York, not just the communities named.

<u>Points for clarification</u>

- Would it be possible to include quantitative data from the survey in the body of the report alongside personal stories?
- Do we have any understanding of where the participants of this work are from – do they represent voices from North Yorkshire and York or York only?

- The report references 2,216 participant at the beginning of the report but the numbers that follow don't seem to add up. Can you say more about the totality of the participation number.

Initial response to recommendations

Action	Responsibility	ICB initial response
Review the referral criteria, working with leading academics within neurodiversity.	HNYHCP	The referral criteria remain under review and we have already implemented adjustments. We will continue to be informed by the experience of users as our approach develops.
Review all the feedback available, involving relevant and appropriate partners.	HNYHCP	We will continue to review feedback and insight received from all sources and use this to inform future decision making.
Commit to investing in meaningful community engagement throughout the commissioning cycle.	HNYHCP	We will continue involving people through the development of our approach to adult autism and ADHD assessments including a programme of work in the autumn to gather further insight from people with lived experience.
Commit to providing the resources necessary to support those not able to access the pathway in its current form, communicating how this will be provided.	HNYHCP	Health professionals are able to make direct referrals to The Retreat for people unable to access the platform. First Contact Mental Health Professionals in Primary Care are also supporting people to access the platform.
Investigate the use of the Do-It Profiler as a digital health technology in accordance with guidance and legislation. This should include the completion of a clinical risk assessment and equality/discrimination assessment.	HNYHCP	A full EQIA including a clinical risk assessment has been developed. Implementation of the pilot was also approved by the Humber and North Yorkshire ICB Ethics Committee. In addition, the ICB is leading a collaborative working group to explore the Adult Autism / ADHD referral pathways across the ICB geography. Information on the use of the Do-IT Profiler as a digital health technology is set out in Annex 1.
Provide effective 'waiting well' initiatives that are accessible to all, working in partnership with others to understand what would produce the best outcomes for people for the best price.	MHP	Data from the platform shows the number of people experiencing mental health issues and data from the sensory profile can be used to map support activity such as executive functioning, independent living skills, time management/organisation, dealing with anxiety and low mood and understanding local pathways to services. The aim is to develop programmes/workshops for people needing such support.

Implement a strategy for neurodiverse service market growth, ensuring a preventative approach to commissioning and delivering.	HNYHCP / MHP	Noted.
Immediately amend the pilot in accordance with legislation and best practice.	HNYHCP	Noted.

We will listen to the concerns which have been shared with us and continue to work with clinicians, other healthcare professionals and people with lived experience of seeking a diagnosis for ADHD or autism to help develop a responsive assessment pathway for the future.

Annex 1 Use of the profiler as a digital health tool

Neurodiverse conditions are complex and interrelated, they have high levels of symptom commonality with other conditions. The DIP takes a dimensional approach which consider an individual's unique needs as a whole, rather than determining whether the individual fits certain diagnostic criteria and providing support only if these diagnostic criteria are met. Dimensional approaches are needs-led rather than diagnosis-led.

A shift away from categorical approaches towards more holistic, profile-based, dimensional approaches have been suggested by some psychiatrists (NIMH, 2014). This approach creates a formulation-based assessment and management plan based on all of an individual's needs, whether they group neatly into diagnostic criteria or not. The key areas of challenge for that individual are identified with respect to their current social and physical environment and appropriate, holistic support is provided.

Dimensional approaches are also typically person-centred – they put the person first and consider them as an individual rather than a category or type. Person-centred approaches are often based on a biopsychosocial model of disability.

The approach taken with Do-IT Profiler is to understand the person in the context of their lives past and present and deliver contextual guidance dependent on the specific profile.

The system is set up in modules which the person completes or additional information is gathered from other sources where triangulation of information is relevant and further improves the data gathering.

Module content in each Profiler pack may be dependent on age and context. Each module is designed in the way it is presented dependent on this e.g.

- Length of module – this considers those who may have attention difficulties associated with ADHD
- Content and layout design – voicing and length of sentences are considered for those with challenges associated with Dyslexia, Literacy, Working memory.
- Presentation of information e.g., use of pictures and voicing may be dependent on age of the person
- Item choice – this is dependent on the specific screening e.g., neurodiversity screener has items that are related to specific cognitive areas. Development of items has been undertaken using Delphi consensus methods to agree content and then tested on typically developing mainstream and specific/clinical populations with known conditions.
- Selected focal areas – this has been drawn from work over the past 10 years by Smythe and Kirby with recognised research expertise in Neurodiversity.

Profiler does not attempt to draw comparisons with other learners/individuals by referring to age or grade equivalence as the aim is to identify the pattern of challenges within the individual to target support and guide provision.

Profiler uses a combination of written and visual guides in individual reports. As a criterion based system, the primary reporting method are raw scores, with detailed error analyses.

To help management and monitor progress, Profiler converts these to four levels to flag levels of support needs and strengths.

- • Good Skills (Green)
- • Reasonable Skills (Blue)
- • Some Challenges (Orange)
- • Significant Challenges (Red)

By reviewing results across modules, it is possible to identify the areas of challenge and the order in which they should be addressed but also crucially understand other factors that may constraining success internally or externally.