

Executive Summary: ADHD and Autism Pilot Pathway: An independent assessment

Introduction

From 27 March 2023 to 27 June 2023 a pilot for a new ADHD and autism assessment pathway for adults was trialled. This trial was implemented by Humber and North Yorkshire Health and Care Partnership (HNYHCP) and took place in York and North Yorkshire.

The full report, ADHD and Autism Pilot Pathway: An independent assessment, is available at:

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

The pilot pathway

The pilot introduces the following criteria for referral for assessment:

1. Immediate self-harm or harm to others. A mental health assessment must have been undertaken and a crisis management plan put 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.

Only those who meet one or more of the criteria will receive an assessment. The pilot also introduced a web-based system as entry to the pathway.

Key findings

Healthwatch York worked with York Disability Rights Forum (YDRF) to get feedback and heard from 245 people. The report found significant issues with the piloted approach. The pilot led everyone to an online tool, the Do-It Profiler. Only those who met specific criteria were referred for further assessment. Everyone else was provided with a report and signposted to online resources. For these people, there was no further healthcare contact or support.

People reported that the new approach was inaccessible for people who weren't online or needed help to fill in forms. 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 a diagnosis and treatment or support. Healthwatch York also found that the pilot approach may have contravened equality legislation and current guidance.

Recommendations

| Action | Responsibility |
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| Review the referral criteria, working with leading academics within neurodiversity. | HNYHCP |
| Review all the feedback available, involving relevant and appropriate partners. | HNYHCP |
| Commit to investing in meaningful community engagement throughout the commissioning cycle. | HNYHCP |
| Commit to providing the resources necessary to support those not able to access the | HNYHCP |

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| pathway in its current form, communicating how this will be provided. | |
| Investigate the use of the <u>Do-It Profiler</u> 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 |
| 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 |
| Implement a strategy for <u>neurodiverse</u> service market growth, ensuring a preventative approach to commissioning and delivering. | HNYHCP / MHP |
| Immediately amend the pilot in accordance with legislation and best practice. | HNYHCP |
| Conduct an audit of commissioning to ensure full legislative compliance and learn from mistakes made. | HNYICB |

Conclusion

Our findings show a disconnect between the experiences of those going through the pathway and the healthcare professionals involved in delivering the pathway.

Had the pathway been co-produced with those diagnosed/and or seeking a diagnosis the issues raised within this report could have been avoided. Communication between primary care providers and the community would have been significantly better, contributing to better prevention and better-quality outcomes for people.

We acknowledge the challenges providers currently face with the increase in demand for diagnostic services, paired with a reduction in available funding. Staff are experiencing very real pressures around contractual obligations. However, failure to engage with the affected communities has resulted in the concerns highlighted.

On 29 June we were made aware that the pilot is continuing for another nine months with an adjustment to the restrictive criteria currently in place. We invite HNYHCP to work with local Healthwatch to ensure people's voices are at the centre of further decision making.

People can still share their experiences of the pilot via our short surveys:

- For people trying to access a referral:
<https://www.smartsurvey.co.uk/s/YorkAADHDPathway/>
- For health and social care professionals:
<https://www.smartsurvey.co.uk/s/VY0L8Y/>