



Adult ADHD and Autism pathway

13 March 2025

Siân Balsom, Healthwatch York

healthwatch
York

Our work on neurodivergence

- 2 reports. First Aug 2023, second Jan 2025.
- Main focus today is our first report
- Work began in Spring 2023 when York Health and Care Partnership announced changes to the pathway



**“I want to know, I want a diagnosis,
I want help”**

Pilot pathway for Autism and ADHD:
Independent evaluation August 2023

healthwatch
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**Listening to Neurodivergent
Families in York**

January 2025

healthwatch
York


What we did to achieve change


- Hosted a public consultation
- Worked alongside York Disability Rights Forum (YDRF) to hold drop-in events in person and online
- Publicised all the ways people could share feedback including offering face to face, telephone and online interviews
- Heard from 249 people
- Report highlighted our key findings and key concerns – accessibility, appropriateness, effectiveness, clarity, risk management, public trust, and patient choice.



“I have concentration and focus issues and I’ve been left with a ton of things to read through and ‘work on’. If it was that easy, do you honestly think I would have put myself through the hell of contacting the doctors for help?!”


“It has been a few weeks since I completed it and my mental health has been awful since then. I’ve been struggling to sleep and to focus on my work. All because I feel that the hope I had from being put on the waiting list has been taken away from me and I’m back to the beginning again.”





“Being rejected from an assessment because I’m not currently a risk to myself... really really made me want to be a risk to myself. It was rather triggering because I’ve previously has very volatile mental health (history of self-harm, suicide attempts etc.)”

“I don’t think [people] appreciate just how vulnerable people are when they go to a GP for an assessment... “Hi, I appear to be a failure as an adult and can’t fit in anywhere. Help!” That’s a really hard conversation to have. To then be told... you’re not struggling enough, or struggling in the right way to get an assessment, is utterly invalidating.”



York patients 'abandoned' by lack of autism referrals

11th August 2023

ADULTS desperate for an assessment to diagnose whether they have autism or ADHD feel 'abandoned' by a new system which means they can't even get a referral, a damning report by Healthwatch York says.

The report, which took into account feedback from 245 people, says the system is 'inaccessible for people who are not online or need help to fill in forms', and adds: 'Many people who did not meet the criteria felt abandoned.'

One person who provided feedback wrote: "I have been in tears for the last four hours. My GP sent me the link to the Do-It Profiler ...which shows I have many traits of autism.

"However, I now understand ... I can't have a full assessment ... as (the ICB) only select certain people."

One person who gave feedback said: "There is no other part of the NHS where you are not allowed to at least be put on a waiting list if you are displaying symptoms of a condition.

THE  PRESS

By Stephen Lewis

Reporter/Community Content Reporter

[StephenLewisYrk](#)

Adult ADHD and autism assessment requests blocked by NHS screening system

Yorkshire pilot scheme to combat rise in waiting times has not resulted in a single appraisal

A new screening system for adults wanting an [autism](#) or [ADHD diagnosis](#) has rejected up to 85% of requests for a referral since it was launched, adding to concerns from campaigners who warn it could become a blueprint across the NHS.

An independent assessment of the first three months of the pilot by Healthwatch York found significant problems with accessibility and a lack of support for those not referred for an assessment by the profiler.

Emily Douse, of Healthwatch York, said the findings highlighted some unanswered questions regarding how decisions have been made and how the pilot was implemented. “We’ve heard some distressing examples of how the pathway has impacted those seeking a diagnosis, and the wider community. ICBs need to meaningfully engage with those impacted, only then can informed decisions be made about how best to serve the neurodivergent community.”

The Observer
Autism

Chaminda Jayanetti

Sun 29 Oct 2023 05.00 GMT

What difference did it make?

- Face-to-face and online engagement with the community by the ICB to continue amending the pathway
- Criteria removed – anyone needing a diagnosis can now go on the waiting list
- GPs and Community Mental Health Team can now make direct referrals to the Retreat
- Online tool no longer part of the assessment process
- Anyone can go through the Referral Support Service

What difference did it make?

- £40,000 investment (being made through the Community Mental Health Transformation project) in VCSE-led peer support service
- National implications for use of digital health technologies that have not been approved for such use
- City of York Council is completing an all-age neurodiversity JSNA and both this work and our subsequent look at the experiences of neurodivergent families are being used as evidence for this JSNA.
- This will shape our new Neurodiversity Strategy for York

For more information

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