

ANNEXE A



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

Pilot pathway for Autism and ADHD:  
Independent evaluation August 2023

**healthwatch**  
York

# Contents

Content warning: contains reference to suicide and suicidal ideation, self-harm, sex work, distress, anxiety, struggles with daily living, family breakdown

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Acknowledgements: Cover photo by Andrew Neel (@andrewtneel) on unsplash (woman seated woman at a desk, using a laptop with connected phone, in front of an open window, handbag and empty cups also in shot)

# 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.

In response to public concern, [Healthwatch York](#) undertook an independent review of this pilot. Via a HWY survey, GP survey and conversations with York residents and health professionals, we have gathered the views of those who have completed the profiler, and those involved in supporting people through the pathway.

We also hosted two drop-in focus groups with York Disability Rights Forum ([YDRF](#)), one online and one in person.

Fifteen primary care workers, including GPs, shared their views.

YDRF also conducted a survey and [HNYHCP](#) has provided us with some of the anonymous data collected via its own survey of user experience. All of which has been included here as part of our assessment.

We also heard from an additional 41 people who shared their experiences via other means including social media and community-led focus groups. These quotes are included towards the end of this report.

**In total we heard from 1144 people; 936 via [HNYHCP](#), 30 via our [HWY](#) survey, 16 via our information and signposting service, 147 via our work with [YDRF](#), 12 via a GP survey and 3 healthcare professionals.**

Thank you to the neurodiverse community for supporting us with our understanding and definitions of autism and ADHD.

**Thank you to everyone who took the time to share their personal experiences with us – your voices count.**

# Summary of Key Findings

From everything we heard, this is what people told us:

- The pathway did not meet their hoped outcomes.
- The [DHT \(Do-It Profiler\)](#) was inaccessible for some.
- Output from the [DHT](#) was informative and useful, but it told people what they already knew. Some found it condescending.
- Many are reluctant to apply or share the output from the [DHT](#) as they don't feel it would be of benefit.
- The pathway lacked clarity for both patients and professionals.
- Professionals welcomed an efficient and direct pathway to diagnosis and support for [neurodivergent](#) individuals.
- People have concerns around whether equality legislation was followed.

There is concern regarding:

- What engagement took place prior to the pilot being implemented.
- The narrow referral criteria which only consider elements of mental health crisis.
- Whether [HNYHCP](#) considered the patient's right to choose.
- Whether the [DHT](#) used within the pathway meets the scientific rigour required for its use within a diagnostic pathway.
- Whether the [DHT](#) used within the pathway meets the requirements for clinical risk management.
- Consideration for wider [NICE](#) guidelines for the use of [DHT](#) to assist and inform patients.
- Consideration of [NICE](#) guidelines on the use of [DHT](#) to direct treatment and collect data to make service delivery decisions.
- Consideration made to the Public Sector Equality Duty.
- Consideration of data protection principles and legislation.
- Consideration made to legal requirements of the 2016 [Accessible Information Standard](#).

# The pilot pathway

## The pilot introduced 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 met one or more criteria would receive an assessment.

The pilot also introduced a web-based system as entry to the pathway. [HNYHCP](#) states: "Patients seeking an assessment can be given access to the [Do-it Profiler](#) from their GP via a code and URL address. The [Do-it Profiler](#) does not provide a diagnosis, but it will identify characteristics and provide a unique profile describing strengths, challenges, and the skills to develop at home, socially and in the workplace. The profile will also identify where reasonable adjustments should be made which should start as a basis for discussion with occupational health, employers, and educational environments.

"The profiler will determine whether the patient meets one or more of the criteria as listed above. It will then refer these patients on to [The Retreat](#) for assessment. Those who are not deemed eligible based on the above criteria, will not be referred for assessment.

"All patients who complete the profiler will receive immediate functional guidance and signposting to support networks. "



# Background

## What are **autism** and **ADHD**?

**Neurodiversity** is a term used to describe the fact that everyone's brain works differently. It is a biological fact that we are diverse in our minds. **Autism** and **ADHD** are both examples of neurodivergence. <sup>1</sup>

**Autism** is lifelong and shapes how people communicate and interact with the world. **Autism** is not a learning disability. Whilst autistic people share certain characteristics, they do not all present in the same way. Common ways of experiencing the world that many autistic people share include: enhanced sensory perception, a preference for honesty and clarity in communication, a preference for agency, predictability and control, self-expressive body language and a passionate enjoyment of interests and hobbies (Hartman et al, 2023). <sup>2</sup>

There are an estimated 700,000 autistic adults and children in the UK<sup>3</sup>.

**ADHD** is a neurological condition that affects people's concentration, activity levels and impulses. The impact this has on people's lives is significant with symptoms varying for each individual. "Many patients and clinicians describe **ADHD** as an iceberg, where most symptoms lay hiding under the surface — out of sight but ever present."<sup>4</sup> The **UK NICE guidelines**<sup>5</sup> report the adult **ADHD** incidence rate as between 3% and 4%. In the UK, a research survey of 10,438 children between the ages of five and 15 years found 3.62% of boys and 0.85% of girls had **ADHD**<sup>6</sup>. **ADHD** is not a mental health condition although it often occurs alongside or is mistaken for other conditions.<sup>7</sup>

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<https://www.humber.nhs.uk/downloads/Adult%20Autism%20Services/Humber%20Autism%20Strategic%20Framework.pdf>

<sup>2</sup> Hartman, D., O'Donnell-Killen, T., Doyle, J.K., Kavanagh, M., Day, A., Azevedo, J. (2023) *The Adult Autism Assessment Handbook: A Neurodiversity Affirmative Approach*, Jessica Kingsley Publishers

<https://www.autism.org.uk/what-we-do/who-we-are/our-mission-vision-and-values>

<sup>3</sup> <https://www.autism.org.uk/what-we-do/who-we-are/our-mission-vision-and-values>

<sup>4</sup> <https://www.additudemag.com/what-is-adhd-symptoms-causes-treatments/>

<sup>5</sup> <https://cks.nice.org.uk/topics/attention-deficit-hyperactivity-disorder/background-information/prevalence/>

<sup>6</sup> <https://journals.sagepub.com/doi/abs/10.1177/1087054715613441>

<sup>7</sup> <https://www.additudemag.com/when-its-not-just-adhd/>

There are significant barriers for women and girls to be identified and diagnosed.<sup>8</sup> There is an active discussion about whether female ADHD and female autism is under-diagnosed.<sup>9</sup>

### **What are the benefits of a diagnosis?**

Getting a diagnosis of ADHD in adulthood is important because: **“many adults have lived with feelings of failure, anxiety, poor self-esteem, depression and other negative emotions for years, never understanding that there is a reason for the challenges they have faced.** For those adults who have always felt ‘off’ or like they just didn’t fit in easily with others, discovering that they have ADHD can be life changing.”<sup>10</sup>

### **Mortality rates**

**“Suicide rates are unacceptably high in autistic people and suicide prevention has to be the number one goal to reduce the worrying increased mortality in autistic people”** Simon Baron–Cohen.<sup>11</sup>

Reporting on recent research, Cambridge University stated: “10% of those who died by suicide had evidence of elevated autistic traits, indicating likely undiagnosed autism. This was 11 times higher than the rate of autism in the UK.” They also reported on previous research findings - 66% of autistic adults had thought about taking their own life, and 35% had attempted suicide. Despite only 1% of people in the UK diagnosed as autistic, up to 15% of people hospitalised after attempting suicide had a diagnosis of autism. In summary: “both diagnosed autistic people and those with elevated autistic traits are more vulnerable to mental health problems, suicidal thoughts and behaviours.”

**“Many adults in the UK find it very difficult to obtain an autism diagnosis and appropriate support post-diagnosis. Our study shows that undiagnosed autistic people could be at increased risk of dying by suicide.”** - Dr Sarah Cassidy

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<sup>8</sup> Connolly, M. (2019) “ADHD in Girls: The Symptoms That Are Ignored in Females”  
<https://www.additudemag.com/adhd-in-girls-women/>.

<sup>9</sup> <https://www.kaleidoscopesociety.com/adhd-in-women-101/>

<sup>10</sup> <https://www.adhdawarenessmonth.org/adhd-in-adulthood/>

<sup>11</sup> <https://cks.nice.org.uk/topics/attention-deficit-hyperactivity-disorder/background-information/prognosis/>

**The researchers concluded: "It is urgent that access to an [autism](#) diagnosis and appropriate support post diagnosis is improved. This is the top [autism](#) community priority for suicide prevention and needs to be addressed immediately by commissioners of services and policy makers."**

The overall prognosis for those with [ADHD](#) depends on how severe their symptoms are and how well they can manage other co-morbidities associated with the condition. [ADHD](#) is associated with an increased risk of mental health issues including substance abuse and depression. [Autism](#), [dyslexia](#), [dyscalculia](#), and [dyspraxia](#) are also common in those with [ADHD](#). All of which can have a significant impact on an individual's quality of life, including their ability to remain in education, work and to form healthy relationships.<sup>12</sup>

In practice, it is only after a diagnosis of ADHD that a person will be offered options of medication and/or therapy.

Therapies have been shown to be useful in helping people manage their [ADHD](#). This is most effective when combined with taking medication. Therapy is also effective in treating the additional mental health issues that often occur in those with [ADHD](#). For an effective pathway of support to be implemented, it is important the individual and the practitioner can express and fully understand what challenges the individual is experiencing.<sup>13</sup>

[NICE](#) guidance<sup>14</sup> states that formal intervention and guidance should only come following a formal diagnosis.

"If you think you may be autistic, you might want to get a diagnosis. There are many online '[autism tests](#)' available, but none of these can guarantee accuracy."<sup>15</sup>

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<sup>12</sup> [Attention-deficit hyperactivity disorder traits are a more important predictor of internalising problems than autistic traits | Scientific Reports \(nature.com\)](#)

<sup>13</sup> <https://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/treatment/#:~:text=If%20you%20were%20not%20diagnosed,may%20then%20be%20gradually%20increased.>

<sup>14</sup> <https://www.nice.org.uk/guidance/ng87/chapter/recommendations#diagnosis>

<sup>15</sup> <https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/pre-diagnosis/adults>



People who have undiagnosed [autism](#) or [ADHD](#) can appear to manage well day-to-day and this can create barriers to identification and diagnosis. However, those who do not manage are often misdiagnosed with [borderline personality disorder](#). Women and LGBTQ+ populations are especially at risk of this misdiagnosis.<sup>16</sup> If challenges are left unmanaged, there is an increasing risk of misdiagnosis within the mental health system. This can have devastating effects including medical trauma, inappropriate hospitalisations and medications, and further challenges with accessing mental health support in the community.<sup>17</sup>

### **Accessing financial support**

According to the [Office for National Statistics](#), 29.9% of people on the [autism](#) spectrum were in employment in 2021/22, compared to 54.3% of all disabled people and 81.1% of non-disabled people. The [National Autistic Society](#) states that 77% of unemployed autistic people want to work.

Depending on how an individual is shown to be impacted by their [autism](#) and/or [ADHD](#), they may be entitled to benefits intended to help with the extra costs associated with being disabled.<sup>18</sup>

February 2023 statistics on success rates for [Personal Independence Payment](#) (PIP) show that success rates vary wildly between recognised conditions. With [ADHD](#) and 'Aspergers' falling below the average success rate, whilst [autism](#) falls above. The statistics don't show us whether these applicants had received a diagnosis.<sup>19</sup>

### **Challenges with getting a diagnosis**

BBC Panorama: Private [ADHD](#) Clinics Exposed<sup>20</sup> explored concerns around the quality of [ADHD](#) diagnoses within the private sector, including assessments funded by the NHS. In response, the ADHD Foundation<sup>21</sup> raised concerns around the report's failure to:

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<sup>16</sup> <https://link.springer.com/article/10.1007/s00406-020-01189-w>

<sup>17</sup> <https://www.healthwatchyork.co.uk/wp-content/uploads/2023/06/Breaking-Point-Mental-Health-Crisis-Care-June-2023-updated.pdf>

<sup>18</sup> <https://commonslibrary.parliament.uk/research-briefings/cbp-7172/>

<sup>19</sup> <https://www.benefitsandwork.co.uk/personal-independence-payment-pip/success-rates>

<sup>20</sup> <https://www.bbc.co.uk/iplayer/episode/m001m0f9/panorama-private-adhd-clinics-exposed>

<sup>21</sup> <https://www.adhdfoundation.org.uk/2023/05/15/response-to-bbc-panorama-private-adhd-clinics-exposed/>

- fully explore the context of why so many people cannot access NHS healthcare and feel compelled to explore private help
- fully examine the historic inequality of access to health services for people with [ADHD](#) and the lack of priority given to patients with [ADHD](#)
- explore the challenges patients experience in trying to access [shared care arrangements](#) following a private diagnosis

The programme fuelled national press interest in [ADHD](#) assessment waiting times<sup>22</sup>. Another story highlighted the number of people being denied assessments.<sup>23</sup> The coverage also brought attention to the lack of central data collection for [ADHD](#) referrals, making it harder to obtain a clear national picture of those coming forward for an [ADHD](#) assessment.

A debate in Parliament on February 6 2023<sup>24</sup> recommended: “the government should create an emergency fund to deal with the massive waiting lists for [autism](#) and [ADHD](#) assessments for children and adults. This would provide resources for local health services to deal with current waiting lists and new patients.

“The government should commission a review of how Attention Deficit and Hyperactivity Disorder ([ADHD](#)) assessments are managed by the NHS, including through [Shared Care Agreements](#), and increase funding to reduce waiting times.”

During [Neurodiversity](#) Month there was a public call to improve diagnosis of [ADHD](#), [Autism](#) and [dyslexia](#) to prevent people ‘falling through the gaps’.<sup>25</sup>

BBC news: Decision reversed to restrict autism assessments in Bristol<sup>26</sup>  
On 28 April 2023, Bristol parents and carers publicly challenged changes made to [autism](#) assessments for children. They argued that by focusing only on the most severe cases, more children, whose needs could otherwise have

<sup>22</sup> <https://inews.co.uk/news/adhd-diagnosis-patients-assessment-specialist-waiting-uk-data-2344513> 16 May 2023

<sup>23</sup> <https://inews.co.uk/news/adhd-diagnosis-patients-denied-nhs-assessment-gp-referral-2348580> 18 May 2023

<sup>24</sup> <https://hansard.parliament.uk/commons/2023-02-06/debates/183A24F1-C943-4D2E-8238-4B03AF11D715/AutismAndADHDAssessments>

<sup>25</sup> [https://inews.co.uk/news/politics/adhd-autism-dyslexia-slow-diagnosis-government-2207011?ico=in-line\\_link](https://inews.co.uk/news/politics/adhd-autism-dyslexia-slow-diagnosis-government-2207011?ico=in-line_link) 14 March 2023

<sup>26</sup> [Decision reversed to restrict autism assessments in Bristol - BBC News](#)

been managed effectively, would reach crisis point. Following the initial steps of legal proceedings to try to overturn the decision, the changes to the pathway were reversed by the [ICB](#).

## Local picture

In 2017<sup>27</sup>, [Healthwatch York](#) looked at the challenges experienced by people in York living with [ADHD](#). The report highlighted concerns including:

- a lack of understanding of [ADHD](#),
- the absence of support and services in the city,
- challenges with getting a diagnosis,
- the challenges of finding good information, advice and support at every stage of life.

The report made several recommendations to [TEWV](#), [Vale of York CCG](#), City of York Council, [The Retreat](#), [SOAAC](#) (Solution Orientated Adult ADHD Carers' Group) and York Health and Wellbeing Board.

In 2022 [Healthwatch York](#) released a snapshot report on child and adolescent mental health services<sup>28</sup> which highlighted concerns regarding access to [autism](#) and [ADHD](#) diagnosis.

*"A girl I referred in year 9 is now in year 11 and still hasn't had a full assessment, only the initial one. I am concerned she will age out of the system before we can get her a diagnosis."*

## Local statistics

There are an estimated 6,000 autistic people living in North Yorkshire<sup>29</sup>.

From a [Freedom of Information \(FOI\)](#) request dated March 2022, Leeds and York NHS Partnership Trust reported that 67.8% of people who receive a full assessment for [autism](#), go on to receive a diagnosis<sup>30</sup>. Although this neighbouring trust no

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<sup>27</sup> <https://democracy.york.gov.uk/documents/s113238/Annex%20B%20-%20Support%20for%20Adults%20with%20ADHD.pdf>

<sup>28</sup> <https://www.healthwatchyork.co.uk/wp-content/uploads/2022/11/Nov-22-Childrens-mental-health-a-snapshot-report-FINAL-2.pdf>

<sup>29</sup>

<https://www.humber.nhs.uk/downloads/Adult%20Autism%20Services/Humber%20Autism%20Strategic%20Framework.pdf>

<sup>30</sup> [https://www.whatdotheyknow.com/request/autism\\_assessments?unfold=1#incoming-1993543](https://www.whatdotheyknow.com/request/autism_assessments?unfold=1#incoming-1993543)

longer provides services in York. The Retreat has provided the service since 2015 and at time of publication the rate remains high at 67.7%.

Another [FOI](#) response showed the increase in people waiting for an assessment. From 1 April 2019 – 1 March 2022, the number of people with suspected [autism](#), who have been waiting for more than 13 weeks, increased from 85 to 225<sup>31</sup>.

A recently published [FOI](#) request<sup>32</sup> presented to the [ICB](#) on 8 November 2022 included an account of local pressures. The information provided to the [ICB](#) included: “.....[The Retreat](#) is currently receiving an average of 180 referrals per month, with the biggest increase being in [ADHD](#) as opposed to [autism](#). This means that as well as the cost impact for the assessments, there is a significant increase in the costs needed for the medication reviews for those individuals who receive a confirmed diagnosis.....”

“.....[\[The Retreat\]](#) update said that, based on the current number of referrals they have on the waiting list and waiting to be triaged, they will have already used 90% of the contracted value for five years and will need the remaining four and a half years of the contract to complete the activity including all of the associated medication reviews for those on the [ADHD](#) pathway.....”

“.....It is important to note that the diagnosis rate has remained consistent at around 85%, suggesting these are appropriate referrals.....”

“.....Prior to the end of the three-month trial period, a paper will be brought back to this meeting to update on the position and make further recommendations for a more sustainable long-term solution.”

## **Health and care related guidance and legislation**

[NICE](#) is there to provide public health and social care bodies with best practice guidance and necessary legislation to deliver the best care for people “fast whilst ensuring value for the taxpayer.”<sup>33</sup>

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<sup>31</sup> <https://www.examinerlive.co.uk/news/local-news/people-yorkshire-waiting-longer-autism-24568234>

<sup>32</sup> <https://ydrf.org.uk/2023/06/24/the-sound-of-silence/>

<sup>33</sup> <https://www.nice.org.uk/about/what-we-do>

NHS England leads the NHS in England. It supports the ICS “to improve health of the population, improve the quality of care, tackle inequalities and deliver care more efficiently.”<sup>34</sup>

One of the five ICS principles is to: “Nurture a culture that systematically embraces shared learning, supporting clinical and care professional leaders to collaborate and innovate with a wide range of partners, including patients and local communities.”

We have listed the relevant legislation and guidance associated with this pathway below in Appendix 1. These include (but are not exclusive): Equality Act 2010, 2016 Accessible Information Standard, Digital Health Technology Requirements, General Data Protection Regime, Health and Care Act 2022, Public involvement legal duties.

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<sup>34</sup> <https://www.gov.uk/government/organisations/nhs-england#:~:text=NHS%20England%20leads%20the%20National,and%20provide%20value%20for%20taxpayers.>



# Our Findings

To make sense of the qualitative data gathered within the HWY survey, we identified and analysed repeated patterns within the feedback. From this, we established the following themes:

**Accessibility** – equality and inclusion OR users' ability to use the tool independently.

**Appropriateness** – the suitability of the pathway for its intended purpose.

**Effectiveness** – the pathway meeting the intended outcomes for individuals on it OR for those implementing the pathway.

**Clarity** – public and professional confidence navigating the pilot pathway.

**Risk management** – associated potential risks of the pilot pathway.

**Public trust** – impact of the pilot pathway on public perception of health and care.

**Patient Choice** – the perceived and real impact of the pilot pathway on the patient's right to choose.

## What people told us

Everyone's feedback has contributed to the findings of this report. Please take the time to read everybody's comments. To read our data in full, see Appendix 6.

### Accessibility

More than a third of our respondents reported that the [Do-It Profiler](#) was either difficult or very difficult to complete.

"I struggled with many of the questions. I felt I needed help in understanding them, I didn't have anyone to help me."

"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?!"

"Clunky system ..... I got very confused trying to use the system from my laptop after receiving the information by SMS on my phone. It's not made

clear that the link is one time use only, so you have to use it on the same device that you open it on.”

“Struggled to understand some of it due to the way it was laid out.”

“I hope this pilot scheme, that amounts to a denial of access to a proper assessment as was highlighted in the Autism Act 2008 for people like myself, can be overturned. It is damaging. I believe it to be discriminatory.”

### **Appropriateness**

The time it took for people to complete the profiler ranged between 10 minutes to several attempts over several days. For those who could specify, the average completion time was 1.34 hours.

“It was very upsetting, patronising and dehumanising. I'm not sure what I was supposed to get out of it. It just took my answers to the questions and replayed them back to me with all the nuance removed. It listed some of my difficulties as strengths because I answered that I ‘can’ do something. It is possible for me to be ‘able’ to do something, and also have debilitating and impacting anxiety and avoidance behaviours associated with it - but the report does not consider that at all. The resources provided were useless. The reason I came to the GP is because I need more help than tips like ‘why not start a new hobby’. I need personalised support from a specialist. Incredibly, a lot of the suggestions in the resources are to ‘talk to your GP’ which is galling, since that's what I did.”

“I can't imagine even sharing it with the mental health practitioner will be helpful because she doesn't have time to read it or help me through it, and she doesn't have the ability to refer me for an assessment or to specialist support. As I mentioned previously, my partner is aware I have been exploring the possibility of [ADHD](#) (his comments initially prompted me to look into it) but he has not yet read the report and I worry that he will soon lose patience with me. He is also not trained or equipped to support me on his own.”

“It took many attempts over several days.”

“I had to listen to music in order to be able to focus on the questions. Of which there were far too many. I didn't have anyone to help me fill out the form so I did the best I could. I know I messed up the workplace section because the questions were related to the last six to 12 months at work but I

am currently on family leave so I couldn't relate to the questions properly and started getting muddled."

## **Effectiveness**

Only three out of 28 people told us that the profiler had either fully or partly given them what they needed.

Over half of respondents told us that the report from the [Do-It Profiler](#) was either not very useful or not useful at all.

"I want to know, I want a diagnosis, I want help."

".....the advice available wasn't helpful. Telling people with [ADHD](#) to 'be more organised'?!? Would you tell a person with no arm to try to grow an arm back to use?!?....."

"The report was very useful for identifying [ADHD](#) and [dyspraxia](#) as things I should definitely look into, as well as questions about [dyslexia](#) and [dyscalculia](#). However, it did not tell me anything new in terms of coping mechanisms, strategies or techniques....."

"I know these things already, completely useless to me. I need a diagnosis."

"I do not feel comfortable sharing my report with people in my life because it is not a diagnosis and therefore unlikely to be taken seriously. I will share the main results (that the profiler found I have many [ADHD](#) traits) with the mental health practitioner on our allocated five-minute follow-up call in about a month's time. I would share the report with a GP if I could get access to an appointment with one..."

"It's not official - it doesn't count according to my employer."

"....my employer requires a diagnosis to make more than very, very basic adjustments."

## **Clarity**

"Your profiler is not clear on whether you have been referred and I cannot get back into it although it clearly said I need support for [ADHD](#) and [autism](#)."

"..... it wasn't clear what was going to happen next etc."

"I'm looking for a pathway to diagnosis. It doesn't even tell me if there is a next step or if this is everything."

"I didn't get a single piece of feedback to say whether I was even being considered for a referral. Finished the profile and... nothing..."

"It was confusing what it was at first as it is poorly explained and I had asked for a referral for a diagnosis. Even now, when I try to get my report it occasionally tries to make me start from scratch. When in, though, it's good."

"I've been to the GP about it three times. After the first visit, I was given forms in my second visit, and another set to complete in my third. When I spoke to a mental health practitioner, I was then given the [Do-It Profiler](#). I don't understand."

"My GP is unaware of how the profiler works and what the report looks like. She assumed I would qualify for an assessment, as she was unaware that the waiting list is closed to new patients. I have now been advised by the GP's receptionist that I need to find an organisation that will do an assessment through [Right to Choose](#), and request my GP to refer me to them. I am struggling to find such an organisation, as the ones who've come back to me say they only offer private healthcare."

## **Risk Management**

"... 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."

"... I spent around four years building up the courage to contact my GP about an [autism](#) assessment. I have been struggling with mental health issues stepping from social anxiety, social isolation, and loneliness... Being put on the waiting list gave me hope that I would get help. ... I am sure you can understand how upsetting it was for the [Do-It Profiler](#) to coldly and impersonally remove me from the waiting list. I cried for around an hour after I went through the [Do-It Profiler](#) and was unable to focus on my work for the

rest of the day. I am now completely at a loss for what to do with my mental health as I'm back at square one."

"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 had very volatile mental health (history of self-harm, suicide attempts, etc)."

"I feel worthless as a human being due to this denial of a pathway to assessment."

"The profiler could be a useful support tool either in conjunction with a professional assessment, diagnosis and treatment or as a screening tool that then leads to further assessment of identified condition(s), but it is not an appropriate or acceptable replacement. ... It is incredibly daunting to find out I am likely to have a condition that has caused me immense difficulty and distress throughout my life, and yet I have no viable or credible avenue open to me to access appropriate support to navigate this or access specialist treatment. I understand that those in urgent crisis need to be prioritised but I don't accept that the rest of us should be left by the wayside without access to explore a diagnosis and then specialist support or medication. This could lead to other mental health problems and people seeking help through dangerous means e.g. self medicating..."

### **Public Trust**

"I don't know who to ask for help and I don't particularly feel I can trust my GP practice either after they referred me on to the [Do-It Profiler](#) without even telling me it was undergoing a pilot trial."

"I think the system that you're running is shocking and a complete disgrace. My partner has reached out for help and begged for some support to be turned away at the first hurdle. He is now feeling completely lost as to where to go ..."

"Please stop doing this stupid profiler. If you don't have enough staff to carry out the assessments you have on the waiting list already then clearly more money needs to be invested and more staff employed!"



## **Patient Choice**

"...nothing available for adults in desperate need of a diagnosis, unless they can pay to go privately, which we can't afford."

# York Disability Rights Forum (YDRF)

## Findings

Led by disabled people, [YDRF](#) works to promote equal access to human rights for all disabled people who live or work in York. [YDRF](#) invited the public to share their thoughts and/or experiences regarding the pilot change to the diagnostic pathway.

[YDRF](#)'s survey findings include:

### Accessibility

"Two words: **digital exclusion**..."

"I was sent the profiler. I can't do it. It is too long. Too hard. Don't understand how to do it. So now what? I asked for help filling it in and was told there isn't any... The profiler is too hard."

"How is it legal to remove rights to access to treatment for a known medical condition?"

### Appropriateness

"Honestly, I cannot get my head around this. What does criteria two even mean? And surely it's better to get people access to support **before** they are about to lose their kids or kill themselves? Ok, yes there is some support out there without a diagnosis, but there isn't much, and without access to the ND ([neurodiverse](#)) community it is almost impossible to find."

"I don't think the decision makers appreciate just how vulnerable people are when they go to a GP to ask for an assessment. You basically have to go to another human being: "hi, I appear to be a failure as an adult and can't fit in anywhere, help?" and that is a really hard conversation to have, to then be told that you may be struggling but you're not struggling enough, or not struggling in the right way, to get an assessment is utterly invalidating."

“As an autistic adult working in [autism](#) research, and as someone who previously worked in [autism/ADHD](#) diagnosis, I am deeply concerned by the changes to the pathway for a number of reasons:

1) Access to diagnosis and self-understanding is extremely important. This can lead to workplace or educational adjustments, and if people are not formally diagnosed they will not be covered under the Mental Health Act, and workplaces will not have to provide support. This is also true for university level support and DSA (Disabled Students Allowance), which require a formal diagnosis.

2) I am aware that waiting lists are extremely long. However, for autistic people who struggle with uncertainty, being on a waiting list and knowing that an assessment will eventually happen is infinitely better than being told that referrals are not currently being accepted. I'm concerned that many people will become lost and will never seek diagnosis following this.

3) I am also concerned about the threshold for needing an assessment and how this will be assessed. It's a known fact that a high proportion of neurodivergent adults struggle with mental health difficulties and suicidal thoughts, largely internally. These will likely be exacerbated by the lack of access to referral. I am concerned that by the time these mental health concerns are recognised and taken seriously, it will be at an inpatient level, rather than a level at which referral for [autism/ADHD](#) assessment is most beneficial.

4) Many relationships are affected by neurodiversity and communication differences. Diagnosis can aid in understanding and communication. A lack of understanding and access to assessment and support may lead to family break-downs.

5) Adults with [ADHD](#) will presumably not be able to access medication without a formal diagnosis. This is a huge deprivation of a right to treatment. It may also lead to dangerous self-medication or risky behaviours.”

## **Effectiveness**

“I wouldn't have gotten an assessment under these new criteria. I wasn't under mental health services, I wasn't seen as being in danger of harm, but I was.”

“I was so desperate to fit in and hated myself so much that I let myself be manipulated and used by multiple people. I was vulnerable, but not in any way that the NHS saw or noticed...”

"I am really worried about not only how this will affect individuals but also the impact this will have on GPs, mental health services, and the health service at large. Simply moving or stalling the problem isn't the answer."

## Clarity

"This has all been communicated terribly, neither my GP nor CPN seem to be able to tell me the process, neither seem to know what happens after I do the profiler. I'm getting conflicting information from everyone I speak to. Honestly this is stressing me out and pushing me towards crisis more than not knowing why I am this way ever did. If it wasn't for the fact that the (Community Mental Health Team) CMHT is insisting that I go through the process (they feel that I need an assessment before they can help me any further) I just wouldn't bother with all this."

"...I live in York and have heard **nothing** about this. It's obviously not been communicated well. My son is on the waiting list for an **ADHD** assessment and I am autistic myself, we know many **ND (neurodiverse)** people and yet have heard nothing. ...I find the lack of transparency and communication very concerning."

"Not only is this a ridiculous and harmful idea it is been communicated so badly..."

## Risk Management

"So, if I want to get diagnosed with **autism** or **ADHD** (both of which I score highly for on self diagnosis tests) and I've been procrastinating on doing for years, the best option for me is to give up not self-harming?"

"My diagnosis literally saved my life. I didn't have a crisis plan, I was not under mental health services, but feeling like I was broken and like I was somehow a bad person because I couldn't do things and couldn't fit in - it was destroying me. I am certain that had I not been diagnosed I would no longer be here."

"Because my **autism** wasn't known about, I suffered misdiagnosis after misdiagnosis, was put through unnecessary treatments, therapies, medications, and have medical related **Post Traumatic Stress Disorder (PTSD)**. When we worked out that I was autistic, when I got diagnosed and got to speak to other autistic people, everything just clicked into place. I essentially lost six years of my life and have ongoing trauma symptoms from unnecessary, and incorrect, mental health treatment. I don't want others to go through the same."

"I am three months free from self-harm, but now thinking I may need to start again in order to be taken seriously."

### **Public Trust**

"I am upset to know that my city sees people like me as essentially disposable, as collateral damage. I am very upset to think of people within my community being potentially harmed by this."

"Well, this got snuck through didn't it? A message for the commissioning bodies - if you are going to do stuff like this at least tell people, all this secrecy and half-truths make you look suspicious."

"I'm disgusted that this pilot has even been considered let alone implemented and it makes me ashamed of the NHS - something I never thought I'd say as I've always been so proud of our NHS."

### **Patient Choice**

"I can't believe what I'm hearing. Outrageous. The potential consequences of this are really scary. Waiting two years for assessment is bad enough, but this removes patient choice altogether."

"I'll be honest, I do believe that the assessment process is outdated and has huge issues, same with the mental health service, it did need a total overhaul. However, just removing the assessment option from the majority of people is not the answer. The process is deeply flawed, but something is often better than nothing and people deserve to have a choice."

"I can't afford to go private and there's no way my GP will be willing to refer me now. I asked them about [right to choose](#) but apparently even that is affected - something about funding? I really just don't know what to do, self-diagnosis isn't enough to get any help."



## YDRF statement



YDRF is speaking out against this plan of action which will deprive people of their access to assessment and diagnosis. We are very concerned that there has been no risk assessment, no engagement with the people who will be effected, and no consideration of the potential deadly impact of this decision. This decision appears to have been made purely for financial and systemic reasons, without due regard for patient wellbeing.



## We also heard

**Through our information and signposting service, we've received an additional 16 calls and emails regarding the pilot approach.**

'[ADHD](#) campaigner asking for information around the new pilot to [ADHD](#) and [autism](#) diagnostic services. Concerned about the approach being taken in York and wanting to understand how they can help. '

'Husband approached GP for [autism](#) assessment. GP was unsure of the referral pathway. He was asked to complete a short paper questionnaire and the GP put a referral in to [The Retreat](#) stating that it was doubtful he'd be given an assessment. The individual wasn't informed of the new pathway or of any changes to the pathway.'

*"I have been in tears for the last four hours. My GP sent me the link to the [Do-It Profiler](#) which I completed today which shows I have many traits of [autism](#). However, I now understand that's it, I can't have a full assessment so can't get a diagnosis under your new system as you only select certain people for further assessment."*

*"I would be really interested how the criteria for further assessment is decided. I am 48 years old, have a child with [autism](#), another on an [ADHD](#) assessment pathway and my traits are seriously impacting my life on a daily basis. I was quite prepared to go on a waiting list and expected it to be at least a two year wait (it took five years for my son to get his diagnosis), but to be told I can't even go on a waiting list is devastating and I feel a waste of resources (my GP has spent time sending me the link, I spent time completing it and I'm not on a waiting list so will no doubt have to go through all this again at some point to get onto a waiting list)."*

*"I'd like an explanation as to why this can't be pursued further. 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. I have worked for the last 30 years and contributed fully to tax and National Insurance so why am I being told I can't access the NHS for further investigation. I am prepared that I may have to wait a considerable amount of time and consent to you looking at my report."*

'Telephone call about experience of seeking an [autism](#) assessment and being referred to the [Do-It Profiler](#). Very unhappy about the outcome and lack of further assessment or support. Called GP a few weeks ago to request assessment, had been thinking about it a long time due to feedback from colleagues, and has received long term therapy for depression and anxiety. Waited a few weeks to be told they needed to use the [Do-It Profiler](#), they found it very difficult because it was so long and so many questions, also found the questions tricky because they weren't always clear. Also, the explainer video at the beginning was 'weird', as there seemed to be some disconnect between the man speaking and the sound. They received a big list of things to think about at the end, but the suggestions were things that they had already tried or were aware of, nothing new, no help on how to get a diagnosis. Feel abandoned, particularly as they can't even get on a waiting list.'

*"I've completed all questions on the [Do-It Profiler](#) and have downloaded all my reports. How do I know what the next steps are or if I have been referred?"*

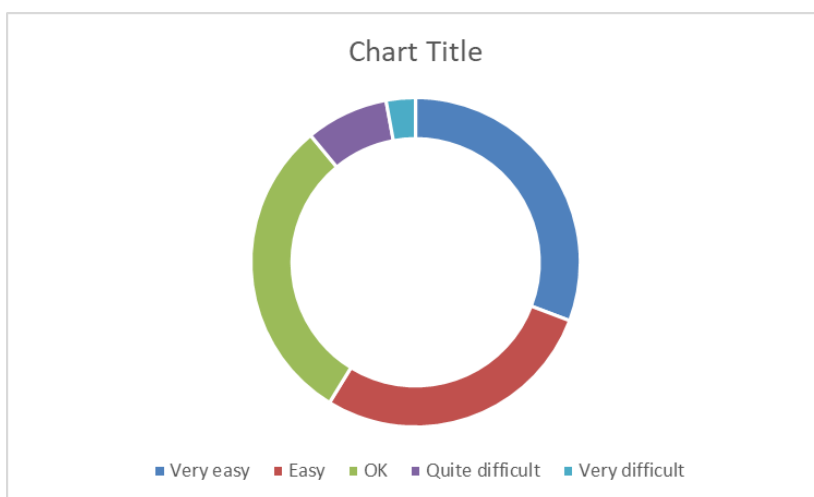
*"I have currently been sent the [Do-It Profiler](#) for [ADHD](#) by my GP which I have successfully filled out. I'm just struggling to see where it says if you are going to be referred or not? Is this information included as it isn't very clear on the report at all I'm afraid... I can see there are helpful tips on how to cope or change behaviours but nothing on the next step..."*

# Data provided by HNYHCP

Once people complete the [Do-It Profiler](#) they are directed to a feedback form (Appendix 5). This information is collected on completion of the profiler modules. From the experiences gathered, we understand that many believed at this point that completing all the modules within the profiler was the first step to accessing a diagnosis. [HNYHCP](#) has provided us with the responses to three of the questions asked within the survey. Answers to open questions were not shared with us and so have not been included in our review. Nine hundred and thirty-six people completed the [Do-It Profiler](#) feedback.

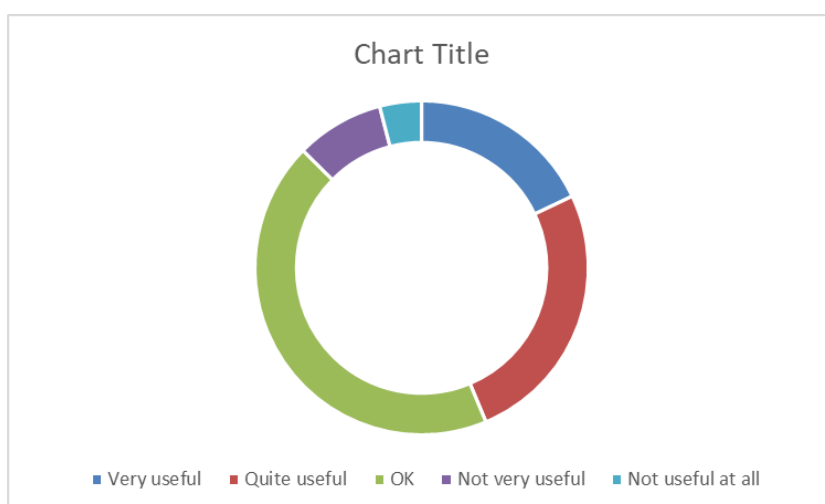
## How easy was it to use the do-it profiler?

Total responses: 936



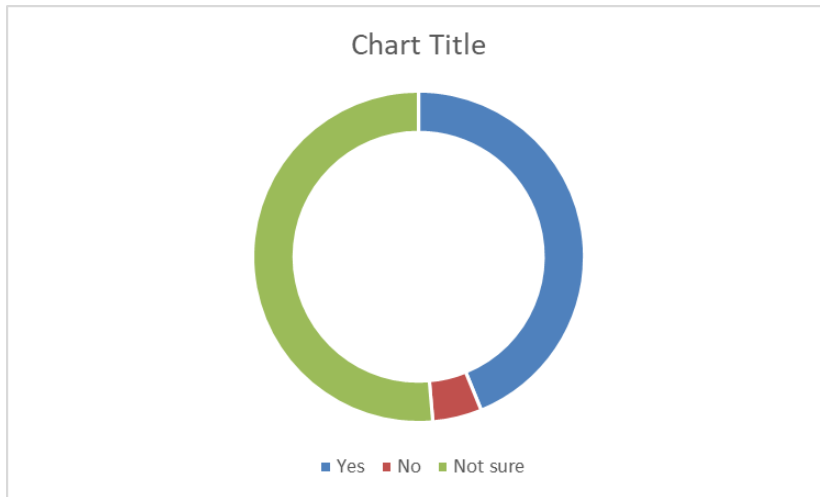
## How useful was the report and practical guidance?

Total responses: 936



## Did you share the report with anyone else?

Total responses: 146



# Feedback from people working in health and care

Outside of the survey, we also received responses from people working within the health and care system. Feedback included:

*"I would just like to give some feedback with regards to the Do-It Profiler for ADHD. Firstly, I do feel that this puts people who may have a disability, unable to read/write or have little or no access to IT, at a disadvantage. From the people that I have given this out to, they have come back saying that they have scored high for certain areas, mostly ADHD. But then the Do-It Profiler does not explain that this is all that they are getting and that they have not been given a full assessment and therefore they are assuming that they are now sat waiting on a list.*

*I am sure that this can be made much clearer. What does happen to those people that do really struggle due to the potential diagnosis and do not meet the four criteria and so are left to just manage. Clarity for patients on if they will receive an assessment or not."*

*"I've just received some feedback from one of my patients who recently completed the Do-It Profiler. He struggles with forms etc and became very overwhelmed when The Tuke Centre emailed him requesting he fill in more forms. He said he would find it much better if there was someone who could go through the forms with him."*

*"So some of the feedback that some people are giving back to me regarding this profiler is that they are not sure what happens at the end of completing this link – they tell me that they are given access to resources but then are not aware what happens next in the sense of if they will be accepted for an assessment or not.*

*I also fear a backlash of people wanting to seek medication for ADHD and coming back to GP surgeries stating that they would like to go down the 'right to choose' option instead so that they can be considered for medication, especially when there is a lot of information around stating that medication is the main route to treat ADHD."*

*I find this really worrying. Potentially we could miss out those most needing help as they will be the ones who find it most difficult to complete unaided. People need to*

*be signposted to the support available. But there are also huge challenges with providing that support. I already have a waiting list of around six weeks for my service. If I had just two or three people in a week needing help to complete the profiler, that's going to have a significant impact."*

## **GP Survey**

As part of a quick 'snapshot' survey emailed to GP staff, we heard from 12 professionals. Of the 12 respondents, 11 were aware of the changes and two could provide feedback from the patient's perspective. Overall, they welcome an easy and direct referral system for patients. Responses included:

*"The only feedback I have had from patients is that when they complete the referral and all the programmes/videos in the process they don't feel it is very clear what happens next and aren't really sure whether it has resulted in a referral being accepted or not, this results in them calling us for advice and we don't really have a clear message to tell them."*

*"Really good that it is direct access, some headache on what patients are asked to fill out. Overall, I'm really supportive."*

*"Easy for us [GP] to use as just send a link. Patient feedback is that it isn't obvious what the outcome of the assessment is. Not sure where it directs patients if they don't meet the criteria? Overall, I'd really like it to continue."*

*"I [GP] was aware of this and the secretaries have been sending out the letter to the patients when I have done a referral. I've not had any feedback regarding this."*

*"Very easy to use from GP perspective. No feedback from patients."*

*"Yes, use it every day but just text information to the requesting patient. No issues, but would be good if parents could use it for their children also."*

*"Very easy to refer those who are eligible and explain to patients what it's about and what to do."*

*"Just ask secretaries to send a link so don't directly use it. One patient was very disappointed that was no support offered at the end of assessment."*



# Conclusion

Our findings show a disconnect between the experiences of those going through the pathway and the healthcare professionals involved in delivering the pathway. Healthcare professionals welcome a straightforward and direct referral pathway for people seeking an [autism](#) and/or [ADHD](#) diagnosis. However, they acknowledge people's want to be referred onto a waiting list (regardless of the wait times); be provided with practical and meaningful support; be able to utilise their legal right to choose - all of which were denied to people as a result of this pilot.

There is a shared desire from healthcare professionals and patients to move to a needs-led model of support, but this is at odds with the current health and social care systems in place, and with the existing stigmas that those with [autism](#) and [ADHD](#) traits experience. [NICE](#) guidance, [NHS England](#) guidance, and legislation exists to help commissioners and providers navigate these challenges.

Although the limited quantitative data provided by [HNYHCP](#) reports that the [Do-It Profiler](#) was 'easy to use' and 'useful', our qualitative data shows that too many people were under the assumption that the [Do-It Profiler](#) was the assessment of their possible [neurodivergence](#), and the next stage would be a referral for diagnosis. Many reported that they weren't sure if they had been referred for a diagnosis, and what the purpose of the profiler was.

Communication of the pathway has been poor throughout its design and implementation both to people seeking diagnosis and those working in the health and care system. As a result, use of the profiler doesn't seem to have been consistent across primary care.

Many have approached [Healthwatch York](#), [YDRF](#), local and national campaign groups to express their frustrations around the pathway's failure to address health inequalities. Women told us the pathway prevented them from accessing a diagnosis in later life for traits that weren't recognised as they grew up. Another told us that, without a diagnosis, they were being challenged when applying for disability benefits. This raises concerns that the pathway could increase the risk of poverty for disabled people.

We also heard from those who were unable to access the pathway, with many reporting that they were waiting for the pilot to end before approaching their GP for

help. When asked, we were told by [HNYHCP](#) that no additional resources would be given to support individuals unable to access the pathway.

In addition, the pathway doesn't appear to meet the needs of individuals or achieve the intended outcomes expressed by [HNYHCP](#). People reported to us that they wanted a referral for: diagnosis, improved understanding and validation, access to meaningful support, guidance and information, access to therapies, access to occupational support. [HNYHCP](#) said that the pathway would outline "strengths, challenges, and skills to develop at home, socially and in the workplace" and identify "where reasonable adjustments should be made which should start as a basis for discussion with occupational health, employers, and educational environments. "

People told us that they felt uncomfortable with the idea of providing employers, and sometimes close relations, with a report that contains their personal information. Even more so when the tool used to identify these traits has little clinical backing.

[HWY](#) has not been provided with information about the reliability and validity testing of the digital health technology ([DHT](#)) used within the pathway. The tool has been designed to inform an individual around challenges they face within their employment/education. We are not aware of any scientific evidence to support its use for identifying, advising, or informing on traits of [autism](#) or [ADHD](#). To add to the confusion, language such as "assessment" and "screening" are used throughout the [DHT](#). There are many readily available free tools that have been scientifically tested to identify [ADHD/autism](#) traits (such as the [Q10](#) for [autism](#)). Users of the [Q10](#)<sup>35</sup> also benefit from only having to complete a short number of easy to understand and less prying questions.

It's important that [HNYHCP](#) improves its communications and engagement, shares the rest of its data and prioritises the analysis of this.

The community has questioned whether [HNYHCP](#) followed necessary legislation and best practice alongside poor communication and a lack of transparency. People have reported losing faith in NHS services because of this pilot. The pilot appears to have reinforced feelings of marginalisation for those already diagnosed and those seeking a diagnosis for [ADHD/autism](#), contradictory to the aims of the [ICS](#). Given the stated expectation that [ICS](#)'s will be rooted in the needs of people, communities and places, this is a disappointing start.

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<sup>35</sup> <https://embrace-autism.com/aq-10/>

Failure to follow legislation and guidance contributes to a lack of regard for prevention and failure to meaningfully promote 'waiting well'. At best the pilot provides some people with general guidance around what they can do to improve their functioning within educational and/or occupational settings (assuming they have digital and literacy capabilities). At worst, the pathway fails to meet legislation, [NICE](#) and [NHSE](#) guidance, resulting in questions around risk management, data management, discrimination, misdiagnosis/inappropriate treatment pathways and disregard for the patient's legal [right to choose](#).

This process has caused considerable distress. Our findings have highlighted risk to the wellbeing of individuals involved, including suicidal ideation and self-harming behaviours. The pilot places significant reliance on considerations that appear irrelevant, the conditions a person must meet to get a full assessment are mostly unrelated to the need for an [autism](#) or [ADHD](#) assessment and are not based on the need for therapeutic support for [autism](#) or [ADHD](#). It is unclear whether the pathway has been assessed for clinical safety.

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. We also understand that those involved in the decision making of this pilot pathway care deeply about those they serve. The staff are experiencing very real pressures around contractual obligations. However, failure to engage with the affected communities has resulted in the concerns highlighted here.

We call on [HNYHCP](#) to review our findings and its own as a matter of urgency. We also call on [HNYHCP](#) to immediately amend the pilot in accordance with legislation and best practice, and to embed the views of those most affected by this change into decision making.

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 believe that this means everyone seeking a diagnosis will now be accepted onto a waiting list, although communication around this was not clear at time of publication.

We invite [HNYHCP](#) to work with local Healthwatch to bridge the gap between community voice and the pressures and contractual obligations [HNYHCP](#) is working within; so we can achieve better outcomes for the community and successfully meet the aims of the [ICB](#).

ICBs should look to this commissioning decision as an example of why engaging people is so necessary in the design and delivery of services.

We encourage people who receive the profiler to continue to share their experiences of the pilot with us. We also welcome feedback from health and care professionals. We would appreciate feedback 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/>

We also understand some people will not want or be able to fill in a further form. Please contact us by any of the other means listed on the back cover of this report if you would prefer.

# Recommendations

Action	For
Review the referral criteria, working with leading academics within <a href="#">neurodiversity</a> .	HNYHCP
Review all the feedback available, involving from 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 pathway in its current form, communicating how this will be provided.	HNYHCP
Investigate the use of the <a href="#">Do-It Profiler</a> 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 <a href="#">neurodiverse</a> 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

# Initial response from HNYHCP

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 conversations 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.

# Appendices

## Appendix 1: Health and care related legislation and guidance

### Equality Act 2010

The Act sets out when someone is considered to have a disability and is protected from disability discrimination. If you can show significant and long-term adverse effects on your ability to carry out day-to-day activities, you do not need to have a medical diagnosis to be protected under the Act. This makes it challenging however if the other person (i.e. professional/employer) doesn't agree that someone has a disability. In this instance, they should seek medical advice, for example an occupational health report or a medical report from the person's doctor.

A requirement of a diagnosis of [ADHD](#) to access support differs across settings despite the Equality Act. For example, although needing a diagnosis to access education support has relaxed recently, traditionally and in practice, this is not a universal approach across all academic settings from primary school to further education.<sup>36</sup>

### 2016 Accessible Information Standard

All organisations that provide NHS care are legally required to follow the Accessible Information Standard. This also applies to services commissioned by [HNYHCP](#). "Everyone has the right to receive information in a format they can access and understand."<sup>37</sup>

### NICE guidance

[NICE](#) states that adults who present with symptoms of [ADHD](#) should be referred for assessment by a specialist with training and expertise in the diagnosis of [ADHD](#).<sup>13</sup>

And, if a person scores six or above on the [AQ-10](#), or [autism](#) is suspected based on clinical judgement, they should offer a comprehensive assessment for [autism](#).<sup>14</sup>

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<sup>36</sup> <https://www.acas.org.uk/what-disability-means-by-law/considering-whether-someone-has-a-disability>

<sup>37</sup> [https://www.healthwatchyork.co.uk/wp-content/uploads/2022/06/Accessible-Information-Report-June-2022\\_0.pdf](https://www.healthwatchyork.co.uk/wp-content/uploads/2022/06/Accessible-Information-Report-June-2022_0.pdf)



## **NHS England (NHSE) guidance**

The 2023 NHS framework for [autism](#) assessments<sup>31</sup> states that:

- [ICBs](#) should not withhold access to an [autism](#) diagnosis because of a local decision to make assessments needs-based.
- Clear, accurate, current and accessible information about the extent to which each service providing [autism](#) assessments complies with [NICE](#) guidance should be available to inform people's choices.
- It is the responsibility of individual clinicians, their respective professional bodies and people in commissioning roles to ensure public resources are spent on well evidenced services and not on un-evidenced or under-evidenced alternatives.
- There is a statutory duty for [ICBs](#) to involve people and communities in developing plans for continual improvement of services.
- Decisions to delay referral for an [autism](#) assessment must be underpinned by a clinical rationale.
- Clarity about [autism](#) diagnosis can be validating for many people in their day-to-day lives. For example, this can help with the development of a positive autistic self-identity and foster connections with the autistic community.

## **Digital health technology (DHT) requirements**

Health organisations have an obligation to ensure that digital health technologies are compliant with the DCB 0160 clinical risk management standard. This is a mandatory requirement under the Health and Social Care Act 2012. This should be carried out and approved by a Clinical Safety Officer before the technology goes live, and then regularly reviewed.

Suppliers of digital health technologies must comply with the DCB 0129 standard<sup>32</sup>. This standard ensures that a full assessment is in place for the use of the technology in a clinical setting and extends to the use of digital technology in pilots.

## **NICE Evidence Standards Framework for digital technology**

Additionally, [NICE](#) guidelines for digital health technologies ([DHT](#)) recommend that there is "evidence to show that the [DHT](#) has been successfully piloted in the UK health and social care sector" before its use.

[NICE](#) provides guidance for the use of [DHT](#) in aiding diagnosis, triage and/or when informing next diagnostic or treatment services<sup>33</sup>. This includes [DHTs](#) used to:

- take an immediate or near-term action to diagnose, screen or detect a disease or condition

- take an immediate or near-term action to treat, prevent or mitigate by means of providing therapy to a human body.

The guidance is split across five areas of [DHT](#):

- design factors (safety and reliability)
- describing value (value of the technology)
- demonstrating performance (meeting performance expectations)
- delivering value (demonstrating value for money)
- deployment considerations (claimed benefits realised in practice).

For design factors the guidance states that:

- [DHT](#) companies should demonstrate that all safety and quality standards relevant to their [DHT](#) have been met.
- Companies should describe how representatives from intended user groups were involved in the design, development or testing of the [DHT](#).
- Health inequalities considerations should be factored into the design and evidenced.
- Datasets used to train, validate or develop the [DHT](#) should be done and be of a high quality.
- Health information provided is valid, accurate, reviewed and sufficiently comprehensive.
- Relevant health or care professional(s) working in the UK health and social care system have either been involved in designing, developing or testing the [DHT](#), or given their support to the UK deployment of the [DHT](#).
- The [DHT](#) is viewed as useful and relevant by professional experts or expert groups in the relevant field.
- Appropriate safeguarding measures are in place including consideration of who has access and why these people/groups are suitable.

Under the category 'demonstrating performance' the guidance states "the [DHT](#) should show real-world evidence that the claimed benefits can be realised in practice." The company should have evidence to show that the [DHT](#) has been successfully piloted in the UK health and social care system, showing that it is relevant to current best practice in the UK (for tier B and tier C [DHT](#)s – see below reference for further information).

Testing should show that:

- the [DHT](#) was acceptable to users
- performed its intended purpose to the expected level

- successfully integrated into current service provision or current best practice
- caused no unintended negative impacts on service users or services
- showed improvements in outcomes (costs saved, efficiencies achieved, health and care improvements)
- was used in line with expectation (who, how, for how long).

### **General Data Protection Regime (GDPR)**

Article five of the UK [GDPR](#) sets out seven key principles<sup>34</sup>:

- Lawfulness.
- Fairness and transparency.
- Purpose limitation.
- Data minimisation.
- Accuracy.
- Storage limitation.
- Integrity and confidentiality (security).
- Accountability.

Under ‘lawfulness, fairness and transparency’, personal data must be used “in a way that is fair. This means [providers] must not process the data in a way that is unduly detrimental, unexpected or misleading to the individuals concerned. You must be clear, open and honest with people from the start about how you will use their personal data.”

### **ICO Right to Be Informed guidance**

[NHS England](#) holds the responsibility for IT systems which support health and social care, as well as the collection, analysis, publication, and dissemination of data generated by health and social care services, to improve outcomes for patients.

One of the five promises [NHS England](#) makes<sup>35</sup> is “people can have confidence that their choices will be honoured and that their data is respected, secure, protected and used appropriately.”

The [ICO GDPR](#) guidance<sup>36</sup> outlines ‘rights related to automated decision-making including profiling’, stating that individuals have the right to be informed about the collection and use of their personal data. This is a key transparency requirement under the UK [GDPR](#).

Article 22 of the UK [GDPR](#) has additional rules to protect individuals if a provider is carrying out solely automated decision-making that has legal or similarly significant effects on them.

Providers must identify whether any of their processing falls under Article 22 and, if so, make sure that they:

- give individuals information about the processing
- introduce simple ways to request human intervention or challenge a decision
- carry out regular checks to make sure that systems are working as intended.

## **Health and Care Act 2022**

Patient choice is the legal right of a patient to choose where they receive their treatment. If you need to be referred due to a mental or physical health condition, you have the legal [right to choose](#) which hospital or service you'd like to attend.

“Each integrated care board must, in the exercise of its functions, act with a view to enabling patients to make choices with respect to aspects of health services provided to them.” This includes pilot projects.<sup>37</sup>

## **Public Sector Equality Duty - Equality Act 2010<sup>38</sup>**

Public bodies are required by the [Equality Act 2010](#) to comply with the [Public Sector Equality Duty](#). This means that providers need to carry out an equality analysis of their services and any proposals for change. They need to ensure that all strategies, policies, services and functions, both current and proposed, give proper consideration and due regard to the needs of diverse groups to:

- eliminate discrimination
- advance equality of opportunity and access
- foster good relations between different groups in the community.

## **Public involvement legal duties**

The legal duties on public involvement require people to be appropriately ‘involved’ in planning, proposals, and decisions regarding NHS services.

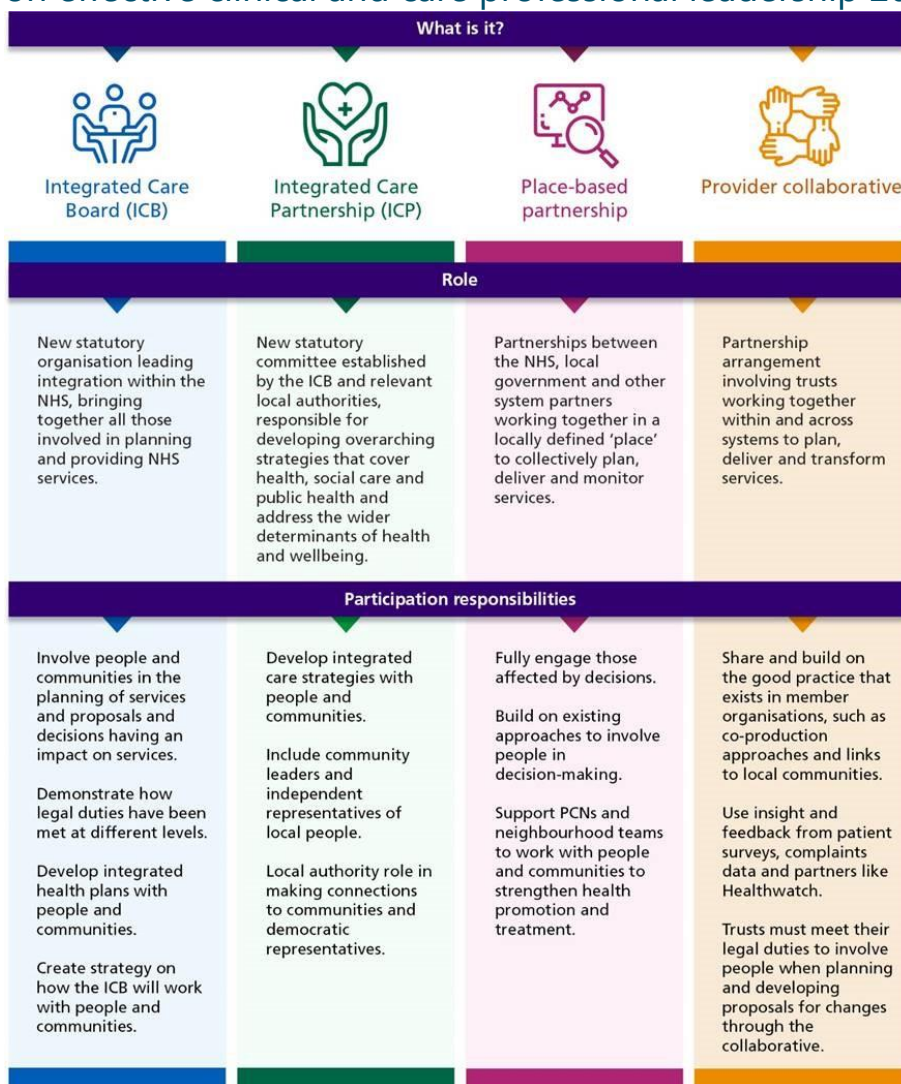
Key requirements of [ICBs](#), trusts and [NHS England](#) include that they:

- assess the need for public involvement and plan and carry out involvement activity

- clearly document at all stages how involvement activity has informed decision-making and the rationale for decisions
- have systems to assure themselves that they are meeting their legal duty to involve

**ICPs** also have specific responsibilities towards participation, summarised below<sup>39</sup>. There are statutory requirements for **ICBs** and **ICPs** to produce strategies and plans for health and social care, each with minimum requirements for how people and communities should be involved.

### Building strong integrated care systems everywhere: **ICS** implementation guidance on effective clinical and care professional leadership 2021



## Autism Act 2009

The Act requires government to introduce and continuously review its adult [autism](#) strategy. The strategy was published in 2010 and includes statutory guidance for NHS organisations and local authorities. This was updated in 2015. <sup>38</sup>

Information for local authorities and NHS organisations on how to support the implementation of the Autism Strategy can be found in this footnote. <sup>39</sup>

## Appendix 2: The Healthwatch York survey

Adult autism and ADHD referral pathway pilot survey

Thank you for taking part in our survey. We want to understand more about the adult [autism](#) and [ADHD](#) assessment process in York and North Yorkshire, particularly whilst the pilot of the [Do-It Profiler](#) is running. [Healthwatch York](#) and Healthwatch North Yorkshire are independent, and aim to make sure what matters to people in York and North Yorkshire shapes our health and care services.

We know not everyone can give feedback online. For people living in York, you can call us on 01904 621133 (choose the option for Healthwatch York), or email [healthwatch@yorkcvs.org.uk](mailto:healthwatch@yorkcvs.org.uk) if you prefer. For people in North Yorkshire, you can call us on 01423 788128 or email [admin@HWNY.co.uk](mailto:admin@HWNY.co.uk).

The survey is anonymous. It takes about 10-15 minutes to fill it in.

Thank you in advance for your time and help. We really appreciate it.

- 1) Please tell us what has led you to seek a diagnosis at this time.  
(This might include things you have experienced, who you discuss them with, any support you receive, the length of time you have considered seeking a diagnosis, resources you have used)
- 2) Do you self-identify as someone with [autism](#), [ADHD](#), or otherwise [neurodiverse](#)?
  - Yes - [autism](#)
  - Yes - [ADHD](#)
  - Yes - [neurodiverse](#)
  - No
  - Not sure
  - Other (please specify):

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<sup>38</sup> [https://commonslibrary.parliament.uk/research-briefings/cbp-7172/#:~:text=The%20Autism%20Act%202009%20requires,authorities%20\(updated%20in%202015\).](https://commonslibrary.parliament.uk/research-briefings/cbp-7172/#:~:text=The%20Autism%20Act%202009%20requires,authorities%20(updated%20in%202015).)

<sup>39</sup> <https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>

- Comments:
- 3) Are you already in contact with any [autism](#), [ADHD](#), [neurodiversity](#) or disability groups?
- Yes
  - No
  - Not sure
  - Comments:
- 4) How long have you been trying to get a diagnosis?
- Less than 3 months
  - 4-6 months
  - 7-12 months
  - 1-2 years
  - 2-3 years
  - More than 3 years
  - Comments:
- 5) How easy was it to use the [Do-It Profiler](#)?
- Very easy
  - Easy
  - Neither easy nor difficult
  - Difficult
  - Very difficult
  - Comments:
- 6) How long did it take you to complete the [Do-It Profiler](#)?
- 7) How useful was the report?
- Very useful
  - Quite useful
  - OK
  - Not very useful
  - Not useful at all
  - Comments:
- 8) Has the profiler given you what you need?
- Yes, fully
  - Yes, partly
  - No



- Not sure
  - Please tell us more:
- 9) Have you shared the report with anyone? For example, family, friends, your employer, colleagues, support workers
- 10) If you have, did you find sharing your report helpful?
- Yes
  - No
  - Not sure
  - Not applicable
  - Comments:
- 11) Has your report helped you with getting reasonable adjustments from other organisations?
- Yes
  - No
  - Not yet
  - Not sure
  - Not applicable
  - Comments:
- 12) Has any person or organisation refused to help you without a diagnosis in place? If yes, please provide details
- Yes
  - No
  - Don't know
  - Not applicable
  - Details
- 13) Whilst you have been looking for help, have you come across any resources, organisations, people or places that you think others would find helpful?
- 14) Is there anything else you want to tell us about your experiences?

- 15) Can [Healthwatch York](#) or Healthwatch North Yorkshire contact you in 3-6 months' time to ask how you are getting on? If yes, please provide your preferred contact details, for example email address or telephone number.
- Yes
  - No
  - Email address, telephone number or other contact info

The next few questions ask about you. You do not need to answer any of these. But it helps us if you do.

16) Please tell us your age

- 18-24
- 25-49
- 50-64
- 65-79
- 80+

16) How would you describe your gender?

17) How would you describe your ethnicity?

18) Do you consider yourself to be

- A disabled person
- A carer
- A person with experience of mental ill health
- A person with a long-term health condition
- None of the above
- Other (please specify):
- Comments:

### **Appendix 3: [YDRF](#) Survey**

Please tell us your thoughts and/or experiences regarding the current change in the [autism/ADHD](#) assessment pathway

(if you have been sent/done the do-it profiler please complete this HealthWatch survey as they are doing the independent evaluation - <https://www.smartsurvey.co.uk/s/YorkAADHDPathway/> )

We would like to share some experiences and statements publicly on our website to help highlight this issue. If you agree to have your statements shared on our social media, blog, or in potential future campaigns please tick below.

Anything else you would like to add?

#### **Appendix 4: Quick GP survey**

1. Are you aware of the pilot pathway?
2. Have you used it?
3. Was it easy to use?
4. Any specific issues with it?
5. Any patient feedback?

#### **Appendix 5: Do-It Profiler survey**

The Do-It Profiler in North Yorkshire and York is new and we value your feedback so we can learn from your experiences. This will help us make improvements and changes where necessary.

Please complete this module/provide us with feedback after completing the neurodiversity screener.

1) How easy was it to use the Do-It Profiler?

- Very Easy
- Easy
- OK
- Quite Difficult
- Very Difficult

2) How useful was the report and practical guidance?

- Very Useful
- Quite Useful
- OK
- Not Very
- Not useful at all

3) What do you feel are the limitations of the Do-It Profiler?

4) Did you share the report with anyone else?

- Yes

- No
- 5) Are there other resources/people or places you have found helpful you could share with us so we can add these into help others?
  - 6) Are there any other comments you think would be helpful to further improve this? You can select more than one.
  - 7) What prompted you to seek a potential diagnosis at this point in time?

## Appendix 6: **HWY Full Survey Findings**

You can request a copy of the full survey data by contacting [healthwatch@yorkcvs.org.UK](mailto:healthwatch@yorkcvs.org.UK)

You can also access the data via this temporary link.

[https://padlet.com/Healthwatch\\_York/neurodiversity-gm7ezwos08v90lw2](https://padlet.com/Healthwatch_York/neurodiversity-gm7ezwos08v90lw2)

## Appendix 7: Glossary

Term	Definition
Accessible Information Standard	The Accessible Information Standard is a legal obligation introduced in 2016. It applies to all organisations that provide NHS care or publicly funded adult social care. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.
Attention deficit hyperactivity disorder (ADHD)	ADHD is a condition that affects people's behaviour. People with ADHD can seem restless, may have trouble concentrating and may act on impulse. In this report, we include three different types of ADHD including inattentive, hyperactive and impulsive and combined when we talk about ADHD.
Aspergers	A form of autism used to describe people at the higher functioning end of the autistic spectrum. It

Autism	<p>is a life-long condition and is more commonly diagnosed in males than females.</p> <p>The NHS defines autism as a lifelong condition that affects how a person communicates with, and relates to, other people.</p>
AQ – Autism Spectrum Quotient	<p>The Autism Spectrum Quotient (AQ) is a 50 item self-report measure used to assess traits of autism in adults and adolescents aged 16 years and over.</p>
Borderline personality disorder	<p>Borderline personality disorder is a mental illness that severely impacts a person's ability to manage their emotions. This loss of emotional control can increase impulsivity, affect how a person feels about themselves, and negatively impact their relationships with others.</p>
Community Mental Health Team (CMHT)	<p>A CMHT can support people to recover from mental health issues. They provide short or long-term care and treatment in the community. Health professionals from different backgrounds work in the CMHT.</p>
Community Psychiatric Nurse (CPN)	<p>A CPN is a mental health nurse who works in the community.</p>
Digital Health Technology (DHT)	<p>DHTs are intended to empower patients to manage their own health and get rapid access to peer support and clinical advice. They also help frontline staff to provide high quality care and make best use of their time.</p>
Do-It Profiler	<p>This is a web-based screening and assessment system for ADHD and autism being used in York, Selby, Tadcaster, Easingwold and Pocklington.</p>
Dyscalculia	<p>Dyscalculia is a specific and persistent difficulty in understanding numbers which can lead to a diverse range of difficulties with mathematics.</p>
Dyslexia	<p>Dyslexia is a common learning difficulty that mainly causes problems with reading, writing and spelling.</p>
Dyspraxia	<p>Dyspraxia (also known as developmental coordination disorder) is a condition affecting movement and</p>

	<p>coordination in children and adults. Dyspraxia affects all areas of life, making it difficult for people to carry out activities that others can take for granted.</p>
Freedom of Information Request (FOI)	<p>An FOI is a request for information held by public authorities, including the NHS and local authorities. They must provide the information unless there are good reasons to keep it confidential.</p>
General Data Protection Regulations (GDPR)	<p>The way organisations use people's personal information is covered by GDPR, which is a law. Personal information means anything that can be used to find out who you are and how to contact you.</p>
Humber and North Yorkshire Health and Care Partnership (HNYHCP)	<p>This is an integrated care system working in partnership with NHS organisations, councils, local Healthwatch, hospices, charities and the community voluntary and social enterprise sector to improve the health and wellbeing of local people.</p>
Healthwatch York (HWY)	<p>Healthwatch York is one of more than 150 Healthwatch across England. It is an independent health and care champion, representing people's experiences and ideas to help improve local health and social care.</p>
Integrated Care Board (ICB)	<p>An ICB is a statutory NHS organisation which is responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in a geographical area.</p>
Information Commissioner's Office (ICO)	<p>The ICO is the UK's independent regulator for data protection and information rights law, upholding information rights in the public interest, promoting openness by public bodies and data privacy for individuals.</p>
Integrated Care Partnership (ICP)	<p>An ICP is a statutory committee jointly convened by local councils and the NHS, comprised of a broad alliance of organisations and other representatives. These work as equal partners to</p>

	improve the health, public health and social care services provided in a geographical area.
Integrated Care System (ICS)	ICS is another name for ICP and is a partnership between organisations that meet health and care needs across a geographical area.
NHSE (NHS England)	NHS England leads the National Health Service (NHS) in England.
National Institute for Health and Care Excellence (NICE)	NICE provides national guidance and advice to improve health and social care.
National Autistic Society	The UK's main charity for autistic people and their families.
Neurodiversity	Neurodiversity suggests that there is not a 'normal' or 'right' way for the brain to develop, in much the same way that there is no 'normal' or 'right' gender, race or culture. Neurodiversity rejects the idea that autism and other neurological differences can be cured.
Office for National Statistics (ONS)	The ONS is the executive office of the UK Statistics Authority, a non-ministerial department which reports directly to Parliament.
Personal Independence Payment (PIP)	PIP is extra money to help people with everyday life if they have an illness, disability or mental health condition. You can get PIP on top of Employment and Support Allowance or other benefits. A person's income, savings, and whether they are working or not does not affect their eligibility.
Post Traumatic Stress Disorder (PTSD)	PTSD is an anxiety disorder caused by very stressful, frightening or distressing events.
Q-10	The Q-10 is a quick questionnaire that primary care practitioners can use to see if a person should be referred for an autism assessment. It provides 10 statements and asks people to agree or disagree with them.
The Retreat	The Retreat is a clinic in York which offers bespoke therapy services to support mental health and



	wellbeing. This includes doing assessments for ADHD and autism for those who meet the criteria.
Right to choose	The NHS provides patients with the right to choose their GP surgery to make choices about their health and care. Patients can also choose the organisation that provides other aspects of their care including hospital treatment.
Shared care agreements	Shared care agreements put the interests and safety of the patient first. They assume communication between the specialist, primary care prescriber (GP or other) and the patient. It is important that patients are consulted about treatment and are in agreement with it.
Solution Orientated Adult ADHD Carers' Group (SOAAC)	The group aimed to raise awareness of ADHD and called for more resources. They were active in 2017.
Tees Esk Wear Valleys NHS Foundation Trust (TEWV)	TEWV is the mental health service provider covering York and North Yorkshire.
Vale of York Clinical Commissioning Group (VoYCCG)	This was the precursor to the Integrated Care Partnership (ICP) and commissioned services for the Vale of York area until 30 June 2022.
York Disability Rights Forum (YDRF)	YDRF is led by disabled people and works to promote equal access to human rights for all disabled people who live or work in York.



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