Notice of a public meeting of

Health, Housing and Adult Social Care Scrutiny Committee

To: Councillors J Burton (Chair), Vassie (Vice-Chair), Baxter, Hook, Moroney, Rose, Runciman, Smalley, Wann and Wilson

Date: Wednesday, 21 May 2025

Time: 5.30 pm

Venue: West Offices - Station Rise, York YO1 6GA

AGENDA

1. Apologies for Absence
To receive and note apologies for absence.

2. Declarations of Interest (Pages 7 - 8)
At this point in the meeting, Members are asked to declare any disclosable pecuniary interest or other registerable interest they might have in respect of business on this agenda, if they have not already done so in advance on the Register of Interests. The disclosure must include the nature of the interest.

An interest must also be disclosed in the meeting when it becomes apparent to the member during the meeting.

[Please see attached sheet for further guidance for Members]

3. Minutes (Pages 9 - 14)

To approve and sign the minutes of the meeting held on 2 April 2025.

4. Public Participation

At this point in the meeting members of the public who have registered to speak can do so. Members of the public may speak on agenda items or on matters within the remit of the committee.

Please note that our registration deadlines are set as 2 working days before the meeting, in order to facilitate the management of public participation at our meetings. The deadline for registering at this meeting is **5:00pm on Monday 19 May 2025.**

To register to speak please visit www.york.gov.uk/AttendCouncilMeetings to fill in an online registration form. If you have any questions about the registration form or the meeting, please contact Democratic Services. Contact details can be found at the foot of this agenda.

Webcasting of Public Meetings

Please note that, subject to available resources, this meeting will be webcast including any registered public speakers who have given their permission. The meeting can be viewed live and on demand at www.york.gov.uk/webcasts.

5. Trauma Informed approaches within Tees, Esk and Wear Valleys NHS Foundation Trust (Pages 15 - 24)

This report provides an update on the transition from a positive risk-taking approach to trauma-informed care (TIC) by Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV), focusing on individuals diagnosed with Emotionally Unstable Personality Disorder (EUPD). It outlines the principles of TIC, the actions taken, and the impact on service users and organisational culture.

6. Update on the Autism and ADHD Health Needs Assessment and Strategy 2025-2030 (Pages 25 - 108)

The committee previously received a report on the Autism and ADHD Health Needs Assessment (HNA) in November 2024. This paper aims to bring the HNA back to members for final discussion and comment prior to publication, and bring the early draft version of the Autism and ADHD Strategy 2025-2030 to members for initial discussion and comment.

7. Work Plan (Pages 109 - 110)
Members are asked to consider the Committee's work plan.

8. Urgent Business
Any other business which the Chair considers urgent under the Local Government Act 1972.

Democracy Officer: James Parker

- Telephone – (01904) 553659
- Email – james.parker@york.gov.uk

For more information about any of the following please contact the Democracy Officer responsible for servicing this meeting:

- Registering to speak
- Business of the meeting
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Ta informacja może być dostarczona w twoim własnym języku. (Polish)

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یہ معلومات آپ کی اپنی زبان (بولی) میں بھی مہیا کی جاسکتی ہیں۔ (Urdu)

Agenda Item 1

Declarations of Interest – guidance for Members

(1) Members must consider their interests, and act according to the following:

Type of Interest	**You must**
Disclosable Pecuniary Interests	Disclose the interest, not participate in the discussion or vote, and leave the meeting unless you have a dispensation.
Other Registrable Interests (Directly Related) **OR** Non-Registrable Interests (Directly Related)	Disclose the interest; speak on the item only if the public are also allowed to speak, but otherwise not participate in the discussion or vote, and leave the meeting unless you have a dispensation.
Other Registrable Interests (Affects) **OR** Non-Registrable Interests (Affects)	Disclose the interest; remain in the meeting, participate and vote unless the matter affects the financial interest or well-being: (a) to a greater extent than it affects the financial interest or well-being of a majority of inhabitants of the affected ward; and (b) a reasonable member of the public knowing all the facts would believe that it would affect your view of the wider public interest. In which case, speak on the item only if the public are also allowed to speak, but otherwise do not participate in the discussion or vote, and leave the meeting unless you have a dispensation.

(2) Disclosable pecuniary interests relate to the Member concerned or their spouse/partner.

(3) Members in arrears of Council Tax by more than two months must not vote in decisions on, or which might affect, budget calculations, and must disclose at the meeting that this restriction applies to them. A failure to comply with these requirements is a criminal offence under section 106 of the Local Government Finance Act 1992.

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City of York Council	Committee Minutes
Meeting	Health, Housing and Adult Social Care Scrutiny Committee
Date	2 April 2025
Present	Councillors J Burton (Chair), Vassie (Vice-Chair), Baxter, Hook, Rose, Runciman, Wilson, Clarke (Substitute), Waller (Substitute) and Fenton (Substitute)
Apologies	Councillors Moroney, Smalley and Wann
In Attendance	Councillor Steels-Walshaw (Executive Member for Health, Wellbeing and Adult Social Care)
Officers Present	Peter Roderick – Director of Public Health
Visitors Present	Debbie Leadbetter – Primary Care Programme Lead, Humber and North Yorkshire Health and Care Partnership

53. Apologies for Absence (5:46 pm)

Apologies were received from Cllrs Moroney, Smalley and Wann, who were substituted by Cllrs Clarke, Fenton and Waller respectively.

54. Declarations of Interest (5:47 pm)

Members were asked to declare at this point in the meeting any disclosable pecuniary interests or other registerable interests they might have in respect of the business on the agenda, if they had not already done so in advance on the Register of Interests. None were declared.

55. Minutes (5:47 pm)

Members considered the accuracy of the minutes of the meeting held on 12 March 2025. An amendment was suggested to correct a typo at item 50 (2024/25 Finance and Performance Monitor 3).

Resolved:

i. That the minutes of the meeting held on 12 March 2025 be amended at item 50 (Urgent Care Delivery) at the second bullet point to replace:

- '… due there being no budget for necessary existing posts and the use of agency staff.'

with

- '…due to there being no budget for necessary existing posts and the use of agency staff.'

ii. That subject to the above amendment, the minutes of the meeting held on 12 March 2025 be agreed as a correct record and signed by the Chair.

56. Public Participation (5:52 pm)

It was reported that there had been one registration to speak at the meeting under the Council's Public Participation Scheme.

Flick Williams, participating remotely, spoke in relation to matters under the remit of the committee, recounting a recent experience in acquiring essential prescription medication involving visits to multiple pharmacies. She noted that many disabled people were adversely affected by supply shortages and suggested that barriers to daily disabled living were little understood by the Mayoral Combined Authority's Inactivity Trailblazer.

57. Humber and North Yorkshire Integrated Care Board - Dental Services and Oral Health Update (6:05 pm)

The committee considered a report setting out a current update on dental services across York, providing a focus on services and the local and national direction for the future of NHS dentistry.

The Humber and North Yorkshire Health and Care Partnership's Primary Care Programme Lead provided an overview, and in response to members' questions it was noted that:

- Recent data suggested dental access for adults continued to fall while access for children was increasing; it was not yet clear if the latter was due to the impact of child-only contracts. Access to urgent appointments had improved. The impact of the handing back of a provider contract in 2022 was emphasised; it had taken until December 2024 for another practice to take on the affected patients.

- The Prevention, Access, and Treatment (PAT) programme involved dentists and dental nurses visiting participating schools; having started in the East Riding the scheme was being rolled out across the whole Humber and North Yorkshire Integrated Care Board (ICB) area. Work was underway to integrate the additional elements of the PAT scheme with existing Public Health programmes such as supervised toothbrushing; and the ICB was liaising with local authority colleagues to identify practices and schools to take part.
- Dental services for care homes were provided through community dentistry services, and the ICB was considering ways to expand the service. Best value considerations affected the feasibility of offering a dental van service to rural areas; it was noted that only certain kinds of work could be done in a van, and managing the process would require significant resource; as such increasing the availability of urgent appointments had been prioritised.
- Four practices in York were taking part in child only contracts; the availability of funding was the main barrier to more practices signing up.
- Reports from dental practices suggested that routine check-ups accounted for most of the increase in children's access. With reference to flexible commissioning practices, children in care had always been included on the priority list, and care leavers had now also been added.
- Much feedback from dentists related to issues with the dental contract, and as such the government's interest in contract reform was to be welcomed. With reference to recruitment, it was noted that there was no dental training institute within York and North Yorkshire, but that work was being done to attract those from the area who had trained elsewhere to return within the NHS. The ICB was looking to engage with local authorities around incentives and housing to encourage trained dental staff into the NHS locally and welcomed a partnership approach.
- The ring-fence on dental budgets within the ICB area had been maintained. There was a budget for all contracted activities, and providers had to pay back for services not delivered; this money was then used to reinvest in urgent access. It was an ambition to incorporate more delivery into contracts.

Resolved: To note the report.

Reason: To keep the committee updated on the current position in respect of dental services across York.

58. Oral Health in York (6:23 pm)

Members considered a report outlining the Oral Health commissioned projects by Public Health, and the collaboration projects with the ICB and other partners.

The Director of Public Health provided an overview, and in response to questions from the committee it was noted that:

- With reference to supervised toothbrushing, there was evidence that positive behaviours acquired in childhood were carried forward into adolescence and adulthood, and other patterns suggested there was likely a positive impact on toothbrushing by other family members; relevant studies could be signposted.
- The Public Health team's emphasis was on a universal approach weighted towards more deprived areas; there was a need for flexibility to address need regardless of postcode, although the budget for oral health projects was limited.
- Due to funding limitations there were currently no active public health programmes on oral health training for adults. There were key messages that could be communicated, and options for doing this could be considered in future.
- The North Yorkshire and York Healthy Schools award included healthy eating within the bronze award; work in schools was already done around a variety of public health issues which it was hoped to expand in future.
- Supervised toothbrushing, fluoride varnish and water fluoridation were all effective preventative measures; a trial of the latter was currently underway in the North East although much of the UK already had fluoridated water.
- Attention was drawn to the currently unallocated work plan item on healthy weight; the developing service offer would move away from stratified weight management to a compassionate approach; this would include conversations around determinants of oral health, and it was suggested that members might wish to consider relevant recommendations at that point.

Resolved:

i. To note the report.
ii. To support, where possible, the provision of dental care access in communities.

Reason: To keep the committee updated.

59. Work Plan (5:56 pm)

Members considered the committee's work plan for the remainder of the current municipal year. It was noted that:

- The committee had previously requested a breakdown of the numbers of people helped in each service area in Finance and Performance monitoring reports to get a clearer sense of relative spending, and it was suggested that more detail could have been provided in the most recent report. It was noted that the volume and complexity of the data requested could present a challenge in how reports were structured, and careful consideration would be needed to ensure narrative detail remained clear; the Chair noted that she would pass members' views to the appropriate officers.
- The Chair and the Executive Member had participated in a recent round table discussion with the Integrated Care Board and Public Health officers in relation to pharmacy provision.
- Council's recent resolution to recommend that the relevant scrutiny committee undertake a task-and-finish review into the likely local impact of government proposals on disability and long-term sickness benefits was noted.
- The scheduled meeting in May would be the committee's last in its current form. The upcoming changes to the scrutiny function which had been approved by Council provided an opportunity through necessity to consider the best way to address remaining unallocated items on the work plan; these outstanding items demonstrated the degree to which the committee had struggled to cover all suggested items, and careful consideration would be needed in deciding which subjects were most appropriate for public committee briefings and informal member briefings respectively.
- A model for scrutiny based on more extensive use of task-and-finish groups could be very effective if done well; while there might be some concerns that fewer formal committee meetings could reduce the level of scrutiny, it was highlighted that a task-and-finish approach offered the opportunity for a more detailed examination of issues which otherwise might have been dealt with briefly at committee.
- There were alternatives to standard reports as a means to access relevant information, and that going forward the opportunity to engage with scrutiny topics in new ways should be taken. It was also suggested that under the new scrutiny model, more detailed

background on when topics had previously been considered should be included in reports to ensure scrutiny members had full access to relevant information.

Resolved: To note the work plan.

Reason: To keep the committee's work plan updated and ensure that opportunities presented by the changing approach to scrutiny were taken.

Cllr J Burton, Chair
[The meeting started at 5.46 pm and finished at 7.31 pm].

Tees, Esk and Wear Valleys
NHS Foundation Trust

Meeting of:	**CYC Health, Housing and Adult Social Scrutiny Committee**
Date:	**21 May 2025**
Title:	**Trauma Informed approaches within Tees, Esk and Wear Valleys NHS Foundation Trust**
Author(s):	**Martin Liebenberg, Care Group Director of Therapies; Amanda Hall, Highly Specialist Psychological Therapist & Trauma Informed Care Lead**

Summary

This report provides an update on the transition from a positive risk-taking approach to trauma-informed care (TIC) by Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV), focusing on individuals diagnosed with Emotionally Unstable Personality Disorder (EUPD). It outlines the principles of TIC, the actions taken, and the impact on service users and organisational culture.

Training and awareness: Since 2021, TEWV has conducted extensive training for staff and community members on trauma-informed practices, with positive feedback indicating improved understanding of trauma's effects.

Collaboration with partners: TEWV is working with local partners, including the City of York Council, to enhance trauma-informed practices and improve service delivery through shared decision-making and mutual support.

Future considerations: The report concludes that while challenges remain, the transition to TIC is positively impacting service users and fostering a supportive environment, with ongoing efforts to refine and expand these practices.

Purpose of report

The CYC Health, Housing and Adult Social Scrutiny Committee requested an update from Tees, Esk and Wear Valleys NHS foundation Trust (TEWV) on its prior application and progress in moving beyond the use of the BPD+ protocol, an assessment of current staff understanding and the outlining of any trauma-informed approaches it is implementing.

This report will outline actions taken in moving from a positive risk-taking approach to a trauma-informed care (TIC) model (including for individuals diagnosed with Emotionally Unstable Personality Disorder (EUPD)). The shift in approach was driven by an increasing recognition of the complexity of EUPD, the role of trauma in its development, and the need for more supportive, empathetic interventions. The report highlights the steps taken by the Trust to implement a trauma informed framework. It also discusses the emerging impact of this transition on service users, staff, and the broader organisational culture, as well as reflections on the challenges and future considerations.

Introduction

Emotionally Unstable Personality Disorder (EUPD), previously known as Borderline Personality Disorder (BPD), is a complex and often misunderstood mental health condition. Individuals with EUPD may experience intense emotions, unstable relationships, impulsive behaviours, and difficulties with self-identity. These symptoms can lead to significant challenges in daily functioning and may result in frequent crises and hospital admissions. Historically, mental health services for people with EUPD often focused on risk management and control, utilising positive risk-taking strategies to minimise harm and protect individuals from their own behaviours. However, over time, evidence has emerged suggesting that these approaches may not be sufficient in promoting long-term recovery or well-being for individuals with EUPD. It’s important to note that there has been a significant shift nationally from “traditional” Borderline Personality Disorder protocols to more Trauma Informed approaches, across the United Kingdom.

The transition from positive risk-taking to trauma-informed care (TIC) represents a fundamental shift in the way services engage with individuals who have EUPD. Trauma-informed care emphasises understanding the impact of past trauma on a person's mental health and behaviour, recognising that individuals with EUPD often have histories of significant emotional, physical, or sexual abuse. By incorporating trauma-

informed principles, mental health services aim to create a safe, supportive environment that empowers service users to manage their symptoms and improve their quality of life. The shift is supported by strengthening principles of care such as rolling out the use of Structured Clinical Management in all services (therefore not creating separate “specialist services”), lived experience, reflective practice and national programmes, e.g. Culture of Care.

Trauma-informed care is an approach that recognises the widespread impact of trauma on individuals' mental, emotional, and physical well-being. It is based on an understanding of the signs and symptoms of trauma and incorporates this knowledge into all aspects of service delivery.

The core principles of care and trauma-informed care are:

1. Safety: Ensuring that the physical and emotional environment is safe for all individuals, including staff and service users. This involves creating a space where service users feel secure and supported.

2. Trustworthiness and Transparency: Building trust between service users and staff through clear communication, consistency, and transparency in decision-making processes.

3. Peer Support: Recognising the value of peer support and incorporating it into treatment. Individuals who have experienced similar trauma can provide valuable insights and encouragement for recovery.

4. Collaboration and Mutuality: Involving service users in their treatment planning and decision-making, ensuring that their voices are heard and respected. This approach emphasises shared decision-making and empowerment.

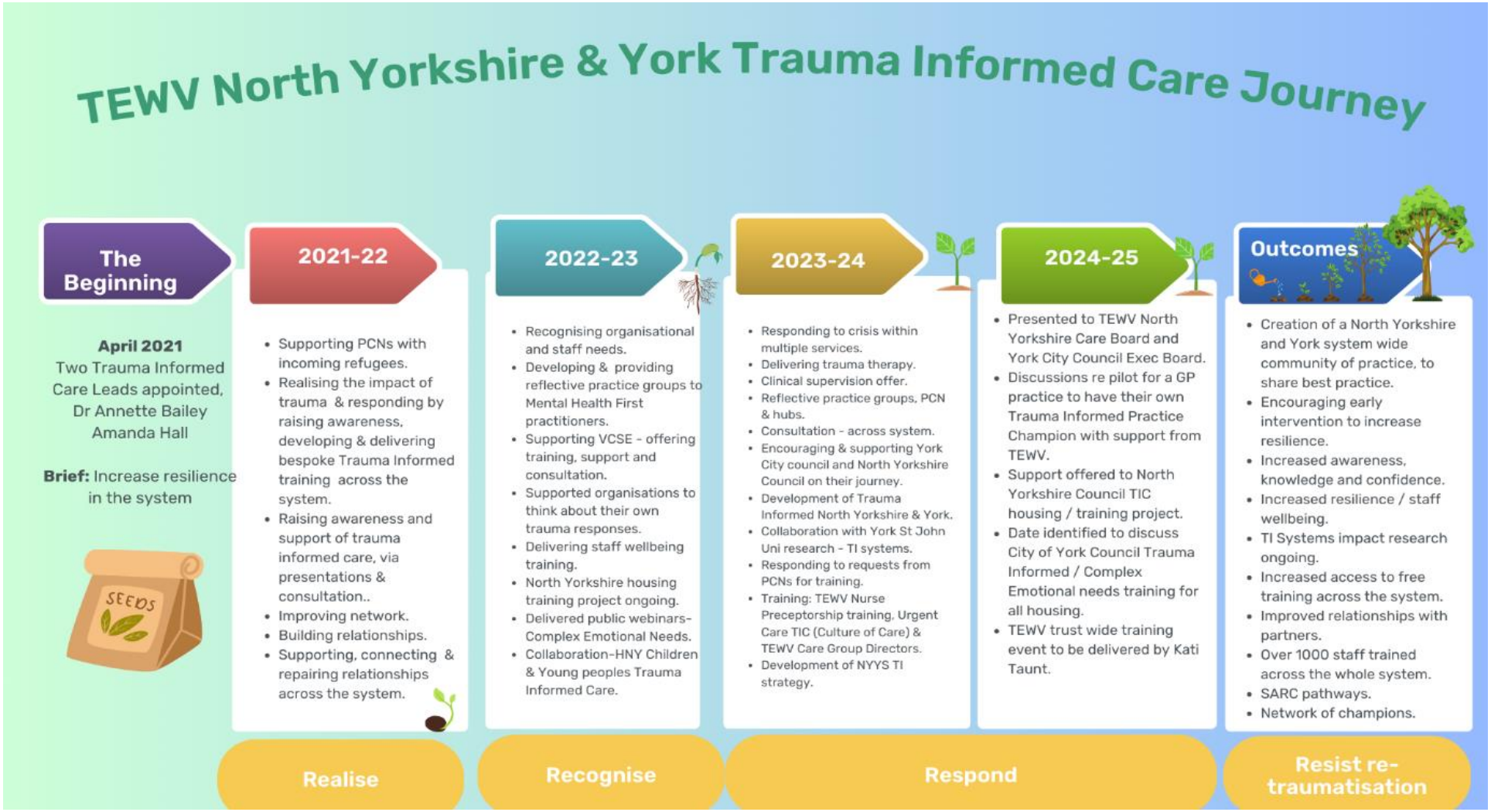
5. Empowerment, Voice and Choice: Supporting individuals in regaining control and making choices about their lives and care.

6. Cultural, Historical, and Gender Sensitivity: Understanding and addressing the unique needs of individuals based on their cultural, gender, and historical contexts. This involves recognising the diverse ways trauma manifests and tailoring interventions accordingly.

There have been considerable efforts in TEWV to consolidate and embed trauma informed principles and practice throughout our services. Within this report we describe the work against each of the 6 principles to demonstrate how they inform our practice as we moved away from the BPD+ protocol, thus reflects a growing understanding of the complex interplay between trauma and mental health.

Within North Yorkshire and York we have named Trauma Informed Care Leads who are in a unique position to not only to work collaboratively and creatively with TEWV staff but also the wider system partners including the City of York Council, Voluntary Sector and other statutory partners who are keen to collaboratively tap into resources that they might not have.

Updates on work undertaken



1. **Safety: In feeling safe both physically and emotionally.**

Since 2021, over a thousand (1000) colleagues in TEWV and the local community have attended training / workshops and webinars, focusing on Trauma Informed Practice, Relational and Complex Emotional Needs with our TEWV specialist practitioners. Although we still have some way to go, colleagues are describing (initially in the training feedback, but also more widely in meetings such as multi-disciplinary discussions) an improved understanding of trauma, its impact on the individual, family, friends and the systems working with them, as well as the importance of staff wellbeing. We recognise that whilst there is good expertise in the system, alongside excellent practice, trauma informed practice is not always consistently applied or embedded into our operational frameworks. This is perhaps not unexpected as the processes of becoming a Trauma Informed organisation is in some respects never completed or linear in nature.

However, we are focussed on continually improving this. A key event planned by the Trust Trauma Informed Care Steering Group during June 2025 will further support the wider Trust workforce in considering how to embed trauma informed practice in all aspects of our work. The event will be supported by Kati Taunt, a nationally respected consultant, trainer and trauma therapist, who is working across the country to help local government, education and NHS to implement Trauma Informed Practice. Kati also has significant experience of using the HNY North Yorkshire TIC Tool Kit and will help us to continue our work on this journey.

There is a growing recognition of the importance in creating safe and stable environments to enable individuals to engage in any helpful support and providing choice and options in what is available. The creation of new roles such as Mental Health First Contact Practitioners in GP surgeries and Complex Emotional Need Specialists (whose work span the wider system but are based within TEWV) in the community are a good example of the need to have early interventions along with time and space to think about what is happening for an individual who may not be receiving the support they want or need. These roles along with Community Transformation and Hubs, which are still in development alongside systems partners are built on Trauma Informed Principles, offering safe spaces, choice, a range of therapeutic options, along with specialist support across the system and creating policies and procedures that promotes safety, reducing harm and stigma.

Building on trauma informed frameworks ensures a collective and consistent way for all partners and allows us to evidence and measure clear outcomes consistently.

2. Trustworthiness and Transparency

As we have been on our journey, we have been using this as an opportunity to work with the wider system and establishing trust through clear communication, honesty, and transparency in decision-making processes.

The aim is that the trauma informed framework provides opportunities for connection and consistency which binds partners collaboratively together in their transformation journey. We are working on this at every level, to improve this with everyone that we work with, the result of this has been an increase in being able to collaborate more effectively and strengthening of our partnerships, including the City of York Council.

3. Peer Support

Providing opportunities for individuals to connect with and support each other, fostering a sense of belonging and validation is at the heart of Trauma Informed Care. We have been working with our own Lived Experience Directors and Co production colleagues to ensure that we are inclusive and not failing to recognise the benefit and recovery that can come from peer support. The strength- based framework has extended to our Experts by Experience in the community and other services such as York Mind who operate a peer support service in the York Hub. Our ambition is to utilise this systemically, not only thinking about our service user experiences, but that of our colleagues and partners. Within York and North Yorkshire we have created a Trauma Informed and Responsive Community of Practice, this is a group for Senior Leaders and anyone else wanting to enhance their care and tailoring interventions to individual needs opposed to medical models. The group is linked in at a local and national level, sharing experience, support, knowledge and resource across the whole system.

4. Collaboration and Mutuality

Within the BPD+ protocol there were elements of collaboration encouraged, this was by involving the individual in formulations. Although the processes are not perfect, they are in development and the roll out of Structured Clinical Management within TEWV services will enable this process further, by offering an extended period of assessment at the start and keeping the individual at the centre of work, focusing on skills building and being involved in the process. Again those principles of transparency are at play, as within this offer we are to be clear about what we can and can't offer and work with the wider system to think about how we can meet multiple needs rather than focusing solely on trauma but also considering their history, strengths and what they think might help them more, involving them more in the planning and implementation of their own care and support.

This is work in progress and other initiatives such as Culture of Care and Right Care Right Person are also infusing these approaches. Moving away from the BPD+ protocol is something that requires systemic change, not only for our services users but also with our partnerships. We have been working with the voluntary sector and City of York Council to think about how we can work together to improve outcomes, evidence of this is the development of the Hub and provided training to the Council as well as supporting them in their trauma informed care journey.

5. Empowerment, Voice and Choice

Supporting individuals in regaining control and making choices about their lives and care. Trauma Informed Care and Complex Emotional Needs Specialists are working with the system to enable what helpful and unhelpful support can look like. Recognising that not all needs can be met by a mental health service and that there can be choice in what care can look like and needs to include the whole person. We are working with our Experts by Experience, carers, families and other community services, to ensure that their voice is heard, listened to and they are involved. Our aim is for them to be involved through every aspect, this includes providing opportunities for individuals to express their needs and preferences, and to make decisions about their own care throughout their journey and contributions to trust processes and procedures.

6. Cultural, Historical and Gender Sensitivity

Recognising the impact of cultural, historical, and gender factors on an individual's experience of trauma and their recovery. This means being sensitive to cultural differences and respecting individual identities. We still have some way to go, despite training for our TEWV staff and partnerships, there remains challenges, around language used and operational changes that need to occur. This again is where collaboration, peer support and empowerment are helpful, as it allows our staff to be curious and consider how we can think about how history has had an impact on our service, service users and families. Moving forward there is now more challenge into why and how we are doing something and we are working more collaboratively with the community to think about how we can meet needs in more creative ways, such as utilising single-sex space or offering to provide an appointment in another environment and offering free Trauma Informed Care and Complex Emotional Needs training across the whole system.

Conclusion

There is a culture shift occurring, not just within TEWV but across the whole of the system. We are making steps to move towards being a Trauma Informed organisation and system. Whilst there will still be some differences in experience, the new roles identified should help colleagues gain more support and understanding when working with trauma, complex emotional needs or anyone with a diagnosis of personality disorder. As services evolve there will be more choice and flexibility in where anyone can go to get the needs met, from a primary to a secondary care level and it will be a while before we see full progress.

The transition from a positive risk-taking approach to a trauma-informed care model represents a significant shift in how services are delivered. By recognising the deep connections between trauma and mental health, we take assurance that increasingly the Trust is creating a safer, more supportive environment for service users, fostering greater collaboration, empowerment, and healing. While the process presents challenges, the overall impact thus far is seen to be positive. The journey is ongoing, and future efforts will focus on refining and expanding trauma-informed practices to ensure that all individuals with EUPD receive the care and support they need for long-term recovery.

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Health, Housing and Adult Social Care Scrutiny Committee **21 May 2025**

Report of the Director of Public Health

Update on the Autism and ADHD Health Needs Assessment and Strategy 2025-2030

Summary

1. Committee members previously received a report on the Autism and ADHD Health Needs Assessment (HNA) in November 2024. This report also detailed plans to develop an autism and ADHD strategy for York.

2. The aim of today's report is to:

   - bring the HNA back to members for final discussion and comment prior to publication
   - bring the early draft version of the Autism and ADHD Strategy 2025-2030 to members for initial discussion and comment

3. This Scrutiny discussion is intended to form part of a broad coproduction approach to the strategy, including public consultation which has been undertaken since December 2024 and will last until the strategy is published in October 2025.

Background

4. Autistic people and people with ADHD are a core and vital part of our community in York. Their health needs, their well-being, their access to good high-quality services constitute an important part of our ambition to make York a ‘health-generating city’ and to fulfil the aims of our Health and Well-being Strategy around reducing inequalities.

5. It is clear that a combination of under-resourcing and a rising number of people coming forward for Autism and ADHD diagnosis and assessment has meant that services are in this area – from health to social care to

education and beyond – are very stretched. This means that individuals and their families frequently report feeling under-supported.

6. Additionally civic society – from our public spaces to our shops, amenities, criminal justice system and beyond – has not kept pace with what we have learned enables an inclusive and equal public sphere for Autistic people and people with ADHD.

7. The draft HNA was brought to Scrutiny committee in November 2024, and the comments of members as well as input from public speakers have been reflected in an updated version which is attached at Annex A.

8. The HNA shows clearly that the health of Autistic people and those with ADHD is worse than the general population. There is nothing inherent in neurodiversity which would mean this group in society should experience significantly poorer health, however Autistic people and people with ADHD have a larger number of mental and physical health conditions, have higher levels of homelessness, have on average 5 years less life expectancy than the general population, higher rates of additions, and experience significant barriers to full inclusion in society.

9. All partners have a role to play in building a more inclusive society and in providing services in a high-quality manner which serve neurodivergent individuals well. In particular, health services and council services have a duty in statutory guidance to plan services, develop partnerships and commission together in response to the national autism strategy, one of the few health-specific strategies named in law.

10. York has not had an autism strategy since 2021; a gap in time which is far too long. This scrutiny discussion today builds on the HNA and is intended to focus on the draft Autism and ADHD strategy covering 2025-2030 (Annex B).

11. It is important for Scrutiny committee members and public readers / participants / observers of the committee meeting to note that this is an early draft strategy, which has had a number of different opportunities so far to be discussed by partners and those with direct experience of Autism and ADHD, but still has a number of months of consultation and coproduction to go, prior to being published at a Council Executive meeting in Autumn alongside the SEND/Alternative Provision Strategy for the city with which it has close links.

Consultation

12. The phases of engagement and consultation are outlined below:

May-November 2024	An Autism and ADHD Health Needs Assessment was produced, using data from health and care services as well as evidence from the literature on the health needs of autistic people and people with ADHD.
October 2024	A strategy working group was formed, including the key partner agencies in York as well as academic, voluntary agencies and lived experience. A full list of steering group members can be found in the strategy.
Nov 24 - Mar 25	'Listening Exercises' were held where members of the strategy group went out to over 20 organisations or boards with 3x 'conversation starters' on the strategy, and captured feedback. A full list of organisations can be found at in the strategy.
May 2025	An early draft strategy was circulated, and published for public discussion at the council's Health, Housing and Adults Scrutiny Committee.
June-July 2025	Consultation events will be held on the draft strategy, to further shape and refine it.
July 2025	Formal public consultation will be carried out on the strategy, and comments incorporated.
Autumn 2025	The final Autism and AHDHD Strategy 2025-2030 will be published.

Council Plan

13. This work is in line with the Council Plan 2023-2027 proposal to ‘Co-produce and publish our approach to supporting people with Learning difficulties, mental health, autism and delivery of adult social care’

Implications

7. **Financial** There are no direct financial implications of this report, which is for members to discuss and feed in to a city wide strategy. Individual organisations are responsible for resourcing the commitments in the

strategy, and for City of York Council all commitments will be delivered within existing budgeted resources.

- **Human Resources (HR)** There are no HR implications of this report
- **Equalities** ACAS state that ‘Some neurodivergent people do not see themselves as disabled. However, being neurodivergent will often amount to a disability under the Equality Act 2010’. There are therefore equalities implications of this strategy, which aims to include Autistic people and people with AHD better within society and services and will have a positive impact on inequalities
- ***Legal*** There are no legal implications of this report
- ***Crime and Disorder*** There are no crime and disorder implications of this report
- **Information Technology (IT)** There are no IT implications of this report
- **Property** There are no Property implications of this report

Risk Management

There are no known risks directly relating to this report.

Recommendations

Members are asked to:

1) Note and discus the Autism and ADHD Health Needs Assessment (HNA)

2) Note and discuss the early draft version of the Autism and ADHD Strategy 2025-2030

Contact Details

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	Report Approved [x] **Date** *13/5/25*

Wards Affected: *List wards or tick box to indicate all* **All** [x]

For further information please contact the author of the report

Annexes

Annex A: Autism and ADHD in York: A Health Needs Assessment (Draft May 2025)

Annex B: A city that works for all: Autism and ADHD Strategy for York 2025-2030 (Draft May 2025)

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Annex A

Draft version for discussion at Health Housing and Adult Social Care Overview and Scrutiny Panel Prior to publication

Autism and ADHD in York

A Health Needs Assessment

CITY OF YORK COUNCIL

Produced by City of York Council Public Health Team, May 2025

Contents

Executive Summary

This is a Health Needs Assessment (HNA) for people of all ages who live in York who have a diagnosis of Autism or ADHD, who believe they are Autistic or have ADHD, or who would like to receive a diagnostic assessment for these conditions.

Some key findings are summarised below

Prevalence and Demographics	In total there are 2,786 people who are registered with a York GP and who have a diagnosis of autism on their health record.	Autism is underdiagnosed in York, particularly in older people. There is a 3:1 male to female ratio in diagnoses of both Autism and ADHD in York
	In the UK, the prevalence of ADHD in adults is estimated at 3% to 4% With 2,311 people in York having a diagnosis of ADHD, this suggests only around 1 in 3 adults in York are diagnosed.	18.4% of people with an ADHD diagnosis in York also have an Autism diagnosis, and 15.3% of people with an Autism diagnosis also have an ADHD diagnosis.
Assessment and waiting lists	In January 2023 there were 1,560 adults awaiting autism and ADHD assessment and a further 2,000 referrals that had not yet been triaged. It was estimated that the waiting list is currently five years.	Compared to 2021, the children and young people's autism service has seen a 50% rise in monthly referrals, and just over a quarter of children and young people have been on the waiting list for more than a year.
Health issues	York GP data shows that 1096 people with an ADHD diagnosis also have a mental health condition, which is 44%.	12% of people with ADHD will develop an alcohol addiction and 28% develop a drug addiction at some point in their lives. 14% of people with ADHD in York are current smokers, higher than general smoking rates
	Autistic people, as a group, face health and wellbeing challenges such as higher levels of homelessness, 5 years lower life expectancy, higher rates of additions, and 40% of this group in York have a mental health condition	Societal awareness and understanding of neurodiversity is still low, and children, adults and carers experience stigma from friends, family and services.

Project Scope and Approach

This HNA considers the health and wellbeing needs of people of all ages who live in York who are Autistic or have ADHD. This includes people with a diagnosis, people waiting for a diagnosis, and people who recognise traits of Autism and/or ADHD in themselves. The purpose of this needs assessment is to consider the current and emerging Autism and ADHD needs of residents who live in York. Health Needs Assessments are a systematic method of identifying the unmet health and healthcare needs of a population, and this HNA has been written in advance of a new Autism and ADHD Strategy for York, in order to form and shape this strategy.

There are two main aims of this project:

1) To build collective understanding of the Autism and ADHD population of York. This includes information about the population size and demographics, current use of health, care, and other key service areas.
2) To make recommendations and support preparation for a city-wide Autism and ADHD strategy that is intended for 2025.

This needs assessment does not make specific recommendations. It identifies topics and needs that should be considered in the development of the York Autism and ADHD strategy. This HNA looks at many local data sources:

- Local authority services: SEND team, adult social care
- Health services: Neurodiversity diagnostic and support services, GP data, hospital data, addiction recovery services, mental health services, children's social care data
- Other sources: Employment data, criminal justice and police data, large scale research studies

This HNA also looks at national and international research for a wider understanding of the health and wellbeing needs of Autistic people and people with ADHD. This can be particularly helpful when local data is incomplete, out of date, hard to access, or does not clearly contain information about Autism/ADHD.

The document was written by the public health team but with input from the Autism and ADHD strategy working group, from academic partners, and through discussion at a council Scrutiny Committee.

This health needs assessment also includes a ‘What Works Guide’. This is a selection of guidance or best practice documents which describe ways of working that can be helpful and inclusive to Autistic people and people with ADHD. In various ways and to various levels, these guidance documents have been developed with input from neurodiverse people.

Definitions and terms used

Neurodiversity means that all people's brains process information differently. To be a neurodivergent person is someone whose brain processes information in a distinctly different way to neurotypical people.

Because neurotypical people make up the largest group of people in our world, the way they process information is thought to be 'typical' or 'normal'. As a result, a lot of our environments are set up to accommodate these typical ways of processing information, which can make some things difficult for neurodivergent people to access.

There are lots of different ways a person can be neurodivergent. It is a collective term to describe people who have conditions such as Autism, ADHD, dyslexia, dyscalculia, dyspraxia, stammering, Foetal Alcohol Spectrum Disorder, or Tourette's syndrome. In most cases, a person is neurodivergent for their whole life. Some forms of brain injury can create this, but this is quite rare. Some people may know they are neurodivergent from a very young age, others may realise this in adulthood.

Specific learning disabilities such as dyslexia are a form of neurodiversity. However, general learning disabilities are not a form of neurodiversity. Some neurodivergent people also have a learning disability, and some do not.

Although there is a wide range of neurodivergent individuals in our society, this needs assessment is only looking at two neurodivergent groups – Autistic people and people with ADHD. This is because York is planning an Autism and ADHD strategy in 2025, and we want this needs assessment to support the strategy planning process.

Autism and ADHD are distinct conditions and experiences; however, we are considering them together in this needs assessment for two reasons.

- Firstly, Autistic people and people with ADHD face somewhat similar challenges, for example, the diagnosis pathway and the societal barriers placed on Autistic people and people with ADHD that impact mental and physical health.
- Secondly, a proportion of people are both Autistic and have ADHD

(around 30%).[1] This is sometimes referred to as 'AuDHD'. We recognise the unique experiences of people with both ADHD and Autism, but also recognise that a proportion of the community may have AuDHD, meaning they have their own unique challenges. For example, individuals with AuDHD may feel a need for routine *and* a need for impulsivity, which may mean they experience internal struggle between these contrasting traits.

The City of York Council has previously committed to supporting the social model of disability when designing places and policies. The social model of disability states that people are disabled by barriers placed on them by society rather than by an impairment or condition.

We recognise that many within the neurodiversity community value this approach. It highlights there is nothing intrinsic to either Autism or ADHD that should mean a person is more likely to become physically or mentally unwell, become homeless, or long-term unemployed; and that these experiences often arise from marginalisation and discrimination.

We also recognise that some within the neurodiversity community do not like the language of 'disability' and do not recognise themselves as disabled. To make things more complicated, some parents reject the social model of disability, especially if their children have additional physical or cognitive needs. Therefore not all members of the neurodiversity community and those that support them agree with the social model of disability, aligning more with traditional medical models.

In this strategy and needs assessment we are using the principles of the social model of disability and neurodiversity, however, the differing opinions of the community are acknowledged despite the use of neurodiversity-affirming language throughout. In relation to Autism, medicalised or potentially stigmatising terminology (e.g., disorder, high/low functioning) have been avoided throughout and identity-first language (e.g., Autistic individual) has been used, following the majority preference of the Autism community.

[1] Matson, J. L., & Goldin, R. L. (2013). Comorbidity and autism: Trends, topics and future directions. Research in autism spectrum disorders, 7(10), 1228-1233.

Chapter 1: Diagnosing Autism and ADHD in York

In this section we will talk about how Autism and ADHD are diagnosed in children and adults in York. This includes:

- the process of making a diagnosis
- information on which organisations fund and provide diagnosis services
- information on recent waiting times
- information on recent changes to diagnosis services for adults

Children and young people

Autism is diagnosed through a detailed assessment by a team of health professionals with expertise in developmental disorders. Diagnosis of Autism is possible from early childhood, with the average age of diagnosis, globally, being 43 months.[2]

The National Institute for Health and Care Excellence (NICE) recommends that individuals referred for an Autism assessment should be seen within three months. However, the actual waiting time across the UK ranged from 218 to 306 days (approximately seven to ten months) between April and December 2023.

ADHD can be diagnosed as early as 4 years old, but this is often delayed until the age of 6 or 7 years when children begin formal education, as characteristics are often noticed more commonly in a school environment.

In York, children under 5 years are assessed at the child development centre at York hospital. The assessment process can take around a year, as paediatricians need to rule out other health or developmental issues before conducting a full Autism assessment.

Children aged 5-18 are assessed by Child and Adolescent Mental Health Services (CAMHS). Referrals can be made by the GP or School Special Educational Needs Coordinator through to the ‘single point of access’ SPA. The SPA collect information through some screening forms and a 30 minute phone call, this is to help the ‘Neurodiversity screening panel’ decide if a full assessment is needed.

[2] Van’T Hof, M., Tisseur, C., van Berckelear-Onnes, I., Van Nieuwenhuyzen, A., Daniels, A. M., Deen, M., ... & Ester, W. A. (2021). Age at autism spectrum disorder diagnosis: A systematic review and meta-analysis from 2012 to 2019. Autism, 25(4), 862-873.

Due to a significant increase in referral numbers, there is currently a long wait for Autism and ADHD assessments assessments within CAMHS As of March 2024 there were 450 children and young people aged 5-18 waiting for an assessment for Autism diagnosis. In March 2024, just over a quarter of children and young people had been on the waiting list for more than a year. Compared to 2021, the service has seen a 50% rise in the number of referral requests each month. [3]

A full assessment of Autism in children and young people will involve meeting with the young person, and a separate conversation with parents and the school. For ADHD the team encourage the young person to come into the appointment on their own, with family supporting from the waiting room. Afterwards, the family receive a brief summary of the assessment and confirmation of the outcome. CAMHS is not commissioned to offer ongoing intervention or support for Autism and so the young person is then discharged.

In 2024, Public Health published a full SEND Health Needs Assessment for York which goes into further detail on topics relating to Autism /ADHD in the context of the SEND system.[4]

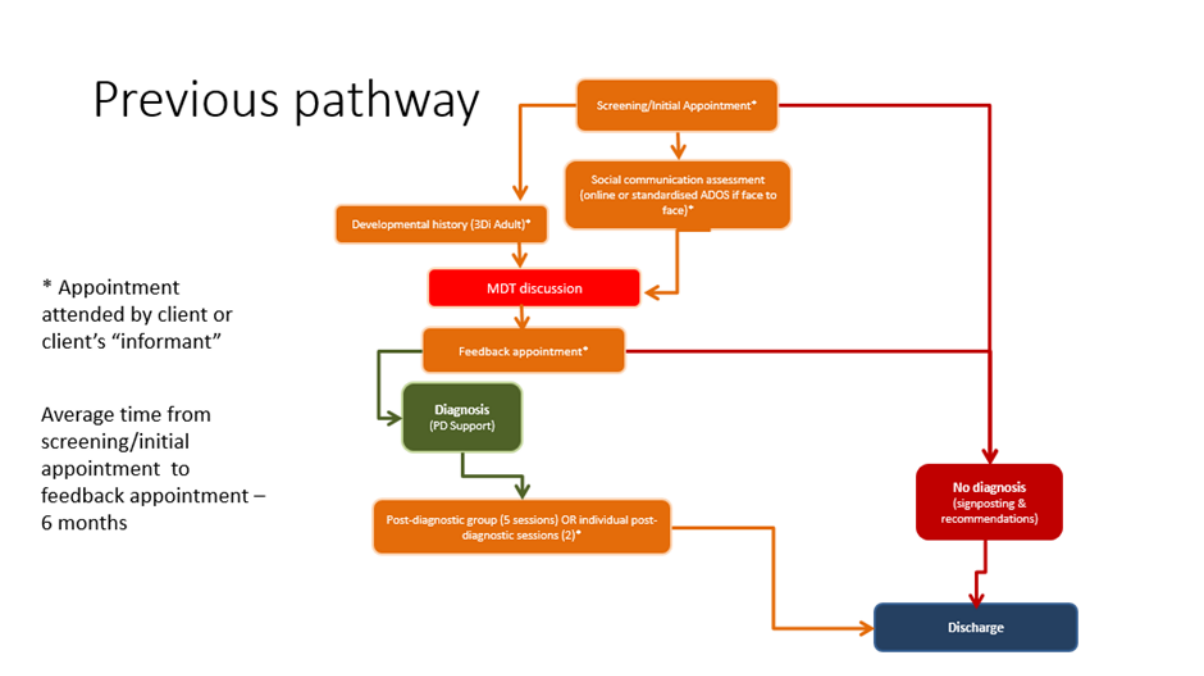
Adults

The NHS adult Autism and ADHD diagnosis service is delivered by The Retreat in York. The service completes diagnostic assessments for both Autism and ADHD but currently there are separate diagnostic pathways for each.

Autism diagnostic assessments at The Retreat are completed in line with the National Institute for Health and Clinical Excellence (NICE) guidelines.[5] Assessments are completed by a specialist multidisciplinary team that includes psychologists, nurses and occupational therapists. All members of the multidisciplinary team are trained in the use of standardised Autism diagnostic tools, including the Autism Diagnostic Observation Schedule (ADOS-2), The Developmental Diagnostic Dimensional Interview (3Di) and Autism Diagnostic Interview – Revised (ADI-R).

[3] York SEND
[4] Children & Young People with Special Educational Needs & Disabilities
[5] Overview | Autism spectrum disorder in adults: diagnosis and management | Guidance | NICE

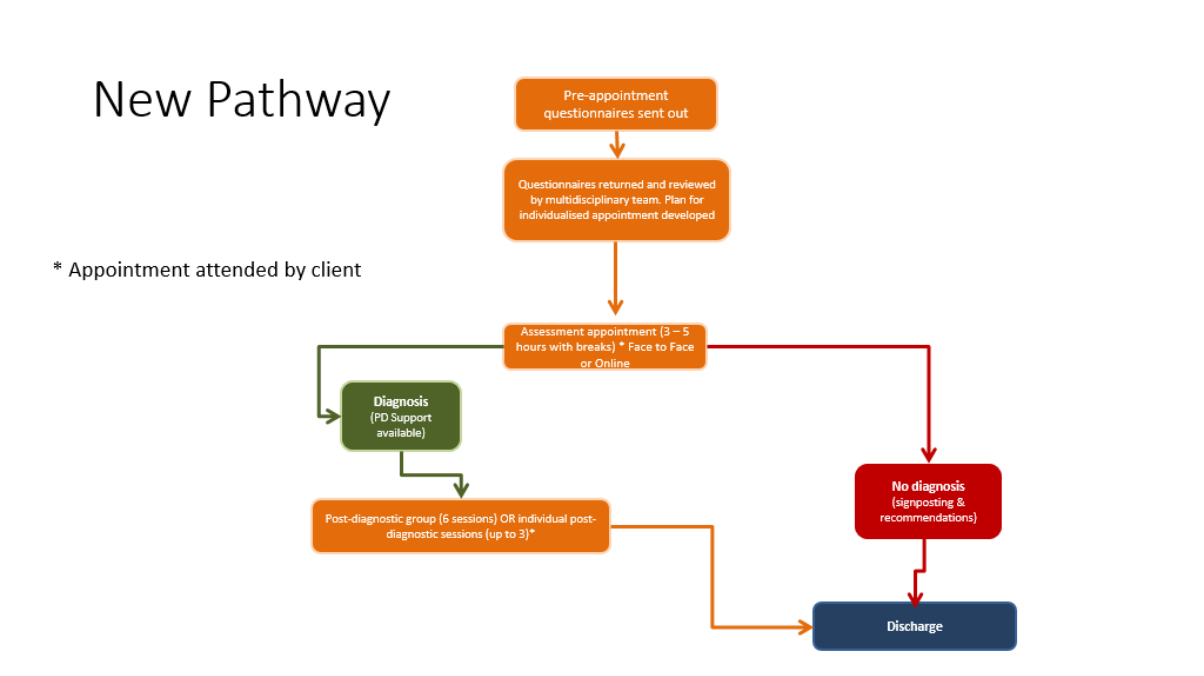
In February 2024, The Retreat updated its diagnostic assessment pathway. Previously the assessment had included three diagnostic assessment appointments, a multi-disciplinary discussion and feedback appointment. The time taken to complete this whole process, could vary but the average time between attending the screening/initial appointment to receiving feedback on the outcome of assessment was 6 months.



Between May and December 2023, a project was trialled by The Retreat using an alternative method of completing Autism diagnostic assessments. This process utilised "front loading", the gathering of extensive information in advance of an individual attending to complete an appointment. This process aims for individuals to then be able to attend for one extended individualised appointment, where the aim would be to provide an outcome for their diagnostic assessment within this one appointment. The questionnaires completed prior to appointment included: Information Questionnaire, Sensory Questionnaire, Repetitive Behaviour Questionnaire, Informant Information, and Well-Being Update Questionnaire. The appointment includes interview, observations, multi-disciplinary discussion, and feedback.

A service evaluation followed this trial and detailed feedback was gathered on this assessment process from those who participated in the

trial. The overwhelming positive feedback from this trial led to the implementation for this to be the standard pathway for Autism diagnostic assessments at The Retreat from February 2024.



The outcome for approximately 80% of assessments completed is a diagnosis of Autism (sometimes referred to as conversation rate). This has remained consistent for the service for a number of years and continues to be the case within the new diagnostic assessment pathway.

ADHD diagnostic assessments at The Retreat are completed are in line with the National Institute for Health and Clinical Excellence (NICE) guidelines.[6] Assessments are currently completed by specialist psychiatrists.

Similar to the Autism diagnostic pathway, the ADHD assessment process includes the completion of forms in advance of the individual attending for their assessment appointment. The forms completed include information from an informant, someone who knows the individual well and ideally knew them during childhood. Most ADHD assessments are completed in an individual appointment which will include a detailed review of current and historic mental health and exploration of examples of the ADHD diagnostic criteria, both during childhood and currently.

[6] Overview | Attention deficit hyperactivity disorder: diagnosis and management | Guidance | NICE

Assessments are individualised and if required will include the completion of standardised ADHD diagnostic assessment tools, including the Diagnostic Interview for ADHD in adults (DIVA), Conners' Adult ADHD Rating Scales (CAARS) and Neurocognitive screening tests.

In most cases an assessment outcome can be confirmed within a single appointment, but in case where there are additional complexities further appointments can be arranged in order to ensure an accurate outcome to the assessment. The outcome from approximately 79% of ADHD assessments is a diagnosis.

Requests for Autism assessments in adults are growing rapidly across England. In England, 80% of adults now wait more than 3 months for an initial assessment, with half waiting more than 9 months[7]. The typical waiting time for a completed assessment is close to two years in England. For ADHD there is no central waiting list record, but ADHD UK have made freedom of information requests to each Integrated Care Board (ICB) individually[8]. Only 15% of ICB boards were able to report their ADHD waiting times, so its not possible to describe the average national wait time for assessment.

In January 2023 there were 1,560 adults awaiting Autism and ADHD assessment and a further 2,000 referrals that had not yet been triaged. These figures are for York and North Yorkshire: between April 2018 and July 2023 54% of these referrals came from the Vale of York area. It was estimated that the waiting list would be five years.

In response, the ICB developed a two-tier pathway in order to prioritise resources to those most at risk of harm; the proposal was that this would be used as an acceptance criteria for the current waiting list and not as an expedite criteria. People would be referred for assessment only if they were at immediate risk of harm to themselves or others, at risk of being unable to have planned life-saving hospital treatment or care, or were at imminent risk of a family court decision determined on diagnosis; dependent on the outcome of the referral being triaged.

A three month pilot (later extended to a year and is now still ongoing) was implemented by the ICB. This pilot directed individuals who did not meet the acceptance criteria to an online tool known as the ‘Do-It

[7] The rapidly growing waiting lists for autism and ADHD assessments | Nuffield Trust
[8] https://adhduk.co.uk/nhs-adhd-assessments-waiting-lists-report/

profiler'. The profiler was intended as a self-help resource and not a diagnosis tool. In response to these changes and the lack of consultation, the York Disability Rights Forum[9] begun a legal challenge against the ICB, and HealthWatch published a report collating and describing the public concern[10]. There were also two presentations to the Health and Wellbeing Board.

In June, an amendment to the referral and acceptance criteria was launched. Referrals can now be made by GPs and by community mental health teams. The backlog of 2000 referrals from January 2023 have now been triaged, but only a limited number of referrals since March 2023 have been triaged. This is partly due to lack of information to enable triage from the Do It Profiler platform.

At the time of writing the waiting time for assessments in September 2024 was, for ADHD, an average of 3.7 years and, for Autism, an average of 3.4 years.[11] Both Autism and ADHD services are assessing referrals from mid 2021 to the end of November 2021.

People who do not meet the updated acceptance criteria will be added to a holding list. They may use the Do-It profiler, but this is not a requirement. The Retreat have also published their post diagnostic support packs for both Autism and ADHD, meaning that anyone who self-identifies as Autistic able to make use of them[12]. The packs are a directory of recommended books, websites, videos, and local groups.

Nationally, there has been an increase in the number of private diagnoses of Autism and ADHD, and, through the NHS 'right to choose' care in another area with shorter waits, complex issues have emerged around shared care and ongoing support.

In conclusion, whilst the diagnosis and assessment process within healthcare is usually intended to have a positive and supportive impact on an individual's health and wellbeing, it is clear that in Autism and ADHD assessment, confusion and lack of clarity around pathways, long waiting lists, delayed access to medications and other support is likely to be negatively affecting the health of Autistic people and people with ADHD in York.

[9] Autism and ADHD Assessment Access - York Disability Rights Forum (ydrf.org.uk)
[10] Guidance (healthwatchyork.co.uk)
[11] https://theretreatclinics.org.uk/waiting-times/ (correct September 2024)
[12] Autism Post-Diagnostic Pack (theretreatclinics.org.uk)

Chapter 2: Patterns and trends in Autism

In this section we will talk about

- How common Autism is in York
- What it means to be Autistic
- What GP data tells us about Autism in York
- What education data tells us about Autism in York
- Autism and gender/sex

How common is Autism?

Autism is a lifelong condition which affects how people communicate and interact with the world. Understanding the prevalence of Autism is hard, as medical or educational records will only tell us how many people have received a formal diagnosis, and therefore are an underdiagnosis which does not truly represent the actual prevalence of Autism in any given area.

One population cohort study suggests that 59–72% of Autistic people may be Autistic and undiagnosed.[13]

Best estimates are that just over 1% of the population are Autistic. This means there are around 700,000 Autistic people in the UK.[14] This rate will vary across age bands, as older people are less likely to have received a diagnosis.

It is quite common for a person to have both Autism and ADHD, although estimates vary. Roughly 50-70% of Autistic people also have ADHD. Equally, roughly 30-60% of people with ADHD will also be Autistic. These studies are usually based on observed characteristics of Autism and ADHD in people, not on diagnosed rates.

What does it mean to be Autistic?

The NHS website lists a number of traits which Autistic younger children may have, including[15]:

[13] Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data - The Lancet Regional Health – Europe
[14] National Autistic society
[15] Signs of autism in children - NHS

- not responding to their name
- avoiding eye contact
- not smiling when you smile at them
- getting very upset if they do not like a certain taste, smell or sound.
- repetitive movements, such as flapping their hands, flicking their fingers, or rocking their body
- not talking as much as other children
- not doing as much pretend play
- repeating the same phrases

Traits which Autistic older children may have include:

- not seeming to understand what others are thinking or feeling
- unusual speech, such as repeating phrases and talking ‘at’ others
- liking a strict daily routine and getting very upset if it changes
- having a very keen interest in certain subjects or activities
- getting very upset if you ask them to do something
- finding it hard to make friends or preferring to be on their own
- taking things very literally – for example, they may not understand phrases like "break a leg"
- finding it hard to say how they feel

Traits which Autistic adults may have include[16]:

- finding it hard to understand what others are thinking or feeling
- getting very anxious about social situations
- finding it hard to make friends or preferring to be on your own
- seeming blunt, rude, or not interested in others without meaning to
- finding it hard to say how you feel
- taking things very literally – for example, you may not understand sarcasm or phrases like "break a leg"
- having the same routine every day and getting very anxious if it changes

Other traits of Autism include:

- not understanding social "rules", such as not talking over people
- avoiding eye contact
- getting too close to other people, or getting very upset if someone touches or gets too close

[16] Signs of autism in adults - NHS

- noticing small details, patterns, smells or sounds that others do not
- having a very keen interest in certain subjects or activities
- liking to plan things carefully before doing them

A joint project between Autisticia[17], Curtin University in Australia and Karolinska Institute in Sweden concluded that many Autistic people have strengths, abilities and interests that non-Autistic people don't have. Everyone is different, but some common Autistic strengths are:

- attention to detail, ability to hyperfocus, and excellent recall memory
- visual perception
- creative and artistic talents
- mathematical and technical abilities.
- interests or expertise in ‘niche’ areas
- character strengths such as honesty and loyalty
- a strong sense of justice
- creative problem solving
- less influenced by social biases and norms

Why are some people Autistic and others not?

It is unlikely that there is a single cause for Autism, and genetic factors and environmental factors both may play a part.

We know that siblings of Autistic people individuals had a significantly higher chance of also being Autistic, compared to the general population. One study revealed that if an older sibling is Autistic, the younger siblings had a 30% chance of also being Autistic. This can rise to 60% for twins. There are similar links between Autistic parents and children. Because of this, people say that Autism can ‘run in families’. This is important for how organisations and teams design services to consider, because for many people families represent an important source of practical advice and support.

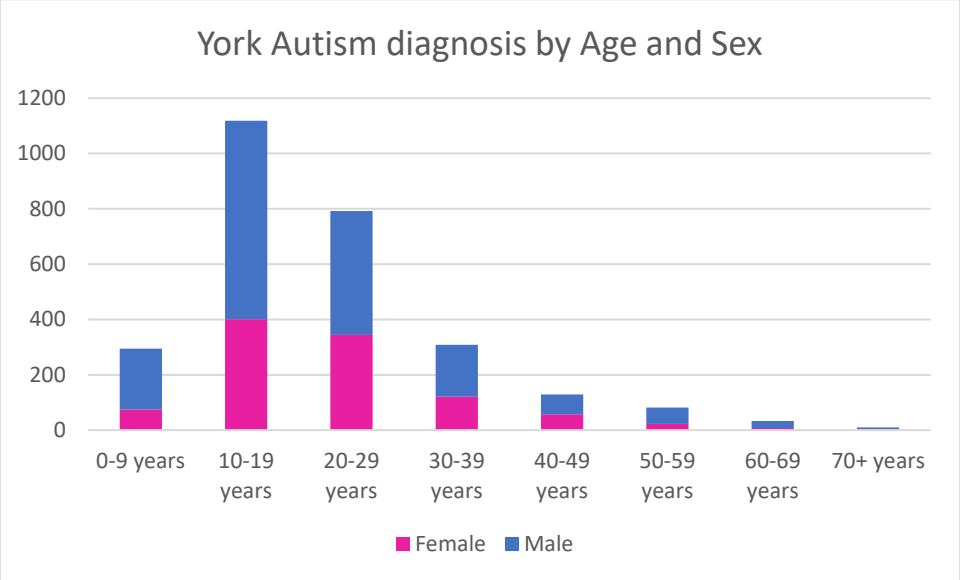
[17] Focus on strengths as well as challenges | Autistica

GP data on Autism in York

Primary care data can tell us about the number of people who are registered with a GP in York and who have a diagnosis for Autism. It is well recognised that not every Autistic person will have a diagnosis recorded.

In total there are 2,786 people who are registered with a York GP and who have a diagnosis of Autism on their health record. This information was collected in summer 2024.

The data is separated by sex and shows that there is roughly a 3:1 ratio of men to women diagnosed Autism. This follows the expected national pattern.



The data is also separated by age band. It shows that very few older adults have an Autism diagnosis (0.2% of the population). The majority of Autism diagnosis are in people aged 0-9 (approximately 300 people), 10-19 (approximately 1100 people), and 20-29 (approximately 800 people). This also follows the national pattern. It is because in previous decades Autism was less recognised and less diagnosed.

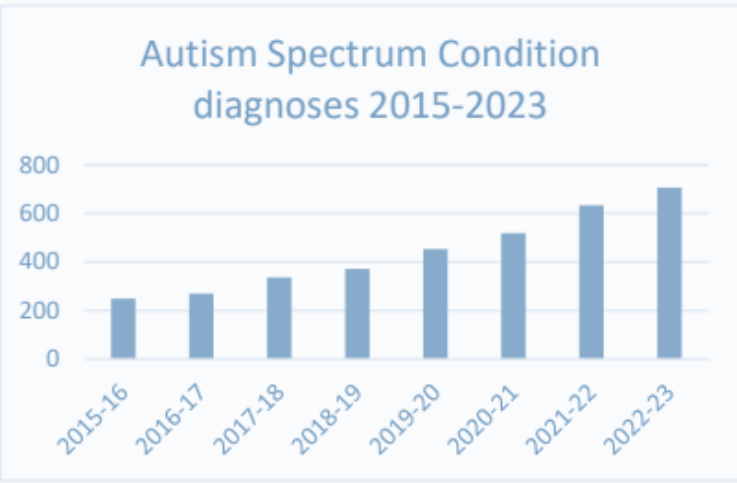
GP data shows that 426 people had a record of both an Autism and an ADHD diagnosis. 18.4% of people with an ADHD diagnosis also had an Autism diagnosis, and 15.3% of people with an Autism diagnosis also had an ADHD diagnosis.

Education data on Autism in York

There is also data on the numbers of Autistic people in the education records. This is held by the special educational needs team.

A child has special educational needs if they need additional or augmented support to access the school or the curriculum. This can come in the form of a SEN-support plan (additional support coordinated by the school) or an Education, Health, and Care Plan (a plan made jointly by these three teams of professionals).

The number of pupils who are SEND and with Autism as their primary need has been rising rapidly over the last decade, and this trend is likely to continue given the backlog of children waiting for diagnostic assessment:



In total, just over 700 children and young people have their primary need listed as Autism. This is a fifth of all pupils with SEND. Children and young people living in deprivation in York (based on postcode and the Index of Multiple Deprivation) are equally likely to have a SEND record for Autism or ADHD as children living in other areas of York.

Autism, gender and sex

It is thought that Autism is more common in males than females. There are different estimates, but most likely the prevalence is one female to every 3 or 4 males[18].

It is also though that Autism in females is sometimes missed or misunderstood. This happens because the traits of Autism in females can be different and may look like other conditions. For example, Autistic girls may be able to 'mask', meaning they can copy others behaviour and behave like a neurotypical person in some social settings. This can be very stressful and is known to increase feelings of anxiety in Autistic females[19].

The estimates of how many Autistic women and girls may be undiagnosed vary considerably, and there is no consensus at this time. The Autistic Girls Network have summarised the current understanding and impact of Autism on women and girls[20].

A UK project looking at 600,000 adults found that transgender and gender-diverse adult individuals were between three and six times more likely to say that they were diagnosed Autistic compared to the general adult population of the UK.

Data from GP practices in York says that there are 48 people with a medical diagnosis of Autism and a record that they are 'trans or non-binary'. This is 1.6% of everyone with a diagnosis of Autism on their GP record, about 3 times the prevalence in the general population. This data would not include people who do not currently have an Autism diagnosis.

[18] https://www.autism.org.uk/advice-and-guidance/what-is-autism/Autistic-women-and-girls
[19] The National Autistic Society
[20] https://Autisticgirlsnetwork.org/keeping-it-all-inside.pdf

Chapter 3: Autism and health and wellbeing

This section looks at health and wellbeing topics and how they relate to Autism. There is nothing intrinsic or inbuilt into Autism or ADHD that makes a person more likely to have most physical ill health conditions, or to become homeless, or addicted to substances or experience many of the other conditions and circumstances that we talk about in this health needs assessment. However, the attitudes of society and the level of access to support make it more challenging to thrive as an Autistic person or a person with ADHD. By talking addressing these topics we hope to move closer to York being a health generating city for all.

We summarise national research and include local information where it is available.

Topics are discussed alphabetically:

- Criminal justice
- Employment
- Homelessness
- Learning disabilities
- Life expectancy
- Mental health
- Other health issues
- Sleep
- Substance misuse (drugs and alcohol)

Criminal Justice

Data is limited on the number of Autistic or neurodivergent people in the criminal justice system. Some characteristics of Autism might make young people more at risk of offending. This might include a having smaller social support network and social naivety, meaning others can ‘take advantage’ of Autistic people in some circumstances. There are also studies which show that juries are more likely to convict autistic/young people with SEND. In a publication for The Children’s

Commissioner the prevalence of Autism among young offenders was estimated to be 15%.[21]
In July 2021, a national review on Neurodiversity within the criminal justice system highlighted insufficient efforts to address the needs of neurodivergent individuals. Responding to this, the Ministry of Justice released a Neurodiversity action plan in June 2022, with updates in January 2023. The revised plan outlines the introduction of Neurodiversity support managers in prisons, with a goal to have one in each facility across England and Wales by 2024.[22]

In York the youth outcome panel, which aims to divert people from criminal justice, knows if young people on their caseload have diagnosed neurodivergence or are awaiting assessment. This means that the actions of the rehabilitation orders can be tailored to suit the young people. The youth justice service also follow up young people with SEND to understand their longer term outcomes.

North Yorkshire police have annual training that includes responding to Neurodiversity and have 'trigger plans' in place for meeting alternative communication or sensory needs for individuals who they routinely support through mental health crisis.

North Yorkshire police have also scoped their custody suits for reasonable adjustments that could be made to support sensory sensitivity. This includes sensory toys, adjustable lighting, ear defenders, and backboard paint walls. The age and layout of some of the buildings create limitations but refresh of the lighting was completed in 2024.

Employment

Employment is associated with better mental and physical health for individuals and is important for the wider economy.

Autistic people are over twice as likely to experience unemployment, despite most people wanting to work. The national Buckland Review[23] of Autism employment found that only 30% of working age Autistic adults are in employment, rising only to 36% for Autistic people with a degree.

[21] https://www.childrenscommissioner.gov.uk/resource/nobody-made-the-connection/
[22] Abreu. L et al., (2024) Autism: Overview of Policy and Services, Research Briefing, UK Parliament
[23] Landmark review calls on employers to boost support for Autistic people - GOV.UK

Employed Autistic people are most likely to be on zero-hour contracts, and have temporary contracts.

The Buckland review also found that application and interview processes are rarely adapted to suit the needs of Autistic people. Autistic jobseekers face barriers from vague job descriptions, ambiguous interview questions and sensory environments. Too often the emphasis is placed on social skills rather than job skills.
Access to reasonable adjustments is inconsistent. In most cases the onus is on the Autistic employee to identify and advocate for adjustments. Around one third of Autistic employees felt unable to discuss their adjustment needs at all, and those who did request adjustments, over a quarter were refused and more than 1 in 10 found the adjustment was poorly implemented.

The Retreat post-diagnosis resources do include some information on employment, but people are not directed towards any schemes operating locally. We are not aware of any York specific data that could indicate the employment rates for neurodivergent people living in York.

Homelessness

The current research suggests that Autistic people are more likely to experience homelessness. In 2017 in the UK a sample homelessness key workers were asked to consider their clients against the diagnostic criteria for Autism[24]. The researchers found that 12% of the group were described as showing ‘strong traits’ of Autism, and another 10% showing some Autistic traits. Although this was not a diagnosis, this research suggests that Autistic traits are much more common in homeless people than in the general adult population.

Homeless Link say that “Personal social challenges, a lack of community understanding and support, and employment disadvantage and discrimination are likely to be key reasons why Autistic adults may be more at risk of homelessness.” In addition, Autistic people who are homeless are more vulnerable to further harms from violence or abuse.

Homeless Link have produced a toolkit[25] which provides resources to help key workers to identify people with traits of Autism in their clients and to consider suggests in reasonable adjustments to working practices

[24] https://homelesslink-1b54.kxcdn.com/media/documents/Autism_and_Homelessness_Toolkit_Edition_2.pdf
[25] https://homelesslink-1b54.kxcdn.com/media/documents/Autism_and_Homelessness_Toolkit_Edition_2.pdf

which can make services more accessible to Autistic people. Homeless Link recognise that in many cases neurodiverse people experiencing homelessness have not received a diagnosis, and levels of self-identification vary.

Currently, the homelessness support services in York don't specifically ask whether a person is Autistic as a standard question, but do seek to understand the health and wellbeing needs of their clients, and recognise Autistic characteristics in many of their client group.

GP data is not a particularly good source of information on homelessness. GP data shows there are currently 19 people with a diagnosis of Autism who also have current homelessness recorded on the GP record.

Learning disabilities

There is a known link between Autism and learning disability. The NHS estimate that 60-70% of Autistic adults also have a learning disability[26]. As a result, Autistic people are more likely to receive help with daily activities than non-Autistic people.

In York, CYC holds a record of 3,900 adults who receive care to help with daily activities. In theory it is possible to know how many people receiving care are Autistic. In practice the local authority care records list just over 100 Autistic adults, nearly all of whom also have a learning disability.

It is widely acknowledged that the true number of Autistic people known to the local authority is higher, but that due to nationally defined criteria we recognise that many people with a primary need of learning disability have not yet had their Autism diagnosis included on their individual care record.

Record keeping is slowly improving as the team are now taking greater steps to record known Autism diagnosis for new and existing customers.

The York GP data can also help us to understand about Autism, learning disability, and care need. Compared to other local authorities nationally, York has a statistically significantly lower prevalence of people

[26] Estimating the prevalence of autism spectrum conditions in adults - GOV.UK (www.gov.uk)

diagnosed with a learning disability. This might suggest that there is an element of under-diagnosis amongst the population.

In total there are 222 people in York who have both Autism and a learning disability coded on their GP health record. This equates to around 7% of all people with an Autism diagnosis. Evidence suggests that around 1 in 3 (33%) of Autistic people also have a learning disability, although this varies by age group. The ICB has piloted various initiatives to improve learning disability recording in GP practices. This is important because people with learning disabilities are eligible for routine Annual health checks throughout their adult lives, will receive a different offer of support through education, and are also eligible for free flu vaccinations.

Life expectancy

The average life expectancy in the UK is 80 years for men, and 83 for women.

The life expectancy for Autistic people is about 5 years shorter, and about 10 years for Autistic people with a learning disability.

	Men	**Women**
General population	80	83
Autism	75 (-5 years)	77 (-6 years)
Autism and Learning Disability	72 (- 8 years)	70 (-13 years)[27]

The reasons for this are likely to be complex. This health needs assessment identifies many factors which can impact life expectancy, and we do know that the main causes of early death include for this are early heart disease and suicide (this could however be said for the general population) and that 69% of autistic adults have untreated health problems.[28] Additionally, the report into life expectancy describes that Autistic people may find it more difficult to explain their health symptoms to others and this can complicate access to healthcare services. It is not possible to report York specific data on life expectancy and Autism.

[27] Premature death of Autistic people in the UK investigated for the first time | UCL News - UCL – University College London

[28] Doherty M, Nielson SD, O'Sullivan JD, Carravallah L, Johnson M, Cullen W, Gallagher L. Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study. medRxiv 2020.04.01.

Mental health

There is no central data set looking at Autism and mental health in England so the best information comes from big research studies that collect information from medical records. This type of research shows that Autistic people are about twice as likely to experience anxiety and also depression as people who are not Autistic[29][30][31]. The research showed that anxiety symptoms rise in teenage and 20s. This is also true of the general population, but the rates of anxiety are higher. The research also shows that Autistic people are particularly likely to have social anxiety or OCD symptoms.

York GP data shows that in total 40% of people with diagnosed Autism also have a mental health condition in York:

33% have an anxiety condition,

21% have depression

3% have a serious mental illness.

In line with national data, this is considerably higher than the expected values for non-Autistic adults.

Other health issues

A cross-sectional study on an American insured population found that Autistic adults had significantly increased rates of all major psychiatric disorders including depression, anxiety, bipolar disorder, obsessive–compulsive disorder, schizophrenia, and suicide attempts. Nearly all medical conditions were significantly more common in adults with autism, including immune conditions, gastrointestinal and sleep disorders, seizure, obesity, dyslipidemia, hypertension, and diabetes. Rarer conditions, such as stroke and Parkinson's disease, were also significantly more common among adults with autism.[32]

[29] Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis | Psychological Medicine | Cambridge Core

[30] Anxiety Disorders in Adults with Autism Spectrum Disorder: A Population-Based Study - PMC (nih.gov)

[31] Association of Comorbid Mood and Anxiety Disorders With Autism Spectrum Disorder | Anxiety Disorders | JAMA Pediatrics | JAMA Network

[32] https://journals.sagepub.com/doi/10.1177/1362361315577517

Sleep

According to the National Autistic Society, 'Sleep problems are the most common co-occurring conditions experienced by autistic individuals', with over 70% of autistic adults said they experienced difficulty falling asleep or staying asleep.[33]

There may be several explanations for this, but the best evidence is the cause being a combination of sensory issues and higher levels of anxiety interfering with circadian rhythm, patterns of rest and sleep hygiene.

Lower quality sleep has been shown to be associated with poorer mental health, relationship issues, and poorer physical health including immune system strength and blood pressure.[34]

Sleep issues for young people and children also negatively affects the health and wellbeing of parents and carers of young people with Autism and ADHD.

Substance misuse

Autistic individuals are less likely to report regularly consuming alcohol or binge-drinking compared to non-Autistic individuals. However, survey data[35, 36] shows they are almost nine times more likely to use alcohol or drugs to 'self-medicate' i.e. to use substances to help manage stress and anxiety. In one study, 20% of treatment-seeking substance misuse disorder outpatients had clinically elevated autistic traits but were undiagnosed.[37] Autistic adults were also more likely to report using drugs at a young age or being coerced into using drugs by others. This is important for people working to support people with addiction and/or mental illness and safeguarding.

The GP data for York records 40 Autistic people who also have 'drug or alcohol abuse' on their health record. This is 1.3% of everyone with diagnosed Autism.

[33] Autistic adults and sleep problems
[34] Sleep problems - Every Mind Matters - NHS
[35] Weir, E., Allison, C., & Baron-Cohen, S. (n.d.). Understanding the substance use of Autistic adolescents and adults: A mixed-methods approach
[36] Understanding the substance use of Autistic adolescents and adults: a mixed-methods approach Elizabeth Weir, BA Carrie Allison, PhD, Prof Simon Baron-Cohen, PhD
[37] https://onlinelibrary.wiley.com/doi/10.1111/ajad.13247

Chapter 4: Patterns and Trends in ADHD

This section looks at:

- How common ADHD is
- What it means to have ADHD
- Why some people have ADHD and others don't
- GP data about ADHD in York
- ADHD and gender/sex

How common is ADHD?

The NHS estimates are that that the prevalence of ADHD is 4%; this figure includes both people with and without a diagnosis. Some estimates suggest that it is closer to 6%, or even higher.

NICE CKS evidence summary states that there are three subtypes of ADHD:

- The inattentive subtype accounts for 20% to 30% of cases.
- The hyperactive-impulsive subtype accounts for around 15% of cases.
- The combined subtype accounts for 50% to 75% of cases. [38]

It also notes that 'ADHD is more commonly diagnosed in boys than girls. Prevalence ratios are generally estimated at 2–5:1, while clinic populations show a ratio as high as 10:1. This sex difference may be due to the fact that boys present more often with disruptive behaviour that prompts referral, whereas girls more commonly have the inattentive subtype and have lower comorbidity with oppositional defiant disorder (ODD) and conduct disorder.'

In the UK, the prevalence of ADHD in adults is estimated at 3% to 4%, with a male-to-female ratio of approximately 3:1.

[38] Prevalence | Background information | Attention deficit hyperactivity disorder | CKS | NICE

What does it mean to have ADHD?

According to the NHS, the characterises of Attention Deficit Hyperactivity Disorder (ADHD) can be described by two broad categories: “inattentiveness” and “hyperactivity and impulsiveness”.

The main signs of inattentiveness are:

- having a short attention span and being easily distracted
- making careless mistakes – for example, in schoolwork
- appearing forgetful or losing things
- being unable to stick to tasks that are tedious or time-consuming
- appearing to be unable to listen to or carry out instructions
- constantly changing activity or task
- having difficulty organising tasks

The main signs of hyperactivity and impulsiveness are:

- being unable to sit still, especially in calm or quiet surroundings
- constantly fidgeting or excessive physical movement
- being unable to concentrate on tasks
- excessive talking
- being unable to wait their turn or interrupting conversations
- acting without thinking
- little or no sense of danger

It is thought that 50%-75% of people with ADHD have both inattentive and hyperactive-impulsive symptoms with the remainder mainly have one type of symptoms[39].

The way in which ADHD affect adults can be different from the way it affects children. Typically, adults have fewer symptoms of hyperactivity, but retain the symptoms of inattentiveness. This means that adults with ADHD may continue to find things like organising, prioritising, finishing tasks, or dealing with stress challenging.

The ADHD Foundation emphasize the strengths of many adults with ADHD, including:

- An ability to ‘hyperfocus’ on things they are interested in

[39] Prevalence | Background information | Attention deficit hyperactivity disorder | CKS | NICE

- Willingness to take risks
- Spontaneous and flexible
- Good in a crisis
- Creative ideas – thinking outside the box
- Relentless energy
- Often optimistic
- Being motivated by short term deadlines – working in sprints rather than marathons
- An eye for detail.” [40]

Why do some people have ADHD and others not?

The cause of ADHD is unknown and it is likely to have a combination of factors. There is a strong between-sibling link for ADHD, and also a strong parent-child link. The link is especially strong for twins, if one twin has ADHD there is a 74% chance that the other twin will also have ADHD[41].

There is a link between a child having ADHD and the family experiencing poverty, but it is not straightforward to explain why. Data from the Millennium Cohort Study links ADHD to living in social housing, to having a younger mother, and to living in a single parent household, and to having a parent with few qualifications[42]. However, many of these factors, together or separately, can link to low income. These studies simply describe a connection, but do not equate to a cause.

GP data in York about ADHD

Not everyone with ADHD has a diagnosis, but GP data is still a valuable source of information about ADHD in York.

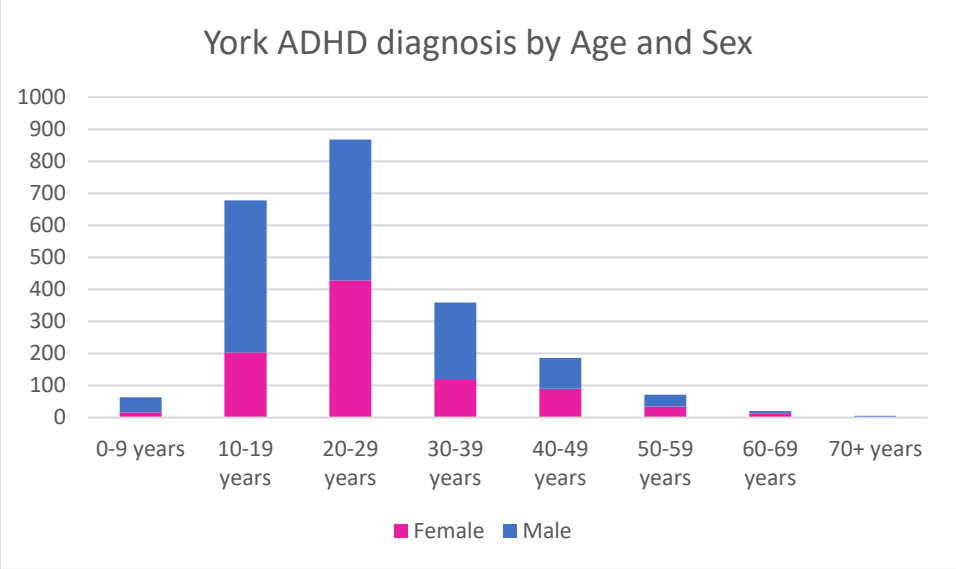
[40] An Employer's Guide to ADHD in the Workplace - Scottish ADHD Coalition (adhdfoundation.org.uk)

[41] https://idp.nature.com/transit?redirect_uri=https%3A%2F%2Fwww.nature.com%2Farticles%2Fs41380%E2%80%90018%E2%80%900070%E2%80%900&code=233eb717-46d0-4955-9812-62cbc1965bd9

[42] Featured news - ADHD linked to social and economic disadvantage - University of Exeter

GP records show that 2,311 people in York have a diagnosis of ADHD. This is 1.1% of the York population. For the whole of England the diagnosed prevalence of ADHD is 0.8%, suggesting that it is more typical to get a diagnosis of ADHD in York than average.[43]

The chart below shows the spread of ADHD diagnosis by age. It shows that most people with an ADHD diagnosis are in their teens and 20s. It is expected that only a small number of young children have an ADHD diagnosis as it is rarely confirmed in early childhood. Additionally, few older adults have a diagnosis of ADHD. This is also expected as the modern understanding of ADHD is relatively new[44], and ADHD was less identified in previous decades. AutismUK estimates there are 2.6 million people in the UK with ADHD (708,000 children, 1,9m adults) based on The Lancet and NICE which give a childhood ADHD incidence rate of 5% and a consistent adult ADHD incidence rate of 3.5% across all adult age bands.



ADHD and Gender or Sex

The prevalence of diagnosed ADHD in the UK is approximately three boys to every one girl. It is generally accepted that ADHD is more common in boys. It is also thought that boys are more thoroughly diagnosed as they have more ‘classic’ characteristics

[43] Attention deficit hyperactivity disorder (ADHD) and epilepsy - NHS England Digital
[44] The history of attention deficit hyperactivity disorder - PMC (nih.gov)

ADHD is usually first suspected because of behaviours that are visible to other people (i.e. difficulty sitting still or impulsivity). Often these visible behaviours are more common in boys than girls. By contrast, females with ADHD are more likely to have difficulty organising their thoughts or anxiety-like symptoms. This has led some people to think that female ADHD is sometimes missed or diagnosed late[45]. This remains an under researched area, although there is a recent commentary on the impact of heritability, diagnostic criteria, societal expectation and more factors which outlines the subject of gender and ADHD in greater detail[46].

There is little academic research on the topic of ADHD and gender diversity or trans. Two systematic reviews, one from 2019[47] and another from 2022[48] both looked at all the available studies on the topic. Both found a lack of research, and in particular a lack of good quality research, and both were unable to draw any firm conclusions.

[45] Gender differences in adult ADHD: Cognitive function assessed by the test of attentional performance - PMC (nih.gov)
[46] Why are females less likely to be diagnosed with ADHD in childhood than males? - The Lancet Psychiatry
[47] Prevalence of Autism Spectrum Disorder and Attention-Deficit Hyperactivity Disorder Amongst Individuals with Gender Dysphoria: A Systematic Review | Journal of Autism and Developmental Disorders (springer.com)
[48] A PRISMA systematic review of adolescent gender dysphoria literature: 2) mental health | PLOS Global Public Health

Chapter 5: ADHD and Health and Wellbeing

This section looks at what we know about the health and wellbeing of people with ADHD. We combine information from national surveys or research, and local data where it is available.

In this section we look at alphabetically.

- Criminal justice
- Employment
- Life expectancy
- Mental health
- Other health issues
- Smoking
- Substance misuse (drug and alcohol addiction)

Criminal justice

The Children's Commissioner estimates the prevalence of ADHD among young offenders is 12%[49]. The ADHD foundation suggest that 25% of adults in prison have ADHD, and that 96% have a further need such as addiction or personality disorder[50].

ADHD is significantly associated with conviction and incarceration, with substance misuse and lower socioeconomic status increasing this risk. ADHD medication is a protective factor in reducing the risk of offending.[51]

In York the youth outcome panel, which aims to divert people form criminal justice is able to know about any young person with diagnosed Neurodiversity or who is awaiting assessment. This means that the actions of the rehabilitation orders can be tailored to suit the young

[49] Nobody Made the Connection | Children's Commissioner for England (childrenscommissioner.gov.uk)
[50] Takeda_ADHD-in-the-CJS-Roundtable-Report_Final.pdf (adhdfoundation.org.uk)
[51] Christina Mohr-Jensen, Charlotte Müller Bisgaard, Søren Kjærsgaard Boldsen, Hans-Christoph Steinhausen, Attention-Deficit/Hyperactivity Disorder in Childhood and Adolescence and the Risk of Crime in Young Adulthood in a Danish Nationwide Study, Journal of the American Academy of Child & Adolescent Psychiatry, Volume 58, Issue 4, 2019, Pages 443-452, https://doi.org/10.1016/j.jaac.2018.11.016

people. Since 2023 the youth justice service also follow up young people with SEND to understand their longer term outcomes such as education, employment or training. This is early data and it describes very small numbers of young people, but it is positive at this stage.

North Yorkshire police have annual training that includes responding to Neurodiversity and have 'trigger plans' in place for meeting alternative communication or sensory needs for individuals who they routinely support through mental health crisis.

North Yorkshire police have also scoped their custody suits for reasonable adjustments that could be made to support sensory sensitivity. This includes sensory toys, adjustable lighting, ear defenders, and backboard paint walls. The age and layout of some of the buildings create limitations, but refresh of the lighting was completed in 2024.

Employment

It is not easy to get UK data on employment and ADHD, but data from other countries suggests people are less likely to be in work and are more likely to lose their jobs. People with undiagnosed ADHD may struggle to obtain reasonable adjustments in the workplace which may make it harder to gain or retain employment.

The Scottish ADHD coalition highlights that many people with ADHD have particular strengths which can be very useful in the workplace[52], for example creative thinking, an eye for detail, and being good with short deadlines.

Life Expectancy

There is no national review of early deaths of people with ADHD. Death certificates would not ordinarily include reference to ADHD. As discussed through this health needs assessment, people with ADHD are more likely to experience obesity, smoking, mental ill health, unemployment, and a range of other chronic physical health conditions. One small study,

[52] An Employer's Guide to ADHD in the Workplace - Scottish ADHD Coalition (adhdfoundation.org.uk)

not from the UK, tried to model the impact on projected life expectancy and found a reduced life expectancy[53].

Additionally, several systematic reviews have found convincing evidence that people with ADHD are at greater risk of early death from 'unnatural causes' such as accidents[54]. However, the way that the studies were presented means the researchers could not look at other important factors, for example other health conditions or social deprivation. People with ADHD have a reduced life expectancy of 8-13 years, but the mortality risk is greatly reduced with earlier treatment. [55]

Mental health

People with ADHD are more likely to develop depression as teenagers and adults, compared with people who do not have ADHD. One large study of nearly a million people estimates people with ADHD are six times more likely to develop depression[56]. One explanation is that people with ADHD are more likely to experience chronic stress linked to social relationships, school, or work, and this can increase the risk of depression. Related to this, a large Swedish study shows people taking ADHD medication are at 20% lower risk of depression than those not taking medication[57].

The York GP data shows that 1096 people with ADHD diagnosis also have a mental health condition, this is 44%.

34% have an anxiety disorder

[53] Hyperactive Child Syndrome and Estimated Life Expectancy at Young Adult Follow-Up: The Role of ADHD Persistence and Other Potential Predictors - Russell A. Barkley, Mariellen Fischer, 2019 (sagepub.com)

[54] Mortality in Persons With Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder: A Systematic Review and Meta-analysis | Attention Deficit/Hyperactivity Disorders | JAMA Pediatrics | JAMA Network

[55] https://journals.sagepub.com/doi/full/10.1177/10870547231158572

[56] Longitudinal association between mental disorders in childhood and subsequent depression – A nationwide prospective cohort study - ScienceDirect

[57] Medication for Attention-Deficit/Hyperactivity Disorder and Risk for Depression: A Nationwide Longitudinal Cohort Study - ScienceDirect

29% have depression

3% have a serious mental illness

These figures are far higher than prevalence in the neurotypical population of York.

Other health issues

There is a significant link between ADHD and obesity, and some studies have shown that treatment for ADHD can improve engagement and success in services aimed at tackling obesity.[58]

In a study in 2023 revealed that a diagnosis of adult ADHD was associated with a nearly three times greater risk of developing dementia, including Alzheimer's disease. There was, however, no clear increase in the risk of dementia associated with adult ADHD among those who received psychostimulant medication.[59]

Smoking

People with ADHD are more likely to smoke and start smoking at a young age[60]. There was no difference in eventual successful quit rates, but people with ADHD were more likely to make a quit attempt.

GP data records 351 people with ADHD who are current smokers, this is 14% of everyone with ADHD, and is higher than you would expect to find in the general adult population of York (around 9%)

The York Stop Smoking Service does not currently collect information Neurodiversity when people are referred to stop smoking.

Substance misuse

The UK Addiction Treatment Centre says that of all people with ADHD, 12% will develop an alcohol addiction and 28% develop a drug addiction

[58] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6826981/

[59] https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2810766

[60] Cigarette Smoking Progression Among Young Adults Diagnosed With ADHD in Childhood: A 16-year Longitudinal Study of Children With and Without ADHD - PMC (nih.gov)

at some point in their lives[61]. In the general adult population, around 1% of people will develop these conditions. It is suggested that ADHD can lead to greater difficulty maintain relationships, achieving academic or career goals, and increase chronic stress and impulsivity, all of which are factors that increase the vulnerability to addiction. Impulsive decisions and a maladaptive reward system make individuals with ADHD vulnerable for alcohol use and up to 43% develop an Alcohol Use Disorder (AUD); in adults with AUD, ADHD occurs in about 20% but is vastly under-recognized and under-treated.[62]

The addiction recovery service askes all clients a set of standard questions about disability or health conditions. In response, 0.8% of clients said they had 'Autism or an other health condition'.

However, the addiction recovery service estimate that more than half of people in addiction recovery show characteristics of Neurodiversity, mainly these are ADHD type characteristics, and predominantly individuals do not have a diagnosis.

GP data shows that 2% of all people in York with ADHD also have drug and alcohol abuse or dependency included on their health record. This is 58 individuals.

[61] https://www.ukat.co.uk/mental-health/adhd-and-addiction/
[62] https://www.sciencedirect.com/science/article/abs/pii/S0149763421003092

Chapter 6: The experiences of neurodivergent people in York

This report has not utilised any qualitative methods in assessing the health needs and experiences of Autistic people and those with ADHD in York, as extensive work will be done on this through the coproduction of the strategy.

Work has however been caried out by York Healthwatch in this area. In their January 2025 report 'Listening to Neurodivergent Families in York', they found that:

- Societal awareness and understanding of ND is still low, and parents experience stigma from friends, family and services.
- Parent blame is still often the first thing parents seeking help experience.
- Parent experiences are also worsened by poor administration and poor communication from services.
- Support is still focused in silos, with thresholds for support, making finding the right help for a range of lower-level issues challenging. Capacity in the system is overstretched, leaving many services looking for how to say "no" to providing a service.
- Some schools are still not considering the needs of neurodivergent children at times of transition. Others support transition well but do not maintain support beyond transition and fail to see the traits when a child begins to struggle.
- School behaviour charters often ask for behaviour that is impossible for neurodivergent children. This reinforces negative views many neurodivergent people already hold about themselves – that there is something wrong with them and they are not good enough. There is a significant challenge in setting behaviour codes that maintain a good environment for all pupils without punishing ND pupils. However, meeting this challenge is vital. Low self-esteem increases the problems many neurodivergent children grapple with, but there are many strengths associated with neurodivergence which need to be recognised, valued and celebrated.
- There is significant overlap between children who are neurodivergent and children who are gender questioning. Our systems are not geared up to support these young people. Many

are asked to choose which they want support with, and may also be advised to ‘hide’ part of themselves to receive support with the other element of their identity

In their 2023 independent evaluation of the new pilot pathway for assessment of Autism and ADHD, they found that:

- The pathway did not meet hoped for 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

Chapter 7: Conclusions and next steps

This report has described the population in York who are Autistic and/have ADHD, set out the diagnostic / assessment pathways in this area, as well as the challenges around underdiagnosis, waiting lists, pathways and patient experience, and explored the available data and research on the health needs of Autistic people and people who have ADHD

These findings demonstrate that:

- our neurodivergent community in York is growing in size, is comprised of those with a formal diagnosis and a large number who aren't diagnosed, and has specific gender, age and geographical patterns

- Autistic people and people with ADHD face a number of challenges around societal structures, culture and practice which don't always enable them to live the lives they would want to live

- there are additional health and social needs faced by Autistic people and those with ADHD above and beyond those related to their neurodivergence, which should be taken into consideration when planning services

- healthcare services to assess and support neurodivergent people are seeing severe capacity issues which, at population level increases the risk of additional health harm for Autistic people and people with ADHD, potential underdiagnosis and lack of adjustments in key settings which would lead in improvements in quality of life

- Autistic people and people with ADHD bring personal and unique strengths to our schools, workplaces and to the city in general without which York would be a poorer place

The next step following this HNA is to work with partners and organisations in the city, alongside Autistic people and those with ADHD, to coproduce a five-year Autism and ADHD Strategy.

Appendix: Examples of good practice in Autism and ADHD

This chapter of the health needs assessment gives some examples of ‘what works’ or ‘good practice’ for neurodiverse people. This includes making adaptations or designing services or places for neurodiverse people. They are examples, not all evidence and research are included.

Example topics:

- Education
- Mental health
- Criminal justice
- Workplaces
- Communication adaptations
- Buildings and public spaces adaptations

Title	Autism: A guide for GPs
Source	https://Autismwales.org/resource/Autism_-A-Guide-for-GPs-English.pdf
Summary	This short guide provides practical advice for GPs that can be impliemnted in their daily practice. It includes: - Identifying traits of Autism - Appointments - Communication style - Pain and physical sensory processing - Assessment and treatment

Title	Autism and education
Source	Good Autism Practice Guidance | Autism Education Trust
Summary	This set of guidelines is written by members of the Autism Centre for Education and Research (ACER) at the University of Birmingham. The guidelines have been generated from a review of the research evidence, current policy documents, expert opinion, statutory guidance and from the accounts of Autistic individuals. They identify eight key principles of good Autism practice in education, from early years through to post-16 education.

	1. Understanding the strengths, interests and challenges of the Autistic child and young person. 2. Enabling the voice of the Autistic child and young person to contribute to and influence decisions. 3. Collaboration with parents and carers of Autistic children and young people 4. Workforce development to support children and young people on the Autistic spectrum. 5. Leadership and management that promotes and embed good Autism practice. 6. An ethos and environment that fosters social inclusion for Autistic children and young people. 7. Targeted support and measuring process of children and young people on the Autism spectrum. 8. Adapting the curriculum, teaching, and learning to promote wellbeing and success for Autistic children and young people.

Title	Delivering talking therapies to Autistic children and adults
Source	Good practice guide (Autism.org.uk)
Summary	Our Mental Health Project, in collaboration with Mind, aims to establish how to make mental health talking therapies better for Autistic people. This guide incorporates the views of over 1,500 Autistic people and almost 1,000 family members who responded to our mental health survey in October and November 2020. It is also based on our in-depth discussions with 17 Autistic people, eight family members and 15 mental health professionals The key points for service design: 1) Improve Autism understanding for all staff through training 2) Make the physical environment in both waiting rooms and therapy rooms less overwhelming 3) Think about ways you can all change the way therapy is delivered in your service to make it more Autism-friendly 4) provide additional support to Autistic clients 5) ask for and use feedback from your Autistic clients

	6) make sure the information about your service is Autism-friendly, clear, concise and specific 7) explain the different therapy delivery types you can offer and give your client a choice about what works best for them. Key points for therapy sessions: 1) make sure the therapy room isn't overwhelming 2) Use simple, plain language 3) Give time for Autistic people to process information and answer questions 4) Ask them if they would like someone close to them to be involved in sessions 5) Support them to be able to label their own feelings and emotions 6) Try to integrate Autistic people's interests if that will help them 7) Note down what you have covered and share this with the Autistic person

Title	Guidance on criminal justice for Autistic people
Source	NAS_Police_Guide_2020_17092020.pdf (thirdlight.com)
Summary	This guide provides background information about Autism and aims to help all police officers and staff who may come into contact with Autistic people meet their responsibilities under the Equality Act 2010 (Disability Discrimination Act 1995, Northern Ireland), Police and Criminal Evidence Act 1984 (Northern Ireland Order 1989) and the Mental Health Act 1983 (Mental Health Northern Ireland Order 1986) It includes help in identifying someone who may be Autistic or have different communication needs. It also includes dos and don'ts for arrest, custody and interviewing, strip searching, being in a cell, and the use of appropriate adults for vulnerable adults.

Title	Statutory guidance for Local Authorities and NHS organisations
Source	Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (publishing.service.gov.uk)
Summary	Statutory guidance for Local Authorities and NHS organisations to support implementation of the adult Autism strategy. The report covers: 1. Training of staff who provide services to Autistic adults 2. Identification and diagnosis of Autism in adults, leading to assessment of needs for relevant services 3. Planning in relation to the provision of services for Autistic people as they move from being children to adults 4. Local planning and leadership in relation to the provision of services for Autistic adults 5. Preventative support and safeguarding in line with the Care Act 2014 from April 2015 6. Reasonable Adjustments and Equality 7. Supporting people with complex needs, whose behaviour may challenge or who may lack capacity 8. Employment for Autistic adults 9. Working with the criminal justice system

Title	The workplace: wellbeing and retention for neurodiverse people
Source	Neurodiversity at Work 2023 (berkshirehealthcare.nhs.uk)

Summary	Birbeck University of London in collaboration with major employers including McDonalds, Roles Royce, and Sage developed a questionnaire on the experience of being a neurodivergent in the workplace. The research outcomes focus on strategies to retain employees and strategies to improve employee wellbeing.

Title	The workplace: Recruiting Autistic people
Source	Employing Autistic people (Autism.org.uk) and Advertising a role - Employment Autism
Summary	The recruitment process can inadvertently create barriers for Autistic individuals. Organisations can implement minor adjustments to make it easier for Autistic candidates to apply and showcase their skills, ultimately benefiting all candidates and improving recruitment efficiency. The resources above list adjustments to: • Job descriptons and adverts • Application forms • The interview process and alternatives to interviewing

Title	Designing work places for people with ADHD
Source	ADHD Reasonable Adjustments (ADHDuk.co.uk) ADHD in the workplace (berkshirehealthcare.nhs.uk)
Summary	These publications by ADHD UK and Berkshire Healthcare NHS foundation trust describe how some aspects of the work place can be additionally challenging to people with ADHD and potential adjustments that can support. These adjustments include: - Modifications to the working environment: protected quiet spaces, working from home, permanent desk spaces - Flexibility in working practices: flexible working (where possible), protected time for hyperfocus tasks - Working practices: communicating deadline and work task expectations,

	- Using feedback: agile working practices, utilising ADHD traits to the benefits of the job role - Useful technology: headphones, diary management tools - HR policies: training for managers, antidiscrimination policies overtly mention Neurodiversity, coaching for employees

Title	Designing public buildings to accommodate neurodiverse people
Source	Environmental checklist for people (southwestyorkshire.nhs.uk) Guide-for-cognitively-inclusive-design-in-primary-care-environments-FINAL.pdf (dimensions-uk.org) Building-Better-Together-Dimensions-Assura-report-web-final.pdf (dimensions-uk.org)
Summary	In 2015 Kirlees Council and the South West Yorkshire Partnership NHS Foundation Trust created an Autism-Friendly Environments Checklist. The Checklist was designed for organisations providing NHS and Local Authority services. The checklist is organised by sensory category (i.e. smell, sight…), with opportunity to make notes about solutions and discussion. Service providers are suggested to start with the smallest spaces and then expand out to larger areas. The 'Designing for Everyone' guide and toolkit brings together current research, evaluation and best practice in design for cognitive impairment and Neurodiversity together with reports commissioned by Assura from the Patients Association and Dimensions which focus on the patient experience of health centre buildings. The report is structured around four themes; - Independence and choice: signage and getting around - Dignity: privacy, reception, and toilet facilities - Feeling relaxed: sensory environment and decor

	- Customer service and patient care: flexibility and involvement

Title	Designing buildings sympathetic to Neurodiversity
Source	Designing buildings sympathetic to Neurodiversity: a new guide (theconstructionindex.co.uk)
Summary	BSI, the British Standards Institution, has published guidance on designing the built environment to include the needs of people who experience sensory or neurological processing differences. These are detailed in PAS-6463

Title	How to design spaces to better meet the needs of neurodivergent groups
Source	How to design spaces to better meet the needs of neurodivergent groups (hdsunflower.com)
Summary	This publication considers - The acoustic environment - Reducing visual noise - An easy entrance - Creating welcoming sanitary facilities - Recalibration and sating

Title	Meeting the needs of Autistic adults in mental health services
Source	https://www.england.nhs.uk/long-read/meeting-the-needs-of-Autistic-adults-in-mental-health-services/
Summary	A guide for ICS and other health organisations that recognises that the NHS has seen a 50% rise in in patient mental health care over 5 years. The guidance is about preventing escellating need, and the importance of ensuring services are accessible and acceptable to Autistic adults.

Title	Making meetings accessible

Source	https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-meetings-accessible/#accessible-meeting
Summary	This best practice describes making meeting accessible to Autistic people and people with a learning disability. It describes a range of adjustments, for example - Before the meeting tell people who will be in the meeting and what their role is - Choose a meeting room with lots of natural light and let people choose where they sit in the room. - During the meeting, keep to the timings on the agenda and make sure only one person talks at a time There is also advice on giving accessible presentations, this includes information about the layout of slides, using handouts, and using the right language.

Title	Tips for communicating with an Autistic person
Source	https://www.Autism.org.uk/advice-and-guidance/topics/communication/tips
Summary	This guide includes information on topics like: - Getting and keeping attention - Processing information and information overload - Avoiding open questions - Asking for help - Being clear and saying what you really mean - Understanding distressing behaviour - Saying no and keeping a boundary

Acknowledgements and thanks

This HNA was produced by the public health team at City York Council, who are responsible for all of its contents. Along the way, we'd like to thank Hilary Conroy from York Disability Rights Forum for providing data and insight, Dr Laura Fax from the University of York for comments and additional material, and a number of providers for providing data.

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A note on this document.

This is an early draft of an Autism and ADHD Strategy for York 2025-2030. It has been prepared before holding consultation events with people who are neurodivergent in the city and with partners. Feedback from these events will further shape and refine the document. We expect to publish the document in Autumn 2025.

A city that works for all

Autism and ADHD Strategy for York 2025-2030

Contents

A word before

We will include here a number of quotes from the coproduction / consultation events, which aim to show an honest perspective on life as an autistic person or someone with ADHD in the city

Introduction to this strategy

Thank you for taking the time to read this strategy.

Autistic people and people with ADHD belong in York. They are a core part of our city: friends, children, co-workers, parents, politicians, sports people, business owners, teachers, and many more. In a city which values its diversity, embeds human rights into its practice, and welcomes all, York gains so much strength and vibrancy from having so many neurodivergent residents living in our city.

But it seems quite plain that our society and public services have much further to go before they can claim to be truly inclusive and supportive of all autistic people and those with ADHD. Over the last years, awareness and discussion of neurodiversity has increased. But efforts to change society, as well as increased resourcing of social, educational and clinical support for neurodivergent people, have not kept pace.

This is as true in York as elsewhere in the UK. Whilst we can't escape the larger context, nor draw upon a huge amount of extra resource, we have written this Autism and ADHD Strategy because we believe we can still work in partnership to make small, medium and large changes, so that **together we create a society that works for autistic people and people with ADHD**.

This document is part of the journey in achieving this. We'd like to invite the whole city to come with us.

Why is this an all-age strategy?

By considering the whole of our population, we can look at how the strengths and needs of autistic people and people with ADHD change through their life. We are also able to consider the importance of families. For many people, families are an important source of advice and practical support. Additionally, we know that neurodivergence often runs in families We hear that many adults first consider their own neurodivergence when their children are going through assessment in schools.

Why is this a strategy specifically about Autism and ADHD?

City of York Council (CYC) and Humber and North Yorkshire Integrated Care Board (ICB) both have a duty to respond to the national autism strategy under the Autism Act. There are two main reasons we are covering Autism and ADHD together in this strategy. Firstly, we recognise that many autistic people also have ADHD. Secondly, we recognise that many of the challenges and the actions of this strategy apply to autism and ADHD equally; for example, the diagnosis pathway and the societal barriers placed on autistic people and people with ADHD.

Why is this strategy just about York?

This strategy is about York specifically because that means that we can plan for the specific strengths and needs of people who live in York. We can take into account local resources such as local charities and support groups. We are working with North Yorkshire Council (our major neighbour) to make sure that our strategies align where they need to. We also recognise that Humber and North Yorkshire ICB covers a wider geography than just York.

Why is this strategy five years long?

By designing a strategy that runs from 2025 until 2030 we can realign with the five-year cycles of the national autism strategy and can renew our strategy with enough time to plan and respond to it. The most recent of these is the National Strategy for Autistic Children, Young People and Adults 2021-2026.

The last Autism strategy for York lapsed in 2021. We acknowledge it has taken far too long for this renewed strategy to be published.

How was the strategy put together?

May-November 2024

- An Autism and ADHD Health Needs Assessment was produced, using data from health and care services as well as evidence from the literature on the health needs of autistic people and people with ADHD

October 2024

- A strategy working group was formed, including the key partner agencies in York as well as academic, voluntary agencies and lived experience. A full list of steering group members can be found at appendix 1

November 24 - Mar 25

- 'Listening Excercises' were held where members of the strategy group went out to over 20 organisations or boards with 3x 'conversation starters' on the strategy, and captured feedback. A full list of organisations can be found at appendix 2

May 2025

- An early draft strategy will be circulated, and published for public discussion at the council's Health, Housing and Adults Scrutiny Committee

June-July 2025

- Consultation events will be held on the draft strategy, to further shape and refine it

July 2025

- Formal public consultatuion will be carried out on the strategy, and comments incorporated

Autumn 2025

- The final Autism and AHDHD Strategy 2025-2030 will be published

Autism and ADHD in York – a picture

Neurodiversity means that all people's brains process information differently. To be a neurodivergent person is someone whose brain processes information in a distinctly different way to neurotypical people.

Because neurotypical people make up the largest group of people in our world, the way they process information is thought to be 'typical' or 'normal'. As a result, a lot of our environments are set up to accommodate these typical ways of processing information. This can make some things difficult for neurodivergent people to access.

There are lots of different ways a person can be neurodivergent. It is a collective term to describe people who have conditions such as Autism, ADHD, dyslexia, dyscalculia, dyspraxia, Foetal Alcohol Spectrum Disorder, stammering, or Tourette's syndrome. In most cases, a person is neurodivergent for their whole life. Some people may become neurodivergent as a result of a brain injury, but this is quite rare. Some people may know they are neurodivergent from a very young age, others may realise this in adulthood.

Autism and ADHD are distinct conditions and experiences; however, we are considering them together in this strategy for two reasons:

- Firstly, Autistic people and people with ADHD face somewhat similar challenges, for example, the diagnosis pathway and the societal barriers placed on Autistic people and people with ADHD that impact mental and physical health.
- Secondly, a proportion of people are both Autistic and have ADHD (around 30%). This is sometimes referred to as 'AuDHD'. We recognise the unique experiences of people with both ADHD and Autism, but also recognise that a proportion of the community may have AuDHD, meaning they have their own unique challenges.

We published a Health Needs Assessment in 2025. This looked at the health needs of people of all ages who consider themselves to be autistic and / or have ADHD. This was regardless of whether they have a diagnosis.

Some key findings are summarised below.

Highlights from the York Autism and ADHD Health Needs Assessment 2025

Prevalence and Demographics	In total there are 2,786 people who are registered with a York GP and who have a diagnosis of autism on their health record.	Autism is underdiagnosed in York, particularly in older people. There is a 3:1 male to female ratio in diagnoses of both Autism and ADHD in York
	In the UK, the prevalence of ADHD in adults is estimated at 3% to 4% With 2,311 people in York having a diagnosis of ADHD, this suggests only around 1 in 3 adults in York are diagnosed.	18.4% of people with an ADHD diagnosis in York also have an Autism diagnosis, and 15.3% of people with an Autism diagnosis also have an ADHD diagnosis.
Assessment and waiting lists	In January 2023 there were 1,560 adults awaiting autism and ADHD assessment and a further 2,000 referrals that had not yet been triaged. It was estimated that the waiting list is five years.	Compared to 2021, the children and young people's autism service has seen a 50% rise in monthly referrals, and just over a quarter of children and young people have been on the waiting list for more than a year.
Health issues	York GP data shows that 1096 people with an ADHD diagnosis also have a mental health condition, which is 44%.	12% of people with ADHD will develop an alcohol addiction, 28% develop a drug addiction at some point in their lives. 14% of people with ADHD in York are current smokers, higher than general smoking rates
	Autistic people, as a group, face health and wellbeing challenges. This includes higher levels of homelessness, 5 years lower life expectancy, higher rates of addictions, 40% of autistic people in York have a mental health condition	Societal awareness and understanding of neurodiversity is still low, and children, adults and carers experience stigma from friends, family and services.

The Social Model of Disability

The City of York Council has previously committed to supporting the social model of disability when designing places and policies. The social model of disability states that people are disabled by barriers placed on them by society rather than by an impairment or condition.

We recognise that many within the neurodiversity community value this approach. It highlights there is nothing intrinsic to either Autism or ADHD that should mean a person is more likely to become physically or mentally unwell, become homeless, or long-term unemployed; and that these experiences often arise from marginalisation and discrimination.

We also recognise that some within the neurodiversity community do not like the language of 'disability' and do not recognise themselves as disabled. To make things more complicated, some parents reject the social model of disability, especially if their children have additional physical or cognitive needs. Therefore not all members of the neurodiversity community and those that support them agree with the social model of disability, aligning more with traditional medical models.

In this strategy and needs assessment we are using the principles of the social model of disability and neurodiversity. However, we acknowledge the differing opinions of the community despite the use of neurodiversity-affirming language throughout. In relation to Autism, medicalised or potentially stigmatising terminology (e.g., disorder, high/low functioning) have been avoided throughout and identity-first language (e.g., Autistic individual) has been used, following the majority preference of the Autism community.

Our Vision and the 3 pillars

Our Vision is that…

Together, we want to create a society that works for autistic people and people with ADHD in York

Our 3 key pillars are …

Pillar 1:	Pillar 2:	Pillar 3:
Change society for inclusion	Make diagnosis and assessment work	Improve support in every setting

This will mean that…

The city we live in, its schools, businesses, public spaces and other settings, present no barriers whatsoever to autistic people and those with ADHD living a full and flourishing life and contributing to York	The policies, pathways and stages of getting an autism or ADHD assessment are clear, well understood by professionals, equitable and just, and as timely as possible	There are better support offers for autistic people and those with ADHD in every sphere of life, professionals are responsive to need, and support and adjustments aren't dependent on diagnosis

To do this, we will need…

- Quick access to clear information
- Better workforce training and development
- Reasonable adjustment with or without a diagnosis
- Inclusive public spaces and work places
- More support around physical health
- Honest and clear communication on pathways
- Access to peer support
- Inclusive education settings
- Culture change and anti-stigma activity
- Equitable and just practice

Pillar 1: Change society for inclusion

Through the coproduction and consultation process, we asked people:

> *'What needs to change in wider society to make York a better place to be autistic or have ADHD?'*

In the table below, we have listed the key themes which were identified ('we heard'), and the commitments and priorities that partners have made to respond ('we will').

We heard…	We will…
We need more quiet and inclusive spaces that meet the sensory needs of neurodiverse communities in the city. By following autism and ADHD good practice in designing public spaces and public services, everyone can benefit. There are particular issues with busy city events such as the Christmas market.	• Evaluate council spaces such as children's centres, libraries and leisure facilities, and work with partners such as Make it York and the Business Improvement District to encourage adjustments to other events and spaces in the city to reflect neurodiversity in our population • Review current policies and practices for the Christmas market and submit a written response to the CYC Safety Advisory Group detailing changes that have been proposed. • Promote to all spaces in York the National Autistic Society's Accessible Environments Resource. • Promote to businesses the use of online resources which give customers information on what to expect before visiting.
Quiet spaces and more neurodiversity inclusive spaces would be especially helpful in schools and health care settings.	• Assess spaces within York Hospital Urgent and Emergency Care Department and provide public and staff with information on how to spot and address sensory challenges this setting • Conduct an annual environmental audit in Child and Adolescent Mental Health Services (CAMHS) in York

We heard…	We will…
	• Encourage GP practices in York to implement the recommendations from the Healthwatch GP access survey 2025, and promote the IHEEM 'Designing for Everyone' guidance • Continue to learn from the Partnership for Inclusion of Neurodiversity in Schools (PINS) programme and ADHD Foundation training to further develop sensory inclusion in education settings and to increase area inclusion bases that meet the needs of the majority of pupils.
It would be helpful for businesses to have neurodiversity champions, and for businesses to have autism inclusive badge schemes. There needs to be more support for people with neurodiversity to get into employment and to have their reasonable adjustment needs met.	• Develop business support packs with practical advice on things like job adverts, interviews, first week inductions, meetings, reasonable adjustments, and performance management • Explore Neurodiversity champions programmes in each of our organisations • Fund businesses to become Autism inclusive employers through the National Autistic Society • Develop a Neurodiversity managers toolkit for staff at York hospital
We need more public education about what neurodiversity looks like and feels like. There are lots of unhelpful stereotypes. This would be especially helpful for people in public facing jobs, and even more so for people in public facing parts of health, education, and care.	• Embed a training offer around Neurodiversity into the Good Business Charter, which covers 25% of York employees • Introduce neurodiversity awareness into Adult Social Care workforce training, with a focus on strengths-based approaches and the importance of person-centred support.

We heard…	We will…
	• Explore ways to share real stories and experiences from neurodivergent adults in the public sphere in York, to highlight the diversity within neurodiversity, reduce stigma, and build empathy. • Work with partners and neurodivergent adults to co-produce public education materials that challenge stereotypes and promote greater understanding of what neurodiversity looks and feels like in everyday life.
We need to recognise that having a neurodivergent child or being a neurodivergent adult can have an impact on family finances.	• We will make sure that Adult Social Care signposts families to access financial advice, welfare benefits, and carers' assessments where appropriate, recognising the additional costs and pressures associated with supporting a neurodivergent young person. This includes reviewing how existing support services, including carers' assessments and welfare advice, can be better promoted and adapted to meet the specific needs of parents and carers of neurodivergent children. • Promote welfare advice and financial inclusion resources, signposted in the 'Talk about Money' guide, to professionals working with neurodivergent people

Case studies will be added at this stage in the document relevant to the first pillar

Pillar 2: Make diagnosis and assessment work

Through the coproduction and consultation process, we asked people:

> *'What can we do to improve the assessment and diagnosis journey for autism and ADHD?'*

In the table below, we have listed the key themes which were identified ('we heard'), and the commitments and priorities that partners have made to respond ('we will').

We heard…	We will…
We need simple and clearly explained referral routes and timeframes, with help to navigate the referral if necessary.	• The Retreat will work alongside the ICB to ensure there is clarity on the information required to triage referrals for adult autism and ADHD assessments, and will contribute to the development of referral forms • Commit to continuous development of the CAMHS website. This will include information on referral processes, key contacts and support whilst waiting, including when the official wait starts. • Ensure organisations have robust and consistent waiting list management protocols, including a fair and equitable approach to people moving into area in line with guidance, and clarity around what to expect when receiving out of area support through right-to-choose, including subsequent consequences on prescribing • Create an ICB-wide service specification for children and young people and one for adults, reducing variation in services across the system • Develop one ICB-wide triage process and criteria to streamline assessment pathways.

We heard…	We will…
We need all professionals who may work with neurodivergent people to know about the pathways and give the same information. This is especially true for school staff and primary care staff where we often hear misinformation is being shared.	• Provide clearer information and continuous communication to primary care staff on pathway changes through GP Friday comms, and do the same with schools through the schools mailer. • The ICB will develop communities of practice to share learning amongst professionals and enhance consistency in access and services. • Development of the SEND Partnership Training strategy and the SEND Communication strategy will support clear and correct information being shared by all partners. This will be driven by the SEND partnership board.
We need clearer and more succinct information about the purpose of the DoIt profiler, and that this information is coproduced with people who have recently used the DoIT profiler.	• Coproduce our websites and printed advice and information about how to complete the DoIt profiler. This will include what will/will not happen as a result of completing it. • Work with York Disability Rights Forum and other groups to understand the particular ongoing challenges with the current information and advice that is available. • Triage a sample of 250 adults who have who the DoIT profiler categorises as least likely to meet the threshold for assessment, to understand the needs of this cohort and shape the next steps. This is intended to drive improvement in support and prevention provided by NHS and wider services, for instance to improve possible adjustments or support without a diagnosis.

We heard…	We will…
We need codesigned communications, both the website and letters/emails sent to people awaiting assessment for diagnosis	• Continue to collaborate with neurodivergent individuals in the development of all communications from The Retreat • Continue to commit to coproduction of CAMHS website/letters/emails with co-creation groups in York, e.g. Parent Carer Forum (PCF) and York Inspirational Kids (YIK). • Evaluate the Raise York and CYC website with young people and adults with autism and or ADHD and make improvements as required • Review communications (letters/emails/ text messages) from primary, secondary and social care services together with people with ADHD / Autistic people to ensure information is consistent
We need a clear explanation of the reasonable adjustments that are available to people with or without a diagnosis, including in schools and mental healthcare services.	• Include information on reasonable adjustments as standard in all diagnostic assessment reports. • Offer advice and consultation through the Retreat clinical team on reasonable adjustments • Work closely between the Retreat team and the Autism Liaison/Complex Needs team at York Hospital to assist with reasonable adjustments for accessing physical health care. • Commit to an ongoing culture change in CAMHS around Neurodiversity • Work towards agreeing as a whole system that support/adjustments can be provided across all parts of the system without a

We heard…	We will…
	neurodevelopmental diagnosis based on individual need. • Coordinate work around Partnership for Inclusion of Neurodiversity in Schools (PINS) to ensure it supports autism and ADHD pathways within health and the offer of support required at a schools level.
We need professionals in public facing roles to be aware of these reasonable adjustment commitments, and to give the same information as each other.	• Promote a toolkit for communication to professionals in different sectors on what their duties and responsibilities are around reasonable adjustment
We need better access to assessment for diagnosis services, and shorter waiting times.	• The Retreat Clinics commit to completing the number of assessments that the ICB commission to do. Should additional funding become available to increase capacity then The Retreat Clinics would be committed to increasing capacity in an attempt to reduce wait times for diagnostic assessment. • We are continuing to work closely with our specialist provider and primary care colleagues to improve the shared care pathway for medication prescribing. Changes to the prescribing pathway will release capacity within our commissioned specialist provider to offer more diagnostic assessments each month to those individuals with the highest level of need on the waiting list.
We need to recognise that there are many neurodivergent adults who are undiagnosed and unsupported. In some cases, this has had a profound impact on their lives, including employment, addiction, homelessness, criminal activity, and relationship breakdown.	• Make post diagnostic resource packs available to those who are awaiting an assessment. In collaboration with the ICB the Retreat Clinics can consider expediting diagnostic assessments if there is indication that lack of formal diagnosis is having a direct

We heard…	We will…
	impact on any of the areas described. • As part of Care Act assessments, we will make sure neurodiversity is considered through strengths-based, person-centred approaches that focus on individual needs and outcomes, not just formal diagnoses • We will implement a trauma-informed approach to City of York Council services, in line with the motion to full council in 2024
Especially for children and young people, we need clarity on the mental health care that they can expect to receive before and after a diagnosis of neurodivergence.	• CAMHS will continue to commit to offer mental health input and therapeutic intervention for any child/young person that is identified as having a mental health need that is considered severe and enduring, irrespective of whether they have a neurodevelopmental diagnosis or not. • The ICB together with partners will review and connect the offer of assessment pathways and specialist clinical advice and guidance to mental health inpatient and community services to improve clinical outcomes. • The ICB together with partners will map out the current offer and levels of need, including under-represented groups. • Review the provision in education settings that is available for Autistic and /or ADHD children and young people in relation to their emotional and mental health and reshape provision to better meet needs.

Case studies will be added at this stage in the document relevant to the second pillar

Pillar 3: Improve support in every setting

Through the coproduction and consultation process, we asked people:

> *'What should support for health and wellbeing look like for those who are neurodiverse, whether with a diagnosis or not?'*

In the table below, we have listed the key themes which were identified ('we heard'), and the commitments and priorities that partners have made to respond ('we will').

We heard…	We will…
We need clarity on the types of support available before and after diagnosis, and for all organisations and professionals to give out the same information.	• Provide post diagnostic support packs and information for adults waiting for diagnostic assessment. • Continue to develop the support section of the CAMHS website and ensure the CAMHS website link features on partner websites and information sources. • Commit to providing resource and signposting support packs to all young people and families pre and post diagnostic assessment. • The ICB will work collaboratively with the education sector to explore what support and action is taking place, including closer work on Neurodiversity with mental health support teams in schools through the Partnership for Inclusion of Neurodiversity in Schools approach
There is no funding or practical help for small peer/community led groups, this is a real gap especially for adults with neurodiversity.	• Use a funding pot to develop community-based support initiatives in York. The aim of this funding is to create needs-led, open-access support specifically for neurodivergent individuals, particularly those facing mental health challenges. This will include developing a formal peer support offering tailored to neurodivergent individuals and creating a neurodivergent-led training

We heard…	We will…
	program to help local organisations in York become more inclusive.
Some of the websites are hard to navigate and have out to date information on them about the support available. We need clear and structured pathways for intervention and ongoing support, with professionals working in all sectors (health, education, social care, employment) all providing the same advice and information about what is available. This information should also be held online on a single website so that individuals and families can access this too. It is essential that this information is accurate, complete, up to date, and specific to York.	• The Local Offer online information will be reviewed and improved through coproduction • The development of the SEND Hub through coproduction, which aims to be a physical representation of the Local Offer. It will enable parents and carers to access the right information and support at the right time. • Delivery of Local Offer engagement events in Family Hubs and Explore library sites to make the Local Offer more accessible. • The SEND Partnership Board will hold partners to account around awareness of the Local Offer so families are better served. • Review information held on the RAISE York and City of York Council websites for accuracy and completeness. Evaluate with Autistic and/ or ADHD young people and adults • Continue to coproduce content on The Retreat website with neurodivergent individuals. • Actively work with young people around the CAMHS website content, and work with partners in the city (Yor Mind, CYC Local Offer, YIKS, PCF) to make sure information is regular reviewed • Develop a central ICB website hub for all-age information on neurodiversity, with Place-specific information which includes resources for the local population

We heard…	We will…
	on pre and post diagnostic support as well as assessment pathways, aligned to web-based channels with our York Local offer site. • Increase Housing Officer awareness and recognising of neurodiversity, increase training uptake, improve communication methods to customers, identify and record need and further improve data on tenants so reasonable adjustments can be supported
We want more preventative support, most especially to prevent physical and mental illness from developing or becoming worse. Families wanted named health professionals that they can recontact when they need. 'Signposting' was not supportive, and people can become overwhelmed by lists of advice sources.	• Include people with an autism or ADHD diagnosis in priority lists for NHS Healthchecks • Use the Good Mental Health Project (York CVS) to design sensitive and helpful mental health and resilience tools to support people with neurodivergence keep mentally well.
Families would value a period of 'aftercare' following a diagnosis where they can come back with questions about the diagnosis and are navigating the support on offer. People of all ages felt that there needed to be more post-diagnosis support.	• Commit to offering the post diagnostic support that is currently commissioned by the ICB within the adult diagnostic pathway. Different options are available for post diagnostic support dependent on individual needs. There is the opportunity for families to be involved in individual post diagnostic support if requested. • Offer regular, free, online workshops aimed at families from the Retreat • Offer post diagnostic support and intervention for young people with ADHD. • Address gaps in provision for those young people who receive a diagnosis of autism but are not identified as having a mental health concern.

We heard…	We will…
Families want opportunity to meet other families before, during, and after diagnosis and get practical advice on things like diet, sleep, and behaviour. This would be a holistic and whole family approach.	• Develop neurodiversity champions in the 0-19 service to provide support and practical advice to families • Promote and support development of social support networks for families
Some schools have unhelpful behaviour policies, and there needs to be more accountability where different advice and support is offered from school to school. There needs to be more support on wellbeing and on school refusal and masking in schools.	• Education settings will review policies in relation to the promotion of belonging • Development of a SEND Partnership Training strategy and schools position statements in relation to inclusive education.
GPs and hospital staff could help by asking what support the person needs in their appointment, and advertising what reasonable adjustments can be offered regardless of diagnosis. For example, asking questions in a different way, providing a written summary of the appointment, or reviewing the waiting room environment.	• Develop an information video for neurodivergent people and their carers on what to expect in a busy hospital environment, who to speak to for help. Use this video as a training video for staff. • Implement hospital passports which people complete with a staff member from the complex care team. Promote this service on the website.
There needs to be more support for preventing suicide and self-harm.	• Support community action groups to coproduce interventions to reduce suicide and self-harm risk in people with ADHD / Autistic people • Ensure that the ICB Suicide and self-harm action plan and strategy details specific attention towards the Autism and ADHD community. Increasing the focus on prevention for Autistic and ADHD individuals whether they are in or out of crisis.
There needs to be more support for those experiencing child to parent abuse and other safeguarding situations	• Work with families, professionals, and community organisations within the child protection process to

We heard…	We will…
	recognise the link between neurodivergence and child-to-parent abuse, ensuring this is considered in assessments, support plans, and risk management approaches. • Ensure Adult Social Care teams are aware of the long-term impacts that child-to-parent abuse can have on parents, carers, and neurodivergent young adults as they transition to independence. • Adopt a whole family approach as part of the Domestic Abuse strategy in York, which will include support for the parent victim of CAPVA cases.

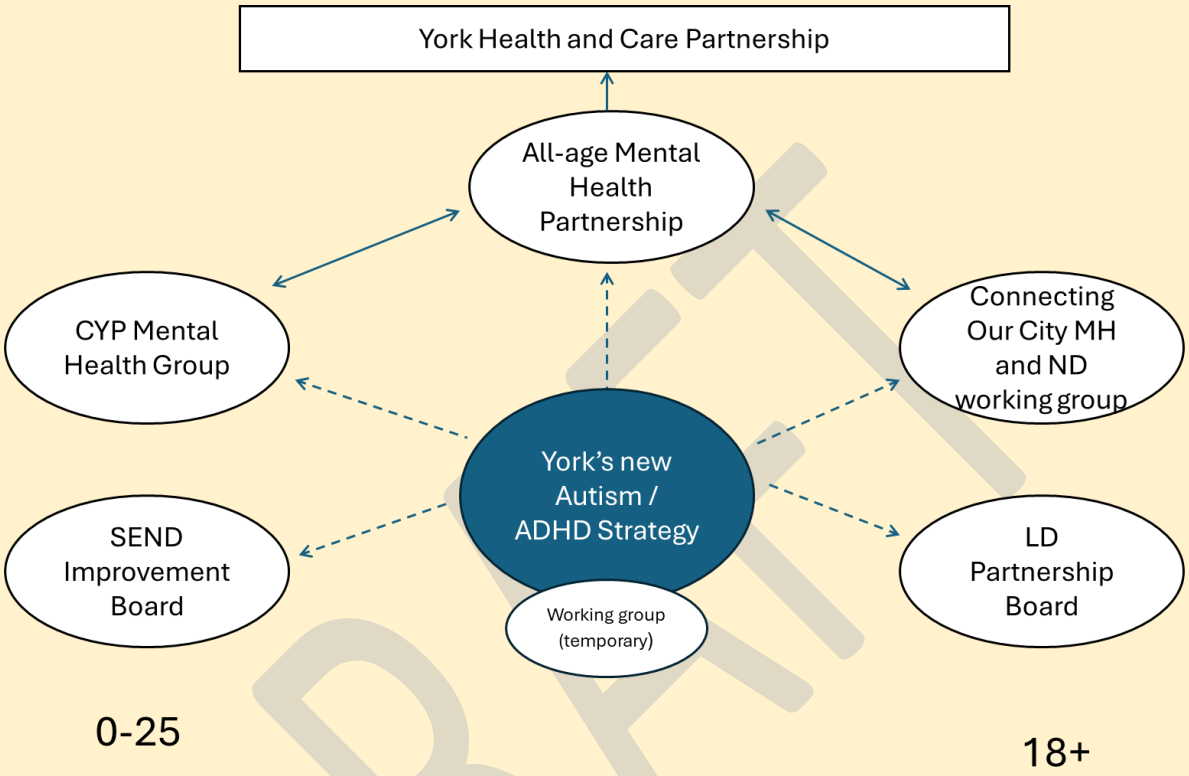
Case studies will be added at this stage in the document relevant to the second pillar

How will we know we've made a difference?

This section will be completed once the further consultation events have been held, and will include direct feedback from participants on what measures we can use, both qualitative and quantitative, to know if we are making a difference.

Who will take this work forward?

The partnership structure which currently exists to support this work is shown below:



During the next period of coproduction, we will be seeking views on how the partnership structures should work in York to ensure this strategy is monitored and delivered, including the evolving commissioner landscape within the Integrated Care Board

Appendix 1 – Steering Group Members

City of York Council (Public Health, CYC Children's and Education, Adult Social Care, Housing)	Healthwatch York
Humber and North Yorkshire ICB	York CVS
North Yorkshire and York CAMHS	York and Scarborough Teaching Hospitals
The Retreat	Change Grow Live
Connecting our City Project	University of York
York Disability Rights Forum	National Autistic Society
Primary Care	

Appendix 2 – Organisations consulted so far

This is an evolving list and more organisations will be added:

Primary SENCO meeting	Snappy
Secondary SENCO meeting	Nothing About Us Without Us
York Business Intelligence Forum	Higher York
York Schools and Academies board	Danesgate school
Gypsy and Traveller Steering Group	York Early Years Leaders and Managers forum
Dynamic support key workers	York Healthy Child Service
York Schools forum	Specialist teaching teams
Connecting our City Neurodiversity and Mental Health working group	York Hospital child development centre
GP clinical directors	SENDIASS
ICB Mental Health, Learning Disability and Autism Collaborative	Youth Justice Service York
York Parent Carer Forum	Employment and skills team
Living Autism	Housing
York Inspirational Kids	Blue = Further engagement needed

Suggested further appendices:

Appendix 3- Strategic landscape mapping partners in this area

Appendix 4- policy and official guidance relevant to this area

Appendix 5- Glossary of terms

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Completed items:

Meeting Date	Item
12 June 2024	• *York pipeline of scrutiny proposals for the Combined Authority* • *Homelessness Future Resettlement Pathway*
10 July 2024	• *York and Scarborough Teaching Hospitals NHS Foundation Trust CQC Update* • *Breastfeeding and Infant Feeding*
11 September 2024	• *Community Pharmacy Provision in York* • *Homelessness Future Resettlement Pathway*
9 October 2024	• *2024/25 Finance and Performance Monitor 1* • *Draft Homelessness and Rough Sleeping Strategy 2024-29* • *Adult Social Care Strategy Update* • *Adult Social Care Peer Review*
6 November 2024	• *Urgent Care Delivery Review in York and the East Coast - an Update on the Emerging Integrated Model and Next Steps* • *Update on the York Autism and ADHD Health Needs Assessment, and progress towards a York Autism and ADHD strategy* • *Winter Planning and Pandemic Preparedness in York*
4 December 2024	• *2024/25 Finance and Performance Monitor 2* • *Updating the Repairs Policy* • *Update on Void Properties*
15 January 2025	• *Establishing a Joint Committee between CYC and Humber and North Yorkshire Integrated Care Board*

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12 March 2025	• *2024/25 Finance and Performance Monitor 3* • *Asset Management Investment Plan*
2 April 2025	• *Humber and North Yorkshire Integrated Care Board – Dental Services and Update* • *Oral Health in York*
21 May 2025	• Draft Autism and ADHD Strategy • Trauma Informed City – update from TEWV NHS Trust

Other:

- **28 April 2025** – Demonstration Session with Telecare Team

Remaining unallocated items for consideration by new committee:

- Adult Social Care Strategy Update *(possibly July 2025?)*
- Urgent Care Update *(possibly July 2025?)*
- Healthy Weight *(possibly July/August 2025 ahead of autumn launch of new service offer?)*
- Draft Pharmaceutical Needs Assessment 2025 *(possibly September 2025?)*
- Dignity in Retirement Council Motion
- Trauma Informed City Council Motion – wider discussion?
- Health and Artificial Intelligence – benefits and challenges
- Telecare/reablement technology – briefing from relevant academic experts
- LD Provision – The Glen and Lowfields
- Task and Finish Group Review of Home Care Commissioning
- Relevant outputs from LGA Peer Review – Housing Partners