

Notice of a public meeting of Health and Wellbeing Board

To: Councillors Steels-Walshaw (Chair), Runciman, Webb

and Mason

Sarah Coltman-Lovell - York Place Director (Vice Chair)

Siân Balsom – Manager, Healthwatch York

Dr Emma Broughton - Joint Chair of York Health &

Care Collaborative

Zoe Campbell – Managing Director, Yorkshire, York & Selby - Tees, Esk & Wear Valleys NHS Foundation

Trust

Sara Storey - Corporate Director, Adults and

Integration

Martin Kelly - Corporate Director of Children's and

Education, City of York Council

Simon Morritt - Chief Executive, York & Scarborough

Teaching Hospitals NHS Foundation Trust

Mike Padgham – Chair, Independent Care Group Alison Semmence - Chief Executive, York CVS

Peter Roderick - Director of Public Health, City of York

Council

Tim Forber - Chief Constable, North Yorkshire Police

Date: Wednesday, 22 January 2025

Time: 4.30 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 and co-opted 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 - 34)

To approve and sign the minutes of the last meeting of the Health and Wellbeing Board held on **Wednesday**, **20 November 2024** and the minutes of the meeting held on **Wednesday**, **25 September 2024**.

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 have changed to 2 working days before the meeting. The deadline for registering at this meeting is at **5.00pm** on **20 January 2025**.

To register to speak please visit www.york.gov.uk/AttendCouncilMeetings to fill out an online registration form. If you have any questions about the registration form or the meeting please contact the Democracy Officer for the meeting whose details can be found at the foot of the agenda.

Webcasting of Public Meetings

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

5. Healthwatch York Report: Listening to (Pages 35 - 152) Neurodivergent Families in York

This report shares work by Healthwatch York, in partnership with the Land, York Carers Centre, York Disability Rights Forum and Parent Carer Forum York, discussing local experiences of families of neurodivergent children and young people.

6. City of York Safeguarding Adults Board Annual (Pages 153 - 208) Report 2023/24

This Annual Report discusses the work of the members of the City of York Safeguarding Adults Board to carry out and deliver the objectives of the strategic plan during 2023/24.

7. Annual Update on the Joint Strategic Needs (Pages 209 - 214) Assessment

This report provides members of the Health and Wellbeing Board with an update on the Joint Strategic Needs Assessment (JSNA), including work undertaken in the last year by the York Population Health Hub, planned work for the coming year, and some key changes in the York population.

8. Update from the York Health and Care (Pages 215 - 272) Partnership

This report provides an update to the Health and Wellbeing Board regarding the work of the York Health and Care Partnership, progress to date and next steps.

9. York's Joint Local Health and Wellbeing (Pages 273 - 296) Strategy 2022-2032: Review of Progress and Future Action Planning

In early 2023, the Board approved the action plan for its 10-year Joint Local Health and Wellbeing Strategy (JLHWS). This paper reports on progress against all the actions in the plan for a first cycle of two years, summarises press so far and asks Board members to consider how future reporting should be undertaken.

10. Report of the Chair of the Health and Wellbeing (Pages 297 - 302) Board

This paper is designed to summarise key issues and progress which has happened in between meetings of the Health and Wellbeing Board, giving Board members a concise update on a broad range of relevant topics which would otherwise entail separate papers.

11. Urgent Business

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

Democratic Services Officer

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

- Registering to speak
- Written Representations
- Business of the meeting
- Any special arrangements
- Copies of reports

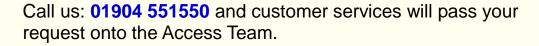
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এই তথ্য আপনার নিজের ভাষায় দেয়া যেতে পারে। (Bengali)
Ta informacja może być dostarczona w twoim
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(Polish)

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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 <u>unless</u> 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 <u>unless</u> 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.



City of York Council	Committee Minutes
Meeting	Health and Wellbeing Board
Date	25 September 2024

Runciman and Webb Siân Balsom – Manager, Healthwatch York

Councillors Steels-Walshaw (Chair),

Dr Emma Broughton – Joint Chair of York

Health & Care Collaborative

Sarah Coltman-Lovell – NHS Place Director for the York Locality - Humber & North Yorkshire Health and Care Partnership Martin Kelly – Corporate Director of Children's and Education, City of York

Council

Alison Semmence – Chief Executive, York

CVS

Present

Brian Cranna - Director of Operations and Transformation, Tees, Esk and Wear Valleys NHS Foundation Trust (Substitute for Zoe

Campbell)

Jodie Farguharson - Head of Public Health, Healthy Child Service (Substitute for Peter

Roderick)

Fiona Willey - Chief Superintendent, North Yorkshire Police (Substitute for Tim Forber)

Apologies Zoe Campbell – Managing Director,

Yorkshire, York & Selby - Tees, Esk & Wear

Valleys NHS Foundation Trust

Tim Forber – Chief Constable, North

Yorkshire Police Councillor Mason

Simon Morritt – Chief Executive, York & Scarborough Teaching Hospitals NHS

Foundation Trust

Mike Padgham – Chair, Independent Care

Group

Peter Roderick – Director of Public Health,

City of York Council

Sara Storey – Corporate Director of Adults

and Integration, City of York Council

10. Declarations of Interest (4:35pm)

Board Members were invited to declare any personal, prejudicial or disclosable pecuniary interests, other than their standing interests, that they had in relation to the business on the agenda. None were declared.

11. Minutes (4:34pm)

Resolved: To approve and sign the minutes of the last meeting of the Health and Wellbeing Board held on Wednesday 24 July 2024.

12. Public Participation (4:35pm)

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

A speaker discussed their difficulties securing a CAMHS referral, and their concerns regarding service providers, including health and social care practitioners.*

*Amended as requested at 20 November 2024 meeting and via subsequent update – details redacted at public participant's request.

13. Children and Young People's Health (4:39pm)

The York Place Director introduced the item, including a PowerPoint presentation on Children and Young People's Health in York, incorporating a one-page summary of the Integrated Care System (ICS) Strategy outlining the aims and outcome priorities, with representation from all sectors.

She also introduced the strategy of Core20PLUS5, which is an approach designed to drive targeted action in healthcare inequalities improvement; it was explained that "Core 20" referred to the 20% most deprived members of the population as identified by the Index of Multiple Deprivation, and the "Plus 5" referred to 5 population groups selected by the ICS, who

were experiencing poorer than average health access, experience or outcomes.

Representatives from the Integrated Care Board, who had coauthored the report, then further discussed elements of the presentation in detail and responded to questions from the board.

The Programme Lead for Children and Young People's Mental Health, further elaborated on the Core20PLUS5 and presented a video entitled "Nothing About Us Without Us" discussing young people's top four priorities for mental health:

- 1. Young people led awareness-raising and training on the signs and symptoms of mental health problems, and issues impacting young people's mental health, including LGBTQ+, racism, etc.
- 2. Easier access to services.
- 3. Young people leading on work and courses about children and young people's mental health, to ensure their voices are heard, their lived experience is valued, and they are not "shrugged off" by professionals.
- 4. Listen to young people more.

She stated that young people's involvement with the development of the mental health strategy had been productive and successful.

The Senior Commissioning Manager Children and Young People discussed the offer for emotional and mental wellbeing using the "I thrive" model which was generally self-directed, with support and advice from specialist services such as York Mind, Beat (the National Eating Disorder Service) as well as Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV), Child and Adolescent Mental Health Services (CAMHS), Improving Access to Psychological Therapies (IAPT), Wellbeing in Mind and the School Wellbeing Service (SWS). She explained that this model moved from signposting, through increasing levels of assistance and involvement.

She summarised how these services are employed, working with schools and social care, to facilitate good mental health for

children and young people in York and discussed funding and challenges.

The Senior Quality Lead for Children and Young People at York Place discussed physical health and services focusing on the five vulnerable groups identified by Core20PLUS5; she advised the board:

- That a post was being set up with funding from York
 Place, to enable children with asthma to live a normal life.
- That continuous monitoring and support was being offered to children with Diabetes across the ICB.
- That integrated bowel and bladder workshops in partnership with the Healthy Child Service were being established.
- That significant work had been undertaken with therapies teams at York hospital to reduce long wait times for children with sensory/processing difficulties.

The board thanked the presenters for their report, noting the quality and comprehensiveness of the presentation.

Board members expressed some concern that the presentation itself had not been incorporated into the pack.

The board asked for further information regarding the transition from Childrens Social Care to Adults Social Care concerning support for mental health, and whether the ICB had looked to other authorities Integrated Care Strategies for guidance regarding good practice?

The Programme Lead for Children and Young People's Mental Health responded that a working group across the six Places within the ICB was focusing on a consistent approach to mental health, aware that people may live in one area and work/school in another, and a move away from an age-led approach towards a needs-led approach. She said that having young people stay within a particular service until a need is met rather than a specific birthday, or having a key worker to guide them can useful in avoiding a "cliff edge" at 18 years.

Regarding the board's question concerning best practices, she answered that she liaised regularly with her counterparts in

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West Yorkshire and South Yorkshire, and she was quite keen to take guidance from other authorities, but also the Humber and North Yorkshire ICB's work on Trauma Informed care was leading the way nationally.

She went on to discuss the need to adapt for new or emerging issues such as Avoidant/Restrictive Food Intake Disorder (ARFID), which she distinguished from traditional eating disorders on the basis of the response required. Senior Commissioning Manager Children and Young People added that the shortage of specialised staff is also an issue across the ICB, particularly when dealing with specialist areas such as ARFID.

Board members raised the example of the East Cambridge model, which utilised social prescribing to lessen the burden on specialists – and asked whether the ICB might be able to do more in the community utilising this model?

The Programme Lead for Children and Young People's Mental Health answered that this highlighted the importance of the list of priorities for each place to best deliver change in each area. The Director of Operations and Transformation, TEWV NHS Foundation Trust added that work was being done in Adult Services regarding the Community Hub concerning the range of early interventions prior to reaching specialist Services and this absolutely needed to be part of the children's work too going forward.

The Programme Lead for Children and Young People's Mental Health added that whereas the ICB were very good at escalating/"stepping up" young people to CAHMS they also needed to work towards a more graduated drop down.

The board discussed family members of children, especially those with specific concerns such as neurodiversity or gender identity, and how they could find someone within the system who was equipped to help them holistically; it was hoped that patients with ongoing health concerns as part of their identity could have these taken into consideration alongside transitory health issues and not have to choose which issue they would like to have dealt with in isolation.

The board also expressed concern at the confrontational nature of parents seeking the best assistance for their child, and the fact it was often presented as a "fight" where healthcare inequalities could be greater dependant on a child's particular condition, dependent on how well their carer was able to advocate for them and dependent on which area they lived. They suggested that better communication was required from healthcare professionals to patients and their families, for example regarding waiting lists.

The Programme Lead for Children and Young People's Mental Health responded that this was very much where the feedback and recommendations from young people had led, with over 80% of respondents had made very modest recommendations concerning communication, such as young people not buying stamps. The Senior Commissioning Manager Children and Young People added that the School Wellbeing Service and Wellbeing in Mind are in all/most schools in York respectively and have overwhelmingly positive feedback but unless it is on their phones, many young people do not express this feedback via forms. For this reason a feedback app was being developed (with digital poverty in mind).

Board members suggested that the public speaker and the upcoming Healthwatch report exemplified that information and advice was not always successfully being conveyed to people – it was suggested that greater proactive contact with patients/families before or during the transition between Childrens Social Care and Adults Social Care could be beneficial.

The Senior Commissioning Manager Children and Young People agreed with this point, commending the Healthwatch report and proclaimed Healthwatch to be one of the key guides she would recommend for mental health. The Programme Lead for Children and Young People's Mental Health added that Centre for Voluntary Services are also very useful, and that she had been doing normalising work with York Mind regarding how podcasts and positive social media (included self-generated material) could further be used to pre-empt young people first hearing about things from a doctor.

The board further enquired whether the funding for York Mind would be continuing, given it was cited as a key service, and whether it may be subject to potential future cuts since the flow of money comes from council.

The Programme Lead for Children and Young People's Mental Health answered that the forward plan would look at where spending was best prioritised within the ICB on different areas. The Executive Member for Children, Young People and Education responded that York Mind was funded by the Local Authority and the executive would reassess contract when it was due for renewal.

The Programme Lead for Children and Young People's Mental Health stated that the forward plan needed to be systems-based and it had to be about all services united; be they national, regional or local, because actually these were all interlinked at the point of delivery, and ultimately young people just want to know there is help there that could benefit them.

Board members agreed that mental health was a complex issue and all partners would need to be involved, encouraging the voluntary sector to seek national funding in addition to that received from the council.

The Corporate Director of Children and Education noted a York led bid had secured £500,000 for care leavers that will come into the system to trial a new approach which is having a clinical psychologist and six Advanced Clinical Practitioner Apprentices across the authority. He encouraged partners to look toward innovative models that possibly do not currently exist.

The Chief Executive, York CVS stated that there should be a management of expectations towards seeking funds outside York – places like grant making trusts are closing their doors and there is fierce competition for funding from places like the National Lottery.

Resolved: That the board noted the report.

Reason: The report detailed the current provision and

plans to deliver against priorities and the gaps that need to be addressed to improve outcomes

for children and young people.

14. Report of the York Health and Care Partnership (5:56pm)

The York Place Director presented the report.

She discussed the success of the 30 Clarence Street Hub, the Conversation Café Forum and the announcement of the £2.4 million next phase of the Mental Health Hub, which had previously been embargoed due to the general election, and the pre-election period, which prevented central and local government from announcing any new initiatives. She discussed the Connecting our City Event, development of YHCP and the future work required to take the partnership forward including digital strategy and integration of teams.

She noted that Lord Darzi's report on the state of the National Health Service in England highlighted some important issues, including an emerging need for seven new hospital wards in York for people aged 75 or over at a time when the hospital is closing wards due to staffing shortages, and there is simply no room to build new wards on the current hospital site.

The York Place Director stated that another key issue was that specialist staff were retiring across sectors, and many people were going out of area which a regional model would be a more effective solution for. The early intervention model would alleviate this to some degree, but major reform was needed. Humber and North Yorkshire ICB discussed this in August, a month ahead of the Darzi report and as such had begun to formulate three areas of focus:

- 1. Local Integrated Primary, Community and Social Care (including social based and de-medicalised mental health and neurodiversity services) The ICB want people to be able to access primary, community, mental health, long-term conditions management, outpatients, social care and end of life care in a joined-up way that is local to their place.
- 2. Mental Health Learning Disability and Autism The ICB want people to be able to receive the specialist health and mental health services that they require least often when they need it, which may mean they are provided at scale and could be from a single location.
- 3. Acute and Specialist services and care The ICB want people to be able to receive best quality planned treatment in a timely way, this may require

people to travel to receive access to health expertise in specific centres of excellence that maximise productivity and improve people's outcomes.

The board asked about accessibility of GP surgeries and pharmacies, both with regard to current housing stock, and in view of the number of new housing developments planned, it was hoped that these new houses would also have access to services as a consideration of the planning process.

The York Place Director said that it was difficult to produce integrated care centres for all communities in a short space of time, but that this was a challenge that the partnership recognised and would look at as a long-term issue. She stated that future planning would most definitely consider access to care services, if necessary, via regular public transport.

The Chief Executive, York CVS stated that this report recognised the challenge of statutory partners referring people to the voluntary sector because they didn't meet threshold, and the necessary investment required for those referrals. Consequently £250,000 had been invested in seven organisations over a period of two years.

The board welcomed this as a positive step, noting that that the voluntary service had hitherto been providing core offer but not being properly compensated for it.

The board asked about the accessibility to all of the Mental Health hub – which was a 24:7 service offer but was not in the centre of York; it would probably not be appropriate for someone experiencing mental health crisis to travel via multiple buses to seek assistance.

Director of Operations and Transformation, Tees, Esk and Wear Valleys NHS Foundation Trust responded that this would be a pilot in one particular neighbourhood, in order to demonstrate its effectiveness for the two-year period, and if successful it would be rolled out citywide, making the service more readily accessible to all. This service will serve as additionality and would not remove existing crisis services; these would remain in

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place, operating alongside the targeted hub, currently in this one neighbourhood.

Joint Chair of York Health & Care Collaborative pointed out that primary care estates were currently fragmented, and while collocation was essential there was not a single estate currently fit for purpose. She encouraged partners to collectively get behind this vision, which would require investment, citing the example of Acomb where there were six GP services in under a mile which could all be collocated.

Resolved: That the Board note the report of the YHCP.

Reason: So that the Board were kept up to date on the work

of the YHCP, progress to date and next steps.

15. Healthwatch York Report - Exploring Access to GP Services in York - Interim Report September 2024 (6:27pm)

The Manager of Healthwatch York presented the report, which summarised the results of a survey exploring people's experiences of accessing GP services within the city of York.

She stated that the intention had been to encourage open, honest conversations about access to primary care and thanked respondents to the survey which formed the basis of the report.

She emphasised that when visiting their GP, respondents overwhelmingly indicated they wanted a consistent point of contact who knew them and who they trusted. Patients with chronic conditions wished to have their doctor understand their condition, but not to attribute or link all health concerns to this condition.

She noted that this report and the other items on the agenda illustrated that capacity and demand were not currently in step with one another, but opportunities had been presented in this report, the urgent care report and the pharmacy report, which could be explored collectively by partners to develop a strategy for how the ideas might take shape.

She cited examples such as integrated Care Community hubs, changing roles for pharmacies and independent prescribing,

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better access to voluntary and community services to alleviate Health and Care Services and early intervention and prevention.

She noted that formal recommendations for the board had not been made in this report, but next steps had been proposed and the board's views and suggestions on these would be welcomed.

The board commended the report.

Since this report was titled an "interim report" the board asked when the final report was due.

The Healthwatch Manager responded that what had been published reflected the full results of the surveys undertaken by Healthwatch, but it was titled an "interim" report at publication because further work on these results had not then been completed by Healthwatch, who sought to explore solutions. She added that they had since undertaken follow up meetings with those in primary care to explore how they might bring people and clinicians together and work on systemic improvements.

The board stressed the importance of people still coming forward for care, and not presenting late or avoiding doing so for fear of overburdening their GP as was suggested by quotes from respondents in the report. Despite the disproportionate pressure on GPs, who see 90% of all contacts, triage in this area has been a key innovation to ensure that those most in need are seen first and patients should contact their GP to allow for this rather than stay silent.

The board expressed concern about situations arising where a specialist/consultant advises that they will send something through to a patient's GP, followed by a break in the flow of the service and a potential breakdown in communication at the patients end, resulting in confusion as to whether or not the GP has actually received this information. Residents have reported believing they had a prescription ready, only to find out this was not the case weeks later.

The Joint Chair of York Health and Care Collaborative responded to this, quoting the NHS Constitution on

responsibility for prescribing between primary and secondary care, stating that secondary care practitioners, if they feel a drug needs to be issued with urgency, can issue it immediately. A GP constitutionally has 28 days to receive a letter from secondary care, read it, action it and put it on a patient's notes. It is therefore reasonable to expect a GP to take up to 28 days to have your prescription prepared and ready. It was conceded that current pressures on the NHS have meant that these targets are not always met, and expectation management for patients was vital.

The Chief Superintendent, North Yorkshire Police agreed that expectation needed to be realistic, and from a police perspective additional services had been launched with no additional staffing resource.

The Manager of Healthwatch York agreed that there was frustration on both sides (patients and GPs) emphasising the pressing need to refocus resources on where they can make the most impact. She stated that more patients were being seen by primary care than before the pandemic; while some of these were seen online, face to face appointments had nearly returned to pre-covid levels and there were more online and more telephone than before.

She stated that it was vital to have a really good conversation about how to make GP services as good as they can be for our population, acknowledging that current demand cannot be met and prioritising a way forward that people respect and understand.

She concluded with three key questions to take away from the report:

- How can capacity be increased?
- 2. How can other areas of the system be utilised more effectively to make sure that that GP support is there for the people who need it?
- 3. How can communication be improved between primary and secondary care so we don't have GPs, members of the public and people working in hospitals chasing each other for things as raised by board members?

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Resolved: That the Board noted Healthwatch York's Report -

Exploring Access to GP Services in York – Interim Report September 2024, and commented on the updates provided within the report and its associated

annexes.

Reason: To keep up to date with the work of Healthwatch

York and monitor progress regarding

recommendations.

Cllr L Steels-Walshaw, Chair [The meeting started at 4.34 pm and finished at 6.46 pm].

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City of York Council	Committee Minutes
Meeting	Health and Wellbeing Board
Date	20 November 2024
Present	Councillors Steels-Walshaw (Chair), Runciman and Webb Siân Balsom – Manager, Healthwatch York Sarah Coltman-Lovell – NHS Place Director for the York Locality - Humber & North Yorkshire Health and Care Partnership Peter Roderick – Director of Public Health, City of York Council Martin Kelly – Corporate Director of Children's and Education, City of York Council Sara Storey – Corporate Director of Adults and Integration, City of York Alison Semmence – Chief Executive, York CVS David Kerr – Community Mental Health Transformation Programme and Delivery Lead - Tees, Esk and Wear Valleys Foundation Trust (Substitute for Zoe Campbell) Lucy Brown – Director Of Communications - York Teaching Hospital NHS Foundation Trust (Substitute for Simon Morritt) Fiona Willey - Chief Superintendent, North Yorkshire Police (Substitute for Tim Forber)
Apologies	Councillor Mason Tim Forber – Chief Constable, North Yorkshire Police Zoe Campbell – Managing Director, Yorkshire, York & Selby - Tees, Esk & Wear Valleys NHS Foundation Trust Simon Morritt - Chief Executive, York & Scarborough Teaching Hospitals NHS Foundation Trust Dr Emma Broughton – Joint Chair of York Health & Care Collaborative Mike Padgham - Chair, ICG

16. Declarations of Interest (4:36pm)

Board Members were invited to declare any personal, prejudicial or disclosable pecuniary interests, other than their standing interests, that they had in relation to the business on the agenda. None were declared.

17. Minutes (4:37pm)

The chair stated that she was happy to approve and sign the minutes of the last meeting of the Health and Wellbeing Board held on Wednesday, 25 September 2024, subject to the following amendment:

The board noted that page 9 the September minutes should state "Grant making Trusts are closing their doors" and not "the National Trust".

18. Public Participation (4:38pm)

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

Jonathon Bateson spoke regarding matters under the general remit of the board. He stressed the importance of good mental health services in York, particularly at this time of year, stating that he felt there was not currently enough provision in this area. He noted the particular importance of such services for men.

Officers present spoke with the speaker after his contribution and took contact details with the intention of following up on the issues raised.

Cllr Warters provided written representation regarding matters under the general remit of the board – expressing concern around the effectiveness of hospital and GP Services and capacity within the system for an increasing population.

The Chair responded to Cllr Warter's submission, noting that some aspects he raised - including access to GPs - had been discussed by the board at recent meetings. She noted that the Health and Care Partnership had a substantial ongoing piece of work underway concerning Integration and Joint

Commissioning, and an item had recently been brought to the Health, Housing and Adult Social Care Scrutiny Committee regarding urgent care services.

The Chair advised that she had provided Cllr Warters with a written response and where relevant she would refer issues to the scrutiny committee.

19. Report of the Chair of the Health and Wellbeing Board (6:24pm)

The chair presented the report, which covered various topics including an update on progression of the tender process for Pharmacy Provision in Clifton; noting that all three applications had been declined, so the board had submitted an enhanced supplementary statement noting the ongoing gap in Pharmacy provision in Clifton to support the appeal process for any of the applicants wishing to apply.

The Director of Place commented that she and the Director of Public Health had also made representations to the ICB regarding the need for local pharmacy provision in Clifton.

20. The approach to working with people and communities in Humber and North Yorkshire and 'We Need to Talk' engagement programme, Summary (5:52pm)

The report was introduced by the Director of Place and presented by the Executive Director of Communications, Marketing and Media relations, NHS Humber and North Yorkshire Integrated Care Board.

The Director of Place noted that following discussion at the previous Board meeting, she had advised that there was a strong case for change in the NHS, and proactive steps towards this were already being taken; the Executive Director of Communications, Marketing and Media relations was the perfect representative to advise how the ICB is doing this and to present early findings.

The Executive Director of Communications, Marketing and Media relations went through the PowerPoint presentation

entitled "We Need to Talk: What's the next Chapter of Our NHS?" which can be found in Annex 1 of this item.

She pulled out several details from the report, strengthening the voice of underrepresented groups. Launching and building a more diverse three tier public membership approach called "Community Voices".

Linked to this, she advised of an NHS pilot project called "Working Voices", delivered across the whole area, which supported employers to improve the health and well-being of their their workers. She advised that this also created a community of practice for employers to share with each other what's working what's not. So far this initiative had met with success in Hull and the plan was to broaden this out across York and the wider area.

She discussed the "Insight Bank" to understand who was doing what, which had recently launched and involved some board members, giving insight and intelligence across the system to avoid duplicating activities and to build a repository that everybody can access.

[The Director of Public Health left the meeting at 6:00pm]

The board suggested acknowledging areas where change was needed was admirable, but this was only meaningful if met with a response. They asked what the ICB intended to about the things they have heard people are most concerned about?

The Executive Director of Communications, Marketing and Media relations acknowledged that this was also the message coming from central government, and that reform and acting on this meant difficult decisions or "trade offs". Consequently they were having a lot of conversations to ensure the right balance was set, while also supplying care for everyone and dispelling myths around where money was being spent.

The board noted the inclusion of Gallows Community Centre in these figures, which was located in Barrowcliff (Scarborough – North Yorkshire) and not the City of York. It was suggested that the figures should be revisited to exclude this inconsistency from York figures going forward.

On the slide about "What's most important to people in York" the board noted the scale went up to 1400 and if there has only been approximately 200 responses from York, it meant only 10% of the responses across the six places were actually from York. It was suggested the Board work to drive up participation in this survey next time.

Three different levels of membership had been identified, which would allow people to be proactively engaged by the ICB – face to face, surveys. The board asked for the engagement details to be included with these minutes:

Get Involved with Humber and North Yorkshire Health and Care Partnership:

https://humberandnorthyorkshire.org.uk/getinvolved/

Humber and North Yorkshire Health and Care Partnership Engagement Hub: https://humbernorthyorkshire.engage-360.co.uk/

The Executive Director of Communications, Marketing and Media stressed that this initiative was not necessarily about new buildings, people or infrastructure but about better customer service.

The board suggested presenters from the ICB come back to a future meeting to present an update on progress made regarding the areas discussed based on all of this information.

21. Update on Goal 10 of the Joint Local Health and Wellbeing Strategy 2022-2032 (4:44pm)

The Director of Public Health introduced the report, highlighting the report's findings that loneliness has a significant impact on people.

The Head of Communities and the Local Area Coordinator presented the report, beginning with a video entitled "Glynn's story" which articulated how the local authority and organisations such as Move Mates could progress people forwards, through social interaction, exercise and increasing service users' confidence.

The case study explained how long-standing, trusted relationships could be built through a Local Area Coordinator facilitating introductions to Housing Managers, Childrens and Adults Social Care and social prescribers. The Head of Communities explained that 50% of ward funding went into community projects to address this, including 140 trained Community health champions. He also discussed partnerships with York Cares, York CVS and The Cares Family national model which created intergenerational social clubs at the Spurriergate Centre and Community Furniture Store.

He discussed other cases in which the Local Area Coordinator supported service users to improve their situation; he explained that the Move Mates charity had recently been awarded the king's award for voluntary service and had created 112 active pairings in the past year between a move Mate walking buddy volunteer and somebody struggling with loneliness, isolation, physical health or mental health challenges.

He noted that the report addressed gaps in provision and discussed an event held at Guildhall to identify loneliness as well as issues of transport – specifically accessing York city centre.

The chair thanked the speakers, noting that this service was invaluable, and that the case study presented in "Glynn's Story" showed that a service user could go on to support others.

The board noted that Annex 5 of the report stated that 25.7% (year on year since 2019) of adults felt lonely, asking by what metric loneliness was being measured, and also how the presenters viewed their relationship with ward councillors.

The Head of Communities answered that figures regarding loneliness indicator were captured annually but the last information received went back to 2019 so there was an issue concerning the methodology around how we're that metric was being captured. He added that how Local Area Coordinators measured service users' loneliness affected the type of relationships they had with them, due to the dynamic involving strengthening a circle of support. He said that the relationship between local councillors and Local Area Coordinators was seen as integral to the relationship being fostered at Place based level.

The Director of Public Health added that the metric around loneliness originally derived from an Active Lives survey carried out in 2019, and the Office of National Statistics had intended to ask the same question every year to build a loneliness index and then they didn't ask that question. As a consequence the ongoing data was erroneous and officers had pushed back to Public Health England to ask whether further information would be available. Further information had been added to the index. but this only covered those who received social care or were themselves carers. He conceded the gap in the current data, and highlighted that the Campaign Against Loneliness website had identitifed specific risk factors, particularly impacting young people, women and those with mental health concerns. He noted that this discussion had raised further risk factors such as lower neighbourhood belonging and low social trust, providing further items which could be picked up in the next couple of years to ensure work going forwards not only reflected the brilliant practice evidenced in this presentation but also moved the work into sections of the population where it could have the greatest impact.

The Local Area Coordinator said that they encouraged people to come and see them at community centres which increased service user's confidence and many became involved at community centres as a result.

The board acknowledged that Local Area Coordinators had experienced a difficult time during lockdown because of its effect on people's mental and physical health, and asked whether this remained the case or had things moved on? The Local Area Coordinator said that while many people still felt a long-term impact, in general things were now moving forward. Some people who were rehoused during the pandemic had been unable to make local contact at the time, and as a result these people have only now been seeking assistance.

The board asked whether there was now a Local Area Coordinator for each ward covering the whole city? The Head of Communities answered that there was not currently coverage for every ward in the city; while the team had grown in accordance with resources provided, 12 of the 21 wards were presently covered, with dispersal reflecting need and demand.

The board asked how they saw their service connecting to prevention and further downstream/specialist services?

The Director of Public Health answered that Local Area Coordinators represented a marked difference in removing the social care burden from primary care practitioners through their work.

He stated that they played a major role in prevention, which provided an invaluable scaffolding for primary care, though he conceded it would be important to challenge that Local Area Coordinators, Social Prescribers and Health Trainers were meeting the most appropriate service users to effect change when looking at the next stage of work around prevention.

The board asked, how do we know Local Area Coordinators were targeting the "right" people with regard to the limited resources available, ie. The people with the greatest capacity to benefit?

The Head of Communities answered that the reasons why people were introduced to the team had always been the same in terms of mental health, loneliness and housing but poverty and the cost of living have especially rocketed over the last three or four years. He stated that they worked with population health management data to build relationships and make referrals to social care/public health. He said they worked with the right people but needed to ensure the right referrals come through, since they are only as good as their referrals.

The board suggested that not everyone who is lonely is receiving or in need of services, and perhaps the loneliness people don't need services or intervention and just require help to connect. The board asked how those people, not on our radar, could be reached?

The Head of Communities answered that the best form of introduction is from people themselves or the community, often as a result of someone having worked with a Local Area Coordinator (or Social Prescriber) previously.

The board asked whether we were using these roles to understand where there are problems a Local Area Coordinator cannot resolve, where another service should be stepping in? How do we prioritise funding the part of the system that will solve the problem rather than holding a service user with someone who cannot help them?

The Local Area Coordinator said that part of the model was to identify problems and draw attention to these problems from appropriate services, feeding things back to bring about improvement.

The Director of Public Health stated that an action point to take away would be the system change behind social isolation, taking into consideration upstream factors including socialisation, isolation and loneliness and additionally considering younger age cohorts.

22. Health Protection Board Annual Assurance Report (5:29pm)

The report was introduced by the Director of Public Health and presented by The Specialist Public Health Practitioner.

The Director of Public Health summarised that this annual report provided assurance that York has a response to such threats as Mpox, measles, whooping cough, and a new influenza variant; he advised that the report detailed York's sexual health services, due to a recent rise in STIs; he advised that the report detailed the reduction to one central air quality plan for York as only one street now exceeded the World Health Organisation recommended amount of pollution; finally he advised that the report covered an uptake in vaccination in York's migrant asylum seeker communities.

The Specialist Public Health Practitioner focused on the discussion of immunisation and health screening; she advised that statistics for men's bowel cancer screening were improving, as were statistics for women's breast cancer screening. She stated that cervical screening figures were less impressive, largely due to the younger age cohort not attending, and as a consequence there had been quite a lot of work around that. She noted that the Abdominal Aorta Aneurysm data looked dreadful in the report, due to significant capacity issues in that programme, but it was in fact getting better. She summarised that generally things were going well with screening and unfortunately some (not always accurate) data let things down.

Regarding immunisation she noted that those particularly susceptible to winter viruses were becoming unwell quickly. She stated that the school aged uptake was well ahead of where we

were last year and the authority was making good progress, particularly in secondary schools. She stated that they had also made progress with MMR catchups, including among home schoolers where there had previously been consent issues. With over 65s flu injections the authority was nearly where they were this time last year when they had started a month earlier. MMR2 is lower than target of 95% but this is possibly due to data cleansing issue - uptake went up by 12% last year without the extra vaccination.

The Director of Public Health added that there had been high levels of Covid in September of this year but this had gone down again in the past week. Flu levels were starting to rise and anticipated to peak in January.

The board asked about oral health in children raised in the report – if there is a 5 year old or 10 year old with oral health concerns, what is the impact regarding this individual going forwards?

The Director of Public Health answered that poor oral health is programmed in at an early age and can be hugely linked to poor cardiac health in later life due to a bacteria that exists in the mouth and can exacerbate symptoms. He stated that this was wrapped up with poverty and disadvantage. Supervised toothbrushing from health visitors or social care can encourage better habits from an early age in vulnerable individuals.

The Chief Executive, York CVS noted recent work from the Travellers Trust and others around vaccine hesitancy, and those not wishing to attend screenings in hard to reach groups, suggesting that social prescribers could be utilised to improve relationships and dispell fears and misunderstandings. She suggested that support like this can be put in to establish the reason for hesitancy and to encourage dialogue.

The Specialist Public Health Practitioner responded saying she would be delighted to work with these groups/volunteers to reach people.

The Manager, Healthwatch York noted a recent report by Healthwatch England which indicated that cervical screenings could be undertaken at home and there was enthusiasm for this among women, which would greatly increase participation if enacted nationally.

The chair asked for clarification whether or not we actually are below 95% for MMR vaccination and whether this was a safe level for herd immunity.

The Specialist Public Health Practitioner answered that the 95% figure was a World Health Organisation statistic. She clarified that there are two MMR vaccines, MMR1 and MMR2, and that within the authority a certain group of people are coded on NHS systems as having received the MMR1 vaccine twice, consequently it is unclear whether this is the literal truth, or whether they are fully vaccinated with both MMR jabs and this is simply a data entry error.

The Director of Public Health note that that this data is from age 5, when the second MMR vaccine is supposed to be administered, so if a second jab is taken after the recommended age they would not be counted in these statistics.

The board asked whether report would benefit from having data that went back further, in terms of establishing whether public health messaging and early help was working. The Director of public Health agreed to take this on board.

Cllr Steels-Walshaw, Chair [The meeting started at 4.36 pm and finished at 6.29 pm].

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Health and Wellbeing Board Report of the Manager, Healthwatch York

22 January 2025

Healthwatch York Report: "Listening to Neurodivergent Families in York" January 2025.

Summary

1. This report is for the attention and action of Board members, sharing a report from Healthwatch York, in partnership with the Land, York Carers Centre, York Disability Rights Forum and Parent Carer Forum York which shares local experiences of families of neurodivergent children and young people.

Background

- 2. Healthwatch York provides information and advice about health and care services, signposts people to support, and listens to their experiences when accessing health and care services. Through our information and signposting service we have recently become more aware of specific challenges being experienced by families of neurodivergent children and young people.
- 3. When we visited the Land to hear more about their plans, we listened to their stories of navigating health and care. Alongside partners York Carers Centre, York Disability Rights Forum and Parent Carer Forum York, we agreed to bring these experiences together. We believe these will be helpful for the work the Public Health team is currently doing completing a Neurodiversity Health Needs Assessment.

Main/Key Issues to be considered

- 4. Our report's key findings are:
 - 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 signs 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.

Consultation

5. In producing this report, we recorded the experiences and concerns of those who contacted our information and advice service, we asked partners to share case studies, and York Disability Rights Forum held a focus group gathering experiences along thematic lines.

Options

6. There are recommendations within this report set out on pages 77-79.

Implications

7. There are no specialist implications from this report.

Financial

There are no financial implications in this report.

Human Resources (HR)

There are no HR implications in this report.

Equalities

There are no equalities implications in this report.

Legal

There are no legal implications in this report.

Crime and Disorder

There are no crime and disorder implications in this report.

Information Technology (IT)

There are no IT implications in this report.

Property

There are no property implications in this report.

Other

There are no other implications in this report.

Risk Management

8. There are no risks associated with this report.

Recommendations

- 9. The Health and Wellbeing Board are asked to:
 - i. Receive Healthwatch York's report,
 - ii. Provide a response to the recommendations to be collated for the July Health and Wellbeing Board,

Reason: To keep up to date with the work of Healthwatch York and be aware of what members of the public are telling us.

Contact Details

Author: Chief Officer Responsible for the report:

Siân Balsom Manager Healthwatch

Healthwatch York 01904 621133

Report Approved **Date** 09.01.2025

Wards Affected: All ✓

For further information please contact the author of the report

Background Papers:

Annex A - https://www.healthwatchyork.co.uk/wp-content/uploads/2025/01/Listening-to-Neurodivergent-Families-in-York-January-2025.pdf



Listening to Neurodivergent Families in York

January 2025

healthwatch

Contents

Content warning: contains reference to mental ill-health, anxiety, distress, violence, suicide and suicidal ideation, struggles with daily living and family breakdown

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Acknowledgements

This report would not have been possible without the support of our partners the Land, York Disability Rights Forum, York Carers Centre and Parent Carer Forum York. We are incredibly grateful to them and the people they support for sharing their experiences with us.

Executive Summary

This report explores the experiences of neurodivergent families in York. Working with partners the Land, York Disability Rights Forum, York Carers Centre and Parent Carer Forum York, it provides an insight into the challenges these families experience.

Our key findings highlight:

- Parent blame is still prevalent in services, and also experienced from friends, family and wider society, as understanding of ND is still limited.
- Experiences are worsened by poor admin and communication.
- Services still work in silos, with families forced to play a key coordinating role.
- Capacity in services is limited; many are looking for reasons to say 'no' to providing help.
- Schools support varies considerably, and school behaviour codes can feel punitive to ND children and young people.
- There is significant overlap between children who are ND and who are gender questioning. Services are not geared up to appropriately support these children and may even ask them to hide part of their identity so they can access support for the other element.

Our recommendations can be found in full on page 77 but in essence we want to see:

- Research into ND friendly school behaviour charters.
- Better administration and communication.
- Training to improve understanding and awareness of ND, PDA, trauma, EBSA, and signs of autistic burnout.
- Improvements to the pathway for ND children who are gender questioning.
- A clear sleep support pathway for York.
- Better support for families, including connections to peer support at the earliest stage.

A message from our Chair

Healthwatch exists to be the voice of local people in our health and care system. We wanted to look at the experiences of neurodivergent families in York for three main reasons:

- Through our work we have become increasingly aware of the many challenges families are experiencing. The bulk of this report is direct quotes from individuals who agreed to share their experiences with us.
- 2. Through conversations with partners it is clear we share concerns about the availability and quality of support for these families.
- 3. City of York Council is currently beginning work to develop a neurodiversity strategy – we wanted to make sure the experiences we have heard are front and centre in shaping the strategy for our city.

This report is in essence a collection of people's stories, sharing their lives, the challenges they have faced, and the things they believe could help make those lives better. We make no apologies for this – indeed, we believe sometimes the only power we have to effect change is the power of our life stories. We hope like us reading this makes you want to be part of that change.

Background

What are autism and ADHD?

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

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

There are an estimated 700,000 autistic adults and children in the UK³.

<u>ADHD</u> is a neurological condition that affects people's concentration, activity levels and impulses. The impact this has on people's lives is significant with symptoms varying for each individual. "Many patients and clinicians describe <u>ADHD</u> as an iceberg, where most symptoms lay hiding under the surface — out of sight but ever present."⁴

The <u>UK NICE guidelines</u>⁵ report the adult <u>ADHD</u> incidence rate as between 3% and 4%. In the UK, a research survey of 10,438 children between the ages of five and 15 years found 3.62% of boys and 0.85% of girls had <u>ADHD</u>⁶. <u>ADHD</u> is not a mental health condition although it often occurs alongside or is mistaken for other conditions.⁷

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

National picture

Long waiting times for diagnosis.

In March 2023, in an opinion piece for the University of Edinburgh Impact bulletin¹, Dr Sinead Rhodes highlighted that many children are now waiting up to three years for an assessment of ADHD, autism or dyspraxia. She highlights that whilst "the Government is acutely aware of the need to help these young people during this time, they remain largely unsupported while on lengthy waiting lists for assessment." She advocates working to understand the strengths and challenges each child has, to upskill them with "a toolkit of strategies they can draw on" and "developing a pre-diagnostic service in the form of a 'self-delivery with support' programme to ensure parents and teachers feel empowered to work with the child and receive support from an expert team."

In October 2024, the Children's Commissioner for England published a report² highlighting concerns about waiting times for assessment and support of neurodevelopmental conditions:

This report sounds the alarm on the largely invisible crisis happening in children and young people's community and mental health services, as well as the wider SEND system. These services have not been resourced to keep pace with the increasing need for assessment and support for children with neurodevelopmental conditions, such as autism and ADHD.

¹ <u>Kids awaiting neurodivergent diagnoses need more help - Edinburgh Impact | The University of Edinburgh</u> 20 March 2023

² <u>Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions | Children's Commissioner for England</u> 15 October 2024

Work is ongoing to improve this situation. For example, in July 2024, NICE recommended a digital technology, the QbTest, to help speed up diagnosis of ADHD in young people aged 6 to 17³. Mark Chapman, director of NICE's HealthTech said:

Children and young people with ADHD deserve to receive a diagnosis in a timely manner. We heard from our patient experts there are challenges with current pathways. We're committed to ensuring we get the best care to people fast while providing value for money to the taxpayer. This

technology has the potential to generate tangible benefits to the lives of those waiting for an ADHD diagnosis. Evidence presented to our committee showed the QbTest could increase the number of children and young people who get a diagnostic decision within six months of starting assessment.

Education challenges.

In October 2023, Dr Emily McDougal of the Anna Freud Centre hosted a webinar about neurodiversity and education. In this, she highlights that the school environment can be challenging for neurodivergent young people. Whilst every child is different, there are some common themes that help understand the adjustments needed to provide a good experience for neurodivergent people. These include sensory processing differences, executive function skills, working memory, inhibitory control and mental health challenges. She urges schools to have a whole school culture of awareness and understanding, and to tailor support in the classroom to the needs of individual students⁴.

³ NICE recommends digital technology to help diagnose ADHD in children and young people | NICE

⁴ <u>Key challenges for neurodivergent students in school settings and how to help - THE</u> EDUCATION HUB

Without this, many young children on the SEN (Special Educational Needs) register are "falling through the cracks". In September 2024, the BBC reported that 22% of the 2,900 children not enrolled in school or being suitably educated elsewhere are children with SEN⁵.

School exclusions are also rising, with 4.1 of 100 pupils being excluded in the Autumn term of the academic year 2023-24. In York this figure was 6 from 100 pupils.⁶

The article also highlights the knock on impact on families, stating that "According to a survey by the charity Support Send Kids, 41% of parents with SEN children say they have had to leave their jobs to spend time pursuing their children's legal rights to support... even those with an EHCP can struggle to find specialist school places and often cannot be provided for in mainstream education.

The Family Fund's September 2023 poll⁷ focused on education, work and wellbeing. Of 360 carers, 57% indicated they were unable to work because of their caring responsibilities, and a further 28% were unable to work as much as they wanted to. From the same number, 54% of parent carers said they provided more than 100 hours of care per week.

Poverty and disabled children

In January 2024, Disability Rights UK shared the results of a DWP progress report. The report identified that nearly half of families with a disabled child are living in poverty⁸. Worryingly, the figures for this

⁵ <u>Hundreds of children with SEN missing from education - analysis - BBC News</u> 10 September 2024

⁶ https://www.yorkpress.co.uk/news/24760283.school-suspensions-york-highest-ever-pupils-violent/ 01 December 2024

⁷ <u>September 2023 Family Poll - Family Fund</u>

⁸ <u>Nearly Half of Families With A Disabled Child Living in Poverty | Disability Rights UK</u> 30 January 2024

calculation were before the rapid rise in the cost of living. In September 2024, Carers UK confirmed that 1.2million carers are living in poverty in the UK, with 400,000 in deep poverty⁹.

Disability Rights UK also shared the <u>Family Fund</u>'s report from a poll of 4,264 families with a disabled child or seriously ill child. This found that nine in 10 families are struggling, or falling behind on their regular household bills and many are forced to forego living essentials such as food, heating, basic furniture like beds, flooring, washing machines and fridges, to try to make ends meet. Over half of parents and carers (54%) report skipping or cutting the size of their meals because there wasn't enough money for food and more than one in ten (13%) say they've had to cut back on essential items for their disabled children.

The local picture

Waiting times

Waiting times locally are lengthy. In October 2024 across Humber and North Yorkshire there were 9,849 people, adults and children, waiting for an autism or ADHD assessment, of which almost 4,000 are children waiting for an autism assessment. In December 2024, York Press reported that 6,270 people were waiting for an autism assessment¹⁰.

Diagnosis

Before the age of five, when referred by a GP or speech and language therapist, children may receive a diagnosis of autism through the Child Development Centre at York Hospital. This will take up to one year. For children five and over, Tees Esk and Wear Valleys NHS Trust (TEWV) is commissioned to provide the Child and Adolescent Mental Health Service (CAMHS) for York. This includes diagnosis of ADHD, autism and other types of neurodiversity for children aged five and above. There is currently a

⁹ Poverty and financial hardship of unpaid carers in the UK September 2024

¹⁰ More patients in North Yorks and Humber waiting for autism diagnosis | York Press 12 December 2024

significant wait for assessment. People can refer their child for assessment, or be referred by a GP or a child's school.

For self-referral, there will be a 30 minute call with the Single Point of Access (SPA) to discuss the referral. If they agree further assessment is needed, they will send out a questionnaire to families or carers and school. This is usually posted, but you can request this electronically if you prefer. The questionnaire must be completed in full, by school, by parents or carers, and with responses from the young person themselves. Once completed and returned, the form is reviewed by the team and a decision will be made on whether to assess. TEWV posts a letter informing people of the outcome. Where they agree to assess, the child will be added to the list. Recently, TEWV has begun inviting children in for a QbTest between reviewing forms and deciding whether to add children to the waiting list.

On diagnosis, families receive feedback and a post-diagnostic pack. For autism, there is no post-diagnostic support from TEWV¹¹. For ADHD, families will also be offered two online sessions, and a further session with school staff supporting the young person. They may also offer post-diagnostic support with medication, though this involves a further wait¹².

In this area, for ADHD assessment TEWV is still using the International Classification of Disease ICD-10 criteria. This does not formally recognise ADHD, but relies on assessing Hyperkinetic Disorder, or HKD. As a result only combined ADHD will be diagnosed. TEWV confirms they are in the early stages of moving to ICD-11.

The Right to Choose and Shared Care

In England, patients have a legal Right to Choose who provides their healthcare. When GPs make a referral for autism or ADHD assessment, they should offer the option to choose a service to be referred to. This service must provide NHS services in England.

[&]quot; https://www.yorksend.org/support-need/diagnosis-pathway#fivetoeighteen

¹² https://www.yorksend.org/supporting-childs-needs/adhd-diagnosis-pathway

However, in York, some GP practices will not enter into shared care agreements with anyone who receives their diagnosis for ADHD through this route. They will only enter into shared care agreements with the Retreat for adults, and with Orca House (CAMHS) for children and young people. This means those people who are given a prescription for ADHD medications through a Right to Choose provider or private provider will need to access a medication review through York's commissioned NHS services. There is currently a significant waiting list for medication reviews.

What we did to find out more

Through our own issues log¹³, we were already aware of a number of challenges facing neurodivergent families. We also heard many stories about family challenges when looking at the adult pilot ADHD assessment pathway.

In meetings with local partner organisations, we heard many more stories of people who were struggling. We agreed as a partnership to bring together these voices. We hope this will be useful for shaping the City of York Neurodiversity Strategy as this work begins.

All names have been changed.

¹³ See Appendix 5 for recent issues raised with us.

Stories from the Land

Personal stories: Lizzie

School was never a good fit for Lizzie. There was so much going on it was overwhelming for her, she would get through the day but have massive meltdowns after I picked her up. Having to sit still so much was a torture, she naturally needed to move her body but this wasn't allowed. The way things were taught was not the way Lizzie learnt, she felt stupid, she knew she was "behind".

She was eight years old and she felt like a failure. In a few years she had gone from being bubbly, curious, confident and engaged with life to a shell of herself. Lizzie was often poorly, tired and had a low mood.

One day Lizzie had a bit of a cold and asked to stay off school. I said she couldn't stay off just because she had a bit of a cold. She said to me "it takes everything I have got to get through the day, I just can't do it if I'm not feeling 100%".

This was like being punched in the guts. I just thought what are we doing? Is this what my daughter's childhood is going to be? What is this doing to her physical and mental health?

Lizzie never went back to school after that. It took years for her to recover, she wouldn't engage in anything that looked too much like school for a long time. We took time to figure out what she needed for her wellbeing and to learn. I had suspected she was dyslexic but the school would not engage with the idea. We had her tested and she was, so we could start a literacy program designed especially for children with dyslexia. Lizzie is also awaiting an autism assessment.

We figured out she learnt by doing, by going and seeing and experiencing things. We adapted life so she has the recovery time she

needs, she can engage in her passions (mainly horse riding) and she felt a sense of control over her life.

Lizzie is now 16, she still has her struggles and things need to be done in the right way for them to work for her, but she is thriving. She has become an expert in her area of special interest – horses. She spends most of her time caring for, riding and competing, which makes her so happy. She has completed her Prince's Trust qualification, plays in a netball team, has done her bronze Duke of Edinburgh award, sat her maths and English GCSEs, has a part time job in a café and has a place at college for September to study equine care.

She always had the potential to do well in life but we had to create the right conditions for her to flourish. We were made to feel like taking her out of school would limit her chances but I firmly believe it has done the opposite.

Due to my work giving me an insight into the system, we decided not to try and get help and support through the school system. I have seen how bad things have to get before any support is given, how damaging it is to leave a child in a situation until they are at breaking point. How many inappropriate resolutions have to be tried before proper, appropriate alternatives are provided and just how hard parents have to battle to get anywhere within the system.

There seems to be a massive problem for teenage girls at the moment. They get through for most of their childhoods masking and finding ways to cope and if they are not being disruptive it is so easy for them to go under the radar in a school. Then 14 hits and everything unravels. Just in our local area in the last year I have met two girls with anorexia – one of whom is currently hospitalized as things have got so bad. One girl who has selective mutism and is so anxious when she leaves the house she can't speak. Another girl who just broke down and couldn't hold it together any longer. All these girls were in

mainstream education until they hit breaking point. All are out of school now with really complex mental health needs. It really scares me to think where Lizzie would be now if we had not removed her from the system – I just wish I had done it sooner but it is very difficult to do something that is so countercultural.

Personal stories: Jim

Jim found starting secondary school incredibly difficult. After just a couple of weeks we were struggling to get him into the building. We tried every approach: bribery, gentle (and not so gentle) encouragement, consequences, trying to get Jim to make 'small steps'. We would sit in the car park for hours, trying to get Jim to put one foot on the tarmac before he could go home. He retreated under a blanket in the car, refusing to talk to us. In October 2022 we made a short visit to the Railway Museum to celebrate my birthday. This was the last time Jim made a trip outside. School stopped, family days out stopped, trips to the supermarket or park stopped. From that moment on life changed for Jim, and none of us knew how to react. It seemed to come out of nowhere, it was extreme and it was very scary.

At the height of burnout Jim stopped eating, reduced any contact with us, could not remember how to form letters when writing and could not tolerate visitors to the house. This had a huge impact on family life (he has an older sister) and was very damaging to immediate and extended family relationships. Jim's physical health deteriorated as well as his mental health. Jim expressed feelings of hopelessness and low mood. It was a very scary, lonely time and we felt as though we were the only family experiencing these things.

I have had to give up work so that I can be with Jim during the day. We can now, very occasionally, take a very short walk round the block at night time - he wraps himself in a blanket so that nobody can see him.

We are slowly beginning to reset, but it has been (and continues to be) a very scary, overwhelming and isolating experience. Everything has changed in our lives, and we are still trying to establish a new path for Jim.



Personal stories: Edward

My name is Edward and I am nine years old. I am autistic with a PDA (Pathological Demand Avoidance) profile and have a diagnosis of generalised anxiety disorder, OCD, a tic disorder and PTSD.

I was a high masker in primary school and academically high achieving but had significant unmet needs. This led to autistic burnout and PTSD at the start of year 3 – I became too unwell to go to school. I stopped eating at school and became distressed every evening worrying about school. I struggled with sitting on the toilet on and off for several hours due to anxiety which meant I wasn't getting enough sleep.

I tried to ask for simple accommodations from my teachers to be told my suggestions weren't possible. My parents were told school would not support an application for an Education, Health and Care Plan (EHCP) and that we had to try different stages of support first but these accommodations were sadly too little too late.

The chronic masking had a catastrophic impact on my mental health leading to a complete loss of skills and being unable to function and complete basic tasks. I lost control of bodily functions and could not bring a cup of water to my mouth to drink without help when I was

previously fully independent. I could also not leave the house for over a year and still struggle to talk about school even though I have been out of education for 19 months.

I am slowly recovering from burnout and am the happiest I have been in a long time due to a combination of factors which include: being in a safe low demand environment at home which doesn't trigger my sensitive nervous system, having my needs met and receiving coregulation and connection from trusted adults around me and importantly not needing to mask anymore. I was also prescribed antidepressants to help with my severe anxiety.

I have just been awarded EOTAS (Education Other Than At School) after 19 months of being out of education. This will enable my health and educational needs to be met in an appropriate way. My parents had to work extremely hard to get this and were told 'no' several times before it was finally approved.

I often need to spend time under my blankets or duvet if I become overwhelmed or feel tired. Spending time engaging in special interests and having my sensory needs met helps me to self-regulate and calm down my nervous system which is easily triggered due to my PDA profile.

Personal stories: Oscar

Oscar went through primary school coping well. He excelled at learning, sport, art, had a lovely group of friends and was a happy, outdoorsy boy. From a young age we saw some small sensory differences and adapted our parenting to meet his needs successfully. His teachers in primary were aware of his tendency to take time to settle in, need for genuine connection, were open to listening and collaborating. He always shone in the summer term. People often commented on what a happy, smiley boy Oscar was.

On transition to secondary school, despite a thorough handover from his year 6 teacher, regarding his anxieties and how his friendships provided huge reassurance and connection, Oscar was placed in a form with no friends. Three of his friends were placed in a form together. Oscar was sick twice on an additional transition day where they had a 'fun' BBQ and he wasn't able to eat anything and unable to speak. We spoke to the SENCO to express our concerns and request settling in support. She told us their way of working was to assess everyone in the first couple of weeks.

Oscar started secondary school – he was sick several times every morning for two weeks. We contacted his form tutor, house pastoral worker and Special Educational Needs Coordinator (SENCO) and were told we needed to practice 'tough love', he needed to develop resilience and we should 'just get him in whatever that takes'. On one occasion two pastoral workers attended our house to take Oscar to school. They sat in the front, didn't speak to him and took him straight to his lesson on arrival. Oscar was told we could be fined in court if he didn't go.

Over the next few months, Oscar's mental health deteriorated and he lost a lot of his daily functioning skills – he became unable to dress himself, his self-care deteriorated significantly, he became very angry, emotional, aggressive, destructive and was petrified of getting bad comments or detentions. He told us how staff at school did not care about him as a person, were only interested in results and how his pastoral worker called him the wrong name when he saw him. We were told Oscar was fine in school and the problem was perhaps elsewhere, that it was a behavior issue and suggested behavioural strategies (which made things much worse.)

We referred Oscar to CAMHS and he was put on the anxiety pathway (no one in school recognised this presentation as autism). He struggled to attend the cognitive behavioural therapy (CBT) sessions

at CAMHS until I suggested having the sessions outdoors. Then he struggled with the concepts being used. CBT is not recommended for autistics unless adapted by skilled professionals. Oscar completed the session in the summer holiday (when he was feeling brighter, less anxious).

Year 8 saw rapid deterioration in Oscar's health and presentation. He masked up for school and exploded when he came through the door at home. It wasn't until spring, when the early help team got involved and deemed school was the cause of Oscar's distress and burnout, the GP signed Oscar off as too anxious to attend school. He stopped playing football, seeing his friends, going out, smiling and laughing. With information gained online and from the early help team, we made a self-referral for an autism assessment.

Year 9 and we have one-to-one teaching at home, three hours per week with the wonderful Sue. They quickly connected, created safety and trust. Bingo, Oscar was flourishing. He started to see his friends again, playing football, cycling and camping. Smiling. Laughing.

End of year 9 and into year 10. Oscar transitioned to Alternative Provision (AP). The head teacher visited us at home and decided one-to-one provision would best meet his needs for his two GCSE years. Oscar steadily increased his attendance and was enjoying his lessons. He developed great relationships with his teachers and was happy. He was enjoying his learning and excelling again.

After a three year wait, in summer 2020, Oscar was diagnosed autistic by CAMHS and immediately discharged.

Year 11: We were told that AP was changing and they no longer offered one-to-one, that he would be in a group with other autistic boys who he didn't know, start earlier in the day, have much shorter lessons, be in an unfamiliar room and with lots of new teachers. We raised our

concerns and were told by the autism specialist and the SENCO that Oscar needed to start functioning in a group as 'one-to-one isn't how the real world works'. We placed our trust in the SENCO and autism specialist, they had worked with many children like Oscar. We were told otherwise the likelihood was that he'd become a boy who never came out of his bedroom. Oscar said he'd been lied to by the AP and they weren't really thinking about him in doing this. He started going to some group lessons. Once again, he really tried. Rapidly, he began to struggle. He'd intend to go, get dressed, then just completely shut down. His eyes would roll into the back of his head and he'd be unresponsive – he was dissociating. From this there was a very rapid decline in Oscar's mental health. He was hurtling into a second burnout.

The next two years for Oscar, age 16, were like this:

- Huge meltdowns, aggressive, destructive, ear-splittingly loud, significant distress.
- Self-harm punching himself in the head and face hard.
 Smashing his head, hard, into walls.
- Screaming out in mental pain, begging us to kill him as he felt he was ruining all our lives.
- Huge shame.
- Sitting in his bedroom, curtains permanently closed.
- Not able to see anyone other than us.
- Devastating loss of skills.
- Started bed wetting (after many years dry).
- Stress induced shingles.
- Unable to touch most things.
- Trusting no one.
- Major toileting issues. Routinely spending seven hours to empty bowels, once 20 hours. Screaming at the distress of not knowing if he's finished / was clean.
- Unable to wear clothes.

We referred back to CAMHS and he was put on the psychiatrist waiting list. A year later, after many calls to the crisis line and police being called out by a neighbour as they thought someone was ending their life, Oscar saw a psychiatrist and a few months later started to access medication for anxiety.

He was later diagnosed with OCD and the Community Mental Health Team (CMHT) Occupational Therapist (OT) has recently explained to Oscar that he has memory loss regarding some of his life because of the trauma and that his brain has been in such a heightened state of anxiety for so long that it now perceives most things as a threat to his safety.

Oscar hasn't left the house since November 2021. He hasn't been able to wear clothes for over a year and a half.

We recently found out that Adult Social Care had closed his case without informing us.

The adult CMHT are using a trauma informed approach and collaborating with Oscar and us. Oscar has complete agency and we are all using a neurodivergent-friendly, trauma informed approach. This is what works for Oscar.

A few weeks ago Oscar dislocated his knee, was in agony and collapsed on the floor. Most people go to A&E for x-rays and treatment for this type of injury. Oscar's anxiety, trauma and OCD are so pronounced that he couldn't access a hospital so we had to wait for six hours for a doctor to ring to advise us how to assess and treat it as best we could ourselves.

The long term impact of early unmet need is devastating, impacting quality of life, mental health, physical health, self-esteem, employability, independence and Oscar's future. A tsunami of trauma has ripped through our family caused by Oscar's unmet needs.

Personal stories: Liam

My son Liam is 12. He struggled with school from the outset.

After year 1 in a mainstream primary school we realised he wasn't coping and his self-esteem was very low. Around that time we learned about {name of independent school} and decided to relocate to York in order to make it possible for Liam to attend {name of independent school.} Despite the nurturing environment and the accommodating teachers he struggled to adjust. He was withdrawn and quiet in the first year and then started being disruptive in class with loud aggressive outbursts. After reaching crisis point both at home and at school, and due to long CAMHS waiting lists, we pursued private assessments and he was diagnosed with dyslexia and autism (PDA) in 2021 and 2022 respectively. He also has sensory processing difficulties and extreme anxiety.

Over the last two academic years, it became clear that Liam requires significantly more one-to-one support to help him attend school and engage in any learning opportunities. Liam is currently struggling to access a full week of school (he has been on a reduced timetable since September 2023) due to strong emotional regulation challenges, impacted by sensory reactivity, and social engagement and learning difficulties. He attends {name of independent school} for some one-to-one tuition (two hours), social interaction in break times three days per week and {name of AP} one day per week, which we are currently funding ourselves. This is difficult considering my ability to work is severely impaired by our son's support needs and limited school attendance.

We got Liam's first EHCP in May 2024 after going through mediation at the need to assess stage. It provides insufficient funding for the level of support needs stated in it. The fact that we choose to proactively search out better options for our son {name of independent school}, now means that we get ignored by the Local Authority and our son is falling through the gaps in the system.

The EHCP funded a course of OT treatment for Liam but we have been refused further funding for the further therapy recommended.

Our home life is often made very difficult by our son's violent outbursts and damaged property. We also have a 16 year old daughter who was diagnosed with ADHD last year.

Liam struggles with getting sleep when anxious and his usual bedtime is well past midnight. This is disruptive for the whole family and has severely impacted on my health as his mum and main carer. He was prescribed melatonin by our GP but is refusing to take it.

I have reached out to CAMHS and to the Multi-Agency Safeguarding Hub (MASH) team without any response or offer for support.



Personal stories: Rose

I'm Sarah. My partner and I live together in York with our two children; Rose aged 13, year 9 of Secondary School, diagnosed with ADHD and Autism Spectrum Condition (ASC) with PDA traits and James aged nine, diagnosed with DCD (more commonly or previously known as dyspraxia) at primary school. When the paediatrician gave James' diagnosis, she also mentioned ADHD due to the way he presented at the appointment and how DCD and ADHD can be linked. This filled me with dread, knowing how long the waiting lists are for CAMHS assessments and knowing how totally exhausted I already am.

My partner and I are both self-employed. I made the decision to become self-employed when Rose began struggling to get into school in year 7. It had been a tricky couple of years previous with school/education due to COVID, and the transition into high school was non-existent for her. Rose is approaching year 10 now. My longer term goal was/is to complete a psychology degree with the Open University and to go into this field when the children have finished school.

James does very well, both academically and socially, at school. The head teacher is very nurturing and is always trying to make the days fun, exciting and a happy place for the children to learn and attend. Although James has DCD I haven't felt the need to engage with the SENCO as he is thriving – it's been enough to have a quick chat with his teacher if I have any concerns. However, James is going into year 5 in September and I already feel anxious about him moving up to high school in 2026.

Rose hasn't been able to attend Secondary School since November 2023. She has Emotion Based Schools Avoidance (EBSA) and is now too anxious to do anything apart from see her one friend, May (at another secondary school) who also has ASC and is primarily out of school. Rose

spends the majority of her time at home alone in her bedroom. We as her family struggle to connect with her.

The constant worry I feel is unbearable. I find myself questioning, daily, what will become of her? How did we get to this point? I worry about the impact this may have on James, and I worry that he too will become a school avoider if his future needs aren't met.

When she was in year 7 Rose begged me daily to home educate her. Some mornings I'd sit for over an hour in the car park at school trying to reassure her and relieve her anxieties. Despite her struggles I believed school was the best place for her. Every obstacle she faced could be used as a learning curve and eventually she'd settle and be able to be happy and thrive. I've always kept the lines of communication open with school and tried to work with them, and I am always very honest about Rose's struggles and the help she needs. But too often, offers come when it's too late.

If I could go back I would heed her pleas and make home education work, because now our life, her life, feels on hold. Home education isn't an option as Rose does not engage with me like she once did. I need to be her Mum, not her teacher. I couldn't possibly embark on a degree when my own child isn't receiving an education. The constant fight to secure some kind of future for Rose, while trying to run a business and home, as well as ensuring the children's wellbeing, means I just wouldn't have the headspace.

Rose doesn't always communicate in a socially acceptable way – she says inappropriate things before she's processed the consequences or possible repercussions. I have always made this clear to everyone involved in her life; we as a family have learnt to take things with a pinch of salt. We have had many incidents over the years that have caused disruption to her own and other children's learning because of her actions. I'm sad to say Rose is the child other parents tell their

children to stay away from. I've had many dealings with other parents because of things Rose has said or done. I've had to become quite thick skinned. If you haven't lived with a neurodivergent person it may be difficult to accept some actions. Some people have no idea or simply aren't interested as long as they and their family are OK. I understand this but the effects on my family remain.

After an incident on social media between Rose and some other children in November 2023, an angry parent sent me messages and we had a visit from the police. School changed Rose's timetable to put things right for another child and their family. The change was made without discussion with ourselves, without Rose's side of the story and without a plan in place to help Rose cope with such big changes to her school day.

Prior to this Rose had completed 10 consecutive days in school. This was a massive achievement. We hoped we were at a turning point. But the timetable change was the final straw for Rose – she doesn't cope well with change. Over the next few weeks I worked closely with school to try and get Rose to return, and engage with her new timetable. I worried for her wellbeing not having the social interactions with her teachers and peers. I feared she would fall further behind with her education as her attendance had been sparse since returning in September 2023.

We sanctioned at home, withdrew electronics and internet usage. At every conversion we reinforced the importance of being at school, that it was an expectation, not a choice. We were in the mindset that she won't rather than can't go. School agreed reduced timetables and offered Rose the use of the inclusion rooms etc. Rose refused to engage – she would only go back if she was given her original timetable. After weeks of disruptions in our home, I asked the school to revert Rose's timetable but was told this wasn't possible.

Within days I came home from work to find Rose drunk. She was completely dysregulated, had been cutting her arms and wrists and was saying she didn't want to be alive. I called my mum for support and called the CAMHS crisis line. I didn't get through, nobody answered. I waited and waited, but nobody picked up the phone. Rose settled eventually and I called the NHS 111 crisis line for advice and reassurance. They were a great help. The wounds were superficial but the intent was there.

Now at my wits end, I contacted MASH. They allocated us a family support worker who has a great understanding of our situation. I also reached out to other parents within the community. I learnt about Alternative Provision (AP) for children struggling in school. The general advice was to contact SENDIASS (an organisation that provides support for children and young people with special educational needs and disabilities), who have been amazing. The care and attention I have received has been second to none. I then arranged to meet with the school SENCO. I informed her of the developments in Rose's mental state and I asked about AP for Rose. She seemed visibly shocked. She said the budget was nearly taken up but agreed to look into it, as it was something that had been bouncing around in her head. We also discussed how reverting to Rose's original timetable wasn't possible as too much time had passed and the head of house had said that wasn't possible.

That evening I got a call from Rose's head of house offering her original timetable back, because we were going round in circles. This after nine weeks of Rose not attending school, of emotional turmoil for our family, and only after I mentioned AP. It came too late. Rose was in total burnout, refusing to engage in any talk of school, not even washing or looking after her own personal hygiene at this time.

Over the next few weeks, we took the pressure off Rose to attend school to concentrate on her wellbeing. We had a Team Around the Family

(TAF) meeting at school. A member of the specialist teaching team attended along with the family support worker, the SENDIASS worker, the deputy head, the SENCO and Rose's head of house. I was thrilled to be all working together to make a plan to help Rose move forward. There were discussions of a salon skills course, {names of two AP providers} and mentions of budgets due to Rose being unwilling or unable to engage. I had previously asked about an EHCP for Rose which she wouldn't have met the threshold for. I asked again and this time the school agreed.

In January 2024 we filled in the forms and I provided a letter/statement to request statutory assessment. In March the Local Authority (LA) refused to assess Rose on the grounds that the evidence provided showed Rose's lack of attendance was due to "ongoing friendship issues"... ugh, if only it was that simple!

I arranged a going forward meeting with a caseworker from LA, the SENCO, the family support worker and the SENDIASS worker. I spoke with CAMHS to keep them informed about Rose's situation and obtained letters from them prior to the meeting. The consultant psychiatrist's letter stated that Rose is highly functionally impaired by her autism. She also stated: 'We haven't identified a treatable condition right now but I would emphasise that the autism appears to be impacting on her engagement with mainstream education'.

I was told in the going forward meeting that the assessment threshold is low but more evidence was needed to take Rose's case back to the panel. I felt desperate. Every day Rose was getting more and more content with not attending school and thus receiving no education. Her sleep was sporadic, she had unhealthy eating habits and no fresh air or exercise. The whole situation is a mum's worst nightmare. I needed to prove that Rose needed the assessment to try to secure a future for her. But I didn't know what her barriers to learning were, I still don't. If I ask

"what is it you don't like about school?" the answers are always "I don't like it, it makes me sad".

I looked through all her old school reports and any feedback ever received from teachers and staff. I considered a private OT sensory assessment to gain insight that might be helpful in securing the assessment and making Rose's life easier. The cost of this was way out of our budget and so I contacted the GP who referred on. But Rose was subsequently rejected by the triage team as it didn't appear that specialist input from OT was indicated at this time.

I mentioned to the caseworker at LA about section 19 of the Education Act at least three times – they haven't offered anything. I have now written a formal request to the Assistant Director of Education, Skills and SEND at City of York Council and await her response. I have arranged visits to {names of two AP providers} as school agreed to fund "limited time" AP to gather evidence, but Rose was unable to get out of the car to speak with staff and look around.

I asked if the LA would overturn their decision to be told a whole lot more work needed to be done on the paperwork. At which I listed what had already been provided as I felt they didn't know. I had no choice but to take the LA to mediation. I spoke with the mediators, reached out to the people I wanted to attend but the LA didn't commit to mediation within the time frame, despite the mediators chasing them up.

I moved on to tribunal. If I hadn't been on the ball we would have lost the right to appeal. I started on the tribunal paperwork and then I received a call from the LA to say the decision not to assess had been overturned. It was the letter from CAMHS that swayed it. The letter that had been presented weeks previously at the going forward meeting. So finally, a positive... yay! BUT ... there's no educational psychologist available and there is a long waiting list...

... in the meantime, I heard from May's mum that her school paid for May to attend a salon skills course, every Tuesday for the next two years. As May is the main person Rose will engage with, I thought it could be a hook to get Rose back into education. High school had already mentioned salon skills so I asked the question, "would it be possible to get Rose there on a Tuesday so she had the support and safety of a familiar face?"

After chasing this, a taster session was arranged for Rose. School and myself also put in an application to the home tuition team, so I felt hopeful Rose would be able to attend, get a qualification in salon skills and with home tuition and with the possibility of an EHCP, finish school in 2026 in good stead for further education or whatever she decides to pursue. I dared to think I could enrol with the Open University, James is happy and settled for now and things are finally turning around for Rose!

On 18 June, I took Rose to visit the course site. I spoke with the salon tutor the day before to have as much information as possible to tell Rose. The session was set up to start at 10am. We arrived late (10.30am) after quite a stressful morning with Rose saying she didn't want to go, she felt sick, she couldn't do it. I phoned ahead to apologise and spoke to the head who informed me that the high school SENCO was already there. Upon arrival, Rose, the SENCO, the head and myself had a meeting to discuss the offer. The Head explained to Rose the qualifications she could achieve and how they anticipated the course to be full in September. We booked in a further three taster sessions and discussed a start date for September. We looked around the salon, spoke to the tutor and saw May doing some work. Rose was asked if she'd like to stay and she agreed. But then I was called to collect her and sensed it hadn't gone well.

{Summary of email correspondence between family and school - confirmed tutor raised concerns about possible bullying, bodyshaming, inappropriate conversation, spending a long time in the toilets and

vaping on site; family responded highlighting extreme anxiety, providing considerable context regarding the nature of friendship between their daughter and the other person present, their shared interest in a TV programme related to the inappropriate conversation, thanking them for the opportunity, but expressing concern she was being written off too quickly.}

I received no reply to my email and started to try to move on from the salon skills offer, feeling totally miffed at this specialist provision and school for not giving Rose another chance and was left wondering who made that decision. And what else we could try?

The following week I emailed the SENCO chasing the LA decision about the home tuition team. She acknowledged receipt but couldn't give me a time frame. I contacted the LA caseworker to chase up the EHCP assessment and reiterate that Rose has had no education in eight months. I was told I need to work with school. An EHCP (if achieved) will only work with a really good reintegration plan. The likelihood of Rose being able to engage with any mainstream setting at this time or in the future is getting slimmer by the day. I asked school what the plan was for Rose if the home tuition team don't accept her and mentioned that Rose may well be in year 11 by the time an EHCP is awarded and finalised (if at all). No reply. I emailed a week later to ask the same questions, but still no firm answers. At which point it was pointed out to me the offers that Rose has been unable to engage with.

In July I received a call from our family support worker, someone who has understood our family and my struggles and has offered help and advice. Unfortunately because Rose has been unable to engage with her, there is no role and therefore she has to sign our family off. Another door shut!

She attended a final TAF meeting at the high school along with the SENCO, the high school head and myself. I was told by the head she had

made the decision to withdraw the salon skills offer. It was put that it was thought it wasn't the best place for Rose but upon reflection, Rose may still be able to attend in September! It's too late! Rose had been rejected and the task of her returning would be mammoth and too much for us all.

Previous to the meeting, I asked about other APs for the year 10 timetable with an option for Rose to change if/when she felt able to pick her options and a reintegration plan so that she has the visuals, time to process and the autonomy she desperately needs. I came away with an options booklet and a serious lack of trust in the school. Upset that there was no discussion again before making the decision to withdraw the salon skills offer. I was told in the meeting that they need Rose's voice, to hear what she needs but actually they haven't heard Rose's voice when it needed to be heard and this is so upsetting.

I was also told that in September the SENCO is moving to another school. This means starting again with a new SENCO who doesn't know our story.

Throughout, I've heard lots about funds and budgets. I'm starting to realise it really is all about who pays. Our lives hang in the balance because nobody wants to foot the bill.

My children are neurodivergent. I've spent quite a lot of time learning about their difficulties. As their mum, their happiness is my happiness. I question how dedicated some people are to actually helping children with SEN. Because the absolute bottom line for me is: seek to understand rather than be understood.

This isn't always the case where SEN children are involved and it needs to be. Rose isn't fitting into any box at the moment and we need to round the edges. I need a change, I need to move on and have this sorted for my children, my family and myself. Rose is going into year 10

in September, and into her GCSE years. She's yet to pick her options, the only AP she would engage with was removed after a very short trial, the EHCP assessment is no further on due to educational psychologist availability. She's 13 years old and at present she has no routine and no future to focus on.

We are just one family in York going through this hell. There seems no end in sight. It's exhausting. I'm sure there are many more families like ours. I'm hopeful if you gain enough insight and feedback that change can be made. I don't know what or how. I don't have the answer for my family at the moment. But I know there are more battles to come. I'm filled with dread to think of the future. Whatever it is that Rose needs will not be handed over easily. Even if it leads her in a positive direction, we may not receive the desired outcome. But as a mother, I'll keep fighting. I have no choice because what is the alternative?

More funding, shorter waiting times and proper hands on staff training for all teachers and staff of SEN children is needed so that our children don't become ghosts. They must receive the help and intervention they need in good time so they don't end up costing the country more in the future as adults. Adults that are out of work, struggling with mental ill health and/or addiction or worse, adults that become part of the prison population.

Personal stories: Mika and his transition to adult services

Mika didn't have an active EHCP at the time of his transition to adult services. In fact he had no provision due to an acute mental health crisis and autistic burnout caused by cumulative unmet needs. We received notification from the SEND team of their intention to cease his plan. And then, before right to reply time expired, a legal cessation letter arrived to say the EHCP had ceased. It was reinstated after we contacted the SEND team and they

consulted their managers. But all this caused extra admin, stress and anxiety for us as parents.

CAMHS/CMHT - we informed the CAMHS psychiatrist when Mika reached 18 and requested a thorough transition to adult CMHT. No one from CAMHS seemed to have considered his age/transition prior to this. A planned and thorough transition needs to be the norm, especially for autistic young people. Mika was placed on the Dynamic Support Register as he was deemed at high risk of hospitalisation. This triggered assessments from CMHT and Adult Social Care. CMHT assigned him a community psychiatric nurse (CPN) who assessed Mika and quickly built trust and safety and quickly led to psychiatrist and specialist OT assessments. Mika was diagnosed with OCD and a treatment plan was agreed. He has had regular, fortnightly appointments, at home, with the specialist OT and the shoots of recovery are evident. It has been an excellent service.

Adult Social Care – during the assessment we were told by his social worker that we would be given advice and support regarding Mika's finances. But we were given none. We were told to contact them again when Mika was able to engage. So we did, to be informed his case had been closed. Neither Mika nor ourselves had ever been informed of this. This was appalling communication and caused stress, anxiety and extra work for disabled young people and their families.

Mika is rarely able to wear clothes or leave the house. His anxiety is high in public spaces which makes them inaccessible to him. There appears to be no offer for these young people.

Whilst we appreciate what York Inspirational Kids and York Ausome Kids provide, for us there is no offer which meets our son's needs.

Personal stories: Felix and his transition to adult services

We had meeting with a new in role social worker and Preparing for Adulthood Coordinator. At the meeting we were told everything for Felix would stay the same as this was working successfully giving plenty of flexibility. We discussed what Felix would like for the future and he had suggested to us speech therapy. We also suggested a cognitive assessment done in a way that would work for Felix. This was all noted and the appropriate paperwork completed for this to move forward.

A few weeks later someone from the Community Learning Disability Team contacted me regarding speech and cognitive assessment. She was really good and left me feeling really positive and like she cared about Felix's situation around communication.

A week later we found the Community Learning Disability Team had denied speech therapy despite Felix having verbal dyspraxia and having significant social issues around talking. Nothing was mentioned regarding the cognitive assessment.

Many meetings have had to be held by Felix's social worker and us to get this decision changed taking over five months and costing services more money and time. Felix is now on a waiting list with a team that only work with individuals until they turn 19. Felix is 19 in July next year and we are highly aware the waiting list means he will probably just be transferred to another waiting list by the time he turns 19. We have heard nothing regarding adult service cognitive assessment.

We had long meeting - three hours - with adult, child social worker and an NHS nurse in our home just to decide who and where the money was going to come from for Felix's social care support. This was gruelling and we were told these meetings can go on a lot longer. The energy needed to go through a meeting like this is massive and you are

looking at your child from a negative angle for hours and all their struggles etc.

We were also then asked to sign forms for Felix's budget to be paid via Salvere which we had tried years ago but their communication was poor and the flexibility was not appropriate for Felix's type of disability. We had to ring the preparing for adulthood coordinator to reassure us this would stay the same as had been agreed in first meetings, as the new social worker was unsure.

We were also completely unaware that Felix had to go through a full and intrusive financial evaluation - nobody had told us about this or the process. We rang York Carers for some back up and they supported and reassured us through this.



Personal stories: Charlie and her transition to adult services

Charlie, our eldest daughter, has autism, ADHD, OCD and anxiety. When we transitioned from children's health and social care to adults we were allocated a social worker who told us she was from the wrong team to deal with my daughter's team. Her team was people who can't dress and feed themselves. We were told this social worker would work on our daughter's plan and "hold" the case until she could be passed onto the appropriate team.

At the same time our daughter was discharged from CAMHS whilst suffering from suicidal ideation. We were told she did not need adult mental health services and that social care would take over things.

Her education placement fell apart at a similar time, leaving us with no education, mental health care or social care.

Social care were unable to tell us what they could offer but we were told they were working on a plan.

After a period of time with no education, my daughter got a place at an alternative provision (AP). This was a lengthy process as the first time it went to panel, they had an EHCP for her which was two years out of date. It had been reviewed but there was no record of that. My daughter's EHPC was urgently reviewed by the Local Authority.

Her social worker attended virtually. She was supportive of the change of education provision but said she was unable to put a social care plan together until education was sorted out. Around February this year my daughter began to struggle mentally and was referred to adult mental health. This was mainly around the fact that she did not know what she was going to do when her time at her education provision ended.

At her EHCP review, her education provision told us that she wouldn't leave without a plan, and that their specialist careers advisor would help. We were told that Charlie need to concentrate on getting through her qualification first, and that help would come for the next steps after that.

Charlie was subsequently discharged from social care, with no plan ever put in place. We were told that this was due to the fact that we hadn't commissioned any services from social care.

Very little help was given from Charlie's education provision about her next steps. Their careers advisor had been off sick until towards the end of the summer term. They contacted United Response about their supported employment scheme but did not hear back. They also contacted the Railway Museum to look into volunteering opportunities for our daughter, but none were available. I was told to contact Scope and given the link to the national careers service website. Scope could

only offer a couple of Zoom appointments as they're based in Leeds. If we lived in Leeds, they could have offered a lot more support.

During the final half term of the summer, I repeatedly left emails and voicemails with the specialist careers advisor service at the transition zone, as this is where a Google search had led me. By this point our daughter was regularly self harming due to the distress of not having a plan. I stated this in my messages but nobody ever got back to me. I contacted my daughters SENDO at the council, towards the end of that term too. I was told her caseworker had changed but that the new one would be in touch.

It took a while for her new SENDO to contact me, by which point things were getting worse and worse with my daughter's mental health. The SENDO I spoke to was lovely and reassured me that, although it felt like we had no support right then, we would soon be surrounded by support. I was told to make another referral to social care, and that our daughter had options open to her to either continue her education or get support to start work.

I had to repeatedly contact our daughter's SENDO after term had finished to try and get an update about what was happening. I was eventually told the SENDO had been off sick, but was working through emails and would get back to me as soon as possible.

Charlie was put on a waiting list for a social worker. This is with the Learning Disability Team, but she does not have a learning disability. There's no indication about when she will be allocated someone, or what, if any, help might be available.

I still did not hear back. Things got so bad with my daughter's self harm that she ended up needing a wound stapling back together in A&E. She now has wounds all over her arm and leg and is finding it virtually impossible to stop self harming.

By the middle of August we still had not heard back from our daughter's SENDO about what was happening. I contacted SENDIASS who told me to contact the Specialist Learning and Advice Team manager. He was on leave at the time but contacted me as soon as he got back.

We saw a careers adviser the week after we contacted him and she was brilliant. We finally had chance to go through Charlie's options. Our daughter applied for a place at a supported internship and funding was approved on 13 September.

If we had been helped sooner, she would have been able to start her internship on 9 September. It would have saved a lot of mental distress. We now have a daughter who has a huge problem with self harm. This would not have got so bad if we'd had the right help. I left multiple messages at Huntington House to speak to a duty worker but nobody phones back. I put in a request to see a GP last week and she's been put on a routine waiting list to see a GP. Apparently we will be contacted in six to eight weeks' time with an appointment to discuss support for her self harm.

The SENDO who dealt with our daughter in the summer was an interim SENDO who has now left. We were told her case would be managed by her previous SENDO. Her previous SENDO told her our daughter's case had been passed onto someone else. I spoke to the new one on Friday and she is also an interim SENDO. The whole situation is exhausting and traumatic for the whole family. We've got a young person who wants to work but needs help to do so.

We thought that having an EHCP would mean that the support would be there for us. This has not been the case at all. Our daughter is probably going to have scars for life from all the self harm this has caused. I also have a 17 year old on an EHCP and I am dreading having to go through this process again.



Further reflections from families

Financial impacts

- Juggling money as a couple with children that are autistic is an absolute nightmare.
- This is also extremely embarrassing to be a family surrounded by high earners and tax payers. Your dignity is stripped back, in fact, it feels like you are not entitled to any dignity.
- Having to go to the job centre to take evidence for a claim is time-consuming and soul destroying. Then to receive advice from the Universal Credit system advising to sell your home was utterly disgusting. It's hard enough to be a carer and try to do a job then the support from the government is non-existent.

Exhaustion

- The exhaustion, the burnout is so real. This past week alone
 we have had audiology appointment, speech observation,
 social care review, a psychiatrist appointment, social care
 meeting for adult services, dentist, and learning disability
 team meeting.
- Being able to work is impossible juggling is real.
- The processing of new information completely derails, chasing services to do their jobs is a full time job in itself.
- All services are so stretched. Not enough money, staff rushing around like headless chickens. Trying to function to eat, to run a home, have a life - is a juggling

act. The only people that understand are those living and breathing this roller coaster ride. Sometimes you can't breathe. You wake up anxious and ready to get on the next rollercoaster. There is only so much families can take.

Trauma

• I feel, as a parent, there is not enough understanding within services around trauma and autistic burnout. Placing a young child into educational environments that are not healthy for a young neurodivergent individual has a detrimental impact on their future mental health and education journey. This can and is evidenced in all the stories we hear at present. It is important we start to listen to our young people in whatever way they communicate with the world. Showing compassion and support to both child and family. If we choose not to, we will continue to see crushed individuals unable to learn, to leave their homes and not want to be here. Costing services a lot more money.

Transition to adult services

• As a parent of a child just transitioned to adult services it seems that there is no team set up to support neurodivergent young adults and because of this they are placed with the learning disability team. The learning disability team said to us in our meeting that there should be a separate team for individuals like our son. As a result you can end up in meetings that are not always appropriate for your child/young person.

Audiology

- The autism friendly audiology team does a great job.
 However, there are many neurodivergent children within
 York with auditory processing disorder. This affects their
 learning, socialisations and processing of information.
 Unfortunately these children go unsupported with families
 just given a leaflet.
- York's commissioners have made the decision to not recognise auditory processing disorder and the impact this has on a child. This means even if the team believes the child has an auditory processing disorder they are not directly allowed to place this in a report and have to fluff around the edges meaning families have to go private if they can then pay for the appropriate hearing device themselves.
- More awareness around this is needed. Other countries like South Africa and America are a lot more understanding around this with appropriate equipment provided.

YDRF Report for Healthwatch: Parents of ND kids

Introduction

York Disability Right Forum (YDRF) is led by disabled people and works to promote equal access to human rights for all disabled people who live, work, or study in York. YDRF created a Neurodivergence subgroup in 2023 in response to the Autism and ADHD assessment pilot. While campaigning for the rights of adults, the concerns of parents for their children kept coming through as a significant concern, so the ND Parent Uprising was set up in response.

ND Parent Uprising is a project started in recognition of the fact that parents of ND kids often feel isolated and alone in their experiences. Constantly fighting systems (schools, local authority, GPs, CAMHS, and many others) means that parents have limited time, energy or motivation to maintain social connections with those who may not understand. We believe that parents coming together in solidarity and sharing their experiences is transformative.

For this report, parents spoke to us directly and reflected on their experiences. Parents fed back that they felt this was a therapeutic exercise as they felt validated and heard, sometimes for the first time. We offered anonymity to ensure the psychological safety of both the parents and their children when engaging in projects such as this one. Below we have grouped quotes from the parents under key headings.

Website: www.ydrf.org.uk Email: ND@ydrf.org.uk Social media: @yorkdrf

Early indications of neurodivergence

"Early indications were an inability to nap/rest/stop through the day from a very early stage. He is adopted so we had awareness of prenatal ill health and substance abuse so that could also have been a factor. He did not reach standard milestones, was late to walk, speech delayed and over

the years had 6 different speech and language interventions, each for new challenges. He was incredibly impulsive, with no danger awareness and was 100 miles per hour, even before walking. He did not play inventive/imaginative games and did not really play fully until much older, 6-7+ and reenacted as opposed to imagined. In pre-school and early years, it was clear he was not at the same development stages as his peers by a long way and now aged 10 chronically often is much younger emotionally than peers."

"Early indicators were a little hard to figure out. We had a lot going on post adoption (9 months)! Difficulties have been clearer the older she is and the more that is expected. Her play and social skills have always been different to others."

"We've got two children, a boy and a girl. Our girl is older (20) boy is younger (17) and have had really different presentations. The girl's ND sort of crept up on us and didn't really start presenting till maybe mid-teens, but looking backwards now we've done the assessments, I can see it more. She's doesn't have many close friends, and that's probably been all the way through. She was having panic attacks in school after going back after lockdown. Nothing anyone was doing was helping because we were going on the anxiety and nobody was joining up the dots or even thinking about neurodiversity. We as a family were going through a very acrimonious divorce at that point so that distracted too."

"Early indications – inconsolable tantrums, suicidal thoughts, conscientiousness, impulsive behaviour (taking things, biting), vocabulary at a young age (loves talking), no spatial awareness, falling often. GP stigma, child psychologist – didn't think of these as unusual, they were stressful, but the norm."

"I've got two kids, both neurodiverse. My daughter's the younger one, it was her that I first had concerns about from about the age of five, because academically she wasn't at the same level as other children her age, and certainly not in terms of comparison with her brother at that stage. So throughout primary school I had concerns about my daughter, but I didn't have any concerns about my son at all. He was academically very, very bright. My only concerns with my son were towards the end of primary school when I realised he was struggling with friendships and was never invited to birthday parties."

"My son, he's definitely autistic and I didn't know, but he was a biting child when he was very little, he had meltdowns all the time, all of primary school, he would have meltdowns. It's just a sensory overload now, looking back, total sensory overload. There was a lot of self-harm as well, when he couldn't work out why he was feeling that way or somebody told him off. I remember him having a tennis table tennis bat and he was hitting his head. It felt like it was all my fault, all my fault. My friend was shocked, she said 'I've never seen anything like that before'. It hasn't been until the last, maybe five years that we've actually been thinking more about neurodivergence, we've just been thinking he'll grow out of it. I just knew he was different, and he needed different things. I just wasn't thinking autism. Now I am and so it's blatantly obvious. He's very compliant, very, very compliant, he will try his best and then have burnout afterwards. He's quite obsessive as well. So, dinosaurs, Pokémon, Xbox. They are his things and he's getting more of them, but more adult things now."

Experiences with Systems

"The good clinicians, the ones who listen, they stick with you and they change your life. It's sad that these experiences are rare."

"It really doesn't help when systems don't talk to each other. It might be one appointment for you but when it comes with 6 questionnaires to fill in first and some of them are the same questionnaires of 90 items that you've already filled in for another professional in the same week, it's exhausting. Giving the same negatives over and over again is an absolute drain."

"Please stop suggesting parenting courses to exhausted parents who are trying to juggle a host of appointments already."

"We're lucky that we have been able to afford some private assessment and meds for ADHD. She would probably have been excluded from school otherwise. We worry for those who can't afford this, it shouldn't be this way. Parent blame is alive and well!!"

"We've experienced so much stigma and a complete lack of understanding from systems. People wanting/thinking they're helping but actually causing harm. They seem to want to link with childhood trauma. Extremes of either wanting to 'fix' everything or that I'm 'mad' for trying to advocate for him (as a woman/mum)."

"The parent guilt never ends and society is so ready to dump that on you."

Education

"School was very supportive for both of them. The college support was oversubscribed but the individual course leader was very supportive for my daughter."

"I feel like I'm forever, throughout their education, hitting my head against a brick wall, trying to just fight for their needs constantly."

"Secondary school said your son's got ADHD which was a surprise. Neither of my kids fit into the stereotypical ADHD – you know people think of that naughty little boy? They never fitted into that mould, so they went a bit under the radar."

"School wanted the child to come and "touch the gate" to "keep connection with school" which was an appalling thing to encourage. How many people connect with a cold hard gate which is designed to keep people out and children in? Again this shows me how out of touch the professionals are with the needs of children and what actually works for them, not to mention trauma."

"My son started getting a lot of codes at school not because he was naughty, but because he had the wrong equipment because he was

disorganised and wasn't allowed his bag with him, so he was forgetting things. I was told he was disruptive in class, so I asked at parents evening, what do you mean he's disruptive? And they said 'he keeps putting his hand up and asking questions or telling me the time's wrong on the clock or telling me the date I've written on the board is incorrect.' So I said, well, was it incorrect? 'Well, yes it was. But that's not the point.' So, hang on, you're punishing my child because you've written the wrong date on the board?"

"School were doing their best with my son but struggling, so they suggested he go to {Name of AP provider} one day a week. I was initially against it, but he loved it. Then instead of the school phoning to say he was doing things wrong, I was getting calls saying your son's a really clever kid, your son's a delight to teach, your son's amazing. One day a week turned into two days a week, and then they decided he could go full time at {Name of AP provider} for half a term. He was actually doing his academic GCSEs and he absolutely loved it. And then he had to go back to mainstream because that half term had come to an end. I told them it wasn't going to work and it didn't, straight away he was suspended. After a lot of back and forth, the Local Authority made an exception because it was only two months before his GCSEs. He passed every single one, he did brilliantly."

"School and the Senco are woefully out of touch with what works for the needs of the child, and are possibly driven by attendance targets, and fear. I was asked directly "do you think he'll prefer alternative provision to school". The other factors not taken into consideration, despite my many conversations on it, and input from the Ed Psych and other professionals, was transition and attachment needs...

The first alternative provision we were offered and tried was within the academy. It involved 4 transitions there and back, in a taxi from school, and then a return directly to school for a further transition into the final 50 minutes of the school day which was not ideal. It was sold as low demand, free flowing etc yet in reality was timetabled, not as outside focussed as

stated, and had a key man dependency so if they were off sick or their kids were, the provision could not run."

"Where to start with school? We've had 3 Sencos over 7 years, the first would not pursue an EHCP and my experience is they "managed me" as opposed to supported interventions to support my child. I now know what should be picked up in the EYFS and believe all signs were ignored and our voice was too. Then Senco 2 came in and she was amazing. She grasped the needs of our child, understood and heard what was happening at home and arranged an Ed Psych assessment, which was the beginning of things being supported. She created a sensory room within the school, ensured teachers understood needs and had simple effective ways to meet them e.g. where a child was sitting in the classroom. She also supported getting an EHCP and 121 help...

Senco 3 has been supportive in some ways, however I do not feel has listened to us as we entered into the difficulties which began in Year 4 and imploded in Year 5. I stated several times we would start to see an inability to come to school, that the timetable was too heavy, that he was being othered, and in December 2023 the Ed Psych attended a review and agreed. I was also visibly upset at this time and whilst it's absolutely ok for a parent to be upset, this was out of character for me and I was open about the stress we were dealing with at home and the impacts to all of us. I do not think it is ok to ignore a parent in this way and continue to say a child is "fine in school"...

At this time afternoon support was also not in place when it should have been, so afternoons were a hotspot for him. This was reintroduced in January 2024 however probably too late. During the Spring term of that year, I continued to say things were not ok, he was not ok and nothing was done. I had been asking for an alternative provision to help with his capacity but to no avail. Alongside this however the Senco submitted a request for increased EHCP funding, so I question this in the sense of on I hand that shows the child has higher needs, yet our challenges were not being responded to...

The funding increase was agreed. By which point, he had reached his limit and was not able to attend. When this happened, I was sent the SEND

graduated pathway by another parent which highlights what interventions should be looked at in each stage. When I showed this to the Senco she said "I am aware of that document", and I wondered why on earth it had not been used within the last 6 months of us continuously saying things were not ok. We were at stage 5-6 of 7 by the time any of the interventions recommended in this were implemented, and even then that was via a large number of conversations and repeated requests."

CAMHS

"My son really didn't like CAMHS. He really, really didn't like them and he refused medication outright. He said 'I don't want to be turned into a zombie. I don't want meds.' He was still doing drugs at this point, and so they just discharged him. They didn't want to know."

"My son got very, very depressed, almost suicidal, about a year ago. I phoned CAMHS and I just said 'I'm really worried he's still on the waiting list, what do I do?' And actually, a psychologist called me which I was quite impressed by. She couldn't do anything about the waiting list or see him any earlier, but at least she called me. He's not suicidal anymore, but he does get very down and I think he could quite easily have suicidal tendencies."

"VERY mixed experiences with different professionals. Notably, we've seen a lot of diagnostic overshadowing: 'she's adopted so it must be Foetal Alcohol Spectrum' (it isn't). CAMHS discharging her from the ADHD assessment list to do life story work because she is adopted without even asking if we had done life story work (of course we had) then not accepting her back on the list since she had been discharged. A conversation would have been so helpful."

"CAMHS gave my son some mental health support, a group session of kids his own age where they share their concerns and their worries. And in that group was one of the boys who bullied him. So of course he didn't want to go there. I told CAMHS my son will not open up because there's one boy in that group session who bullies him. They said they could maybe take him

out and put him forward for a future one in a few months. I said we need help now. Can't you do any one to one stuff with him? Oh, no. This is all we can offer you. He never completed the course, he did a few more which I had to drag him to kicking and screaming and pay him to attend. And then he just said I'm not going to anymore and I didn't push it."

"We are within CAMHS currently, after I had to contact them frequently to put him on their ADHD medication waiting list. They kept us in limbo whilst debating whether our NHS-but-funded-by-the-CCG diagnosis was sufficient for them to take him (after they refused to assess some time before). In the end I requested with insistence that he go on the list whilst they decided, so time did not tick on, and we also had to contact the emergency line a number of times because the situations we were dealing with at home were completely untenable. When I have interacted with CAMHS, I've had a very mixed experience. From "it's 4.45pm so the person can't take your call" to quite a helpful ADHD session with their team and other families. That said, it was clear some of the professionals in that session did not realise how difficult the reality for some families is."

"It's heart breaking to hear your son tell you he can't take it anymore, that he doesn't want to be alive, that he wants to kill himself."

"My daughter went into an absolute mental breakdown and depression, not getting out of bed type of thing. She had to stop going to 6th form. The GP referred her to CAMHS for depression and anxiety. They did an assessment of four areas and she was in red plus plus in all four. They told her to choose one area to go through the CAMHS counselling and at this point she was 17 ½, so she did some OCD work and ignored everything else as there was no scope to expand that."

"We're still waiting for CAMHS. We keep getting automatic letters saying 'you're still on our books, here are some web links if you require them, blah blah'. I contacted them recently and said please I don't want to get forgotten. He's already 17 1/2. Please don't forget. They've said that they will

not discharge him and won't pass him on to the adult services until they have seen him."

Health Professionals

"The GP has washed her hands of us. She's tried two lots of SSRIs which worked for a short amount of time to lift her mood to get her out of bed. But then the anxiety just overran that. So she just stopped because the anxiety was worse than having the SSRI."

"Doing right to choose was a bit difficult because it wasn't a provider that the GP was aware of, so she said she would contact the ICB to see if we can use them. I said, well, if you give me the ICB contact as well, I will contact them as a parent. I got a reply within a week as a parent and when we went back to the GP, they were still waiting for a response. So the GPs, even though they are the clinical professional, are not getting the response from the ICB."

"The speech and language team were excellent and one of the few professionals I have connected with over the years who had a good understanding of Foetal Alcohol Spectrum and tailored their sessions perfectly to meet the needs of the child – e.g. using a ball to throw in the exercises so it wasn't sitting still and trying to process. They also had a strong link with school and so that worked in terms of sharing the interventions and school could then do them within his timetable."

"The GP has always completed any referral we've asked for which has been helpful. The paediatric team at York hospital were good to a point, and did complete an important referral to a specialist clinic in Surrey for assessment, and the CCG agreed to fund it. I found the consultant didn't fully grasp the system nor the day-to-day challenges he faced. She expected things like an EHCP to be granted without issue, and did not agree that starting school later would have been helpful for him. Similarly, before starting school, we met with portage, nursery, the school early years teacher and queried waiting a further year, all advised to start school within his age group. I do not believe this was the right advice."

Local Authority

"The local authority continue to be a challenge. We have been thrown around different teams/social workers/case workers over the last couple of years and not had consistency of support. We've recently requested Learning Support Hub intervention for not being able to attend school, which was from April last year, and were told we don't meet the threshold because they count from the start of the academic year. I do not feel the LA understand the needs of the child, nor follow the SEND law and guidelines. Everything feels like a push or a fight to get what should be legally provided."

"Poor experience of social care since pre adoption."

"With my son I had to contact the Local Authority a few times. First of all, school changes because of the bullying and so on. Then we had early help when he was 13 when he was doing drugs and starting to truant from school. Looking on his phone I saw that he was being offered drugs via text messages from some much older people and adults. I spoke to the school but they didn't want to know because they said, that's outside school, that's nothing to do with us. I was too scared to go to the police so I contacted early help and I just said look, I'm worried about my child and what do I do? They gave me an early help support worker, a man, and he was no help whatsoever. My son didn't like him. He made no effort to try and get a relationship with my son and he turned around to me and he said 'I don't know why you need our help, lots of children take drugs.' Then we went into lockdown and that's when I needed this guy the most, but he turned around and said, I can't do any face to face visits and if your son's not going to engage with me, there's nothing I can do for you. So he closed the case. My son really went off the rails then, left home and got addicted to class A drugs during lockdown...

After lockdown, my son was really anti-school; he'd had a summer of doing what the hell he wanted and was a drug addict by then. Within two weeks of going back, his best friend died of a drug overdose. His world fell apart. He'd never had a best friend before. That was his first ever best

friend, and it was a very, very short-term relationship. He couldn't go to the funeral because of the COVID measures. He wasn't offered any counselling at school or anything, and I was trying to do my best at home, but I had an awful relationship with him at that point. He used to climb the fences and escape school to go to the graveyard and just sit smoking at his best friend's grave for hours. I'd get a phone call from school. 'He's escaped again.' Right. I bet I know where he is, drove to the graveyard and he was there...

In desperation, I contacted social services again. He was already in trouble with the police and was caught with class A drugs. Suddenly, social services wanted to know; I was assigned a social worker, and I was given help and support. The social worker was brilliant and cared. It took a while, but my son eventually built up a rapport with the social worker. He was great. He was also assigned a youth justice worker who, again, was brilliant. And because I had a great relationship with the youth justice worker and the social worker, between us all, we started turning him around. Youth justice helped us get his assessment fast tracked and he was assessed and diagnosed straight away."

"The local authority in terms of post adoption support have been great and we've been able to receive funding and access for the therapies we felt would work and have had two experiences of post adoption therapeutic interventions. (Sadly one was stopped by the pandemic)."

"We have had some support from the Virtual School Team/Social Worker, and they have answered any questions we've had, made recommendations and are on hand if needed. The alternative provision that we now have in place have a positive offering, however we have had to initiate transition and attachment-based approaches after 7-9 weeks of the child struggling to attend and stay without a parent. We now have a graduated transition plan in place to try to support this."

"I wanted to make sure that my daughter was on the SEND register and that she would get support going forward. So I contacted the Council and I just said, can you see whether she's been flagged up as SEND and they told me the primary school had registered her a few years previously, but never bothered telling me."

Community Groups

"I know in a couple of the YDRF ND parent sessions that we've had I've been in tears a couple of times and I know some of the other mums have. I don't think any of us would regret having those discussions or anything. I think the reason that we're crying is because it's just so nice to get it out and talk about it and it's a relief."

Impact on parents and wider family

"Our child's experiences have had a major impact on us all."

"I haven't told my family because of the stigma."

"I'm so tired all of the time. I'm determined to give my son the life he deserves."

"The impacts on us have been big. Both children have suffered as a result of additional needs, school trauma and the dysregulation brought about by that. Our house has been damaged repeatedly, we have been injured and been in fear of one of the children getting seriously hurt. My husband has experienced a particularly severe episode of depression with suicidal ideation and had to be signed off from work, funded private counselling and increased/changed his medication to Prozac. I have had periods where I do not feel I can see people socially and have had to maintain focus on day-to-day needs. We are both struggling to exercise and have time for our own health and self-care needs. We do not see friends and family as much as we don't have the capacity to navigate what's needed as well as manage day to day."

"My son told his dad about being autistic and he said 'you're not autistic, you can't possibly be because you're not rocking in a corner, and you're

not hyperactive, so you can't be anything'. He is not supportive. We don't have a relationship at all."

"Support from my side of the family is more or less non-existent. I don't think they really get neurodiversity, so I don't talk about the kids. I haven't talked to them at all."

"I told my mum my son was diagnosed with ADHD and she turned around and went 'well, who's faults that then? Who's he caught that off of?"

"I told my brother and his response was "all the best people are"."

"When my son left home, my mother-in-law took him in for a while. She was elderly. She was in her early 80s at that point and she just said if he won't come home, he can come and live with me. But he started bringing dodgy people back to her house so it impacted on her as well. My parents didn't want to know him. It's a shame, he's sort of like an outcast to a lot of the family."

"For 8 months I have done every single bedtime and evening routine mostly, as he can't tolerate someone else doing it. Our eldest child has suffered and would describe his experiences from his sibling as abusive. We've had daily aggression and upset to deal with which has been incredibly stressful. Our eldest child is also at risk of barriers to attendance so we are trying to manage that and his needs within all of this. (and ensure our voice is heard with his school). I should add the positive side of this is that since not attending school, and once a severe burnout was recovered from, our child is considerably more regulated and whilst we still have to manage outburst and aggression at times, this is significantly lower than when he was in school."

"When my son went off the rails, it was very, very difficult because it impacted the whole household. My daughter was a lot younger, she was probably about 10-11 years old when everything was going on. She knew there was a lot of arguments and slammed doors, trashing of his bedroom, all this sort of thing. She used to have a lovely relationship with her brother when they were little, but they have no relationship at all now. She will never forgive him for what he did to his family."

Work/Finances

"Our life is changed and feels incredibly bleak at times. Every single day is a struggle. The anticipation of the explosion which we often see the minute she wakes, it does dreadful things to be in a constant state of negative anticipation. Work is really important to both of us but there's guilt in having a job and we've had issues with the amount of time we need off."

"It's been hard financially. I've always been the main earner, but on a part time salary. I used to work extra for financial things knowing that my exhusband was at home, but not anymore. I'm working 32 hours a week and I feel scared to increase my hours or to change my job because the kids need me."

"I'm fortunate to have understanding employers and have managed to progress my career alongside being a single parent - I won't ever apologise for the commitments I have as a parent and I advocate for that. I do have to leave work at times to ensure I can be there to sooth and comfort - he might get told off at school and the aftermath is immense - people don't understand the masking that goes on. Both with him and with me."

"We have constantly had to research methods that work to keep everyone regulated, to change styles to meet the varied needs of both children and cannot leave our youngest child with any other adults so have to do things separately or all together. I have spent hours reading, researching, watching webinars etc to try to educate myself on our rights, on the law, on what should be offered. We then have countless meetings, calls, emails etc, the list is endless. It is practically a nearly full time job in itself."

"With my daughter, the fighting with school took up a lot of my time outside my full-time working hours. But with my son, I had to give up work. School were phoning me every 5 minutes. Every day there was something

going on, so there was no way on Earth I could have gone to a physical office and held down a job, so I had to give up work."

"I have had to give up I of my jobs, and reduce my working hours considerably, to 2 evenings per week, Fridays when my husband doesn't work and Saturday mornings. I have been able to do this as I am fortunate enough to be self-employed however were I in a different position, I would have had to stop working completely. So our income is much lower, and my needs as an independent adult have had to be vastly adjusted. We have been given DLA which has gone some way to help here. We have privately funded a specialist dyslexia assessment because the primary school were not listening to our worries about reading ability and challenges there either."

Social Connection

"Sometimes I feel I can't be myself with my friends, because I can't talk freely, you know."

"I can't talk about it to any of my friends. In fact, I don't really have that many friends anymore because relationships with other parents got a bit strained. The few friends I've got, their kids are non-neurodivergent goody two shoes. Kids that comply with what their parents tell them to do and everything so you can't have conversations with them about anything. Or I can, but they don't understand."

"Dating was incredibly difficult - being a single parent, your stigmatised as it is - being a single parent with a child with additional emotional needs is hard. I'm incredibly proud to be his mum and I always state that. He's an asset. But the emotional burden of supporting a child with the needs that he has, that could be considered baggage - I've spent a very long time feeling so shit."

Impact of waiting

"I think we've had to wait for every single intervention pretty much, apart from speech and language because they kept us on their records and so rereferrals were picked up quickly."

"I think we're so used to having to wait now, it is simply part of our day to day lives."

"Waiting is really mixed. Currently we have the opposite struggle that everything came at once and we can't space it out or keep up. We are told 'there is no option to delay, or you lose the funding and we have to start again with the application."

"I know my son, I know about ND, I know my sons struggles, and I know he's ADHD - what am I waiting for? The diagnosis doesn't come with the support, but it comes with the understanding - even when people don't want to understand - schools etc have to offer that additional support. The additional support doesn't truly come without the diagnosis, stigma and judgement comes with the self-diagnosis - not support."

"It's very frustrating because my daughter has already been through CAMHS and they didn't join up the dots. If they joined up the dots then she wouldn't still be waiting. Now, we've had to go through private counselling and medication that wasn't appropriate. We've gone through all these things because she's been waiting."

"My son is just telling people he's autistic because he is and he's finding it very frustrating that he just can't speak to somebody officially about it. The waiting is very, very frustrating. The letters that you get from CAMHS, the standard letters, that every time we go 'oh, hooray, we've got an appointment!' But, no, we haven't, it's just another useless letter. Oh, it's painful. It's painful."

"With my son it all just went a bit wrong because his support was too late, because by then his mental health was in really, really bad shape. He

ended up getting in with the wrong crowd and he ended up doing drugs and all sorts."

"We had to wait and/or push for CAMHS to take him onto their waiting list – so a wait to be in the waiting! This is ongoing and means we're delayed in looking at medications - although what we have asked for is a conversation about medication, so we can learn and understand the benefits and challenges and make informed decisions from there."

"The wait for the FASD/ASC/ADHD assessment was about 3 years however was also impacted by lockdown and we knew that would be the case, however it was worth it in terms of having all aspects assessed in 1 go, and the detail of the assessments and reports has been excellent."

Changes that could have made a difference

"Had my son received the diagnosis early on when we first went for it, and not waited 4 years+, he would have received the correct educational support. He would have received additional emotional support. I wouldn't have experienced the stigma I have. He would have received the school place in the school we'd selected for his needs. Because of this he experiences emotional ill health due to educational pressures that I know will live on with him. Not having the recognition of a diagnosis has risked his educational future. Education isn't everything but it's such a huge part of their lives as they're growing up. Children feeling like they're failing continuously and being told off constantly for things they simply can't help - it kills their confidence."

"I think the first one is to be heard, for professionals to be curious, even when they have experience and knowledge. Secondly for school to follow guidance, to have reduced the timetable and implemented other alternatives sooner. I also think conversations between the LA and the Senco, without our involvement have not helped. Our voice has not been included so we are then given a response back via the Senco which doesn't align to the processes we believe are in place nor the law around SEND provision. I then have to contact places like Sendiass to unpick what has happened and advocate for what should have happened. Meanwhile the child continues to struggle in the middle of it all. I do not feel it is ok for professionals to ever say a child is "fine in school" in response to a parent saying a child is not ok. This is also whilst they are seeing the child not being able to come into the building etc. There needs to be much more knowledge on ND in schools. Teaching assistants who are 121s should have mandatory training and they should be required to have knowledge and awareness. Schools need to shift their thinking to create simple, and often without any money required, changes to support children in school. A relationship first approach will work with all children."

Key messages

"Listen. Please stop diagnostic overshadowing. Adopted kids can be neurodivergent too!!!"

"The diagnosis process is degrading - don't ask deficit-based questions in front of the child you're assessing."

"If you're a parent with an ND child - lean on the support you have and don't feel guilty for it. It's for you and for your child. Also advocate, advocate, advocate. Be the pushy 'neurotic' mum. Even if people don't listen, your child will know you have their back. They need a safe space. If it makes things better for them, that's the aim. If the systems don't listen at first, make them - you know what your child needs."

"Asking for help is hard - make it easier."

"There is such a lack of understanding of the parent's point of view and a lack of support and knowledge for us. Parents not being able to work as much because you're trying to look after your child for whatever their need is. And feeling guilty, so guilty, because you know, you've got to finance the household. But actually you are treading that tightrope all the time thinking 'how are they now, can I do some extra shifts, can I not'?"

"It's awful for parents because you can never let go. You can let go to a degree, but you can't let them go on their own fully. So you're always preparing for the future and that's the hard bit."

"Diagnosis can be life saving. It's not for everyone and in some instances it's not helpful. But when someone is asking for it - there's a reason for that."

"Listen to parents. Believe us when we say there's something wrong, no one knows our kids more than us. Trust that if we're saying we think they need support, just listen to us and believe us and work with us. We're not doing it for the attention or anything. We're doing it because we're trying to help our child, and if we can get the help for our child that they need, that's going to help everyone. If my son hadn't got the help that he needed, he'd be dead by now, or in prison."

"I would like people to know that is very hard, however having seen the difference in my child from being a desperately unhappy and frightened to much more settled and able to enjoy their life has been an eye opener. With hindsight and the knowledge I now have, I wish I had taken steps to push for either flexi-schooling with alternative provision much sooner, and not been afraid of it myself. If professionals had this knowledge, they would be able to help so many more children and families before things get so severe more issues come into things. It shouldn't have to be a fight to get the support that is needed, especially when all the evidence is there."

"If a parent is speaking up for their child, listen - they're not doing it for fun."

"Services need to pull their socks up and get organised. Don't ration support for children! What are you doing!? These kids are going to be our bankers, councillors, social workers, farmers – why would you hold them back from what their capable of? The North/South child funding divide is criminal."

"People need to value neurodivergence and support people to live their full selves - ND people, when supported to live fully, have a LOT to offer - my sons a legend and I have no doubt he'll excel, just provide him with the right opportunities to do so."

"Employ commissioners that value, are informed and care about equity and diversity."

Stories shared with Healthwatch York

Personal stories: Mary



I grew up in York. About age 15 I went to my local GP with multiple issues. I was struggling with my mental health and they thought it was anxiety and depression.

I was a good student, although I was always anxious. I also had stomach issues, but nothing was done. Later I realised that all my symptoms were related to ADHD but at the time I didn't know and the doctors didn't investigate or suggest anything other than anxiety / depression.

I started playing ill at school as I didn't want to be there. I was doing a lot of masking (I can see that now) and then I was able to be normal at home. I was referred to CAMHS but I never had an appointment and after that I didn't try again.

I went into sixth form with no support and struggling. I had a lot of depression and anxiety around my A levels and was prescribed Propranolol which didn't work and then Sertraline before my A levels.

When I went to university (outside York) I didn't have a diagnosis, just a prescription and had to ask my new university GP to write a letter to the university so I could access the appropriate support.

The Sertraline also didn't work and I was prescribed Mirtazapine and tried that for a year. At this time, again there was no investigation that my issues could be something else and no discussions about wider issues.

I began sleeping all the time and decided to stop all medication.

In the September of my third year at university (2023), a friend said they thought I might have ADHD. I thought I was more likely to be autistic as I needed time out and alone. I asked my university GP for a reassessment and was sent a questionnaire. I missed the deadline and had to restart the process. I had to wait for an appointment until the January when I was diagnosed with ADHD via Psychiatry UK on the NHS.

It took five months to titrate the medication, but we got to a point where it was working for me. In this time I moved back to York and they sent the medication to me at home.

The medication made a huge difference and meant that I could be in control of my life. Before I had 20 things whizzing through my head. With the medication, it is more like four things and they move much more slowly. I am exhausted without the medication, but with it, I can cope and am not so tired by everything.

By December 2023 my medication was working and Psychiatry UK said to get a Shared Care Agreement with the GP practice (close to York). I was planning to do some travelling and when I told them, they said to wait to sort the medication until I got back.

I checked with Psychiatry UK about medication, but they said no. So, I went to New Zealand for two months without medication.

When I got back I started to look into getting the medication again. I know what I need as it was working really well before. I went to my GP who said that I needed a new agreement. Psychiatry UK said I needed to fill in the forms again. I did that and was told by both the GP and Psychiatry UK that I had to go to the back of the waiting list. That was two months ago. I heard from Psychiatry UK last week who said they will arrange a meeting for me about getting back on the

medication/titration. I don't have a date for the assessment, but I do have the pre-assessment forms so I am hopeful it will be soon.

But I am not sure what happens after that with the Shared

Care Agreement to make sure I can continue to get the medication that helps me so much.

Personal stories: Ray

Ella shared her experiences supporting her child Ray. They are female leaning non-binary, born male. They came out aged 12 in the middle of distressing autistic burnout. There were no signs of gender questioning in early childhood so this came out of the blue for the family, but they are doing everything they can to support Ray and reduce their distress.

The path to autistic burnout began in year 6 as a reaction to a lack of flexibility in the teaching process. There were further incidents at school including another parent making inappropriate contact with their child. Parents were led to believe this was dealt with, but with benefit of hindsight wish they had taken the matter to the police. This led to autistic burnout at end of year 6, and a complete breakdown in year 7. Then lockdown happened.

Ray told Ella in March of their new name, Ray, and their new gender and pronouns. A few months after, as they were in burnout and non-verbal Ray communicated by What'sApp that they did not understand why their parents had not got them hormone blockers. Ella confirmed she wouldn't know how, and Ray sent them a link to Gender GP.

Ella informed CAMHS of what was happening - CAMHS were visiting monthly at this point. Staff visiting were really unsupportive and disapproving of Gender GP. Ella understands this, but feels there were no other choices made available to them. Every day Ray said "if you don't do this I will kill myself." One of the staff members responded with

"I guess they will just have to learn to sit with it." There seemed to be no compassion or understanding around what hearing this would feel like for a parent. A referral was made to Tavistock clinic but there was a four year waiting list.

In August there was an MDT meeting where it was agreed to take a watch and wait approach. In November without parents' knowledge CAMHS made a referral to the Safeguarding team. In December the family received a call as an urgent safeguarding referral following the November meeting. Other people at the MDT meeting do not remember a discussion about referring to safeguarding.

A doctor at the gender clinic in Leeds provided very supportive feedback regarding the actions the family had taken. As well as concluding there was no safeguarding issue, the safeguarding lead asked to share this advice with the rest of the team anonymously as it would be helpful for such referrals in future. The family is grateful they resolved this quickly as it could have negatively impacted on care had it not been.

The crux of the issue for the family is this – they are facing a new situation which they don't know how to do the things that they need to do. They want help, a professional to walk alongside them, help them work through options who they can talk to and who knows their child and wants to help. The family feels like they have no option but Gender GP but everything costs money, from £7 just for a chat to getting blood tests done. They know things are going wrong – blood tests show that their cholesterol is high, their blood pressure is high, but they have no one to talk to about what might help. There is no gender care at the GP, no specialist, no lead. They are being refused shared care as the doctor won't do anything private.

TEWV has said they will put training in place, but in three years the family has seen no evidence of a change in their behaviour which has

been judgemental, stigmatising and unsupportive. At the very least health services need to do no harm, but the family feels that by invoking safeguarding at such a time they increased the potential for harm to occur. They are also concerned about the quality of advice around autism – if they had followed the advice provided by TEWV they believe that this would have damaged their child's wellbeing further. They feel there is an absolute failure to understand their child and what good support would look like for them. Workers need to patiently build trusting relationships.

The family wants to know, given the situation with the Tavistock Clinic, the long waiting lists for gender identity clinics, and the increasing number of young people identifying as trans, what are commissioners doing to meet this gap. Are they working to establish leads in all provider services, GPs, hospitals, mental health services, with additional knowledge / specialisms? It is clear services are not ready but at this time it seems that people lose their basic humanity when interacting with trans individuals.

When their child was diagnosed with autism, they wrongly thought someone would tell them what this meant, but in reality they had to figure it out by themselves, find their own information sources. They don't think it should be like this for trans individuals and their families. There is nowhere to go and just talk to someone helpful.

The family would also like to see clear information on shared care and how this can be put in place. The system is all about box ticking, have you had this assessment, jumped this hurdle. Not about "are you ok? Is this having an impact on your mental health?" "All families want is people they can trust, who care about their child. Currently it appears this is too much to ask for."

Personal stories: Jodie



I have a number of health issues. When my children got diagnosed with ADHD (after a five year wait for a CAMHS appointment), I realised that I probably had the same.

I was diagnosed with ADHD when I was 48. I feel it is a similar experience for other women with peri-menopause as this seems to make the ADHD symptoms much worse. In fact the worst times for my ADHD have been hormone related: puberty, pregnancy and after birth and menopause.

My children also have ADHD, but they are not on medication.

My son Charlie was diagnosed just before he was 16. The issues for him got particularly bad at secondary school where teachers suggested he probably had ADHD. He was fast-tracked to Alternative Provision (AP) which was a very positive experience.

The school helped with the referral to AP and social care was involved. After diagnosis, he refused medication. As he was over 16, we were not allowed to input into this and were told that his decision had to be respected, so he was discharged. I don't think he should have been discharged as he still needed support from CAMHS even if not medication.

My daughter Daisy was 10 when we realized she was struggling. I thought she may be dyslexic. The school did not support this, so we went ahead with a private diagnosis which identified dyslexia. The assessor also thought that she might have ADHD. I mentioned this to the school who said that yes, she definitely had ADHD.

The symptoms and evidence of ADHD were very different for my son and daughter. Daisy was good at school and quiet, then at home could be a tom boy whirlwind or zombie. But she struggled at school (due to

the dyslexia) and was put on the table with the naughty children, but wasn't naughty. She was very unhappy about that as she really tried.

At 10 she was referred to CAMHS where there was a long wait. She was booked for a pre assessment but the psychologist had been double booked so she had to see someone different. She saw a male nurse who said that as she also had Irlen Syndrome and was changing schools that we should wait and see if it all settled down. I agreed but I didn't realise this meant my daughter was being discharged.

When Daisy had been at secondary school for a year, I rang CAMHS to follow up and found she had been discharged. I asked about a rereferral and was told it needed the school's support. The school refused. I went to the SENCO who contacted the teachers about evidence but every teacher just said 'no signs of ADHD'. But what they were seeing was no classic male signs.

At home Daisy could be one of two things, a zombie or manic. When I took her to a GP appointment when she was 10 to ask about ADHD, the GP and a trainee responded as if I was stupid saying 'what on earth makes you think it is ADHD ... if she had ADHD she would be banging her fists on the desk and rocking in her chair'.

Daisy really struggled during Covid and we moved her to a different school. I talked to the SENCO and explained the situation. The SENCO met Daisy and said that she definitely had ADHD and the school would support a referral as soon as it could (six months later).

Daisy was diagnosed at 15 and was on a waiting list for medication. She was offered a medication appointment the week before her GCSEs which I thought was not helpful, so I asked for it to be delayed. The new appointment came when Daisy was ill and so I emailed to ask for the appointment to be changed. However, instead Daisy was discharged and told she would need a new referral for medication consideration in

the future or to wait until she is 18 and get an adult referral to the Retreat.

My family have had no support at all.

Knowing I have ADHD is important as it explains why my head works in the way it does. I want medication and my psychiatrist and GP to communicate and work together. When I went to the GP to talk about HRT and mentioned ADHD I was told that the GP doesn't deal with that, but they are connected.

There are also issues with shared care agreements for ADHD medication at GPs in York. I feel that this is the GP rejecting ADHD diagnoses.

Personal stories: Ben

When Ben started mainstream school at four, I was concerned that he might be dyslexic as there was a strong male line of dyslexia in my family. Ben had excellent spoken language skills and had started to talk when he was relatively young, but he had shown no interest in books.

In reception his teacher suggested getting his eyes tested because he wasn't looking at the board. But no one was worried as his language was so good.

At five he had a partial assessment for dyslexia as it was so clear he was dyslexic. But his school wasn't supportive. They were trying to get him to do more of the things that weren't helping him and put him in a group with other children who were struggling, but struggling for very different reasons.

When Ben was seven, he was aware of what he couldn't do and some felt his behaviour was about self-confidence. There was an autistic boy

at the same school who Ben was friendly with. So, Ben's behaviour was seen as situational when he was with the other boy.

When Ben was seven, we moved to York. This was a difficult time for him, he had broken his arm and was getting over chicken pox. My mum was also planning to move as well but didn't. It also marked the break-up of our family as Ben's dad had still been involved in his life, but wouldn't be as much once we moved.

Ben started at {Name of Independent school} after moving to York. The school was focused on exams and students going to university and was not supportive of Ben having an assessment, so we went private. ADHD was flagged but there wasn't the evidence and so it wasn't followed up. The focus was on his dyslexia.

Also, the structure at the school effectively supported Ben. I did a lot of research and together Ben and I found ways to cope at home so we didn't feel the need to pursue a diagnosis. I thought Ben might have autism with a PDA (pathological demand avoidance) profile and inattentive ADHD.

The lockdowns in 2020 and 2021 exacerbated things and I recognised that we would need other things in place for when Ben was sitting exams. The school SENCO referred Ben to CAMHS. This was a dual referral. I believe we only got this as I know how to fill in forms! However, the process was very repetitive with two sets of forms to be completed with much of the same information, then two very similar Zoom interviews, followed by a face to face meeting.

At this stage Ben had self-identified with ADHD and that seemed the priority as it was affecting school.

However, at the face to face meeting we were told that CAMHS would not pursue a diagnosis as Ben's behaviour did not show any risk taking

and he wasn't physically hyperactive. The referral to the autism team would still happen.

I was very frustrated. If I had known that these traits were needed for the diagnosis, I would not have continued as I knew he would not fit the CAMHS criteria. Because of this experience I questioned whether there was any point bothering with the autism referral.

While the assessments were happening, Ben moved to another school. They were asked to fill in paperwork for the ADHD referral and did it too late to be considered. The feedback did say the school felt Ben had ADHD.

For the autism referral the school said that he had normal interactions and they did not think he is autistic. They also commented on his behaviour out of school even though they were not aware of it as Ben had only been at that school for a year.

However, the psychiatrist we met for the assessment said that he is autistic. They said he communicates in different or unusual ways and commented on his use of American terminology (due to watching a lot of US television). The psychiatrist could see autism in several things. I feel that Ben presents with a style of autism more associated with female presentation.

The assessment was again frustrating for me as there was no consideration of Ben's ADHD and autism working together and presenting differently to others. There was no understanding of the interplay between the two for him and how this impacted on him and his day to day life.

The assessment process was all about challenges and crisis rather than looking at what was working and how Ben (or others) were currently coping. This meant it was skewed and not at all holistic. After the diagnosis the school asked me if I was shocked and then asked how they could help – two months before Ben's GCSEs!

Ben went on to college, but I was disappointed that college wasn't as supportive as it could be. However, Ben did not want to be singled out so he didn't seek help. I feel the college wasn't equipped for the variety and complexity of student needs and the number of students that need different support.

Society and the education system are making it harder for neurodiverse young people to fit in, particularly with the increasing use of technology and the lasting impact of lockdown.

If Ben had to navigate the current assessment process it would have been debilitating. The process and assessments were inaccurate and outdated when he was going through them and they haven't improved. It all lacks clarity and honesty.



Personal stories: Freddie

My son is amazing. Kind, caring, sweet, affectionate, and very, very funny. He has an infectious laugh that you can't help but join in with. He's bright, curious, joyful, friendly. I've also suspected he has ADHD from a very early age.

We're still at the start of our journey and in many ways we're really lucky. Our school has been supportive. They've provided lots of extra help at school – from one to one support for reading, writing and basically anything that you need to concentrate on, sessions with the Emotional Literary Support Assistant (ELSA) to improve his ability to manage his emotions, to breaks part way through tests so he can burn off some of his 'fizz' and then come back to it. They suggested we should work on the forms for an ADHD referral at about the earliest

stage you can because there are issues we need to work on that they'd welcome specialist input on.

I think for me the biggest challenge is that it always feels like you are flying blind. He's my only child, he's all I know, but I am expected to know whether what we're experiencing is usual or unusual. Where do you go for a conversation on the 'acceptable' level of violence from a school-age child? There's no place for real conversations about what to be worried about and what to accept. Instead, you find yourself documenting only the worst of their behaviours so you can persuade health professionals there's something they should be helping with. But I am also surprised at how little co-ordination there is between services, and that it's up to me to keep them all informed, usually having to share quite difficult personal information in front of Freddie, which has a clear emotional impact on him.

We actually got rejected for an ADHD assessment before we even asked for one – long story short there was a miscommunication about some other tests we needed to have done. But when we first really put the referral in for assessment through school we got a straight no back, plus forms to complete for a possible autism assessment. He definitely has some autistic traits, but they're not the issue that's most concerning for us right now. However, as all of this is done via forms without ever seeing anyone you don't have the opportunity to explain any of this. I immediately challenged their reason for rejection and lo and behold they'd made a mistake. He's since had a QbTest and been put on the ADHD waiting list with an autism 'clip-on'.

We made a request when making the referral to have the forms by email, to have letters by email and to get responses by email, but we always get written to. I don't know what class of post they use but it weirdly seems to take several weeks after the date on the letter. So for example we received the original ADHD forms just before school broke up for summer, and we then had to wait until September to work with

school on them. It seems to make a mockery of all the early intervention talk when the process itself seems to involve stalling tactics over and above the lengthy delays for assessment.

We're just hopeful we get an assessment within the one and a half to two year timeframe they've suggested, so support can be well-documented before he goes to secondary school.



Partner statement from York Carers Centre

Many of these stories are truly harrowing and we should all be affected by reading them. York Carers Centre supports families who are experiencing an increase in their caring role due to a reduction in services and support, and the demand on the services available. The complexities involved in accessing and navigating services adds a burden on to families who already have enough on their plate. Support is meant to be just that; services are meant to be there to help the people who need them, not cause further distress.

When a family is left to care for their child with limited support there is a significant impact on family relationships, finances, the physical and mental wellbeing of family members, the ability to work or study, and the opportunity to connect with others. It is vital that parent carers and their children have quality support and choice so they can create a life that works for everyone in their family and is one they can sustain.

We believe this is about more than finding ways for children to be in education. It is about changing our approach to understanding what families need and finding ways to deliver this. It is clear from some of the case studies that things need to change, and we need to stop causing further trauma to families and children, but work with them, hear them and support them to find meaningful ways forward in the best way possible.

Partner statement from Parent Carer Forum York

The Parent Carer Forum York is an independent charity who is commissioned to represent the voice of parent carer lived experience in York. We represent parent carer views to Education, Health and Social Care to inform development of services for young people with additional needs aged 0-25.

This powerful report captures the journeys and stories of many families whose experiences are reflected in the common themes heard by PCF York. We urge all decision-makers to take the time to read each story, as they describe the wide impact on both the children and their families.

York Local Authority and Health Services have a genuine interest in working with us to shape strategies and services with lived experience. We hope that this report will inspire innovation and drive meaningful change, both locally and within national systems, to better support neurodivergent individuals.

If you would like to find out more about how your family experience can inform current and future plans, or support us in the work we do please email: connect@pcfyork.co.uk

Key findings

- 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 signs 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.

Recommendations

Recommendation	То
Consider how to embed across the health and care workforce the importance of connections, and signposting to peer support at the first moment people approach for help. Make sure this includes not just parent carer awareness but recognises young sibling carers too.	All York system partners including City of York Council, York Health and Care Partnership, Tees Esk and Wear Valleys NHS Trust, York & Scarborough Teaching Hospital Foundation Trust and Primary Care leads.
Make a commitment to stopping parent blame.	All York system partners as above.
In partnership with local ND and parent carer groups, seek funding and support through local research networks to develop a Neurodiversity friendly schools charter and encourage local schools to adopt this, covering:	All York system partners as above.
 ND training for educators. How to recognise the signs of EBSA, burnout and school trauma. Developing a best practice mental health pathway where such signs are observed. Developing school behaviour models that do not discriminate against people who are neurodivergent. Transition planning and help to support young people through transition and beyond, with a menu 	

of potential reasonable adjustments that can be accommodated within the school environment.	
This will rely on identifying funding to support such research. This should also consider the links to the Human Rights schools approach in York.	
Develop local expertise around neurodivergence and gender identity. Put in place a clear policy around shared care arrangements and an escalation process for those whose GPs cannot or will not support them.	HNY ICB, York's PCNs, TEWV
Develop and deliver local training around PDA for health, care and education professionals.	HNY ICB, LD MH & Autism Provider Collaborative, City of York Council
Bring York into line with the wider ICB by making sure there is a clear sleep pathway that offers behavioural support and further specialist help where this does not address the problems experienced, including identifying who will prescribe melatonin where this is clinically assessed as right for the child, and how the transition to adulthood will be managed. Provide clear information about the offer for the workforce and parent carers.	HNY ICB
·	All York system partners as above.

Make sure all services comply with the Accessible Information Standard and that providers seek to understand the communication needs of parents and children and respect requests for information in particular formats. This duty sits with providers, not families.

All York system partners as above.

As per the recommendation in our Children's Mental Health snapshot report, improve administration processes for paperwork related to the formal assessment and diagnosis pathway in secondary care. As above, this must include seeking to understand and respecting people's communication preferences. Checking preferred communication methods should form part of any initial SPA conversation.

Tees Esk and Wear Valleys NHS Foundation.

Consider ways to improve support for families of neurodivergent young people. This must include considering how existing services such as school SENCOs, SENDIASS, Local Area Co-ordination, Family Navigators and Social Prescribers can play a role connecting families, and consider how integrated approaches and multidisciplinary teams can address the challenges families experience, with more proactive and co-ordinated support.

City of York Council, VCSE partners.

Initial response from Humber and North Yorkshire ICB

The Humber and North Yorkshire Integrated Care Board (ICB) and Mental Health, Learning Disabilities & Autism Collaborative were anticipating the opportunity to develop this report together with Healthwatch York and as such would have welcomed more time to consider the draft content describing the local picture and findings. Receiving the report just before Christmas has limited the time to digest, discuss and respond. The findings will be discussed at a future Executive meeting of the Mental Health, Learning Disabilities & Autism Collaborative, which will enable a more comprehensive response to the recommendations and reflect these in programmes for neurodivergent families. We would like to develop this response in partnership with Healthwatch York, voluntary sector organisations, and representatives of children, young people, and families.

Moving forward the Integrated Care Board is committed to building sustainable and equitable services, balancing diagnostic capacity with appropriate support and ensuring that the right interventions are in place across the system. This demands careful planning, collaboration and a long-term strategy. We are working with both regional and national teams to address the demand for autism and ADHD (Attention Deficit Hyperactivity Disorder) services, while our Mental Health, Autism, and Learning Disability Collaborative drives pathway improvements. This includes learning from other regions, taking direction from NHS England's national team and sharing resources to better manage demand and meet the needs of the population.

A number of key workstreams have been identified as part of our programme of work include:

- Reviewing waiting lists to ensure accuracy and transparency.
- Creating unified service specifications for both adult and children's assessment services.

- Developing consistent thresholds for assessment eligibility across the system.
- Ensuring diagnostic tools are applied consistently.
- Aligning transition policies between children's and adult services.
- Mapping commissioned and non-commissioned pre- and postdiagnostic support services to identify gaps and assess levels of need.
- Piloting early identification and support initiatives.
- Expanding peer support networks and community advocacy programs.
- Planned development of a central website hub for autism and ADHD resources.

These initiatives aim to address the complexities of autism and ADHD pathways by improving access, quality and outcomes. While this report focuses heavily on autism and ADHD, in York, we are also undertaking several key workstreams around other neurodiverse conditions. These include initiatives related to Down Syndrome, Foetal Alcohol Spectrum Disorder, Tics and Tourette's Syndrome, Epilepsy, Deaf Autism and ADHD Assessments, hearing checks, and Project SEARCH among others. These efforts reflect our commitment to supporting the diverse needs of our population and ensuring that individuals with a wide range of neurodiverse conditions receive the care and support they need.

Inaccuracies/Potentially Misleading Information

Assessments for children under 5 take a year to ensure a thorough evaluation over a longer period of time to distinguish between developmental delays and autism.

The report says there is no support available pre and post assessment, however there is a variety of support available depending on the needs of the young person, individual and family. This includes NHS and York Council commissioned services, as well as support from our partners in the Voluntary Community Social Enterprise (VCSE) sector. Some examples

include Autism Central, SHOUT, MIND Cafes, Autism Plus, Neurodiverse Parents Group and Castaway Music Theatre. In addition, there are more specialised support services available, tailored to specific needs, such as help with managing finances or getting active. We are also strengthening our collaboration with local businesses within York to better support their neurodiverse customers, ensuring that our communities becomes more inclusive and an increased understanding of diverse needs.

TEWV (Tees Esk Wear And Valleys NHS Foundation Trust) currently use International Classification of Diseases (ICD)-10, and there are other organisations within our Integrated Care System that also use this tool. There is no mandatory implementation for organisations to use ICD-11, however our aim is for all organisations to use ICD-11 as we move forward with our programme of work to ensure consistency across our geography.

There is no blanket policy preventing GPs from entering shared care; decisions are made based on clinical judgment and the validity of the assessment and we are advising families to remain with the same provider for the entire episode of care to ensure continuity, as switching between independent and NHS providers often causes delays.

The section on auditory processing disorder (ADP) should note that there are services available for assessment and support, such as the Royal National Ear Nose and Throat Eastman Hospital and Great Ormond Street Hospital. These centres accept referrals from York families, with eligibility assessed case-by-case, typically requiring prior hearing checks. Support strategies, while not curative, are widely available and effective in helping individuals manage auditory processing disorder.

The Designated Clinical Officer (DCO) for Special Educational Needs has oversight of health's statutory duties and/or Disabilities (SEND) in York and Associated DCOs have reviewed the guidance for education setting regarding requesting health information for Annual Reviews with colleagues from the Local Authority. This guidance has been shared

across school networks and the DCO and ADCO have attended Special educational needs coordinators network meetings, both in person and virtually to deliver training regarding this guidance and the process for education settings to request health advice. Alongside the guidance we have also shared Single Point of Contact email directory for health providers, a timeline for the process and a digital health questionnaire that can be provided to parents/carers and young people to complete ahead of their annual review which informs which health services are currently involved with the child or young person. The timeliness of initial health advice provided for Education Health Care Plans is monitored by the DCO and ADCO and this information is shared with the SEND Partnership Board. In Quarter 2 (2024/25) 97% of health advice was returned within the statutory timeframe 6 weeks, 1 piece of advice was returned late by 1 day.

Engagement Opportunities

It would be beneficial for Healthwatch York to engage with children's and young people's organisations that specialise in this area. Two key partners to consider are the Parent Carer Forum York and the Nothing About Us Without Us Group. We also link in closely with several local groups and national organisations, such as the National Autistic Society and ADHD360 and would be happy to connect these organisations with Healthwatch York, if they are not already linked in.

Nothing About Us Without Us is a Humber and North Yorkshire Wide lived experience advisory group which includes representation from Children and Young People aged 10–25 from across our diverse communities including those with autism and ADHD and learning disabilities. The group holds regular place based and system wide events to enable children and young people to share their lived experience and collaborate with senior leaders to coproduce solutions to recommendations from consultations, improve access and experience of services and to shape the mental health priorities for 2025 and beyond. For more information please contact **Be.Heard@nhs.net**.

Sarah Coltman-Lovell

York NHS Place Director York Health and Care Partnership

Conclusion

It is clear from the stories shared in this report that there are specific challenges being experienced by neurodivergent young people. Our current systems for supporting them and their families are over-stretched.

There has been a significant societal shift, with more people's neurodivergence being recognised. Change is essential for services to adapt their offer to better meet the needs of neurodivergent children and their families. A positive and successful future life for many neurodivergent children depends on this, the ability of these services to adapt and change. Such change is essential to preventing inflicting and reinforcing trauma and anxiety.

We need to see change in schools. They must have access to expert support and advice, to make sure they can provide an environment where more neurodivergent children can thrive. It is clear that many are already managing transitions well – but there is a need to improve the ongoing support after transition. We urge partners across York to work together to develop a neurodivergent schools charter. We acknowledge that funding will need to be found for this, and will reach out to local academic institutions to gauge appetite for working on this with us, neurodivergent families and local schools.

But beyond this, we need to see a change in approach – recognising these families as experts in their own child, and working together to wrap support around them. There are opportunities in the increased focus on integrated care, and multi-disciplinary team approaches, and serious consideration needs to be given to how some of this work addresses the challenges outlined throughout this report.

There are also inequalities across Humber and North Yorkshire in terms of access to services. We call for change in particular around support with sleep. In York, we have a more robust offer for under 5s than our neighbours in North Yorkshire, through the Healthy Child Service. But no



Appendices

Appendix 1: Glossary

Term	Definition
Accessible Information Standard	The Accessible Information Standard is a legal obligation introduced in 2016. It applies to all organisations that provide NHS care or publicly funded adult social care. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a
Alternative Provision (AP)	disability, impairment or sensory loss. Alternative education options for children who cannot go to mainstream schools, for any reason. In York, this includes services like Danesgate School, Medical Tuition Service, Teach Me Happy, and Bilborough Country Classrooms.
Attention deficit hyperactivity disorder (ADHD)	ADHD is a condition that affects people's behaviour. People with ADHD can seem restless, may have trouble concentrating and may act on impulse. In this report, we include three different types of ADHD including inattentive, hyperactive and impulsive and combined when we talk about ADHD.
Auditory Processing Disorder (APD)	APD is where you have difficulty understanding sounds, including spoken words. It often starts in childhood, but some people develop it later. It cannot be cured, but there are things that can help. Testing for

APD is not usually done on children under the age of 7. The NHS defines autism as a lifelong **Autism** condition that affects how a person communicates with, and relates to, other people. The Autism Spectrum Quotient (AQ) is a 50 AQ – Autism Spectrum item self-report measure used to assess **Quotient** traits of autism in adults and adolescents aged 16 years and over. Dyscalculia Dyscalculia is a specific and persistent difficulty in understanding numbers which can lead to a diverse range of difficulties with mathematics. Dyslexia Dyslexia is a common learning difficulty that mainly causes problems with reading, writing and spelling. Dyspraxia Dyspraxia (also known as developmental coordination disorder) is a condition affecting movement and coordination in children and adults. Dyspraxia affects all areas of life, making it difficult for people to carry out activities that others can take for granted. Emotionally Based Schools Avoidance - a term **EBSA** used to describe children and young people who experience challenges in attending school due to negative feelings such as anxiety. It is thought to currently affect around 3 in 10 children of secondary school age. Education, Health and Care Plan - An EHCP can **EHCP** be put in place to support a young person with special educational needs (SEN) if their educational setting feels they don't have the

resources required to support them. The EHCP

	will identify the child's particular needs, and
	what additional support should be put in place
	to meet those needs. An EHCP can stay in place
	until the young person reaches the age of 25 if
	they remain in education to that age.
EOTAS	Education Otherwise Than At School – the legal
	mechanism whereby a child with an EHCP can
	receive educational provision despite being
	unable to attend school.
EP	Educational Psychologist – educational
	psychologists assess children's learning and
	emotional needs; design, develop and support
	therapeutic and behaviour management
	programmes; support other professionals by
	advising on the best approaches to use. There is
	a national shortage of Educational
	Psychologists in the UK with many local
	authorities finding it hard to meet demand for
	their services.
MASH	Multi Agency Safeguarding Hub – York's multi
	agency single point of contact for anyone with
	concerns about a child. Their role is to make
	sure children get the right support. MASH is also
	the home of the Early Help team – who provide
	extra support for families who need it.
NICE	National Institute for Health and Care Excellence
OCD	Obsessive compulsive disorder
PDA	Historically Pathological Demand Avoidance
	syndrome. However, many Autism professionals
	suggest it be renamed Pervasive Drive for
	Autonomy.
QbTest	A digital technology recommended by NICE for
	young people aged 6 to 17 that can help speed
	up the diagnosis of ADHD.
<u> </u>	

Salvere	A not for profit community interest company
	who support people to employ their own health
	and care support workers.
Section 19	Section 19 of the Education Act places a duty on
	local authorities to make suitable alternative
	education available for children of compulsory
	school age who cannot attend school because
	of illness, exclusion, or for any other reason.
TAF	Team Around the Family – used to get everyone
	together who is or could be working with your
	family. They work together to identify family
	needs and strengths, and the best way to put in
	place any extra support needed. TAFs are
	voluntary.

Appendix 2 – Services and support

Local Services

The Land

The Land's aim is to support families of children with high anxiety who find it difficult to leave home. They are currently creating a tranquil nature reserve offering small group sessions, parent carer meet ups, and workshops.

Email <u>info@theland.org.uk</u> https://theland.org.uk

York Disability Rights Forum

York Disability Right Forum (YDRF) is led by disabled people and works to promote equal access to human rights for all disabled people who live, work, or study in York. ND Parent Uprising is a project started in recognition of the fact that parents of ND kids often feel isolated and alone in their experiences.

Email: <u>hello@ydrf.org.uk</u> <u>https://ydrf.org.uk</u>

Parent Carer Forum York

The Parent Carer Forum York is an independent charity who is commissioned to represent the voice of parent carer lived experience in York. We represent parent carer views to Education, Health and Social Care to inform development of services for young people with additional needs aged 0-25.

Email: connect@pcfyork.co.uk

https://www.parentcarerforumyork.org

Their website includes a useful resources section with information about York's Local Offer, SENDIASS service, Raise York and CAMHS amongst other useful links.

https://www.parentcarerforumyork.org/useful-resources

York Carers Centre

York Carers Centre is an independent charity and a network member of the national Carers Trust. We work in partnership with carers, statutory and voluntary organisations to ensure unpaid carers throughout York have access to confidential information, advice and support. We work with carers to influence positive change in service delivery with local government, employers, schools and health providers.

York Carers Centre supports carers of all ages:

- Adults
- Young adults (18 to 25)
- Young carers (5 to 18)

Tel: 01904 715490

Email enquiries@yorkcarerscentre.co.uk

https://yorkcarerscentre.co.uk/

York Inspirational Kids (YIP)

Have a number of Facebook groups including York Inspirational Kids main page, with 16 channels, York Hemi Kids for parents and carers of children with hemiplegia, York Inspirational Adopters for families who have adopted a child with additional needs, and York Ausome Kids for parents and carers of children with autism. Details are on their website or find them on Facebook

https://www.keyworking.co.uk/what-we-do.html.

YDANN - Your Dyslexia and Neurodiversity Network

A support group for adults impacted by Dyslexia, Dyspraxia, Irlens and ADHD. They meet to talk, share.

Contact via Facebook:

https://www.facebook.com/YorkshireAdultNeurodiversityNetwork/

York Neurodiverse Adults Meetup

An opportunity to meet with other autistic, neurodiverse adults in York for informal chat, board games, and cards etc.

Venue: De Grey Building, Room 019 at St John's University

Date: The second Monday of every month

Time: 7.00pm to 9.00pm

https://www.facebook.com/groups/422784726311376

The Mind Garden - York support group for neurodivergent families Offer support for children, young people and their families whether you have received a diagnosis, are on the waiting list or displaying signs of neurodivergence. Website has details of the support they offer:

Email: hello@mindgardenyork.co.uk

https://mindgardenyork.co.uk/neurodivergent-families/

The Island

Local mentoring service for young people:

https://www.theislandyork.org/how-to-support-neurodiverse-children

TEWV Single Point of Access (SPA)

01904 615345 - to self refer for assessment

Gender Identity Services

Tel: 0113 855 6346

Email gid.lypft@nhs.net

https://www.leedsandyorkpft.nhs.uk/our-services/gender-identity-service/

or contact the Gender Outreach Workers on 0800 183 1486

York SENDIASS (Special Educational Needs and Disability Information, Advice and Support Service)

York SENDIASS can help you understand support in educational settings and advise on a range of issues, your rights and the law, writing and seeking an EHCP or solving disagreements and helping when things go wrong.

https://www.yorksendiass.org.uk/

National Resources

Autistic Girls Network – a small registered charity working to support, educate, and bring change. The website contains lots of resources for individuals, families and professionals about autistic girls and gender diversity among autistic people https://autisticgirlsnetwork.org/

Spectrum - is a multi-award-winning, parent-led children's charity. They provide events, sessions, and support for families of children with Autism, additional needs, learning difficulties, and disabilities. Membership is free.

Tel: 01223 955404 M-F 10-4 Email: hello@spectrum.org.uk

https://spectrum.org.uk/

The Sleep Charity

Tel: 01302 751416

Email: info@thesleepcharity.org.uk

https://bit.ly/SleepandADHD

Cerebra – provide a range of information guides for parents, run an expert sleep service and a legal rights service, have a bespoke equipment and modification team, and a toy and book library.

Email: sleep@cerebra.org.uk

https://cerebra.org.uk/

PDA Society

https://pdasociety.org.uk
Introduction to PDA youtube video – the PDA Society
https://www.youtube.com/watch?v=diHUmhPWXUY

ADDitude

Website with guidance and support for living better with ADHD and its related mental health conditions.

https://www.additudemag.com/

ADHD Foundation

General contact details:

Phone: 0151 541 9020

Email: info@adhdfoundation.org.uk

They also have a parenting team, who run courses and who might be able to provide more specific support and advice, this is their email address:

parenting@adhdfoundation.org.uk

https://www.adhdfoundation.org.uk/services-for-families/

ADHD and you

Large range of resources including guide for parents, templates and checklists of questions to ask school about adjustments they could make and support they could offer.

www.adhdandyou.co.uk

Specific questions to ask school which might be helpful in requesting reasonable adjustments at school:

https://www.adhdandyou.co.uk/child-with-adhd/helping-your-childseducational-development/

Ambitious about Autism

A national charity for children and young people with autism, has a lot of resources, including information about education at different stages and for parents on assessment processes.

Email: <u>info@ambitiousaboutautism.org.uk</u> <u>https://www.ambitiousaboutautism.org.uk</u>

Autistic Minds

Run HelpHub, a national helpline providing support, information and guidance to autistic adults, parents of autistic children and professionals working with the autistic community.

https://autisticminds.org.uk/how-we-can-help/the-helphub/

The National Autistic Society

A website with various resources and a number of specialist helplines, including a parent-to-parent emotional support helpline, website:

https://www.autism.org.uk/

https://www.autism.org.uk/advice-and-guidance/topics/education - information about rights in education

Neuroclastic

A collective of Autistic people responsive to the evolving needs and trajectory of the Autistic community. Publishing autistic voices, to catalogue the intersectional experiences, insights, knowledge, talents, and creative pursuits of Autistics. They follow a unique model of interdependence, leveraging the passions, skills, and specialisations of contributors to create a living repository of information cataloguing the autistic experience.

https://neuroclastic.com/

IPSEA: Independent Panel for Special Education Advice

Registered charity providing advice on LEA's legal duties towards children with special educational needs.

Advice line: 0800 018 4016 or 01394 382814

General enquiries: 01394 380518

Specialist Autism Services

Works exclusively for and with adults (18+) on the autism spectrum and their families since 1999. A non-profit organisation that works with the charity Sacar to provide autism specific services across the Yorkshire region.

They provide a range of services including group social skills workshops (through an autism-specific learning programme), information and guidance, autism-specific counselling, employment support, autism awareness training and community outreach support. Under the name Autism First they also provide bespoke support for adults with autism and additional needs.

https://www.specialistautismservices.org/

Appendix 3 – PMG statement on Right to Choose and Shared Care

Priory Medical Group statement reflecting their position regarding Right to Choose and Shared Care arrangements:

https://www.priorymedical.com/latest-news/updated-private-shared-care-policy/

Private shared care agreements

ADHD in adults

We have been reviewing PMG's guidance around adult ADHD and shared care with the multiple providers that we get these requests from. Having discussed with other local practices and the local LMC over the last few months we have published an updated policy that will go live on 1st June 2024.

We will only agree to shared care guidance with the Retreat – the locally NHS commissioned service. To ensure safe, well-monitored and evidence based prescribing, we will not be accepting any new or requests for ongoing prescribing from any other clinics.

Any patients with shared care agreements we have already accepted will be offered a referral to the NHS medication review service via the Retreat. We will continue prescribing under shared care guidance with the Retreat or these patients can remain under their Right to choose or private provider but we won't be taking over responsibility for prescribing medication going forward.

See policy here (https://www.priorymedical.com/seecmsfile/?id=78) - this will be reviewed regularly.

ADHD in children

Similarly, we will not be taking on any shared care agreements from Right to Choose or private providers for children with ADHD. We will take over

shared care agreements with the locally commissioned NHS service via TEWV (Orca House is their community base for children and young people's services. It is also known as York CAMHS).

Gender Identity Disorder

PMG will not take on any new requests for shared care agreements (SCA) for GID medications. As a local system, we have raised concerns about patient safety in the absence of a funded, formal shared care agreement process with NHSE, as unmonitored hormone prescribing can cause serious complications to a patient's health.

Patients already prescribed hormone therapy by PMG will continue to be reviewed, but should complications or concerns arise- the medication may need to be stopped or reduced and re-referral back to the Leeds Specialist Clinic- as there is no current SCA support for prescribers.

Unfortunately we are unable to continue prescribing for patients that newly register with us, even if stable and prescribed by your previous practice. We ask that you approach your private provider or NHS GID clinic for ongoing prescriptions.

Appendix 4 – Views from an independent social worker supporting parents with EHCPs

LAs rarely deliver anything in timescales - this leaves parents frustrated and children without the support they are entitled to.

Despite being the responsibility of the authority, LAs do not have oversight of the 'contracted out' EHCP review - they rely on schools who 'convene' reviews to do everything accurately and in time (schools do not). Where reviews are convened by schools, there is no LA oversight regarding whether they are in timescales. Schools delay and delay because of workload and availability of invitees.

Example - the school will convene the meeting later than the review date. They may fail to consult with health and care, so an incomplete review is conducted. They complete the review paperwork late and the LA compounds this by accepting poor evidence or a poorly constructed plan on the basis that 'if the school didn't consult, it must not have been relevant' and 'if it's a bad plan, it's the school's responsibility'. The LAs show no professional curiosity. The system relies on parents and/or a good advocate to say what's missing and what's going wrong.

Parents often do not know they can use an advocate.

Transfers in and out from neighbouring areas continue to be a problem (e.g. York to wider North Yorkshire or vice versa) in respect of timescales; these do not appear to happen automatically – the systems rely on parents chasing both LA teams.

Issues with the quality of plans

The plans do not clearly articulate needs. Often there are some (perhaps six) learning goals clearly articulated by schools, but they fail to encapsulate the wider support needed - an example might be a wheelchair using young person has support for writing using a tablet/writing aid, but no consideration for how the young person is going

to get from one classroom to another, access the toilet, change themselves etc.

There appears to be little oversight in terms of how realistic the aims of the plan are, or how appropriate. Example - I have seen a plan where the main aim was for 'correctly formed cursive script'.

Needs are generally identified in relation to 'education provision' - which schools see narrowly as the learning targets, not broader support required.

There is a consistent failure to address the isolating nature of SEND and plans do not routinely reflect the support needs around this. Support for forming friendships, interacting with peers, or taking any part in social exchanges is limited or missing.

Child's needs not being met. There is an inconsistency around how it is appropriate to support/respond to a young person where their behaviour is 'unwelcome' - stimming etc.

Support around a young person's coping strategies is a need, but mostly not articulated as such as it does not sit anywhere obvious in the plan paperwork.

Language used - parents who have fought very hard for a plan may prefer diagnostic labels to be used - e.g. autistic - there seems to have been a shift toward phrases like "neurodivergent traits" - parents should be asked how their child's condition/diagnosis/issue should be described (the young person should be asked where possible).

Phrases like 'what am I going to do or learn to meet my outcomes' is a weird shift of responsibility to the young person. How about 'what is the school hoping to teach this young person, how does the school hope to do that' and 'how will success be measured'? There should be some sense of why these things are the most important (who decided them and why parent involvement in this part is usually entirely absent - I go back to my

earlier example of a school thinking the most important goal for a young person was to write in cursive script!). The young person has no accountability here - how can they have? The school is accountable (as is the LA) - so why is it all "what am I going to...."

Layout - LAs have their own interpretations of the layout of an EHCP plan - these are confusing and make transfer difficult. The logic of the layout is unclear - EHCPs often have a need, an aim and then support. Such a formulaic approach is oddly constructed and excludes the broader picture.

The rules around updating the plan are bizarre - outdated data is struck through rather than deleting. It makes people involved reluctant to make changes because 'it looks messy' - it dissuades change and the idea of the plan should be that it is responsive, a living document.

I would love to see big changes every year - young people do change a lot in a year, but I often see tiny variations on a theme, so no forward progress. In fact, EHCPs fail to be forward looking - they read as what's happening now, rather than what do we want to happen in the coming year.

Schools are acting as gatekeeper to an EHCP – parents are frequently given the impression that educational psychologist input is required prior to requesting an assessment. This is not the case. An advice leaflet for parents would be helpful – setting out their rights and each agency's responsibilities.

Nobody is on top of health - health input is rarely received and the NHS does not follow the agreement (they do not have a list of young people with review dates, they routinely fail to contribute anything and the reason for this is unclear). Health advice is often missing from plans.

Rushed reviews - reviewing a plan is a big job, it should take time, it should not be rushed, it should not be seen as a paperwork exercise. This is the



Appendix 5 – Healthwatch York issues log entries

Issues logged between July and September 2024

Person's son (8) has been on the autism assessment list for four years. They have been told it will be another 12 months before their son gets an assessment. The person has just been diagnosed with ADHD themselves and they have been waiting for 18 years for that diagnosis.

Person has been waiting for years for an ADHD assessment and diagnosis. She is also worried about her son but has been told he is too young to have an assessment despite signs and behaviour issues.

Man has a number of mental health conditions and ADHD (and their sons, age 13 and 9 also have ADHD). He was assessed and diagnosed privately and has been paying for medication. He was told he wasn't eligible for support via the NHS for either himself or his children. He is having problems affording the medication so has stopped taking his medication but it has left him suicidal to the extent that he has attempted suicide twice in the past few months. When he approached the hospital in crisis, they turned him away, but the crisis team helped. He has tried his GP practice but he has been told there is a ban on GPs talking to people about condition controlled medication and that there is a two year wait for a medication review via The Retreat. The crisis team told him that York is a bad area regarding ADHD medication and doctors can't talk to you about it you need to go to the Tuke Centre but there is a five year waiting list for an assessment. He is finding it all very scary and doesn't know where to turn. He is thinking of registering with a GP in Harrogate as he has a friend there who is getting medication.

Person's great niece is autistic. They are struggling at school and their father (single parent) isn't sure where to turn for help.

Person is struggling with a child who can't sleep. She said that her daughter aged 13 had struggled to sleep. Her daughter is autistic and has help from CAMHS. She had been on a waiting list since March and has now been told there is no sleep service in York. She also said that the transition to adulthood with mental health services and sleep support is a nightmare. She has three children who are all autistic and who all have issues with sleep. Her eldest child was prescribed melatonin which really helped. But when he reached 18, he was told that they don't prescribe melatonin for adults, was given a three day supply and that was it. It took him 2 - 3 hours to relax and so he started self-medicating with alcohol. This later led to him having to seek help for addiction. The person's second child was also prescribed melatonin and is still receiving it even though she is 18. But when the person asked about melatonin for her 13 year old, she was told no. The child's lack of sleep is significantly affecting her, her schooling and the rest of the family. "It is absolutely awful and there is no help."

Issues logged between April and June 2024

Person's daughter is 15 and has complex issues including mental health issues and she is autistic. The problems have been building for a long time and they are in touch with CAMHS. It was clear she was going to need a hospital admission for the past four months, but nothing was put in place. Now she has been sectioned. She is in York Hospital on a children's ward with young children as there is no appropriate mental health bed available. "All the healthcare professionals say there is nothing they can do to help as my daughter is not in the right place and she isn't." Mother said: 'I am

astonished that TEWV only started looking for a bed for her when she was sectioned even they knew this was going to happen for months'.

Very poor support from TEWV and school

Person's son is now out of school. He is neurodiverse and has severe anxiety. The school has not been helpful and neither has TEWV. The person is trying to find other support to help their son and them.

Issues logged between January and March 2024

Assessment has taken a year

Person shared their experience of trying to access help through Orca House "They have not helped, they haven't contacted the school, absolutely shocking service."

Still waiting for a CAMHS assessment

My child has been waiting for a CAMHS assessment since 2021. In April 2023 we were told his file had been lost. Three weeks later I was told it had been found, but we are still waiting to be seen as my child's mental health spirals and no one will confirm we're at the appropriate place in the queue (i.e. joined 2021, not when the file was rediscovered) or how much longer we will have to wait.

Lack of mental health care for child

My child (13) has had EBSA (Emotionally Based Schools Avoidance) for more than five years now. We eventually got them autism and ADHD diagnoses at ages nine and 11 (I had been trying to get these since kindergarten). They were prescribed ADHD meds but couldn't take them as they can't take pills. They began showing trauma symptoms after a toxic friendship, but we were unable to get help from CAMHS and paid for private therapy, without a diagnosis because we could not afford both. They have been displaying escalating anxiety symptoms for more than six years, in the last two years including panic attacks and dissociation. They are further damaged by the

evidence that nobody outside the family cares. We finally got some support last year, but the Face Your Fears intervention did not give them any tools that I had not already taught them. Now they are displaying symptoms of depression as well. They have desperately low self-esteem and despite a move to a specialist school which does not pressure them, and which they cope with if we can get them in, we are still failing to get them there three days out of four. This isn't surprising as they struggle to get to their hobbies too, often failing or arriving for the last five minutes. Their sleep has been severely disrupted for five years. We feel very alone. My spouse and I are struggling to care for them and work. We feel they desperately need to see a child psychiatrist, but this is not on offer and I don't even know how to find one. Does Right to Choose exist for CAMHS? Are there even any private ones? We can't find out. I am extremely worried about the things they are saying about themselves, their selfesteem is nothing. But they are not - that we know of - self harming, so there's no support. I can't bear to see how bad they are and it's not enough?! The GP is currently monitoring their weight but wouldn't refer them back to CAMHS "because nothing would happen".

How do I access autism support for daughter?

I hope you might be able to advise on a route for diagnosing autism in the case of a child. It's my daughter, she is 13 years old. Few weeks ago I read a post on a Facebook – a lady shared her experience with her autistic daughter and I've realised that it looks very much like us. (I've remembered several people mentioning before that it might be the case with my daughter, including our GP. But then I didn't want to accept this possibility. Also I was so busy with survival, no room for dealing with that.) But now, as I realised that it can lead to some serious issues, I've decided to learn what it is about and learn how to better support, organise and live our lives so that it is safe and bearable for my daughter. At times it is not, unfortunately, for her.

Would you please be able to direct me? Perhaps there are some communities, some organisations, etc. providing some special advice and support with such cases?

Issues logged between October and December 2023

Short breaks and need for a diagnosis

Early help short breaks. I applied for short breaks for my daughter in the summer. At that time it allowed you to apply without the child needing to have a diagnosis. We never got anywhere as a couple of months later they announced they were closing the scheme, and would then relaunch and everyone would have to reapply. The new form was launched this week. However, the first page says we need to provide the diagnosis, date of diagnosis and by who. My daughter does not have a diagnosis. Interestingly I have been told this year by TEWV for myself that they don't find diagnosis helpful, it's about meeting the need, and by CAMHS 'What do I think a diagnosis will do for her anyway'! She has a My Support Plan and receives Disability Living Allowance (DLA), but according to Short Breaks she isn't eligible for support. This really feels like we are not being believed!

Shortage of ADHD medication is having a significant impact on mental health and ability to act as a young carer.

M cares for mum whose wellbeing and capacity fluctuates, impacting her ability to consistently advocate for M's needs. M has a diagnosis for ADHD which requires medication in order to help him regulate his emotions and sleeping patterns. It is essential that M is prescribed a specific ADHD medication due to a known health condition. Due to the challenges around the supply of ADHD medication currently, M's mum is having to contact different pharmacies and travel across York in taxis to try and source this – this is a challenge due to her own support needs and also a financial challenge. M is also currently trying to access a diagnosis for autism with CAMHS – M's mum is

struggling with this process, made worse as CAMHS seem to have lost the paperwork on two different occasions. M is struggling to stay in school due to his ADHD not being managed and the impact this has on his sleep and wellbeing. Although it's been highlighted that M has other possible diagnoses, these are not currently being addressed. M is also navigating the challenges of growing up and supporting his mum. As a result M feels very isolated from his peers; he feels different to other people his age and finds it hard to maintain friendships. M has been missing from home on occasions, finds it impossible to engage with mainstream school and has been in mental health crisis resulting in police interventions. When asked, M states that his top priority is getting help with his sleep and regulation. He feels this will be made possible by securing a consistent supply of ADHD medication. He's been referred to Early Help for Targeted Intervention and a crisis meeting has been held with CAMHS.

Appendix 6 – Supporting statement from a family carer

My name is Pauline Rogers, 85 years of age and the mother of Alison, who has moderate learning disabilities and who was diagnosed in her 40's with autism. Alison is now 60 years old. I am delighted to have been asked to support Vanessa and her whole family in their inspired quest to provide meaningful services for those unable to access existing provision as a consequence of their individual difficulties.

In around 2010 after having been involved with various groups in York, actively working towards improving the lives of people with learning disabilities and their families, I had become frustrated and demoralised by the bureaucratic process which involved meeting after meeting with much being said, but with little real improvements in families lives. I set up a group of 7 mothers of children of various ages who had different learning disabilities. I wanted to find a new approach to getting the voice of family carers heard.

We started writing about our lives and eventually self-published our book, in 2015 which we called "Uncut Cords", a reference to our feelings of always being connected to our child. I still believe that sharing our lived experiences with the general public and all those working in the learning disability field is vital to get carers issues and rights at the top of the governments agenda to achieve a better quality of life for all carers and their families.

In the final chapter of the book entitled "Hopes and fears for the future" I say "Alison's life now is better than I could have dreamed it could be, but that is in spite of the social care system in this country, not because of it. It has been the culmination of a great deal of determination and effort by the people who care about her and is testament to their commitment to ensure that Alison is as happy, secure and independent as it is possible for her to be. Many of the obstacles we had to overcome were products of the social care system – the fact that she had to live in so many different places, often with people she didn't get on with, the fact that her autism wasn't diagnosed until she was in her 40's, the fact that family carers get

so little support that many of us crack under the strain, unable to cope any longer with the stress of trying to do our best for our son's or daughters. This has to change. At the age of 85, despite my best efforts to let go, I am still very involved in my daughters life, as current support agencies are limited by the budgets that the Council provides and are unable to provide the level of care and support she needs. She has been deemed to have 'capacity' in most areas of her life. This is plainly not the case. In terms of 'capacity' to manage her financial affairs, she does not understand very much about money, consequently she pays for purchases with notes as she is unable to count out the required coins. Cheques she sees as bits of paper. I have only recently discovered that no-one has an overall view of her finances, including things like checking what her utility and insurance companies are charging.

My wider vision is for a completely different approach, a kinder, more compassionate system, which actually supports the whole family, instead of constantly creating barriers and difficulties.

I have been greatly saddened after talking to current family carers of young people to find that little has changed in their lives. Getting the right sort of support for their children is still fraught with difficulties. I cannot understand why the social care system fails to care and support our families.

The huge amount of thought, planning and physical work already carried out by Vanessa and her family at The Land project is truly awe-inspiring and could result in many young people who cannot access the provision available to them, receiving the sort of input that will change their lives. It is the most exciting and innovative project with new views of the future for these children, which is so badly needed in York and I fervently hope the City of York will support it wholeheartedly.

healthwatch York

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Health and Wellbeing Board

22 January 2025

Report of Jane Timson, Independent Chair of City of York Safeguarding Adults Board

City Of York Safeguarding Adults Safeguarding Board Annual Report 2023/24

Summary

 The Annual Report discusses the work of the members of the City of York Safeguarding Adults Board to carry out and deliver the objectives of the strategic plan during 2023/24. The Annual Report is at **Annex A** to this cover report.

Background

2. The City of York Safeguarding Adults Board (CYSAB) is a statutory and multi-agency partnership that leads the strategic development of safeguarding adults work across York. As specified in the Care Act, the CYSAB includes three core statutory members, that is, the City of York Council, NHS Humber and North Yorkshire Integrated Care Board, and North Yorkshire Police Authority. Our membership is also made up of nominated lead representatives from a wide range of non-core partner agencies, who actively contribute to the work of the Board.

The CYSAB has three core duties, in accordance with the Care Act 2014:

- Develop and publish a strategic plan setting out how we will meet our objectives and how our member and partner agencies will contribute
- Publish an annual report detailing how effective our work has been
- Commission Safeguarding Adults Reviews (SARs) for any cases which meet the SAR criteria.

Main/Key Issues to be Considered

3. A detailed report is at **Annex A** to this report and contains a number of themed sections including information about the City of York Safeguarding Adults Board; what the CYSAB has recently achieved, strategic priorities for 2023-24; looking ahead to the next year and the four core themes for 2024-2025.

Consultation

4. This report was developed in conjunction with all partners represented on the City of York Safeguarding Adults Board.

Options

- 5. Whilst there are no specific options for the Board to consider Health and Wellbeing Board members are asked to:
 - note the contents of the annual report 2023/24
 - consider how they can contribute to the joint work of the Board and note strategic plans for 2025 onwards and how they can be supported. Potential themes for CYSAB Strategic plan 2025-28 include:
 - > Governance and learning lessons
 - > Improved Response to young people at risk of exploitation
 - > Rough Sleeping, Homelessness
 - Self-Neglect and Hoarding

Analysis

6. Not applicable.

Strategic/Operational Plans

7. Safeguarding adults at risk of harm or abuse is a fundamentally important issue throughout the York Joint Local Health and Wellbeing Strategy 2022-2032

Implications

• **Financial**: There are no direct financial implications arising from this report. Funding for the Safeguarding Adults Board is provided by the three core statutory members, that is, the City of

York Council, NHS Humber and North Yorkshire Integrated Care Board, and North Yorkshire Police Authority.

- Human Resources (HR) No Human resources implications
- Equalities In compliance with existing policies
- Legal: The report highlights the strategic direction of the Safeguarding Board and its partners. It is in line with the duties and responsibilities set out in the Care Act 2014. There is a statutory duty for the Safeguarding Board to produce an annual report setting out the work of the Board to improve the outcomes for Adults at risk of abuse.
- Crime and Disorder:
- Information Technology (IT): City of York web services support the hosting of the CYSAB website and the communications team have provided the design work for the annual report and will also be doing the design work for the new strategy.
- Property: no property implications

Risk Management

The Safeguarding Board is required to produce an annual report and would be in breach of the legislative requirement if it failed to do so.

Recommendations

Health and Wellbeing Board members are asked to:

- note the contents of the annual report 2023/24
- consider how they can contribute to the joint work of the Board and note strategic plans for 2025 onwards and how they can be supported. Potential themes for CYSAB Strategic plan 2025-28 include:
 - Governance and learning lessons
 - > Improved Response to young people at risk of exploitation
 - Rough Sleeping, Homelessness
 - Self-Neglect and Hoarding

Reason: to keep the Health and Wellbeing Board informed of the work of the CYSAB

Contact Details

Catherine Law Safeguarding Adults Board report:

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Chief Officer Responsible for the

City of York Safeguarding Michael Melvin, Director of Adults

Safeguarding

City of York, Adult Social Care, Assessment and Safeguarding

077836380774

Jane Timson Independent Chair of the City of York Safeguarding Adults Board

Wards Affected:

ΑII

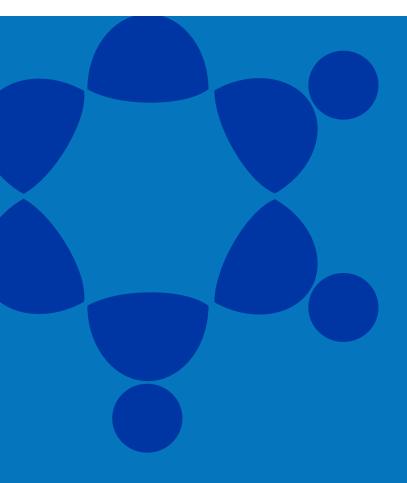
For further information please contact the author of the report **Background Papers:**

Annexes

Annex A: Annual Report of the City of York Safeguarding Adults Board https://www.safeguardingadultsyork.org.uk/downloads/file/33/annualreport-2023-to-2024

Glossary All abbreviations used within the Annual Report are explained within the document





Annual Report 2023-24

OUR VISION

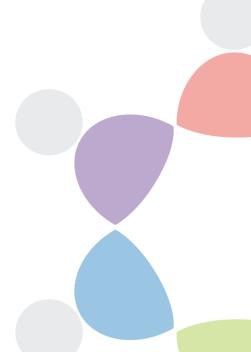
For individuals, communities and organisations to work together to ensure that the people of York can live fulfilling lives free from abuse and neglect and to ensure that safeguarding is everybody's business.

For more information visit: safeguardingadultsyork.org.uk



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Foreword

I have been the Independent Chair of the City of York Safeguarding Adults Board since 2018 and this is my last year as I retired in May 2024. Pressure on safeguarding services still remains across the city as a result covid recovery and the cost-of-living crisis. The resilience of safeguarding services has remained consistent throughout 2023-24 and the individuals and teams across the partnership have continued to work incredibly hard to deliver effective outcomes for adults with care and support needs, their families and carers.

Mental health and self-neglect are still significant areas of need including pressure from adults who are vulnerably housed or facing homelessness. We have continued to work as a partnership to meet the needs of these areas and I would like to pay tribute to colleagues across all services in adult safeguarding, who have continued to play a vital role in improving the outcomes for those adults facing these risks, helping to prevent abuse and neglect.

I would like to thank colleagues working to ensure the Board not just fulfils its statutory duties but also play key roles in improving the quality of life for some of the most vulnerable in our communities.

The Board has been fortunate enough to increase the support for running of the board and has successfully appointed a new

Business Manager who starts in May 2024. This will add a much-needed resource to allow the Board to meet its ever-increasing workload and support the increase in referrals for safeguarding adults reviews. The pressure on colleagues has been significant over the last few years, and so it is vital for the future of safeguarding services that both within the partnership and in individual organisations, we find a range of ways to support colleagues well into the future.

I am pleased and proud to have got the Board into the position it is now and wish to thank all my colleagues and partners who have come along with me on this journey. With the capability of the new Board Business Manager and a new Independent Chair I can see the Board going from strength to strength as I step down to make way for positive changes.



Tim Madgwick

Independent Chair, City of York Safeguarding Adults Board (CYSAB)

1. About the Board

Who we are:

The City of York Safeguarding Adults Board (CYSAB) is a statutory and multi-agency partnership that leads the strategic development of safeguarding adults work across York. As specified in the Care Act, the CYSAB includes three core statutory members, that is, the City of York Council. NHS Humber and North Yorkshire Integrated Care Board, and North Yorkshire Police Authority. Our membership is also made up of nominated lead representatives from a wide range of non-core partner agencies, who actively contribute to the work of the Board.

What we do:

The work of Safeguarding Adults Board is directed by legislation the Care Act 2014. The Act sets out the core purpose of the Board is to ensure that local safeguarding arrangements are effective and take account of the views of the local community. The Board also seeks assurance that safeguarding practice is person-centred and outcome focused. The purpose of the CYSAB is to help safeguard people who have care and support needs. Its main objective is to improve local safeguarding arrangements to ensure partners act to help and protect adults experiencing, or at risk of, neglect and abuse.

Our statutory duties:

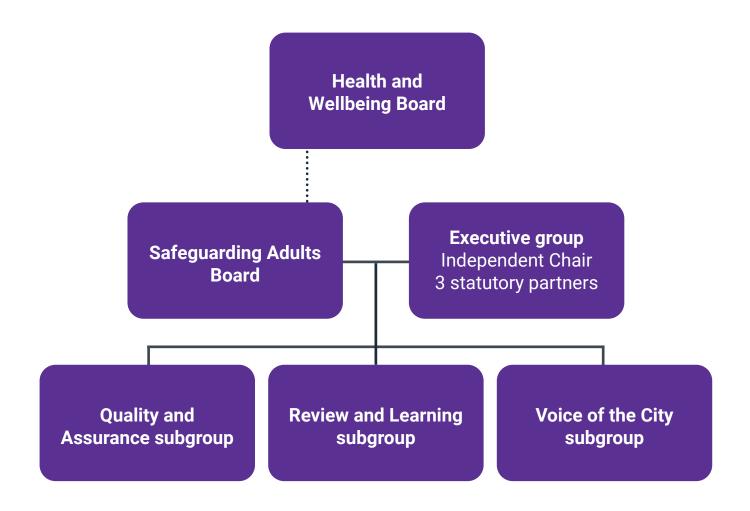
The SAB has three core duties, in accordance with the Care Act 2014:

- Develop and publish a strategic plan setting out how we will meet our objectives and how our member and partner agencies will contribute
- 2. Publish an annual report detailing how effective our work has been
- 3. Commission Safeguarding Adults Reviews (SARs) for any cases which meet the SAR criteria.



How we function:

As a Board we meet four times a year and have four sub-groups. These are the Executive Group, Quality and Assurance, Review and Learning and the Voice of the City.





2. The Voice of the Adult

J is a young adult who has several complex mental health issues, and experienced childhood trauma and abuse. J is estranged from their family and has a limited support network. J has been well known to Adult Safeguarding and other services; they have difficulties with attachment and abandonment issues and struggle to build positive relationships with professionals due to feeling let down by services previously.

Getting safeguarding and support

J was referred to safeguarding due to concerns regarding contact with their previous abuser, and they were also experiencing harassment. J felt unsafe in their home, and this led to them sleeping in vulnerable accommodation and placing them at further risk of harm and exploitation.

What did the adult want to happen

J expressed that the outcomes they wanted to achieve from the safeguarding process were to be rehoused away from their current neighbourhood, and to receive trauma informed therapy from mental health professionals, who have often discharged them from services. A key outcome they also described was to be listened to without feeling judged.

What was achieved for the adult

A number of partners were involved in the safeguarding enquiry in addition to the City of York Safeguarding team, including Independent Domestic Abuse Service (IDAS), Primary Care (GP), City of York Local Area Communities Team and Housing Team, in addition to City of York mental health services. A series of safeguarding and multidisciplinary meetings were held.

The safeguarding worker advocated on J's behalf and was able to challenge the assumptions of others, with an emphasis on trauma informed practice. The worker met with J on various occasions including face to face and telephone contact, and this led to a positive and trusting relationship being established.

J is now receiving input from mental health services and has been rehoused. As part of the safeguarding process J was provided with a range of support including practical support with budgeting and managing their accommodation. J is also no longer in contact with their previous abuser.

Voice of the person

J gave some brief feedback during face-to-face meetings but, they struggled to articulate their thoughts when speaking in person, so they chose to provide further feedback in a letter, about what the safeguarding support has helped them achieve. J was invited to attend the safeguarding meetings but they were happier for their safeguarding workers to advocate their wishes and views on their behalf. J described how things have changed for the better for them and that they are now safe.

J feels their voice has been heard and is now hopeful that they can trust professionals, and that they want to help.

J emphasised that they were spoken to like a 'normal person'.

'You've genuinely made me feel so heard and understood and like I can tell you anything without judgement. You've helped me do things that I never thought I would be able to do.'

'Because unlike other professionals you genuinely do help and care. Others deserve that too, especially since you make people feel safe and I am safe now.:

'Thank you for all your help over the last year, I am so lucky to have been able to meet you, you have changed things for the better for me. To have someone I can trust and rely on to understand me, listen to me and be there for me. You've proven to me that good people do exist, and that despite my frequent doubts, you have made me feel worthy of kindness. You've always made me feel no matter what I tell you, I will always be heard and empathised with.'

You have made a difference to my life, not just being safe and managing things better, you've proven that I am able to be cared about, liked. Which as you know, is something I believed wasn't possible for me. The fact that you have managed to change my way of thinking, my ability to trust people, to open up and not feel judged or ignored, is something I cannot be more grateful for.'

- J

3. What the Board has achieved at a glance

Transitional safeguarding protocol:

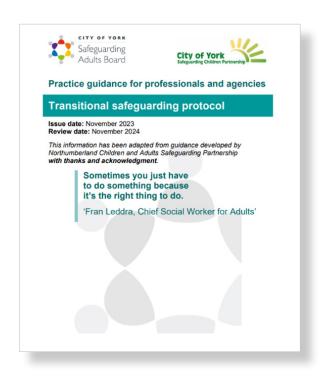
Developing an all-age approach to safeguarding is a key priority for the Board, who recognise that abuse and neglect is likely to continue post 18 years old, and that adults at risk are targeted due to their vulnerability irrespective of age.

Learning from reviews has found that transitioning from childhood to adulthood can be extremely challenging and complex, particularly from a safeguarding perspective. It is recognised that to respond to these complex risks and harms there is a need to safeguard young adults more effectively, to avoid them falling between the thresholds and legal frameworks.

During 2023-24 the SAB developed and published a Transitional Safeguarding Protocol, which was endorsed by both the CYSAB and the Safeguarding Childrens Partnership (CYSCP).

This framework provides early opportunities to identify the most appropriate pathway for a young person, facilitating joint working, and ensures appropriate referrals and signposting take place in a timely manner to reduce safeguarding risks. Planning has been underway for a joint Board development session to take place and partnership in June

2024, focusing upon embedding and operationalising this protocol across the partnership, and to drive forward this work at a strategic and practice level.



There is also ongoing work to set up multi-agency operational and strategic arrangements to align transitional safeguarding and Preparation for Adult hood approaches. There is a CYSAB commitment to monitor and oversee progress on this work moving forward, and ensure outcomes and impact are measured.

Joint multi-agency safeguarding adults policy and procedures

We have built on the work undertaken in 2022-23 when the CYSAB launched their multi-agency online Safeguarding Adults Policy and Procedures across all agencies. These procedures were produced as part of a regional consortium, and this year we have developed our local contacts and resources section which contains a range of CYSAB referral, process and guidance resources. A local 'People in Positions of Trust' (PiPoT) process has also been launched, and an online PiPoT referral form.

These multi-agency policies and procedures are a valuable safeguarding resource, which are reviewed and updated bi-annually based on national policy, publications and best practice. Moving forward we want to continue to promote these resources, to raise awareness and use of these procedures across all partner agencies. The policies and procedures can be found at the following website: wynyy-cityofyork. trixonline.co.uk

Safeguarding adults guidance and practice resources

During 2023-24 the SAB has developed and published a range of guidance and practice resources. This includes some key guidance for practitioners and organisations about 'How to make a good safeguarding referral', a 'Safeguarding adults and falls protocol', and a range

of 7 minute briefings. A number of easy read leaflets and posters have been produced, and a series of public animations, created with other national safeguarding boards, including 'Tricky Friends', 'What to do about Self-neglect' and 'Hidden Harms'. These resources are available on both the Resources section of the CYSAB website and online procedures.



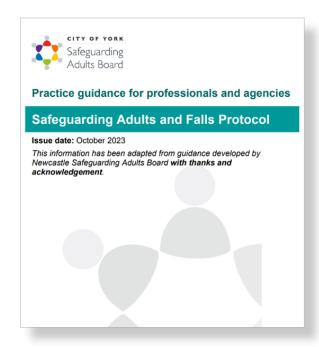
Safeguarding Adults is everyone's responsibility. Timely, accurate and well-constructed referrals help agencies work together to keep adults with care and support needs safe.

Purpose of this guidance:

To provide professionals and agencies with guidance about what constitutes a 'good' safeguarding adults referral, to support timely and robust assessments and responses to safeguarding concerns.

Top tips - don't forget to include:

- What have you seen? (where, when) What have you heard? (when, who from)
- When, who from:
 Basic information about the adult(s) at risk. What care and support needs do they have? Why are they unable to protect themselves from the abuse/neglect or the risk of it? Do they have mental capacity to make decisions about keeping themselves safe/other relevant decisions (please specify)?
- Basic information about the person alleged to be causing the abuse or neglect. Do they have any care and support needs? Do they work with children or vulnerable adults? Are they in a position of trust? Oo you know if they have a history of posing a risk to others?
- Why are you worried? What abuse/neglect is the adult(s) at risk of or experiencing? This could include (but not limited to) physical, emotional, sexual, neglect, financial, organisational, self-neglect, modern slavery, exploitation or discrimination. Has



Developing multi-agency data and information

During this year, initial discussions have taken place with partner agencies to map what safeguarding data is available across the safeguarding sector, and how this can be reported into the Board.

Work has taken place to update the online safeguarding referral to ensure we are capturing appropriate referral sources and information from partners, to inform the development of a multi-agency dashboard.

This work is a key priority and area of development for the Board in 2024-25 to ensure key safeguarding trends and themes can be identified and responded to.

Continued partnership working

The SAB structures and subgroups have worked well to provide multi agency forums in which safeguarding can be discussed.

Partners have reported benefiting significantly from these groups in identifying ways to address gaps or multi-agency shared risk, in particular through the Learning and Review subgroup and Rapid Review group.





4. What does our data tell us?

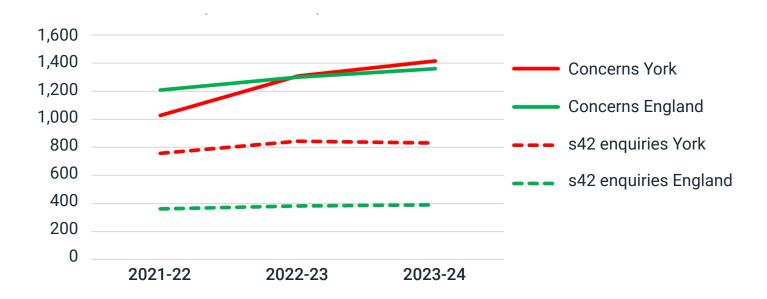
This section outlines our key safeguarding activity data relating to our safeguarding arrangements, and any arising themes and observations.

The full data set is published on the NHS Digital website: digital.nhs.uk/data.

Safeguarding activity over the last three years			
	2021-2022	2022-2023	2023-2024
Safeguarding concerns reported	1,715	2,219	2,438
Section 42 (s42) enquiries completed	1,266	1,431	1,428
Other enquiries completed	9	12	18
Section 42 enquiries as % of safeguarding concerns - York	73.8	64.5	58.6
Section 42 enquiries as % of safeguarding concerns - England	29.9	29.5	28.7



Safeguarding concerns / Section 42 enquiries per 100,000 adults, 2021-22 to 2023-24



Overview:

- There has been a continued increase (10%) in the volume of safeguarding concerns received, compared with the previous year. There has been a 42% increase in safeguarding concerns reported in York since 2021-22.
- During 2023-24 58.7% of safeguarding concerns resulted in a section 42 enquiry, which is lower than previous years, but is significantly higher than the England average of 28.7%. During this year we have undertaken some further work with partners about what constitutes a 'good safeguarding referral' and have published some guidance around this.
- Whilst the number of individuals involved in safeguarding enquiries has remained stable, there has been a positive increase in 'other' enquiries. In accordance with the Care Act 'other' enquiries are those where there is no duty to undertake enquiry, but the local authority deems it to be the most appropriate and proportionate response to the circumstances
- The CYSAB will continue to work with Adult Social Care to identify and analyse any key trends or anomalies in the next year.
- There were no Safeguarding Adults Reviews completed during 2023-24, however the Review and Learning subgroup have led and overseen two ongoing Safeguarding Adults Reviews.

Safeguarding demographics by age				
Age band	2021-2022	2022-2023	2023-2024	% change 2021- 22 to 2023-24
18-64	487	576	570	17
65-74	106	147	171	61
75-84	223	305	319	43
85-94	316	354	366	16
95+	68	77	106	56
Not Known	0	3	5	N/A

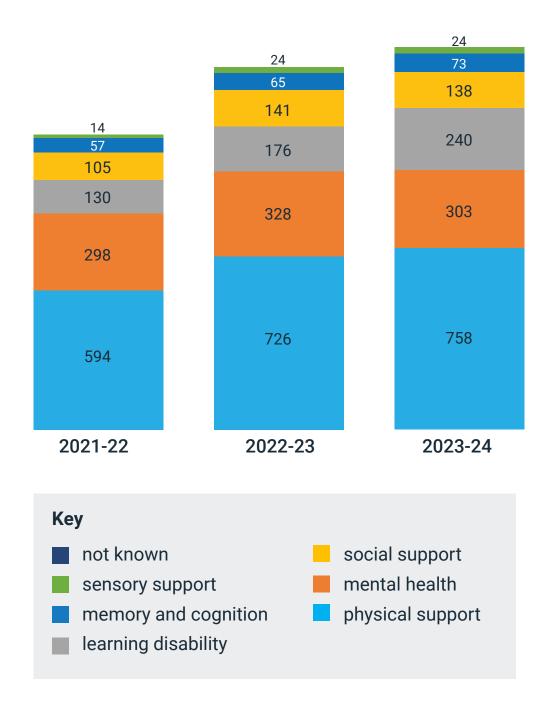
Safeguarding demographics by sex				
Sex	2021-2022	2022-2023	2023-2024	% change 2021- 22 to 2023-24
Female	716	900	906	27
Male	476	548	568	19
Not known	8	14	63	688

Safeguarding demographics by ethnic origin				
Ethnic Origin	2021-2022	2022-2023	2023-2024	% change 2021- 22 to 2023-24
White	1,100	1,323	1,354	23
Other	15	22	39	160
Refused/Unknown	85	117	144	69

The increase in concerns in recent years has mainly been driven by those aged 65-84 and 95 or over, and by females. Although the number of concerns reported by ethnic minorities has increased, they still make up a relatively small proportion of all concerns, in line with the proportion of adults in the York population that have ethnic minority backgrounds.

Primary support reason (PSR)

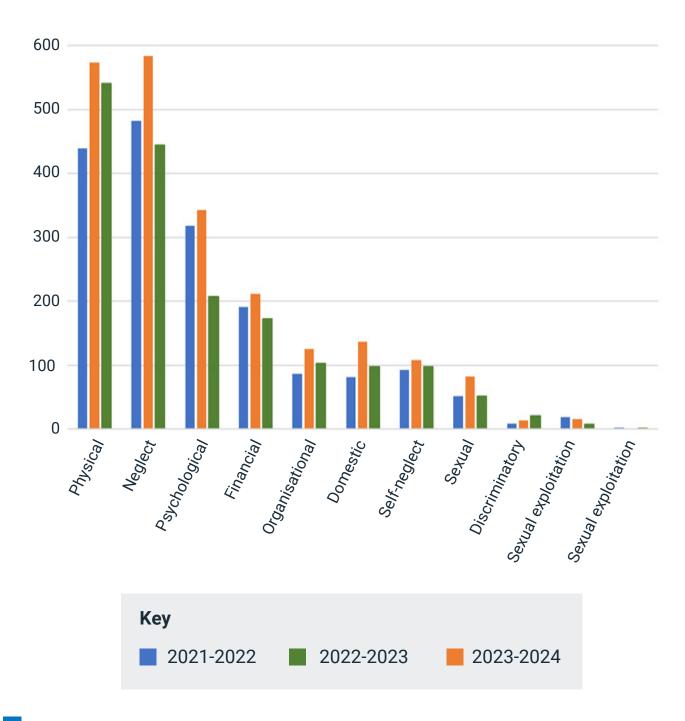
Individuals involved in safegaurding concerns by PSR, 2021-22 to 2023-24



Approximately 50% of safeguarding concerns each year have been reported by people with physical support issues, although there has been a notable increase during recent years in the number recorded with social support issues.

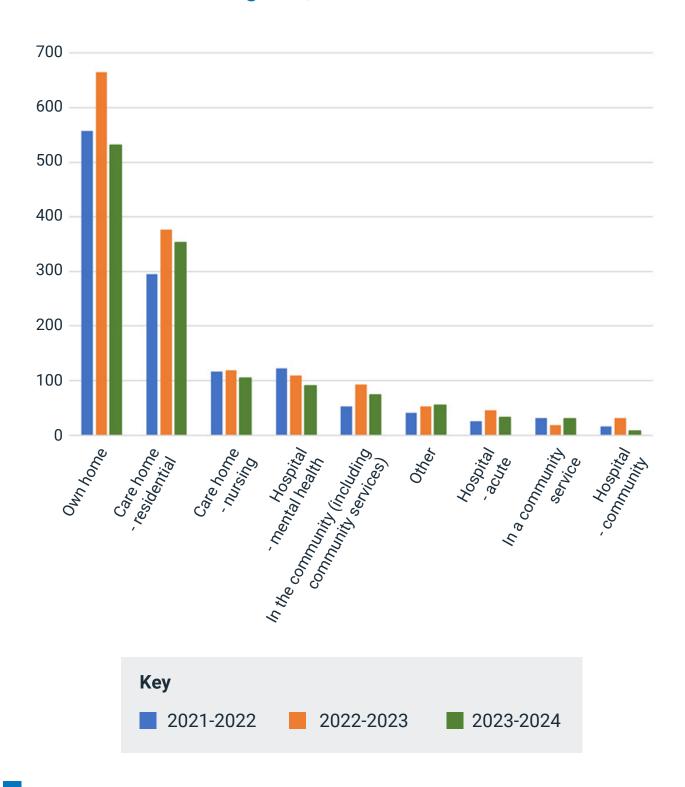
Type of abuse investigated by Section 42 enquiries

Section 42 enquiries by type of abuse investigated, 2021-22 to 2023-24



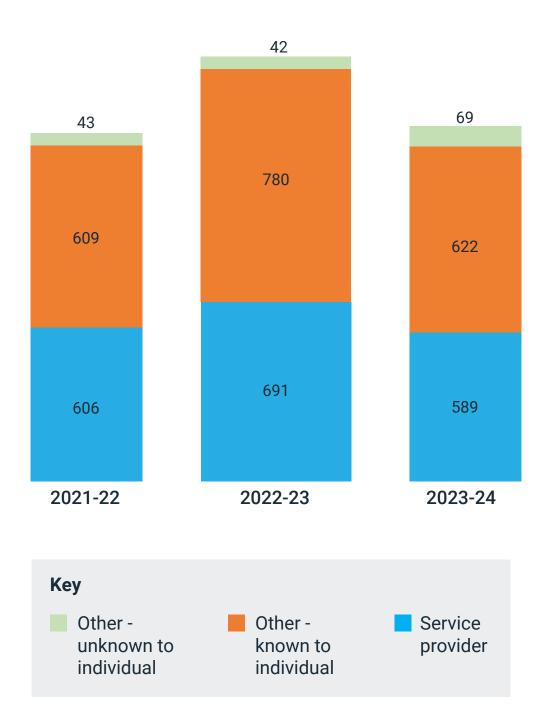
Neglect and physical abuse was the most common type of abuse recorded in 2023-24, and similarly in 2021-22 and 2022-23 this was neglect. Almost all forms of abuse have lower counts in 2023-24 than in 2022-23, and there is work being undertaken to ensure multiple abuse types are being captured appropriately.

Section 42 enquiries by location of abuse investigated, 2021-22 to 2023-24



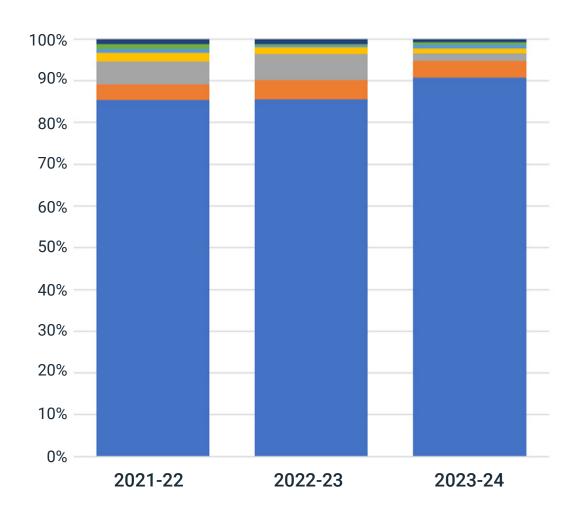
An individual's "own home" continues to be the most common location of abuse, followed by a care home or a mental health hospital.

Section 42 enquiries by source of risk, 2021-22 to 2023-24



The most likely source of risk to an individual continues to be someone known to an individual.

Outcomes from Section 42 assessments, 2021-22 to 2023-24

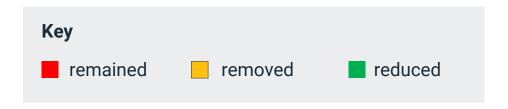




A risk was identified, and action taken in 86% of enquiries during 2023-24, which represents an increase compared to the previous two years.

Change in risk where identified by Section 42 enquiry, 2021-22 to 2023-24





Where a risk was identified this was reduced in 83% of cases and removed in a further 14% of cases; in only 3% of cases did the risk remain during 2023-24.

94%

of individuals involved in section 42 enquiries were asked to express an outcome.

77%

of individuals expressed their outcomes when asked.

46%

lacked capacity to be involved in Section 42 enquiries.





5. Our strategic priorities for 2023-24

We have embedded the SIX PRINCIPLES as set out in the Care Act:		
Empowerment	Promoting person-led decisions and informed consent.	
Protection	Support and protection for those in greatest need.	
Prevention	It's better to act before harm occurs.	
Proportionality	Proportionate and least restrictive/intrusive.	
Partnership	Working together.	
Accountability	There is a multi-agency approach for people who need safeguarding support.	

Strategic priorities

- To develop an all-age approach to safeguarding which maximises the potential and skills of teams and reduces the risks to young people transferring between services
- Preventing abuse and neglect by adopting best practice, locally, regionally, and nationally.
 Ensuring that all the learning from SARs are implemented in a timely manner.
- To ensure that commissioners and service providers ensure a consistent high quality of care.

- To ensure the adult is clearly heard and create opportunities for an approach where co production is at the heart of future safeguarding policy.
- To ensure a robust governance and challenge ethos ensures effective quality assurance and performance management processes.
- of York Community Safety
 Partnership, to support work to
 raise awareness of, and reduce
 the harm caused by 'Hidden
 Harms', and abuse associated with
 County Lines activity, domestic
 abuse and modern slavery;
 reducing duplication of effort and
 maximising effectiveness.

6. Meeting our objectives for the year - partner highlights



To develop an all-age approach to safeguarding which maximises the potential and skills of teams and reduces the risks to young people transferring between services.



City of York City Council Adult Social Care (CYC ASC)

CYC ASC have led on the development and agreement of a joint transitional protocol with the Children's Safeguarding Partnership. Operationally they have worked with children's services and other partners to implement these arrangements.

This has involved setting up and leading a strategic and operational group to oversee this work, reporting to the CYSAB on a regular basis. This approach has involved aligning with the Preparation for Adulthood protocol work, to ensure there is a consistent, safe and all age approach to young people transitioning into adult services and support.



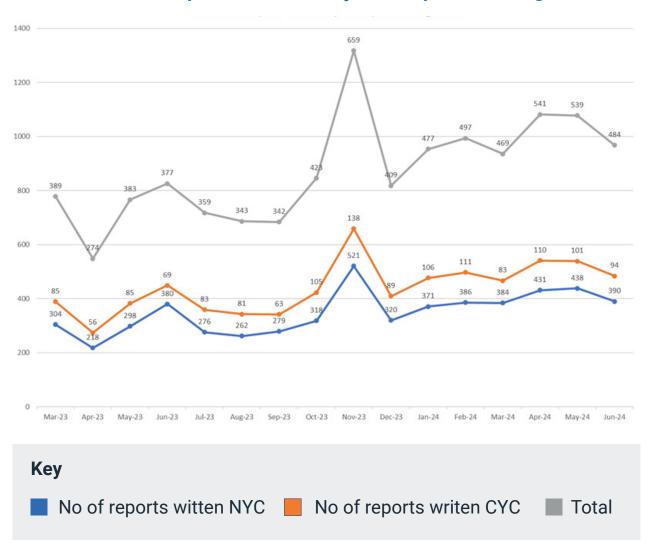


North Yorkshire Police (NYP)

The NYP Vulnerability Assessment Team (VAT) acts as the conduit through which all child and adult safeguarding concerns are referred, thus providing a consistent, joined up approach for adults, children and young people transferring between Social Care Services. Referrals are received from a range of partners as well as from front line officers and staff. All referrals are jointly triaged with statutory partners, assessed, and actioned as required.

Co-location and partnership working enhances information sharing to better serve young people transferring between services. The VAT is omnicompetent, providing resilience across all its teams, across York and North Yorkshire, across adult and children, to maximise all opportunities to safeguard the vulnerable whatever their age. The graph below demonstrates the number of reports produced by the team for both adult and child safeguarding concerns. Due to the way this data is collated, it is not possible to separate adult reports from the overall total.

Number of reports written by the report writing team





NHS Humber and North Yorkshire Integrated Care Board (HYNICB)

The safeguarding training delivered to Primary Care in York and North Yorkshire follows an 'all age' approach and in 2023-24 included a focus on review processes in safeguarding children (Arthur and Star National Panel Review); engaging with fathers; child sexual abuse; and domestic abuse experienced by people with disabilities. Almost 1000 staff working in primary care settings have accessed the training delivered by the Humber and North Yorkshire Integrated Care Board (HNY ICB) safeguarding team in York and North Yorkshire, which is a lower number than last year but remains consistent with previous years.



North Yorkshire Fire and Rescue Service (NYFRS)

'Transitional safeguarding' has been had added to the consideration within our review of existing, and development of new, youth engagement activities and interventions. A new Youth and Schools Engagement Manager, who is a skilled youth engagement practitioner has been recruited and is supporting the service to improve our understanding and approaches in this area.



Tees Esk and Wear Valley NHS Foundation Trust (TEWV)

The Trust safeguarding team follow the Think Family principles in many areas of its work. Although we have professionals in the team who are aligned to children's or adults much of our work covers both.

This supports us as an organisation when providing support to our services in embracing the Think Family approach. One of the strategic Trusts priorities is to 'improve consideration of the impact of parent / carer mental health needs on children'.

The Key driver is for improvements in clinicians considering the potential impact of parental / carer mental health on children and / or consistently documenting that this has been considered with the appropriate level of detail and regular review. This work started in 2023-24 and will continue into 2024-25. The Trust delivers joint safeguarding adult and children mandatory training at all levels, aligned to the Intercollegiate documents for adults and children's.

The Trust also supports the promotion of the Think Family agenda. Over 2023-24 the training packages have been reviewed and have evaluated very positively with an average score of 4.5/5 consistently.

York and Scarborough NHS Foundation Trust

The Trust Safeguarding Adult and Children teams integrated in August 2022. The integrated team works collaboratively to deliver a Think Family approach to all patients. Adult patients attending our hospital (whether admission or attendance at emergency department) are reviewed for any child affected by an adult in our care.

The team works closely with the trust Transition Nurse and Mental Health Transition Nurse to ensure seamless safeguarding into adult services.

The Safeguarding Liaison Nurse's role continues to support 16-17-year-old young persons on adult wards to ensure any safeguarding risks are managed and staff on the ward have a holistic awareness of their patient.

2

Preventing abuse and neglect by adopting best practice, locally, regionally, and nationally. Ensuring that all the learning from Safeguarding Adults Reviews (SARs) are implemented in a timely manner.



City of York City Council Adult Social Care (CYC ASC)

CYC ASC highlights for 2023-24 include the review and pilot of two new CYC safeguarding adults training courses. The online referral has been reviewed to ensure it captures the correct information to inform timely and robust decision making in relation to our section 42 duties. To further support, this guidance has been developed for all agencies around safeguarding and falls and how to make good safeguarding referrals. Development of the online referral and case recording system to capture referring information has been undertaken, to support the identification of any multi-agency themes.

CYC ASC have also:

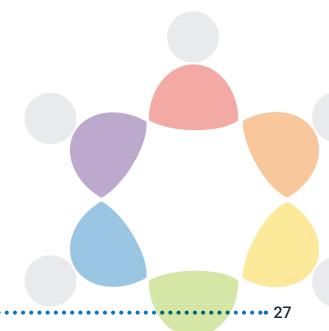
- delivered briefings to elected members in relation to safeguarding adults, safeguarding children and domestic abuse duties, which continues to be available to elected members as a recording.
- rolled out the Oliver McGowan e-learning training, and are now developing our Tier 2 training offer, to provide the CYC ASC workforce with the right skills and knowledge to provide safe, compassionate, and informed care to autistic people and people with a learning disability.

- developed a new quality assurance framework and audit tools and schedule to assure the quality of practice across the service. This includes a safeguarding adults audit tool.
- developed, consulted on, and rolled out a new practice framework for adult social care practitioners. Safeguarding is the golden thread running through the practice model and Making Safeguarding Personal is key to this approach and ensuring practitioners have the tools and resources to support adults at risk, to promote their safety and achieve their outcomes.
- revised their local safeguarding adults process and timescales and have updated our case management system to reflect this
- added local content and safeguarding resources to the online multi-agency safeguarding adults procedures and work has continued to embed these across the service.
- circulated a range of Safeguarding Adults Review (SAR) learning information from national and regional networks, and these have also been shared with practitioners via the Principal Social Worker teams channel.



North Yorkshire Police (NYP)

In the past year the Adult Mash (Multi-Agency Safeguarding Hub); a dedicated Adult Safeguarding Hub, has been developed within NYP (one Detective Sergeant and two Police Constables), who continue to jointly screen adult safeguarding referrals with Health, Adult and Mental Health Services. The team deal with all adult safeguarding referrals, thus ensuring continuity and consistency. The aim is to work with partners to develop an Adult MASH and work is ongoing to see how this can be achieved.



Adult planning meetings in the last 12 months



This graph demonstrates the range of adult planning meetings across both North Yorkshire and York. **Please note**: Data regarding Outcome Review Meetings has only been recorded since the introduction of the Adult Safeguarding Hub in Jan 2024.

- Safeguarding Adults Reviews (SARs): NYP's Adult Safeguarding Manager reviews all cases known to the police where an adult with care and support needs has suffered a serious incident or who may have died following a serious incident or had care and support needs. During 2023-24 the Police made 24 referrals for review at the Section 44 Panel meeting where agencies discuss and identify if any of the cases meet the threshold for a SAR or Learning.
- CYSAB are fully committed and supportive of the SAR process and the associated Review and learning subgroup.



NHS Humber and North Yorkshire Integrated Care Board (HNYICB)

- The Director of Nursing for the York area of the ICB continues to support the work of the CYSAB and attend strategic meetings. The ICB safeguarding team at place continue to represent the ICB and actively support the health contribution to safeguarding partnership meetings across the city. The Designated Nurse Safeguarding Adults chairs the Review and Learning subgroup for CYSAB.
- In York and North Yorkshire, the ICB safeguarding team at place have a well-established Health Partnership Group meeting which is held quarterly and a communication network of NHS and independent health providers. It is through these established systems that learning from reviews and best practice is shared.
- In August 2023 the ICB safeguarding team at place were requested to offer support following a major incident at a GP Practice in North Yorkshire. The incident, an arson attack and assault caused significant damage and resulted in the temporary relocation of staff and services. The Designated Professionals responded in a timely way to provide support to affected staff and worked with colleagues in the ICB Primary Care team and the Local Medical Committee (LMC) to start the process of gathering information and learning from the incident. This was one of a number of incidents which posed risk to those working in and those accessing primary care. This has led to a review of how people with vulnerabilities themselves but who also pose a risk to others are managed safely in their access to healthcare.
- Over the last year the NHS has launched a new framework for investigating incidents related to patient safety. The Patient Safety Incident Response Framework (PSIRF) replaced the NHS Serious Incident Framework (2015). The PSIRF sets out the approach to developing and maintaining effective systems and processes for responding to patient safety incidents for the purpose of learning and improving patient safety within the NHS england.nhs.uk/patient-safety/incident-response-framework. The Designated Professionals for Safeguarding have been involved in training and supporting the cross-over with statutory frameworks in safeguarding. As implementation of PSIRF progresses and where a concern is raised into both frameworks it is hoped that a joint approach taken by CYSAB and NHS providers working together may help avoid duplication and unnecessary distress to the individuals involved and/or their families.



North Yorkshire Fire and Rescue Service (NYFRS)

Key roles with the Fire and Rescue service, including the Head of Prevention, Senior Director, and Safeguarding Manager are connected with Safeguarding Adults Board and can contribute to SARs as requested. The Fire and Rescue Service, has further developed approaches review and have expanded the Fire Fatality Review process to a Serious Incident Review process, enabling learning from a broader spectrum of events. A key change in this process has been to embed the Safeguarding Manager and safeguarding as a key reflective issue. The Safeguarding Manager is also full embedded in regional and national working groups/forums, enabling continuous learning and improvement into the heart of those reviews.

Tees, Esk and Wear Valleys

NHS Foundation Trust

Tees Esk and Wear Valley NHS Foundation Trust (TEWV)

- Following the Whorlton Hall Safeguarding Adult Review, and a response for assurance nationally, one example of changes to practice was the cultural assessment work that took place across the Trust. A tool was developed to assess the risk of closed cultures within our inpatient services. This has since progressed and questions around closed cultures have been incorporated into our peer review tool alongside the Care Quality Commission (CQC) quality statement.
- The Trust held an internal Safeguarding Adults week in June 2023 dedicated to self-neglect after recognising this was a particular area that featured in Safeguarding Adults Reviews. As part of this briefings were developed on Learning from SARs, Mental Capacity Act and Executive Functioning, resources, toolkits and training which comprised of resources from other Safeguarding Adult Boards/ Partnerships. Additionally, a self-neglect training session was devised and delivered and continues to be available to Trust staff as a recording.
- Monthly safeguarding bulletins are sent out across the Trust.
- Partnership bulletins sent out to Trust via Safeguarding Link Professionals.
- Learning from reviews are shared routinely through the trust safeguarding and public protection committee and the 2 care groups for dissemination across the trust. The trust also has a learning library whereby reviews that have involved TEWV are saved and accessible to all trust staff.

- The Trust has a newly developed organisational learning meeting held monthly to share relevant learning from reviews (including safeguarding, complaints, internal reviews, CQC etc) and review relevant action being taken to address key themes.
- North Yorkshire, York and Selby Fundamental Standards Group and the Care Group Governance and Assurance Support Program (GASP) work that contributes to Key focus areas reflected in TEWV safety priorities including workforce, length of stay, restrictive interventions, formulation safety planning, environmental safety, report out, ward routine future ways or working, workforce development and leadership oversight. Examples of positive impact of this work has included significant reduction in restrictive interventions and a consistent increase in patient's reporting feeling safe within the inpatient care. The ongoing program of work will continue the collective learning and quality improvement to continually improve patient care, carer experience, staff experience and optimise ward to board communication and information flow.

healthwotch

York Community Voluntary Sector



- Staff members at York CVS continue to undertake safeguarding training to a level that is appropriate for their role (between levels 1-3)
- Training sessions for members and continues to offer voluntary, community and social enterprise (VCSE) organisations with advice on safeguarding.
- Healthwatch York (as part of CVS) have escalated issues through the CYSAB, including flagging concerns around the system.



York and Scarborough NHS Foundation Trust

- The Trust are currently involved in 13 statutory SARs and 2
 Domestic Homicide Reviews (DHRs) with our local authorities, all at various stages within the review process. Each SAR will generate a final report with recommendations and action plans which will be overseen by the SABs and monitored at the Trust Learning from Deaths Group.
- There is representation at the Board's Rapid Review Group and Learning and Review Group – an escalation of a community occurrence was identified through this route, and this enables sharing amongst agencies including our Emergency Department. For example, including in training "Professional Curiosity" and "Robust documentation".

To ensure that commissioners and service providers ensure a consistent high quality of care.



City of York City Council Adult Social Care (CYC ASC)

CYC ASC have developed a provider failure policy and also a lessons learned process. This is aligned with a new organisational abuse enquiry process. This has provided an opportunity to review working relationships and undertake a safeguarding briefing with service providers. The ongoing early alerter process and meetings, and the newly developed 'person approach to professional visits in care homes' support a preventative approach to identifying low level concerns. Good working relationships have been established between the Safeguarding and Contracts team and other stakeholders to assess priorities and help inform Quality Assurance visits and schedules.



North Yorkshire Police (NYP)

Domestic abuse victims: NYP's Domestic Abuse (DA) team engage with vulnerable victims of DA. Domestic Abuse Officers assess every referral submitted by our front-line officers, engage directly with victims and signpost to specialist services such as IDAS. Victims of sexual offences are referred to Independent Sexual Violence Advisers (ISVAs). Whilst reports of Independent Domestic Abuse Service (IDAS) incidents have reduced in recent years, those graded as high risk have increased.

Domestic abuse victims					
	2021-2022	2022-2023	2023-2024		
Incidents	11386	11756	11195		
High Risk grading	1994 (17.5%)	2136 (18%)	2337 (20.8%)		

The data shown above relates to both York and North Yorkshire. Given that victims and perpetrators may live across York and North Yorkshire, it is important to present the data across the entire force area.



NHS Humber and North Yorkshire Integrated Care Board (HNYICB)

The ICB has continued to develop as a new organisation in 2023-24 and guide its workplan and workforce through transformation https://humber-and-north-yorkshire-integrated-care-board-marks-one-year-of-transforming-healthcare.

In the areas of domestic abuse and the health offer to Care Leavers targeted work has been completed to scope what is currently in place to provide assurance, deliver consistency, identify gaps and learn from good practice.

As part of an ongoing programme of work a HNY ICB wide Domestic Abuse and Sexual Violence forum has been established to bring together health providers, share good practice and provide peer support in these challenging areas of safeguarding. As part of the work the ICB signed up to the NHS England Sexual Safety Charter launched in September 2023 england.nhs.uk/long-read/sexual-safety-in-healthcare-organisational-charter and encouraged health providers to do the same.



York and Scarborough NHS Foundation Trust

The governance of the Trust Safeguarding Team is via the Trust Integrated Safeguarding Group quarterly meeting. This is attended by the Designated Nurse for Safeguarding Adults from the ICB. This affords external challenge and scrutiny.

Internally the Integrated Safeguarding Group reports to the Patient Safety and Clinical Effectiveness Group and then onto the Trust Quality Committee. Within the meeting progression of the work of the Trust Safeguarding Team is presented and where necessary challenged where there are risks to the organisation.

Safeguarding is also a standing item at the Trust weekly Quality and Safety meeting where care groups escalate any safeguarding matters, and the team can raise ongoing concerns that are a risk to patient safety.



City of York City Public Health

All Public Health commissioned service providers submit their Safeguarding policies as part of procurement process. These are reviewed annually through contract monitoring arrangements.

To ensure the person is clearly heard and create opportunities for an approach where co production is at the heart of future safeguarding policy.



City of York City Council Adult Social Care (CYC ASC)

- CYC ASC have embedded a survey developed by Healthwatch into our safeguarding practice and case recording system. This provides individuals and their representatives with an opportunity to provide feedback regarding their experience of the safeguarding adults process at the point procedures end.
- Safeguarding and Adult Social Care teams continue to ask individuals for their views and desired outcomes (94% 2023-24).
- CYC ASC also undertook a mystery shopper exercise and as a result made improvements to the website so that safeguarding information was more accessible.
- CYC ASC Communications team also produced a range of easy read material (leaflets/posters) during safeguarding week, which were circulated and published with a series of animations (safeguardingadultsyork.org.uk/resources-2/leaflets-and-posters).
- Moving forward CYC ASC are developing their approach to co-production and research, supported by people with lived experience and the Curiosity Partnership.



North Yorkshire Police (NYP)

- Policy and procedure: NYP support a wide range of safeguarding policies internally, as well as supporting multi-agency partnership service level agreements and policies such as the Safeguarding Adult Procedure. Policies and procedures have a victim focus and are subject to equality impact assessments. NYP's Operational Pledge has been in place since 2023, to provide assurance to any members of our workforce experiencing domestic abuse that their case will be dealt with in confidence. Equally, where members of our workforce are identified as perpetrators, they will be investigated thoroughly as would any other individual.
- Community engagement: The NYP DA team worked with partners
 to engage innovatively with communities to raise awareness
 of abuse. NYP collaborated with IDAS to deliver a Christmas
 campaign this year, delivering a Christmas themed postcard to
 public spaces frequented by women, such as hair salons. The

postcard identified behaviours that amount to domestic abuse, including controlling and coercive behaviour, and signposted the help available from IDAS.



NHS Humber and North Yorkshire Integrated Care Board (HNYICB)

- Through delivery of healthcare to our population HNY ICB has identified key priorities for safeguarding in the Joint Forward Plan with a focus on addressing the needs of victims of abuse. These include Domestic Abuse, Serious Violence Duty, and the health offer to Care Leavers - https://humberandnorthyorkshire.icb.nhs.uk/wp-content/uploads/2023/07/Joint-Forward-Plan-How-we-will-deliver-our-strategy-from-2023-to-2028.pdf
- The safeguarding conference being planned for June 2024 opens with a session from a victim/survivor of domestic abuse, who will share his family's story of coercive control and domestic homicide.



Tees Esk and Wear Valley NHS Foundation Trust (TEWV)

- The Trusts 'Journey to Change' sets our commitment to cocreate a great experience for our patients, carer and families; to co-create a great experience for our colleagues and to be a great partner.
- The Trust has invested in appointing Lived Experience Directors and further enhancing the lived experience roles within the organisation to enhance the voice of patients including children and young people.
- The Co-Creation leads are employed to increase the voice of patients.
- TEWV safeguarding team are working with the Co-creation leads to consider how the safeguarding team can use lived experience in the work we do.



North Yorkshire Fire and Rescue Service (NYFRS)

NYFRS must comply with a series of national Fire Standards, one of which is Safeguarding. This standard includes are working in accordance with a Person-Centred Approach, and working to a national Person-Centred Framework. To ensure support and governance around this compliance, the Service has a quarterly Safeguarding Compliance Group, which is chaired by a Director.



York and Scarborough NHS Foundation Trust

The Trust Safeguarding Adults Policy and Procedures and the safeguarding adult training is underpinned by Making Safeguarding Personal to ensure Safeguarding is done with not to a person. Staff raising concerns on behalf of the patient are supported to discuss with the patient where possible, using the legal framework of Mental Capacity Act (MCA) to underpin and apply in practice, if required.

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York Community Voluntary Sector



York CVS's activities incorporating Healthwatch continue to engage with the CYSAB at a strategic level which ensures that the voice and needs of safeguarding adults in the community is heard. During 2023-24 the Healthwatch Lead for Safeguarding chaired the CYSAB Voice of the City Subgroup.

5

Agencies (like and health and social care providers) must prove they provide good quality services and be asked to prove this.



City of York City Council Adult Social Care (CYC ASC)

- A provider failure policy and a lessons learned process has been aligned with a new organisational abuse process.
- CYC ASC have contributed to a multi agency self assessment under Working Together 2023 (Section 11) and Governance audit undertaken by the City of York Safeguarding Children's Partnership (CYSCP), and regionally with North Yorkshire SAB and Community Safety Partnership (CSP). This has provided us with an opportunity to benchmark our arrangements and identify any gaps.
- The CYC Contracts and Quality Improvement Managers continue to apply the Provider Assessment and Market Management Solution (PAMMS) Quality Assurance tool to assess levels of quality services are being delivered across York.
- The CYC All Age Commissioners, Contract and Quality Improvement Managers and Brokerage teams continue to review and assess our internal processes and procedures and include these in any new services commissioned. We also monitor key performance indicator's (KPIs) with providers and additional support where improvements are required.



North Yorkshire Police (NYP)

- Multi Agency Risk Assessment Conference (MARAC) and Multi agency Tasking and Coordination (MATAC) report into a joint MARAC/MATAC Steering Group, which is held quarterly and provides partnership scrutiny.
- Domestic Abuse (DA) data is shared via the DA Local Partnership Board, where themes and trends can be considered in a multiagency setting.
- Learning and good practice from the DA Scrutiny Panel is shared with front line officers within North Yorkshire Police and work is underway to share this information more widely, via the Community Safety Partnership (CSP).
- NYP has recently been subject to a His Majesty's Inspectorate
 of Constabulary and Fire and Rescue HMICFRS Point, Evidence,
 Explanation, Link (PEEL) Inspection (2023-2025), where its
 gradings demonstrated a marked improvement from the last
 inspection in October 2022. The force was graded as good for
 "Protecting Vulnerable People" in October 2023, compared to
 being graded as "Requires Improvement" in 2022. In relation
 to "Preventing Crime and anti-social behaviour and reducing
 vulnerability" it was graded as good in October 2023, compared to
 "adequate" in 2022.



NHS Humber and North Yorkshire Integrated Care Board (HNYICB)

- All policies relating to safeguarding procedures and practice are in place and reflect the large-scale system change of HNY ICB.
- In the areas of domestic abuse and the health offer to Care leavers, targeted work has been completed to scope what is currently in place to provide assurance, deliver consistency, identify gaps and learn from good practice.
- As part of an ongoing programme of work a HNY ICB wide
 Domestic Abuse and Sexual Violence forum has been established
 to bring together health providers, share good practice and
 provide peer support in these challenging areas of safeguarding.
 As part of the work the ICB has signed up to the NHS England
 Sexual Safety Charter launched in September 2023 england.nhs.
 uk/long-read/sexual-safety-in-healthcare-organisational-charter
 and encouraged health providers to do the same.

- The Learning from lives and deaths 'people with a learning disability and autistic people' (LeDeR) programme delivered by the ICB has published its annual report.
 - » <u>humberandnorthyorkshire.icb.nhs.uk/wp-content/</u> <u>uploads/2024/06/ICB-Annual-LeDeR-Report-2023-2024.pdf</u>.
 - » humberandnorthyorkshire.icb.nhs.uk/wp-content/ uploads/2024/06/Annual-LeDeR-Report-2023-2024-Easy-Read. pdf.
- The report robustly evidences quality improvements for people with a learning disability living in York and North Yorkshire, a key outcome of focussed work has been the increase in annual health checks completed in primary care, which exceeds the target set nationally by NHS England. The ICB safeguarding team advise on LeDeR reviews where safeguarding is a feature in order that lessons can be learnt across the multi-disciplinary partnership.



Tees Esk and Wear Valley NHS Foundation Trust (TEWV)

- TEWV have presented at the Board outcomes from CQC inspections and recent Nurses Improving Care for Healthsystems Elders (NICHE) review alongside update on work carried out following this and any improvement plans moving forward.
- TEWV recently submitted an annual Quality assurance framework (QAF) tool to all safeguarding partnerships which gives assurance to the partnership on the Trusts safeguarding work and highlights any areas which are of particular focus for the coming year and any areas of improvements identified in the QAF. Historically the trust has submitted the QAF at different times to different partnerships/Boards and in many different forms. We have recently reviewed this and created a generic version of the QAF tool and populated this and taken this through internal governance structure before asking the partnerships/Boards to accept this document. To date we have received very positive feedback in relation to this submission and the openness and transparency of it and how comprehensive it was. We plan to update this on a yearly cycle and submit.
- TEWV safeguarding annual report 2023-24 been completed and approved through internal governance structure.



North Yorkshire Fire and Rescue Service (NYFRS)

NYFRS comply with the Section 11 and Governance Audit. We are also required to report to a quarterly governance forum. NYFRS also has an assurance function, and is inspected by His Majesty's Inspectorate of Constabularies and Fire and Rescue Services.



York and Scarborough NHS Foundation Trust

2023 2024 saw the planning and recruitment to launch a Complex Needs Service to start co-production work in the areas of Learning Disability (LD), autism and dementia to evidence where we are engaging people with lived experience - the challenge will be about how we prove the services are of good quality.

More widely the launch of the Nursing Quality Assurance Framework, which uses a range of methodologies including the use of a quality dashboard, weekly ward manager safety check and monthly peer review audit to triangulate outcomes with workforce data, identify areas for improvement and celebrate progress. The weekly back to the floor visits serve to seek further assurance on key topics from the framework, with a focus on fundamentals of care as part of our Year of Quality. The next step is to formally build an accreditation programme which will be tested out in September 2024.



City of York City Public Health

Public Health service providers are monitored through robust contract monitoring arrangements and are held to account by commissioners.



Work together with the City of York Council Community Safety Partnership, to support work to raise awareness of, and reduce the harm caused by 'Hidden Harms,' and abuse associated with County Lines activity, domestic abuse, and modern slavery.



City of York City Council Adult Social Care (CYC ASC)

- Domestic abuse: CYC ASC have reviewed and improved their contributions to both MARAC and MATAC processes. The Adult Safeguarding team have also been provided with some bespoke training, to ensure we are recognising domestic abuse and making MARAC referrals appropriately. Further work is underway with Public Health to analyse further training needs across Adult Social Care.
- Modern slavery: CYC ASC have worked successfully with commissioning, health, police and home office partners to respond to modern slavery concerns within provider services.
- A series of animations (tricky friends, self-neglect and hidden harms) have been created, shared with practitioners and published on the CYSAB website.



North Yorkshire Police (NYP)

- Domestic Homicide and Suicide Prevention: NYP share any incidents of DA related homicide and/or suicide victims with the national Domestic Homicide Project. The aim of the project is to identify emerging trends and share any key learning. There has been 1 potential instance of a DA-related suicide and 1 potential DA-related homicide. Any potential DA-related homicide is referred to the Domestic Homicide Review (DHR) Panel for consideration.
- Multi Agency Risk Assessment Conference (MARAC): is the multi-agency process for keeping our high-risk domestic abuse victims within North Yorkshire safe. MARACs are convened weekly being held remotely, and whilst attendance for some agencies has improved in the last 12 months, further improving multi-agency attendance and engagement remains a key focus this year. Information sharing is critically important, and it is crucial that relevant agencies attend those cases open to them. Equally, MARAC provides a valuable opportunity for agencies not directly involved to share their wider knowledge and experience, which can enhance the safety planning for victims and their families. Only together can we ensure that every opportunity to minimise harm is seized, with absolute accountability and confidence.

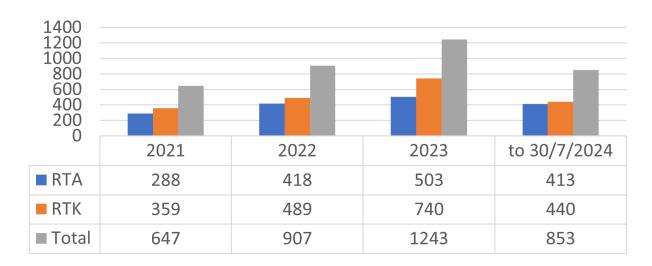
 As can be seen from the below figures, MARAC cases have risen by over 50% in the last 5 years. MARAC is essential in ensuring that all agencies contribute to safeguarding victims that are not always known to the Police.

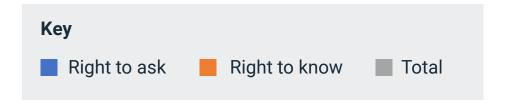
Multi Agency Risk Assessment Conference (MARAC) cases						
Year	2019	2020	2021	2022	2023	
York	303	444	515	525	474	
Whole Force Area	1038	1420	1745	1916	1998	

- Whilst the total number of cases across the Force have continued to rise, the number of cases in York reduced by 10% from 2022 to 2023. However, the first 6 months of 2024 has seen an increase again in York, with 307 cases already discussed so far.
- Multi Agency Tasking and Coordination procedure (MATAC): the MATAC procedure works to identify serial perpetrators of domestic abuse, aiming to prevent and/or disrupt their offending behaviour to break the cycle of domestic abuse. A key focus this year has been to improve our internal processes, ensuring our front-line officers are aware of our highest harm perpetrators living in our communities. They are tasked to engage with perpetrators to encourage them to seek help for harmful behaviours, and where appropriate, disrupt their activity and thus safeguard their victims from further abuse. Since its introduction, MATAC has adopted over 350 perpetrators, with 82% showing a lower Recency, Frequency, Gravity, Victims (RFGV) score 12 months after adoption. Since the introduction of the MATAC process, 47% of adopted perpetrators have been archived, indicating no new offences have come to light within 12 months of being archived.
- Domestic Violence Disclosure Scheme (DVDS), is an excellent preventative tool with which to engage victims/potential victims of domestic abuse, providing disclosures to assist them in making informed choices. There has been a rise in both Right to Know and Right to Ask applications in the past 12 months. The multiagency DVDS Panel was successfully launched in 2024. The panel considers the most complex applications, maximising information sharing and increased scrutiny of police disclosure decisions.

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Domestic Violence Disclosure Scheme applications throughout North Yorkshire and York





The above table indicates the total number of DVDS applications throughout North Yorkshire and York. The figure is given as a total because a victim may live in North Yorkshire and the perpetrator live in York and vice versa.



NHS Humber and North Yorkshire Integrated Care Board (HYNICB)

- The Serious Violence Duty commenced in January 2023 with a key role for the ICB as one of the specified authorities. The ICB Director of Nursing-Governance and Designated Professionals have worked with other key agencies to support the completion of the York and North Yorkshire Serious Violence Strategic Needs Assessment and the Serious Violence Response Strategy.
- Following the recommendations made in the Statutory Guidance issued under the Domestic Abuse Act 2021, the national charity Standing Together Against Domestic Abuse (STADA) has been awarded a three-year contract by the Home Office to identify and understand domestic abuse interventions across healthcare settings. In North Yorkshire and York as part of the Standing Together Crossing Pathways project our local domestic abuse specialist charity IDAS (Independent Domestic Abuse Services) have been commissioned to work with Primary Care and local

health providers. The project aims to raise awareness of domestic abuse and support services available for people in isolated rural communities. The GPs in York have also benefited as IDAS delivered workshop sessions on Domestic Abuse at a Protected Learning Time event attended overall by 160 GPs and primary care practitioners.

- The Designated Professionals have been supporting the project with their knowledge of the health network. The project is set to run until autumn 2024.
- Following cases of suspected modern slavery across North Yorkshire and York, the ICB hosted three lunch and learn sessions to raise the awareness of labour exploitation in the care sector. Over 170 people attended the sessions from a range of organisations including health, local authorities and the Fire Service.



North Yorkshire Fire and Rescue Service (NYFRS)

As a Service NYFRS regularly engage in forums and meetings held by relevant partners such as North Yorkshire Police. As the Regional Chair of the Serious Violence Working Group. The Director is responsible for driving and leading a range of activity to reduce serious violence. Many service staff are trained to identify a range of hidden harms including domestic abuse, and the new two year rolling training programme for specialist prevention officers within the service, includes a broad variety of training in key areas such as domestic abuse, prevent, modern slavery and trauma. The Head of Function has been grateful for the opportunity to attend training such as Alarm Receiving Centre (ARC) training, to ensure that strategy and policy in relation to prevention, which is inclusive of hidden harms where adult abuse is potentially undetected or unreported.



Tees Esk and Wear Valley NHS Foundation Trust (TEWV)

- The Trust is represented in all Safeguarding Board/Partnership arrangements including subgroups/task and finish groups (Trust attendance at Safeguarding Boards/executive mtgs is 100%).
- The Trust delivers joint safeguarding adult and children mandatory training at all levels, and this includes raise awareness of, and reduce the harm caused by 'Hidden Harms', and abuse associated with County Lines activity, domestic abuse and modern slavery.



York and Scarborough NHS Foundation Trust

Managing risks relating to our patients experiencing, disclosing, or suspected to have suffered domestic abuse, county lines activity and modern slavery is the day-to-day work of the Safeguarding Team. In acknowledging the increase scope of support an application has been made to increase the team's establishment to meet the expanding scope and legislative requirements for domestic abuse which will include non-fatal strangulation and incidence of honourbased harm risk. There is currently a gap in compliance with the Safeguarding Assurance and Accountability Framework for a Named Nurse for Safeguarding Adults. This has been subject to escalation and investment requests since 2019. The establishment required to manage the Trust duty under the Domestic Abuse Act (legislation. gov.uk/ukpga/2021/17/introduction) and the work for non-fatal strangulation (NFS) will re-enforce this bid.



City of York City Public Health

Public Health are a core member of the Community Safety
Partnership Board and actively update board members on Domestic
Abuse (DA) strategy, recommendations, and action plans. Public
Health work closely with North Yorkshire Council and the Office for
Policing, Fire, Crime and Commissioning to look at any duplication
or overlap between DA and other Violence Against Women and Girls
(VAWG) related crimes such as stalking and sexual exploitation,
crimes recognised under Serious Violence Duty and county lines
activity.



7. Safeguarding Adults Reviews (SARs)

The CYSAB Review and Learning subgroup (RLG) has continued to consider cases which may fit the criteria for a Safeguarding Adults Review under section 44 of the Care Act i.e. "SABs must arrange a SAR when an adult in its area dies as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked more effectively to protect the adult." Care and support statutory guidance - GOV.UK (gov.uk) and make a recommendation to the Independent Chair of CYSAB.

- Two SARs, which began in 2023-24 are currently being conducted involving neglect in care settings both involving older adults. The findings of these will be known in 2024-25 but early lessons have been acted upon to prevent abuse and neglect in the future.
- The learning from completed SARs continues to be embedded to improve practice across the Adult Care sector workforce. The completed SAR reports and 7-minute briefings are available on the cysab website safeguardingadultsyork.org.uk/sar
- The CYSAB three Statutory partners met monthly during 2023-24 for a Section 44 panel which looked at 50 cases during the year to assess whether these should be referred for a SAR. Of these

50 cases several went to a CYSAB Rapid Review group which allowed all partner agencies, including non-statutory organisations to provide more detail regarding each case. This provided a robust mechanism for identifying and checking cases allowing discussion between all partners to ensure learning opportunities were not missed.

- From these two subgroups, three cases were referred to the Learning and Review Subgroup for SAR consideration. One case was agreed to meet the criteria for a SAR which will be concluded in 2024-25 and two cases will be considered by the Review and Learning group in 2024-25 to see if they meet the criteria for a SAR.
- Any learning from all the cases considered by the CYSAB groups that did not meet the criteria for a SAR, was cascaded and actioned upon by CYSAB partners and individual organisations.
- A review of the SAR policy and procedure took place, which is available on the CYSAB website in the SAR section.
- The CYSAB partners took part in regional SAR learning events related to self-neglect and suicide as well as attending the Teeside thematic review of Whorlton Hall.

8. Looking ahead to next year

With increased capacity created by the appointment of the CYSAB Business Manager in 2024/25 and the new Independent Chair for CYSAB, the Board will have increased resources to deliver its new safeguarding strategy. Our partners were asked their priorities in the coming year both as individual agencies and for the Board.

Below are some of the suggested priorities for the Board to focus on:

- To develop a multi-agency safeguarding adults training offer, and quality assure partner agency training. Develop collaborative training opportunities for all levels of safeguarding practitioners with the partner agencies to improve everyone's knowledge and understanding.
- Review of governance structure and develop the engagement and accountability of partner agencies in the work of the SAB.
- To develop a multi-agency safeguarding adults performance framework/dashboard.
- To develop a robust and multiagency Quality Assurance Framework.
- Undertake self-assessment as a Board to provide a benchmark position, to provide assurance for improvement and enable challenge where the base line is not showing improvement in compliance with the Care Act.

- To align with and develop relationships and with other partnerships e.g., Children's Safeguarding, Community Safety, Domestic Abuse Partnerships.
- To seek assurance on the embedding of the Transitional Safeguarding Protocol and multiagency operational arrangements
- Establish a framework to revisit and track learning from SARs at regular intervals to ensure learning from SARs is embedded across agencies and to ensure that actions that support recommendations are completed with agency accountability.
- Continue to work with partners around what constitutes a safeguarding concern and ensuring clear pathways are in place.
- Develop opportunities for community engagement so that the voices of adults with lived experience are heard and help inform our future practice.
- Establish ways of responding to preventing the rise in homelessness and self-neglect.
- Establish a CYSAB multiagency escalation process to ensure all organisations are able to report issues to achieve professional resolution.

9. Safeguarding priorities for partner agencies for 2024-25

Below are some of the areas of focus for individual partners next year:



North Yorkshire Police (NYP)

Continuing to:

- Prevent and reduce crime and anti-social behaviour.
- Effectively respond to investigate and solve crimes.
- Manage offenders.
- Safeguard the vulnerable and service victims of crime.



Tees Esk and Wear Valley NHS Foundation Trust (TEWV)

- Parental/Carer Mental Health and the impact on children –
 increasing awareness across the organisation and seeking
 assurance that we are considering this and evidencing this in
 records.
- Strengthening of safeguarding linking the professional role across our clinical services to support clinicians.
- Safeguarding supervision across the organisation to review existing processes and consider a revision to provide greater assurance that all relevant staff are accessing some form of safeguarding supervision.
- Multi-agency public protection arrangements (MAPPA) further embedding the Trusts duty to cooperate responsibilities in line with MAPPA guidance.
- Quality of referrals to the Local Authority to develop guidance and support for staff to improve the quality of safeguarding referrals made to the local authority and audit quality on a regular basis.
- Safeguarding reporting internal and external by working with the Trusts performance and CITO (patient recording system to be able to identify and analyse how what and where we report safeguard measures across the trust and partners).
- Embedding learning from safeguarding into Trust wide organisational learning.



City of York City Council Adult Social Care (CYC ASC)

- Embedding the new safeguarding adults' processes internally and raising awareness.
- Continuing to work with and support partners on what constitutes a good safeguarding referral.
- Develop domestic abuse training offer across the service to ensure practitioners can recognise domestic abuse and report appropriately.
- Develop the safeguarding adults training offer to include a wider range of training, and a multi-agency offer.
- Develop approaches to self-neglect, and to work with North Yorkshire colleagues to develop a range of practitioner resources.
- Develop understanding of safeguarding data and Intelligence.
- To improve safeguarding response based on the outcomes of safeguarding audits, through a quality assurance framework.
- To continue to embed the transitional safeguarding protocol to ensure clear pathways are in place for young people.



North Yorkshire Fire and Rescue Service (NYFRS)

- Organisational training with a focus on more enhanced training for key staff and job roles.
- Further develop approaches around learning from serious incidents.
- Further refine our approaches to managing allegations against staff.



NHS Humber and North Yorkshire Integrated Care Board (HNYICB)

- A programme of communicating the health responsibilities under the Serious Violence Duty will be ongoing during 2024/25, alongside establishing a data dashboard around hospital admissions for knife crime injuries and alcohol/substance misuse.
- Continue work on key priority areas of domestic abuse and the health offer to care leavers.

- A safeguarding conference is in the planning stages to be held in June 2024 at University of York which will contribute to level 4 development and competencies for safeguarding specialist practitioners. The conference will focus on Domestic Abuse, Domestic Homicide and the Serious Violence Duty. We are fortunate to have secured the services of Professor Jane Monkton-Smith who is internationally renowned for her pioneering research into coercive control, stalking and domestic homicide. The findings of Professor Monckton-Smith's 2018 groundbreaking study – the Homicide Timeline: the eight stages – is a model used by police forces and agencies across the UK and Europe.
- A virtual safeguarding conference will be held in October 2024 with a focus on exploitation, online safety and transitional safeguarding.
- The HNY ICB will be working with our health providers to develop assurance against the revised Safeguarding Accountability and Assurance Framework (published June 2024) - england.nhs.uk/ long-read/safeguarding-children-young-people-and-adults-atrisk-in-the-nhs.



York and Scarborough NHS Foundation Trust

The Safeguarding Forward Strategy actioned through the Integrated Safeguarding Group will form a monitoring mechanism for assurance and a work plan underpinning service development.

Next steps are outlined in brief below:

- Domestic abuse service planning for patients and staff
- Expand workforce to meet needs of the expanding Domestic Abuse scope (which will include pathways for Non-fatal strangulation (NFS))
- Policy development



10. Our four core themes for 2024-25

1. The adults voice



- 1. Promote person-centred support for adults at risk of harm.
- 2. Hear the voice of the adult and ensure adults feel empowered.
- 3. Promote dignity and respect across all aspects of safeguarding.

2. Creating assurance



- 4. Develop a range of measures to help identify and prevent abuse.
- 5. Promote strong partnership working and collaboration.

3. Developing the workforce



6. Embed a culture of continuous learning and improvement to enhance safeguarding practice.

4. Learning lessons



- 7. Be responsive and proactive in addressing safeguarding.
- 8. Ensure transparent reporting in safeguarding.

11. Contacts

If you are concerned about an adult in York, please report concerns via the City of York Safeguarding Adults board website: safeguardingadultsyork.org.uk/home-page/6/raise-a-concern

The preferred method of reporting a concern is via an online form.

If you are a professional, please complete the 'raise a concern professionals form': safeguardingadultsyork.org.uk/raise-concern/raise-concern-professionals-form

If you are a member of the public, please complete the 'raise a concern residents form': safeguardingadultsyork.org.uk/raise-concern/raise-concern-residents-form

If you are a member of the public and would prefer to speak to someone or report information anonymously you can contact the City of York Adult Social Care:

Call: 01904 555111, Monday to Friday, 8.30am to 5.00pm

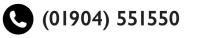
If you have a hearing impairment text: 07534 437804

Out of hours help: 0300 131 2131





If you would like this document in an alternative format, please contact:









It is available in the following languages:

我們也用您們的語言提供這個信息 (Cantonese)

এই তথ্য আপনার নিজের ভাষায় দেয়া যেতে পারে। (Bengali)

Ta informacja może być dostarczona w twoim własnym języku. (Polish)

Bu bilgiyi kendi dilinizde almanız mümkündür. (Turkish)

Publication date: December 2024

For further information: West Offices, Station Rise, York YOI 6GA



Health and Wellbeing Board

22 January 2025

Report of the Director of Public Health

Joint Strategic Needs Assessment – Annual Update

Summary

- 1. This report provides members of the Health and Wellbeing Board with an update on the Joint Strategic Needs Assessment (JSNA), including work undertaken in the last year by the York Population Health Hub, planned work for the coming year, and some key changes in the York population.
- 2. At the Board meeting, officers will take the Board through a slide set introducing the JSNA. With JSNAs now nearly 20 years old, and with several new members recently joining the board, this will be an opportunity to remind members of the key role JSNAs should play within the Health and Wellbeing Board's work, and outline the approach we have chosen to take in York.

Background

- 3. Health needs assessments (HNA) are a key tool within the public health field and specialism, used internationally as a coherent and robust tool to understand the needs and inequalities of populations and to underpin planning and decision-making. Whilst a variety of approaches can be beneficial, most HNAs incorporate elements of epidemiological assessment (e.g. trends in disease prevalence, service activity), comparative assessment (evidence and data from other areas) and stakeholder/patient assessment (e.g. focus groups, surveys).
- 4. Work on the JSNA is closely aligned to local work on a 'population health management' approach to health and care services.

 Because of this, the JSNA is routinely discussed as part of the Population Health Hub (PHH). The hub's purpose is to put the development and delivery of population health management (PHM)

programmes and the data which sits within the JSNA at the heart of local decision-making in health, care and other services.

Summary of work in 2024

- 5. As requested by HWBB, the population health hub are refreshing the cost of living pack. Highlights from this are presented in annex A.
- 6. The York approach of the population health hub approach was presented as an example of good practice at the Yorkshire and Humber Sector Led Improvement conference in 2024.
- 7. The population health hub has produced a core20plus5 information pack highlighting the health inequalities and needs of people living in deprivation or experiencing social marginalisation in York.
- 8. New website look successfully launched. This site has greater functionality, and importantly is fully accessible. With support from CYC IT there will be additional infographics and further content coming in 2025. www.healthyork.org
- 9. Specialist educational needs and disabilities HNA was completed in 2024. It was requested by the SEND board as one tool to review their progress against their strategy and in preparation for future OFSTED/CQC inspections. The HNA uses local and national statistical information as well as insight collected directly from children and young people, their parents, and professionals working in education, health and social care. The recommendations were developed in partnership with members of the SEND board and have been integrated into the SEND board action plan for 2024/2025.
- 10. Public health are coordinating the Autism and ADHD Strategy. To support this a provisional first draft of the Autism and ADHD health needs assessment has been developed, and a strategy development group formed. We are currently in a two month listening phase and hope to have fuller versions of both the HNA and the strategy out for consultation in May and June 2025.
- 11. Public health are currently engaging on the scope of a women's health needs assessment with professional stakeholders and community leaders. We intend to continue this work into 2025.

Three big changes in the population of York in 2024

- 12. Healthy life expectancy in York is falling. (62 years for men, 63 years for women). People in York have lost more than a year of healthy life expectancy for the last three years consecutively. Healthy life expectancy is linked to loss of employment opportunity and higher use of health and care services. Healthy life expectancy is very sensitive to life circumstances, people living in deprivation in York have a healthy life expectancy of around 52. It can be even lower for many socially marginalised and inclusion health groups.
- 13. Fewer than 5% of new mothers in York now smoke at the time of delivery. The stop smoking service and midwifery are working effectively together to identify women. However, our smoking at time of first midwife appointment is 17% which is double the smoking rates in the general adult population of York.
- 14. The proportion of over 65s in York continues to be slightly higher than the England average, and is rising gradually year on year. The latest figures show that 20% of the whole York population are aged 65+

Implications

15. There are no specialist implications of this report.

Recommendations

- 16. The Health and Wellbeing Board are asked to:
 - Note the changes to population and demography highlighted in this report and consider how this insight should inform the 2025 HWBB workplan.
 - b. Comment on the use of the JSNA within their own organisations, and suggest how this use could be increased.

Reason: To keep the HWBB updated on the work of the Population Health Hub and the JSNA

Contact	Details
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Author: Chief Officer Responsible for the

report:

Jen Irving
Public Health Specialist
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City of York Council

Chief Officer's name: Peter Roderick Title: Consultant in Public Health

Report Approved V

Date 13.01.2025

Wards Affected:

AII √

For further information please contact the author of the report

Background Papers:

All content relating to the overarching JSNA and the associated health needs assessments can be accessed on the JSNA website at www.healthyork.org

Annexes:

Annex A: Highlights from the updated cost of living pack produced by the population health hub.

Highlights from the updated cost of living pack produced by the population health hub.

The Population Health Hub published a data pack in response to the sudden increase in the cost of living in 2022/23. The pack outlined the links between reduced household finances and changes in health status.

This year's updated report is due to be published online shortly, as we are still awaiting some data from partners.

HWBB are provided with some content highlights.

- 1. Cost of everyday purchases is still a challenge for many. The consumer prices index including owner occupied housing costs was set at 3.5% in November 2024, far lower than previous years, indicating a slow-down in the rise of the cost of everyday goods, services, and housing. Even so, national evidence from Healthwatch, and results from the Opinions and Lifestyle survey published in November 2024 describe that many people are still impacted by higher cost of living.
- 2. Use of Foodbanks is still high and rising. The Trussell Trust report a 120% increase in foodbank usage in York between 2018-2024. There were 8846 emergency food supplies distributed over financial year 2023/24; a 20% rise from the previous financial year.¹
- 3. Access to Dental Care remains a financial challenge A lack of local access to NHS dentists is a recognised barrier to accessing dental care for those on lower incomes. Oral health inequalities have particularly been highlighted amongst vulnerable groups such as Gypsy and Traveller communities, refugees and asylum seekers, as well as those using temporary accommodation and food banks.

The consequences of poor oral health are far-reaching and significantly impact directly on tooth decay and indirectly on mental health, heart disease, and diabetes. There is a project currently underway delivering evidence-informed prevention programmes for children and a few schools in York.²

1. Fuel Poverty and respiratory health.

1

¹ York Foodbank

² Dental Care Report, Humber & Yorkshire ICB

The difficulty keeping a home warm is amongst the most commonly reported issues with rising cost of living. In York, 14% of households are thought to be in fuel poverty meaning their homes are difficult to heat based on their income. Homes that are poorly insulated or poorly heated are prone to damp and mould and are linked to respiratory illness and mental ill health especially in young children and the very old.

Whilst there is more work to do, the rates of COPD exacerbations in York have fallen in 2024 compared to 2023. This promising trend is largely attributed to respiratory social prescribers who are working with COPD patients to manage their symptoms, become more active, make use of support, and set their own goals.



Health and Wellbeing Board

22 January 2025

Report of the York Health and Care Partnership

Summary

- 1. This report provides an update to the Health and Wellbeing Board (HWBB) regarding the work of the York Health and Care Partnership (YHCP), progress to date and next steps.
- 2. The report is for information and discussion and does not ask the Health and Wellbeing Board to respond to recommendations or make any decisions.

Background

- 3. Partners across York Place continue to work closely together to integrate services for our population. The YHCP shares the vision of the York Joint Local Health and Wellbeing Strategy that in 2032, York will be healthier, and that health will be fairer.
- 4. The YHCP has an Executive Committee (shadow) which is the forum through which senior Partnership leaders collaborate to oversee the delivery of the Partnership priorities. Since 2022, the YHCP has been an Executive Committee of the ICB, drawing on membership across Integrated Care Board (ICB) senior officers, City of York Council senior officers, York and Scarborough NHS Teaching Hospital, Tees, Esk and Wear Valley NHS Mental Health Trust, primary care, York Centre for Voluntary Services, Healthwatch York, the university and education sectors, and City of York Council elected members.
- 5. The Executive Committee meets monthly, and minutes from the September 2024 meeting are included at **Annex A** to this report.

Update on the work of the YHCP

September 2024 Executive Committee Meeting (minutes at Annex A)

6. The September meeting of the Executive Committee focused on the following four items:

- Feedback to the ICB on the Design for the Future Blueprint **Proposition:** The NHS Place Director for York confirmed she had shared the feedback from YHCP on the Design of the Future Blueprint Proposition with colleagues in the ICB. The Design for the Future Blueprint Proposition sets out the potential future design of services intended to meet the challenge of the next two decades. It has been developed to set a strategic direction that supports the Humber and North Yorkshire Health and Care Strategy and to provide the basis for conversations, gather views, opinions, comments and perspectives and to support the co-production of proposals to deliver the design for the future. A summary of the YHCP's feedback along with an outline of the proposition was presented as part of the NHS Place Director's report to the HWBB in September 2024. Additionally, the Executive Director of Communications, Marketing and Media Relations attended the November meeting of the HWBB to present a report regarding the engagement approach (public and patient) delivered by Humber and North Yorkshire NHS Integrated Care Board (ICB).
- Community Frailty Services: in November 2023 YHCP started a pilot scheme with the aim to shift how care for those living with frailty would be delivered. The York Frailty Crisis Response Hub is a model that supports York's intermediate care offer. The hub brings together a range of services that had previously been working in isolation into a shared physical workspace, co-locating teams and embedding a multidisciplinary approach. The pilot has boosted the amount of capacity available to support frail people in crisis in the community, enabled partnership working and supported the wider system pressures. The model emulates the Jean Bishop core offer in that the service operates at a tier above the level of core primary and community services and raises the bar of what can be achieved at the tier below acute services, enabling the re-direction of demand away from the Emergency Department (ED) and into a community environment. YHCP supported the next phase of this work to develop a fully integrated community frailty service for the population of York. In its first full year, the service is predicted to support 4700 cases of crisis, avoid 1800 attendances, avoid 900 hospital admissions, and 33,000 work hours per year (based on the assumption that hub working saves 7 hours of staffing time in 25% of crisis cases).

- > York Joint Committee Establishment (Section 75) Agreement between Humber and North Yorkshire ICB and City of York Council): In April 2024 the YHCP Executive Committee approved the intention to fully explore the option of forming a joint committee from April 2025. A Joint Commissioning Forum was duly established to oversee the work and report back to the Executive Committee in September 2024. The creation of a Joint Committee is intended to improve the quality of health and care for residents in the city. As an enabling mechanism, it will not directly change services overnight, but the partnership working, joint planning and joint funding arrangements it allows between the council and health will lead to greater integration between health and care services. YHCP approved a decision in principle to develop and establish a Section 75 Partnership Agreement starting from 1st April 2025. In furtherance of this work, the ICB Board and the City of York Council Executive Committee both received a report in November 2024 setting out a proposal to form a Joint Committee (Section 75 agreement) between Humber and North Yorkshire Integrated Care Board and City of York Council. This proposal was approved by both organisations and work is now underway to set up the Joint Committee by 1st April 2025.
- > **System Assurance Report**: this report provided some progress updates against Place priorities as follows:

Strengthening York's integrated community offer:

- ➤ Mental Health Hub following the establishment of the first City of York hub in May 2024, non-recurrent funding (2 years) has been awarded by NHS England to develop a second hub in the city which will operate 24 hours a day.
- A health and social care bridging service supporting discharge from hospital has been in place since 4th June 2024, supporting around 70 discharges per month, and reducing the amount of time that patients spend in an acute hospital bed once medically fit for discharge by allowing the assessment of their ongoing needs to take place in their home environment.

Implementing an integrated urgent and emergency care offer

➤ Intense focus on urgent and emergency care recovery with three immediate recovery actions put in place over July,

August and September 2024 in readiness for the busy winter months. The three main areas are plans which return ambulances to the road more quickly; let the Emergency Department (ED) be ED and leadership at every tier

Further develop primary and secondary shared care models

➤ The Primary/Secondary Care Interface Group is now also acting as a forum for discussion and resolution of issues that present through General Practice Collective Action. Collective action is GPs taking action that may stop or reduce certain work. It is not the same as industrial action and staff are still working and seeing patients.

Develop a partnership based, inclusive model for children, young people (CYP) and families

- Developing resources to support CYP with sensory processing differences and difficulties. These locally coproduced resources will enhance the universal offer and support those around CYP to provide targeted support. This work is being led by York and Scarborough Hospital CYP Occupational Therapy (OT) team and supported by ICB. The resources and changes to the delivery of the York and Scarborough Hospital CYP OT Service launches end of January 2025
- There is significant concern around NHS speech and language waiting list times. An options paper is being shared with YSTHFT senior board members September 2025. Significant service development has taken place, but referrals continue to increase.
- Partnership for Inclusion of Neurodiversity in Schools (PINS), neurodiversity in schools project (NHSE) and ADHD foundation project (commissioned by CYC) are now underway across chosen settings in York.

Embed an integrated prevention and early intervention model

- Meeting held with providers of prevention services following scoping exercise carried out for integrated prevention model. Priority areas identified and actions to be developed.
- York took part in the national 'Know Your Numbers' week campaign with an event at York Designer Outlet featuring our

health kiosks and community pharmacy to target diagnosis and treatment of hypertension.

Drive social and economic development

Development of a future service model and associated infrastructure is progressing well, with workshops held in September and October with a wide range of system partners to review and feedback.

October 2024 Executive Time Out Session

7. The focus of the October 'time-out' session was Radical Place Leadership. Radical Place Leadership creates an enabling environment to work in a person-centred approach with a genuinely shared vision and priorities, empowerment and engagement, enabling anchor institutions, community decision making and action, and release of tangible financial savings. The YHCP has agreed to use the model as a basis for developing relationship-based practice across York's health, care, voluntary sector practitioners to create a better working environment and experience of joined up care for residents.

November 2024 Executive Committee Meeting (The minutes for this meeting have not yet been approved and will be included as part of the next update to HWBB in March 2025)

- 8. The November meeting of the Executive Committee focused on the following three items:
 - i. Place Priority #2: integrated urgent care update and planning considerations:
 - ii. York Bereavement Alliance: Progress of York Bereavement Alliance work has been steady and productive over the first year of its delivery. Gaps in provision have been identified, relationships with stakeholders deepened and a universal York place desire to improve citizens bereavement support is encouraging to note.
 - iii. YHCP Partner Finance and Efficiency Overviews/VCSE State of the Sector Report: A summary of the financial challenges, efficiencies and system opportunities for each of the health and care organisations represented on the committee was presented. The committee also received a report on the recent VCSE state of the sector survey, designed to capture how York's VCSE sector is doing, to identify challenges and opportunities, and to evidence

where more support is needed. This work will inform our joint commissioning approaches and decision making as we make our preparations for establish the Joint Committee from April 2025.

<u>December 2024 Executive Committee Workshop</u>

iv. The focus of this workshop was for partners to take some time to discuss how joint committees can take decisions; in contrast to committees where member organisations represent their own interests and take decisions in that context. The discussion covered a number of areas such as membership of the joint committee; budgetary concerns; governance structures; transparency; and a framework setting out how the organisations represented around the table might best work together.

Work of the York Population Health Hub

9. The York Population Health Hub (PHH) serves as a vital collaborative platform uniting diverse stakeholders from health and the local authority to enhance population health management in York. The PHH includes members from the Integrated Care Board's York place, Business Intelligence Team, General Practice, Secondary Care, the Community & Voluntary Sector, and City of York Council's Public Health and Business Intelligence Teams. This multi-organisation approach facilitates the development and implementation of population health strategies that address the unique needs of York's residents.

The PHH actively produces resources and initiatives to promote population health management, such as a quarterly newsletter that provides updates and highlights opportunities for engagement. The latest issue promoted the Winter Directory of Services, designed for professionals to use to signpost to support available for York residents. The Winter Directory of Service for the public is available on the Live Well York Website and on the LCB's website and is included as **Annex B** to this report. The Directory of Service for Health Professionals is at **Annex C** to this report.

10. Additionally, the team organise and hold quarterly Lunch & Learn events. Delivered virtually, recorded, and published online, the events offer the opportunity to hear from subject matter experts. The latest session focussed on Hypertension Case Finding and included a talk by representatives from community pharmacy. The upcoming session (January 30th) will focus on Staying Well during the Winter.

11. These collaborative efforts extend to the compilation of significant reports, including Joint Strategic Needs Assessments and the forthcoming Impacts of Poverty report. Over the coming months the hub will be contributing essential data to support the development of York's Integrated Neighbourhood Teams (INTs). The PHH remains open to new members, fostering a culture of shared learning and innovation in population health.

York Mental Health Partnership

- 12. Key highlights from the Mental Health Partnership include:
 - Work on the development of the existing Mental Health Hub at Clarence Street continues.
 - ➤ A further 24/7 Neighbourhood Mental Health Centre at Acomb Garth continues to be developed supported by NHSE funding. A manager for the centre has been recruited.
 - ➤ A recruitment event was held in Acomb in December and there was a great deal of interest in a variety of roles at the 24/7 centre. Formal recruitment will be taking place in the first quarter of 2025
 - ➤ The Mental Health Partnership are developing a strategy on a page and accompanying narrative. Work on this is progressing well. Once this is complete this will be shared widely.
 - Work is ongoing to establish a Children and Young People's Mental Health Group and an initial meeting has been held to discuss how this might happen. Further meetings to progress will take place soon.

Contact Details

Authors:	Chief Officer Responsible for the report:
Compiled by Tracy Wallis, Health and Wellbeing Partnerships Co-ordinator,	Sarah Coltman-Lovell, NHS Place Director
City of York Council	Report Approved √
	Date: 10 th January 2025

Wards Affected ALL

For further information please contact the author(s) of the report

Annexes

Annex A – Minutes of the September 2024 Meeting of the York Health and Care Partnership

Annex B – Directory of Services for the Public over Winter

Annex C – Directory of Services for Health Professionals

Annex A:



York Health and Care Partnership Executive Committee

Thursday 19 September 2024, 10:00 - 12:30 Severus Meeting Room; First Floor, West Offices Chair: Ian Floyd

Present		
lan Floyd (Chair) (IF)	Chief Operating Officer	City of York Council (CYC)
Mark Bradley (MB)	Place Finance Director, North Yorkshire and York	Humber and North Yorkshire Integrated Care Board (H&NY ICB)
Professor Karen Bryan (KB)	Vice Chancellor	York St John University
Sarah Coltman- Lovell (SCL)	York Place Director	H&NY ICB
Dr Rebecca Field (RF) - part	Joint Chair of York Health and Care Collaborative	York Medical Group
Professor Mike Holmes (MH) – on Teams	Chair	Nimbuscare
Anne-Marie Roberts (AR) – on behalf of Emma Johnson	Director of Clinical Services	St. Leonards Hospice
Peter Roderick (PR)	Director of Public Health	CYC
Alison Semmence (AS)	Chief Executive	York Centre for Voluntary Services (CVS)
Cllr Lucy Steels-Walshaw (LSW)	Executive Member for Health, Wellbeing and Adult Social Care	CYC
Michael Melvin (MM) – part, on behalf of Sara Storey	Director Adult Safeguarding	CYC
Melanie Liley (ML)	Chief Allied Health Professional	York and Scarborough Teaching Hospitals NHS Foundation Trust (YSTFT)
Dr Helena Ebbs (HE) - on	Clinical Place Director, North	H&NY ICB
Teams	Yorkshire and York	
In Attendance		
Rachael Hammond (RH)	Graduate Trainee	York and Scarborough Teaching Hospitals NHS Foundation Trust (YSTFT)
Natalie Caphane (NC)	AD System Planning and Improvement	York Place, H&NY ICB
Zoe Delaney (ZD	AD Community Integration	York Place, H&NY ICB

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Stephen Eames (SE) -	Chief Executive	H&NY ICB
part		
Hannah Taylor (HT)	Project Support Officer	York Place, H&NY ICB
Tracy Wallis (TW)	Health and Wellbeing Partnerships	CYC
	Co-ordinator	
Apologies		
Gail Brown (GB)	Chief Executive	Ebor Academy Trust
Michelle Carrington (MC)	Place Director for Quality and Nursing, North Yorkshire and York	H&NY ICB
Brian Cranna (BC)	Director of Operations and	TEWV
	Transformation, North Yorkshire	
	and York	
Cllr Claire Douglas (CD)	Leader of City of York Council	CYC
Claire Hansen (CH)	Chief Operating Officer	YSTFT
Simon Morritt (SM)	Chief Executive	YSTFT
Sian Balsom (SB)	Manager	Healthwatch, York
Gary Young (GY)	Deputy Director Provider Development	York Place, H&NY ICB
Sara Storey (SS)	Director Adult Social Care and Integration	CYC
Martin Kelly (MK)	Corporate Director of Children and	CYC
	Education	
Emma Johnson (EJ)	Chief Executive	St. Leonards Hospice
Zoe Campbell (ZC)	Managing Director North Yorkshire	Tees, Esk and Wear Valleys
. , ,	and York	NHS Foundation Trust (TEWV)

1. Welcome, apologies for absence and minutes.

The Chair welcomed everyone to the meeting. Apologies were as noted above.

MH, ML and AS all declared an interest for Item 3 Community Frailty Services and Core Principles of an Integrated Commissioning Model; the Chair agreed there was no need for them to leave the room for this item.

The minutes of the meeting held on 8 August 2024 were approved.

There were no matters arising.

2. Feedback to the ICB on the Design for the Future Blueprint Proposition and York Future Model (for Internal Partnership Circulation only)

SCL informed she had shared the feedback within the report pack with the Executive Director of Communications, Marketing and Media Relations. Workshops for the York Future Model have taken place and feedback is due by the end of September 2024.

The ICB's System Leaders Forum have agreed to move the Future Blueprint forward to a strategic outline case and this will be agreed at the October System Leaders Forum.

3. Community Frailty Services an Core Principles of an Integrated Commissioning Model

SCL introduced the item explaining that the approvals for Frailty Services currently sit with the Place Director but over the coming months there is an intention to bring some of the strategic planning decisions through to the Place Board as part of the Place delegation plans. ZD shared some background on what services the Frailty Hub offers, the Jean Bishop Centre being the inspiration for the York Frailty Hub model focusing on patient experience and how the service has expanded from the original Advice and Guidance line and which services are involved in the Frailty Hub. The Frailty Hub model aligns with the Humber and North Yorkshire (HNY) Core Community offer and the commitments proposed in the HNY Design for the Future Blueprint.

ZD shared that since the Hub's implementation in November 2023 it has supported 3000 crisis cases which has resulted in over 1100 Emergency Department attendances. A deep-dive showed that only five out of the first sixty Frailty Crisis Response Hub clinical contacts on 4-week follow up had been admitted to hospital showing the service helps people to stay at home. A pilot by Yorkshire Ambulance Service (YAS) of Call before Convey began on 12 August which has so far resulted in 34 conveyances prevented which if the rate continues the service could support 603 YAS ED conveyances to be prevented each year.

Ending ZD shared some case studies from people using the system and feedback received from some paramedics who have used the Frailty Hub service, one example showing that around six hours were saved by using the Frailty Hub service.

Detailed discussion included:

- Shifting resources from acute into community services and the pace in which they are shifted
- Offering student placements at the Hub if possible
- Performance at the trust has not been impacted by having the Frailty Hub and at what scale would the trust start to see an impact
- Further strengthening the Hub with other interfaces
- What is on offer for people who do not meet the Frailty Hub criteria
- Scaling up moving from a pilot to transformation for more impact
- Assurance that the Frailty Hub will continue
- How the Frailty Hub is being publicized

York Health and Care Partnership approved the recommendations within the report:

- Approve the ongoing service delivery of the York Frailty Crisis Response Hub.
- Note the intention for York Place to run a contract award process under the Provider Selection Regime (PSR) with the intention of awarding the contract for the Frailty Crisis Response Hub.

Support the ongoing discussions and strategic steer over the next 18 months
with particular a view to proposing a longer-term commissioning model to
facilitate the integration of primary, community and social care services in line
with the Core Offer developed and led through HNY community reconfiguration
and Design for the Future work.

Action:

- ML, MH and RF to explore the option of Student placements within the Frailty Hub with the Trust and Primary Care
- NC to look at cost per contact within the frailty hub and compare to the indicative resource savings in avoided conveyances and ED attendances.
- NC to look at longer term projections for frailty and the impact of the hub, including consideration of scaling up the model to deliver system efficiency by reducing resource required in an acute setting.

4. York Joint Committee establishment, Section 75 Agreement between Humber and North Yorkshire Integrated Care Board and City of York Council

IF presented the report and reminded members of previous discussions that demonstrated the importance of creating something that doesn't limit ambition and is owned by all partners. A report was approved by the Committee in April 2024 to explore options of a Joint Committee between the City of York Council and Humber and North Yorkshire Integrated Care Board to explore a Joint Committee operating with a Section 75. It was agreed a report would come in September 2024 as a stop/go point to proceed to the ICB/Council for approval. Currently across the system there is a £25m Section 75 Better Care Fund and this proposal would increase the Section 75 to £37m from 1st April 2025, with the potential to increase to £337m.

SCL informed some of the reasons for setting up a joint committee include having better joined up services for residents, it will help to avoid costly decisions and it can facilitate provider organisation-agnostic and team-based approaches at all levels and evolving to more joined up care. The model for the Joint Committee will all be brought together with a signed partnership agreement signed by all partners. SCL emphasised that the model we want to create is much more than a mutually agreed Section 75 between the ICB and Council, and that this was really about Place operating as an Integrated Provider Organisation, working as one system, taking decisions together, for the benefit of our staff and population. Sharing the timeline SCL informed the plan to outline the proposal, process and governance to the Council and ICB Executive, followed by formal Council meeting and the ICB Executive Board in November 2023. Shadow arrangements would commence in December or January culminating in a final decision point in February/March 2025 outlining the intended outcomes and budgets.

PR continued the presentation and stated that the Joint Committee model will mirror North East Lincolnshire but strenthen the financial section and reflect the complexity of the geographical issues within York Place's Bounderies. Continuing PR shared some of the principles underpinning the Joint Committee Section 75 and services and funding proposed for inclusion, noting that some services will be brought in at a later date for the best outcome.

Detailed discussion ensued on:

- Proposal of a six-month review point to check in with how it is working.
- Making decisions that don't compromise what is already taking place.
- Importance of creating something that works for York and not simply offering the same as other places, to ensure we deliver the very best possible outcome for the Place, the ICB, the Council and Humber and North Yorkshire.

York Health and Care Partnership were happy to approve the recommendations to:

- i) Note the progress that has been made since the last Board update.
- ii) Approve the decision in principle to develop and establish a Section 75 partnership agreement, and the NHS Place Director and Council Chief Executive to request approval from the ICB Board and City of York Council Executive to enable the new agreement to start on 1st April 2025.
- iii) Approve the decision in principle for supplementary legal advice being sought to undertake revisions to the financial section of the agreement.
- iv) Approve in principle that the Section 75 should be completed and signed in time for the agreement to become operational from 1st April 2025.
- v) Note the intention to develop a signed partnership agreement to sit alongside the Section 75 partnership agreement to formalise integration arrangements.

5. System Assurance Report

NC shared some key areas of the System Assurance report including some improvement in Urgent and Emergency care but still some work needed to stabilize. The Trust are not meeting the 2024/25 improvement trajectory for the 4 hour A&E target though it has seen some improvement, Ambulance Handover times have improved to just under 40 minutes in August.

NC indicated that there are 702 people over the 52 week wait for Children and Young People's speech and language therapies, and an item will be going to the Trust's board meeting in September, the Primary /Secondary care interface group is continuing and areas where we are not meeting the trajectory are seen.

Discussion ensued that speech and language therapies, noting it is a national issue, York St John's University will be opening a master's course in September 2025 for speech and language therapies.

PR noted that the flu vaccination campaign dipped below 50% uptake in 2023/24 and encouraged all to push the campaign within their organisations.

Action:

NC to look to include the impact on people within the System Assurance report. SCL acknowledged the need to review the assurance report in the context of Joint Committee plans.

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6. Any other Business and Close

There was no other business raised.

Next Meeting: Thursday 24 October 2024

Annex B:



<u>Directory of Services to Support People to Stay Well in Their</u> <u>Communities Over the Winter – Information for the public.</u>

This document outlines the services that are available to support you to stay well in your communities over the winter.

Services

1.	A&E	12. <u>Local Area Coordinators</u>
2.	Brain Health Café	13. Mental Health Support
3.	Carers support	14. <u>NHS 111</u>
4.	Citizens Advice Bureau	15. Older Citizens Advocacy York
5.	First Contact Mental Health	16. Pharmacy First
	<u>Practitioners</u>	17. Self-care minor illnesses and injuries
6.	Help with food	18. Social prescribing in York
7.	Healthier Together	19. Warm places in York
8.	Home Energy Efficiency	20. Winter Bills Scheme
9.	Home from Hospital	21. York and Selby Heart failure nursing services
10	. <u>Let's get better</u>	22. York Energy Advice
11	. <u>Live Well York</u>	

Service Name	Detail of the service available
1.A&E (accident and emergency)	Name of service: A&E is for serious injuries and life- threatening emergencies only. It is also known as the emergency department or casualty.
	Who is this service for? Life-threatening emergencies, please visit NHS England website When to go to A&E
	How to access the service: your local York Hospital Emergency Department (A&E) in York .

	 Opening hours: 24h services Telephone/email contact: 999, or if you're not sure what to do, NHS 111 can help you.
2.Brain Health Café	 Name of service: Brain Health Café, to support people whilst they are on the waiting list for the memory clinic. The aim is to improve the experience of people awaiting a possible diagnosis of mild cognitive impairment or dementia. Who is this service for? Anyone who has any concerns about their memory or wants to know more about how to keep their brain healthy.
	 How to access the service: Free service and everyone is welcome! Café takes place every: Wednesday 10-12pm at Nimbuscare Acomb Garth Friday 1-3pm at Wigginton Recreation Hall (except Bank Holidays) Opening hours: Dementia Forward, Monday – Friday, 9-4pm Telephone/email contact: Dementia Forward helpline Tel: 03300 578592, email: info@dementiaforward.org.uk
3. Carer support	All Carers from age 5+ York Carers Centre is an independent charity offering free support and advice to unpaid carers in York. Includes specific services for young carers (age 5 - 18 years), and young adult carers (age 16 - 25 years) Phone: 01904 715490 Website: www.yorkcarerscentre.co.uk Young Carers - essential support for under 25s The Mix www.themix.org.uk/young-carers

 Parent Carers: <u>Parent Carer Forum</u> supports parent carers of children aged 0 – 25 years

Email: connect@pcfyork.co.uk

Website: www.parentcarerforumyork.org

All Carers over 18

Local Social Prescribing Offer Phone: 01904 437911

All Carers

 City Of York Council social care support for carer and the person they care for.

Phone: Adult Social services 01904 555111

Website: www.livewellyork.co.uk

o Support and benefits for carers - NHS

Website: www.nhs.uk

4. Citizens Advice Bureau

 Name of service: CAY Advocates aim to help you achieve an outcome which will have a positive effect on your wellbeing.

Advocacy simply means supporting people to speak up for themselves when there is something they want to say. Advocacy is a way of making sure a person's voice is heard when issues affect their lives.

Advocates are skilled staff and volunteers trained to assist with everyday issues. They will not tell you what to do.

- Who is this service for? people over 50 in York who may be:
 - Experiencing financial hardship
 - Overwhelmed by bureaucratic processes
 - Facing communication barriers or digital exclusion
 - Lacking support systems
 - Unaware of their legal entitlements
- How to access the service: self-referral,

All clients have an initial meeting (currently over the phone) but usually face to face with our Lead Advocate. They chat through and agree with the client what help or support is needed. The volunteer works with the client for as long as is required. The service is client-led, free and confidential.

- Opening hours: Monday Friday 10am 3pm
- Telephone/email contact:

Tel: 01904 676200

Email: info@ocay.org.uk

Website: https://oldercitizensadvocacyyork.org.uk/

5. First Contact Mental Health Practitioner

- Name of service: First Contact Mental Health
 Practitioner's (FCMHP) based in your local GP Practice,
 is an experienced professional who can support you with
 either a diagnosed or undiagnosed mental health
 concern. This could be one or a number of mental health
 feelings and symptoms such as anxiety, low mood,
 loneliness, grief, hallucinations or stress.
- Who is this service for? Anyone that is wanting to seek support with their Mental Health.
- How to access the service: Your local GP surgery, please contact reception and ask for an appointment with the FCMHP.
- Opening hours: Varies on the opening hours of the surgery in your area.
- **Telephone/email contact**: Your GP surgery contact number.

6.Help with food

- Name of service: <u>Help with food</u>, if you're struggling to pay for food, free independent advice and support about social welfare issues is available for all residents, covering benefits, debts and employment.
- Who is this service for? Available for all residents

	 How to access the service: for a range of support with food available, please visit Help with food website. Opening hours: Monday – Friday, 9-5pm Telephone/email contact: Benefits and Contributions Advisors, Telephone: 01904 552044, email: incomeservices@york.gov.uk
7. Healthier Together	 This website provides parents, carers, pregnant women and birthing people, babies, children and young people across Humber and North Yorkshire with consistent and high-quality advice from local health professionals. You'll find clear information on common childhood illnesses, including advice on what 'red-flag' signs to look out for, where to seek help if required and how long your child's symptoms are likely to last. Website: https://www.hnyhealthiertogether.nhs.uk/
8.Home Energy Efficiency	 Name of service: The Home Energy Efficiency Team are passionate about helping you to save energy, money and carbon, making sure that you feel warm and healthy in your own home all-year-round. Who is this service for? Available for all residents How to access the service: please contact the team on the number below or visit The Home Energy Efficiency Team website to find out more. Opening hours: Monday – Friday, 9-5pm Telephone/email contact: Home Energy Efficiency Team, Telephone: 01904 555520, Email: saveenergy@york.gov.uk
9.Home from Hospital	Name of service: Home from Hospital. Age UK hospital services scheme is a flexible service of up to 6 weeks, to

	 support you when you leave hospital or intermediate care. Who is this service for? A free service enabling older people to be more confident and comfortable at home after their hospital stay. How to access the service? Please visit the Age UK website for more information click here or see leaflet here Opening hours: Monday – Friday, 9:30-3:30pm Telephone/email contact: 01904 726191, ageukyork@ageukyork.org.uk
	ageuryorn wageuryorn.org.un
10. Let's Get Better	 Name of service: Let's get better offers comprehensive resources, support and signposting to help you and your family Start Well, Age Well and Live Well. Who is this service for? If you live in any part of the
	Humber or North Yorkshire, Let's Get Better is the ultimate destination for all your health and wellness needs.
	How to access the service: free online resources, please visit the Let's get better website.
	Opening hours: Find a pharmacy - NHS (www.nhs.uk)
	Telephone/email contact: hnyicb.communications@nhs.net
11. Live Well York	Name of service: Live Well York, website offers a number of resources for community support and social care in York, for example, advice about money, legal issues, housing.
	Who is this service for? An Information and Advice community website for all adults.

	 How to access the service: please visit Live Well York website https://www.livewellyork.co.uk/ Opening hours: free online resources Telephone/email contact: Adult Commissioning Team, Telephone: 01904 551006, Email: livewellyork@york.gov.uk
12.Local Area Coordinators	 Name of service: Local Area Coordinators (LACs): They help raise awareness of available resources within the local community and support people with a wide range of issues. Who is this service for? LACs work with individuals and families of all ages and abilities. They take time to get to know you, your family, friends, carers and your community, so they can help you to build a strong support network. How to access the service? This directory contains contact details of all LACs working within local communities in York, please visit LACDirectory Opening hours: Monday- Friday, 9-5pm Telephone/email contact: CYC Customer Services team 01904 551550
13.Mental Health Support	 Name of service: Community mental health services, if you are feeling low, sad or worried but are not experiencing a mental health crisis, there is a range of mental health support you may wish to consider. Who is this service for? Providing community-based support to people aged between 18 and 65 years old who are experiencing challenges with their mental health. How to access the service: to contact the right support for the area please visit TEVW/services/communitymental-health.

- Opening hours: Monday-Friday, 9-5pm
- Telephone/email contact: Mental health crisis call: 0800 0516 171, the line is open 24/7 Healthwatch York have also produced a user friendly guide on how to seek help in a crisis which is available here.

Other useful contacts:

- **TEWV crisis services**, 24 hours a day, seven days a week, Freephone 0800 0516 171
- The Haven @ 30 Clarence Street, 6pm-11pm, every day, Tel. 07483 141 310
- Drug and alcohol services, 8.30am 4pm, Monday-Friday, Tel. 01904464680 (York), Tel. 01723 330730 (North Yorkshire)
- Samaritans, 24 hours a day, seven days a week, Tel. 01904 655888
- Citizens Advice Bureau, 9.30am 12.30pm, Monday, Wednesday and Thursday, Tel. 03444 111 444

14.NHS 111

- Name of service: NHS 111 is the fast, easy and free NHS non-emergency contact offering clinical advice. When you call 111 you will speak to a highly trained adviser who is supported by healthcare professionals. The adviser will ask you a series of questions to assess your own, or the patient's symptoms, and you will then be directed immediately to the most appropriate medical care.
- Who is this service for? If you think you need medical help right now, 111 online can tell you what to do next.
- How to access the service: You can call 111 or fill in an online form at 111.nhs.uk/
- Opening hours: 24h services

Telephone/email contact: call 111 • Name of service: Citizens Advice York offers free, 15. Older confidential and impartial advice on a wide range of issues Citizens including benefits and tax credits, debt, housing, employment, Advocacy York and much more. • Who is this service for? Anyone over 18 How to access the service: please call number below Opening hours: 10am - 4pm Monday – Friday • **Telephone/email contact:** free Adviceline: 0808 278 7895 (Mon-Thurs, 10am-4pm) Website: https://www.citizensadvicevork.org.uk 16. Pharmacy Name of service: Your local pharmacy team are **First** healthcare professionals who can give you clinical advice and treatment for a range of common conditions, minor illnesses as well as help you decide whether you need to contact other healthcare services, understand the medicines you've been prescribed and review your prescription if you have any concerns. Pharmacy First 7 common conditions: Uncomplicated UTI – women 16-64 years Shingles – 18 years and over Impetigo – 1 year and over ○ Infected Instect Bites – 1 year and over Sinusitis – 12 years and over Sore Throat – 5 years and over Acute Otitis Media – 1 to 17 years If you go to a pharmacy with one of these conditions, the pharmacist will offer you advice, treatment or refer you to a GP or other healthcare professional if needed. Pharmacy First referrals for minor illness (previously)

Pharmacy First urgent repeat medicines supply service

Community Pharmacist Consultation Service (CPCS)

Who is this service for?

- Pharmacy First 7 common conditions can be accessed by the age ranges listed above.
- Pharmacy First referrals for minor illnesses can be accessed via your GP Practice.
- Pharmacy First urgent repeat medicines can be accessed via NHS 111 or urgent treatment centre.

How to access the service:

- Pharmacy First 7 common conditions can be accessed via visiting a community pharmacy or referral from your GP Practice or NHS 111
- Pharmacy First referrals for minor illnesses can be accessed via a digital referral from your GP Practice, NHS 111 or urgent treatment centre.
- Pharmacy First urgent repeat medicines can be accessed by contacting NHS 111 or visiting an urgent treatment centre.

Opening hours:

- Pharmacy First 7 common conditions: Community pharmacy opening hours are available on <u>Find a</u> <u>Pharmacy</u>.
- Pharmacy First referrals for minor illnesses: A digital referral for this service is available when your GP practice is open or contacting NHS 111 A consultation with a pharmacist is available when the community pharmacy is open.
- Pharmacy First urgent repeat medicines: NHS 111 is open 24 hours and opening hours for urgent treatment centres can be found at <u>Find urgent and emergency care</u> <u>services.</u>

• Telephone/email contact:

- Contact details for a community pharmacy can be found at <u>Find a Pharmacy</u>.
- Contact details for your GP Practice can be found on their website.
- o Contact NHS 111 by ringing 111.
- Further information about urgent treatment centres can be found at <u>Find urgent and emergency care services</u>.

17. Self-Care Name of services: Visit the NHS website for a full medicine cabinet list. You 'Stay Well This can often self-treat many minor illnesses and injuries at home by keeping your medicine cabinet and first aid kit Winter' well-stocked with medicines. 'Stay Well This Winter' offer advice on keeping well during the winter months to: those with long-term health conditions, those over 65, pregnant women parents of under-7's. Advice to help you stay well this winter: Watch these short videos of York GPs sharing their advice on a range of common conditions: Who is this service for? Available to everyone How to access the service: please visit 'Stay Well This Winter' for more information Opening hours: Find a pharmacy - NHS (www.nhs.uk) Telephone/email contact: Find a pharmacy - NHS (www.nhs.uk) Name of service: Social Prescribing is a term which 18.Social means linking people to non-medical sources of support to improve people's health and wellbeing. Social **Prescribing in** York Prescribers are not Support Workers, Counsellors, Social Care or Mental Health Workers – they support patients to connect with these services **Primary Care Link Workers** are part of the Social Prescribing Team at York CVS. The Primary Care Link Workers are Social Prescribers based in GP surgeries across York, working alongside individuals to get to know them, and ultimately help them improve their health and wellbeing. • Eligibility: people with social issue, (e.g. loneliness, isolation, financial problems), social prescribing helps

	 provide individuals with an alternative to medical intervention. The team supports people aged 18+ living in the area served by City of York Council. How to make a referral: via GP practice or self-referrals. Opening hours: Monday-Friday 9-5pm Telephone/email contact: 01904 437911 More information on the York CVS website.
19.Warm places in York	 Name of service: A Warm Place is somewhere you can go, free of charge, to spend time to keep warm if you're struggling to heat your home. You can find a list of Warm Places in York on the Live Well York Service Directory, all offering a Warm Place with seating and facilities open for at least 2 hours a week. Who is this service for? Free to everyone, with no requirement to buy anything. How to access the service: There are lots of community venues in York offering a Warm Place this winter: Explore York libraries and Warm Places on Live Well York Opening hours: please visit above websites for opening hours. Telephone/email contact: Shaping Neighbourhoods, Email: shapingneighbourhoods@york.gov.uk
20.Winter Bills Scheme	 Name of service: Winter Bills Scheme, provided by City of York Council to support vulnerable households with significantly rising living costs. Please also visit Help with utility bills website. Who is this service for? The scheme is open to City of York residents who are over 16 years of age, who require urgent financial assistance.

- How to access the service: Please visit City of York Council for eligibility criteria Household Support Fund.
- Opening hours: Monday Friday, 9-5pm
- Telephone/email contact: please contact Benefits Team on 01904 551556, Email: <u>benefits@york.gov.uk</u>

21. York and Selby Heart Failure Nursing Services

- Name of service: York and Selby Heart failure nursing services: The specialist heart failure team are involved with the care of patients with heart failure in both the hospital and community settings, from the time of diagnosis of this condition.
- Who is the service for:
- Rapid Access Clinic urgent review of any deteriorating heart failure patient with the option to offer IV diuretics to prevent hospital admission
- Community clinic face to face clinic reviews to optimise management of heart failure with EF <45% until stable
- Home visiting face to face reviews of housebound patients with an EF <45%
- How to access the service: Referrals are accepted from cardiologists, GPs, district or practice nurses.
 Once a referral is received the team will telephone the patient to make the appointment. Nurses can visit patients in their home or invite them to a clinic setting of their choice.
- Opening hours: Monday Friday 9:00-17:00

Telephone/email contact:

- Health care professionals:01904 721344
- Patients with EF < 45%:
 Urgent 01904 721445
 Non urgent 01904 721200

o Patients with EF >45%: 01904 721445

The patient advice line closes at 15:30

22. York Energy Advice

- Name of service: York Energy Advice offers a range of home assessment services for different budgets that can help you understand more about energy efficiency upgrades in your home.
- Who is this service for? free support on energy issues to anyone in York on a low income, or aged 65+, or experiencing a long term physical or mental health condition or disability.
- How to access the service: self- refer
- Opening hours: Monday Thursday
- Telephone/email contact: Phone: 01904 922249

Email: info@yorkenergyadvice.org.uk

SMS: 07418 364631

Website: https://yorkenergyadvice.org.uk/



Annex C:

<u>Directory of Services to Support People to Stay Well in Their</u> <u>Communities Over the Winter – Information for Health and Care</u> <u>Professionals</u>

The below table includes a directory of support services, aimed at supporting the public during the winter months, with a specific focus on community and frailty elements.

Health and care professionals can efficiently guide individuals towards the assistance they require, fostering a resilient and healthy community during the challenging winter season. This resource highlights the support available to York residents to navigate winter with confidence and ensuring that help is readily available when needed the most.

Services:

- 1. Adult Social Care Community Team
- 2. Adult Social Care Emergency Duty Team
- 3. Age UK Out and About Service
- 4. Asylum Seekers support
- 5. Be Independent
- 6. Cardiac Prevention and Rehabilitation Team
- 7. Community Diagnostic Centre
- 8. Community Response Team
- 9. Continence Advisory Service: Selby and York
- 10. Dementia Forward
- 11. District Nursing
- 12. Extra Discharge Support Service
- 13. Frailty Advice & Guidance Line
- 14. Frailty Same Day Emergency Care
- 15. Heart Failure Virtual Ward
- 16. Heart failure nursing services York and Selby
- 17. Health Navigator
- 18. <u>Home Oxygen and review service (not an acute service)</u>
- 19. Immedicare Telemedicine Service
- 20. Local Area Coordinators

- 21. Long Covid Service
- 22. <u>Medical Same Day Emergency Care</u> (MSDEC)
- 23. Mental health support /other support
- 24. Move the Masses
- 25. One team
- 26. Pharmacy First
- 27. Practitioners Guide to Carers Support in York
- 28. Rapid Assessment Therapy
- 29. Reablement (Adult Social Care Intensive Support Service)
- 30. Social Prescribing in York
- 31. St Leonard's Hospice @Home and Carer Support service
- 32. TEWV MDT
- 33. TEWV services on offer
- 34. TEWV First Contact Mental Health Practitioners
- 35. Urgent Community Response Team
- 36. Virtual Frailty Ward
- 37. York Integrated Care Team
- 38. York Place Quality and Nursing Team Care Provider Support

Service name	Details of the service available
1.Adult Social Care Community Team	 Name of service: Adult social care is about providing personal and practical advice and support to adults who need help to live an enjoyable life as independently as possible. Eligibility: In order to get support from City of York Council, you must – be aged 18 or over be living within the City of York Council Local Authority area have needs which are eligible for support based on the National Care Act eligibility criteria (2014) How to make a referral: refer directly via Adult Social Care team Opening hours: Monday -Thursday 9-5pm, 9-4.30pm on Fridays Telephone/email contact: 01904 555111, Textphone: 07534 437804 adult.socialsupport@york.gov.uk For more information please see guide attached: A_quick_guide_to_Adult_Social_Care.pdf
2.Adult Social Care Emergency Duty Team	 Names of Service: Contact the Emergency Duty Team for an urgent social care assessment and support outside of normal office hours. They provide advice and guidance, and carry out urgent assessments of adults, young people and children. Eligibility: All social care, housing and homelessness emergencies Opening hours: Monday to Thursday: from 5.00pm to 8.30am Weekends: from 4.30pm on Friday to 8.30am on Monday Bank Holidays: 24 hours a day Telephone/email contact: 0300 131 2131
3.Age UK Out and About Service	 Name of service: Age UK Out and About Service Providing support for 6-8 weeks post discharge, helping frail and elderly people to integrate back into their communities, reducing isolation and loneliness and admission avoidance.

	 Eligibility: frail and elderly people How to make a referral: this service is free of charge. You can refer directly by calling Information and Advice service on 01904 634061. Opening hours: 9:30- 3:30 pm Monday to Friday
	Telephone/email contact: 01904 634061, firstcall@ageukyork.org.uk For more information please visit the website Age UK website
4.Asylum Seekers support	 Name of service: Asylum Seekers support to some of our most vulnerable patients and families with children. To proactively manage their care, the ICB has commissioned bespoke support via Nimbuscare which provides a specialist in-reach service to manage what are often complex needs for these people. Eligibility: Asylum Seekers staying at hotel accommodation in York. How to make a referral: Patients cannot be referred into this service. Opening hours: Monday-Friday 8-8pm Telephone/email contact: 01904 943 690, nimbuscare.operationalservices@nhs.net. to find out more please visit Nimbus care
5.Be Independent	 Name of service: Be Independent helps citizens to live independently by bringing emergency care and specialist equipment to their home; services can play a key role in supporting their better health and care, and to maintain their own independence, in York. Eligibility: anyone needed specialist equipment to live
	independently

How to make a referral: Be independent professional partners can refer customers here

- Opening hours: General enquiries: 9.00am to 5.00pm, Monday to Friday
- Telephone/email contact Telephone: 01904 645000, email: be.independent@york.gov.uk
- Find out more about what Be Independent offers including:
 - York Telecare Response Service
 - o Equipment Loan Service

6. Cardiac Prevention and Rehabilitation Team

• Name of service: Cardiac Prevention and rehabilitation Team Cardiac Rehabilitation is a service provided by clinical nurse specialists and a specialist physiotherapist following a diagnosis of a heart condition (acute or elective).

Patients and their families are provided with up to date information and support to help with their recovery from both a physical and psychological perspective, with the overall aim of getting people back to 'normal' and reducing further heart complications in the future.

- Eligibility: Post MI/ heart surgery/ TAVI / Stenting procedures
- How to make a referral: email yhs-tr.crehab@nhs.net
- Opening hours: 08.00-16.00
- Telephone/email contact: 01904 725821 (Monday to Friday, excluding bank holidays)

7. Community Diagnostic Centres

 Name of service: The new Community Diagnostic Centre (CDC) at Askham Bar Community Care Centre, York, and offers a range of services to help diagnose life-threatening conditions, such as cancer and heart problems, more quickly.

Provided in partnership between York and Scarborough Teaching Hospitals Foundation Trust and Nimbuscare, the CDC offers a broad range of diagnostics, including checks, scans and tests which patients can be referred to by their GP.

Askham Bar is providing:

1. CT – mobile

- 2. MRI mobile
- 3. Dexa
- 4. NOUS
- 5. ECHO
- 6. Phlebotomy (via Nimbuscare)
- 7. Spirometry / Feno (via Nimbuscare)
- 8. ECG (via Nimbuscare)
- 9. ABPM (via Nimbuscare)
- 10. Holter Fitting and monitoring

How to make a referral:

IMAGING

- Trust referrals: For all imaging from primary care, refer as usual electronically and the Trust will allocate to the main site or CDC, dependent on the information provided in the referral. and the closest suitable site to the patient's home address (unless requested otherwise). Please put in up-to-date contact details for the patient. Results will be returned electronically to the surgery of the referring clinician.
- Nimbuscare Provided Modalities: via email to <u>nimbuscare.cdc@nhs.net</u> Referral information should include: Referral Modality, NHS Number and preferred contact number for patient. Results will be sent back via S1 or EMIS to the patient's registered GP practice.

PHLEBOTOMY at Askham Bar.

This service is for all patients that require blood testing. GP requires to complete the form on ICE send it to the patient.
 There is no need to collect blood forms in advance. An appointment can then be booked at the CDC by calling 01904 943690. Service hours are Monday to Friday 8:00-18:00.

Opening times

The centre is open Monday to Friday between 8am to 6pm. CT scanning is also available on Saturdays between 8am to midday.

For more information about CDCs please see:

	w=
	20240917_CDC Comms Document.do
8.Community Response Team	 Name of service: The York Community Response Team (CRT) is a large multi-disciplinary health care team consisting of nurses, therapists, and support workers. The team provide assessment, short term intervention, rehabilitation, reablement and recovery, supporting both discharge and admission avoidance.
	 The same team also delivers Urgent Community Response (care with 2 hours) and supports the Frailty Virtual Ward, however the CRT element is typically care provided within 1-2 days for a period of around 6 weeks.
	Eligibility: Patients 18 years and over, within their own home environment (including care homes), registered with a York GP (except Pocklington).
	How to make a referral: Call the CRT telephone number below
	Opening hours: 8am – 8pm, 7 days per week, 365 days per year
	Telephone/email contact: 01904 721343 / 07943876398
9. Continence Advisory	Name of service: Continence Advisory Service: Selby and York:
Service: Selby and York	 Comprises of a team of nurses and physiotherapists who are specialists in the treatment and management of bladder and bowel conditions including urinary incontinence and bowel incontinence. Aim is to treat and cure bladder and bowel dysfunction where possible. When all possible improvement has been achieved the team aims to manage any residual problems as best as possible to maintain each individual's comfort and dignity. The team provides training for community based health and social care staff to broaden and maintain knowledge of continence care; for people in their own homes and in residential care.

	 The team, also acts as a resource for queries and specialist information regarding continence for all health and social care staff within North Yorkshire and York and the East Coast. Eligibility: provide services for adults and older people across
	North Yorkshire running accessible clinics in local areas and providing home visits when required.
	 How to make a referral: Referral is open in most localities, although a letter if preferred from a GP outlining the person's symptoms and previous medical history. Patients may be referred from their GP or other health professional. Continence assessment and reassessment documents can be found here.
	 Opening hours: service operates Monday to Friday 8.30am - 5.00pm (excluding public holidays)
	Telephone/email contact: Telephone: 01904 721200
10. Dementia Forward	Name of service: Dementia Forward (DF) is the leading dementia charity for York and North Yorkshire that provide support, advice and information to anybody affected by dementia across the county, and have developed a comprehensive range of services; all with people living with dementia at their heart.
	Eligibility: people living with dementia
	How to make a referral: via DF service
	Opening hours: Mon-Fri 9am-4pm
	 Telephone/email contact: helpline on 03300 578592 or by email to <u>info@dementiaforward.org.uk</u> more info on website: <u>https://www.dementiaforward.org.uk/</u>
11. District Nursing	 Name of service: District nurses supporting patients living in their own homes, including residential care homes and meet the definition of housebound are able to access the service. Housebound is an individual who is unable to leave their home environment due to a physical or psychological illness. An

individual is not housebound if they are able to leave their home environment with minimal assistance from other e.g. family, friends or Carers to attend the Doctor, Dentist, Hairdresser or leisure venues.

- Eligibility: Each patient will be individually assessed to determine their eligibility for home nursing visits by a qualified community nurse". This decision is based on individual needs and clinical judgement. Care needs typically addressed by the district nursing team include:
 - o end of life/ palliative care
 - o wound care/leg ulcer management
 - o catheter management
 - o administration of medication.
 - Care of Hickman/PICC lines and discontinuation of chemo pumps
 - This list is not exhaustive, referrals will be triaged, refers will be advised if patients are not suitable for the district nursing service
- How to make a referral: via DN team
- Opening hours: 24 hour service accessed via single point of access
- Telephone/email contact: 01904 721000

12.Extra Discharge Support Service

- Name of service: Age UK Home From Hospital: A free service enabling older people to be more confident and comfortable at home after their hospital stay, support for up to six weeks for older people in York when they leave hospital.
- Eligibility: those aged 60 or over who live in the York area and who have either: • Been in A&E • Had a day procedure • Had a hospital stay • Have CYC reablement support. Unable to offer support for • those aged under 60 with some complex long term care needs.
- How to make a referral: refer directly via Age UK
- Opening hours: Monday Friday 9:30-3:30pm
- Telephone/email contact: 01904 726191, ageukyork@ageukyork.org.uk

13. Frailty Advice & Guidance Line	Name of service: The Frailty Advice & Guidance line is ran by a GP with a specialist interest in Frailty working the in the Frailty Crisis Response Hub (see below), and is available to the whole system to offer advice and guidance for frail patients experiencing a crisis in the community in order to support admission avoidance.
	Eligibility:
	Inclusion Criteria: o Living in own home or residential/care setting with frailty (Rockwood Score of 5 or more prior to acute illness)
	 Exclusion Criteria: Patients requiring acute pathways, eg. PPCI, Stroke, #NOF etc. (unless YAS clinician feels conveyance is not in the patient's best interests – refer to Advance Care Plan) Patients experiencing a mental health crisis requiring assessment by a specialist mental health team Patients needing acute/complex diagnostics and clinical intervention in hospital
	How to make a referral: Call YICT team and ask for the Frailty Advice & Guidance Line
	 Opening hours: Monday – Friday 8am – 8pm and Sat and Sun 10am – 6pm
	Telephone/email contact: 01904 928844
14.Frailty Same Day	Name of service: Frailty Same Day Emergency Care Located at York Hospital
Emergency Care (FSDEC)	 Eligibility: services available to all patients in the York area who fit the following criteria: Patient is 75 yrs or older AND has a Clinical Frailty Score (CFS) of 5 or more

- Patients are likely to be able to return to their usual place of residence same day following assessment
- Patient is presenting with a medical condition that cannot be managed in the community
 NEWS2 is 4 or less and less than 3 in any one parameter.

Examples of suitable conditions include (but not limited to) UTI, confusion, falls, COPD, heart failure, syncope, cardiac arrhythmia, anaemia, urinary retention, dementia, Parkinson's, low-risk chest pain (now pain free and no ECG changes). Patients **should not** be referred to FSDEC if outside of the above criteria or:

- -Infection risk (e.g, Covid, Flu, D&V)
- -Suspected #NOF or undiagnosed fracture
- -Trauma related problems including head injury
- -Patients requiring specialist pathways (e.g. PPCI, Stroke, red Flag Sepsis, Vascular, Major Trauma)Sepsis,
- How to make a referral: via the service, call to discuss if unsure of suitability. <u>Last referral must reach the unit before</u> <u>5pm, 7 days per week.</u>
- Opening hours: Mon Sun, 8am 4pm
 Telephone/email contact: 01904 725199

15. Heart Failure Virtual Ward

Name of service: Heart Failure Virtual Ward Eligibility:

- Patients must have a confirmed diagnose of Heart Failure (HFpEF/ HFrEF) on echocardiogram or cardiac MRI (CMR) scan
- Patient has evidence of decompensated heart failure requiring diuresis.
- Patient must be registered with a Vale of York GP.
- Patient must be 18 years and older and consent to the referral.

How to make a referral:

By email: yhs-tr.heartfailurenursesyork@nhs.net

By telephone call: 01904 721344

Opening hours:

Monday to Friday 8am to 5pm

Telephone/email contact:

As above

16. Heart Failure Nursing Services York and Selby

 Name of service: York and Selby Heart failure nursing services: The specialist heart failure team are involved with the care of patients with heart failure in both the hospital and community settings, from the time of diagnosis of this condition.

- Eligibility:
- Rapid Access Clinic urgent review of any deteriorating heart failure patient with the option to offer IV diuretics to prevent hospital admission
- Community clinic face to face clinic reviews to optimise management of heart failure with EF <45% until stable
- Home visiting face to face reviews of housebound patients with an EF <45%
- How to make a referral: Referrals are accepted from cardiologists, GPs, district or practice nurses.
 Once a referral is received the team will telephone the patient to make the appointment. Nurses can visit patients in their home or invite them to a clinic setting of their choice.
- Opening hours: Monday Friday 9:00-17:00
- Telephone/email contact:
 - o Health care professionals:01904 721344
 - Patients with EF < 45%:
 Urgent 01904 721445
 Non urgent 01904 721200

o Patients with EF >45%: 01904 721445

The patient advice line closes at 15:30

17.Health Navigator	Name of service: Health Navigator: Health coaching for individuals with long term conditions to provide additional support, to individuals to manage their conditions and stay well.
	 Eligibility: This programme is currently open to patients registered with Haxby Group Practice, Priory Medical Group, and York Medical Group, although referrals from other York practices may be considered. Typical patient profiles include those with 2+ LTCs that may include: diabetes, respiratory conditions, cardiovascular diseases, and anxiety/depression.
	Exclusion criteria: Under 18s, Primary diagnosis of an acute mental health issues, cognitive impairment, end of life, homelessness.
	How to make a referral: Professional referrals accepted only via email.
	Opening hours: Standard office hours, 09:00-17:00, excluding bank holidays.
	Telephone/email contact: for general queries only info@hn-company.co.uk Please do send patient identifiable information to this address.
18. Home	Name of service: Home Oxygen and review service (not an
Oxygen and review service (not an acute service)	 Eligibility: All non-smoking (includes vapes/e-cig) defined as smoke free for a minimum of 12 weeks registered with a GP in the Vale of York who met the BTS criteria for Home Oxygen. How to make a referral: Referrals which have been completed fully including all the mandatory investigation are accepted via GPs (referral forms are available of the Vale of York RSS website). Palliative care team and Consultants. Opening hours: 08:30-16:30 Monday to Friday (excluding Bank holidays) Telephone/email contact: 01904 726448 or e-mail yhs-tr.yorkrespiratorynurses@nhs.net
19. Immedicare	Name of service: Available to 31 nominated older adults and
	The state of the s

LD/MH care homes in York, the Immedicare service aims to

support response to deterioration early and help keep care

Telemedicine

Service

home residents within their place of residence, preventing hospital conveyance and calls to other services.

- Able to support with all urgent care contacts, with the most frequent calls received for falls, suspected UTI's, chest infections, skin complaints and medication issues. The team provides video-assessment, supervision, advice and guidance, and can support staff while awaiting an ambulance, and can perform virtual verification of death where appropriate and issue prescriptions.
- Eligibility: Care home residents within nominated homes.
- How to make a referral: Homes provided with a secure clinical laptop to access a remote consultation. Staff are encouraged to call as soon as they are concerned about a resident/notice deterioration.
- Opening hours: 24/7, 365 days a year
- For further information please contact:

Email: hnyicb-voy.yorkplacequalitynursingteam@nhs.net **Phone:** 07593 382927- ICB lead for the service.

20. Local Area Coordinators

- Name of service: Local Area Coordinators work with individuals and families of all ages and abilities. They help raise awareness of available resources within the local community.
- Eligibility: support people with a wide range of issues.
- How to make a referral This directory contains contact details of all Local Area Coordinators working within local communities in York LACDirectory
- Opening hours: Monday-Friday 9-5pm
- Telephone/email contact: via <u>LACDirectory</u> If your area isn't covered by a Local Area Coordinator, contact our <u>Community</u> Facilitator.

21. Long Covid Service

• Name of service: Long Covid Service

- Providing practical support and advice to patients with Long Covid and ongoing post viral symptoms, aiming to give patients the skills to self-manage their symptoms.
- Via telephone, Living with Covid Recovery app and F2F appointments.
- The team is Consultant led, with in-house specialist Occupational Therapists providing support with fatigue management, cognitive issues and vocational rehabilitation, specialist Physiotherapists supporting patients with breathlessness management and return to activity, a dedicated Psychologist and strong links with Talking Therapies to support emotional wellbeing.
- Patients have an initial holistic assessment by specialist nurses, are enrolled onto Living with Covid Recovery app, offered on-line Group Education/self-management sessions to give an overview of Long Covid symptoms and management. Onward specialist referrals following completion of the group sessions.

Eligibility:

- Referrals accepted from York, Selby, Scarborough, Whitby and Ryedale GPs. Referrals from other local HCPs following discussion.
- Over 16yrs, with ongoing post viral symptoms for 12wks or more following infection.
- Other causes for symptoms must be ruled out prior to referral by relevant blood tests, CXR and ECG as appropriate.
- Patients should complete the C-19 YRS screening tool prior to referral.

How to make a referral: Via Choose and Book, professional letter

Opening hours: 09.00-17.00 Mon - Fri

Telephone/email contact:

Office No. 01904 721506

Email: yhs-tr.longcovidmdt@nhs.net

• Name of service: Medical SDEC is the provision of same day care for emergency patients who would otherwise be admitted

22. Medical Same Day Emergency Care (MSDEC)-

York Hospital

to hospital.

Under this care model, patients presenting at hospital with a suspected medical condition not suitable for referral elsewhere when in the community can be rapidly assessed, diagnosed, and treated without being admitted to a ward, and if clinically safe to do so, will go home the same day their care is provided.

Consider Medical SDEC first, no pathways, using the standardised exclusion criteria below.

Eligibility

Inclusion criteria:

- NEWS score <5 and/or 3 in one parameter, and age 18+
- A medical condition is the primary working impression (ie. no trauma/surgical/urology/ENT problems etc.)
- All medical patients will be considered for SDEC unless meeting exclusion criteria
- All GP/Primary Care referrals which meet criteria
- o See below for additional criteria for patients with chest pain

Exclusion criteria:

- Not suitable for management via primary care or community pathway
- o Trauma/surgical/gynae presentations
- o NEWS2 score ≥5 and/or 3 in any one parameter
- Acute mental health crisis
- Intoxicated (alcohol/drugs)
- Requires isolation
- New oxygen requirement
- o Active bleeding
- Requires specialist pathway (stroke, STEMI, vascular etc.)
- Confirmed diagnosis where admission is required

CHEST PAIN EXCLUSIONS

- Sudden onset of severe or ongoing pain
- Acute ecg changes
- o Pain occurring with minimum exertion
- o Pain lasting longer than 15 mins
- o Nausea/vomiting/sweating/syncope
- o Pain radiating to left arm/jaw/back

How to make a referral:

- In-hours, if patient meets criteria, bring patient straight to Medical SDEC - no phone call
- Out-of-hours, call unit to discuss/agree referral before conveying
- o Medical SDEC is located at Second Floor, Junction 5 at YDH
- If patient has any infective symptoms that require isolation, but otherwise meets criteria, call to discuss
- If conveying directly to the unit, please record in ePR under Clinical Outcome > Meets criteria for hospital conveyance > SDEC York Medical > Accepted
- If SDEC then decline to accept patient at point of handover, amend ePR Clinical Outcome screen to say referral Declined and add notes in comment section

• Opening hours:

5 days a week (Monday - Friday)

- o 08.00-18.00: phone call not required*, unless IPC risk
- o 18.00-08.00: call ahead to discuss/agree referral

2 days a week (Saturday-Sunday)

- 09:00 15:00 phone call not required*, unless IPC risk
- o 15.00-09.00: call ahead to discuss/agree referral

York SDEC now located at Ward 24, Junction 5, 2nd floor

• Telephone/email contact:

- SDEC Direct Line: 01904 726024 (to call first before bed managers)
- Bed Manager: 01904 725986SDEC Consultant: 01904 721247



23. Mental health support /other support

• Crisis Line – York (TEWV): a free phone line, open 24 hours a day, 7 days a week. For all ages, offering support for anyone in a mental health emergency. 0800 0516 171

- The Haven: offers out of hours mental health support to anyone aged 16 or over. Monday to Friday 6pm-10pm and Weekends 12pm -10pm. 30 Clarence Street, York, YO31 7EW
- Ways to Wellbeing: Connecting people to local community support to make them feel better, phone number: 01904 621133, Option 4 email <u>waystowellbeing@yorkcvs.org.uk.</u> Mon - Fri 9am - 4.30pm
- York Carers Centre: an independent charity to ensure unpaid carers throughout York have access to confidential information, advice and support, phone number 01904715490
 enquiries@yorkcarerscentre.co.uk . The telephone lines are open Monday to Friday 9.30am to 4.30pm (4pm on a Friday) for information and advice. Free evening Advice Line on Wednesdays from 5 to 8pm on main number: 01904 715 490.
- Live Well York: an information and advice community website for adults and families. They have a page signposting to health and wellbeing support in York. www.livewellyork.co.uk
- Qwell: a safe and confidential space online to share experiences and gain emotional wellbeing and mental health support from users and qualified professionals. https://www.qwell.io/

24. Move the Masses

- Name of service: Move the Masses is a charity which aims to create healthy communities by enabling people to improve their wellbeing through exercise. One of their most well known projects is called Move Mates, which sees volunteer walking buddies pair up with people who do not have the confidence to go out of their home by themselves.
- **Eligibility:** people who do not have the confidence to go out of their home by themselves.
- How to make a referral: via Move the Masses team
- Opening hours: Monday Friday 9-5pm

Telephone/email contact hello@movethemasses.org.uk Call 01904 373017

• Further information on the activities offered by them can be found here.

25. One Team

- Name of service: The One Team is multi-provider collaboration that meets daily to collaborate in the provision of support to enable patients to be discharged to their own homes. The team consists of CRT, YICT, Reablement and Social Care, Domiciliary Care Providers, voluntary care services supporting discharge and the York Hospital Discharge Team.
- **Eligibility:** Inpatient at York Hospital suitable for discharge to home with support.
- **How to make a referral:** N/A all suitable patients at York Hospital reviewed routinely.

26. Pharmacy First

Name of service: The Pharmacy First service builds on the NHS Community Pharmacy Consultation Service (CPCS) which has run since October 2019. The service enables patients to be referred (not signposted) into community pharmacy for a minor illness or an urgent repeat medicine supply.

The new Pharmacy First service, launched 31 January 2024, enhances what was CPCS and introduces a third element to the service – 'Clinical Pathways', which enables community pharmacies to complete episodes of care for 7 common conditions following defined clinical pathways.

- Pharmacy First 7 common conditions:
- Uncomplicated UTI women 16-64 years
- Shingles 18 years and over
- Impetigo 1 year and over
- Infected Insect Bites 1 year and over
- Sinusitis 12 years and over
- Sore Throat 5 years and over
- Acute Otitis Media 1 to 17 years

Further information, patient group directions and protocols can be found at Community Pharmacy advanced service specification: NHS Pharmacy First Service

When a patient visits a community pharmacy with one of these conditions, the pharmacist will offer the patient advice, treatment or refer the patient to a GP or other healthcare professional if needed. Guidance on escalation is found within Annex D shared by the ICB. If you require a copy, please contact: hnyicb-ny.pharmacycontracts@nhs.net.

- Pharmacy First referrals for minor illness (previously Community Pharmacist Consultation Service (CPCS)).
- Pharmacy First urgent repeat medicines supply service.

Eligibility:

- The Clinical Pathways element of Pharmacy First (7 common conditions) can be accessed by the age ranges listed above and further information can be found at Community Pharmacy advanced service specification: NHS Pharmacy First Service and appendix 1 Aide-Memorie for Pharmacy First.
- Minor Illness referrals for Pharmacy First can be accessed by patients over 1 year old. Further information can be found in Appendix 2 which includes what conditions are suitable for referral.
- Urgent Repeat Medicines Supply for Pharmacy First is for patients who need urgent access to their repeat medication outside of their GP practice opening times and bank holidays. This does NOT include Controlled Drugs.

How to make a referral:

- Clinical Pathways Pharmacy First (7 common conditions) are accessed by a digital referral from a GP practice or NHS 111 or a patient visiting a participating community pharmacy with one of the 7 common conditions e.g. via PharmRefer.
- Minor Illness Pharmacy First referrals are accessed by a digital referral from a GP practice or NHS 111. A digital referral is required to access this service as outlined in the <u>Community</u> <u>Pharmacy advanced service specification: NHS Pharmacy First</u> <u>Service</u>- e.g. via PharmRefer.

For both the Clinical Pathways and Minor Illness elements of Pharmacy First, a digital referral needs to be sent to the community pharmacy of the patients' choice. A digital referral means a patient can be treated for either the minor illness pathway OR the clinical pathway. This reduces the chance of the patient being escalated back to their GP practice as two pathways can be explored under a digital referral. If the patient is with a SystmOne practice, please see Appendix 3 for how a referral is made. If the patient is with an EMIS practice, please see Appendix 4 for how a referral is made.

 Urgent Repeat Medicines Supply Pharmacy First is accessed by a patient contacting NHS 111 outside the opening hours of their GP practice and bank holidays. This does NOT include Controlled Drugs.

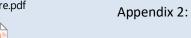
Opening hours:

- Clinical Pathways Pharmacy First (7 common conditions):
 Community pharmacy opening hours are available on Find a Pharmacy
- Minor Illness Pharmacy First referrals: A digital referral for this service is available when the patient's GP practice is open or contacting NHS 111. A consultation with a pharmacist is available when the community pharmacy is open.
- Urgent Repeat Medicines Supply Pharmacy First: NHS 111

Telephone/email contact:

- Contact details for a community pharmacy can be found at Find a Pharmacy.
- Contact details for a GP practice can be found on their website.
- NHS 111







HNY%20Pharmacy% Appendix 3: 20First%20Referral%2 HNY%20Pharmacy% Appendix 4: 20First%20Referral%2

27. Practitioners Guide to Carers Support in York

Practitioners Guide To Carers Support in York

	One document with all the headline information that Health teams need to identify, support and signpost carers in York.
28. Rapid Assessment Therapy (RATS)	Name of service: (RATS) Rapid Assessment Therapy team are a group of occupational therapists' physiotherapists and social workers who work within ED and cover the frailty FSDEC and urgent care centre.
	Eligibility: The RATS team focus is admission avoidance rapid assessment and discharge. They are able to access support services and step-up patients in the local area via CRT, IPU or temporary respite. They have greater access to these services than other therapy teams in the acute setting.
	How to make a referral: They team take referrals from each area via a morning and afternoon handover but can also screen and see patients who are frail or have mobility issues
	Opening hours: The RATS team operate on a 7 days service 8:00 till 20:00 cover.
	Telephone/email contact: To contact any members of the RATS team for advice or to handover patients who have attended ED, you can contact on 01904 726656.
29.Reablement (Adult Social Care Intensive	Name of service: Reablement can help people who need support with daily activities because, for different reasons, they are finding it more difficult to do them.
Support Service)	 Often provided when a person is discharged from hospital and needs support to get back to their usual level of independence ('step-down'), or when they have experienced a stressor event in the community and require support for a time-limited period to get back to their baseline ('step-up').
	Eligibility: The service is for anyone over the age of 18 who is eligible for social care support and who would benefit from a period of reablement. It is not suitable for people who already have a long term care provider or people who have a serious illness which requires specialist care and pain support (palliative care).

	How to make a referral: refer directly via Adult Social Care
	Opening hours: Monday-Friday 9-5pm
	 Telephone/email contact: Adult Social Care on 01904 555111 <u>adult.socialsupport@york.gov.uk</u>, emergency outside office hours, or at the weekend contact Emergency Duty Team for advice on 0845 0349417.
	For more information please see guide attached: Reablement_print_art work_file.pdf
30.Social Prescribing in York	 Name of service: Social Prescribing is a term which means linking people to non-medical sources of support to improve people's health and wellbeing. Social Prescribers are not Support Workers, Counsellors, Social Care or Mental Health Workers – they support patients to connect with these services Primary Care Link Workers are part of the Social Prescribing Team at York CVS. The Primary Care Link Workers are Social Prescribers based in GP surgeries across York, working alongside individuals to get to know them, and ultimately help them improve their health and wellbeing. Eligibility: people with social issue, (e.g. loneliness, isolation, financial problems), social prescribing helps provide individuals with an alternative to medical intervention. The team supports people aged 18+ living in the area served by City of York Council. How to make a referral: via GP practice or self-referrals. Opening hours: Monday-Friday 9-5pm Telephone/email contact: 01904 437911 More information on the York CVS website.
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31. St Leonard's Hospice @Home and	 Name of service: Services supported by Single Point of Coordination re: York Hospital's Macmillan Community Palliative Care Clinical Nurse Specialist service St Leonard's Hospice@Home service

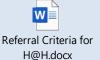
Carer Support service

- St Leonard's Sunflower Wellbeing Hub
- o St Leonard's Carer Support service
- St Leonard's Bereavement Support service (call our dedicated bereavement phone number 01904 777 760)
- o Marie Curie night sit referrals and allocations
- **Eligibility:** The referral criteria to access Carer Support is essentially:
 - Patients must be 18 years of age or above and have a life limiting condition.
 - o All referrals must be Fast Track funding eligible.
 - Patients must consent to a referral being made to the Carer Support Service or a Best Interests decision made on their behalf.
 - Patients must be registered and assigned to the District Nursing service.
 - All patients must have a carer in need of a break, whom otherwise would not be able to get out due to their caring responsibilities.
- How to make a referral: via Single Point of Coordination team
- Opening hours: The service operates daily from 8.00am until midnight.

The **Hospice@Home service** is extending from 8am – 12mn to a full 27/7 service from January 2024 to enable us to care for more patients in their own homes. This is a responsive service that prevents admission to hospital but also enables rapid discharge home to die if patients are identified in ED. Contact with SPOC to co-ordinate support as an alternative to 999 is crucial.

 Telephone/email contact A single point of co-ordination for end of life and palliative care advice and support, phone number 01904 777 770.

Access to the Hospice@Home Leaflet and Referral Criteria: <u>Hospice@Home - St Leonard's Hospice</u> (stleonardshospice.org.uk)



32. TEWV:

Multidisciplinary team (MDT)

Name of service: Multi-disciplinary team (MDT) meetings:

- MDT meetings have been created to allow professionals from a wide range of services to come together to discuss and meet their client's needs.
- The meetings cover a variety of physical, mental and biopsychosocial needs. This can help tailor and formulate a plan to meet someone's overall needs, rather than a specific need in isolation.
- By professionals coming together to discuss cases they can identify what treatment / approach would be most effective and often discover new and alternative approaches.
- The meetings can also ensure multiple needs are met at one time, it's a coordinated response with clients being referred to the right service at the right time rather than waiting for referrals to other services further down the line or discovering an initial referral wasn't appropriate.
- Meetings are held twice monthly, diary slots offered. For more information contact <u>tewv.transformationnyy@nhs.net</u>.

33.TEWV: Menta Health services for young people and adults

Menta Health services for young people and adults available from TEWV:

- 1. Home York and Selby Talking Therapies
- 2. <u>Acute hospital liaison service in North Yorkshire Tees Esk</u> and Wear Valley NHS Foundation Trust
- 3. Community learning disability service in the Vale of York for adults Tees Esk and Wear Valley NHS Foundation Trust
- 4. Community mental health services for older people in York and Selby Tees Esk and Wear Valley NHS Foundation Trust
- 5. Community mental health services in the Vale of York for older people Tees Esk and Wear Valley NHS Foundation Trust

- Early intervention in psychosis service in York and Selby for young people and adults - Tees Esk and Wear Valley NHS Foundation Trust
- 7. Outreach recovery service for adults in York and Selby Tees
 Esk and Wear Valley NHS Foundation Trust
- 8. <u>Individual Placement and Support (IPS) service for adults</u> -Tees Esk and Wear Valley NHS Foundation Trust
- 9. Crisis resolution and intensive home treatment service (CRHT), Trustwide, for people aged over 16 years old - Tees Esk and Wear Valley NHS Foundation Trust

34. TEWV: First Contact Mental Health Practitioners

 Name of service: The First Contact Mental Health Practitioner Team (FCMHP) is a multi-disciplinary health care team consisting of nurses, occupational therapists, and social workers. The team provide assessment, short term intervention, and appropriate signposting within Primary Care.

The Team are based across North Yorkshire and York, and have practitioners based in GP Practices.

- **Eligibility:** Patients that are not currently under a Secondary Mental Health Team that are needing support for their Mental Health.
- **How to make a referral**: Contact your local GP Practice to book an appointment with the FCMHP.
- Opening hours: Vary depending on local GP Practice.
- Telephone/email contact: Local GP Practice Number, pleases see document attached



• Name of service: The Urgent Community Response Team (UCR) provides urgent care to people in their homes (including

35. Urgent Community Response Team

care homes) to avoid hospital admissions, and care is typically provided within 2 hours.

- Conditions typically referred to Urgent Community Response
 Teams include falls (with no apparent serious injury requiring
 hospital admission), reduced function/mobility/decompensation
 of frailty/confusion/delirium caused by a minor stressor event
 such as a UTI, cellulitis, chest infection.
- Eligibility: Over the age of 18 experiencing a health or social care crisis that requires urgent treatment or support within 2 hours and can be safely delivered in the home setting.
 Patient's must be registered with a York GP to access this service.
- How to make a referral: UCR referrals are made via the CRT single point of contact. This is a clinician-to-clinician triage conversation to establish suitability of referral for UCR service.
- Opening hours: 8am 8pm, 7 days per week, 365 days per year
- Telephone/email contact: 01904 721343 / 07943876398

36.Virtual Frailty Ward

Name of service: The Virtual Frailty Ward (Hospital at Home) offers a safe community-based alternative to hospital for patients living with frailty. Patients will be overseen by a Consultant Geriatrician with daily monitoring, and treatments provided at home by a multidisciplinary team to enable patients to remain independent whilst recovering.

Referral inclusion criteria:

- Aged 65+ and in acute crisis or in need of early supported discharge
- Rockwood score of 4 or more
- Registered with a York GP
- Can independently mobilise to the toilet
- Can be safely managed at home

Referral exclusion criteria:

- Cannot be seriously injured
- Not be in a mental health crisis

Cannot need end of life care.

How to make a referral:

The ward take verbal referrals only as it is important to have a discussion with the referring clinician. This is to ensure the ward can meet the patients' needs both clinically and in a timely way.

If you feel your patient meets the FVW criteria and would benefit from being cared for by the FVW team rather than being admitted to hospital, please call the Frailty Virtual Ward office on 01904 721483.

The ward can accept referrals Monday to Friday between 8am and 4pm. For patients referred in the morning we will see the patient that afternoon, for patients received in the afternoon we will see the patients the next morning.

Patients should consent to being referred to the FVW and should be safe to manage independently overnight.

On acceptance to the ward, a pop up box will appear in the patient's Systmeone record to confirm the admission.

- Opening hours: 24/7. Referrals accepted Monday to Friday between 9am and 4pm
- **Telephone/email contact:** If you think a patient would benefit form care from the Virtual Frailty Ward, please call the Virtual Frailty Ward office on 01904 721483. The ward also welcomes any clinical queries.

37.York Integrated Care Team

- Name of service: The York Integrated Community Team (YICT) is a multi-disciplinary Anticipatory Care Team that provides an initial Comprehensive Geriatric Assessment and then regular reviews thereafter to ensure concerns identified are addressed early to prevent crisis situations.
- An agile, holistic, empathetic & personalised response is at the core foundation of what YICT offer. YICT also provide an inreach service to expediate and support discharges from York Hospital when capacity allows, and patients on the YICT caseload can get in touch with the team directly when in need of support.

- Eligibility: The most frail and vulnerable residents in York.
- How to make a referral: Refer directly via YICT team
- Opening hours: YICT are available 8-9pm, 7 days a week to support patients coming from RATS in ED or as part of the Inreach service.
- Telephone/email contact: 01904 928844, nimbuscare.yict@nhs.net

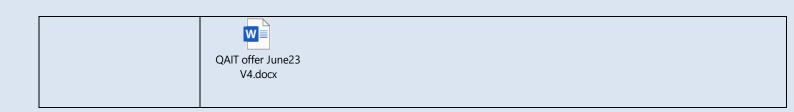
38. York Place Quality and Nursing Team-Care Provider Support

- Name of service: Care Provider Support, ICB Quality and Nursing Team. work as part of an integrated quality team alongside North Yorkshire Council and closely with other partner Local Authorities to promote delivery of high quality care.
- Support delivery of best practice through React to Falls Prevention, React to Red, Identifying and Responding to Deteriorating Residents and Improving Hydration training programmes. Act as a link between health and social care services, leading workforce and leadership in the care sector and closer integration between services through digital enhancement.
- **Eligibility:** quality improvement support to all care providers across North Yorkshire and York
- How to make a referral: via York Place Quality Nursing Team
- Opening hours: Monday-Friday 9-5pm
- Telephone/email contact

hnyicb-voy.yorkplacequalitynursingteam@nhs.net

- Find out More About our Quality Assurance and Improvement <u>Team-Working With Care Providers Across North Yorkshire</u> and York
- MULTIDISCIPLINARY SUPPORT TO INDEPENDENT CARE PROVIDERS, please see document for more details:

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Health and Wellbeing Board

22 January 2025

Report of the Director of Public Health

York's Joint Local Health and Wellbeing Strategy 2022-2032: review of progress and future action planning.

Summary and Background

- 1. In 2022, the Board conducted an extensive exercise including codesign and public consultation and brought forward its 10-year Joint Local Health and Wellbeing Strategy (JLHWBS).
- 2. The ambition of the strategy was for York to become a health generating city, and the overarching vision was that 'In 2032 York will be healthier, and that health will be fairer'.
- 3. In early 2023, the Board approved the action plan for the strategy, including 28 actions aligned to the ten population health goals intended to the cover actions in the first two years of the strategy's life. Having reported on progress against all the actions in the plan for a first cycle of two years, this paper summarises progress so far and asks Board members to consider how future reporting should be undertaken.

Background

4. The 'vision' of the York Joint Health and Wellbeing Strategy 2022-2032 is around both increasing health and distributing that health more fairly. In York, people in poorer communities are dying earlier. Rather than increase the overall life expectancy of the population, therefore, the Board decided to aim to focus on improving healthy life expectancy (the amount of time spent living in good health) for the city and reducing the gap in life expectancy between the least and most deprived areas.

- 5. The six 'ambitions' of the strategy are focussed around the large scale shifts which will be needed by partners in order to achieve this vision:
 - Become a health-generating city
 - Make good health more equal across the city,
 - Prevent now to avoid later harm
 - Start good health and wellbeing young
 - Work to make York a mentally healthy city
 - Build a collaborative health and care system
- 6. Alongside these, in order to ensure concrete and tangible actions could be planned and measured, the strategy used the <u>Joint Strategic Needs Assessment</u> to identify ten key 'goals' to focus on in terms of the factors which lead to the greatest health loss and inequality in the city:
 - Goal 1: OVERARCHING GOAL: Reduce the gap in healthy life expectancy between the richest and poorest communities in York
 - Goal 2: Support more people to live with good mental health, reducing anxiety scores and increasing happiness scores
 - Goal 3: Bring smoking rates down below 5% for all population groups
 - Goal 4: Reduce from 20% to 15% the proportion of York residents drinking to the Chief Medical Officer alcohol guidelines (under 14 units a week)
 - Goal 5: Reverse the rise in the number of children and adults living with an unhealthy weight
 - Goal 6: Reduce health inequalities in specific groups: people with a severe mental illness, a learning disability, those from an ethnic minority, or a marginalised group
 - Goal 7: Reduce both the suicide rate and the self-harm rate in the city
 - Goal 8: Improve diagnosis gaps in dementia, diabetes and high blood pressure, and increase the % of cancer detected at an early stage

- Goal 9: Reduce sedentary behaviour and increase physical activity by 5% across the whole population
- Goal 10: Increase the proportion of carers and care users who have their desired amount of social contact
- 7. The strategy was clear throughout that the predominant driver of the population's health is not the clinical care people receive during various periods of life, but the circumstances in which we are born, raised and grow old. These were described as the 'building blocks' of health': housing, education, income, employment, commercial influence and other factors which play a crucial role in determining how our health progresses. These local, national and international factors create an uneven distribution of power and resources which shape the conditions of daily life. They determine the extent to which different individuals have the physical, social and personal resources to identify and achieve goals, meet their needs and deal with changes to their circumstances. This is why the strategy was launched alongside the Climate Change and Economic strategies, as three strategic pillars which guide a decade of renewal for the city and aim to lay the foundations for good health in our social, economic and civic life.

Main/Key Issues to be Considered

How have we done – the data

- 8. At most Health and Wellbeing Board meetings since the action plan was published, data has been produced against the ten goals of the strategy, demonstrating the current city position.
- 9. Annexes 1 and 2 show an overview, the first giving an 'at a glance' view with one indicator visually represented over time for each goal in the strategy, the second a more in-depth scorecard with further indicators relevant to each goal.
- 10. The table below summarises the key messages within this data. It should be recognised that the goals were chosen based in part on the areas where York's health needs are the greatest, not where we know we are already doing well, and also that two years is not a long time period to see sustained change in population-level outcomes. The data summarised below shows a stage in the journey of our ten-year strategy.

Goal	What the data tells us
1 OVERARCHING GOAL: Reduce the gap in healthy	Life expectancy is static in females and declining slightly in males
life expectancy between the richest and poorest communities in York	Healthy Life expectancy is declining slightly in males and substantially in females
	 These trends mirror what is happening nationally, and overall York's data is similar or slightly better than average.
	The gap in life expectancy between more and less deprived wards in York is widening for males and static for females
2 Support more people to live with good mental health, reducing anxiety scores and	Self-reported high anxiety has been persistently higher in York than nationally, and is not improving
increasing happiness scores	Self-reported low happiness has been persistently higher in York than nationally; the most recent year saw an improvement but it is too early to tell if this is a trend
3 Bring smoking rates down below 5% for all population groups	 Smoking rates have been reducing consistently in York over the last decade, faster than national reductions
	Smoking rates are still highly unequal, with people in York from routine and manual occupations 3.3x as likely to smoke and those with a long term mental health condition 2.7x as likely to smoke
4 Reduce from 20% to 15% the proportion of York residents drinking to the	A similar number of adults meet the CMO alcohol guidelines in York as elsewhere; data availability hinders how useful this indicator is
Chief Medical Officer alcohol guidelines (under 14 units a week)	Other indicators of alcohol-related harm, such as hospital admissions, liver disease and mortality, continue to show York has worse outcomes than national averages, which are not improving
5 Reverse the rise in the number of children and adults living with an unhealthy weight	A similar, and high, number of children at reception age are overweight or obese in York compared to the national average. This has remained static over the last decade at around in 1 in 5 reception-aged children
	 A slightly lower number of children at year 6 are overweight or obese in York compared to

	the national average. This is rising in line with the national trend; locally it was 1 in 4 in 2009/10 and is now 1 in 3 in 2023/4
	 A similar number of adults are overweight or obese in York compared to the national average. This is rising in line with the national trend and is now nearly 2 in 3 adults
6 Reduce health inequalities in specific groups: people with a severe mental illness,	 Data on these groups is harder to gather, however the York Population Health Hub is working on a CORE20PLUS5 data pack
a learning disability, those from an ethnic minority, or a marginalised group	 Employment gaps between the general population and those with a serious mental illness or a learning disability are high.
	 Excess mortality for those with a serious mental illness means people from this group are 4.5x more likely to die in any given year, this is worst ratio in the region.
7 Reduce both the suicide rate and the self-harm rate in the city	 Suicide rates have historically been higher in York than national averages; the most recent year saw an improvement, but it is too early to tell if this is a trend.
	 Self-harm emergency admissions have been declining in York over the last decade.
8 Improve diagnosis gaps in dementia, diabetes and high blood pressure, and increase the % of cancer	 There has been a significant improvement in the diagnosis of hypertension and diabetes, but diabetes detection rates remain lower than national average.
detected at an early stage	Dementia diagnosis rates remain poor
	 Early detection of cancer data has not been recently updated.
9 Reduce sedentary behaviour and increase physical activity by 5% across the whole population	 Physical activity levels in York remain higher than national averages, including adult and children meeting the national guidance and active travel indicators
	 Recent data is not available to tell if the goal is heading in the right direction
10 Reduce the proportion of adults who report feeling lonely from 25% to 20% of	The data behind this goal has not been updated and we have asked national partners to update when this will become available
our population	 Social contact among social care users has recovered following the pandemic

How have we done – the action

11. At board meetings, information against the agreed actions has been produced against the ten goals of the strategy, demonstrating the current city position. Below is a high-level snapshot of some of the highlights reported to the HWBB over the last 12-18 months.

Goal	HWB Lead	What have we done
1. OVERARCHING GOAL: Reduce the gap in healthy life expectancy between the richest and poorest communities in York	Director of Public Health/All Board Members	Actions not set – strategy states 'This is the ultimate goal we are trying to reach for our population, but it will only be met if the other goals are too'
2. Support more people to live with good mental health, reducing anxiety scores and increasing happiness scores	Co-chairs of the York Mental Health Partnership in conjunction with the NHS Place Lead for York	 3 actions set that have led to: Opening of a mental health hub at Clarence Street with developments underway to open further hubs Work towards becoming a Trauma Informed and Responsive County Administration of Community Mental Health Transformation Grants through the VCSE
3. Bring smoking rates down below 5% for all population groups	Director of Public Health	 A programme of work through the CYC Public Protection function focused on illicit tobacco and enforcement of age of sale legislation Work to reduce the sale of vapes to under 18s Commencement of an acute pathways Tobacco Dependency Treatment service at York Hospital An increase in the number of successful smoking quits through the Health Trainer Service

4. Reduce from 20% to 15% the proportion of York residents drinking to the Chief Medical Officer alcohol guidelines (under 14 units a week)	Director of Public Health	 2 actions that have led to: An offer of Alcohol Identification and Brief Advice training to any professional or volunteer in the city who regularly comes into contact with residents Introduction of an alcohol harm reduction online tool and supporting Lower MY Drinking App
5. Reverse the rise in the number of children and adults living with an unhealthy weight	Director of Public Health/Consultant in Public Health	 Health Trainer Service provides advice and guidance on healthy eating, physical activity and how to maintain a healthy weight Healthy Child Service supports parents/carers and young people wishing to make changes to reach a healthy weight NHS and ICB provide various weight management programmes aimed at those who need more complex weight management initiatives There is good coverage of the National Child Measurement Programme across York schools. In 2022/23 96% of children at cohort ages were weighed and measured compared with 93.2% nationally Working proactively to encourage breast-feeding Continuation of the delivery of the HENRY programme which delivers practical support around increasing self-esteem and emotional wellbeing alongside guidance on diet, nutrition and oral health
6. Reduce health inequalities in specific groups: people with a severe mental illness, a	Director of Public Health and Chief Executive at York CVS	2 actions that have led to: • A delegated budget from the ICB Health Inequalities fund of around £270k per annum to tackle health

learning disability, those from an ethnic minority, or a marginalised group		inequalities in the city. Project areas include maternal and child nutrition; asthma friendly schools; York brain health café; mental health related school absence; ways to wellbeing small grants programme; York Health Mela; GP Outreach at the Women's Centre and more In Autumn 2023 nine community commissioners were joined by civic commissioners representing key organisations in York as part of the Poverty Truth Commission. The commissioners reported back to the HWBB in 2024 with their findings
7. Reduce both the suicide rate and the self-harm rate in the city	Director of Public Health	 3 actions that have led to: A Suicide Audit was undertaken in 2024 The York Ending Stigma (YES) programme led by YES champions has been awarded a contract until July 2025. Funding for this is specific to the ongoing promotion of suicide awareness prevention training Work has started to refresh/relaunch the Suicide Safer Community Strategy
8. Improve diagnosis gaps in dementia, diabetes and high blood pressure, and increase the % of cancer detected at an early stage	NHS Place Director for York GP Representative	 4 actions that have led to: Collaboration between the ICB Place team and public health on a CVD prevention programme Delivery of NHS health checks to the residents of York Development of a Dementia Strategy for York along with a delivery/action plan Working to reduce the number of York patients waiting over 62 days for a cancer diagnosis

9. Reduce sedentary behaviour and increase physical activity by 5% across the whole population	Consultant in Public Health	 2 actions that have led to: Updating the Playing Pitch Strategy and Built Facilities Strategy which are used to audit current provision The Physical Activity and Sports Strategy was published in 2022 along with an action plan however the lasting effects of the pandemic halted the delivery of much of this. The physical activity strategic group was
10. Reduce the proportion of adults who report feeling lonely from 25% to 20% of our population	Chief Executive York CVS Director for Adult Social Care	re-established in the latter part of 2024 to refresh the action plan. 4 actions that have led to: Both Local Area Coordination and Social Prescribing programmes have been successful in building trusted relationships with local residents thus helping to reduce loneliness and social isolation Neighbourhood action plans are being developed to complement ward working and the delivery of local priorities. An asset based community development (ABCD) approach has helped map community assets, connections and associations thus helping to build the social connections between citizens Family hubs have been introduced to areas the most in need The Age Friendly York model continues to provide the opportunity for citizens and providers to develop a shared approach to solving solutions that impact older people

Options and Analysis

- 12. The Board will want to consider how we measure and enable progress against the action plan in the remaining 8 years of the strategy.
- 13. There are several options for how this could be achieved:
 - a. Continue another cycle through the current 28 actions in the plan, which would see further embedding and assurance on what partners have committed to, but risk overlooking key areas of work outside the current actions.
 - Agree with the board lead for each goal a combination of new and old actions in each area appropriate for 2025-2027, and then cycle through reporting on these new actions from May 2025.
 - c. Take a different approach, for instance focussing on the six ambitions in the strategy, or on using themed sessions around the 'life course' areas (Start Well, Live Well, Age Well, Die Well), or focussing on the 'building blocks of health'.

Recommendations

- 14. The recommended option is b), which builds on good progress and clear assurance around measurable goals but recognises that the actions need to be flexible as time passes, that some may have been achieved, and some new actions may now be relevant.
- 15. If this is agreed by the board, work will commence with each goal lead and the new action plan will be presented at the March Board before the first actions reported at the May Board.
- 16. The board are asked to delegate permission to the report authors to agree HWBB leads for each goal and new action.

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Author: Chief Officer Responsible for the report:

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Peter Roderick Director of Public Health City of York Council Peter Roderick Director of Public Health City of York Council

Report Approved V

Date 13.01.2025

Annexes:

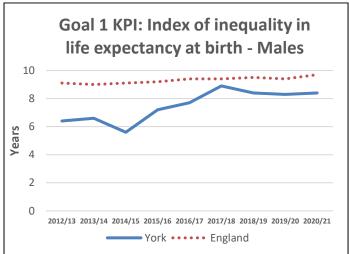
Annex 1: HWBB 10 Goals Trend Data

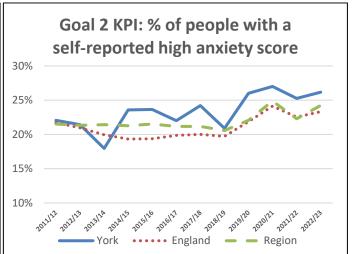
Annex 2: HWBB Scorecard

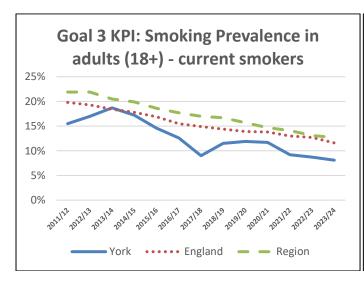


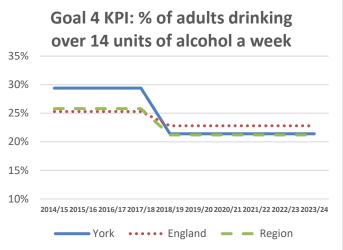
Annex 1: Joint Health and Wellbeing Strategy 2022-2032 – KPI Trend Charts.

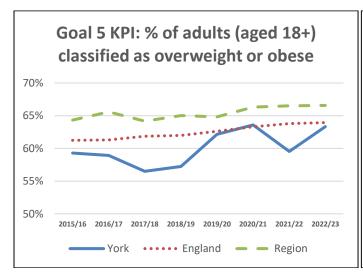


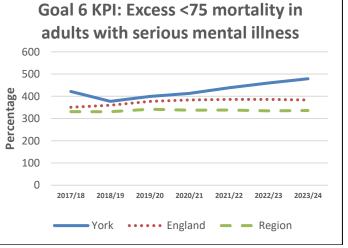




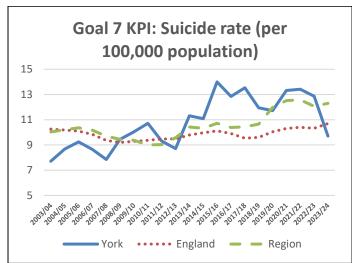


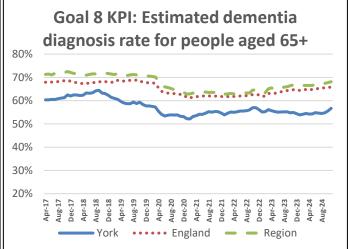


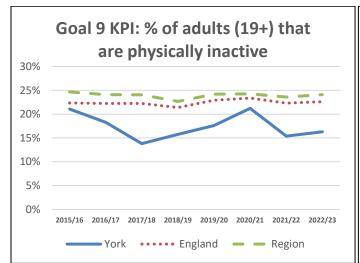


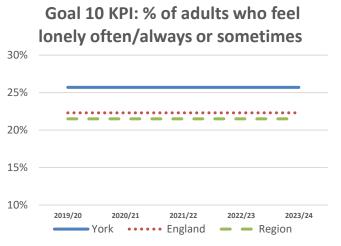














Health and Wellbeing 10 Year Strategy (2022-2032) 2023/2024

Annex 2:

No of Indicators = 36 | Direction of Travel (DoT) shows the trend of how an indicator is performing against its Polarity over time.

Produced by the Business Intelligence Hub January 2025

		Previous Years							2023/2024			
	Collection Frequency	2015/2016	2016/2017	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022	2022/2023	Year	Polarity	DOT
lope index of inequality in life expectancy at birth - emale - (Three year period)	Annual	4.3	4.2	5.2	6.2	6.2	5.7	Due Feb 25	Due Feb 25	Due Feb 26	Up is Bad	⋖ ► Neutral
enchmark - National Data	Annual	7.1	7.3	7.4	7.5	7.6	7.9	Due Feb 25	Due Feb 25	Due Feb 26		
egional Rank (Rank out of 15)	Annual	2	3	3	3	3	3	Due Feb 25	Due Feb 25	Due Feb 26		
lope index of inequality in life expectancy at birth lale - (Three year period)	Annual	7.2	7.7	8.9	8.4	8.3	8.4	Due Feb 25	Due Feb 25	Due Feb 26	Up is Bad	⋖ ► Neutra
enchmark - National Data	Annual	9.2	9.4	9.4	9.5	9.4	9.7	Due Feb 25	Due Feb 25	Due Feb 26		
egional Rank (Rank out of 15)	Annual	3	3	2	3	3	3	Due Feb 25	Due Feb 25	Due Feb 26		
ifference in healthy life expectancy at birth etween females and males (yrs)	Annual	0.84	0.87	0.39	1.15	1.11	1.13	1	0.47	0.67	Neutral	Neutr
enchmark - National Data	Annual	0.95	0.78	0.67	0.81	0.54	0.96	0.99	0.51	0.36		
enchmark - Regional Data	Annual	0.65	0.77	0.23	0.93	0.78	0.82	0.47	0	0.48		
of people with a self-reported high anxiety score	Annual	23.66%	22.02%	24.20%	20.90%	26.00%	27.01%	25.26%	26.17%	Due Feb 25	Up is Bad	⋖ ▶ Neutral
enchmark - National Data	Annual	19.37%	19.87%	20.01%	19.72%	21.88%	24.13%	22.55%	23.32%	Due Feb 25		
enchmark - Regional Data	Annual	21.52%	21.17%	21.18%	20.57%	22.06%	24.88%	22.30%	24.24%	Due Feb 25		
egional Rank (Rank out of 15)	Annual	12	12	14	7	15	11	14	11	Due Feb 25		
o of people with a self-reported low happiness core	Annual	6.75%	8.33%	9.50%	11.25%	9.33%	8.86%	10.80%	6.21%	Due Feb 25	Up is Bad	⋖ ▶ Neutral
enchmark - National Data	Annual	8.75%	8.54%	8.21%	7.81%	8.76%	9.21%	8.41%	8.85%	Due Feb 25		
enchmark - Regional Data	Annual	9.92%	9.48%	9.06%	9.41%	9.78%	10.33%	7.88%	9.57%	Due Feb 25		
egional Rank (Rank out of 15)	Annual	1	5	9	12	4	7	14	2	Due Feb 25		
er ei ei lo la ei ei ei ei ei ei ei ei	male - (Three year period) nchmark - National Data gional Rank (Rank out of 15) pe index of inequality in life expectancy at birth- ale - (Three year period) nchmark - National Data gional Rank (Rank out of 15) ference in healthy life expectancy at birth tween females and males (yrs) nchmark - National Data nchmark - Regional Data of people with a self-reported high anxiety score nchmark - Regional Data gional Rank (Rank out of 15) of people with a self-reported low happiness ore nchmark - National Data nchmark - National Data nchmark - Regional Data	ppe index of inequality in life expectancy at birth male - (Three year period) Inchmark - National Data Annual Annual	ppe index of inequality in life expectancy at birth male - (Three year period) Inchmark - National Data Annual Annual 7.1 Annual 7.2 Annual 7.3 Annual 7.4 Annual 7.5 Annual 7.6 Annual 7.7 Annual 7.8 Annual 7.9 Annual 7.9 Annual 7.9 Annual 7.0 Annual 7.1 Annual 7.2 Annual 7.2 Annual 7.2 Annual 7.2 Annual 7.3 Annual 7.4 Annual 7.5 Annual 7.6 Annual 7.7 Annual 7.8 Annual 7.9 Annual 7.9 Annual 7.0 Annual 7.2 Annual	ppe index of inequality in life expectancy at birth male - (Three year period) Annual Annual	Prequency Prequency Prequency 2015/2016 2016/2017 2017/2018 2016/2017 2016	Prequency 2019/2016 2019/2016 2019/2018 2019	Prequency 2013/2015 2013/2017 2017/2018 2013/2019 2013	pepe index of inequality in life expectancy at birth male - (Three year period) Annual 4.3 4.2 5.2 6.2 6.2 5.7 Annual 7.1 7.3 7.4 7.5 7.6 7.9 gional Rank (Rank out of 15) Annual 7.2 7.7 8.9 8.4 8.3 8.4 Biglional Rank (Rank out of 15) Annual 9.2 9.4 9.4 9.5 9.4 9.7 Annual 9.2 9.4 9.4 9.5 9.4 9.7 gional Rank (Rank out of 15) Annual 9.2 9.4 9.4 9.5 9.4 9.7 Annual 9.2 9.4 9.4 9.5 9.7 Annual 9.2 9.4 9.4 9.4 9.5 9.7 Annual 9.2 9.4 9.4 9.5 9.7 Annual 9.2 9.4 9.4 9.5 9.7 Annual 9.2 9	prepried to the expectancy at birth male (Three year period) Annual 4.3 4.2 5.2 6.2 6.2 6.2 5.7 Due Feb 25 northmark - National Data Annual 7.1 7.3 7.4 7.5 7.6 7.9 Due Feb 25 gional Rank (Rank out of 15) Annual 2 3 3 3 3 3 3 Due Feb 25 gional Rank (Rank out of 15) Annual 7.2 7.7 8.9 8.4 8.3 8.4 Due Feb 25 northmark - National Data Annual 9.2 9.4 9.4 9.5 9.4 9.7 Due Feb 25 gional Rank (Rank out of 15) Annual 9.2 9.4 9.4 9.5 9.4 9.7 Due Feb 25 gional Rank (Rank out of 15) Annual 9.2 9.4 9.4 9.5 9.4 9.7 Due Feb 25 gional Rank (Rank out of 15) Annual 9.2 9.4 9.4 9.5 9.4 9.7 Due Feb 25 gional Rank (Rank out of 15) Annual 0.84 0.87 0.39 1.15 1.11 1.13 1 Inchmark - National Data Annual 0.95 0.78 0.67 0.81 0.54 0.96 0.99 Inchmark - National Data Annual 19.37% 19.87% 20.01% 19.72% 21.88% 24.13% 22.55% Inchmark - National Data Annual 19.37% 19.87% 20.01% 19.72% 21.88% 24.13% 22.55% Inchmark - Regional Data Annual 12 12 14 7 15 11 14 Of people with a self-reported low happiness Annual 12 12 14 7 15 11 14 Of people with a self-reported low happiness Annual 8.75% 8.54% 8.21% 7.81% 8.76% 9.21% 8.41% Inchmark - National Data Annual 8.75% 8.54% 8.21% 7.81% 8.76% 9.21% 8.41% Inchmark - National Data Annual 8.75% 8.54% 8.21% 7.81% 8.76% 9.21% 8.41% Inchmark - National Data Annual 8.75% 8.54% 8.21% 7.81% 8.76% 9.21% 8.41% Inchmark - National Data Annual 8.75% 8.54% 8.21% 7.81% 8.76% 9.21% 8.41% Inchmark - National Data Annual 8.75% 8.54% 8.21% 7.81% 8.76% 9.21% 8.41% Inchmark - National Data Annual 8.75% 8.54% 8.21% 7.81% 8.76% 9.21% 8.41% Inchmark - National Data Annual 9.92% 9.48% 9.06% 9.41% 9.78% 10.33% 7.88% Inchmark - National Data Annual 9.92% 9.48% 9.06% 9.41% 9.78% 10.33% 7.88% Inchmark - National Data Annual 9.92% 9.48% 9.06% 9.41% 9.78% 10.33% 7.88% Inchmark - National Data Annual 9.92% 9.48% 9.06% 9.41% 9.78% 10.33% 7.88% Inchmark - National Data Annual 9.92% 9.48% 9.06% 9.41% 9.78% 10.33% 7.88% Inchmark - National Data Annual 9.92% 9.48% 9.06% 9.41% 9.78% 10.33% 7.88% Inchmark - National Data Annual 9.92%	Annual A	Proguency 2015/2016 2016/2017 2017/2018 2018/2017 2018/2018 2018/2	Frequency Annual 4.3 4.2 5.2 6.2 6.2 6.2 5.7 Due Feb 25 Due Feb 25 Due Feb 26 Due F

		Previous Years								2023/2024			
		Collection Frequency	2015/2016	2016/2017	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022	2022/2023	Year	Polarity	DOT
	Smoking Prevalence in adults (18+) - current smokers (APS) (2020 definition)	Annual	14.60%	12.60%	9.00%	11.50%	11.90%	11.70%	9.20%	8.70%	8.10%	Up is Bad	▼ Gree
DUOE400	Benchmark - National Data	Annual	16.90%	15.50%	14.90%	14.40%	13.90%	13.80%	13.00%	12.70%	11.60%		
PHOF188	Benchmark - Regional Data	Annual	18.60%	17.70%	17.00%	16.70%	15.70%	14.70%	14.10%	13.10%	12.70%		
	Regional Rank (Rank out of 15)	Annual	2	2	1	1	2	3	1	1	1		
	Smoking prevalence among adults aged 18-64 in routine and manual occupations (APS) (2020 definition)	Annual	28.10%	26.40%	24.60%	18.60%	26.90%	22.30%	20.90%	15.20%	18.80%	Up is Bad	⋖ ▶ Neut
PHOF187	Benchmark - National Data	Annual	28.10%	26.50%	25.70%	25.40%	24.50%	24.50%	23.60%	22.50%	19.50%		
PHOF 187	Benchmark - Regional Data	Annual	30.00%	28.90%	28.20%	27.40%	27.60%	25.50%	24.20%	21.70%	21.60%		
	Regional Rank (Rank out of 15)	Annual	4	4	3	1	6	5	4	1	6		
	% of women who smoke at the time of delivery - (CYC)	Annual	12.30%	11.10%	10.40%	11.60%	10.40%	10.30%	8.00%	8.10%	6.20%	Up is Bad	⋖ I Neur
DUOE40	Benchmark - National Data	Annual	11.00%	10.70%	10.80%	10.60%	10.40%	9.60%	9.10%	8.80%	7.40%		
PHOF10	Benchmark - Regional Data	Annual	14.60%	14.40%	14.20%	14.40%	14.00%	13.10%	12.00%	11.60%	9.30%		
	Regional Rank (Rank out of 15)	Annual	4	2	1	2	1	3	1	1	1		
PHOF195	Smoking prevalence in adults with a long term mental health condition (18+) - current smokers (GPPS)	Annual	29.80%	28.50%	21.30%	30.30%	19.30%	26.30%	23.10%	20.90%	Due March 25	Up is Bad	Gree
	Benchmark - National Data	Annual	33.00%	30.30%	27.80%	26.80%	25.80%	26.30%	25.20%	25.10%	Due March 25		
	Benchmark - Regional Data	Annual	34.80%	31.60%	29.80%	28.20%	27.60%	27.50%	27.50%	25.40%	Due March 25		
	Regional Rank (Rank out of 15)	Annual	3	5	2	10	1	4	4	3	Due March 25		

HWBB scorecard.xlsx Page 2

						Previou	ıs Years				2023/2024		
		Collection Frequency	2015/2016	2016/2017	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022	2022/2023	Year	Polarity	DOT
	Admitted to hospital with alcohol-related conditions (Broad): Males, all ages (per 100,000 population) - (New methodology)	Annual	-	2,411	2,912	3,103	3,057	2,468	2,913	2,976	Due May 25	Up is Bad	▲ Red
LAPE12	Benchmark - National Data	Annual	-	2,534	2,585	2,752	2,826	2,309	2,682	2,646	Due May 25		
	Benchmark - Regional Data	Annual	-	2,718	2,731	2,812	2,800	2,300	2,678	2,727	Due May 25		
	Regional Rank (Rank out of 15)	Annual	-	7	10	11	11	9	10	10	Due May 25		
	Admitted to hospital with alcohol-related conditions (Broad): Females, all ages (per 100,000 population) - (New methodology)	Annual	-	978	968	1,084	1,118	942	1,075	1,001	Due May 25	Up is Bad	⋖ ► Neutra
LAPE13	Benchmark - National Data	Annual	-	837	855	911	938	801	906	881	Due May 25		
2,11210	Benchmark - Regional Data	Annual	-	932	941	986	991	831	955	943	Due May 25		
	Regional Rank (Rank out of 15)	Annual	-	10	9	10	12	11	12	8	Due May 25		
	Percentage of adults drinking over 14 units of alcohol a week - (4 year Aggregated)	Annual	29.40% (2014/15)	29.40% (2014/15)	29.40% (2014/15)	21.40%	21.40% (2018/19)	21.40% (2018/19)	21.40% (2018/19)	21.40% (2018/19)	21.40% (2018/19)	Up is Bad	⋖ ▶ Neutr
DU 05:5:1	Benchmark - National Data	Annual	25.30% (2014/15)	25.30% (2014/15)	25.30% (2014/15)	22.80%	22.80% (2018/19)	22.80% (2018/19)	22.80% (2018/19)	22.80% (2018/19)	22.80% (2018/19)		[
PHOF191	Benchmark - Regional Data	Annual	25.80% (2014/15)	25.80% (2014/15)	25.80% (2014/15)	21.20%	21.20% (2018/19)	21.20% (2018/19)	21.20% (2018/19)	21.20% (2018/19)	21.20% (2018/19)		
	Regional Rank (Rank out of 15)	Annual	12 (2014/15)	12 (2014/15)	12 (2014/15)	9	9 (2018/19)	9 (2018/19)	9 (2018/19)	9 (2018/19)	9 (2018/19)		

						Previou	s Years				2023/2024		
		Collection Frequency	2015/2016	2016/2017	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022	2022/2023	Year	Polarity	DOT
	% of reception year children recorded as being overweight (incl. obese) (single year)	Annual	22.37%	20.83%	24.07%	23.65%	21.40%	NC	22.70%	19.90%	22.80%	Up is Bad	⋖ ► Neutral
NOMBOO	Benchmark - National Data	Annual	22.14%	22.63%	22.38%	22.59%	23.00%	27.70%	22.25%	21.31%	22.10%		
NCMP03	Benchmark - Regional Data	Annual	22.39%	22.19%	22.93%	23.68%	24.10%	29.50%	23.73%	22.50%	23.80%		
	Regional Rank (Rank out of 15)	Annual	8	3	9	9	3	NC	3	2	4		
	% of children in Year 6 recorded as being overweight (incl. obese) (single year)	Annual	27.99%	29.05%	31.78%	29.97%	33.80%	NC	31.54%	32.50%	33.50%	Up is Bad	▲ Red
NOMBOA	Benchmark - National Data	Annual	34.17%	34.25%	34.32%	34.29%	35.20%	40.90%	37.76%	36.57%	35.80%		
NCMP04	Benchmark - Regional Data	Annual	34.63%	34.64%	34.71%	35.09%	35.80%	42.20%	39.19%	38.10%	37.50%		
	Regional Rank (Rank out of 15)	Annual	1	1	3	1	4	NC	1	1	2		_
NCMP10	Absolute gap in % of Year 6 recorded obesity between highest and lowest York ward (3 year aggregated)	Annual	13.10%	19.50%	15.80%	14.40%	18.60%	NC	19.70%	19.29%	17.04%	Up is Bad	▼ (C)
	% of adults (aged 18+) classified as overweight or obese (New definition)	Annual	59.30%	58.90%	56.50%	57.20%	62.20%	63.60%	59.50%	63.30%	Due May 25	Up is Bad	Neutr 6
5110544	Benchmark - National Data	Annual	61.20%	61.30%	61.90%	62.00%	62.60%	63.30%	63.80%	64.00%	Due May 25		
PHOF44a	Benchmark - Regional Data	Annual	64.30%	65.60%	64.20%	65.00%	64.80%	66.30%	66.50%	66.60%	Due May 25		
	Regional Rank (Rank out of 15)	Annual	1	2	1	1	4	5	1	2	Due May 25		

						Previou	s Years				2023/2024		
		Collection Frequency	2015/2016	2016/2017	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022	2022/2023	Year	Polarity	DOT
	Gap in employment rate for mental health clients and the overall employment rate (new definition 21/22 onwards)	Annual	-	-	-	-	-	-	64.80%	Due May 25	Due May 25	Up is Bad	∢ ► Neutral
PHOF40a	Benchmark - National Data	Annual	-	-	-	-	-	-	69.40%	Due May 25	Due May 25		
	Benchmark - Regional Data	Annual	-	-	-	-	-	-	66.50%	Due May 25	Due May 25		
<u>5</u>	Regional Rank (Rank out of 15)	Annual	-	-	-	-	-	-	5	Due May 25	Due May 25		
G021 06:	Gap in employment rate for those with learning disabilities and the overall employment rate	Annual	66.30%	69.20%	68.60%	70.10%	71.30%	68.90%	74.30%	76.30%	Due May 25	Up is Bad	▲ Red
PHOF41	Benchmark - National Data	Annual	68.10%	68.70%	69.20%	69.70%	70.60%	70.00%	70.60%	70.90%	Due May 25		
PHOF41	Benchmark - Regional Data	Annual	65.90%	66.10%	66.10%	68.00%	67.70%	67.80%	69.40%	69.60%	Due May 25		
	Regional Rank (Rank out of 15)	Annual	9	12	8	11	12	7	15	15	Due May 25		
D.	Excess under 75 mortality rate in adults with serious mental illness (New definition from Aug 2021)	Annual	-	-	421.7	377.2	399.7	412.9	438.5	459.8	478.8	Up is Bad	Rec
PHOF75a	Benchmark - National Data	Annual	-	-	350.6	359.7	377	383.5	385.9	385.9	383.7		
	Benchmark - Regional Data	Annual	-	-	331.2	330.6	341.8	337.7	338.1	334.7	335.7		3
	Regional Rank (Rank out of 15)	Annual	-	-	14	11	12	14	15	15	15		

						Previou	s Years				2023/2024		
		Collection Frequency	2015/2016	2016/2017	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022	2022/2023	Year	Polarity	DOT
	Suicide rate - Female (per 100,000 population)	Annual	5.1	6.8	8.6	7.3	5.6	5.4	6.3	6.4	4.3	Up is Bad	⋖ ► Neutral
	Benchmark - National Data	Annual	4.7	4.8	4.6	4.6	4.8	4.9	5.1	5.2	5.4		
PHOF107	Benchmark - Regional Data	Annual	4.6	4.6	4.8	4.8	5.9	6.1	6.5	6.1	6.3		
	Regional Rank (Rank out of 15)	Annual	9	12	13	14	5	4	9	8	1		
	Suicide rate - Male (per 100,000 population)	Annual	23	19.3	18.7	17	18.3	21.7	20.9	19.6	15.5	Up is Bad	Green
PHOF108	Benchmark - National Data	Annual	15.8	15.4	14.7	14.9	15.6	16	16	15.8	16.4		
	Benchmark - Regional Data	Annual	17.2	16.5	16.4	16.8	18.4	19.3	19	18.3	18.5		
	Regional Rank (Rank out of 15)	Annual	15	13	11	6	6	12	11	11	3		_
	Suicide rate (per 100,000 population)	Annual	14	12.9	13.5	11.9	11.7	13.3	13.4	12.9	9.7	Up is Bad	Gree C
B.10500	Benchmark - National Data	Annual	10.1	9.9	9.5	9.6	10	10.3	10.4	10.3	10.7		7
PHOF32	Benchmark - Regional Data	Annual	10.7	10.4	10.4	10.7	12	12.5	12.6	12.1	12.3		,
	Regional Rank (Rank out of 15)	Annual	14	13	13	11	6	11	11	11	3		
	Hospital stays for self harm, per 100,000 population	Annual	257.7	237.4	213.9	197.6	170	180.9	155.1	93.9	Due May 25	Up is Bad	▼ Green
5.150	Benchmark - National Data	Annual	195.9	184.5	184.5	194.8	191.2	180.4	163.7	126.3	Due May 25		
PHE02	Benchmark - Regional Data	Annual	190.5	195	195	206.8	197.8	174	146.6	120.6	Due May 25		
	Regional Rank (Rank out of 15)	Annual	6	11	11	4	2	3	9	3	Due May 25		

						Previou	ıs Years				2023/2024		
		Collection Frequency	2015/2016	2016/2017	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022	2022/2023	Year	Polarity	DOT
PHE11a	Estimated number of people (65+) with dementia	Monthly	-	2,613	2,644	2,695	2,744	2,754	2,828	2,883	2,945	Neutral	⋖ ► Neutra
PHE11b	Number of people (65+) diagnosed with dementia	Monthly	-	1,577	1,645	1,631	1,570	1,465	1,558	1,618	1,605	Neutral	⋖ ▶ Neutr
	Estimated dementia diagnosis rate (%) for people aged 65+ as recorded on practice disease registers	Monthly	NC	60.40%	62.20%	60.50%	57.20%	53.20%	55.10%	56.10%	54.50%	Up is Good	⋖ ▶ Neutr
PHE11	Benchmark - National Data	Monthly	NC	67.90%	67.50%	68.70%	67.40%	61.60%	62.00%	63.00%	64.80%		
111211	Benchmark - Regional Data	Monthly	NC	71.30%	71.20%	71.60%	70.20%	63.20%	63.10%	65.10%	66.50%		
	Regional Rank (Rank out of 15)	Monthly	NC	15	15	15	15	14	14	13	15		
PHOF192 c	Calculated Diabetes Diagnosis Rate	Annual	77.70%	77.60%	78.20%	79.20%	77.70%	77.20%	80.20%	82.70%	81.10%	Up is Good	⋖ I Neut
	Benchmark - National Data	Annual	79.70%	80.70%	81.60%	83.60%	85.70%	85.50%	88.70%	92.40%	89.70%		
	Benchmark - Regional Data	Annual	81.20%	82.60%	84.10%	86.10%	87.80%	87.80%	90.80%	94.60%	92.80%		
	Calculated Hypertension Diagnosis Rate	Annual	64.00%	64.60%	65.20%	65.90%	66.40%	65.90%	67.50%	71.40%	75.00%	Up is Good	Gree
PHOF193 c	Benchmark - National Data	Annual	67.50%	68.10%	69.10%	70.40%	72.30%	71.80%	73.00%	76.40%	79.40%		
	Benchmark - Regional Data	Annual	68.50%	69.40%	70.50%	71.80%	72.80%	72.30%	73.60%	77.20%	80.40%		
	Percentage of cancers diagnosed at stages 1 and 2	Annual	54.95%	52.59%	56.26%	51.82%	51.13%	49.51%	52.60%	Due Feb-25	Due Feb-26	Up is Good	⋖ I Neut
	Benchmark - National Data	Annual	54.81%	54.60%	54.32%	54.56%	54.88%	52.35%	54.42%	Due Feb-25	Due Feb-26		
PHOF194	Benchmark - Regional Data	Annual	53.00%	52.73%	51.88%	52.36%	53.38%	50.69%	52.64%	Due Feb-25	Due Feb-26		
	Regional Rank (Rank out of 15)	Annual	4	7	1	7	13	12	8	Due Feb-25	Due Feb-26		

						Previou	s Years				2023/2024		
		Collection Frequency	2015/2016	2016/2017	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022	2022/2023	Year	Polarity	DOT
	Access to Healthy Assets & Hazards Index (Persons, All ages) - % of the population who live in LSOAs which score in the poorest performing 20% on the AHAH index	Annual	-	5.10%	5.40%	NC	NC	NC	NC	3.20%	NC	Up is Bad	∢ ► Neutra
HLTH55	Benchmark - National Data	Annual	-	21.20%	21.1.%	NC	NC	NC	NC	22.60%	NC		
	Benchmark - Regional Data	Annual	-	22.20%	14.10%	NC	NC	NC	NC	19.90%	NC		
	Regional Rank (Rank out of 15)	Annual	-	4	7	NC	NC	NC	NC	1	NC		
PHOF02a	% of adults (aged 19+) that are physically inactive (<30 moderate intensity equivalent minutes per week)	Annual	21.10%	18.30%	13.80%	15.80%	17.60%	21.20%	15.40%	16.30%	Due May 25	Up is Bad	⋖ ► Neutra
	Benchmark - National Data	Annual	22.33%	22.24%	22.23%	21.39%	22.90%	23.38%	22.30%	22.60%	Due May 25		
	Benchmark - Regional Data	Annual	24.66%	24.08%	24.06%	22.66%	24.20%	24.24%	23.60%	24.10%	Due May 25		
	Regional Rank (Rank out of 15)	Annual	1	1	1	1	1	3	1	1	Due May 25		(
	% of children in school years 1-11 that are active for 60+ minutes everyday	Annual	-	NC	49.20%	40.50%	NC	41.81%	NC	NC	Due Feb 25	Up is Good	⋖ ▶ Neutr
	Benchmark - National Data	Annual	-	NC	43.26%	46.81%	44.89%	44.63%	47.20%	47.00%	Due Feb 25	Neutral	⋖ ▶ Neutra
PHYS08	Benchmark - Regional Data	Annual	-	-	41.27%	45.88%	43.22%	46.40%	45.70%	47.50%	Due Feb 25		
	Regional Rank (Rank out of 15)	Annual	-	-	3	12	NC	7	NC	NC	Due Feb 25		
	Proportion of adults who do any walking or cycling for any purpose at least three times per week	Annual	-	57.80%	60.40%	56.00%	60.50%	58.90%	55.00%	59.40%	57.30%	Up is Good	⋖ ► Neutra
PHYS12	Benchmark - National Data	Annual	-	45.70%	47.00%	47.20%	47.70%	46.00%	45.60%	45.80%	46.40%		
	Benchmark - Regional Data	Annual	-	43.60%	44.20%	44.70%	45.90%	44.60%	43.00%	43.00%	43.60%		

						Previou	s Years				2023/2024		
		Collection Frequency	2015/2016	2016/2017	2017/2018	2018/2019	2019/2020	2020/2021	2021/2022	2022/2023	Year	Polarity	DOT
	Proportion of people who use services who reported that they had as much social contact as they would like	Annual	45.80%	49.50%	44.50%	43.40%	45.50%	35.40%	39.70%	41.30%	(Due Dec 2024)	Up is Good	▲ Green
റ & ASCOF1I1	Benchmark - National Data	Annual	45.40%	45.40%	46.00%	45.90%	45.90%	34.40%	40.60%	44.40%	(Due Dec 2024)		
110	Benchmark - Regional Data	Annual	46.00%	45.60%	47.50%	48.00%	46.20%	NC	40.20%	46.30%	(Due Dec 2024)		
Reduce th	Regional Rank (Rank out of 15)	Annual	9	6	12	14	10	NC	11	13	(Due Dec 2024)		
the proportion	Loneliness: Percentage of adults who feel lonely often / always or some of the time	Annual	NC	NC	NC	NC	25.70%	25.70% (2019/20)	25.70% (2019/20)	25.70% (2019/20)	25.70% (2019/20)	Up is Bad	⋖ ► Neutral
	Benchmark - National Data	Annual	NC	NC	NC	NC	22.30%	22.30% (2019/20)	22.30% (2019/20)	22.30% (2019/20)	22.30% (2019/20)		
of adults	Benchmark - Regional Data	Annual	NC	NC	NC	NC	21.50%	21.50% (2019/20)	21.50% (2019/20)	21.50% (2019/20)	21.50% (2019/20)		
who rep	Regional Rank (Rank out of 15)	Annual	NC	NC	NC	NC	13	13 (2019/20)	13 (2019/20)	13 (2019/20)	13 (2019/20)		
who report feeling lonely	% of adult social care users who have as much social contact as they would like (65+ yrs)	Annual	41.00%	48.70%	41.30%	37.00%	40.40%	NC	39.20%	37.40%	(Due Dec 24)	Up is Good	Rec S
ing lone	Benchmark - National Data	Annual	43.70%	43.20%	44.00%	43.50%	43.40%	NC	37.30%	41.50%	(Due Dec 24)		Rec S
PHOF99	Benchmark - Regional Data	Annual	44.80%	44.40%	44.90%	44.60%	43.40%	NC	36.80%	44.10%	(Due Dec 24)		Ċ
	Regional Rank (Rank out of 15)	Annual	13	5	12	15	11	NC	6	12	(Due Dec 24)		

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Health and Wellbeing Board

22 January 2025

Report of the Chair of the York Health and Wellbeing Board

Chair's report and updates

Summary

1. This paper is designed to summarise key issues and progress which has happened in between meetings of the Health and Wellbeing Board (HWBB), giving Board members a concise update on a broad range of relevant topics which would otherwise entail separate papers.

Key Updates for the Board

<u>Partnership</u>

- 2. The **Ageing Well Partnership** have provided the following updates:
- 3. **Happy to Chat Bench** Age Friendly York is working in partnership with Rotary York Ainsty to increase the quantity of Happy to Chat benches. The trial introduced by Age Friendly York was well received so we are now looking at suitable places for permanent plaques and have secured funding through Rotary York Ainsty to purchase the plaques. The initial locations will be Acomb Front Street and North Street Gardens.
- 4. **Warm Places** the communities' team have recently offered grants to 22 venues in York that will ensure there is a warm place and welcome for residents. Older people feel the cold more so can be particularly challenging to stay warm if they are on a low income. In addition we have been working with the York Humber and North Yorkshire Health and Care Partnership to create a <u>service directory over the winter</u>.
- 5. Your Home as a follow on from the Your Home workshop in partnership with York Older People's Assembly in September we are exploring working in partnership with U3A (University of the Third Age) to bring social activities to social housing retirement schemes (Independent Living Schemes). Many communal living rooms are underutilised, and this provides an opportunity to reduce social isolation and feel more part of the community with local residents joining the activities. This also provides an informal way for older residents to understand what it might be like to live in one of these schemes and to

- start planning ahead. The proposal is going to the U3A board in January.
- 6. York Frailty Hub Dr Emma Olandj, Director of Community Services at Nimbuscare provided a presentation on the Frailty Hub to the Partnership on the excellent work that has been developed. Through a spirit of collaborative partnership working a multi-disciplinary team has been brought together made up of a GP with a special interest in frailty, a social worker, 2-hour responder from a Community Response Team, social prescriber and Age UK Home from Hospital service. The York Integrated Community Team already support 3000 of the most vulnerable residents in York who are frail. Through working more closely together, the Frailty Hub has identified those who would benefit most from an MDT approach and hold those 3000 patients, visiting once a year to check in.
 - In the first year the team spoken to over 4,000 people.
 - From those 4,000 approximately 1,800 were prevented from going into the A&E department inappropriately.
 - Followed those people up for wrap around support and found that most of those patients for up to a month after, were still in their usual place of residence and are managed to keep them home safe and rehabilitate them back to good health.
- 7. **Better Care Fund (BCF)**: Since the decision to stand down the BCF Performance and Delivery Group last year, officers have been working to reinstate this forum with a renewed set of objectives and outcomes which promote openness and transparency.
- 8. The first step in this journey was to hold a BCF Winter Workshop which took place in December. It was great to see so many partners coming together to celebrate the fantastic work of the BCF.
- 9. The workshop was a great opportunity to hear examples of real-world delivery from the schemes and to see how often there are interdependencies. It also provided partners with the chance to get to know each other, network and make some helpful links, strengthening partnership working and collaboration.
- 10. Everyone who attended the session agreed that what we all have in common, and what really sums up 'why we do what we do' is the person. A person behind every statistic is one of the standout statements that many people took away from the session and it was fantastic to hear some of the case studies that were at times very moving and demonstrate the power some of these schemes have.

- 11. We talked about being stronger together and how we all acknowledge that there has been a real shift towards integration and this session only reiterates that ethos. There are things that we can do together that we cannot do alone and working together, outside of organisational boundaries and seeing ourselves as 'one' will help create the resilience and strength that we talked about, fundamentally improving how we work and crucially, improving the lives and experiences of the people accessing these services.
- 12. The next steps in our journey will be to re-establish the Performance and Delivery Group with the first meeting taking place in late January. Following this, the group will meet regularly, aligning with the NHSE planning submission timeframes to enable transparent and collaborative discussion to inform the planning cycle.

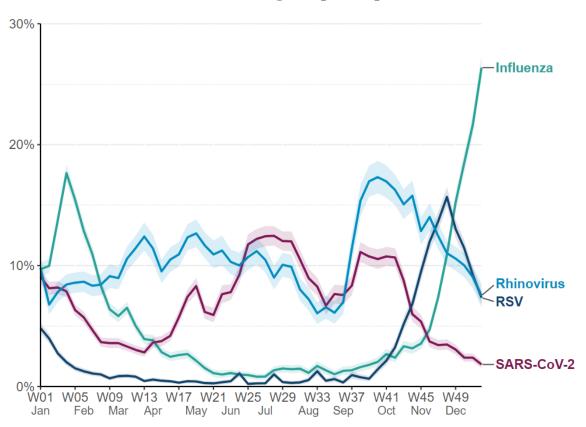
Public Health

- 13. **Smoking cessation** success: New NHS figures show that York's Health Trainer team, who provide the specialist stop smoking service for the city, are providing the most effective stop smoking service in the country. 82 per cent of people who set a quit date with the service in the last quarter had successfully stopped smoking four weeks after that date, the highest reported percentage in England. 2 in every 3 people who smoke will die early from smoking-related causes, and this is still over 14,000 people in York so this is a key plank in our strategy to improve health and reduce health inequalities. People can self-refer to the Health Trainers at CYC Health Trainers City of York Council or call 01904 553377
- 14. **Baby week**: York's first <u>Baby Week</u> was held in November, with events at each of the three main Children Centres/Family Hubs, Clifton, Avenues and Hob Moor as a jointly organised initiative working with Raise York (York's Family Hub Network) and Health Services. The first 1001 days (from conception to age 2) have been shown to be the period of life which most impacts human health, and these events are geared to raising the profile of this crucial time, and helping parents and carers increase knowledge and capacity around infant feeding, developmental support, weaning and nutrition, speech and language, parent and infant mental health and wellbeing, and accident avoidance / use of healthcare.
- 15. **Sexual Health Services**: Public Health has been reviewing and reshaping the sexual health service offer in the city together with York Hospital who provide the service, and has recently published the consultation results and next steps
- 16. **Supporting asylum seeker health**: In collaboration with Refugee Action York, Nimbuscare and Vaccination UK catch up vaccination

clinics have been commissioned within the contingency accommodation for asylum seekers in York. Prior to the clinics, the total number of vaccinations received for this group of people had been 137. By April last year it had reached 264, with almost all the additional vaccinations being for measles. Most of the children are now vaccinated. This work was highlighted in an <u>LGA Case Study</u> on Inclusion Health in York.

17. **Winter pressures**: Levels of pressure within NHS and care services are high currently, and as the chart below shows, winter pressures are (as of 3rd Jan) predominantly driven by a surge in influenza cases, which has happened earlier this year than previous years. RSV infections are heading downwards and COVID positivity is low; reported cases of Norovirus are high. NHS leaders have nationally been reinforcing messages about choosing the appropriate place for seeking healthcare. The autumn flu vaccination window is still open and data is being analysed around take up in York and how to target the 2025/6 campaign best. JCVI have announced the eligibility criteria for the spring COVID booster. RSV vaccine offer is available all year round in pregnancy through midwifery services.

Figure 6a. Respiratory DataMart weekly percentage of tests positive for influenza, SARS-CoV-2, RSV and rhinovirus, England [note 7]



18. **Neighbourhood working**: In December the council's executive approved the design principles of a 'Neighbourhood Model' for York, which proposed a shift from reactive models of service delivery, with thresholds for access, to a model where community-based teams,

primary and secondary services, social and voluntary sectors share information and codesign support that addresses the holistic needs of different neighbourhoods. This focused effort to join up services at a local neighbourhood level, with targeted interventions based on the needs of the individual, will equip and empower residents to take control of their health, adopt more positive lifestyle choices and make informed decisions about their, and their families, health and wellbeing. The full paper can be read here

- 19. **Pharmacy Provision in York**: York Health and Wellbeing Board (HWBB) have received an application to relocate a pharmacy from Green Lane in Acomb to Cornlands Road in Acomb. The chair of the HWBB has responded to the application with the view that the proposed move results in a significant change to the availability of pharmacy services in this area. The Chair highlighted the following in her response:
 - There is no indication in the application if the re-located pharmacy will continue to provide needle exchange and supervised consumption in the new location. These are important services for some of our residents and are only provided by a small number of pharmacies. It is our strong preference that this service is continued at any new location.
 - The current pharmacy operating at Cornlands road is a '100 hour' pharmacy. It provides a seven day service, and six evening openings through the week. This year, it is also providing Christmas day pharmacy coverage. By contrast, the applicant is proposing a five day service with no evening or weekend opening. It is our strong preference that the evening and weekend operation remain in place as we know this is valued by residents.

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Health and Wellbeing Partnerships Co-ordinator	Cllr Lucy Steels-Walshaw Executive Member for Health, Wellbeing and Adult Social Care
Specialist Implications Of Not applicable	Report √ Date 08.01.2025 Approved fficers

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For further information please contact the author of the report

Wards Affected: