Public Document Pack

North Yorkshire Council Health and Adult Services - Executive Member & Corporate Director Meeting

Friday, 3 November 2023 / 1.30 pm

AGENDA

1 **Apologies for Absence**

- 2 **Declarations of Interest**
- 3 Exclusion of the public from the meeting during consideration of each of the items of business listed in Column 1 of the following table on the grounds that they each involve the likely disclosure of exempt information as defined in the paragraph(s) specified in column 2 of Part 1 of Schedule 12A to the Local Government Act 1972 as amended by the Local Government (Access to information)(Variation) Order 2006:-

Item number on the agenda	Paragraph Number
Item 5 – Infection Prevention Control Options Appraisal	3
Item 6 – North Yorkshire Horizons Supporting Annex	3

Items for Executive Member decision

4 Autism Strategy Consultation

Items for Director of Public Health decision

5 Infection Prevention Control Report (Pages 95 - 104) 6 North Yorkshire Horizons contract extension (Pages 105 - 118) 7 Date of next meeting - 8 December 2023

Circulation:

Executive Members	Officer attendees	Presenting Officers
Michael Harrison	Richard Webb	Naomi Smith
	Louise Wallace	Angela Hall
		Dr Victoria Turner



(Pages 3 - 94)

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Agenda Item 4

North Yorkshire Council Health and Adult Services: Executive Member Meeting 3rd November 2023

REPORT TO Executive Member for Health and Adult Services

Draft All-Age Autism Strategy for North Yorkshire: Proposed Public Consultation

1.0 Purpose Of Report

1.1 The purpose of this report is to seek approval for a proposed public consultation on the draft North Yorkshire All-age Autism Strategy.

2.0 Background

- 2.1 Autism is lifelong neuro-development condition that affects how people perceive the world, communicate and interact with others. Approximately 1% of the UK population is autistic, meaning around 6,155 autistic people live in North Yorkshire based on the 2021 Census.
- 2.2 Autism is often called a spectrum condition because it can impact on people in many different ways. They may need to access different levels of support across their lives in areas such as education, employment, housing, health and care or within their communities. Many different organisations across North Yorkshire have a part to play in this, working together with autistic people of all ages and their families.

3.0 Issues

- 3.1 The new draft All-Age Autism Strategy (Appendix 1) builds on the <u>previous local strategy</u>. It addresses key issues facing autistic people, outlining a local system-wide response to the <u>national strategy</u>, available data, evidence and what people have told us.
- 3.2 The overall aim is that "Autistic children, young people and adults and their families enjoy full, happy, and healthy lives". To achieve this, we will work together on 8 key priorities:
 - Education and preparing for adulthood
 - Employment
 - Housing
 - Carers

- Assessment, diagnosis and support
- Health and care
- Criminal and youth justice
- Inclusive communities

To help us to deliver our strategy, we will also focus on a number of cross-cutting themes: working together; workforce; data and research; and making the best use of resources.

4.0 **Performance Implications**

- 4.1 Working together across the partnership to deliver on our shared priorities within the strategy should impact positively on performance in a number of key metrics including:
 - Waiting times for assessments (eg diagnosis, education, carers)
 - Numbers of people supported to gain and/or maintain employment
 - Training sessions delivered and completed
 - Feedback from autistic children, young people and adults, and their carers / families
- 4.2 The strategy also recognises that in some areas we need to understand more about the current position in North Yorkshire in order to ensure that we make the biggest impact through the strategy and can demonstrate the difference we have made.

5.0 Policy Implications

5.1 This strategy aligns with a number of other local strategies in place or in development:



OFFICIAL

- <u>Joint Health and Wellbeing Strategy</u> (draft) autistic people are identified as a priority group in the draft North Yorkshire Joint Health & Wellbeing Strategy with the ambition of 'adding years to life and life to years'
- <u>Economic Growth Strategy</u> (draft) includes a commitment to inclusion, health and employability for our residents, supporting people to overcome barriers that hold them back from moving into employment or progressing in work
- <u>Housing strategy</u> (draft) the vision is to deliver "good quality, affordable and sustainable homes that meet the needs of all of our communities", and there is a priority around "meeting supported housing needs and the needs of specific groups"

6.0 Alternative Options considered6.1 The partnership Steering Group co

- The partnership Steering Group considered a number of options for the strategy scope:
 - <u>Age range</u>: a single all-age strategy (rather than separate strategies for children & young people and adults) was preferred. Considering the whole life course means that autistic people of all ages can benefit from our collective action under the strategy, though we recognise that some chapters such as education or employment may be more relevant to people at particular stages of their lives; and that some pathways or services will continue to be targeted at specific groups.
 - <u>Conditions</u>: it is recognised that autism is one or a number of neuro-developmental conditions and that autistic people may have multiple neuro-diversity. We have brought forward a strategy specifically focussed on autism for the period 2024-2027 aligned to the national strategy. We recognise also that we need to better understand the needs of our neuro-diverse population more widely and have included a commitment to this within the strategy

7.0 Financial Implications

7.1 Within North Yorkshire Council there is no specific budget ring-fenced for autism, but rather, a range of services and budgets which are used to meet the needs of autistic people. There are no plans for the Council to derive savings specifically as a result of the autism strategy, and any incidental savings may be re-invested. There is no new funding for work on autism and any expenditure must be resourced from existing budgets. Through our work on the strategy, we will work towards improving value for money of Council services and making best use of resources by joining up across agencies. More widely, the strategy will have a positive economic impact through the priority focus on supporting autistic people to gain and/or maintain employment. A number of proposed actions within the strategy are preventative in nature, which supports best value for money across public sector organisations.

8.0 Legal Implications

8.1 Producing a local autism strategy was a requirement from the national strategy "Fulfilling and Rewarding Lives" which stemmed from the Autism Act 2009. The requirement was reiterated in the refresh of the national strategy 'Think Autism' (2014) and the accompanying 'Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy' (2015). In 2021, the government launch a new <u>national</u> <u>strategy</u> (2021 -2026). The draft local strategy (Appendix 1) has been developed as a local response to the national strategy as well building on the work of previous local strategies.

9.0 Consultation undertaken and responses

9.1 This report seeks approval for a proposed 3-month public consultation on the draft Autism Strategy. An overview of plans is at Appendix 3. Easy-read versions of the key documents and consultation materials will be prepared. Extensive joint working with autistic people, their carers / families and partner agencies has informed the draft strategy as follows:

- Our work is led by the North Yorkshire Autism Group which includes representatives from across the partnership and a parent/carer (see acknowledgements page)
 - We have built a wider Autism network of autistic children, young people and adults, their carers/families, staff, partners and wider community services whose experiences, views and ideas have been shared through events, workshops, surveys and conversations over the past 6 months
 - April May 2023: 8 events (local & virtual) for autistic children, young people and adults plus carers/families, and a survey which received 170 responses.
 104 people attend the events with 72 autistic people / carers present.
 - July 2023: 104 practitioners from across organisations attended 7 events, and 40 colleagues were reached through 2 partnership meetings
 - Sept 2023: autistic children, young people and adults, carers/families, practitioners and partners came together for 7 thematic action-planning workshops (mixture of virtual and local), with 77 different people participating

10.0 Impact on other services/organisations

- 10.1 Delivering this strategy will impact on a number of services and organisations (see page 5 in the strategy, Appendix 1). Successful implementation requires commitment from:
 - North Yorkshire Council departments Health and Adult Services (Adult Social Care, Prevention/Service Development and Public Health), Children & Young Peoples Services (Inclusion, Education), Community Development (Housing, Libraries, Culture, Leisure), Stronger Communities
 - Health Services including Integrated Care Boards, Primary Care, commissioned Autism Diagnosis Service providers, General Hospitals and Mental Health Community Services and Hospitals
 - Schools, colleges and other education and childcare providers
 - Criminal & Youth Justice: Probation, Police, Youth Justice Service
 - Providers of care, support and activities for autistic people and their families
 - Wider community & voluntary sector
 - Employers, businesses and organisations within the community

11.0 Contribution to Council priorities

11.1 The draft strategy contributes to a number of ambitions in the <u>North Yorkshire Council Plan</u>, in particular those under the Health & Wellbeing and People priorities, as well as having links to economy (employment priority) and locality working (autism-friendly communities).

12.0 Equalities Implications

12.1 Autism is considered a disability under the Equality Act (2010), although we know that not all autistic people see themselves as disabled. An Equality Impact Assessment (EIA) for the draft strategy has been completed, this can be found at appendix 4. An Easy Read summary will also be produced. Both will be made available for comment as part of the public consultation and will be reviewed during strategy adoption and implementation.

13.0 Climate change implications

13.1 A climate change impact assessment screening for the draft strategy was completed. Following advice from a Climate Change specialist within North Yorkshire Council, it was deemed that a undertaking a full Climate Change Impact Assessment would not be proportionate. This is because the potential impact on the environment is minimal (mostly associated with the potential to slightly increase or decrease travel for around 1% of the local population who are autistic). This will be kept under review during strategy delivery.

14.0 Community safety implications

14.1 The draft strategy includes a priority on the Criminal and Youth Justice systems, which should impact positively on community safety across North Yorkshire.

9.2

Page 5

15.0 Reasons for recommendation/s

15.1 The draft strategy presented at Appendix 1 has been prepared with extensive involvement from autistic children, young people and adults, their carers/families, a range of staff and practitioners from the key partners as well as representatives from communities and employers. However, it is good practice for a strategy of this significance to also seek feedback through a formal public consultation.

16.0 Recommendation/s

16.1 To approve the proposed 3-month public consultation on the draft North Yorkshire All-age Autism Strategy (Appendix 1) in line with the plans which can be found at Appendix 2.

Report author: Naomi Smith (Head of Health and Adult Services Planning)

Appendices:

- 1. Draft strategy for consultation (full version)
- 2. Consultation plan
- 3. Supporting data pack
- 4. Draft Equality Impact Assessment for consultation

Health and Wellbeing Board North Yorkshire

AUTISM

DRAFT VERSION FOR KEY DECISION TO APPROVE PUBLIC CONSULTATION (3rd November 2023)



Contents page and key information













Chapter name	Page	Title			
Our Strategy – Introduction	3 - 7	What is Autism? Working Together, Our Partnership and Plan on a Page			
Education and Preparing for Adulthood	8 - 11	All priority themes follow this format: Why does it matter? What is happening in North Yorkshire, What have people told us? What are we proposing to do 2024-2027? Case study (where applicable)			
Employment	12 - 16				
Housing	17 - 19				
Carers	20 - 22				
Assessment and Diagnosis	23 - 27				
Health and Care	28 - 33				
Criminal and Youth Justice	34 - 36				
Inclusive Communities	37 - 40				
Delivering our strategy	41 - 42	Cross-cutting themes and monitoring progress			
Glossary	43 - 47	You can find a short explanation of the words in red, in the glossary at the end of this strategy.			

This document contains direct quotes from Autistic people and carers which we heard through our engagement. These are identified in this type of gold box throughout the strategy.







Page P

4th

Autism is a lifelong **neuro-development condition** that affects how people perceive the world, communicate and interact. Being **autistic** means your brain works differently to how other people's brains work.

What is autism?

"Autism is individual... If you have met one autistic person, you've met one autistic person."

Whether people find out they are autistic as a child, young person or adult, being autistic is often an important part of a person's identity for the whole of their lives. We have heard examples of children and young people being diagnosed with autism and then parent carers later also being diagnosed or self – identifying as autistic.

We understand that autistic people have different ways of describing themselves and that they may identify with a wider group of people who are "**neurodivergent**" or "**neuro diverse**". We recognise that the Equality Act (2010) considers autism as a disability, but we also know that not all autistic people see themselves as disabled.





Autism is often called a **spectrum condition** because it can impact on people in many different ways. They may need to access different levels of support across their lives in areas such as education, employment, housing, health and care or within their communities. Many different organisations across North Yorkshire have a part to play, working together with autistic people of all ages and their families (see next page).

















Our partnership in North Yorkshire

Working together to enable autistic people and their families to enjoy full, happy, and healthy lives.

Autistic children, young people, adults and their carers and families

Health Services	Council S	ervices	Key Partners	
Integrated Care Boards (Humber North Yorkshire & West Yorkshire): <i>fund and quality-assure health services for autistic people</i>	Children and Young I Early help and targete children & young peop	ed support to keep ple safe. Education,	Providers of care, support and activities for	Local Employers
Primary Care (GPs & Pharmacies)	Health and Care Plan learning and e		autistic people and their families	Job Centre
Autism Diagnosis Services (provider is dependent on age / location) Tees, Esk and Wear Valley NHS FT Harrogate and District NHS FT The Retreat	Health & Adult Services Adult Social Care Assessments and Support. Living Well support to improve adults' health, wellbeing and independence. Public Health: health protection, promotion and prevention		Schools, colleges and other education and childcare providers	Criminal and Youth Justice: Probation, Police, Youth Justice Service
ABL Care Services Airedale NHS Trust Bradford District Care Trust Bradford/Airedale Neurodevelopmental Service South West Yorkshire FT	Housing To meet the needs of our communities and make NY a great place to live	Libraries, Culture & Leisure services within our communities	Wider community and voluntary sector	Businesses and service operators in communities
General hospitals Mental Health Community Services & Hospitals Tees, Esk and Wear Valley NHS FT Bradford District Care Trust	Stronger Communities Locality working at the heart of what we do	Economic Development enabling people and places to prosper	Note that some named providers and organisations may change over time	













Data limitations

There are wide variations between the data sources on autism. This makes it difficult to accurately estimate the size and characteristics of the population within the community that have autism. However, a common factor across most data sources is increasing prevalence over time. This reflects improved recognition and diagnosis, particularly among children and younger people.

Long waiting times for assessments are thought to contribute to continued underdiagnosis, including for those in younger age groups. This means that levels of autism may still be underreported. Together with low levels of historic diagnosis, particularly for females and minority groups, this suggests that the actual number of people living with autism is likely to be far higher than is reflected in the data.

Approximately 1% of the UK population is autistic, which means around 6,155 autistic people live in North Yorkshire based on the 2021 Census. Nationally 1.8% of males are autistic and 0.2% of females. Research also shows that autistic people are more likely to have multiple conditions such as **ADHD** or **dyspraxia** or a **learning disability**. There is potential for a larger number of under diagnosis or self identification in autistic females.







Working together to develop this strategy

"A lot of people think my son is 'naughty' as they don't understand autism."





We have also looked at what local and national data and research tells us. We reviewed the progress made under our previous strategy, **'Changing the landscape of Autism'** and have included some case studies in this document. We know that there is still a lot of work to do: our new strategy addresses the areas which are most important to people as well as being a local response to the <u>national strategy</u>.







Education and Preparing for Adulthood

Vision: Autistic children and young people thriving at school and into adulthood

"Gaining and reviewing EHCP has been a battle and extremely stressful for both parents and autistic son. Adjustments made by schools have all been done where possible"

Why does it matter?

Providing the right support to children and young people in education settings is vital to enable them to reach their full potential and to prepare them well for adulthood.

Education, Health and Care Plans have doubled in both primary and secondary schools between January 2019 and January 2023. SEN support has increased by 0.5% in primary and 0.6% in secondary in the same period.

What is happening in North Yorkshire?



Thin

We know that the highest proportion of children with an Education, Health and Care Plan (EHCP) is for a primary need of Autism Spectrum Disorder (ASD). At the start of 2023 this equated to 0.8% of all school-aged children in North Yorkshire. In addition 1.1% of primary and 1.48% of secondary students were receiving Special Educational Needs (SEN) support for Autism.



The SEND Hub provides intervention and support for children and young people aged 0-25, to allow them to access educational provision. This includes using evidence – based interventions and providing coaching and training for professionals. The hub team use The Autism Education Trust guides to support children's transitions from early years settings to primary school, primary to secondary school and secondary school to post-16 provision. Our programme of training, Unlocking Autism, is designed to support parents and practitioners and has been updated to ensure it is neurodivergent affirming and accessible to all (see case study).



Yage



Vision: Autistic children and young people thriving at school and into adulthood

"He needs good relationship with teacher, to feel understood and cared for, not just to feel like a number."

What have people told us?

There has been a significant mix of experiences around schools supporting autistic children and young people. People shared good examples of how knowledgeable and experienced staff in education settings support autistic children and young people. Other people shared negative experiences and told us that what matters to them is ensuring that all staff in both mainstream and specialist provision have good quality training to help them with earlier identification of autistic traits and support autistic children and young people well at the point of identification rather than diagnosis.



Having access to appropriate education provision and suitable placements as close to the local community as possible is important to people. There are currently challenges with knowledge, understanding and interaction between the different services which support autistic children and young people. Quality assurance of these services across North Yorkshire was also identified as an area to improve.

Preparing for adulthood was a key theme throughout the engagement feedback. In particular parents and carers were keen that autistic children and young people had aspirational targets and were encouraged to think about their future in terms of leaving school and going on to further education or employment.





**** ****





Rage 16





Education and Preparing for Adulthood

Vision: Autistic children and young people thriving at school and into adulthood

What are we proposing to do? (2024 - 2027)

- Continue to support autistic children and young people with one-to-one sessions around developing self-identity and understanding their diagnosis.
- Work with **SENCOs** to improve earlier identification of needs to improve children and young people's outcomes.
- More courses for parents, carers and families continue rolling out and enhancing the Unlocking Autism and Unlocking Autism Plus programmes (see case study)
- Training for schools and education settings to support autistic people well (including pre-diagnosis support and reasonable adjustments)
- Strengthen the range of education provision for autistic children in North Yorkshire, including local provision for autistic children and young people who are formal learners and more placements in Targeted Mainstream Provision.
- Establish a framework for children that have been identified as unable to access education in a school or setting.
- Implement changes to the preparing for adulthood pathway and joint working with partners to support autistic children from 14 years old including:
 - review short break offers for families
 - develop needs analysis for education, care and accommodation provision to expand the market
 - training for employers to support autistic people well.



Education and Preparing for Adulthood

Case Study: Unlocking Autism Training



Page A

Unlocking Autism

2 day (or 5 weekly sessions) training programme for parents, education practitioners and social care colleagues

Unlocking Autism Plus

Stand alone sessions that build on Unlocking Autism for parents/ practitioners on specific areas of communication and interaction



Autism strengths, differences and how to support

Communication expressing, understanding and interacting

Sensory preferences and impact and how to get ready to learn

Resilience self-reflection and responding to difficult situations

Behaviour understanding the purpose of behaviour and knowing how and when to respond

Girls and Autism

Identity

Pathological Demand Avoidance (PDA)

Selective Mutism

All share the same message, same strategies for all adults around the child/young person

Open Access – no diagnosis required

Courses face to face, online and downloadable

Practical Support – not just theory!



















Employment

Vision: Autistic people thriving at work

"I have learnt a script for explaining my needs that minimises disruption and makes it clear how businesses can fulfil their obligations."

Why does it matter?

In 2021, only 21.7% of autistic people were in employment, the lowest rate of any disabled group (Office for National Statistics, 2021). Research also shows that autistic people are underpaid, underemployed and poorly supported in the workplace, with many autistic people unable to disclose their autism. For Personal Independence Payments (PIP) claimants with autism, those aged 16-24 made up 62% of all claimants, whilst those aged 45-64 made up a further 32% in April 2023, reflecting the increase in diagnosis among younger age groups and the likely underdiagnosis among older working age adults.

What is happening in North Yorkshire?

We believe that autistic people should have the same job opportunities as other North Yorkshire residents. The new draft Economic Growth Strategy for North Yorkshire includes a commitment to inclusion, health and employability for our residents, supporting people to overcome barriers that hold them back from moving into employment or progressing in work.

North Yorkshire Council's Supported Employment Service work with adults who have an assessed eligible social care need to develop a personalised action plan which builds on the person's strengths and aspirations for employment. Intensive support is provided to enable people to develop additional skills and work experiences and to find the 'right' role. This includes support through application and interview stages and to put in place reasonable adjustments or other support for the employer in order to gain or maintain employment. This service holds the Advanced Award of Autism Accreditation (see slide 29).



















Employment

Vision: Autistic people thriving at work

"My employers are very understanding."

What is happening in North Yorkshire?

For adults who would benefit from help to find or maintain work but are not eligible for social care, NYC's Living Well Team can support people to develop their skills and confidence in this area. The service is free for up to 12 weeks and holds Autism Accreditation.

The Humber North Yorkshire Integrated Care Board (ICB) and TEWV NHS Trust both offer opportunities for paid work to experts by experience as part of their involvement in projects. North Yorkshire Council is working on our Involvement Framework which will set out how Health and Adult Services will involve people and communities in our work.

Jobcentres are Disability Confident and have programmes to provide advice and guidance to customers. This includes a new Employability support programme (in place by Dec 2023) which supports neurodiverse people and those with learning difficulties to gain meaningful and sustainable employment. Reasonable adjustments are available for people attending appointments, including private rooms and quiet time. Work coaches have received autism training, and a Disability Employment Advisor (DEA) is available in each job centre to support work coaches. Subject to eligibility; funding may be available to remove barriers to work e.g. interview clothes, laptops, mobile phones, push bikes.

RISE is a 1-1 support programme for adults in NY who are out of work and have barriers to engaging with employment or training. It is delivered through a partnership of community organisations. People can receive advice, mentoring and employability support.









What have people told us?

Some people told us about good quality support that they had accessed in the community to gain employment. However, many more people told us that they were not aware of existing support or that it was insufficient. Autistic people said they would like support to prevent them feeling overwhelmed from job application and interview processes. They would also like support with managing anxiety, expectations and burnout within the workplace.

Employment

Vision: Autistic people thriving at work

"There is little to no support available for those with autism who are transitioning

through big life events. Schools and workplaces are unequipped to support people

and are unaware of the severe trauma and difficulties these events can cause."



In the workplace autistic people have experienced stigma, a lack of support and assumptions being made based on autistic stereotypes. They would like more support around the disclosure of autism, how to deal with bullying at work and how to promote awareness of autism amongst colleagues. Employers told us that they are not always aware of the reasonable adjustments they can make to support autistic people, and that they sometimes lack confidence to provide these.



Autistic young people, their parents and practitioners from different agencies told us that there is not enough information and support for young people leaving school and entering the workplace. When organisations do not communicate well with each other, this leads to negative experiences which can affect confidence.





Page Page







Vision: Autistic people thriving at work

What are we proposing to do? (2024 - 2027)

- Work together with autistic people to develop a programme of training, information and guidance for employers around workplace wellbeing. This will include information about reasonable adjustments, autism inclusive recruitment practices and a person-centred approach which enables autistic employees to gain employment and thrive at work.
- Work with existing networks and services who offer support around employment to increase partnership working; improving knowledge and access for autistic people to existing support and opportunities. Review referral pathways into NYC Supported Employment service in response to NAS recommendations around improving access to timely support.
- To increase post 16 support and information for schools, young people and families around employment. This should include information and access to supported employment, supported internships, apprenticeships and work experience opportunities. Explore ways to enable young people with an EHCP to use support information in their plan to inform employers about how to accommodate their needs.











"A" had begun a part-time degree level course in Computing & Mathematics which was online but had no work experience. He was keen to find paid work, rather than voluntary work. Jo from NYC supported "A" with CV building, writing covering letters & job applications, identifying potential work placements, interview preparation and support at interview. Jo arranged an information session with a colleague from the Council's IT Security team, which developed "A"'s interest in cyber security.

Employment

Case Study: A's story

Service. He is a young autistic man with an interest in IT.

"A" was a new job-seeker at the time of referral to the North Yorkshire Council Supported Employment



"A" applied for a Cyber Security apprenticeship, but was overqualified and therefore was not eligible for the programme. "A" applied for a IT Services position. He interviewed well and met the benchmark but at the time there were not enough positions available to offer him a job. Two months later, the same job came up again. He was offered a full-time position which he accepted.

"A" is enjoying his new role. He mainly works from home but once a fortnight he drives into the office to work alongside colleagues in his team.

Through gaining employment, "A" is now more communicative, assertive and positive. He is thinking about the future and has a spring in his step. He is enjoying the role, enjoying learning on the job and coping well.







Page a



Vision: to support autistic young people and adults with appropriate housing

"I want to be able to live away and go to university."

Why does it matter?

Everyone needs a safe place to call 'home'. Supporting someone's housing needs can provide stability and a foundation to building a fulfilling life. Autistic people should be able to access suitable and appropriate housing.

In the summer of 2023 the government published the new Supported Housing Bill, which when it becomes operational in 2024 will place the following duties on the council: Licensing of supported housing, The enforcement of National Supported Housing Standards, Obligations to develop five-year strategic supported housing plans.

What is happening in North Yorkshire?

In April 2023, the county council and seven district and borough councils in North Yorkshire became one council, making North Yorkshire Council the largest council in the region. The new unitary council is now responsible for a full range of housing services across the county. North Yorkshire Council are undertaking a housing strategy consultation. A key priority is 'Our People' around supporting people who require supported housing provision, older people, Gypsy, Roma, Traveller and Show communities, refugees, asylum seekers, and those who are homeless or at risk of homelessness.

North Yorkshire Council commissions the delivery of around 800 units of supported living across more than 200 properties. There is significant variation across size and type of accommodation.



Rage 24

Housing

Vision: to support autistic young people and adults with appropriate housing

"We are in our 70's and would like our granddaughter to be independent."

North Yorkshire Council provides Occupational Therapy services for both children and adults. The services provide assessment and intervention to children, young people and adults with a variety of disabilities and illnesses including autism, learning disability, cognitive and physical disabilities. Core services include: major (bathroom adaptations, stair lifts, secure gardens funded through Disabled Facilities Grants (DFG) and minor adaptations (grab rails, banisters, half steps), moving and handling assessments to support people with reduced mobility, assistive technology (tele care/ technology enabled care) to increase safety, wellbeing and independence (epilepsy sensors, GPS sensors), rehousing support and specialist equipment.

What have people told us?

Throughout discussions with autistic people, carers and practitioners who support autistic people, housing has been a key theme. There have been some positive examples regarding good support from a former borough council. However, North Yorkshire has several different pathways and application process for housing which has led to some challenges.

Other areas that have not worked as well have been around the high risk of homelessness where provision has broken down and suitable alternatives have not been available. Feedback also included the inappropriateness of some accommodation (specifically emergency accommodation) and the lack of suitable social housing for autistic people, and the limited appropriate provision for under 55's.

Finally people reported challenges with waiting for accommodation to become available; long waits for repairs or faults with no support in the interim; costs and permissions for safety adjustments; and a lack of knowledge and understanding of autism amongst those who work in the housing sector.







| | | | >>>>













Housing

Vision: to support autistic young people and adults with appropriate housing

What are we proposing to do in response? (2024 - 2027)

Understanding local needs

North Yorkshire Council and the Integrated Care Boards are undertaking a housing needs analysis for autistic people and/or people with a learning disability. This analysis will commence in the Autumn of 2023 through to the Spring of 2024 and the outcomes will inform the delivery of local supported housing and supported living for Autistic people over the next five years and beyond.

Training and support:

For autistic people and carers

Create clearer, simpler and more accessible housing pathways and processes with tailored information and guidance to support autistic people and carers with understanding the type, appropriateness and availability of different accommodation options (including general needs, independent living with 24/7 care, extra care and supported living). Support with the development and/or improvement of independent skills (e.g. completing paperwork, budgeting, cooking cleaning and accessing health care).

For housing and care providers •

Develop understanding and awareness training and techniques to support housing and care providers who support autistic people with making reasonable adjustments around housing and care issues; such as changes with tenancies, issues with the environment and access to technology, equipment and adaptations where appropriate. We will encourage all providers (including non-specialist autism providers) to be autistic inclusive, this will be reflected within the specifications for commissioned services. Review and understand accommodation needs for all North Yorkshire's autistic residents (living in and out of county), from general needs housing up to complex or crisis support, in order to reduce the number of people living out of county and develop accommodation and models of support to enable people to stay at home longer.







PRage 26



Vision: Parents, carers and families of autistic people are supported to thrive

"I have been left to cope alone with zero support."

Why does it matter?

Carers can often see themselves as lifelong partners, sons, daughters, siblings, neighbours and friends, rather than carers. They play a vital role in maintaining the health and wellbeing of those who need help. We know that most carers are happy to support the person they care for and want to be able to continue offering that support, but the caring role can often affect their own health and wellbeing.

What is happening in North Yorkshire?

In 2021, the census showed that across North Yorkshire the age standardised proportions for usual residents providing unpaid care hours per week were: 4.7% providing 19 hours of less, 1.6% providing between 20 and 49 hours and 2.4% providing 50 or more hours.

Following the Covid-19 pandemic, training for parents and carers of autistic children and young people has been refreshed to enable support to be provided prior to diagnosis. This training is now available in person, online and on demand to better support parent carers at a more suitable time.

Carers has been identified as one of 7 Adult Social Care Improvement Priorities by North Yorkshire Council, with the overall Aim to support people to remain in their own homes for longer. We are aiming to develop an innovative and improved offer across North Yorkshire to improve the wellbeing and resilience of carers, supporting them in having a life outside caring.



Vision: Parents, carers and families of autistic people are supported to thrive

What have people told us?

There are areas of good practice and areas of improvement in terms of what is working well for carers. There have been some positive examples of access to carers assessments and self-referrals for support. Challenges include the waiting process for assessments and the availability of support outside of standard office hours or if practitioners are on annual leave.

Carers shared the emotional and mental strain of 'living in a neurotypical world' as a 'neurodivergent person'. Older carers are often worried about future planning for their loved one, especially around housing provision and support for autistic child or young person to remain independent. Concerns were also raised around the financial implications for carers who cannot work due to their caring responsibilities, and older carers around pensions.

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Rage 28





What are we proposing to do in response? (2024 - 2027)

In partnership, North Yorkshire Council is refreshing its Carers Strategy. Individuals, carers and partners will work together to develop and implement a strategy which considers what priorities are needed to support autistic carers and carers/ family members of autistic children, young people and adults.

Carers

Vision: Parents, carers and families of autistic people are supported to thrive

Strengthen and deliver training programmes including:

- for carers and families to better understand autism and different techniques and approaches which can support an autistic person, their carers and the wider family
- for practitioners to understand the impacts of autism for carers and families, including through people's experiences

Supporting Carers is a key priority for North Yorkshire Council and we will develop an integrated model to direct carers to a full range of support including prevention offer, on-line resources, direct payments and commissioned services.

Review carers assessment process: to increase number of carers assessments, improve and ensure timely access by reducing waiting times for assessment, developing an online assessment and review process for carers. North Yorkshire Council is also undertaking a programme of work called Waiting Well, aiming to bring about improvements for people who are waiting for services, wherever they may be in their social care journey. This includes autistic adults and carers.

Review support interventions including professional support and access to carers direct payments.

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Assessment, Diagnosis and Support

Vision: Everyone can access the support they need when they need it. Access to assessment and diagnosis happens as early as possible in a person's life, with priority for those with the greatest need

"My 12-year-old daughter has recently received a formal diagnosis for Autism, mostly positive experiences but hoping for more understanding from school with the difficulties she has."

Why does it matter?



For autistic people to have the right support when they need it, it is important to identify need early, reduce the time that people are waiting for an assessment and improve how people access assessment and diagnosis services. We recognise that autism is often under-diagnosed in women and girls. School-based data, shows that the ratio of boys to girls with a diagnosis is around 3:1 while the POPPI and PANSI models use a ratio of 9:1 male to females.

What is happening in North Yorkshire?

There are a number of different pathways for autism support, assessment and diagnosis in North Yorkshire. Which system people access depends on their age and where they live. Under the previous strategy we worked together to improve these pathways. However we recognise the challenges in providing timely, equitable and consistent assessment and diagnosis due to finite resources, workforce pressures and increasing demand. We aim to provide appropriate and timely support based on the need of the individual, and we do not want diagnosis to be a barrier to this.



Our data shows us that demand has increased significantly across Children, Young People and Adult assessment which means that waiting lists will be much higher than we would like. In most services across North Yorkshire, more than 80% of people who are assessed receive a diagnosis of autism. This means that our triage processes are effective and that people should be accessing appropriate support while they are waiting for a diagnosis.



Rage 30



Through our engagement, people have told us that waiting times for autism assessment and diagnosis are too long. Children, young people and parents highlighted the lack of support prior to, during and after the assessment and diagnosis process, along with the impact this had on the social, emotional and mental health of the individual child as well as their parents, siblings and wider family dynamics.

Assessment, Diagnosis and Support

Vision: Everyone can access the support they need when they need it. Access to assessment and

diagnosis happens as early as possible in a person's life, with priority for those with the greatest need

"It's too long to wait for an assessment, with very little support"

Assessments from private providers are not always recognised by the NHS and not everyone knows about the "right to choose" an appropriate provider. People who are autistic often face other health challenges (for example with mental health) which can get worse while they are waiting for an assessment because at present an autism diagnosis is needed to access some types of support or reasonable adjustments.



Being able to access support when autistic children, young people and adults and their families feel they need it would make a difference. Many people told us that their diagnosis of autism is **an important part of their identity.**





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Assessment, Diagnosis and Support

Vision: Everyone can access the support they need when they need it. Access to assessment and diagnosis happens as early as possible in a person's life, with priority for those with the greatest need

- What are proposing to do in response? (2024 2027)
- Improve the pre and post diagnostic support offered to children, young people and adults (especially to under represented populations such as women and girls), as well as their carers and/or families based on a needs-led approach, including
 - Exploring options to use the roles of community connectors, social prescribers, care navigators, autism champions and peer support subject to available resources.
 - Working across the wider system to enable access to support and reasonable adjustments while waiting for an assessment
- Explore use of resources to reduce waiting times for assessment focussed on those with the greatest need.
- Work towards improving the equity of access and consistency of assessment across North Yorkshire where possible, including:
 - Clarifying, simplifying and (where possible) aligning pathways and referral routes
 - Communicating pathways to people, carers and practitioners/services.
 - Working with private providers of autism assessments to develop and implement quality assurance criteria in order to prevent duplication of assessments
 - Transparency and awareness of the "right to choose" in respect of autism assessments.

















Assessment, Diagnosis and Support

Case Study: 5-Year-Old with Mixed Presentation and Social Challenges

During the assessment of a 5-year-old child, the Harrogate District Foundation Trust's Autism Team encountered a complex situation with mixed evidence and features suggesting possible ADHD, along with challenging social circumstances. The team faced difficulties in clearly distinguishing between different presentations due to varying behaviours observed at home, school, and during clinic visits.

Recognizing the need for a comprehensive understanding of the child's situation, the team employed multiple assessment methods. They conducted a school observation to gather additional information. However, even with this observation, the picture remained unclear. Consequently, the assessment resulted in a diagnosis of "No diagnosis" at the time, acknowledging the complexity of the child's presentation.

To address the challenges encountered, the team developed a plan for ongoing review in 18 months. This extended timeline would allow for the child's development and maturation, hoping to gain more clarity as they grow. In the interim period, the family was recommended to undertake Solihull training and Understanding Autism training. These training programs aimed to enhance their understanding of the child's needs and facilitate attachment-building strategies.

The provision of attachment-building resources to the family further emphasized the team's commitment to addressing the child's social challenges. By equipping the family with valuable tools, the team sought to promote healthy attachment and strengthen the child's overall development.

This case demonstrates the Harrogate District Foundation Trust's Autism Team's dedication to thorough assessment and ongoing support. Despite the complexities and uncertainties surrounding the child's diagnosis, the team took proactive steps to involve the family in training programs and provide valuable resources. This approach exemplifies their commitment to continuously evaluating the child's progress, adapting interventions as needed, and striving for a clearer understanding of the child's needs as they mature.

















Assessment, Diagnosis and Support

Case Study: Social prescribing Wharfedale, Airedale and Craven Alliance

S was referred via the Adult Social Prescriber (SP) for Wharfedale, Airedale and Craven Alliance (WACA) PCN who was supporting mum. She had started secondary school and had been assaulted by her peers. This had understandably resulted in disengagement from school and heightened anxiety.

A home visit was carried out, and S was reluctant to engage with the SP, however they did manage to discuss schooling options. S wasn't keen to engage in a move to another school or to return to her current school. S had been allocated a CAMHS worker who was leaving and a new worker hadn't been allocated.

The SP initiated a meeting between mum and school to see if there was any support school could offer. The meeting went well, with school accepting S's reason for non attendance. It was agreed that the SP would help mum to apply for an EHCP assessment., which would then allow additional support to be provided to S. School also suggested some good education resources for S to access at home.

Mum and the SP met up and completed the request for the EHCP, which we are awaiting the outcome of. The school have provided a home tutor 3 times a week which S is engaging well with.

S is on the waiting list for an Autism Assessment, and the hope is that the EHCP and enhanced support from school, initiated by the social prescriber, will help support S during this time.





Rage 34

Health and Care

Vision: Autistic people of all ages live healthier and longer lives, supported by autism-friendly health and care services

"Longer appointment rarely available and not having a diagnosis I often get refused adjustments"

Health inequalities are avoidable, unfair and systematic differences in health between different groups of people. They

Why does it matter?

are created by the conditions in which we are born, grow, live, work and age. We all have some influence over our own health through the lifestyle choices that we make, but the conditions we live in and whether we have fair access to services will have a much greater impact. These factors are often referred to as the **wider determinants of health**.

National research and data (further detailed in the accompanying data pack) shows that:

Autistic adults report barriers in accessing primary care including identifying predictability, sensory processing and communication. Only a minority of GPs feel confident when treating autistic patients.

18.1% of pupils with a diagnosis of autism also have learning difficulties

Almost 80% of autistic people without a learning disability experience mental health difficulties

Autistic people are three times as likely as the whole population to be admitted to hospital as an inpatient.

Links between autism and poor health outcomes are well known with up to 30 years shorter life expectancy for autistic people.

Autistic people of all ages may be at a higher risk of dying by suicide than those who are not autistic



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Health and Care

Vision: Autistic people of all ages live healthier and longer lives, supported by autism-friendly health and care services

"My experience of health professionals has been positive."

What is happening in North Yorkshire?

Under our previous local strategy, we have expanded autism training and support for health and care staff (see case study). North Yorkshire Council Adult Social Care Services achieved and have since maintained accreditation with the National Autistic Society, receiving advanced accreditation in some services (see case study). However, we know that it is still hard for some autistic people to lead healthy and fulfilling lives. In recognition of this, autistic people are identified as a priority group in the draft North Yorkshire Joint Health & Wellbeing Strategy with the ambition of 'adding years to life and life to years'.

What have people told us?

We heard examples of people receiving excellent support from the health and care system as well as less positive experiences, such as a lack of reasonable adjustments or communication between services. Physical environments which have not been designed with autistic people in mind can lead to sensory overload but where consideration is given, this improves accessibility. The Covid-19 pandemic has also affected accessibility. Sometimes standard appointment lengths may be too short for autistic people. People's experiences of the health and care system are significantly influenced by the staff they encounter. Good training is essential to build a knowledgeable and understanding workforce.



Rage 36



Health and Care

Vision: Autistic people of all ages live healthier and longer lives, supported by autism-friendly health and care services

- What are we proposing to do in response? (2024 2027)
- Design and deliver guidance, resources and training programmes including:
 - For autistic people and carers to identify barriers to accessing services, support and guidance to work together with staff to plan reasonable adjustments
 - For health and care staff to improve understanding of autism and support autism-friendly service delivery in terms of communication, reasonable adjustments, practice and culture.
 - For regulated service providers across health and social care continuing to roll out and refresh <u>Oliver McGowan</u> <u>Mandatory Training</u>.
- Work to improve physical environments in the health and care system so that they are accessible for autistic people
- Increase access to regular health checks for autistic people, building on the national pilot/roll-out
- Consider the needs of autistic people in suicide prevention activity and local system response (including education and the wider community) to the national suicide prevention strategy for autistic children, young people and adults
- Developing the care and support market to enable providers to support autistic people through different models of intensive support such as distress behavioural intervention or positive behavioural support
- Respond to national developments around quality of care and workforce development in services for autistic people
- Implement and share learning from recommendations for NYC Care Provider Services NAS Re-Accreditation (2023)

















Health and Care

Case Study – North Yorkshire Council Autism Accreditation

North Yorkshire Council (NYC) Adult Social Care (ASC) have undertaken the <u>Autism Accreditation programme run by the National Autistic Society (NAS)</u> which is internationally recognised.

NYC is the largest cohort of staff to undertake the programme. NYC first accredited its services in 2016 as part of the 3 year rolling programme. Since then, further accreditation reviews have taken place in 2019/20 and 2023/24.

Following accreditation, dates are then confirmed for an Autism Accreditation Review which is undertaken by NAS staff and an external moderator. Timetables are completed, surveys are sent to parents/carers and autistic people and an assessment introduction form is also completed.

After a 3 day review, the autism accreditation lead will provide feedback and their final report is sent to a panel who can award autism accreditation status.

NYC has 16 services within the accreditation process with 14 reaccredited in 2023 and 2 to be reviewed in 2024. The Supported Employment Service was awarded Advanced Autism Accreditation in 2023. Accreditation Standards which are scored, highlighting areas of strengths and areas of development

Commitment and consultation

Social communication, interactions and relationships

Function skills and self reliance

Sensory experiences

Emotional Wellbeing

Personalised standards to reflect individual service



















Health and Care

Case Study – Tees, Esk and Wear Valleys NHS Foundation Trust: Trust wide Autism Service

Tees, Esk and Wear Valleys (TEWV) NHS Foundation Trust now have a permanently established and growing Trust-wide Autism Service which provides clinical support and training to all services across the organisation. Examples of the services' work and impact include:

- Delivering "Understanding Autism" training which is mapped against Health Education England's Core Capabilities Framework to meet the requirements of Autism legislation and CQC baselines. Developing and implementing bespoke autism training in response to Trust needs.
- Working to provide care pathways that can be adjusted to meet the needs of autistic people within both inpatient and community services.
- Provide access to clinical supervision and consultation when services and teams are working with autistic children, young people, and adults for staff across all specialities (over 300 sessions delivered to date in 2023 across the Trust, which operates in North Yorkshire and beyond)
- Provide support and consultation to corporate services in relation to patient safety, complaints and human resources to meet the requirements of autism legislation and CQC baselines.

The team are currently working to make Adult Mental Health wards more autism inclusive with a focus on:

- Service user and carer involvement
- Reasonably adjusted communication
- Autism inclusive environment and ward processes
- Autism training and specialist supervision
- Autism inclusive care planning and risk assessment



















Health and Care

Case Study – West Yorkshire ICB (Social Care and CAMHS) – Dynamic Support Register

Young autistic person (YP) has recent experience of being arrested, leading to a significant deterioration in mental health of YP and a suicide attempt. YP was at risk of admission into a Tier 4 (T4) Children and adolescent Mental Health Service (CAMHS) inpatient bed.

YP's psychiatrist was very proactive in ensuring YP was part of **Dynamic Support Register (DSR)** process and family/school have been very supportive.

A Care (Education) and Treatment Review (C(E)TR) was undertaken with regular reviews to support the multiagency response required to support this YP. Outcomes achieved include professional support from a network including forensic mental health services, Intensive home treatment support, support for Barnardo's key worker service and the youth justice team resulting in a joined up approach supporting this YP.

Key outcome for the YP was an increase in specialist education provision and avoiding a high probable hospital admission. YP is now doing well.















Criminal and Youth Justice

Vision: Supporting autistic children, young people and adults to be well supported when accessing the criminal and youth justice systems

"The criminal justice system should focus generally on rehabilitation. It would not be appropriate to punish people for their autism. I find talking to police scary and uncomfortable."

Why does it matter?

People may come into contact with the criminal and youth justice systems as victims, witnesses or defendants. Nationally available evidence suggests that autistic people may have more contact with the criminal and youth justice systems than the UK population as a whole. It is important that autistic people can access the care and support they need in these situations.

What is happening in North Yorkshire?

Across North Yorkshire there is increasing awareness of Neurodiversity generally within the Criminal Justice System, though there is scope for improvement in recording data in this area so a more accurate picture can be gained. In the Probation Service, a new Neurodiversity service has been developed to provide support and information to Probation Officers and people on probation. This is provided by the National Autistic Society.

Within local prisons, all prisoners are screened for neurodiverse conditions. This then leads on to individual support plans if required.

Autistic people are supported in North Yorkshire through a number of services provided by courts, probation and prison service where appropriate. There are also a number of community based services such as the Resettlement and Community Support (RACS).







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Criminal and Youth Justice

Vision: Supporting autistic children, young people and adults to be well supported when accessing the criminal and youth justice systems

What is happening in North Yorkshire?

North Yorkshire Police have done a number of key actions to support neurodiversity within the police force including :

- the launch of a Neurodiversity Network in 2016, offering direct advise on neurodiverse issues. This
 network expanded the "all things Autism" awareness to cover all Neurodiversity.
- The training and support of staff; all new recruits (officers and PCSOs) having direct training on neurodiversity and all trainers having specialist training from Creased Puddle (Consultancy run by an ex NY Police Officer who jointly started the Neurodiversity Network in 2016). North Yorkshire Police also has 130 + Positive Action champions which have received direct awareness training from Autism Plus. All Equality Impact Assessments are passed through staff networks and therefore all new process and policies are assessed for any Neurodiversity Issues.
- Strategic membership of the North Yorkshire Council All Age Autism Strategy Groups and Member of the North Yorkshire Autism Community of Practice.
- Refit our custody suites with Autism inclusive environment.
- Community/Neighbourhood Policing and our Partnership Hub engage with local groups and also sit as part of the North Yorkshire Inclusive Communities Working Group – covering vulnerable groups and hate Crime Strategy across the County.







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What have people told us?

We know that access to information, sharing of information and good communication across various systems and services is a challenge. This can lead to a lack of joint working and an experience of services which is impersonal. The way in which criminal justice services are organised and funded can build in exclusions and make it hard for people to engage with criminal and youth services.

Criminal and Youth Justice

Vision: Supporting autistic children, young people and adults to be well supported when accessing the

criminal and youth justice systems

Autistic people and carers have fed back that support is not usually available where a diagnosis is not disclosed, and that individual needs may not be recognised and supported. Concerns about active consent and power dynamics between individuals and staff have also been highlighted. There have also been issues with the use of independent advocates within the criminal justice system.







Page A



Criminal and Youth Justice

Vision: Supporting autistic children, young people and adults to be well supported when accessing the criminal and youth justice systems

What are we proposing to	o do in response? (2024 -2027)
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- Implement recommendations from the Ministry of Justice report on neurodiversity across police, judges, courts, prisons and probation. This includes:
 - The development of a universal screening tool.
 - Work to improve physical environments for neurodiverse people.
 - Improving data collection and recording.
 - Improve information sharing and joint working between agencies and other services.
 - Staff training.

These are national recommendations which are already being implemented and reviewed regularly.

In addition, locally we will aim to;

- Explore the opportunity to develop a liaison and diversion service for autistic people which is similar to the model for mental health.
- Increase the use of the Neurodiversity Service available to Probation staff.
- Office for Police, Fire and Crime Commissioner (OPFCC) now has a public Confidence & Inclusivity Directorate and • is in the process of recruiting a Inclusivity and Public Confidence Manager who will work directly with North Yorkshire Police, North Yorkshire Fire and Rescue Service and Enable North Yorkshire to realise the Commissioners priority to Enhance positive Culture, Integrity and Public Trust. This role will be key in ensuring we understand our people's specific needs, and how in turn our services take those needs into account to operate effectively. **OFFICIAL**



















Vision: North Yorkshire is an inclusive place to live, work and visit

"Most people have little understanding of autism/neurodiversity or have a very rigid/stereotypical approach."

Why does it matter?

We all want to feel understood and accepted in our communities. Autistic people will often experience inequality, stigma and challenges in the places where they live, work and visit which can lead to loneliness, isolation and fewer opportunities.

National Research shows that:

Transgender and gender diverse adults are 3 – 6 times more likely as cisgender adults (individuals whose gender identity corresponds with their sex assigned at birth) to be diagnosed as autistic. (Cambridge University)

Autistic individuals are more likely to be LGBTQIA+. In addition, the study found that autistic adults and adolescents are approximately eight times more likely to identify as asexual and 'other' sexuality than their non-autistic peers. And there were sex differences in sexual orientation: autistic males are 3.5 times more likely to identify as bisexual than non-autistic males, whereas autistic females are three times more likely to identify as homosexual than nonautistic females.

that black and Chinese pupils were 26% and 38% more likely to be autistic respectively.

The prevalence was found to be highest amongst pupils of black ethnicity (2.1%) and lowest in Roma/Irish Travellers (0.85%).

By increasing public understanding of autism, we can help communities to become more accepting and inclusive of autistic children, young people and adults. Changing how autistic people are viewed and treated will enable everyone to feel more welcomed in their local community and support a good quality of life.



















Vision: North Yorkshire is an inclusive place to live, work and visit

"I can take my son to the barbers, and they will be so patient with him and give him the extra time he needs."

What is happening in North Yorkshire?

Since launching the previous local Autism Strategy in 2015, we have delivered activities and events across North Yorkshire. We have made improvements to online information about support and activities for autistic children, young people and adults through <u>North Yorkshire Connect</u> and the <u>SEND Local Offer</u>, although further expanding this information remains a key priority for us. Prior to the Covid 19 pandemic, we also began a programme to make North Yorkshire libraries Autism Inclusive and have delivered a number of improvements and new resources to support this (see case study). Staff at Skipton Town Hall Cultural Hub have all undertaken autism awareness training and have introduced a number of autism and neurodiverse inclusive events, activities and opportunities.

What have people told us?

We know that there are some areas of good practice but also some areas to improve. During our recent working together sessions people have highlighted that sigma is still a huge challenge for autistic people. They experience a range of barriers including the use of language and negative attitudes, stemming from a lack of understanding of autism. This is across the general public and local businesses but also across all other sectors including health and social care, police, teaching staff, transport and leisure facilities staff. Increasing understanding and awareness of autism is key to reducing stigma and creating inclusive communities.

People also told us about positive experiences through the use of national schemes (sunflower). Where individuals have personal or professional experiences of autism, this increases their understanding of supporting autistic people in their communities. When people offer reasonable adjustments, changes to environments where practical or other support, this helps autistic people to feel more comfortable accessing local communities and services like everyone else.



















Vision: North Yorkshire is an inclusive place to live, work and visit

What are we proposing to do in response? (2024 – 2027)

- Co-produce a social initiative/movement to make North Yorkshire communities, businesses and services Autism Inclusive.
- Develop a comprehensive communication and engagement programme for awareness-raising events and access to information, promotion of services, activities and offer throughout the year.
- Build on opportunities to work more broadly across North Yorkshire Council services following local government reorganisation to raise awareness, training and improve support and access for Autistic people, linking into services including housing, leisure, culture (museums, galleries, performance venues and outreach support), tourism, businesses, town centres, transport, locality community partnerships.
- Work with communities and organisations to access appropriate training that improves understanding of autism, supports with communication, culture and reasonable adjustments to support autism friendly communities.
- Work to improve physical environments and provide reasonable adjustments to support individuals to access services and facilities within their communities.
- Work with organisations to understand diversity across services and consider how to improve access and inclusion across all strategy themes.
- Working with Community Sport organisations on autism awareness raising, education programmes and promotion of the benefits of sports for autistic people.
- Learning from training undertaken by the Skipton Town Hall Cultural Hub will be shared across the new North Yorkshire Council's cultural Hub to support neurodiverse people.

















Case Study: Inclusive Libraries

The North Yorkshire Council's Library Service (42 libraries) have been working to become Autism-inclusive:

• Availability of autism resources

- 27 books about autism has been added to the collection, including novels and memoirs focusing on autistic characters which aim to raise awareness. The books are available in 12 libraries across the county and can be reserved through any North Yorkshire branch.
- 6 Stim kits are now available to be booked for individuals and groups across the county. These provide sensory resources which can be used in a relaxing environment to support autistic people of all ages.

Autism-inclusive Libraries

- Skipton became the first library to achieve autism inclusive status in April 2018. They produced a site plan and social story to explain what happens when someone visits the library, helping to reduce the uncertainty Autistic people may feel about visiting. Site plans have now been produced for the majority of libraries and a social story has also been written for Ripon library. Whilst this work was paused due to Covid-19, it is still a key ambition for libraries and is under review.
- Consultation was carried out with autism groups to inform the new design of Scarborough library
- Regular activities and groups are hosted at a number of libraries, e.g. Selby neurodiversity group

Training for staff and volunteers

• Library staff have received training to help them support autistic people. Autism Awareness training is mandatory as part of staff induction, and sessions have also been held with local organisations and the Adult Learning and Skills Service.















Delivering our strategy: cross-cutting themes

From our discussions with partners and our engagement work, we have also identified some themes which are important to consider as we deliver actions across all our priorities. These key areas of focus are:

Working together – everyone has a part to play in the delivery of this strategy. In particular we will continue to ensure that partner organisations work together with autistic children, young people, adults and their families and carers as we refine, deliver and evaluate the actions in this strategy.

Workforce – training and support in relation to autism is important for all parts of North Yorkshire's workforce. This includes autistic people themselves; their employers and colleagues; those providing individual services in the health, care and education sectors; and those who work in North Yorkshire's wider public services and communities.

Data and research – We recognise that in some areas of our work, we need to understand more about the current position in North Yorkshire as well as evidence-based practice in order to ensure that we make the biggest impact through the strategy and can demonstrate the difference we have made. We also need to understand more about autism in some groups of people such as the military community as well as more widely about the various needs of our **neurodiverse** population.

Making best use of our resources – We will work together across organisations to make best use of our collective resources (our people, our finance, our buildings). Efficient use of these resources will avoid duplication, maximise impact at a community level and enable delivery at scale where appropriate.

Delivering our strategy









In developing this strategy, we have built strong working relationships through by the North Yorkshire Autism Group. This partnership will lead the delivery of a public consultation on the draft strategy, the completion of a final strategy in response, the development of more detailed annual delivery plans to take the commitments forward, the monitoring of progress and the measurement of the impact we have had.

We will continue to work with and grow the **wider Autism network** of autistic people, carers, staff, partners and community services who have already contributed to this strategy. The feedback that people give us about their experiences and how involved they are in making the changes will be vital to the delivery of our strategy as well as an important measure of success.

We will also use other strategic partnership groups such as the North Yorkshire Place Board to provide leadership and accountability on key issues. We also recognise the importance of local ownership and delivery in our diverse communities across North Yorkshire, and will use the emerging local community partnership structures to support this.









Glossary

ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is a condition where an individual finds it hard to concentrate, may be over-active and can struggle to manage their behaviour.

Autism Spectrum Disorder

A condition that someone is born with that affects their ability to communicate and interact with the world around them. It is also called autism and covers a wide range of symptoms.

Autistic

Many people who have been diagnosed with autism prefer using the term 'autistic' to describe themselves. They consider autism to be part of their identity, not a condition to be treated.

CAMHS

Children and Adolescence Mental Health Team in patient services.

C(E)TR and CETR

Care (Education) and Treatment Review (Children) and Care and Treatment Review (adults) to support people admitted to mental health hospital or at risk of admission. Undertaken by commissioners to ensure people are only admitted to hospital where necessary and for the minimum amount of time.





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Dynamic Support Register enable systems to identify adults, children and young people with increasing and/ or complex health and care needs who may require extra support, care and treatment in the community as a safe and effective alternative to admission to a mental health hospital.

Glossary

Dyspraxia

DSR

Dyspraxia, also known as developmental co-ordination disorder (DCD), is a common disorder that affects movement and co-ordination.

Education, Health and Care Plan (EHCP)

A legal document for a child or young person up to the age of 25 if they have a disability or special educational needs. It describes the child or young person's particular educational, health and social needs, and sets out the support and extra help they should have to meet those needs.







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MM

Health inequalities

Differences in how healthy different groups of people are, and how easily they are able to get the health care they need. These differences may be affected by things like poverty, housing and education.

Glossary

Learning disability

A term that is used to describe a brain impairment that may make it difficult for someone to communicate, to understand new or complex information, or to learn new skills. Learning disability starts in childhood and has a lasting effect on a person's development. It can affect people mildly or severely.

Neuro-development condition

Neurodevelopmental condition is an umbrella term for conditions and diagnoses such as autism, ADHD, learning disability, dyslexia, dyscalculia and motor disorders.

Neurodivergent

Neurodivergent is a nonmedical term that describes people whose brains develop or work differently for some reason. This means the person has different strengths and struggles from people whose brains develop or work more typically.

Neurodiverse

Variations between individual people in the way their brains and minds work.



Page of

Office of Police, Fire and Crime Commissioner

The Police, Fire and Crime Commissioner is responsible for overseeing how crime and community safety are tackled, and for providing services for victims of crime.

Glossary

Spectrum condition

Any of a group of disorders each having symptoms that occur on a continuum and certain features that are shared along its spectrum but that manifest in markedly different forms and degrees

Special Educational Needs (SEN)

Special educational needs (SEN or SEND) is a term used to describe learning difficulties or disabilities that make it harder for a child to learn compared to children of the same age.

SEN support

Support provided by a nursery, school or college, such as extra help from a teaching assistant or working in a smaller group.

SENCOs

Special educational needs co-ordinators (SENCOs) lead and co-ordinate a school's provision for children and young people with special educational needs and disabilities.

Wider determinants of health

Wider determinants of health are the social, economic and environmental factors that affect our health and well-being



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With thanks to everyone who has contributed their experiences, views and ideas to the development of this strategy, and in particular to the members of the North Yorkshire Autism Group for their leadership of this work:

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- North Yorkshire Council
- His Majesty's Prisons & Probation service
- Community First Yorkshire
- Healthwatch North Yorkshire
- Inclusion North
- Autism diagnostic providers ABL Health, Harrogate District Foundation Trust, The Retreat
- Parent/carer representative, Hazel Griffiths.



North Yorkshire

AUTISM

a North Yorkshire Strategy

North Yorkshire Council, County Hall, Northallerton DL7 8AD Please call <u>0300 131 2131</u> if you want to request a paper strategy or you need the information in a different format or language.

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Autism Strategy 2024-2027 Consultation Plan Summary

Background

The draft North Yorkshire All-age Autism Strategy has been developed across a number of partner agencies working together with autistic people, their carers and families. Building on this work, approval is being sought to run a public consultation from 27th November 2023 to 15th March 2024 (12 weeks plus additional time to account for Christmas period). The consultation will gather views and feedback from autistic people, their carers and families, the general public, practitioners and partners.

Aims

The consultation has a number of key aims covering the following areas:

- Strategy content: To gather feedback on the content of the strategy including whether the content of each key priority areas reflects and responds to the key issues in North Yorkshire and whether any areas are missing
- **Prioritising actions:** To encourage people to give their views on the most important action within each priority area and the order of priority for actions to be delivered in Year 1, 2 and 3 of the strategy
- **Measuring success:** To invite people to give their views on what success looks like for them and how they would like us to measure success against the strategy.
- **Design:** To gather feedback on the layout, design and accessibility of the draft strategy and to encourage people to be involved in a design group to coproduce the strategy design (for example front cover, back cover, artwork and poetry)
- Working together: To understand people's views about what good co-production looks like and to explore and encourage ongoing involvement of individuals with clear, accessible and regular opportunities to work together. To understand how long people have been involved with the autism strategy (throughout the engagement or just for formal consultation) and how people became aware of the consultation, to inform future work.

Stakeholders

Throughout the consultation, we will seek the views of autistic people of all ages (children, young people and adults), their families, friends and carers; as well as autistic people who are carers themselves. Our Equality Impact Assessment findings to date have highlighted that we need to ensure we hear feedback during consultation from people of different ages as well as different genders, given that diagnosis rates vary between these different groups. Similarly as the prevalence of autism nationally varies between different groups, we will aim to reach people from different groups. Inclusion North will be commissioned to support some of the consultation events.

Autistic people and their families are supported by a range of practitioners, services and agencies across localities. These colleagues understand specific local challenges, the day-to-day realities when carrying out their roles, and the practicalities of turning a strategy into reality. We will therefore also seek the views of those who work with autistic people including schools, service providers, health care workers and social workers.

Methodology

The consultation will follow mixed methodology of surveys, in-person local events and online webinars. This will include:

- A virtual launch event with information about the consultation, key messages, links to the strategy and accompanying documents, links to the survey and events schedule.
- A number of local in-person events (World café) taking careful consideration of existing groups, time of year (weather), accessibility of the venue (local / transport connections), location and target audience
- A number of online sessions (World Café) including at different times of day including a weekend session to enable as many people to participate as possible.
- An online survey aimed at autistic people and carers (plain English) also available in other formats (audio, paper, etc as required)
- An online easy read survey to support autistic people with a learning disability (also available in paper as required).
- Online / paper surveys aimed at children and adolescents (one primary age focus, one secondary age focus).
- Attendance at individual sessions of existing groups as appropriate (such as Learning Disability Partnership Board, Disability Forums, Older People Forums/ Groups, Partnership Groups – Equality, Diversity and Inclusion forum, CYPS provider forum etc)
- Discussion at Scrutiny of Health committee

The partnership consultation planning group will continue to review, refine and update the plan during consultation as required, for example to provide further opportunities to reach specific groups, depending on initial response levels.

A full schedule of events will be provided at the launch of the consultation.

Risks

The key risks and mitigations around the consultation are:

Risk	Mitigation
 A number of consultations / engagements are ongoing over similar time periods – potential for confusion or lack of engagement. These include: Autism Strategy Consultation North Yorkshire Housing Strategy (live) (closes 11/12/23) North Yorkshire Housing Options process (live) NY ICB Adult Autism and Engagement assessments process (Do it profiler screening) (due) – launch Oct – Feb 2024. It is anticipated that this exercise will generate significant interest Learning disability and autism housing needs assessment (due) (winter 2024) 	Discussions are ongoing with housing colleagues and ICB colleagues to review consultation plans and join up key sessions (events etc) and communication where possible, including to clarify as much as possible for Autistic people and carers. Any feedback given in one session will be shared with relevant colleagues
The EIA and previous engagement has highlighted potential barriers to reaching individuals with one or more protected characteristics with the consultation, and the importance of their voice. Groups identified include women and girls, LGBTQIA+ communities, autistic people with co-occurring conditions. Consultation window falls over Christmas bank holiday period. Given the consultation will be taking place over the winter season, there is a risk that poor weather may impact on attendance at events	The consultation group have identified key stakeholders and groups that can support with extended reach. Variety of methods to cater for different preferences – surveys/ events, online and in-person, accessing groups that people are already attending. Consultation extended to 16 weeks to allow sufficient opportunity for participation People will be asked to register for events so that they can be contacted with any changes due to adverse weather, eg re- arranging the date and/or moving the session online.



Autism Data Sources October 2023



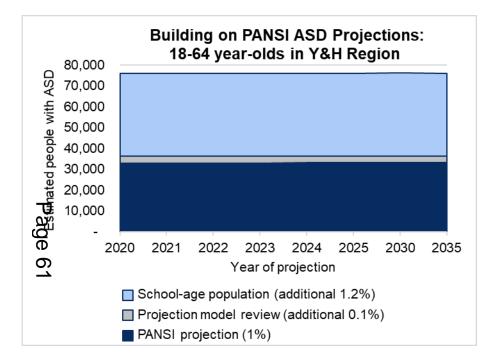
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Autistic Spectrum Disorder (ASD) Population Estimates

There have been a range of population estimates for the autistic population, which use different methodologies, these estimates are summarised below:

- The 2007 Adult Psychiatric Morbidity Survey (APMS) (1.0%) appears to be the key driver for population estimates and sits behind POPPI and PANSI's 1% figure and
- the significant variation across gender 1.8% for men and 0.2% for women. An NHS-IC research project in 2012 extended the APMS to include people w
- An NHS-IC research project in 2012 extended the APMS to include people with
 Bearning disabilities, raising the population rate to 1.1%. The National Autistic Society use this for their estimate of 700,000 people in the UK.
- Annual school census data for 2022/23 indicates 2.4% of pupils nationally have autism identified as a primary need, which falls to 2.3% for YHR with a range at local authority level from 1.0% to 3.7%.
- The Learning Disability Profiles convert this to a rate of 16.0 per 1,000 pupils for autistic children known to schools across the Yorkshire & Humber Region (YHR) in 2020.
- The 2017 update of the periodic report on trends in the Mental Health of Children and Young People in England, indicated that 1.5% of 5-10 year-olds and 1.2% of 11-15 year-olds were identified as having Asperger's or autistic, reflecting the upward trend in younger age groups.

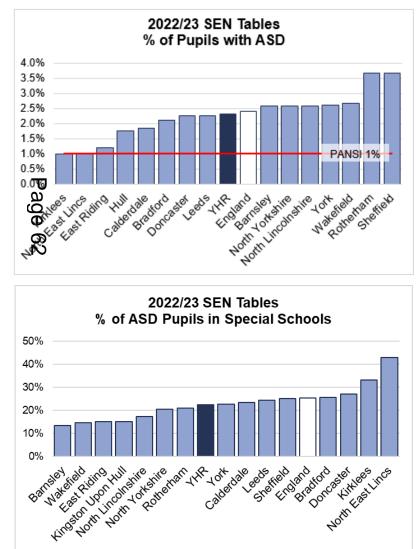
Prevalence Projections



- Projecting Adult Needs and Service Information (PANSI) estimates of the autism population are based on 1% of the ONS population projections. The populations projections indicate a 2% reduction in the age-group across YHR 2020 to 2035.
- Underlying 2007 research extended in 2012 to include people with learning disabilities which indicted a revised prevalence rate of 1.1% (additional 0.1%).
- Annual school census data for 2022/23 indicated a prevalence rate across all age groups of 2.3% for YHR (additional 1.2%).
- The original research included a higher prevalence amongst men 2% compared with women 0.3%. POPPI and PANSI extend that difference to 9:1.
- In the school-based data, the gender split reduces to 3:1, with boys having the higher prevalence.

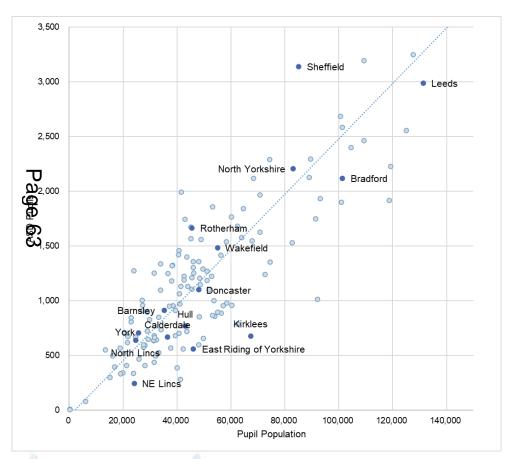
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School-age Prevalence



- Annual school census is taken in January each year.
- SEN tables focus only on primary need. Children may have a secondary need of autism which is not included in the SEN data.
- Yorkshire and Humber Region at 2.3% overall compared with 2.4% for England, substantially higher than the 1% rate used for PANSI population projections.
- Education, Health and Care (EHC) plan levels increase from 1.2% at age 5 to 1.5% by age 12 but then decline to 1.0% by age 17.
- Small step change at secondary school entry for other SEN support – total of autistic pupils at 2.5% at the end of primary, 2.8% in Y7-Y8 before declining to 1.8% by Y13.

School-age Prevalence



As expected, LAs with higher pupil populations tend to have more pupils with ASD. However there is considerable variation between different local authorities, e.g.:

Local Authority	Pupils with ASD	Total Pupils
Kirklees	678	67,374
North Yorkshire	2,206	83,133
Sheffield	3,138	85,194

Further work is needed to understand the reasons for these variations, e.g. possible links to deprivation, or differences in the capacity to diagnose pupils in different areas.

School-age Prevalence

There are variations between boys and girls and level of need nationally. While prevalence among boys remains much higher, possibly due to more successful 'masking' by girls, the gap continues to narrow.

Autistic Spectrum Disorder - Primary SEN Need (2022/23)

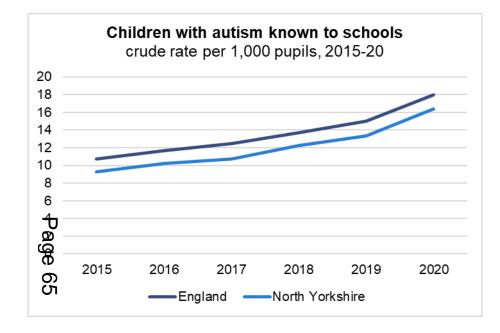
ag	Во	ys	Gi	rls	All Pupils
Pupils on SEN support	63,854	70%	26,924	30%	90,778
Puppils with SEN with statements or EHC plan	91,730	79%	24,251	21%	115,981
Total	155,584	75%	51,175	25%	206,759

ASD Identified as Primary or Secondary Need (2022/23)

	Primary Need	Secondary Need	Total	Primary Need	Secondary Need	Total
Pupils on SEN support	90,779	16,497	107,276	1.0%	0.2%	1.2%
Pupils with SEN with statements		22 577	139,561			
or EHC plan	115,984	23,577	139,301	1.3%	0.3%	1.5%
Total	206,763	40,074	246,837	2.3%	0.4%	2.7%

Source: <u>https://explore-education-statistics.service.gov.uk/</u>

Trends in Autistic Spectrum Disorder Diagnoses



There has been a consistent increase in the proportion of children with autism known to schools. North Yorkshire rates have remained broadly in line with the national average.

Source: Learning Disability Profiles, OHID Fingertips

This is in line with wider diagnosis trends, for example, a study by <u>Russell et al. 2021</u>, showed that between 1998 and 2018 there was a 787% exponential increase in the incidence of autism diagnosis. This increase was largest in adults and in females compared to children and males respectively.

Reasons for increasing rates

Research including a 2021 study published in The Journal of Child Physiology and Psychiatry have found that:

- There has been a strong policy directive to provide earlier recognition and diagnosis.
- Autism symptom thresholds for diagnosis had dropped.
- There is a greater public awareness of autism and increased recognition of it among __some minority ethnic groups.

De-stigmatisation of the label, due to work by the neurodiversity movement and parent-led lobby groups, may have contributed to rising demand for diagnosis in order to access support.

- There have been concerted campaigns to raise awareness of autism among females and adults which may have led to increases in diagnosis in these cohorts.
- Some studies have suggested that an increase in 'autistic burnout', driven by longterm 'masking', may have driven a growth in demand for diagnosis, particularly amongst girls.
- Long waiting times for NHS diagnosis has led some families to seek assessment from private practitioners. Diagnoses made by private services are not routinely fed back to GPs, so the Clinical Practice Research Datalink (CPRD) is likely to underreport autism diagnoses. The actual increase in diagnosis may be even higher than is reported.

Source: The Journal of Child Physiology and Psychiatry and UK Parliament

Carers Survey

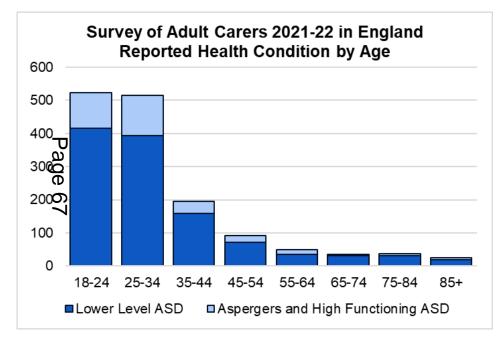


Table 2a of the Carers Survey provides a profile of answers for all questions by demographic group, based on two reported health conditions. It is not available at LA or region levels.

- It indicates 5.4% of cared for people have an ASD condition – 4.2% with lower level ASD and 1.0% with Asperger's or high functioning ASD.
- 'High-functioning' refers to those with autism who can generally function well in society. 'Lower level' refers to those who cannot generally function well in society and may need more support.
- The Carers Survey includes a table that extrapolates these survey figures to the number of carers identified in the Short and Long-Term care report (SALT), which gives 9.7% with lower level ASD and 5.7% with Asperger's or high functioning ASD.

Autism Waiting Times (March 2023)

	-	-	Aged 18
Sub ICB	under 10		and over
NHS Barnsley	0%	16%	11%
NHS Bradford District & Craven	25%	25%	0%
NHS Calderdale	15%	14%	19%
NHS Doncaster	52%	54%	29%
HS East Riding of Yorkshire	0%	5%	0%
MATHE Hull	12%	9%	0%
Kirklees	22%	23%	0%
NXXHS Leeds	22%	21%	43%
NHS North East Lincolnshire	15%	13%	0%
NHS North Lincolnshire	17%	15%	0%
NHS North Yorkshire	9%	11%	0%
NHS Rotherham	10%	11%	31%
NHS Sheffield	31%	40%	32%
NHS Vale of York	21%	22%	0%
NHS Wakefield	0%	0%	22%

- Proportion of patients with an open "suspected autism" referral in the month, that has been open for at least 13 weeks, receiving a first appointment after more than 13 weeks, March 2023.
- Guidance from NICE nobody should wait for more than 13 weeks between being referred and first being seen.
- Data for England has not been released, due to a cyber attack.

Source: Autism Waiting Time Statistics, NHS Digital

Health Outcomes for Autistic People

Autistic people are more likely to have higher rates of physical and mental health conditions and additionally are more likely to receive poorer quality healthcare.

Some of these differences relate to the nature of autism, for example, autistic people may struggle to communicate symptoms. Additionally barriers may also arise from healthcare settings not sufficiently accounting for the needs of autistic patients.

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- Chapter 6 of the government's autism strategy 2021-26 focuses on <u>Tackling Health and Care Inequalities for Autistic People</u>
- Autistic adults have poorer quality healthcare and worse health based
 on self-report data Weir et al. 2022

A public health approach to reducing health inequalities among adults with autism – Sharpe et al. 2019

Physical & primary health inequalities for autistic people:

- Most medical conditions are more prevalent in the autistic population including diabetes, hypertension and obesity. Autistic people experience premature mortality with life expectancy potentially reduced by 16–30 years. In-hospital mortality is also increased. Autistic people are over two times as likely to use A&E departments and to die after attending emergency care and three times as likely to require inpatient admission. (Doherty et al (2022)
- Autistic people were far less likely than non-autistic people to say that they could describe how their symptoms feel in their body, describe how bad their pain feels, explain what their symptoms are, and understand what their healthcare professional means when they discuss their health. Autistic people were also less likely to know what is expected of them when they go to see their healthcare professional, and to feel they are provided with appropriate support. (Weir et al (2022)
- Links between autism and poor health outcomes are well known with up to 30 years shorter life expectancy. GPs have limited training on autism and only a minority feel confident when treating autistic patients. Telephone triage has long been part of primary care delivery and the proportion of consultations offered by telephone increased markedly during the pandemic and continues to play a significant role in the delivery of health care. This can be challenging for autistic patients and affect access to care. Autistic adults report that barriers to primary care lead to poorer health outcomes, identifying predictability, sensory processing, and communication as key domains under which such barriers fall. Johnson, Doherty and Shaw (2022)

Mental health inequalities for autistic people:

Mental health inequalities:

- Almost 8 out of 10 autistic people without a learning disability experience mental health difficulties, more than 3 out of 10 autistic adults have attempted suicide (UK data) Cassidy and Rogers (2017)
- Autism and autistic traits are risk factors for suicidal behaviour this study showed that evidence of autism was significantly higher in those who died by suicide (11.8%)
 than the 1.1% prevalence of autism in the UK and when autistic traits were taken into account this rose to 41%. Cassidy (2022)
- Mental health assessments and interventions developed for the general population often do not meet the unique needs of autistic people; for example, differences in social communication and camouflaging one's autistic traits, in order to "fit in" in social situations. Therefore, interventions need to be adapted in order to meet their needs. Camm-Crosbie et al (2018)
- the % of autistic people with mental health problems is 4 x higher (51%) than people without (11%), more than 25% of autistic people receive two or more diagnoses of mental health problems and around 15% of autistic people (compares to 2.8% of non autistic people) are hospitalised due to a mental health problem. Taylor (2021)

Autism and Mental Health

Whilst autism is not a mental health condition, autistic people are more likely to suffer from poor mental health. There is also evidence that autistic adults have higher rates of suicidal ideation and attempted suicide.

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 $\frac{6}{3}$ Cassidy S, Rodgers J. Understanding and prevention of suicide in autism. Lancet $\stackrel{1}{\sim}$ Psychiatry. 2017 June 4(6)

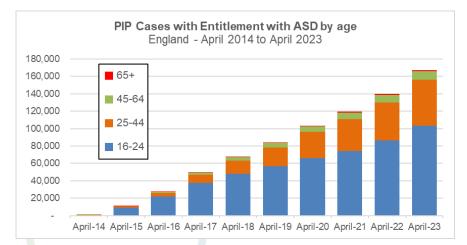
- Mental health problems in autistic people Taylor (2021) MQ Mental Health Research
- Mona Johnson, Mary Doherty, Sebastian CK Shaw Overcoming barriers to autistic health care: towards autism-friendly practices British Journal of General Practice 2022; 72 (719): 255-256.
- Department of Health and Social Care: Suicide prevention strategy for England: 2023 to 2028 (Sept 2023)
- Arnold et al. 2019 Cohort profile: the Australian Longitudinal Study of Adults with Autism (ALSAA)

Benefits Data

- 4.9% of Personal Independence Payments (PIP) recipients nationally had an autistic spectrum disorder recorded as their main condition (October 2022).
- 75% of PIP claimants with an autistic spectrum disorder as their main condition were male.
- The specific disabilities recorded for these claimants were Autism (79%); Asperger syndrome (21%); and Retts disorder (0.3%)

• These figures above include only those for whom an autistic spectrum disorder was precorded as their main condition on their PIP claim. Other PIP claimants may have an mautistic spectrum disorder in addition to their main recorded condition.

Source: Autism: overview of policy and services, House of Commons Library, April 2023



- Between April 2014 and April 2023 the number of PIP cases with entitlement who had ASD increased year on year from 802 to 167,064 nationally.
- In April 2023 cases for those aged 16-24 made up 62% of all cases with ASD whilst those aged 45-64 made up a further 32%.

Source: PIP data: Stat-Xplore

Rates across minority groups

Findings from University of Newcastle research published in March 2021:

- 1.76% of children in the UK were on the autistic spectrum.
- Black and Chinese pupils were 26% and 38% more likely to be autistic respectively.
- Prevalence was highest in pupils of black ethnicity (2.1%) and lowest in Roma/Irish
 Travellers (0.85%).

Pupils with a record of autism in schools were 60% more likely to also be socially disadvantaged, and 36% less likely to speak English than pupils overall.

- 18.1% of pupils with a diagnosis of autism also had learning difficulties.
- Boys showed a prevalence of autism of 2.8% and girls showed a prevalence of 0.65%, with a boy-to-girl ratio of 4.3:1.

Source: University of Newcastle



Limitations of data sources

There are wide variations between the data sources on autism. This makes it difficult to accurately estimate the size and characteristics of the population within the community that have autism. However, a common factor across most data sources is increasing prevalence over time. This reflects improved recognition and diagnosis, particularly among children

Long waiting times for assessments are thought to contribute to continued underdiagnosis, including for those in younger age groups. This means that levels of autism may still be underreported. Together with low levels of historic diagnosis, particularly for females and minority groups, this suggests that the actual number of people living with autism is likely to be far higher than is reflected in the data.

Conclusions

- Key projection tools have not kept up with improving data sets that better reflect wholepopulation prevalence and established trends amongst young people. Consider the wider range of data that is readily available for needs assessment and strategy development work.
- Data from schools census show rates of autism are higher in boy compared to girls (ratio of 4.3 to 1) and are highest in people of black and Chinese ethnicity.
- Rates of autism diagnosis are increasing, especially in adults and in women and girls.
- Chool data shows substantial variation in the proportion of pupils with ASD by local authority.
- Wait times show that across the Y&H an average of 16% of people with a suspected autism referral wait more than 13 weeks for their first appointment
- Data on prevalence in the adult population is limited and where it is collected it is not made available in useful formats. Discussions have begun with NHS Digital around this point. Consider identifying key data items for NHS Digital to make available at local authority and/or regional levels.
- Consider sharing data items held by individual authorities to extend this summary analysis

 e.g. Survey of Adult Carers in England (SACE) reported health conditions, which could
 also be shared in future, each time the survey is submitted.



Equality impact assessment (EIA) form: evidencing paying due regard to protected characteristics

(form updated June 2023)

North Yorkshire joint all age Autism Strategy

If you would like this information in another language or format such as Braille, large print or audio, please contact the Communications Unit on 01609 53 2013 or email <u>communications@northyorks.gov.uk</u>.

Equality Impact Assessments (EIAs) are public documents. EIAs accompanying reports going to County Councillors for decisions are published with the committee papers on our website and are available in hard copy at the relevant meeting. To help people find completed EIAs, we also publish them in our website's Equality and Diversity section. This will help people to see for themselves how we have paid due regard in order to meet statutory requirements.

Name of Directorate and Service Area	Health and Adult Services (lead), Children & Young People's Services [note this is a partnership strategy] Impacts a range of service areas including Public Health, Adult Social Care, Prevention & Service Development, Inclusion, Wider Council services and departments
Lead Officer and contact details	Louise Wallace, Director for Public Health (<u>louise.wallace@northyorks.gov.uk</u>) and Abigail Barron, Assistant Director for Prevention and Service Development (<u>abigail.barron@northyorks.gov.uk</u>)
Names and roles of other people involved in carrying out the EIA	Stacey Annandale, Strategic Service Development Manager (NYC) Naomi Smith, Head of HAS Population Planning (NYC) Members of the Autism Steering Group which includes senior representatives from



How will you pay due regard? for example, working group, individual officer	 Humber & North Yorkshire Integrated Care Board (North Yorkshire Place) West Yorkshire Integrated Care Board (Bradford District and Craven Place) Tees, Esk & Wear Valley (TEWV) NHS Foundation Trust North Yorkshire Council HMP Prisons & Probation service Community First Yorkshire Healthwatch North Yorkshire Parent/carer representative Through the Autism Steering Group
When did the due regard process start?	During the review of the current Autism Strategy which began in winter 2022.

Section 1: What are you proposing to do?

The co- development, publication, and implementation of a new all age strategy for meeting the needs of all people with autism in North Yorkshire 2024-2027.

The strategy is being developed and overseen by lead officers for autism across the following agencies

- Humber & North Yorkshire Integrated Care Board (North Yorkshire Place)
- West Yorkshire Integrated Care Board (Bradford District and Craven Place)
- Tees, Esk & Wear Valley (TEWV) NHS Foundation Trust
- North Yorkshire Council (Health & Adult Services and Children & Young People's Services)
- HMP Prisons & Probation service
- Community First Yorkshire
- Healthwatch North Yorkshire
- Parent/carer representative

Co-production is being undertaken throughout the strategy with autistic people, carers, and families, as well as practitioners supporting them through a range of events from April through to September 2023 (further details below). This has created an autism 'network' of interested parties who are keen to continue to be involved with the development of the strategy. There will be a public consultation during end of November 2023 through to March 2024 which will provide the opportunity for people to comment and feedback about the strategy. Following the consultation period, the strategy will be

amended and strengthened as necessary to reflect the input of respondents. The final strategy will be adopted and published in Summer 2024.

The data and research referenced in this EIA can be found in more detail along with source information in the accompanying data pack. This is a draft EIA that will be shared for comment as part of the public consultation and updated before the strategy is finalised and adopted to reflect the views provided during consultation. It will also be reviewed during strategy implementation.

Section 2. Why is this being proposed? What are the aims? What does the authority hope to achieve by it? (For example, to save money, meet increased demand, do things in a better way.)

Producing a local autism strategy was a requirement from the national strategy "Fulfilling and Rewarding Lives" which stemmed from the Autism Act 2009, the first single-disability statue in the UK. The requirement was reiterated in the refresh of the national strategy 'Think Autism' which was published in April 2014 and its statutory guidance document 'Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy', published March 2015. In 2021, the government launched a new national strategy, 'the national strategy for autistic children, young people and adults 2021 -2026 and associated action plan 2021/2022. The new autism strategy for North Yorkshire has been developed as a local response to the national strategy as well as in order to build on the work of previous local strategies.

The vision set out within the draft North Yorkshire all-age autism strategy is that "Autistic children, young people and adults and their families in North Yorkshire enjoy full, happy, and healthy lives". There are several draft priorities with actions which aim to improve the lives of autistic people across a various areas including education, employment, housing, criminal justice, health and supporting carers. This work will be enabled by a focus on working together, workforce, data & research and making best use of our resources.

This strategy sets out plans to improve information, support, guidance, and services available for autistic people of all ages in North Yorkshire across a wide range of partners and organisations as well as communities. These actions have been developed to work towards the vision for each of our priority areas, as follows:			
Priority Area	Vision		
Education &	Autistic children and young people thriving at school and into		
Preparing for	adulthood		

Section 3. What will change? What will be different for customers and/or staff?

Preparing for Adulthood	adulthood
Employment	Autistic people thriving at work
Housing	To support autistic young people and adults with appropriate housing

Carers	Parents, carers, and families of autistic people are supported to
	thrive
Assessment,	Everyone can access the support they need when they need it.
diagnosis, and	Access to assessment and diagnosis happens as early as
support	possible in a person's life, with priority for those with the greatest
	need
Health and care	Autistic people of all ages live healthier and longer lives,
	supported by autism-friendly health and care services
Criminal and Youth	Supporting autistic children, young people, and adults to be well
Justice	supported when accessing the criminal and youth justice systems
Inclusive	North Yorkshire is an inclusive place to live, work and visit
communities	
	·

Following the completion of a final strategy in response to feedback from the public consultation, more detailed annual delivery plans will be developed to take the commitments within the strategy forward.

Section 4. Involvement and consultation (What involvement and consultation has been done regarding the proposal and what are the results? What consultation will be needed and how will it be done?)

The strategy has been co-produced, designed and developed by autistic people and carers and practitioners supporting individuals. This has been achieved through the partnership of the Autism Steering group and the development of an 'Autism network' created thought several engagement sessions.

The steering group journey commence in 2022, with the establishment of the network from April 2023. Engagement sessions were undertaken in April 2023 with a mix of in person and virtual events taking place across each of North Yorkshire's main market towns. 104 people attend the events in April with 72 autistic people / carers. Supporting these sessions was also a robust questionnaire that was completed by 170 people with almost 6000 individual responses, with around 74% being an autistic person (126 people) or on behalf of an autistic person and 26% being a family/ parent carer. 82% of individuals were between the ages of 16 and 64 (with 22% of these between 16 years and 34 years and almost 60% between 34 and 64 years). The remaining 12% were over 65 and 6% preferred not to say. The respondents were located across all the 7 districts of North Yorkshire with approximately, 9% in Craven, 14% in Hambleton, 26% in Harrogate, 10% in Richmondshire, 5% Ryedale, 18% Scarborough, 15% in Selby and 3% other. Approximately, 77% of people responding identify as female, 17% identify as male, 5% prefer not to say and just under 1% describes myself in another way (92% answered that their gender was the same as assigned at birth, 7% preferred not to say and 1% answered no). 95% of people answered their ethnic group as white, almost 1% answered mixed / multiple ethnic groups, almost 3% preferred not to answer, almost 2% answered other. Almost 70% of people answered that they were heterosexual/ straight, almost 3% answered gay/lesbian, almost 10% answered bi-sexual, 3% other sexual orientation and

14% preferred not to say. Around 52% of people considered themselves not to be disabled and around 42% considering themselves to be disabled and 6% preferring not to answer. The survey captured several key themes but in particular we heard that there is a lack of understanding around autism, especially around presentation in women and girls with comments such as 'you don't look autistic' and 'autism in women is chronically underdiagnosed or ignored in women'.

A further 7 events were held in July for practitioners with around 104 people in attendance and additional attendance at community groups. A mix of in person and virtual events. Following this a further 7 events, specifically around action planning have been undertaken in September 2023 with around 77 people in attendance, with around 11 neurodiverse individuals or carers in attendance (noting that some people also attended multiple workshops). Feedback from this extensive engagement has been used to develop the first draft of the strategy ready for consultation.

Consultation planning is in progress for a 3-month consultation due to be undertaken from the end of November 2023 through to the end of March 2024. It is anticipated that this consultation will have a mixed methodology of virtual and in person events and surveys. A full consultation plan will be available.

Our EIA findings to date (see below) have highlighted that we need to ensure we hear feedback during consultation from people of different ages as well as different genders, given that diagnosis rates vary between these different groups. Similarly, as the prevalence of autism nationally varies between different ethnic groups, we will aim to reach people from a range of groups. We will aim to reach the armed forces community. The prevalence of autism is higher amongst transgender people and people identifying as LQBTQIA+. We will aim to reach as many people as possible as part of this consultation.

Section 5. What impact will this proposal have on council budgets? Will it be cost neutral, have increased cost or reduce costs?

Cost neutral? Yes. Increased cost? No Reduced cost? No

Within North Yorkshire Council there is no specific budget ring-fenced for autism, but rather, a range of services and budgets which are used to meet the needs of autistic people. There are no plans for the Council to derive savings specifically as a result of the autism strategy, and any incidental savings may be re-invested. There is no new funding for work on autism and any expenditure must be resourced from existing budgets. Through our work on the strategy, we will work towards improving value for money of Council services and making best use of resources by joining up across agencies. More widely, the strategy will have a positive economic impact through the priority focus on supporting autistic people to gain and/or maintain employment. A number of proposed Page 81



actions within the strategy are preventative in nature, which supports best value for money across public sector organisations.

Section 6. How will this proposal affect people with protected characteristics?	No impact	Make things better	Make things worse	Why will it have this effect? Provide evidence from engagement, consultation and/or service user data or demographic information etc.
Age		X		Diagnosis rates are highest among children and younger people. School-based data, shows that the ratio of boys to girls with a diagnosis is around 3:1 while the Projecting Older People Population Information (POPPI) and Projecting Adult Needs and Service Information (PANSI) models use a ratio of 9:1 male to females. These models project population trends in adults (18 – 65 PANSI and 65+ POPPI). Therefore, showing that there are different age and gender ratios across diagnosis.
				Between April 2014 and April 2023, the number of PIP cases with entitlement who had autism increased year on year from 802 to 167,064 nationally. Cases for those aged 16-24 made up 62% of all cases with autism in April 2023 while those aged 45-64 made up a further 32%.
				Evidence suggests that autism may have a hereditary component. We have heard examples of children or young people being diagnosed with autism and then parent carers later also being diagnosed or self- identifying as autistic.
				Most of the local provision is focused on children and young people, as evidenced through a recent quote from engagement: "lots of people believe that autistic children become normal adults, so don't need support after adulthood".
			Page	The strategy seeks to improve support and information available for adults. However, the strategy will also improve access and 82

		 provision for children with autism. It should be noted that Covid has had a detrimental effect on access to services due to close downs and therefore the strategy aims to improve access around services. We recognise that some chapters maybe more relevant to particular age groups e.g., education, employment, housing, and age-appropriate services, but anticipate overall benefit throughout the changes being proposed.
Disability	X	Autism is a recognised disability. University of Newcastle research published in 2021 found that 18.1% of pupils with a diagnosis of autism also had learning difficulties. There are links between Autism and ADHD, dyslexia and dyspraxia, insomnia, anxiety, depression, obsessive compulsive disorder, learning disability, epilepsy, joint issues such as joint hypermobility syndrome / Ehlers – Danlos syndromes (NHS). The strategy aims to improve the experience of accessing information, guidance, and support for people with autism, and reduce barriers to access. The strategy also recognises that people may have autism and another condition which may increase the challenge for accessing services and increase the likelihood of poor health outcomes based on data/evidence. As we deliver our autism strategy, the challenges faced by autistic people with one or more additional conditions will also be considered.
Sex	P	We recognise that autism is often under- diagnosed in women and girls. School- based data, shows that the ratio of boys to girls with a diagnosis is around 3:1 while the POPPI and PANSI models (to project adult population trends) use a ratio of 9:1 male to females. Local engagement information highlights some of the challenges women and girls face around people's understanding of the Tage 83

		 way autism presents differently in girls; 'you don't look autistic, there is a lack of understanding as I'm female'. We will monitor the number of girls/women being diagnosed to identify whether numbers of girls and women diagnosed with autism are changing over time. The strategy aims to improve pre and post diagnosis support for all based on a needs led approach. The strategy will explore the use of resources to reduce waiting times for assessment focussed on those with greatest need. The strategy will also work to improve equity of access and consistency of assessment.
Race	Х	There is limited evidence available about
Gender	X	the prevalence within these groups locally.
reassignment	X	However national figures from the
Sexual orientation	X	University of Newcastle published in March 2021 showed that black and Chinese pupils
Religion or belief	X	were 26% and 38% more likely to be
Pregnancy or	X	autistic respectively. Prevalence was found
maternity		to be highest amongst pupils of black
Marriage or civil partnership	X	ethnicity (2.1%) and lowest in Roma/Irish Travellers (0.85%). It is anticipated that with target communication and appropriate support, the strategy should have a positive effect in reducing stigma and improving awareness across these groups. We know that gender identity and sexuality
		are more varied amongst autistic people than in the general population. Autism is more common amongst people who do not identify as their assigned sex at birth, a 2022 study stated that it was three to six times as common.
		National research also shows that autistic girls and women are more likely to identify as LGBTQIA+ and the prevalence of autism is higher amongst transgender people, which can result in discrimination when accessing care, cultural stigmas, violence and poor mental health outcomes and higher rates of suicidality.
	─── [⊥] ── [⊥] ₽	age 84

	During local engagement in North Yorkshire, people told us they "don't feel like people understand how autism presents differently in everyone. Especially how autistic people can mask, which is very common in women, trans/ nonbinary and ethnic minorities."
	There has been some research undertaken by Sarah Hampton, Carrie Allison, Ezra Aydin and Simon Baron-Cohen, and Rosemary Holt from University of Cambridge in Feb 2022 that suggest that autistic women and other pregnant autistic people might be at a higher risk of perinatal mental health conditions given that autism and mental health conditions commonly co- occur, and that autistic people face additional stressors such as barriers to appropriate maternity care. The study explored self-reported stress, depression, and anxiety during the third trimester of pregnancy and self-reported parenting confidence and parenting styles explored at 6 months after birth. Autistic participants scored significantly higher than non-autistic participants on stress, depression, and anxiety across the time points although there were no group differences for satisfaction with life. Anxiety scored significantly decreased over time for both groups. No group differences were found for parenting confidence nor parenting anxiety, nurturance involvement or routine, although the autistic group scored lower on parenting discipline.
	We know that more work needs to be done to understand each group and it will be included within the strategy delivery plans.

Section 7. How will this proposal	No impact	Make things better	Make things worse	Why will it have this effect? Provide evidence from engagement, consultation and/or service user data or demographic information etc.
Page 85				

affect people who		
.live in a rural area?	X	 North Yorkshire is the largest non-metropolitan counties in England, covering an area of 3,342 sq. miles with around 40% of the county covered by a national park (including Yorkshire Dales and North York Moors. North Yorkshire comprises of 7 district areas: Hambleton, Richmondshire, Harrogate, Craven, Scarborough, and Ryedale. Due to the size and geography of North Yorkshire, some provisions are concentrated around the populous towns and villages. One of the aims of the strategy is to provide improved services and support/advice to all parts of North Yorkshire, regardless of
have a low income?	X	rurality. One of the strategy's priorities is to support more autistic people to gain and sustain paid employment. Autistic adults are significantly under-represented in the labour market, with only 21.7% of autistic people in employment, the lowest rate of any disabled group. This means that many are dependent on benefits, and the under representation also indicates that employers are not benefitting from the skills and talents which autistic people can offer in the workplace. The commitments contained in the all-age strategy aim to make things better for autistic people who wish to gain employment, need support to continue working and/or wish to progress in their careers.
are carers (unpaid family or friend)?	X	Carers have been actively involved in the steering group and autism network to help develop the strategy. There is a key priority on support for carers with information, advice, and guidance, as well as practical support.
are from the Armed Forces Community	X	It is recognised that Looked After Children, children from military families and those from travelling communities may be less likely to be referred for a diagnosis of autism. There may be a reluctance to

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engage with services either because of a lack of trust or a lack of knowledge of services available. The transient nature of these people's lives may mean that they are not settled in one place long enough to complete necessary assessments to receive a diagnosis. A key issue for armed forces families is around moves resulting in children/family members moving down the waiting list.
Robust data to evidence these statements is lacking, both nationally and locally. We will have a focus on improving data and research through our strategy which will include consideration of how we can learn more about autism within these groups.

Section 8. Geographic impact – Please detail where the impact will be (please tick						
all that apply)						
North Yorkshire	X					
wide						
Craven district						
Hambleton district						
Harrogate district						
Richmondshire						
district						
Ryedale district						
Scarborough						
district						
Selby district						
If you have ticked one or more districts, will specific town(s)/village(s) be						
particularly impacted? If so, please specify below.						
All districts within North Yorkshire should see a positive impact from the strategy as it						
aims to look at key improvement areas, whilst also considering consistency across						
geographical areas. We understand that there are differences in pathways and						
services across North Yorkshire in part due to the different systems and organisations						
which operate in different areas, however the partnership and strategy aims to help to						
improve consistency where possible.						

Section 9. Will the proposal affect anyone more because of a combination of protected characteristics? (For example, older women or young gay men) State what you think the effect may be and why, providing evidence from engagement, consultation and/or service user data or demographic information etc.

Autism is classified as a disability and therefore some autistic people will have a combination of protected characteristics, e.g., that they are a female and autistic.

It is envisaged that the commitments in the strategy will affect autistic people in a positive way, so we do not anticipate a detrimental impact because of a combination of protected characteristics. We recognise that this will need to be monitored as the strategy is implemented.

We will develop nuanced approaches for people who have two or more protected characteristics where this may impact of their diagnosis and experience as autistic people, for example the lower diagnosis rate for girls and women.

It is anticipated that the strategy will have a positive impact on all autistic people including those with the protected characteristics of age, disability, sex, race, gender reassignment, sexual orientation, religion/ belief, pregnancy, marriage/civil partnership, and those from the armed forces community. We also believe the strategy will have a positive impact across

North Yorkshire, regardless of rurality, however we recognise that there are differences in pathways and services across North Yorkshire due to the different systems and organisations which operate in different areas. The partnership and strategy aim to help to improve consistency where possible. Given the specific focus on employment and carers within the strategy priorities, we anticipate that there will be a particularly positive impact for those people who have a low income or are carers.

Section 11. If the proposal is to be implemented, how will you find out how it is really affecting people? (How will you monitor and review the changes?)

The wider autism network comprises of autistic adults, carers/parents and practitioners supporting autistic people who have contributed to the development of the strategy. We will continue work together to deliver on our priorities. The feedback that people give us about their experiences and how involved they are in making the changes will be vital to the delivery of our strategy as well as an important measure of success and impact. The implementation of the strategy will be monitored via the Autism Strategy Steering group to ensure that people with protected characteristics are not adversely affected and opportunities to enhance quality of experience and outcome are identified. Other strategic partnership groups such as the North Yorkshire Place Board will be used to provide leadership and accountability on key issues where required.

Section 12. Action plan. List any actions you need to take which have been identified in this EIA, including post implementation review to find out how the outcomes have been achieved in practice and what impacts there have actually been on people with protected characteristics.

Action	Lead	By when	Progress	Monitoring	
				arrangements	
As part of the		Winter 2023	Initial	The initial data	
strategy	Health		information has	pack will be	
development,	Intelligence		been collated,	shared as part	
an initial data	Team		however, there	of public	
pack has been			are limited,	consultation,	
prepared. This			accurate data	with further data	
data pack will be			sources around	to be added as it	
updated			autism	becomes	
throughout the			statistics.	available.	
development of					
this strategy.			Actions for the		
			strategy will be		
We have made			to consider how		
a commitment			to expand		
to improve our			access and		
data access and			development of		
to consider how			data sources to		

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this information into the line of the line	nava data	
	prove data	
	ality.	
further JSNA's.		
5 1		Steering group
	5	will monitor the
5 1	,	consultation
		planning and
consultation to of		whilst
5		engagement is
		ongoing and
		evaluation of
	5	consultation.
	otect aracteristic	
e.g.,	oups.	
women/girls,		
different ages,		
those who are		
gender diverse,		
those from the		
armed forces		
community and		
those from		
different ethnic		
groups		
Review Steering Group Easter 2024 Cor	onsultation	Steering Group
feedback from plan	anning	and approval
	Iderway	routes
and refine EIA		
	onsultation to	
response. take		
	etween	
	7/11/23 and	
5	/03/23 using	
engagement, mix		
	ethodologies:	
	tual launch	
	ent, 7 in erson events	
	id 3 online	
3 • • • • • • • • • • • •	ssions.	
	bread across	
	orning,	
	ternoon, early	
	ening, and a	
	ekend	
•	ssion.	

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consultation				Surveys – plain	
plan that there				English, easy	
are groups we				read version	
wish to				and 2 YP	
specifically				versions	
reach. We have				(primary/	
started to pull				secondary age)	
together a wider				, , ,	
stakeholder list,					
learning from					
previous					
experiences					
and are looking					
to how we can					
improve our					
approach to					
ensure we					
reach:					
Women, girls,					
LGBTQIA+					
communities,					
older autistic					
people, carers					
and younger					
adults and					
children's voice					
(as far as					
possible) and					
autistic people					
with co-					
occurring					
conditions.					
Continue to	Steering Group	Summer	2024		Steering Group
seek feedback		onwards			
and monitor					
impact on					
protected					
characteristics					
throughout					
annual action					
planning,					
delivery, and					
review					
	1	1			

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Section 13. Summary Summarise the findings of your EIA, including impacts, recommendation in relation to addressing impacts, including any legal advice, and next steps. This summary should be used as part of the report to the decision maker.

This EIA reflects the due regard considered as part of the development of the North Yorkshire all-age autism strategy which has been led by the partnership Autism Steering Group, with extensive engagement and support from the wider Autism network through a series of workshops, events, and surveys over a 6-month period.

The vision set out within the draft North Yorkshire all-age autism strategy is that "Autistic children, young people and adults and their families in North Yorkshire enjoy full, happy, and healthy lives". There are several draft priorities with actions which aim to improve the lives of autistic people across various areas including education, employment, housing, criminal justice, health and supporting carers. This work will be enabled by a focus on working together, workforce, data & research and making best use of our resources.

It is anticipated that the strategy with have a positive impact on all autistic people including those with the protected characteristic of age, disability, sex, race, gender reassignment, sexual orientation, religion/ belief, pregnancy, marriage/civil partnership, and those from the armed forces community. We also believe the strategy will have a positive impact across North Yorkshire, regardless of rurality, however we recognise that there are differences in pathways and services across North Yorkshire due to the different systems and organisations which operate in different areas. The partnership and strategy aims to help to improve consistency where possible. Given the specific focus on employment and carers within the strategy priorities, we anticipate that there will be a particularly positive impact for those people who have a low income or are carers.

We recognise that local data about autistic people in terms of protected characteristics is limited and therefore further development of data is required to understand and monitor the impact as the strategy is refined and delivered more fully.

Our EIA findings to date have highlighted that we need to ensure we hear feedback during consultation from people of different ages as well as different genders, given that diagnosis rates vary between these different groups. Similarly, as the prevalence of autism nationally varies between different ethnic groups, we will aim to reach people from a range of groups. We will aim to reach the armed forces community. The prevalence of autism is higher amongst transgender people and people identifying as LQBTQIA+. We will aim to reach as many people as possible as part of this consultation.

Section 14. Sign off section

This full EIA was completed by:

Name: Stacey Annandale Job title: Strategic Service Development Manager Page 92



Directorate: Health and Adult Services

Name: Naomi Smith Job title: Head of Population Planning Directorate: Health and Adult Services

Name: Leo Beacroft Job Title: Senior PH Specialist Directorate: Strategy and Performance

Name: Shanna Carrell (quality assurance / review) Job title: Equalities Manager Directorate: Health and Adult Services

Signature:

Completion date: 29/09/23, updated 11/10/23, 17/10/23

Authorised by relevant Assistant Director (signature): authorised via Health and Adult Services Leadership Team review and approval including Abi Barron: Assistant Director, Prevention & Service Development; and Louise Wallace: Director of Public Health

Date: 19/10/23

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Agenda Item 5

North Yorkshire Council

Health and Adult Services

Executive Member Meeting

3 November 2023

REPORT TO Director of Public Health in consultation with the Corporate Director and Executive Member for Health and Adult Services

Infection Prevention and Control (IPC) Service

This report includes a supporting Annex which contains exempt information as described in paragraph 3 of Part 1 of Schedule 12A to the Local Government Act 1972 (as amended).

1.0 Purpose Of Report

To seek approval for the development of a new contract and legal framework for the community Infection Prevention and Control (IPC) Service.

2.0 Background

The current community Infection Prevention and Control (IPC) service has been operational in North Yorkshire and York for over a decade. Since the responsibility for Public Health under the Director of Public Health moved from the NHS to local authorities, North Yorkshire Council (NYC), City of York Council (CoY), North Yorkshire and West Yorkshire ICBs (previously North Yorkshire, Vale of York, and Airedale Wharfedale Craven CCGs) have commissioned Harrogate District Foundation Trust (HDFT) to deliver the community IPC service, along with the community TB service. Prior to the COVID-19 pandemic, the commissioners began a review of the service specifications for the IPC and TB contracts; however, due to the pandemic the updated specifications were never ratified.

Partners have recently regrouped to proceed with a review of the IPC service in particular, in light of the lessons learned around local IPC needs from the pandemic. NYC has held joint discussions with the other service commissioners (CYC, HNY and WY ICBs) and agreed to undertake an options appraisal for the future commissioning of the services. The full options appraisal is included in the exempt section of this report.

Current provision

The North Yorkshire and York Community Infection Prevention and Control (NYY CIPC) service is hosted by, and is an integral part of, the Harrogate and District NHS Foundation Trust (HDFT) Infection Prevention and Control Service.

The NYY CIPC service provides advisory, responsive, investigative and educational Infection Prevention and Control (IPC) support for North Yorkshire and York (NYY) providers of health and social care in the community. This is achieved through collaboration and a structured proactive programme to actively promote strategies to raise awareness of infection prevention and control based on national requirements, best practice and local need. Where necessary the service provides a responsive service to any peaks in activity as a result of local outbreaks of infection. The NYY CIPC Service contributes to a continuous reduction in the burden of infectious disease, including healthcare associated infection (HCAI), in all NYY Community Health and Social Care settings.

With regards to assurance, the service provides quarterly and annual reports covering surveillance, incidence and trends, Root Cause Analyses (RCAs), services (including target IPC visits, audits and training) and progress against the CIPC Annual Plan.

3.0 Issues

The contract and the service specification under which the service operates needs reviewing and updating.

The current service is predominantly focused on adult care homes; the pandemic has highlighted the need for IPC support to a wider range of settings including special schools, contingency accommodation settings, public health commissioned services and others. More flexibility is needed to manage urgent issues outside the standard remit of the service and to increase the focus on prevention.

4.0 Alternative Options considered

The alternative to proceeding with the development of a new contract and legal framework for the community Infection Prevention and Control (IPC) Service would be to carry on without change to existing arrangements, or doing a light-touch review of the service specification. However, neither of these options would be sufficient to address all the issues identified above.

5.0 Financial Implications

No additional financial costs to develop a new contract and legal framework for the community Infection Prevention and Control (IPC) Service have been identified at this stage.

6.0 Legal Implications

Legal colleagues have already been engaged in early work identifying the need for review and discussion of potential options for legal frameworks for the IPC service. There will be some continued commitment required from legal, although the amount of input will depend on the legal framework chosen.

7.0 Contribution to Council priorities

This work is likely to contribute towards the following priorities:

People can access good public health services and social care across our different communities

- To support and develop care providers, improving sustainability and quality.
- To work with a range of organisations from the health, independent and voluntary sectors to develop a sustainable, diverse and innovative care market that meets the varied needs of the people of North Yorkshire and ensures quality and dignity for all.
- To work with the NHS to develop integrated models of commissioning and service delivery in each area of North Yorkshire to ensure that the people of North Yorkshire have a cost efficient, effective and joined up health and social care provision.

8.0 Risk Management Implications

There is a risk that by not undertaking a review of the current IPC service delivery the system will be inadequately prepared for future pandemics or other issues or outbreaks requiring a robust community IPC response.

9.0 Human Resources Implications

Additional staff time will be required to support the contract review. Project management support has been agreed along with public health capacity.

10.0 Equalities Implications

An equalities impact assessment will be undertaken as part of the development of the new contract and legal framework.

11.0 Climate change implications

A climate impact assessment will be undertaken as part of the development of the new contract and legal framework.

12.0 Reasons for recommendation

• Commissioning partners are universally supportive of the need to undertake the development work for a new IPC contract and legal framework due to the issues outlined above and the lessons learned from the pandemic around community IPC requirements in North Yorkshire and ensure resilience for to deal with future health protection issues.

13.0 Recommendation

• Approval to proceed with development of a new contract and legal framework for the community Infection Prevention and Control (IPC) Service

Name and title of report author

Dr Victoria Turner, Public Health Consultant

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By virtue of paragraph(s) 3 of Part 1 of Schedule 12A of the Local Government Act 1972.

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Agenda Item 6

North Yorkshire Council Health and Adult Services

Executive Member Meeting

3 November 2023

REPORT TO Director of Public Health in consultation with the Corporate Director and Executive Member for Health and Adult Services

PROPOSED EXTENSION OF CONTRACTS FOR SPECIALIST DRUG AND ALCOHOL SERVICES FOR YOUNG PEOPLE AND FOR ADULTS

This report includes a supporting Annex which contains exempt information as described in paragraph 3 of Part 1 of Schedule 12A to the Local Government Act 1972 (as amended).

1.0 Purpose Of Report: To approve the extension of contracts for the provision of North Yorkshire Horizons (specialist adult drug and alcohol service) and North Yorkshire RISE (specialist young people's drug and alcohol service) to 30 September 2025.

2.0 Executive Summary

The North Yorkshire Horizons (specialist adult drug and alcohol service) and North Yorkshire RISE (specialist young people's drug and alcohol service) contracts are due to expire on 31 March 2024 and 30 September 2024 respectively.

The North Yorkshire Horizons contract currently includes an extension facility of +3 years, +2 years – up to 30 September 2029.

The North Yorkshire RISE contract currently includes an extension facility of +2 years, +2 years – up to 30 March 2027.

The <u>independent review of drugs led by Dame Carol Black</u> (2021) reinforced that investment in drug and alcohol services has reduced significantly over the last decade nationally. In response, central government has placed increased priority on drug and alcohol services, implementing significant additional (Universal and <u>SSMTRG Section 31 grant</u>) investment over the period 2021-2025.

North Yorkshire has so far received, invested and benefited from over £1.4 million, and is due to receive at least £1 million additional funding in 2024/25. A condition of the grant monies, paid to local authorities, is that investment in drug and alcohol treatment from the public health grant is maintained in line with the outturn reported to DLUHC in 2020/21.

A number of local contextual developments mean that there is a unique opportunity to review the services that directly support and contribute support to people who experience harmful patterns of substance use. These include:

- Unmet need and increasing profile of a cohort of people who experience substance use and multiple disadvantage;
- Drug and alcohol services are more expensive to deliver than they were in 2019 and 2021, when current arrangements were procured – driven by economic factors including cost of living rises and inflation;
- The COVID-19 pandemic has changed the ways in which drug and alcohol services are delivered;

- The creation of North Yorkshire Council a unitary authority which provides new opportunities to strengthen the overall council and community contribution to substance use, including support for people who experience harmful patterns of substance use. Alongside Public Health, there is a unique contribution for economic development, housing, stronger communities/localities, community safety, adult social care services including mental health services, and children's services.
- A range of partnership strategies are currently in draft, subject to engagement and/ or consultation – including the Substance Use Strategy and the Housing Strategy. These provide an opportunity to reflect the current and future needs of people across North Yorkshire;
- North Yorkshire Connected Spaces a recently formed lived and living experience group– are highlighting strengths within existing support services, as well as opportunities for development – including the important and vital role of lived experience and recovery organisations (LERO).

The council will therefore embark on a drug and alcohol service transformation programme between 2023 – September 2025, involving directorates across the council, as well as key partners such as the Office for the Police, Fire and Crime Commissioner (OFPCC), Police, Probation and the Integrated Care Boards (ICBs). The council will provide leadership for the development of a system of support for people who experience harmful patterns of substance use, that delivers the ambition set out within the draft partnership Substance Use Strategy:

"Deliver effective support for people who experience harmful patterns of substance use across North Yorkshire – harms are reduced, and people have the best chance of achieving and maintaining their goals"

This is the minimum timeframe that a transformation programme of this nature, value and scale could be delivered within. New commissioning arrangements will be implemented from 1 October 2025. The council will therefore need to establish a variation to existing contracts to extend them to 30 September 2025. Governance will be managed through the Procurement Assurance Board.

3.0 Background

Public Health Grant conditions:

The Council is expected to ensure the provision of local drug and alcohol services as part of its action to promote population health improvement, protect health and reduce health inequalities.

Background – evidence base/ return on investment:

Evidence shows that drug and alcohol (substance use) treatment services are cost effective to the public purse, and clinically effective in terms of outcome for the individual. Investing in substance use services not only helps to save lives, but also substantially reduces the economic and social costs of harms associated with harmful patterns of substance use.

Research has shown that every £1 invested in treatment services results in a £4 social return on investment – a total of £21 over 10 years; and every £1 invested in alcohol treatment results in a £3 social return on investment – a total of £26 over 10 years (Source: <u>Must Know: Treatment and recovery</u> for people with drug or alcohol problems | Local Government Association).

For many who experience harmful patterns of use of substances, engaging in substance use services can be the catalyst for getting the medical and social help they need to address the underlying causes of their use of substances, and current physical, mental health and social symptoms.

Engagement with treatment services reduces offending behaviour (by up to half for alcohol users), reduces drug and alcohol related deaths, and reduces the spread of blood borne diseases such as

Hepatitis C. The public values drug and alcohol services - 82% said that the greatest benefit of treatment was improved community safety.

Background – North Yorkshire Horizons/ North Yorkshire RISE contracts:

North Yorkshire Horizons

The Council originally procured North Yorkshire Horizons - adult specialist drug and alcohol service - in October 2014. It was the first public health commissioned service transformation programme that the council delivered, following the transfer of public health functions in April 2013. The contracts were awarded to Humankind and Lifeline, with a combined value was £3.9 million per annum – comprising £3.6 million from the ring-fenced Public Health Grant, £266k from council budgets that were previously committed to adult substance use service provision (namely residential rehabilitation); and a contribution from the Office of the Police, Fire and Crime Commissioner (c.£159k).

The contracts were awarded on a 3-year basis, with a 2-year extension facility. The extension facility was enacted in 2017. The council then re-procured North Yorkshire Horizons and awarded the existing contract from October 2019 to Humankind, on a 5-year basis, with the provision to extend by +3years and + 2years (i.e. a potential ten year contract). There has been a contribution of £394k per annum recurrent savings from the North Yorkshire Horizons service since 2017 as part of the public health savings programme.

North Yorkshire Horizons has significantly increased overall numbers engaging with the service since 2014: 2500 are currently engaged with structured treatment interventions (June 2023). Engagement has specifically increased by people seeking support for alcohol dependence (from 730 – 1160), and drugs other than opiates (by c.50%). The number of people engaging with the service for support for opiate use only has declined over the same corresponding period, and whilst this is in line with the national trend, the decline has been more pronounced in North Yorkshire – source: <u>NDTMS - ViewIt - Adult</u>.

The service has achieved outstanding ratings during two CQC inspections: <u>North Yorkshire Horizons -</u> <u>Care Quality Commission (cqc.org.uk)</u> and <u>https://www.cqc.org.uk/location/1-5029002092</u>. Liverpool John Moores University Public Health Institute conducted an independent evaluation of North Yorkshire Horizons in 2016. At peak levels of investment (£3.9 million per annum), the findings of the cost effectiveness evaluation demonstrated that spend on substance use services at that time in North Yorkshire was low per head of population compared to similar local authorities, and that North Yorkshire Horizons could be considered cost effective for all substance groups (e.g. people who need support with opiates only or alcohol only), as well as cost saving to the public purse in the long-term. The results showed that investment is a cost-effective use of North Yorkshire resources, and generates a high return on investment.

Opiate only clients

3 clients gained 3 years of quality adjusted life expectancy through services moving people into recovery, increasing their quality of life, and making them live longer. **£72k** Services produced **£72k** in cost savings over a client's lifetime, through reducing the risk of crime associated with drug use, which can add up to a considerable cost over an individual's drug taking career.

Non-opiate only clients

3.6 v clients gained 3.6 QALYs more than if treatment was not available through improved quality of life while in treatment and recovery.

£64/QALY Treatment for non-opiate users cost £64 per QALY gained which would be considered to be very cost effective, although not cost saving.

Alcohol only clients

8 clients gained eight years of quality adjusted life expectancy through services moving people into recovery, increasing their quality of life, and making them live longer. £60k Services produced £60k in cost savings, through reducing the healthcare costs of alcohol use, and through a reduced risk of crime and antisocial behaviour associated with alcohol use.

Alcohol and non-opiate clients

•8.5 clients gained 8.5 years of quality adjusted life expectancy through services moving people into recovery, increasing their quality of life, and making them live longer. £56k services produced cost savings of £56k per client through reduced healthcare costs (such as hospital admissions) and reduced crime and antisocial behaviour costs.

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Source: Independent academic evaluation

North Yorkshire RISE

The Council originally procured a combined specialist substance use and low-level mental health service for young people – Compass REACH – in 2015, as part of the Healthy Child Programme. The contract value was £182k per annum, and the contract was extended until 2021. The council reprocured a bespoke specialist substance use service as part of the Healthy Child Programme transformation programme in 2020.

Following a full procurement process, the North Yorkshire RISE contract was awarded to Humankind from April 2021, with a value of £178k per annum, on a 3-year basis, with the provision to extend by +2years and + 2years (i.e. a potential five year contract). There has been a contribution of £8,500 per annum recurrent savings from the North Yorkshire RISE service since 2020 as part of the public health savings programme.

Numbers of young people engaging with specialist service support for substance use declined between 2019 and 2021 (from 123 to 62). North Yorkshire RISE has significantly increased engagement again – with 123 young people engaged as at June 2023.

Other spend

The council also separately funds prescriptions issued by North Yorkshire Horizons (budget £496k), and GP practices that are contracted to deliver the APL services (budget £60k).

Dame Carol Black Review/ Drug Strategy and additional investment:

The independent review of drugs led by Dame Carol Black (2021) reinforced that investment in drug and alcohol services has been significantly reduced over the last decade nationally, and called central and local Government, the broader system and communities to action. She referenced the need and advocated for significant financial investment in drug and alcohol services; to 'rebuild' accessible, professional, and effective treatment services. The independent review led government to prioritise drug and alcohol services, and commit to the current three-year national funding programme: SSMTRG Section 31 grants.

North Yorkshire has so far received, invested and benefited from over £1.4 million, and is due to receive at least £1 million additional funding in 2024/25 – subject to Treasury confirmation. A condition of the grant monies, paid to local authorities, is that investment in drug and alcohol treatment from the public health grant is maintained in line with the outturn reported to DLUHC in 2020/21.

A key decision and grant decision were approved, and investment has utilised to support delivery of a number of schemes including Multiple Disadvantage and Outreach approaches in Scarborough and Harrogate, Strategic Harm Reduction activity, additional and specialist roles, needs assessment and data review activity, workforce development/training, inpatient and residential placements and equipment to support enhancements to service offers in North Yorkshire Horizons.

The Council, North Yorkshire Horizons, North Yorkshire RISE and criminal justice partners have committed to deliver a range of targets to improve engagement and continuity of care for people who use substance as part of the delivery of the national treatment plan.

Plans for 2024/25: Planning is underway across the system, including with North Yorkshire Horizons and RISE. Given that we anticipate that the level of funding we receive through the national treatment plan in 2024/2025 will be greater than the 2023/2024 grant, it is likely that the council will maintain investment in posts established in 2022/23 and 2023/24. Additional investment decisions will be informed by the priorities in the North Yorkshire Substance Use Strategy and shaped by member organisations of the

North Yorkshire Drug and Alcohol Partnership Board. Governance will be managed through Procurement Assurance Board.

Local contextual developments - opportunities:

A number of local contextual developments mean that there is a unique opportunity to review the services that directly support and contribute support to people who experience harmful patterns of substance use. These include:

- The creation of North Yorkshire Council a unitary authority which provides new opportunities to strengthen the overall council and community contribution to substance use, including support for people who experience harmful patterns of substance use. Alongside Public Health, there is a unique contribution for economic development, housing, stronger communities/localities, community safety, adult social care services including mental health services, and children's services.
- A range of partnership strategies are currently in draft, subject to engagement and/ or consultation – including the Substance Use Strategy and the Housing Strategy. These provide an opportunity to reflect the current and future needs of people across North Yorkshire;
- North Yorkshire Connected Spaces a recently formed lived and living experience group

 are highlighting strengths within existing support services, as well as opportunities for
 development including the important and vital role of lived experience and recovery
 organisations (LERO).

4.0 Alternative Options considered

The council will embark on a substance use service transformation programme between 2023 – September 2025, involving directorates across the council, as well as key partners such as the Office for the Police, Fire and Crime Commissioner, Police, Probation and the ICB.

New commissioning arrangements will be implemented from 1 October 2025. This is the minimum timeframe that a transformation programme of this nature, value and scale could be delivered within. Other timeframes were considered, for example aligning to current contract end dates and/or existing extension provision, however 1 October 2025 is the preferred option in order to respond to the opportunities presented by local contextual developments and key issues and challenges outlined above.

The existing contracts only include provisions for NYC to unilaterally extend for +3 years and +2 years for North Yorkshire Horizons, and +2 years and +2 years for North Yorkshire RISE. The council will therefore need to establish a variation to existing contracts to extend them to 30 September 2025 only. Governance will be managed through the Procurement Assurance Board.

5.0 Financial Implications

The contracts will be extended to 30 September 2025 on the basis of their current value (this excludes additional SSMTRG grant which is anticipated but not yet confirmed):

- North Yorkshire Horizons £3,676,200.00 per annum
- North Yorkshire RISE £173, 575 per annum

It is highly likely that the council will also invest SSMTRG Section 31 grant funding in 2024/25 within these services. The value of current additional investment is £442,327. Governance will be managed through Procurement Assurance Board.

6.0 Legal Implications

The original contracts for North Yorkshire Horizons and North Yorkshire RISE each contain extension options and provisions beyond 30 September 2025, therefore the proposed variations are permissible



under regulation 72 Public Contracts Regulations 2015. The proposed extensions will be subject to the usual gateway process in order to comply with governance requirements.

7.0 Consultation undertaken and responses

Initial discussions have taken place with the current provider of both contracts. Office of the Police, Fire and Crime Commissioner are also aware of the proposal, as a contributing organisation.

8.0 Impact on other services/organisations

The council receives a financial contribution for both services from the Office of the Police, Fire and Crime Commissioner. Representatives from the Office will be invited to support the transformation programme.

9.0 Contribution to Council priorities

The delivery of specialist substance use services for adults and young people through North Yorkshire Horizons and Rise supports a number of ambitions within the Council plan as follows:

- People are supported to have a good quality of life and enjoy active and healthy lifestyles
- Reduced variations in health by tackling the root causes of inequality
- People can access good public health services and social care across our different communities
- People are free from harm and feel safe and protected
- In times of hardship support is provided to those who need it most
- Good quality value for money services that are customer focussed and accessible to all

10.0 Risk Management Implications

There is no change to risk management arrangements as part of the contract extension. Requirements around CQC registration, clinical governance and other areas of risk are clearly documented in the specification, regulated where appropriate by external bodies and monitored via contract management arrangements.

11.0 Equalities Implications

An Equality Impact Assessment was completed at the time North Yorkshire Horizons was last reprocured. Estimates suggest that unmet need for specialist adult treatment services exists across North Yorkshire. A new Equalities Impact Assessment will be completed as part of the transformation programme.

12.0 Climate change implications

A Climate Impact Assessment will be completed as part of the transformation programme.

13.0 Community safety implications

The contracts contribute to community safety outcomes. The chair of the North Yorkshire Community Safety Partnership is the co-chair of the Drug and Alcohol Partnership Board. Community Safety Team representatives will be invited to support the transformation programme.

14.0 Reasons for recommendation/s

This arrangement ensures that effective specialist drug and alcohol services are maintained throughout the transformation programme; that the council maintains investment in line with the outturn reported to DLUHC in 2020/21; and that partners can optimise additional grant investment in the final year of the current investment programme (2024/25) facilitated by the Dame Carol Black Review.

14.0 Recommendation/s: To approve the extension of contracts for the provision of North Yorkshire Horizons (specialist adult drug and alcohol service) and North Yorkshire RISE (specialist young people's drug and alcohol service) to 30 September 2025.

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