

NORTH YORKSHIRE COUNTY COUNCIL
HEALTH OVERVIEW & SCRUTINY COMMITTEE

23 JANUARY 2015

PARTNERSHIP COMMISSIONING UNIT UPDATE ON AUTISM ON BEHALF OF
THE NORTH YORKSHIRE AND YORK FOUR CLINICAL COMMISSIONING
GROUPS

Purpose of Report

1. To update Members of the Health Overview & Scrutiny Committee on progress of the Joint All Age Autism Strategy and related work streams
2. To provide an update on NHS adult and child autism diagnostic services procurement.

Background:

The Partnership Commissioning Unit (PCU) works on behalf of the four local Clinical Commissioning Groups (CCG's) in developing and managing services for children and for vulnerable adults, people with mental illness or disability. The Commissioning team within the PCU are supporting the development of autism services across the county on behalf of the local NHS. This report provides an update on overall progress including developments in commissioning services for adults.

1. **Strategy for meeting the needs of children, families and adults with autism in North Yorkshire 2015-2020**

The joint strategy for meeting the needs of children, families and adults with autism in North Yorkshire 2015-2020 (Appendix 1) is being developed by North Yorkshire County Council (NYCC) and NHS Partnership Commissioning Unit (PCU) on behalf of the 4 North Yorkshire and York Clinical Commissioning Groups (CCG) with input from neighbouring CCG representatives and others.

A joint strategy offers a much better chance of succeeding in our ambitions. Joint working is not confined to the Local Authority and Health but to other public and independent sector organisations. During the consultation phase for the strategy, other public and independent sector organisations will be asked for their views on the strategy's proposed aims and outcomes, and invited to formally endorse the strategy.

To support the strategy and understand progress made with our ambitions for children's autism assessment services, the PCU are collecting and collating data on local activity including waiting times which NICE guidelines state that once a decision for an autism diagnostic assessment has been made, this should start within 3 months of the initial referral to the autism team, this

remains a challenge for service providers. The PCU will be commencing a quality review of service provision in 2015.

From April to October 2014, 215 new referrals were received by the four children's diagnostic centres and 191 1st appointments for an Autism Diagnostic Assessment were offered. The wait from date of the referral to the autism team to the 1st appointment date offered was for the majority of children not within 3 months as per NICE guidelines. As of October 2014 288 young people were waiting for a 1st appointment across the 4 services. The PCU will continue to work with the CCGs and providers to ensure that there are improvement plans and trajectories in place to bring waiting times in line with the NICE guidance. Over the last year Harrogate and Rural District CCG and Hambleton, Richmondshire and Whitby CCG have increased investment into the local services and are closely monitoring trajectories. The PCU has also worked with Scarborough and Ryedale CCG and Hambleton, Richmondshire and Whitby CCG to enable a number of long waiters from the Scarborough waiting list to be seen under a waiting list initiative at Socrates, Huddersfield. This represents additional CCG investment.

This strategy builds on the progress and achievements to date of the separate existing children's and adult autism strategies and sets out plans for the next five years to continually improve services, information and support for people with autism.

Whilst the strategy highlights achievements to date these are not viewed as end points but indicators of what has been and what can be achieved.

The overarching ambition of the strategy is to use the eight 'Think Autism' targets below. Whilst these are ambitious and challenging they are seen as being priorities which both health and social care will work to achieve.

1. Increase awareness and understanding of autism among all services and professionals;
2. Develop a clear, consistent pathway for diagnosis and post-diagnostic support in every area, including early intervention;
3. Improve access to services and support, ensuring good quality, clear and accurate information on the range of services available;
4. Enable local partners to plan and develop appropriate services for people with autism and ensure that agencies work together;
5. Increase the involvement of families and people with autism in service planning and delivery and involve people and their families in making decisions that affect them;
6. Reduce any barriers to the participation and inclusion of families and people with autism particularly at stages of transition;
7. Provide sustainable services which are managed within available resources;
8. Help adults with autism into work.

The strategy is complete in draft form and will go out for public consultation during summer 2015. Priority areas for development are already being proactively progressed including:

- raising the awareness and understanding of autism among all services and professionals; we are already in the process of making available to all health professionals a free autism awareness online training course alongside the more specialised RCGP online autism training course for GP's and Practice Nurses <http://www.rcgp.org.uk/courses-and-events/online-learning/ole/autism-in-general-practice.aspx>
- Promoting the NAS Autism Access Award Scheme which is suitable for *all* front line services and it is hoped will be included in service specifications going forwards. <http://www.autism.org.uk/accessaward>
- Continuing to support 18 day, respite and outreach services that are working towards achieving full National Autistic Society accredited status. Continuing to roll out an autism champions programme across the wider workforce following the successful implementation in NYCC's Health and Adult Services; Planning and developing communication and engagement with people with autism and their families on the strategy
- Exploring joint commissioning with NYCC to enhance the development of autism pathways for adults

2. An update on adult and child autism diagnostic service procurement

The PCU is due to tender a county-wide service on behalf of the local Clinical Commissioning Groups in 2015, providing assessment and diagnosis for adults with developmental conditions including Attention Deficit Disorder with Hyperactivity (ADHD) and autism. This will provide a central focus for training and development and pathway redesign within the NHS. The contract will be awarded in summer of 2015. In January 2015 the NHS will be consulting with people with autism and ADHD on their views on how this service should look, learning lessons from the NYCC draft adult strategy and recent commissioning of children's services.

The Vale of York Clinical Commissioning Group is undertaking a mental health re-tender which will incorporate children's mental health services, including children's autism provision. The award of the new contract will commence from autumn 2015. Extensive consultation and engagement with local service users and carers as well as professionals has taken place, and further work to support the NHS in hearing the point of view of children and young people is planned across North Yorkshire in 2015.

Through the existing feedback gained through the Vale of York engagement programme, a key theme that stands out is the need for seamless transitions for children and young people into adult services. The PCU hosted a discussion with children's and adults autism providers in November 2014 around how this could be developed and opportunities for joint commissioning of children and adults services in the future will continue to be explored by the PCU in conversation with the CCG's.

Recommendations

3. Members of the Committee are requested to note and comment on the information in this report.

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14 January 2014

Background Documents: None

Annexes: Appendix 1

Strategy for meeting the needs of children, families and adults with autism in North Yorkshire 2015-2020

VERSION 14 – as at 14 January 2014

Chapter 1 – Introduction

About this strategy

This is a strategy for meeting the needs of people with autism in North Yorkshire. It runs for a five-year period from October 2015 – October 2020.

People with autism deserve the same life opportunities as all local residents. They should have fair and equal access to services and support as required to meet their life aspirations. Following the implementation of the strategy for meeting the needs of children and young people with autism and the interim strategy for meeting the needs of adults with autism, it is imperative that work continues to raise awareness of autism and to improve services for people with autism.

This strategy has been developed as a joint strategy between North Yorkshire County Council's Children & Young People's Service (CYPS), Health & Adult Services (HAS) and the Partnerships Commissioning Unit (PCU) on behalf of the four Clinical Commissioning Groups (CCGs) that operate within North Yorkshire.

North Yorkshire's boundaries also extend into parts of the county administered by Airedale, Wharfedale and Craven CCG and South Lakes CCG (representing the town of Benthams). Senior colleagues from these two organisations have been involved in the development of this strategy.

Vision statement

The partner organisations in North Yorkshire that have collaborated to produce this strategy share a vision that people with autism will receive an assessment in line with NICE guidance and diagnosis as early as possible, that they will be able to access additional support if they need it and to know that they can depend on mainstream public services to accept and understand them and to treat them fairly as individuals.

Why this strategy has been produced

People with autism and their families have expressed the need for local services that meet their needs, central government have also identified this need and have produced guidance for local authorities to adopt.

The National Autism Plan for children was published in 2003. This was followed by the Autism Act which was passed in 2009. The Autism Act placed a number of obligations on a range of public bodies to improve opportunities for people with autism. The strategy for adults with autism in England 'Fulfilling and Rewarding Lives' followed in 2010 and provided clear direction in terms of how public services must transform to better address the needs of adults with autism. More recently 'Think Autism', published in April 2014 shared detailed consultation and research into the views of people with autism and their families on how progress has been taken forward in implementing the 2009 Autism Act. The findings include a set of "1 statements" which emphasis what is important to people with autism and their families.

The total estimated UK cost of autism is around £28 billion. This averages out at £500 each year for everyone with autism. The economic costs include lost job opportunities, impact on the criminal justice system, and the cost of supporting vulnerable adults via, for example, social housing and state benefits.¹

The overall objective of a strategy for autism is to ensure that services are identified, commissioned and improved to meet current and future needs and improve services for people with autism.

Scope of this strategy

This strategy is for people with autism and their families and carers. It recognises that there is a range and severity of need.

The strategy has been informed by national priorities and best-practice models. It reflects the work that has been carried out in the previous children's and adults' autism strategies and extends this work to set new longer-term targets.

The strategy does not cover details of interventions for autism. Autism means many different things to each individual person, family and setting, and can present very different challenges. Each person is an individual and, as such, pathways and interventions need to be individualised.

A message from North Yorkshire's autism leads

A five year joint strategy for meeting the needs of people with autism in North Yorkshire will ensure that there is more effective support for people with autism and reinforces the enormous potential benefits that can result from collaboration.

¹ Knapp, M. et al (2009). Economic cost of autism in the UK. Autism, 13(3), pp317-336

The benefits of developing one strategy that meets the needs of all children, young people and adults across North Yorkshire are that one strategy will enable a more integrated coordinated approach across CYPS, HAS and Health. It means we can plan more efficiently and support people more effectively from a very early stage of their lives.

A joint strategy offers us a much better chance of succeeding in our ambitions by working together as agencies, with families and carers, and with the voluntary and community sector. Together, we are determined to improve services for people with autism.

We are proud that we have worked alongside people with autism and their families and carers to develop this strategy. Further details on engagement and consultation can be found in Chapter 4. Their views have enabled us to set targets which will have benefits for all people living with autism in North Yorkshire.

Signatures of:

Councillor Tony Hall, Lead Executive Member for Children's Services

Councillor Clare Wood, Chair of Health and Wellbeing Board

Richard Webb, Corporate Director of Health and Adult Services

Pete Dwyer, Corporate Director of Children and Young People's Services

Janet Probert, Director, Partnership Commissioning Unit, on behalf of the following CCGs:

- Hambleton, Richmondshire and Whitby
- Harrogate
- Scarborough and Ryedale
- Vale of York

CYPS Health representative

This strategy is endorsed by a number of organisations that work with people with autism in the North Yorkshire area.

Chapter 2 - Aims and principles

In April 2014 the Department of Health published 'Think Autism', its review of the Government strategy for adults with autism 'Fulfilling and Rewarding Lives'. 'Think Autism' states three aims for improving the lives of people with autism. These are:

1. An equal part of my local community
2. The right support at the right time during my lifetime
3. Developing my skills and independence and working to the best of my ability

In North Yorkshire, health, social care and education share these three aims. Our ambition in this strategy is to use the targets set out in Think Autism to improve the lives of everyone with autism. We will do this by:

1. Increasing awareness and understanding of autism among all services and professionals;
2. Developing a clear, consistent pathway for diagnosis and post-diagnostic support in every area, including early intervention;
3. Improving access to services and support, ensuring good quality, clear and accurate information on the range of services available;
4. Enabling local partners to plan and develop appropriate services for people with autism and ensuring that agencies work together;
5. Increasing the involvement of families and people with autism in service planning and delivery and involve people and their families in making decisions that affect them;
6. Reducing any barriers to participation and inclusion for families and people with autism particularly at stages of transition;
7. Providing sustainable services which are managed within available resources;
8. Helping adults with autism into work.

Chapter 3 - What do we know about autism?

In line with the national autism strategy, North Yorkshire has chosen to use the word 'autism' as an umbrella term to include all conditions on the autistic spectrum. These include Autism, Autistic Spectrum Disorder, Autistic Spectrum Condition, Kanner's Syndrome, Asperger Syndrome, High Functioning Autism, Rett Syndrome, Childhood Disintegrative Disorder, Pervasive Development Disorder Not Otherwise Specified (PDD-NOS), and Neuro-Diversity.

'Fulfilling and Rewarding Lives'²: defines autism as:

'A lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them'

This definition is used by North Yorkshire throughout this strategy. The extent to which an individual is affected varies from person to person. There is a wide range of cognitive, social and communicative abilities which can include people with profound learning difficulties, with little or no verbal communication through to those with average or high levels of functioning (we use the term autistic spectrum to describe this).

There is strong evidence to suggest that there are more males with autism than females. Brugha surveyed adults living in households throughout England, and found that 1.8% of males surveyed had autism, compared to 0.2% of females³.

However, females are less likely to be identified with autism, even when their symptoms are equally severe. Many females are never referred for diagnosis and are missed from the statistics.

Autism is considered a disability which is recognised by the Equality Act of 2010. Autism is not a mental health condition or a learning disability although it is estimated that between 44% - 52% of people with autism may have a learning disability⁴. One study suggested 71% of young people with autism were going to have one existing mental health condition and 40% have two or more⁵.

As the population changes and life expectancy increases, there are likely to be more people over 65 with autism, although older people are less likely to have received a diagnosis.

² Fulfilling and rewarding lives: the strategy for adults with autism in England (2010), Department of Health

³ Brugha, Autism Spectrum Disorders in Adults Living in Households Throughout England (2007), Report from the Adult Psychiatric Morbidity Survey

⁴ <http://www.autism.org.uk/about-autism/myths-facts-and-statistics/statistics-how-many-people-have-autism-spectrum-disorders.aspx>. Accessed 26/11/14.

⁵ Sims, Mental Health and autism: a guide for child and adolescent mental health practitioners (2011), National Autistic Society

There is limited research around ethnicity and autism which has given an inconsistent picture as to whether autism is more prevalent or frequently diagnosed in particular ethnic groups. However the NAS Black and Minority Ethnic Communities Project⁶ and other information collated for a recent NAS report has highlighted that some minority ethnic communities have a limited understanding of autism and that the condition is perceived differently by some communities. This is important as it is likely to have implications for how families, carers and professionals respond to autism and how likely and easy an individual may find it to access appropriate support. Of the adult population of North Yorkshire, 97% are white. However it is important to note that this information does not reveal if they are British, or speak English as a first language. The distribution of BME adults does not differ dramatically across the districts of North Yorkshire; however there is the greatest proportion of white adults in Ryedale and Selby, and the smallest proportion of white adults in Harrogate and Richmondshire.

Looked After Children, children from military families and those from travelling communities are also less likely to receive a diagnosis of autism.

National context and prevalence

Recent prevalence studies of autism indicate that 1% of the population in the UK may have autism⁷. This means that over 695,000 people in the UK may have autism. This is an estimate derived from the 1% prevalence rate applied to the 2011 UK census figures.

What remains unclear is whether the actual prevalence of autism is on the rise, or whether the increasing number of people with autism is the result of broadening or improved diagnosis.

Local context and prevalence

We estimate there are 5643 people with autism under 65 living in North Yorkshire and 1,272 people over 65⁸. Locally, our understanding of how these people are supported is evolving and we know that a multi-disciplinary approach is necessary. Data on people with autism is held by a number of providers and we need to improve the way we analyse data.

⁶ Corbett & Perepa, Missing Out? (2007), National Autistic Society

⁷ <http://www.autism.org.uk/working-with/autism-strategy/local-planning/data-collection/prevalence-rates-of-autism-in-adults.aspx>. Accessed 27/11/14

⁸ [http://www.streamlis.org.uk/\(S\(p3x4wdiksn2xb2jvod5kbi55\)\)/code/MasterFrame/MasterFrame.aspx?type=Profiler](http://www.streamlis.org.uk/(S(p3x4wdiksn2xb2jvod5kbi55))/code/MasterFrame/MasterFrame.aspx?type=Profiler). Accessed 27/11/14. (1% prevalence rate applied to North Yorkshire population).

People's needs should be met on an individual basis. There is a continuum of provision to support positive outcomes for people with autism ranging from universal services to highly specialist support.

Some local facts about autism

A small number of children and young people with autism (154) have a statement of SEN. This reflects 23% of all statements (as at 2013). The local authority will work with families to review statements and convert them to Education, Health and Care Plans over the forthcoming years.

There has been a 25% increase in the number of children and young people with autism who require additional support from the Specialist Support Service since 2010. Projection figures for 2015 suggest a further increase in requests for assessment and diagnosis services and the involvement of the Specialist Support autism outreach service of approximately 30%. This puts a huge pressure on all diagnostic, educational, specialist support services and social care.

In 2014, 49 young people with autism transitioned from school to post 16 provision. Consideration needs to be given to how to support young people leaving school. We estimate that a further 50 young people with autism known to the children and young people's service became adults (18 years old) in 2014. Consideration also needs to be given to how services will support the increased prevalence of young people moving into adult services.

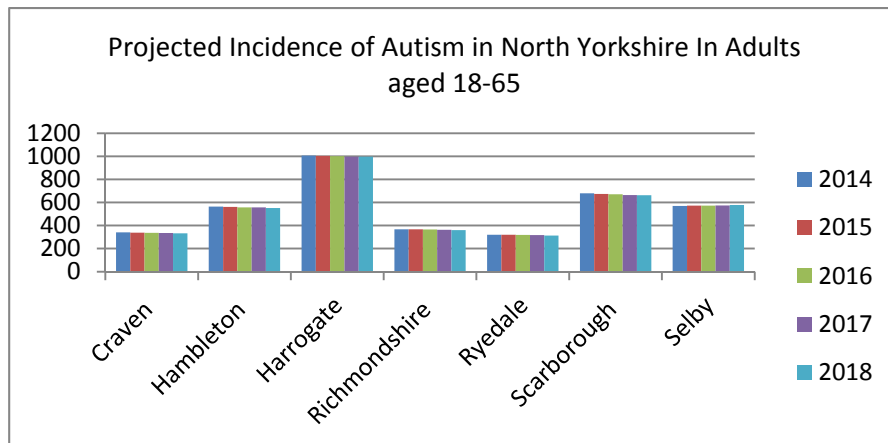
From April 2014 Health commissioners have been collating data relating to the autism diagnostic service locally across North Yorkshire and York. In 2014, 17 adults per month were referred for diagnosis by their GP across the four CCG areas (which includes City of York). Current rates of referral (205 for a practice population of 752,346) are well below the expected prevalence rates for ADHD and ASD. The average age of patients referred in 2014 was 28 years old.

People with autism are more likely to have mental health issues. The PCU is undertaking a review of the provision currently commissioned and aims to radically improve service provision for children, young people and adults with autism who require specialist mental health support and services in 2015.

There are 345 adults with autism supported by Health and Adult Services (as at November 2014). There are many more people with autism who may never come to the attention of services. This is because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents.

According to the projected figures for adults between 18-65 with autism in North Yorkshire, there will be a decrease of around 1% of the adult population, which equates to 54 fewer adults with autism in this age group by 2018⁹.

Figure 1 – projected incidence of autism in North Yorkshire in adults aged 18-65



Overall population figures for the North Yorkshire districts (from the 2011 census)¹⁰ are as follows:

Craven: 55,409

Hambleton: 89,140

Harrogate: 157,869

Richmondshire: 51,965

Ryedale: 51,751

Scarborough: 108,793

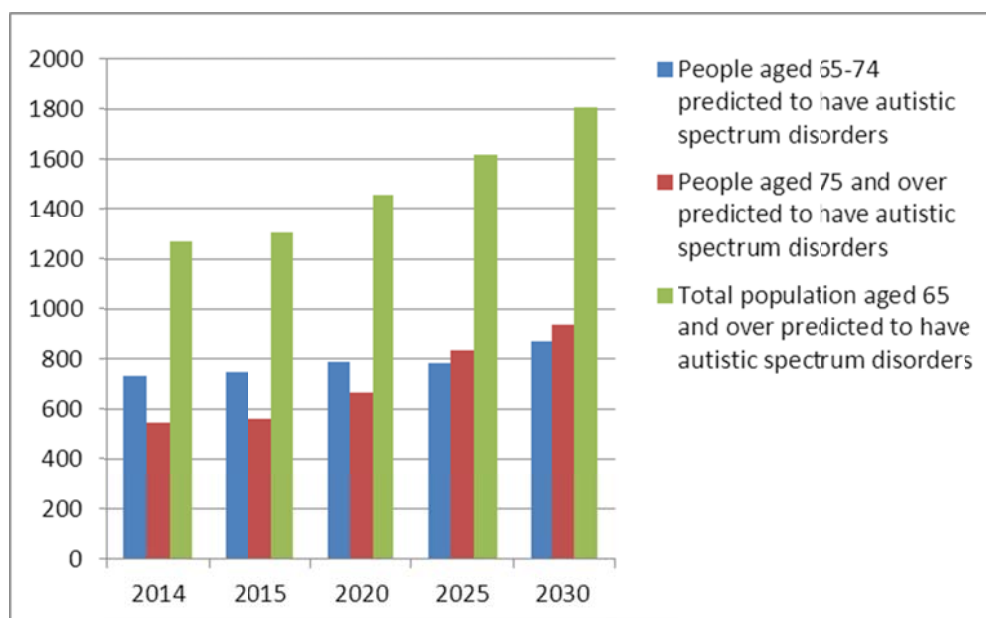
Selby: 83,449

⁹ Projecting Adult Needs and Service Information. Available at www.pansi.org.uk. Accessed 27/11/14

¹⁰ [http://www.streamlis.org.uk/\(S\(p3x4wdiksn2xb2jvod5kbi55\)\)/code/MasterFrame/MasterFrame.aspx?type=Profiler](http://www.streamlis.org.uk/(S(p3x4wdiksn2xb2jvod5kbi55))/code/MasterFrame/MasterFrame.aspx?type=Profiler). Accessed 27/11/14

Using the 1% prevalence rate it is expected that there are around 1,272 adults over the age of 65 with autism in North Yorkshire. As the older adult population grows it is estimated that this figure will increase by over 500 people by 2030¹¹.

Figure 2 - Number of over 65's in North Yorkshire estimated to be on the autistic spectrum (POPPI)



Implications for education, health and care

There is an increasing demand for diagnostic services for people of all ages in health services and an increase in the overall volume of referrals to the teams that support those with a diagnosis. Many people will require support from a range of services at various points, including education, social care, and primary and secondary health services, including mental health.

A prevalence level of 1% will mean that most teachers, social care workers and health professionals will support a person with autism at some point during their career. One in three children in special schools now have an educational need related to autism which highlights the need for an effective educational approach to meet the needs of this complex population of students. It is essential that all staff have an awareness and understanding of autism and how to implement strategies to enable these children and young people to access all aspects of school life and to reach their full potential.

¹¹ <http://www.poppi.org.uk/index.php?pageNo=428&loc=&mapOff=1>. Accessed 27/11/14

Chapter 4 – How are we going to find out what people think about the strategy?

In order to formulate this strategy our first priority is to engage with children, young people, adults with autism and their families living in North Yorkshire. We want to gather their views, opinions and experiences, understand what is working well for them, and what areas they would like to see improve. The aim of engaging with people with autism and their families is to identify priority areas for development.

We propose to consult on this draft strategy between May 2015 and July 2015 through existing autism networks across the partnership agencies. We will hold a number of consultation events across North Yorkshire. We will invite people with autism, their families and other interested parties to attend. We will hold additional focus groups for children and adults with autism via the Enhanced Mainstream Schools and the Flying High group.

We will also give people the opportunity to comment via an online survey or by emailing their feedback to a dedicated email address. In addition we will promote the consultation via social media such as Facebook and Twitter. Existing Facebook groups will be approached to help disseminate the information to a wider audience.

Once the consultation period has concluded, we will reflect the feedback received in the final version of the strategy.

Chapter 5 - What is on offer in North Yorkshire?

This strategy reflects the local ambition to improve the range of services available locally. The information below highlights the different types of provision for adults and children with autism. In future we aim to reduce the impact of transitions from children's to adults' services. The policy framework governing our work on autism is extensive, an overview of this can be accessed at ([add link to framework document](#)). Further information on all North Yorkshire services can be found on our local offer <http://www.northyorks.gov.uk/article/23542/SEND---local-offer>.

There are many routes to access help, support and advice should you think a child young person or adult has autism (for example, by contacting your GP, speech and language therapist or paediatrician). These specialists can provide advice and guidance and refer onwards to the most appropriate service. This may include a referral to an assessment and diagnostic team.

Assessment for autism

There are five autism diagnostic assessment teams for children (0-19) across North Yorkshire. These are commissioned from the following NHS providers:

- Harrogate District NHS Foundation Trust (2 autism diagnostic assessment teams for children)
- York Teaching Hospital NHS Foundation Trust
- Airedale NHS Foundation Trust
- Leeds & York Partnership NHS Foundation Trust

The autism diagnostic assessment teams are multidisciplinary in line with NICE guidance for assessment and diagnosis of children with autism. The teams consist of a paediatrician or a child and adolescent psychiatrist, a speech and language therapist, and a clinical and/or educational psychologist. These teams have specialist skills in autism diagnostic assessments and inform and advise parents and colleagues of their findings.

The diagnostic process can be complex and challenging for some families and individuals. Professionals working in this area are sensitive to the emotional impact of this process. It is also important that the correct diagnosis is given; therefore this process can sometimes take up to 30 hours of clinical assessment. If there is uncertainty regarding the diagnosis, in some instances, professional clinical judgement may indicate the need for 'watchful waiting' to take into account any new information. Children and young people in this category will be monitored for up to 12 months. NHS England commission some specialised services for very complex assessments.

The assessment and diagnostic services across North Yorkshire are currently using the International Classification of Diseases (ICD) 10 (World Health Organisation WHO 2010) or ICD 10 and DSM-V as a diagnostic assessment tool. This is due to be revised in 2015. They also assess through interaction with and observation of the child or young person's social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-V criteria.

During the post-diagnostic follow-up meeting provided by the assessment diagnostic team, the key worker will provide a North Yorkshire autism information pack ([add link](#)) for parents and discuss the possibility of attending a parent training programme. These are jointly commissioned by the NHS and the Local Authority Specialist Support Service. A range of training programmes are available to suit individual circumstances.

The Partnership Commissioning Unit are undertaking an exercise to procure a local diagnostic service for adults in North Yorkshire. Currently this is provided outside of the county, so people may have to travel for their appointment.

When a person does not meet the criteria for a diagnosis of autism the diagnostic assessment team will signpost them and their family to relevant and appropriate services.

Education provision for children with autism

The majority of young people with autism attend their local nursery, pre-school, maintained mainstream school or academy and have their needs met within the mainstream from delegated funding. Resources are delegated to Early Years settings and schools to enable them to meet the needs of pupils with SEN including autism. For children with higher levels of need, the local authority may provide resources through an Education, Health and Care Plan.

The local authority encourages all education settings to develop their knowledge, skills and competencies to meet a wide range of needs including autism. The Autism Education Trust Quality Standards and Competency Framework are recommended to enable settings to evaluate their practice in addressing the needs of pupils on the autism spectrum and the Specialist Support Service encourages all settings to continually develop their provision for children and young people with autism.

All children and young people, including those with autism, benefit from quality first teaching. Some will require additional specialist support from the Autism Outreach service ([link to local offer](#)), others will need a personalised approach to teaching and learning.

In line with the 2014 SEN Code of Practice, local authorities have a duty to ensure that they provide adequate and efficient educational provision for any child or young

person with additional support needs including children and young people with autism. The code emphasises that having a special educational need is not a reason for poor educational attainment. North Yorkshire promotes the personalisation of learning for children and young people with autism. The local authority pattern of provision aims to develop the capacity of local education provision, by sharing expertise in autism.

North Yorkshire recognises the need to have the right specialist support in place and the right pattern of provision to meet the needs of children with autism and their families. We promote a mixed economy of provision, some provided directly through centrally based local authority staff and other services procured on its behalf.

Some children and young people will require specialist educational provision. Specialist educational provision available within North Yorkshire includes:

Enhanced Mainstream Schools (EMS)

The EMS form part of the Specialist Support Service. The provision is commissioned by the local authority and is led and coordinated by the Children and Young People's Service, through the Access and Inclusion directorate. There are five primary EMS for communication and Interaction and five secondary schools that are enhanced for students with a diagnosis of autism. ([Link to local offer](#))

Special School provision

North Yorkshire's special schools are highly regarded by the local authority and Ofsted. Two of the special schools have National Autism Society Accredited Status. Appropriate provision is based on individual needs ([link to local offer](#))

Autism outreach team

The autism outreach team (previously known as ASCOSS) operates across North Yorkshire to provide support for children, Early Years settings, schools and families. The service is able to offer specialist support, advice and training to enhance learning, development, achievement and the social inclusion of children and young people with autism.

All educational establishments can request involvement from the autism outreach team. Further information on the team can be found at:

<http://cyps.northyorks.gov.uk/index.aspx?articleid=15825>

<http://cyps.northyorks.gov.uk/index.aspx?articleid=13162>

Social care services for children with autism

Parents or professionals of children and young people with autism may consider a referral to access services provided by Children's Social Care (higher functioning conditions) or Disabled Children's Services (for children with a Learning Disability). They can request that a Child in Need Assessment is carried out to see if their child is eligible to receive support or short breaks, either from social care or from Inclusion Services under the Common Assessment Framework (CAF).

Short Breaks are available to some children, young people and their families where their caring responsibilities are significant and where they need a break. Information on Short Breaks provision can be found on the local authority website www.northyorks.gov.uk/SEND.

There is also advice available around parenting, behaviour management and sleep. Agencies work together to coordinate support in order to provide a consistent response.

Training and education for short break services (TESS) delivers individual training to leisure short break providers to enable disabled children to access inclusive activities. Children and young people with a diagnosis of autism, and who are in receipt of short break services are eligible for this service.

Preparing for adulthood

Making the transition from childhood, through adolescence and into adulthood is challenging for any young person. Young people with special educational needs or disabilities generally and those with autism can face additional barriers. This period of time, often referred to by professionals as 'transition' can be both daunting and frustrating for young people and their parents.

Transition is most successful where there is good communication and planning between the young person, their parents, school and professionals.

Significant work has been undertaken to improve the process of transition for young people. In 2008 the National Transitions Support Programme was introduced by the government to develop systems which would improve the experience of young people including those with autism. Further work has been undertaken by the Preparing for Adulthood Team.

Ambitious about Autism (www.ambitiousaboutautism.org.uk) are leading on a government funded project in which North Yorkshire schools and Askham Bryan College in York are involved. This project focuses on supporting young people with autism making the transition from school into further education. North Yorkshire is committed to:

- improving local provision for post-16 learning opportunities, including the development of flexible and personalised packages of support to continue in education or training;

- integrated and person-centred planning and assessment approaches through the transition period, using the Preparing for Adulthood section of the Education, Health and Care Plan;
- closer working with colleagues in Health and Adult Services and with NHS health providers and commissioners to improve the pathway from children's services to adulthood;
- further improvements to information, advice and support to families;
- implementation of the Local Offer.

Adults with autism

Following diagnosis health professionals, such as a person's GP will be informed. Adults who have been diagnosed with autism are entitled to have a social care assessment that will consider individual communication preferences. Those with social care needs may be eligible to receive support from the local authority. This support is means-tested, and may be free of charge subject to eligibility. North Yorkshire County Council's brokerage service has access to a wide range of social care providers who can support a range of needs. Social care assessors will liaise with the brokerage service on behalf of the person with autism.

Alternatively North Yorkshire County Council has an online community directory where providers list the services they offer. The community directory can be accessed via this link ([add link](#)).

Often adults with autism also need support with mental health issues or a learning disability. Further assessment may be required to ensure people access appropriate services.

Carers of people with autism are also entitled to request a carers assessment should they feel this is appropriate.

Helping adults with autism into work

Job Centre Plus is part of the Department for Work and Pensions. It provides services that support people of working age from welfare into work, and helps employers to fill their vacancies. Disability Employment Advisors (DEAs) are available to support people who have disabilities, including people with autism. DEAs will act as advocates for those who experience difficulty in communicating with employers. DEA training covers a wide range of conditions including autism, and advisors undertake autism specific training.

In addition, North Yorkshire County Council's Health and Adult Services offer a Supported Employment Service which includes support for people with autism. Staff are based in adult social care teams and integrated mental health teams countywide. They are able to support people with autism to gain and retain employment. Supported Employment staff also work with employers to advise on reasonable

adjustments in the workplace. The Supported Employment Service is undertaking the NAS Autism Accreditation process alongside 16 other North Yorkshire Health and Adult Services providers.

Provision in the local community

There are a number of organisations and independent groups that support people with autism, such as the National Autistic Society (NAS). The NAS website, www.nas.org.uk, contains a list of useful local contacts and support groups.

There are a range of local community groups and support available in the community for people with autism and their families. These include leisure and sport activities, youth provision, after school clubs and peer support groups. As part of developing this strategy we have liaised with, and will continue to work with, a number of voluntary organisations to map activities available and signpost families to opportunities.

This information will be included in the local authority's Local Offer which advertises the range of things on offer for children and young people with special educational needs and disabilities. The local offer can be found here:

<http://www.northyorks.gov.uk/article/23542/SEND---local-offer>

Chapter 6 – what have we achieved so far?

The actions stated within the previous North Yorkshire autism strategies have ensured progress towards developing services for autism. This strategy builds on the progress and achievements made to date and sets out the plans for the next five years to continually improve services for children, young people and adults with autism in North Yorkshire. [Link to highlight reports and implementation plans.](#)

Some targets already achieved – the highlights:

- The establishment of joint strategic groups comprising officers from HAS, CYPS, Health, parents and the voluntary sector working collaboratively to improve services for people with autism in North Yorkshire;
- A business case for an autism assessment and diagnosis service for adults with autism has been developed;
- As the prevalence of autism is on the rise, and our understanding of autism and available training for professionals is increasing, NYCC are ensuring that staff are appropriately trained in autism. The NHS are raising awareness of available autism training through signposting to online resources;
- 1431 of North Yorkshire County Council's workforce have undertaken online autism awareness training; 123 non-local authority staff have also undertaken this training (as at Jan 2015);
- The above online autism awareness tool is available from NYCC and the aim is for this to be made available for all NHS staff through the e-learning portal;
- North Yorkshire has been awarded the position of Yorkshire and Humber Autism Education Trust Early Years training hub;
- North Yorkshire Police PCSO training based on NAS resources is provided;
- 61 Health and Adult Services operational staff are registered Autism Champions and have received enhanced level training on autism;
- 18 North Yorkshire County Council services are undertaking a National Autistic Society programme to achieve accreditation for autism-friendly services;

- The number of autism-specific training programmes for families has increased extensively;
- York St John University have established a community of practice for staff working with people with autism across the Vale of York;
- A 'virtual reference group' has been created in order to involve people with autism, their families and interested groups in the development of autism provision across the county;
- A young people's DVD has been produced – describing their views on how to best support young people with autism. This will be used as an educational resource for teachers;
- A mental health and emotional wellbeing in autism prevalence study of children and young people with autism in North Yorkshire has been undertaken;
- A "Review of Evidence Based Educational Interventions for Autism in North Yorkshire" has been written to highlight the national recommendations and best practice guidelines; leading to an NYCC statement regarding autism and evidence based intervention.

Chapter 7 - Actions for 2015-2020

The actions below are grouped within our 8 key aims and principles stated in Chapter 2. An implementation plan will be developed following the publication of the strategy. During the consultation period we will be asking people for their views on the actions we need to take to achieve the following targets.

1. Increase awareness and understanding of autism among all services and professionals. To do this we will:
 - Provide guidance on implementing autism standards and competency frameworks within schools and education settings (Early Years and post-16);
 - Map current training and produce a training needs analysis;
 - Develop a detailed training pathway monitored by the learning and development multi-agency group and publish this to raise awareness of available training to other organisations locally;
 - Continue to support front line services that are working towards achieving NAS accredited status;
 - Continue to roll out an autism champions programme across the wider workforce following the successful implementation in HAS;
 - Develop peer mentoring within staff teams to increase levels of knowledge and awareness of autism.

2. Develop a clear, consistent pathway for diagnosis and post-diagnostic support in every area, including early intervention. To do this we will:
 - Procure local autism assessment and diagnostic services within North Yorkshire as identified through on-going reviews of service availability and quality;
 - Collaborate with agencies that support adults to facilitate pathways of support (for example, Department for Work and Pensions, North Yorkshire Police and the criminal justice system);
 - Continue to offer autism-specific training programmes to families that have received a diagnosis of autism (0-18 years);
 - Review opportunities to develop autism specific training programmes for family carers (post 18);
 - Establish, develop and evaluate a mechanism for data collection and monitoring of the autism diagnostic process;
 - Implement the new international criteria for diagnosis once published.

3. Improve access for all people with autism to the services and support they need by ensuring good quality, clear and accurate information on the range of services available. To do this we will:

- Support the development of autism friendly communities through the NYCC community delivery managers;
- Ensure the local offer is, and continues to be a source of quality information for children, young people and adults with autism and their families;
- Use a range of methods to provide information in an accessible format (e.g. email, text, Skype, letter, face to face);
- Listening to the voice of those with autism and their families to ensure their views are heard within the relevant statutory assessment framework. Review the autism information pack for parents;
- Develop an autism information pack for adults post diagnosis.

4. Enable local partners to plan and develop appropriate services for people with autism and ensure that agencies work together. To do this we will:

- Create a multi-agency Steering Group for this strategy to ensure that agencies are working collaboratively;
- Continue to include autism within the North Yorkshire Joint Strategic Needs Assessment;
- Implement Education, Health and Care Plans for all children with autism who currently have a statement;
- Develop personalised pathways of support for people with autism through maximising personal health budgets and direct payments;
- Develop a multi-agency training pathway;
- Scope joint commissioning opportunities for post diagnostic support.

5. Increase the involvement of families and people with autism in service planning and delivery and involve people and their families in making decisions that affect them. To do this we will:

- Continue to use the expertise of people with autism and their families via the virtual reference group;
- Support parents or adults with autism to be involved in planning using person-centred approaches;
- Give people with autism the opportunity to use personal budgets;
- Include people with autism and their families in the development and delivery of training;
- Improve pathways and better managed expectations for young people moving from being a child to an adult;
- Increase parent support and sibling groups.

6. Reduce any barriers to the participation and inclusion of families and people with autism particularly at stages of transition. To do this we will:

- Seek the guidance of the virtual reference group to establish the most appropriate way to ensure participation of children, young people and adults with autism, including expanded use of social media, email and online methods of communication;
- Promote the NAS accreditation and access award to all organisations to reduce barriers and increase awareness ([link to access award](#));
- Develop appropriate methods of gaining children, young people and adults' views to establish how we can improve provision for them;
- Explore opportunities for developing a joint commissioning pathway to support a smooth transition into adulthood;
- Work with universal services to raise awareness of how young people with autism may present differently (GP's, hospitals, schools, youth centres etc.);
- Ensure that all mental health staff can identify the mental health needs of people with autism effectively particularly during a point of crisis.

7. Provide sustainable services which are managed within available resources. To do this we will:

- Consider the need to develop traded services and/or social enterprise initiatives to develop non-statutory services for autism;
- Ensure that existing services are accountable and providing good value for money;
- Explore opportunities for joint commissioning to ensure resources are pooled effectively;
- Collaborate to review new funding opportunities as these arise;
- Maximise the use of personal budgets to ensure that support is tailored to the individual needs of the person with autism;
- Explore community development opportunities to support people with autism (e.g. sports and leisure).

8. Help adults with autism into work. To do this we will:

- Continue to improve local personalised pathways for post-16 and post-19 learning opportunities;
- The NYCC Supported Employment Service will continue to support people with autism;
- Ensure the Transitions steering group consider the needs of young people with higher functioning autism/Asperger syndrome;
- Include support for employers within the post diagnostic pathway for adults with autism e.g. advice on reasonable adjustments within the workplace;
- Promote the rights of people with autism in the workplace;

- Encourage large employers within North Yorkshire to provide apprenticeships or supported internships for people with autism;
- Ensure that young people with autism are supported through the proposed Integrated Transitions pathway;
- Link with the Department for Work and Pensions to develop approaches to support people into work.

DRAFT

Chapter 8 - How will we measure what we have achieved in this strategy?

Chapter 7 summarised the actions we will take to improve local services and provision for children, families and adults with autism. A comprehensive implementation plan will be developed and published after the strategy is launched.

The implementation and monitoring of the action plan relating to this strategy will be overseen by the North Yorkshire and York Steering Group (Autism). This group will be jointly chaired by senior managers from North Yorkshire County Council and the Partnership Commissioning Unit. Members will include representation from NYCC Health and Adult Services, Children and Young People's Service, NHS Clinical Partnership Commissioning Unit and NHS Foundation Trust service providers. The virtual reference group members will also have the opportunity to contribute to the steering group.

They will receive regular reports on progress against the actions within Chapter 7 and will hold those responsible for action to account for delivering these commitments. We will publish an annual summary of progress against the commitments made within this strategy.

The North Yorkshire and York Steering Group will report progress made within this strategy to the following groups (see visual 1 overleaf):

Children's Trust Board
Integrated Commissioning Board
The Health and Wellbeing Board
Care and independence Overview and Scrutiny Committee
Partnership Commissioning Unit Management Board

The success of the strategy will be measured against the priority actions summarised in chapter 7. We will also track the outcomes of a cohort of children families and adults with autism throughout the life-span of the strategy to ascertain whether the actions have had a direct impact on individuals with autism and their families.

Visual 1 – Governance arrangements

