

# The changing landscape of autism in North Yorkshire

**North Yorkshire autism strategy 2015-2020**

**NHS**

Partnership Commissioning Unit  
Commissioning services on behalf of:  
NHS Hambleton, Richmondshire and Whitby CCG  
NHS Harrogate and Rural District CCG  
NHS Scarborough and Ryedale CCG  
NHS Vale of York CCG

**NHS**

Airedale, Wharfedale and Craven CCG



# Contents

## **Foreword 3**

## **Executive Summary 4**

## **1. Introduction 7**

- Why has this strategy been produced?
- What is the scope of this strategy?

## **2. What do people with autism tell us? 9**

- What are the themes that have come up so far?
- What people would like to see

## **3. What's the bigger picture? 11**

- How does national policy influence this strategy?
- What is the national prevalence of autism?
- What is the local prevalence of autism in North Yorkshire?
- What about people with protected characteristics and autism?

## **4. What is on offer in North Yorkshire? 15**

- What health provision is available for people with autism?
- How do I get a diagnosis of autism?
- What education provision is available for people with autism?
- What provision is available for families with autism?
- How do we prepare young people with autism for adulthood?
- What support is available for adults with autism?
- What provision is available in my community?

## **5. How will the strategy make a difference for people with autism? 19**

- Theme 1 – Support for people with autism and their families
- Theme 2 - Assessment and diagnosis
- Theme 3 – Raising awareness and training
- Theme 4 - Information and signposting
- Theme 5 - Employment and education
- Theme 6 - Supporting people with autism during key life changes
- Theme 7 - Working together

## **6. How will we make the aims of this strategy happen? 43**

## The changing landscape of autism in North Yorkshire

### North Yorkshire autism strategy 2015-2020

#### Foreword: A message from North Yorkshire's autism leads

According to 'Fulfilling and Rewarding Lives' the 2010 national strategy for autism, autism is "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".

Autism is a condition that can have a great impact on children, adults and their families. Usually, difficulties are present in early childhood although sometimes they are not evident or significant until a time of change or transition.

Autism is a development disorder, which is also considered a disability, recognised by the Equality Act of 2010.

We hope you find this strategy a positive step forward with the challenges facing us in meeting the needs of people with autism. We want this document to be aspirational.

We want to see North Yorkshire becoming an "autism friendly" place, so that the unique perspective of people with autism is a welcome part of the

local community, and that people with autism can contribute fully to local life, through education, employment opportunities and support for families.

This strategy is only the first step in our journey. We are living in challenging times and we need to work together to realise the aspiration. Together, we are determined to empower people with autism and their families to live their lives to their full potential.

This strategy is endorsed by a number of organisations, listed below, that work with people with autism in the North Yorkshire area. We look forward to working together to implement the priorities you have told us matter most.

North Yorkshire County Council

Hambleton, Richmondshire and Whitby  
Clinical Commissioning Group

Harrogate and Rural District Clinical  
Commissioning Group

Scarborough and Ryedale Clinical

Commissioning Group

Vale of York Clinical Commissioning Group

Airedale, Wharfedale and Craven  
Clinical Commissioning Group

North Yorkshire Police  
Office of the Police and Crime Commissioner  
Hambleton District Council  
Harrogate Borough Council  
Selby District Council  
Craven District Council  
Scarborough Borough Council  
Richmondshire District Council  
Ryedale District Council

We would also like to thank mental health and other specialist providers for their support on the journey to develop this strategy.

# Executive Summary

## What is this strategy for?

The overall objective of this strategy is to ensure that services are identified, commissioned and improved to meet current and future needs and improve support for people with autism in North Yorkshire, in line with current national policy e.g. Think Autism (2014). It runs for a five-year period from October 2015 to October 2020.

This strategy achieves the following objectives:

- One strategy across children, young people and adult services in the county
- Highlights the key priorities of local people
- Considers national policy and guidance

The partner organisations in North Yorkshire that have collaborated to produce this strategy share a vision that within local communities people with autism can depend on mainstream services, to understand them and treat them fairly as individuals.

## What will this strategy do?

People with autism see things differently, and we want to see North Yorkshire as an 'autism friendly' place, so that this unique perspective is a welcome part of the local community, and that people with autism can contribute fully to local life, through education, employment opportunities and support for families.

Engagement with children, young people and adults with autism and their families has highlighted a number of local themes that are important to people. This strategy considers these emerging themes and identifies priority actions.

## Themes highlighted by people with autism

Support for people with autism and their families

Assessment & diagnosis

Awareness raising and training

Information and signposting

Employment and education

Supporting people with autism during key life changes

Working together

## Why do we need a strategy for people with autism in North Yorkshire?

- There are an estimated 7,000 people with autism across North Yorkshire. This is assuming 1% prevalence.
- There is a projected growth in demand for diagnostic assessment and support services.
- There should be a continuum of provision to support positive outcomes for people with autism ranging from universal services to highly specialist support.

## How have we developed this strategy?

We have developed this strategy with direction from a virtual reference group of people with autism, their families and organisations that work with people with autism. We also held a public consultation in the summer of 2015 consisting of five consultation events about the strategy and an online questionnaire. We gathered the views of people with autism, their families and frontline professionals, reviewed the strategy and made changes to it as necessary.

## What work has already been done for people with autism in North Yorkshire?

As a result of previous autism strategies in North Yorkshire there have been a number of achievements, including the establishment of joint strategic groups consisting of senior managers from the NHS and North Yorkshire County Council (NYCC). The joint strategic groups are driving the work around the development of the autism strategy and the associated actions within it. This strategy will supersede the previous strategies and build upon the foundations established.

## How will we know whether the strategy is working?

The actions within the strategy will be monitored regularly by the joint strategic groups and the virtual reference group. Reports on progress will be taken to the North Yorkshire Health and Wellbeing Board on a regular basis.

This strategy is endorsed by a number of organisations that work with people with autism in the North Yorkshire area. These organisations will be provided with regular updates on progress of the strategy actions.





# Chapter 1 – Introduction

## Why has this strategy been produced?

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. The Autism Act (2009) statutory guidance places a duty on all local authorities to produce an autism strategy. North Yorkshire's strategy is written with due regard for all relevant UK legislation and statutory guidance. A summary of this can be found in the accompanying document, "Autism Policy Framework".

People with autism have the right to the same life opportunities as all local residents. They should have fair and equitable access to services and support as required to meet their life aspirations. The Equality Act 2010 requires that NYCC and its partners advance equality of opportunity, foster good relations between people and eliminate unlawful discrimination. Following feedback from the public on the two previous autism strategies, NYCC and partners have decided on a joint approach that will continue to raise awareness of autism and to improve services for people with autism.

In order to produce this strategy, our priority was to engage with people living in North Yorkshire who have autism. We wanted to gather their views, opinions and experiences on what was working well for them, and what areas they would like to see improve.

We have used feedback from public consultation events held for the separate children's and adults' autism strategies published in 2012 and 2014, as well as feedback from public consultation events in 2015 and an online questionnaire about this draft strategy. Feedback from our virtual reference group has also been vital in developing this strategy. Finally, we have used feedback from the 2014-15 development of a commissioning plan for NHS assessment and diagnosis service to help us to identify the key themes that are important to people with autism and their families in North Yorkshire.

## What is the 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. It reflects upon 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 objectives. 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 personalised.

Through early identification of autism and by providing appropriate support we plan to improve opportunities for people throughout their lives with the aim of reducing unemployment and the need for mental health services in adult life. Through this strategy we will review commissioning activity and monitor key performance indicators in line with NICE guidance. The strategy will also consider services available for people with autism and their families locally and aim to ensure the services available meet the needs of those who access them.



## Chapter 2 - What do people with autism tell us?

### What are the themes that have come up so far?

The views of children, young people and adults with autism and their families have been central to the development of this strategy. Together we have identified some key themes in North Yorkshire that are important to people with autism and their families. These themes have been raised frequently by a number of people; however, different people rated the different themes as having higher or lower priority depending on their individual circumstances and the locality within which they lived.

**1. Support for people with autism and their families:** we know that it can be challenging for people with autism and their carers to know where to go for support.

**2. Assessment and diagnosis:** we know families and people with autism would like to be able to receive a diagnosis closer to home, without waiting for long periods of time.

**3. Raising awareness and training:** we know people with autism and their families would like to access mainstream services and find suitable “reasonable adjustments” have been made to ensure provision is “autism friendly”.

**4. Information and signposting:** we know that navigating services is difficult for people with autism and their families and it can be difficult to understand different access criteria.

**5. Employment and education:** we know that many young people find school difficult and understanding of autism varies significantly across educational settings. We also know that not enough people with autism are able to find or maintain work.

**6. Supporting people with autism during key life changes:** we know that key life changes, such as moving from school to university or employment can be particularly challenging for people with autism and their families.

**7. Working together:** we know that it is important to get all agencies that work with or support people with autism to play a part in implementing the aims of this strategy.

In order to respond to the needs of local people, we have used these themes to plan the priorities for action for 2015-2020 in Section 5 below. We will continue to gather people’s views, opinions and experience to help us understand what works well and what needs to improve locally.

In the summer of 2015 we held five consultation events across the county and asked people to complete an online questionnaire. Those people that contributed to the consultation included parents of children, young people and adults with autism and professionals working across a range of services and organisations. The information received provided a valuable insight into their experiences of autism, the positive aspects of their lives and the challenges that they have faced. We have incorporated people’s views and additional actions to improve the strategy.

People told us what they would like to see and these have been considered and reflected within the strategy.

## What people would like to see

- An early diagnosis, support from professionals, more information during assessment and after diagnosis, service user feedback to inform commissioning going forwards, better links with education.
- Open and transparent diagnostic process, focus on NICE guidelines and positive relationships with parents.
- Schools, GP's, job centres, universities and the police having a good understanding of the needs of children, young people and adults with autism.
- Carers require good information pre and post diagnosis about services and resources available. They would like a single point of support during crisis and would benefit from additional training to learn strategies in relation to behaviour management.
- More support for parents that continues throughout the child or person with autism's life, to ensure they retain good emotional and mental health and plan for the future.
- There is a need for knowledgeable teachers, staff and employers within all settings who value the strengths of people with autism, have high aspirations and promote a positive perception of autism.
- Parents want schools and other professionals to acknowledge parents' expertise in relation to their child's needs.
- Education, health need to work better together post diagnosis to ensure that information is shared and influences future support.
- Better information, guidance and support is needed for parents, carers and individuals with autism for children moving from primary to secondary school and for those leaving school for FE/HE/employment. This is particularly true for families of children and young people with high functioning autism.
- There needs to be better identification and assessment for girls with autism and support needs to reflect the gender differences.

# Chapter 3 - What's the bigger picture?

## How does national policy influence this strategy?

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. In March 2015 "Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy" was also published. The policy framework governing our work on autism is extensive and can be found in the accompanying 'Autism Policy Framework' document.

### What is the national prevalence of autism?

Owing to variable identification rates and a general lack of data, it is difficult to quantify with certainty the number of people with autism. Studies have found the prevalence of autism is approximately 1% in the UK and this estimate is used by the National Autistic Society (NAS) and National Institute for Clinical Excellence (NICE). If the 1% prevalence figure is applied to the UK population, this means that over 695,000 people in the UK may have autism.

Uncertainty about the prevalence of autism means that it is also difficult to estimate its associated cost. It is estimated that autism costs the UK economy around £28.2 billion per year (£25.5 billion for adults, and £2.7 billion for children). Of the £25.5 billion cost for adults, 59% is accounted for by services, 36% by lost employment for individuals with autism, and the remainder by family expenses. (Knapp et al. 2009).

### What is the local prevalence of autism in North Yorkshire?

Between April 2014 and March 2015 in the areas covered by the four North Yorkshire and York Clinical Commissioning Groups (CCGs), there were 245 children diagnosed with autism. 23 children were diagnosed with autism between April 2014 and March 2015 in the Craven area. As at March 2015 there are 1,721 children and young people with autism up to the age of 25 in North Yorkshire known to service providers. There are 154 children and young people who have a statement of special educational needs (SEN) or an Education Health and Care Plan (EHCP) with autism identified as their primary need. This reflects 23% of all statements/EHCPs.

There has been a 25% increase in the number of children and young people with autism who require additional support from the Inclusive Education Service since 2010 and as of April 2015 there are 489 requiring additional educational support from the service. This is equivalent to 28% of all children and young people 0-25 that are known to the local authority. Projection figures for 2015

onwards suggest a further increase in requests for assessment and diagnosis services and the involvement of the Inclusive Education Service of approximately 30%. This puts a huge pressure on all diagnostic, educational, and social care services and is in line with increases nationally.

In 2015, 50 young people with autism moved from school to post-16 provision. Further consideration needs to be given to how to support young people with autism when preparing for adulthood e.g. moving into further education and employment.

In 2014, 17 adults per month were referred for assessment of autism and/or Attention deficit hyperactivity disorder (ADHD) by their GP across the four Clinical Commissioning Group (CCG) areas (which include City of York). Current rates of referral (0.03% of practice population) are below the expected prevalence rates for ADHD and autism. In 2012, the (NICE) reported a 25-fold increase in the diagnosed prevalence of autistic spectrum conditions over the last 20 years (National Collaborating Centre for Mental Health 2012). This is probably a result of widening diagnostic categories, including the relatively recent subgroup of Asperger's syndrome, and the growth of services, better awareness and improved detection. This increase has had a significant impact on referrals to diagnostic services. There are 410 adults with

autism supported by Health and Adult Services (as at October 2015). 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 employment.

### **What about people with protected characteristics and autism?**

People may have stereotypes and preconceptions about what someone with autism is like. For example, "male", "white", "good at maths" are often things people have in their mind. Some of these preconceptions may prevent people accessing support that they need, for example, in relation to their sexuality or what is considered to be "right" for their cultural or religious background. It may also lead to significant under-diagnosis amongst certain groups, for example, people from a Black or Minority Ethnic (BME) background.

There is strong evidence to suggest that there are more males with autism than females. However, females are less likely to be identified with autism even when their symptoms are equally severe. This is because their traits can be more subtle and females may be more able to mask their difficulties by modelling their behaviour on others. In addition autism diagnostic criteria has historically

been developed using the behaviours that males display. Many females are never referred for diagnosis and are missed from the statistics.

Although autism is not a mental health condition or a learning disability, it is estimated that between 44% - 52% of people with autism may have a learning disability and an estimated 71% of people with autism are likely to have a mental health condition at some point during their life.

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. Some minority ethnic communities have a limited understanding of autism and 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.

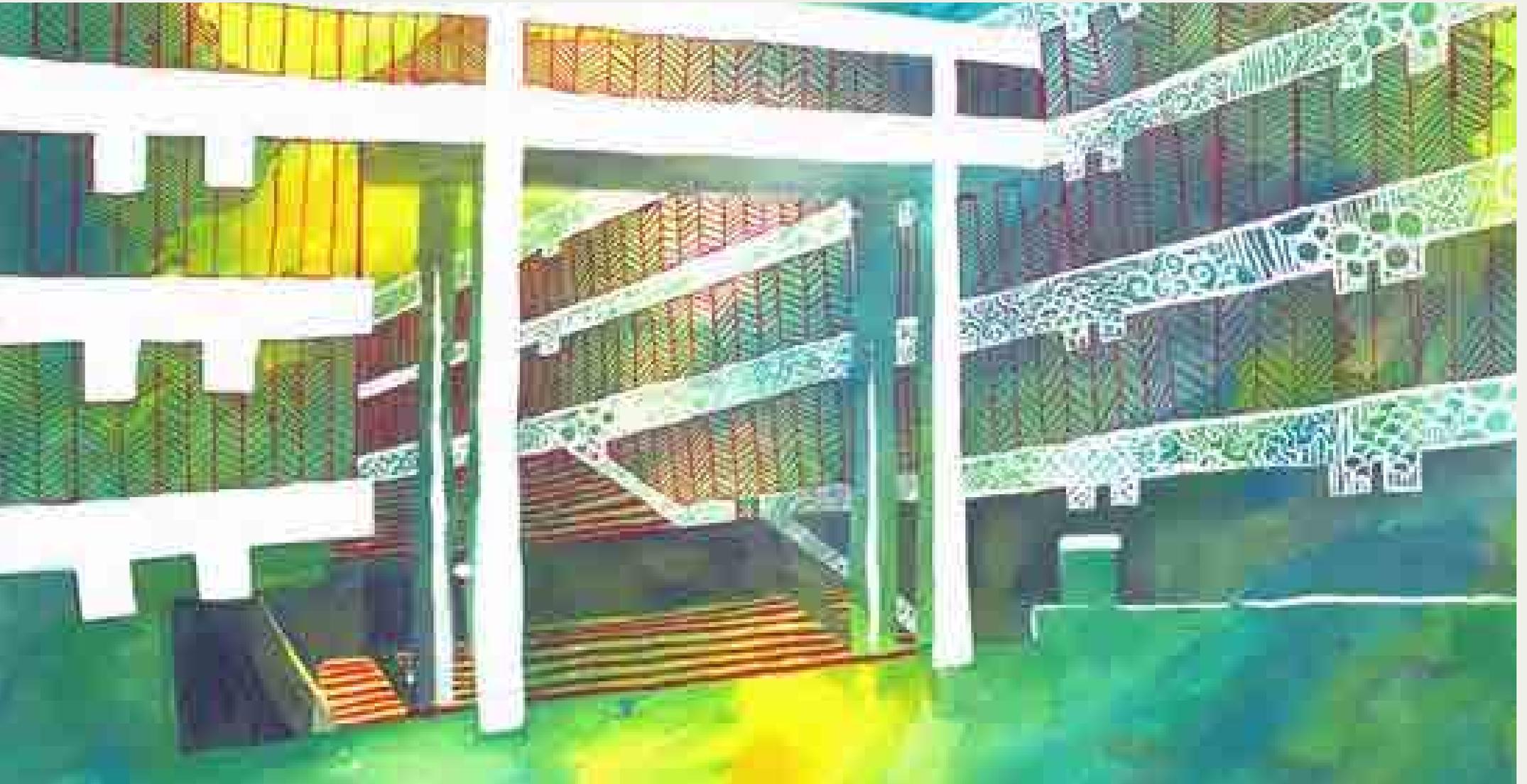
It is recognised that Looked After Children (LAC), children from military families and those from travelling communities may be less likely to be referred for a diagnosis of autism. There may be a reluctance to engage with services either because of a lack of trust or a lack of knowledge of services available. Sometimes there are difficulties with diagnosis due to the

behaviours of attachment disorder which some children display being similar to autism.

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 2030. Older people are less likely to have received a diagnosis.

We don't yet know enough about the Lesbian, Gay, Bi-sexual and Transgender (LGBT) population and autism. Nationally the Department of Health has committed to bring together groups and networks that work on equality issues, including race, gender and sexuality, with third sector and other experts on autism to look at the issues experienced by people who are lesbian, gay, bi-sexual or transgender, and members of BME groups, who have autism.





## Chapter 4 - What is on offer in North Yorkshire?

This strategy reflects the ambition to improve the range of services available locally and aligns with the ambitions within the Health and Wellbeing Strategy for North Yorkshire. 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. Further information on all North Yorkshire services can be found on our [local offer](#).

There is a continuum of provision to support positive outcomes for people with autism ranging from universal services to highly specialist support. The needs of children, young people and adults with autism will be met on an individual basis and support will be personalised to the needs of each person.

### What health provision is available for people with autism?

All people with autism have access to universal health services, for example primary care, and there will be some who will require access to more specialist services.

### How do I get a diagnosis of autism?

A health professional will make the referral for an autism diagnostic assessment. For children and young people, a health professional will carry out an initial assessment, and then make the decision to refer on to the autism diagnostic assessment team. The assessment should start within three months of the initial referral to the autism diagnostic assessment team. A health professional could include a paediatrician, child psychiatrist, clinical psychologist or speech and language therapist.

There is a local service provider in each locality for children and young people (Harrogate, York, Scarborough, Northallerton and Skipton).

For adults over 18 years of age, a GP, or another health professional involved in their care will make a referral for an autism diagnostic assessment. Assessments for adults will change in the winter of 2015 to provide a more localised service. Previously adult diagnosis services were provided out of county.

The autism diagnostic assessment teams are multidisciplinary in line with NICE guidance QS51. For children and young people the team may

consist of a paediatrician, psychiatrist, speech and language therapist, clinical psychologist, and specialist Child and Adolescent Mental Health Service (CAMHS) consultant. The adult autism diagnostic team may include a psychologist, psychiatrist and other mental health professional. These teams have specialist skills in autism diagnostic assessments. They can advise other professionals involved in the patient's care about the impact of a diagnosis or treatment, education or social support. 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 and work within the most up to date NICE guidance and diagnostic tools e.g. ICD 10 or DSM-V for children and young people.

Following an assessment, support will be offered dependent on the presenting healthcare needs of the patient. This may include further signposting and support to access relevant services for people who have not received a diagnosis. For those who do receive a diagnosis, post diagnostic support for children and young people includes a parent information pack and access to autism specific parent training programmes which are offered jointly

by the NHS and Children and Young People's Service at NYCC. Post diagnostic support is provided on an individual basis for adults and may include carer support, signposting to support networks, provision of information or attending a support group.

If further NHS provision is required or is more appropriate the person with autism may be signposted to an alternative service. For example, children may be referred to CAMHS, therapy services, and adults to social support or counselling. This may involve joint working with mental health or learning disability NHS providers to achieve a personalised approach for the individual.

## What education provision is available for children and young people with autism?

The majority of children and 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 Special Educational Needs (SEN) including autism. For children with higher levels of need, the local authority may provide resources through an Education, Health and Care Plan (EHCP).

The local authority encourages all education settings

to develop their knowledge, skills and competencies to meet a wide range of needs including autism. The Inclusive Education Service encourages all settings to continually develop their provision through the implementation of 'The Autism Education Trust Quality Standards and Competency Framework'.

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 an SEN 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. Some children and young people will require specialist educational provision. Further information on the specialist educational provision available can be found [here](#).

The local authority has an Inclusive Education Service who offer specialist services for schools and settings requiring support to improve their inclusive provision.

## What provision is available for families with autism?

Parents of, or professionals working with 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 the Prevention 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 [here](#).

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

Carers of people with autism are also entitled to request a carers' assessment to identify their own support needs in caring for an adult with autism. Carers can include spouses, family, children and young people. A range of carers' resource centres have been established across the county to provide information and signposting.

## How do we prepare young people with autism 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 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. 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. It will also ensure integrated person-centred planning and assessment approaches through the transition period, using the Preparing for Adulthood section of the Education, Health and Care plan. Young people with autism are able to request

a care assessment and carers can request an assessment of their needs. Special Educational Needs Coordinators (SENCOs) in schools should make young people with autism and their families aware of their right to request such assessments.

In the past, transition was largely seen as being the move from one council service to another, whereas Preparing for Adulthood (as Transitions is now known nationally) involves supporting young people aged 14-25 to achieve positive outcomes in many different aspects of young adult life, with a focus on maximising skills and achieving independence. NYCC have developed an integrated Preparation for Adulthood Service that came into effect from 1 November 2015. Young people who are eligible for support from this service will have access to a support planner who will act as a key worker, and there will be links with specialist careers advice, supported employment and travel trainers.

Adopting a more holistic approach to post-19 Personalised Learning has already seen significant reduction in spending on out of county placements, and the development of local provision. The proposed Preparing for Adulthood model will build on this success, way of working and making provision so that a larger group of young people either do not go out of county, or are able to return at an earlier stage.

## What support is available for adults with autism?

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.

The local authority will consider prevention measures that reduce social care needs, e.g. adults with autism can also access adult education classes and local support groups where these are available, and for those in further education, disability advice workers may be able to signpost students to the right support and help to maintain their education.

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 advisers 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. 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.

### **What provision is available in my 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](http://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 for people with autism and their families. These include leisure and sport activities, youth provision, after school clubs, parent support groups and peer support groups.



# Chapter 5 - How will the strategy make a difference for people with autism?

In the following pages each theme highlighted by people with autism and their families is considered and joint priorities have been identified.

- 1 Support for people with autism and their families**
- 2 Assessment and diagnosis**
- 3 Raising awareness and training**
- 4 Information and signposting**
- 5 Employment and education**
- 6 Supporting people with autism during key life changes**
- 7 Working together**

## **Theme 1 - Support for people with autism and their families**

We know that caring for someone with autism can be extremely rewarding but can also be hugely challenging. We want families to feel supported at all stages, starting before diagnosis and continuing throughout the person with autism's life. Many people with autism find it difficult to make friends. It is important that all people with autism can easily access information in their local area about what support from peers, charities and other community groups is available.

### **What is the progress so far?**

- Autism specific parent programmes are available for families of children and young people that receive a diagnosis of autism.
- In line with the requirements within the Care Act 2014, all carers are entitled to a carer's assessment and may be eligible for a personal budget to support their needs.
- A new Prevention Service became operational in April 2015. The new service has 12 area prevention teams which work across the 0-19 age range. Their service provides targeted support for individuals, families and groups.
- A Local Crisis Care Concordat has been agreed for mental health services, which includes developments for people with autism.
- Mental health staff employed by NYCC's Health and Adult Services (HAS) have received specialist training on how autism can affect a person's mental health and three mental health staff are autism champions.
- NYCC and NY Police are jointly developing Safe Places with third party, voluntary sector and statutory bodies. Safe Places have been created so that people are able to travel independently and safely in their own communities. There will be a formal launch of Safe Places in 2016, but the system is being trialled from September 2015.

<b>Support for people with autism and their families</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
<p>Ensure that the support available for families is of a high standard and that families feel confident that the support they receive is appropriate</p>	<p>Provide information for families about autism, local services and support networks available</p> <p>Ensure that professionals working directly with children, young people and adults with autism and their families develop the skills, knowledge and understanding of autism and challenging behaviour</p>	<p>Deliver effective and timely autism specific parent support programmes</p> <p>Promote the AET parent guides among parents of children who receive a diagnosis of autism</p> <p>Map and facilitate the development of parent support groups led by parents for parents in partnership with the NYCC Stronger Communities Managers</p> <p>Develop local information for families in relation to interventions and publish this on the NYCC website</p> <p>Provide flexible support for families through the Prevention Service</p> <p>Explore autism training pathways across NYCC and the NHS</p> <p>Expand the number of autism champions within the Prevention Services, children's social care and Health and Adult Services</p> <p>Develop a structure for on-going support for autism champions</p>

<b>Support for people with autism and their families</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Support active engagement of PWA in local communities	Support children and young people with autism and their families in accessing mainstream universal services	<p>Offer additional short term support to access universal services through the Prevention Service</p> <p>Provide advice and training for providers or short term additional support to enhance their confidence and skills in supporting children and young people with autism</p> <p>Offer activity based groups for children with disabilities including those with autism</p>
Ensure that all mental health staff can identify the mental health needs of people with autism effectively particularly during a point of crisis	Review mental health provision and ensure that those providing mental health treatment are knowledgeable about autism	<p>Evaluate training programme by providers to mental health staff</p> <p>Update the service specification for child and adolescent mental health services</p> <p>Review the Child and Adolescent Mental Health Service (CAMHS) pathway for children in crisis</p> <p>Ensure that the Looked After Children CAMHS have access to information on differential diagnosis</p> <p>Look to develop autism champions within the Healthy Child programme including, Compass Reach and CAMHS</p> <p>Review the urgent care pathway for adults ensuring services are inclusive for people with autism</p>

<b>Support for people with autism and their families</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
<p>People with autism feel included and safe within their local communities</p>	<p>Explore community development opportunities to ensure people with autism have local access and involvement</p>	<p>Continue to develop safe places for people with autism to access</p> <p>Explore community development opportunities to support people with autism (e.g. sports and leisure)</p> <p>Support the development of autism friendly communities through the NYCC Stronger Communities team to reduce isolation and develop opportunities for friendship</p>

## Theme 2 – Assessment and Diagnosis

There is an increasing demand for diagnostic services for people of all ages 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 the same time as accessing an autism assessment, including education, social care, and primary and secondary health services, including mental health.

### What is the progress so far?

- A 0-19 years pathway for local assessment and diagnosis is now well established.
- An information pack for parents and autism specific parent training is available for parents of children and young people who receive a diagnosis of autism.
- A North Yorkshire and York autism assessment and diagnosis service for adults with autism which is close to home, will be procured in 2015 on behalf of NHS Vale of York, NHS Hambleton, Richmondshire, Whitby, NHS Scarborough, Whitby, Ryedale and NHS Harrogate and Rural District.
- A diagnostic service was commissioned from Bradford District Care Trust in April 2015, in the Craven area of North Yorkshire, as part of Bradford and Airedale, Wharfedale and Craven CCG's commissioning plan. This is the Bradford and Airedale Neuro Developmental Disorder Service (BANDS) and assesses for Autism Spectrum Condition (ASC), Asperger's and ADHD in adults. It then works in support and consultation with other services to provide for mental health problems which may be encountered.
- A GP survey has been completed to assess current understanding of the adult referral pathway and areas for improvement.
- From April 2014 the Partnership Commissioning Unit (PCU) began collecting baseline data around referrals and NICE compliance, which will be used to inform future commissioning intentions for children and young people.

<b>Assessment and diagnosis</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
<p>To review local pathways for assessment and diagnosis to ensure services have effective feedback mechanisms in place to continually improve</p>	<p>Improve and develop local autism assessment and diagnostic services within North Yorkshire as identified through on-going reviews of service availability and quality</p> <p>Build on existing established baseline data within children's services to monitor activity across all ages</p> <p>Monitor data on how assessment services are accessed by groups with protected characteristics e.g. Looked After Children, older people, women, BME and Lesbian, Gay, LGBT communities</p> <p>Implement any new international criteria for diagnosis (ICD) once published, relevant statutory guidance and NICE Quality standards</p> <p>Include suggested tools for identifying and supporting differential diagnosis in children that are looked after within relevant service specifications</p>	<p>Undertaking a quality review of autism diagnostic services, service user feedback will be used to inform future service development</p> <p>Continuing to collect autism monitoring activity reports</p> <p>Ensure services are able to monitor data on those with protected characteristics</p> <p>Consider any new changes with providers</p> <p>Ensure relevant service specifications include tools for identifying children that are looked after</p>
<p>To look to review pathways for additional needs</p>	<p>Review pathways for additional needs. Diagnosis and assessment services have clear pathways into mainstream provision for all provision</p>	<p>Review pathways and listen to patients' experience feedback which should be shared with commissioners</p>

<b>Assessment and diagnosis</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Consider the need for post diagnostic support for people with autism in understanding the diagnosis and living with autism	<p>Review existing diagnostic support provision for children and young people and their families</p> <p>Review and improve existing post diagnostic support pathway for adults with local partners</p>	<p>Reviewing the provision, coverage, uptake of post diagnostic support and feedback from families.</p> <p>Include post diagnosis support as a theme within the Autism Quality Review</p> <p>Monitor post diagnostic support requirements</p>
Provide diagnostic services which are accessible	Review current provision alongside user feedback	Patients' experience feedback to be shared with commissioners
Post diagnostic support, information and signposting	Review existing support and information provided	North Yorkshire Steering Group for autism to review information that is currently available using feedback received from the consultation and will identify needs going forward

### Theme 3 - Raising awareness and training

Raising awareness is key to improving the lives of people with autism in all areas of day to day life. A prevalence level of 1% means that most teachers, social care workers, general practitioners and other health professionals will support a person with autism at some point during their career.

#### What is the progress so far?

- As at September 2015 over 1500 of North Yorkshire County Council's workforce have undertaken online autism awareness training; over 150 non-local authority staff have also undertaken this training
- North Yorkshire has been awarded the position of Yorkshire and Humber Autism Education Trust Early Years and Post 16 training hub, it also offers the school programme through a reciprocal arrangement with Leeds STARS
- North Yorkshire Police Community Support Officer (PCSO) training based on NAS resources is provided
- Over 60 Health and Adult Services operational staff are registered autism champions and have received enhanced level training on autism
- 65 children's social care and Prevention Service staff have gained accredited autism training through the Cygnet practitioner programme
- 18 North Yorkshire County Council services have commenced the National Autistic Society accreditation process with a view to achieving accreditation for autism-friendly services



<b>Raising awareness and training</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Raise awareness of autism generally within local communities	Target specific audiences during World Autism Week each year i.e. older people who may not have received a diagnosis, women, Looked After Children	Support voluntary sector groups in promoting autism awareness through the development of resources
Map current training on autism throughout public sector agencies in North Yorkshire and identify training pathways for professionals who work with people who have autism	Develop a training pathway for all public sector services in line with the standards for care requirements including safeguarding	<p>Develop a training pathway</p> <p>Seek approval from all public sector agencies</p> <p>Develop an autism training offer with reciprocal arrangements between teams for CYPS wider workforce</p> <p>Measure the number of staff within each agency at universal, enhanced and specialist level</p> <p>Look to setting targets with each agency in respect to autism training</p>

<b>Raising awareness and training</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Support the development of universal, targeted and specialist training opportunities available to all public sector agencies	<p>Contribute to the development of skills, knowledge and understanding of the autism workforce, enabling them to promote the positive aspects of autism</p> <p>Develop a traded autism training offer for educational establishments</p> <p>Identify new opportunities for commissioning training within the NHS</p> <p>Raise awareness of the different ways peoples' autism may affect them</p> <p>Improve knowledge, understanding and inclusive practice in educational settings</p> <p>Commissioned service specification to include reference to autism where relevant</p>	<p>Promote the autism champion model across NYCC and the NHS and with other agencies i.e. housing, police, district councils etc</p> <p>Promote the Autism Education Trust (AET) tiered training programme with all educational establishments (Early Years, schools and Post 16 providers) through the SENCO networks, School's forum and School Improvement Network (SIN) meetings and Inclusive Education Service information</p> <p>Emphasise the importance of understanding the individual and raise awareness of the needs of girls, those with Pathological Demand Avoidance (PDA) and the subtle complexities of people with high functioning autism</p> <p>To scope and explore avenues to increase training opportunities for clinical and non-clinical healthcare staff</p> <p>Work with universal services to raise awareness of how people with autism may present differently and their responsibility to make reasonable adjustments (GP's, hospitals, police, schools, social workers etc.)</p> <p>NHS, public health and social care commissioners will include reference to autism in service specification for commissioned services where relevant e.g. signposting to the NAS access award or equivalent</p>

<b>Raising awareness and training</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Encourage frontline services to become “autism friendly”	<p>Successful achievement of the NAS accreditation</p> <p>Promote the National Autism Society accredited status and Access award.</p> <p>Improve knowledge, understanding and inclusive practice in educational settings</p> <p>Commissioned service specification includes reference to autism where relevant</p>	<p>Support the NAS accreditation of 18 NYCC day, respite and outreach services through allocating resources for accreditation and providing specialist advice and support as appropriate</p> <p>Monitor the number of services undertaking NAS accreditation and those implementing the Access award</p> <p>Promote the Autism Education Trust Standards and Competency framework and support their implementation through the Inclusive Education service</p>

## Theme 4 - Information and signposting

Key to achieving a fulfilling life with autism is having easy access to information and advice about what support is available. This is important regardless of whether someone wishes to sit exams at school, leave home and go to university, apply for a new job or maintain a new tenancy. Later in life, it may be important for someone with autism to have consistent caring arrangements in place for themselves or a loved one, and to have clear information about accessing welfare, benefits or other welfare rights information. Adults with autism and their families involved in national consultations have said that it can sometimes be hard to know where to go for advice and information locally.

### What is the progress so far?

- An information pack for parents was developed in 2012 jointly between parents, the NHS and NYCC, for assessment and diagnostic teams to share with parents after assessment/diagnosis
- 18 day, respite and autism outreach provider services within North Yorkshire have been given tablet computers for use by people with autism and others in their services. The tablets contain apps that have been designed for people with autism and include apps to enhance sensory experiences, learn life skills and improve communication
- Some libraries in North Yorkshire contain autism-specific resources for use by the public
- Autism specific parent training is available for parents of children and young people who receive a diagnosis of autism
- The local offer has been developed
- NYCC's Customer Service Centre staff have undertaken basic autism awareness training in order to better understand the needs of people who ring up requesting advice and guidance
- A member of staff in NYCC's customer service centre is an autism champion and has undertaken enhanced training modules in different issues around autism, enabling a greater level of knowledge of autism within the customer service centre
- NYCC has developed a guide to developing accessible information

<b>Information and signposting</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
<p>Improve the way we communicate with children, young people and adults with autism and their families</p>	<p>Use a wide range of communication methods to interact with people with autism and their families that are designed with the needs of people with autism in mind</p>	<p>Public sector agencies will provide information that is “autism friendly” i.e. use clear and straightforward language</p> <p>Maintain web-based information including information on interventions for families and services that support people with autism</p> <p>Review existing information on the NYCC website in relation to autism</p> <p>Include children, young people, adults with autism, parent support groups, voluntary organisations and the virtual reference group in the design of key communications</p> <p>Canvass how best to promote and publicise autism information and signposting</p> <p>Use social media to promote key messages as widely as possible</p>
<p>Provide easily accessible information about autism</p>	<p>Develop autism information hubs and networks</p>	<p>Make autism resources available within NYCC public libraries for those with autism locally and for those moving into the area</p> <p>Develop and deliver training for library staff to ensure that they are able to signpost appropriately</p> <p>Get advice from people with autism to ascertain what resources would be useful for people with autism and the wider public</p> <p>Develop an online network for autism champions to share information.</p> <p>Invite further participation from public and private sector organisations and local voluntary groups on the virtual reference group</p>

<b>Information and signposting</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Improve information and signposting available	Develop local information and signposting pre and post diagnosis	<p>Review pre and post diagnosis information available</p> <p>Ensure that GP's are aware of the autism diagnostic pathway and signposting for those who move into the area</p> <p>Explore the role of the key worker within the assessment and diagnostic process to ensure appropriate signposting relevant to individual circumstances</p> <p>Signpost parents to relevant services and materials through the parent support programme</p>
Make it easier for people to know how to access appropriate services and support	Reduce the number of referral points for the families of children and young people with autism	<p>Single point of referral for the Inclusive Education Service (Education)</p> <p>Single point of referral for the Prevention service (Family Support)</p> <p>Single point of referral for the Healthy Child Service (Health)</p>

## Theme 5 - Employment and education

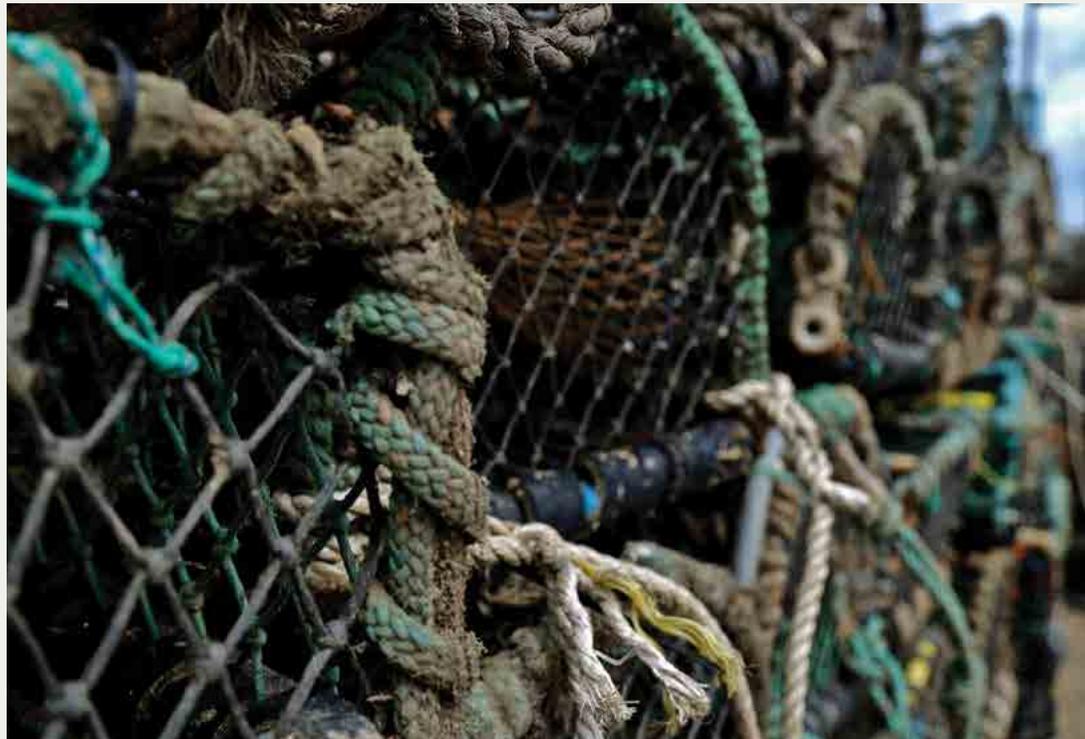
Education and employment are critical for ensuring a positive future with good outcomes for people with autism. We know that young people with SEN including those with autism do less well than their peers at school and college and are more likely to be out of education, training and employment at 18. In order to aspire high for people with autism we need to improve education and employment opportunities locally.

### What is the progress so far?

- 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
- A range of training and development opportunities have been made available for schools and settings to access
- The Inclusive Education Service

has developed a single point of referral to ensure that schools can easily access support required

- Schools have been supported to implement Lego Therapy as an intervention to increase social competence.



<b>Employment and Education</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
<p>Improve the knowledge, understanding and inclusive practice in educational settings (0-25)</p>	<p>Provide training opportunities, offer interventions and develop resources to support schools' understanding of their statutory requirements and understanding of autism</p>	<p>Implement continuing professional development opportunities for staff across all educational establishments</p> <p>Promote the Autism Education Trust standards and competency framework across educational establishments to support them in improving their offer to children and young people with autism.</p> <p>Develop SEND guidance for mainstream schools to support them in their understanding of the Code of Practice and the Equalities Act</p> <p>Support schools in developing their knowledge of therapeutic and educational interventions and their implementation through the "assess, plan, do, review" model</p>

<b>Employment and Education</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Develop appropriate peer support for children and young people with autism	Support the quality and availability of peer mentors in schools through developing and rolling out training	Work with Barnados/Flying High to; <ul style="list-style-type: none"><li>• Formulate an action plan</li><li>• Investigate and consider peer mentoring training availability nationally.</li><li>• Create peer mentoring training package to be used by specialist staff in schools</li><li>• Pilot in schools and evaluate before general roll-out</li></ul>

<b>Employment and Education</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Children, young people and their families report the school that they attend is autism friendly	Support parents in making decisions about the most appropriate educational setting for their child	<p>Promote the AET parent information</p> <p>Provide advice, guidance and advocacy for parents through the Special Educational Need and Disability Information, Advice and Support Service (SENDIASS) service</p>
Improve and expand employment opportunities for people with autism	<p>Ensure that people with autism seeking work feel enabled to do so and that employers feel confident in employing people with autism</p> <p>Ensure people with autism are able to access support if required to maintain their employment</p>	<p>Provide opportunities for young people with autism to become autism trainers for NYCC</p> <p>Provide support for people with autism seeking work</p> <p>Guide employers in making reasonable adjustments in order for people with autism to maintain their employment</p> <p>Include support for employers within the post diagnostic pathway for adults with autism e.g. advice on reasonable adjustments within the workplace</p> <p>Link with the Department for Work and Pensions regionally to discuss their targets and objectives for supported adults with autism into employment</p>

## **Theme 6 – Supporting people with autism through key life changes including preparing for adulthood (transitions)**

Appropriate support during periods of change is important for many people with autism and their families. Planning key life changes such as a transition from primary school to secondary school or from education to employment involves bringing together all of those involved with the person and is vital in helping to support people with autism to lead independent lives and fulfil their potential.



<b>Supporting people with autism during key life changes</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Remove the perceived 'cliff edge' for young people and their families through implementing a seamless model of support	<p>Provide a Preparation for Adulthood Service for young people with autism who meet the eligibility criteria</p> <p>Improve transition from primary to secondary school for children with autism</p> <p>Improve transition to Further Education (FE) for young people with autism</p> <p>Promote and where possible increase levels of independence for people with autism</p>	<p>Work together to improve pathways and better manage expectations for young people preparing for adulthood</p> <p>Offer personalised pathways for people with autism who have EHCPs and cannot access mainstream post-16 provision locally</p> <p>Have increased levels of support in place through linking services such as Inclusive Education Service, Health and Adult Services (Adult Team), Housing and Leisure</p> <p>Have an identified team in place who work together to ensure that the needs of the young person are met</p> <p>Improve the links with schools to ensure curriculum offer in relation to employment underpins vocational profiling and builds on skills learnt in the work environment</p> <p>Provide an outreach visit for all children and young people transitioning from primary to secondary and secondary to post 16 provision</p> <p>Promote the AET transition guide across all schools and settings</p> <p>Develop enhanced partnerships with independent providers, offering training and tracking pupils at the transition phase</p> <p>Promote adult learning opportunities for people with autism</p> <p>Facilitate appropriate travel training through early intervention and through later life</p>

<b>Supporting people with autism during key life changes</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Provide high quality support locally to meet the needs of people with autism	<p>Increase the level of support for people to move back into the local area</p> <p>Ensure that support planners and Specialist Careers Advisors are knowledgeable about autism</p>	<p>Improve partnerships with specialist providers who are out of area with the local authority providing the opportunity to monitor the quality of the provision being delivered at residential colleges</p> <p>Have increased levels of support for young people to move back into the local area after completing their placement at a residential college</p> <p>Support Planners will receive training in autism</p>

## Theme 7 - Working together

The 2015 “Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy” sets out that every local area is expected to have an Autism Partnership Board (APB) or a similar mechanism in place to ensure that all relevant stakeholders, including people with autism and their families and senior commissioners of health and care services, help identify local need and plan appropriate services and support.

We think it is vital that individuals, families and organisations know what the priorities are, that they have contributed to the development of these priorities and know how they are going to be achieved. That way, everyone can be confident that we are working together as consistently and effectively as possible.

## What is the progress so far?

- Governance structures were set up to support the development of this strategy.
- 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. People expressed a preference to be proactively engaged and involved in producing this strategy and the group operates mainly by email to reflect that not everybody is able, or wishes to attend meetings.
- North Yorkshire Police, the Office of the Police and Crime Commissioner and the seven district and borough councils in North Yorkshire have been engaged in the development of the strategy and have endorsed its priority areas for action

<b>Working together</b>		
<b>What are the priorities going to be?</b>	<b>What will we do?</b>	<b>How will we do it?</b>
Improve communication with the voluntary sector	Provide opportunities for all relevant public and voluntary sector organisations to be involved in autism development	Ensure that all relevant public and voluntary sector agencies are invited to join the virtual reference group and all other relevant groups
Continue to ensure people with autism and their families are centrally involved in developing autism support in North Yorkshire and feel empowered and involved in autism developments	Expand representation from people with autism and their families on the virtual reference group	Promote representation on the virtual reference group with people with autism and their families  Continue to engage with people regularly by producing annual reports about progress against this strategy and seek views to ensure full and transparent discussions about the perceived success of the strategy
Share progress and celebrate success	Be transparent and honest about progress by regularly sharing progress against the priorities in the strategy to as wide an audience as possible	Publish regular reports to update on progress against the priorities set in this strategy  Take regular reports on progress to the North Yorkshire Health and Wellbeing Board

# Chapter 6 – How will we make the aims of this strategy happen?

A key piece of feedback, raised a number of times during the consultation was that the strategy was a long document. People said they wanted a document to sit alongside the strategy that clearly communicated key ambitions, the vision and what will be different by 2020. Therefore we have produced a document entitled

**‘The changing landscape of autism in North Yorkshire, North Yorkshire’s autism strategy made simple 2015-2020’.**

(please see document attached on lefthand panel).

An implementation plan containing Specific, Measurable, Achievable, Realistic and Timely (SMART) targets will be written following the publication of the strategy clearly demonstrating what we aim to achieve and how we will measure progress towards this.

Governance and accountability will be agreed and the success of the strategy will be measured against the themes presented in Chapter 5. The Health and Wellbeing Board will provide overall governance and overview.

Credits: some of the images in this strategy have been generously supplied by Rachel Moody and Sam Guy, two people with autism who live in North Yorkshire. Sam and Rachel use different media to create landscapes and they liked the idea of depicting the autism strategy as a changing landscape where services and support will look different between the start in 2015 and the end in 2020.

If you want to see more of Sam and Rachel’s work please contact them via their websites.

[www.remporfolio.tumblr.com](http://www.remporfolio.tumblr.com)  
[www.sguyphotography.com](http://www.sguyphotography.com)

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