

**North Yorkshire County Council****Health and Wellbeing Board****13 February 2015****Strategy for meeting the needs of children, families and adults with autism in North Yorkshire 2015-2020****Report of the Corporate Director – Health and Adult Services and Director of the Partnership Commissioning Unit****1.0 Purpose of report**

- 1.1 This report seeks to gain Health and Wellbeing Board's approval for the draft strategy for meeting the needs of children, families and adults with autism in North Yorkshire 2015-2020 to go out to formal consultation in Summer 2015.

**2.0 Issues**

- 2.1 This strategy has been written by the lead officers for autism in Children and Young People's Services (CYPS) and Health and Adult Services (HAS) within North Yorkshire County Council and colleagues from the Partnership Commissioning Unit (PCU) on behalf of the four Clinical Commissioning Groups. The draft strategy is available at Appendix 1. The strategy was approved for consultation by Health and Adult Services Leadership Team (HASLT) on 3 December and the PCU Management Board in mid-December 2014. CYPS agreed the draft strategy in December 2014.
- 2.2 Scrutiny of Health Committee reviewed the draft strategy on 23 January 2015. People with autism, their families and other organisations involved in working with people with autism were also given the opportunity to review the strategy during December 2014. Members of the Scrutiny of Health Committee and members of the reference group made suggestions for amendments to the strategy. Some amendments have been made to the strategy accordingly and are included within the draft strategy (see Appendix 1). More significant suggestions for amendment will be considered as part of the consultation exercise to take place over summer 2015. The strategy will be a much improved and more inclusive document as a result of people's comments and suggestions and the Autism Project Board would like to gratefully acknowledge the feedback received to date.
- 2.3 The strategy needs approval to go out to consultation by the Health and Wellbeing Board in order to ensure the project remains on target and the

strategy is published to its deadline of October 2015. The project timeline is provided at Appendix 2.

- 2.4 Partner organisations in North Yorkshire are currently implementing two autism strategies; one for adults (published April 2014) and one for children (published 2012). Following recent legislation; “The Children and Families Act” (2014); national guidance “Think Autism” (2014), NICE guidance, “Autism: recognition, referral, diagnosis and management of adults on the autism spectrum” (2012) and NICE guidelines, “Management and support of children and young people on the autism spectrum” (2013), this all-age strategy for North Yorkshire has been drafted for publication in October 2015.
- 2.5 Following formal approval for the draft strategy to go out to consultation, more work will be carried out to refine the strategy. NYCC’s corporate communications team are involved in this project and will edit, proof read and format the document in advance of formal consultation. On approval of the final content, the communications team will design the strategy to be published as an interactive, searchable online document.
- 2.6 The consultation process will run from mid-May to late July 2015. The consultation is currently in the planning stages but will involve face to face events, incorporating workshops/focus groups; an online questionnaire and the facility to comment via social media including Facebook and Twitter. The consultation will be publicised via the corporate Communication Unit’s press and media channels and by using existing HAS, CYPS and PCU networks to ensure the widest possible coverage and attendance.
- 2.7 Following the consultation period the Autism Project Board will review the feedback and changes will be made to the draft strategy as required. The Health and Wellbeing Board will consider the final content of the strategy at its September 2015 meeting and will be asked to grant approval for the strategy to be published. Work will then take place to edit and design the document for publication during October 2015.

### **3.0 Policy Implications**

- 3.1 This strategy will drive the work on autism in North Yorkshire for the forthcoming five-year period between 2015-2020.
- 3.2 The strategy will encompass people with autism of any age and their families. It recognises that there is a range and severity of need. The strategy will be informed by legislation, a number of national priorities and best-practice models.

### **4.0 Financial Implications**

- 4.1 The cost of consultation is estimated to be approximately £3,000. Approval will be sought for costs to be jointly shared between the partner organisations/directorates. Although this is intended to be an online publication only, there will be a design cost to make the document look professional. This

would be in the region of £200. Approval will be sought for all partners to contribute to the design and the cost of this exercise.

4.2 The Department of Health has awarded each local authority in England a one-off capital grant of £18,500 (to be awarded in February 2015). In North Yorkshire this will be spent on a suite of tablets loaded with autism-specific software for the day service and respite providers currently working towards autism accreditation. However, there is no further Government funding at this time for autism and all services/support identified within the strategy will have to be resourced from existing budgets within the PCU and NYCC.

## **5.0 Legal Implications**

5.1 The national strategy for adults with autism in England, 'Fulfilling and Rewarding Lives' (2010) and its subsequent review 'Think Autism' (2014), gave the NHS, local authorities and other partners statutory duties with regard to improving the lives of those living with autism. The national autism strategy sets out a clear directive for change to ensure that those with autism are included in society and supported to lead full and rewarding lives.

5.2 The strategy will help to meet statutory duties around autism for North Yorkshire's Health and Wellbeing Board. There would be strong challenges from national and local bodies and individuals should this project not be delivered.

## **6.0 Consultation Undertaken and Responses**

6.1 There is a requirement for public consultation via online methods and face to face events between mid-May and mid-July 2015. A draft consultation plan can be found at Appendix 6.

6.2 A 'virtual reference group' of people with autism, their families and carers will help to develop the strategy by reviewing and providing feedback on draft documents, including the draft strategy itself. They will comment on plans for the design of the document and give their thoughts on the best ways to conduct meaningful consultation, and to successfully launch the strategy. This group will operate primarily by email, but some or all members may meet at key points during the development of the strategy.

## **7.0 Impact on Other Services/Organisations**

7.1 HAS, CYPS and the PCU are joint partners in this strategy and, therefore, will be required to put actions into place to fulfil the requirements of the strategy. For example, the PCU are currently going to procurement for a local diagnostic service for autism and ADHD for adults in North Yorkshire.

## **8.0 Risk Management Implications**

- 8.1 Key partners need to jointly contribute to the strategy to the agreed timescale. To mitigate this risk regular editorial meetings take place between NYCC and PCU staff and Project Board meetings are held every three months to monitor progress.
- 8.2 Key stakeholders such as people with autism, their families and organisations providing support for people with autism need to feel ownership of the process and the final strategy. The virtual reference group are contacted regularly by email and receive updates about current work as well as contributing to key project tasks.
- 8.3 The strategy will help to meet statutory duties around autism for North Yorkshire's Health and Wellbeing Board. There would be strong challenges from national and local bodies and individuals should this project not be delivered.
- 8.4 This project will not result in cashable savings, but ensuring appropriate and effective support is provided for children, young people and adults with autism is likely to reduce the incidence of crises, reduce the breakdown of school placement, necessity for mental health involvement and the need for residential care or supported living.

## **9.0 Equalities Implications**

- 9.1 The draft Equalities Impact Assessment (EIA) is attached at Appendix 4 for approval. The EIA will be made available online alongside the published strategy in October 2015. A draft Easy Read version of the strategy has been produced and will be consulted on alongside the main strategy.

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| <h2><b>10.0 Recommendation(s)</b></h2> |
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| <ul style="list-style-type: none"><li>10.1 That the draft strategy for meeting the needs of children, families and adults with autism in North Yorkshire 2015-2020, including the executive summary, easy read version and the equality impact assessment be approved by the Health and Wellbeing Board to move to formal consultation.</li></ul> |
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Janet Probert  
Director, Partnership Commissioning Unit

3 February 2015

Author of report – Sally Ritchie, Development Officer (Autism Strategy)

Presenter of report – Anne Marie Lubanski, Assistant Director Operations

**List of appendices**

- Appendix 1 – draft all-age strategy
- Appendix 2 – project timeline
- Appendix 3 – Easy Read version of the strategy
- Appendix 4 – draft EIA
- Appendix 5 – executive summary
- Appendix 6 – proposed consultation plan

# **APPENDIX 1**

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

**VERSION 15 – as at 3 February 2015**

### **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 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. 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 Bentham). 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.<sup>1</sup>

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.

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

## **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.

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, executive member for children's services, special needs, youth justice, youth service and adult learning

Councillor Clare Wood, executive member for adult social care and health integration

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'<sup>2</sup>: 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 enormously 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). It is important to note that people on the spectrum with average or high levels of functioning can still be disabled and vulnerable with regard to some skills and abilities and may therefore be at risk of missing out on the support they need due to a lack of understanding from professionals.

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 females<sup>3</sup>.

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.

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 disability<sup>4</sup>. One

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

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

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

study suggested 71% of young people with autism were going to have one existing mental health condition and 40% have two or more<sup>5</sup>.

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.

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 Project<sup>6</sup> 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.

It is recognised that Looked After Children, children from military families and those from travelling communities may be less likely to be referred for a diagnosis of autism. There may be a reluctance to engage with services either because of a lack of trust or a lack of knowledge of services available. The transient nature of these people's lives may mean that they are not settled in one place long enough to complete necessary assessments to receive a diagnosis. Data to evidence these statements is lacking, both nationally and locally. In recognition of this lack of data we have put an action in this strategy to improve the data collated in relation to these vulnerable groups.

### **National context and prevalence**

In 2009 Brugha carried out a study looking at autism spectrum disorders (ASDs) in adults living in households throughout England. Brugha found that the prevalence of ASDs found in the adults surveyed was 1 in 100. The National Autistic Society and National Institute for Clinical Excellence (NICE) both use this 1% prevalence rate in

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

<sup>6</sup> Corbett & Perepa, Missing Out? (2007), National Autistic Society

the UK <sup>7</sup>. If the 1% prevalence figure is applied to estimated population figures this means that over 695,000 people in the UK may have autism.

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**

Applying the same prevalence rate to predicted local population estimates there are likely to be approximately 5643 people with autism under 65 living in North Yorkshire and 1,272 people over 65<sup>8</sup>. Locally, our understanding of how these people are supported is evolving and we know that a multi-disciplinary approach is necessary to improve the way that people are supported. Data on people with autism is held by a number of providers and we need to improve the way we analyse data.

People's needs will 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.

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

<sup>8</sup> [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).

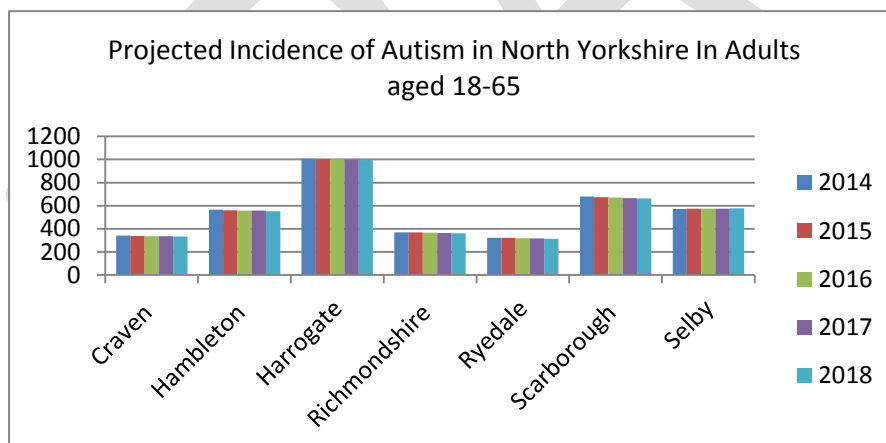
From April 2014 Health commissioners have been collating data relating to the autism diagnostic service locally across North Yorkshire and York. In 2014, 17 adults per month were referred for diagnosis by their GP across the four CCG areas (which includes City of York). Current rates of referral (205 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 2018<sup>9</sup>.

**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)<sup>10</sup> are as follows:

Craven: 55,409

Hambleton: 89,140

<sup>9</sup> Projecting Adult Needs and Service Information. Available at [www.pansi.org.uk](http://www.pansi.org.uk). Accessed 27/11/14

<sup>10</sup> [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

Harrogate: 157,869

Richmondshire: 51,965

Ryedale: 51,751

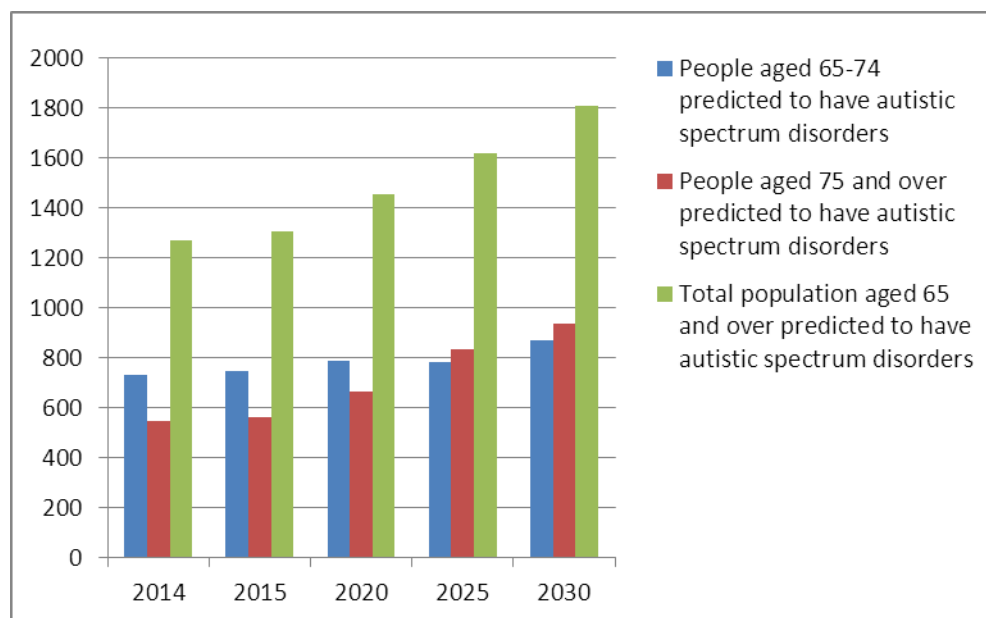
Scarborough: 108,793

Selby: 83,449

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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<sup>11</sup>.

**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, general practitioners and other 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.

<sup>11</sup> <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 ask our existing adult Partnership Boards for their feedback.

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. If required we will post out questionnaires to individuals and receive feedback via post

Once the consultation period has concluded, we will reflect the feedback received in the final version of the strategy. There will be a public launch event following the strategy's publication in October 2015.



## 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>.

The first route to access help, support and advice should you think a child, young person or adult has autism would be to contact your GP. GPs 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](http://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](http://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](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 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 Community Support Officer 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 and make this available to all adults with autism whether they have had a recent or past diagnosis, or remain undiagnosed.
  
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 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.

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## **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.

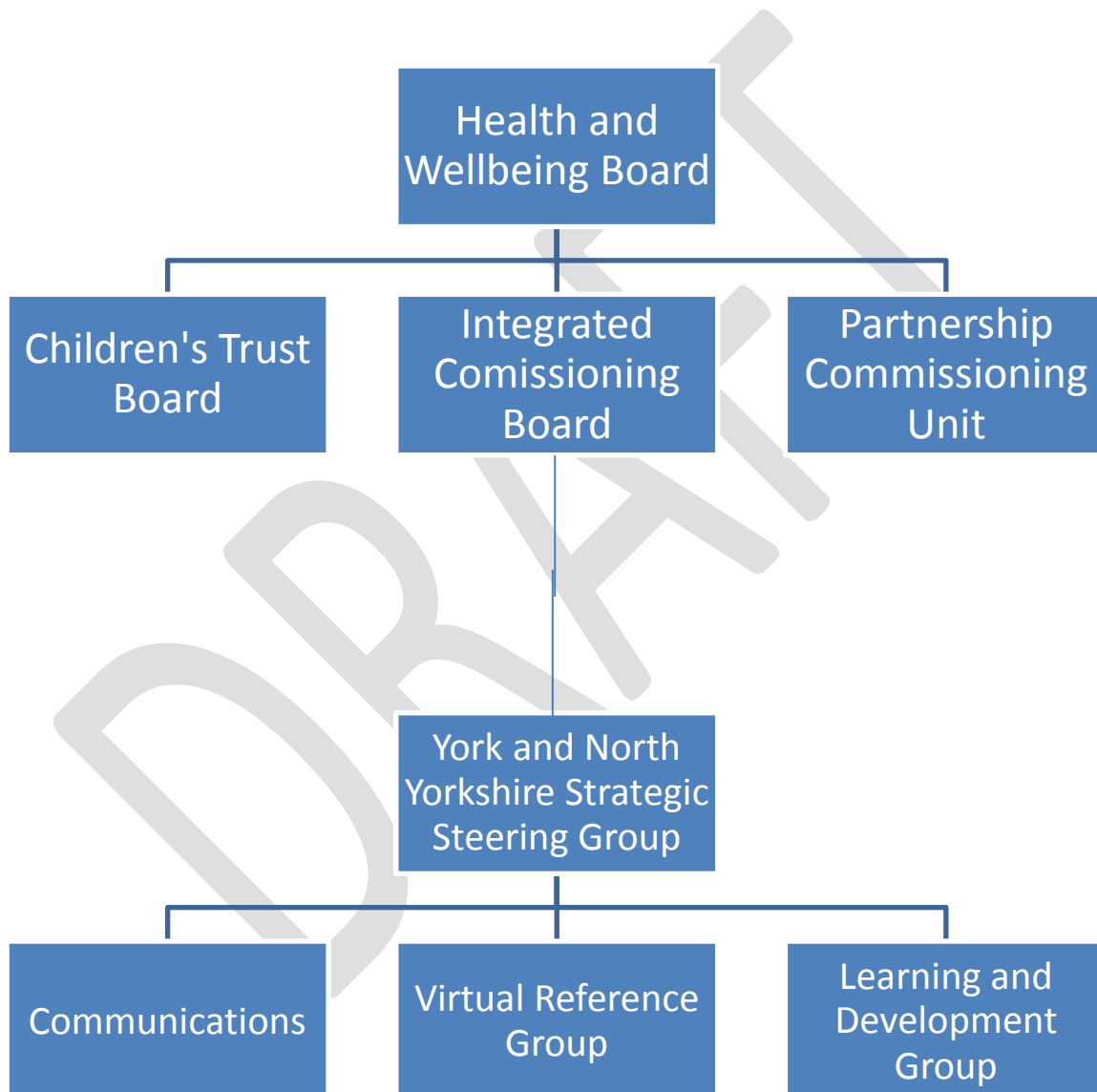
They will receive regular reports on progress against the actions within Chapter 7 and will hold those responsible for action to account for delivering these commitments. We will publish an annual summary of progress against the commitments made within this strategy.

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  
Scrutiny of Health Committee  
Partnership Commissioning Unit Management Board  
CYP Leadership Team  
HAS Leadership Team

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**



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## APPENDIX 2

### Strategy for meeting the needs of people with autism in North Yorkshire 2015-2020

#### Project overview

| Oct 2014 |   |   |   | Nov 2014 |   |   |   | Dec 2014 |   |   |   | Jan 2015 |   |   |   | Feb 2015 |   |   |   | Mar 2015 |   |   |   | Apr 2015 |   |   |   | May 2015 |   |   |   | Jun 2015 |   |   |   | Jul 2015 |   |   |   | Aug 2015 |   |   |   | Sep 2015 |  |  |  |
|----------|---|---|---|----------|---|---|---|----------|---|---|---|----------|---|---|---|----------|---|---|---|----------|---|---|---|----------|---|---|---|----------|---|---|---|----------|---|---|---|----------|---|---|---|----------|---|---|---|----------|--|--|--|
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|          |   |   |   |          |   |   |   |          |   |   |   |          |   |   |   |          |   |   |   |          |   |   |   |          |   |   |   |          |   |   |   |          |   |   |   |          |   |   |   |          |   |   |   |          |  |  |  |
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|  |  |
|--|--|
|  | Revised project brief and timeline agreed by Autism Strategy Project Board |
|  | Draft strategy document  |
|  | Prepare for Consultation   |
|  | Revision of Draft  |
|  | Consultation period  |
|  | Preparation for launch of strategy   |







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## APPENDIX 3

# North Yorkshire's Plan for Autism

How we will meet the needs of  
children, families and adults with autism

**2015 - 2020**



There are lots of children and adults with autism living in North Yorkshire. This is the plan to say how we will make sure we support everyone with autism living in North Yorkshire.



We want people with autism to get good support and have the same opportunities as everyone else.



This plan has been written for people with autism, their families and carers. It is a 5 year plan from **October 2015** to **October 2020**.



It has been written by North Yorkshire County Council's Children and Young People's service, Health and Adult services and North Yorkshire Clinical Commissioning groups.



Everyone has worked together to support this plan because we all want to make life better for people with autism and their families.

## Why we have written this plan



In 2009 the Government passed a law saying that people with autism should be treated better. This is called the Autism Act.



In 2010 the Department of Health wrote a plan called Fulfilling and Rewarding Lives.



It said what changes needed to be made and how everyone should work together to make lives better for people with autism.



In April 2014 a report was written, called Think Autism. This was written after listening to what people with autism and their families said needs to change.



To make sure we buy the services and support that people with autism and their families need, we need to spend our money carefully.



Autism is different for every person so some people with autism may only need some support and other people might need a lot of support.



Having just one plan for autism for children, adults and young people across North Yorkshire will help everyone to work better together.

## What we need to do

The Think Autism report said there are 3 main things that will make lives better for people with autism.



- 1) Being a part of the community
- 2) Getting the right support at the right time for the rest of my life
- 3) Developing my skills and independence and working to the best of my ability

## What we know about autism



There are lots of different types of autism, for example Asperger syndrome and high functioning autism. We will use the word autism when we talk about autism in this plan.

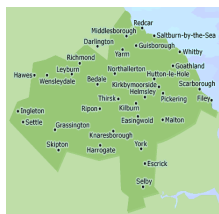


Autism affects people all their lives and you can't always tell that a person has autism. Autism is not a mental health condition or a learning disability but some people with autism also have a learning disability or a mental health condition.



To help us work out what services we need to buy we need good information about people with autism in North Yorkshire. We do this by collecting lots of different information.

We have found out:



There are almost 7000 people with autism living in North Yorkshire

We expect there will soon be a lot more people over the age of 65 with autism



There are a lot of children and young people in schools who have autism and need extra support



We need to find better ways to support young people with autism when they leave school and start to use adult services



Many people with autism will need support from different services during their life. For example, school, social care, health services and mental health services.



This means that most social care workers, health professionals and teachers will support a person with autism.

## What is available for people with autism in North Yorkshire?



There are lots of ways to get help, support and advice if you think a child, young person or adult has autism. You can speak to your doctor or a speech and language therapist.



They will be able to give good advice and people may be referred to a group of health professionals called the diagnostic team. To find out if someone has autism they will need to have an assessment.



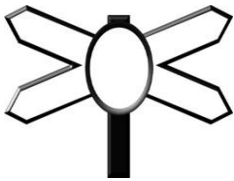
When someone has an assessment for autism it can be a very difficult time for the person involved and their family.



Even though it may be a difficult time, the team will do their best to make sure they are given the support they need.



If a child or young person is told they have autism, parents will be given information and advice. They will have the chance to take part in a parents training course.



If we find out that someone does not have autism they will be told where they can go for support and advice.

## **Education for children and young people with autism**



We want children and young people to have the best chance to learn when they are at school. This includes children and young people with autism.



Some children and young people with autism may need extra support to help them to learn.



They can get this support in a mainstream school, a special school, a specialist support service for autism or social care services for children with autism.





Any young person can find the change from being a child to becoming an adult difficult. Young people with disabilities and young people with autism may find this time much more difficult.



This time is sometimes called transition. This works well if the young person, their parents, schools and professionals all work together.



We want to make sure that young people with autism in North Yorkshire have good opportunities for further education when they reach the age of 16.

## **Support for adults with autism**



Adults who have autism will be able to have a social care assessment. They will be told what services, support and help they can get.



Other adults with autism may need extra support, for example with a mental health issue or a learning disability. They may need another assessment to make sure they find a service that is right for them.



Carers of people with autism can ask for a carer's assessment if they want one.



There are lots of local groups for people with autism and their families across North Yorkshire. We want to make sure everyone knows what is available.

## **Support to find a job**



Job Centre Plus supports adults to find a job. Disability Employment Advisors, who work for Job Centre Plus, can give extra support to people with disabilities, including autism.



North Yorkshire County Council Health and Adult Services have a Supported Employment service. They support adults across North Yorkshire, who may need extra support to find and keep a job.

## **What we have done so far**



Over the last few years, we have worked hard to make services better for people with autism and their families.

These are just a few of the things we have done so far:



North Yorkshire County Council, health services and other organisations have all taken part in autism training.



We have also have given autism training to families of children with autism.



There are now over 60 professionals around North Yorkshire who are Autism Champions. This means they know a lot about autism and can support others to learn about the people with autism need.



18 North Yorkshire County Council services are working with the National Autistic Society. They are working hard to make sure they have an excellent service that is right for people with autism.



We have been working with a group of people with autism and their families who help to plan services for people with autism across North Yorkshire.



We made a DVD made about the support young people with autism need. This will be shown to teachers to help them to support young people with autism better.

## **Our plan for the next 5 years (2015 – 2020)**



Over the next 5 years we plan to do much more to support people with autism and their families. We will ask people what they think of our plans from May to July 2015.



These are the 8 things we will do to make life better for people with autism:

- 1) Make sure more services and the staff who work there have a better understanding of autism
- 2) Have a clear way for people to find out if they have autism and how they can get the support they need afterwards
- 3) Make sure people with autism are able to use services and get the support they need. Information about all the different services they can use needs to be easy to read and understand

- 4) Make sure organisations across North Yorkshire plan services to support people with autism
- 5) Have more people with autism and their families involved in planning services
- 6) Find better ways to make it easier for people with autism and their families to be involved and included. This is really important especially when young people are getting ready to leave school
- 7) Make sure that we think carefully about how to spend our money on the services people with autism need
- 8) Help more adults with autism to find a job

## How will we find out what people think about our plan?



To help us to work out what we need in our plan, we need to hear from people with autism and their families who live in North Yorkshire.



We want to hear what is working well and what things need to change between May 2015 and July 2015.



There will be smaller groups for children and adults to have their say. For example, in schools and through the Flying High group which is a social group for young people with autism between the ages of 18-25. The Learning Disabilities Partnership Board is a group for adults, and this group will be involved in commenting on the strategy.



People will also be able to have their say by answering questions on the internet, or through a special email address.



After July 2015, we will look at all the information that people have told us or written about and we will make our final plan for autism. We will publish this on the internet in October 2015.



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## APPENDIX 4

# Equality Impact Assessment (EIA): evidencing paying due regard to protected characteristics July 2013

If you would like this information in another language or format such as Braille, large print or audio, please contact the Communications Unit on 01609 53 2013 or email [communications@northyorks.gov.uk](mailto:communications@northyorks.gov.uk).

যদি আপনি এই ডকুমেন্ট অন্য ভাষায় বা ফরমেটে চান, তাহলে দয়া করে আমাদেরকে বলুন।

如欲索取以另一語文印製或另一格式製作的資料，請與我們聯絡。

اگر آپ کو معلومات کسی دیگر زبان یا دیگر شکل میں درکار ہوں تو برائے مہربانی ہم سے پوچھئے۔



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

|   |  |
|---|--|
| Name of Directorate and Service Area                                | HAS  |
| Lead Officer and contact details                                    | Sally Ritchie x5843  |
| Names and roles of other people involved in carrying out the EIA    | Sally Ritchie, development officer (autism strategy), HAS<br>Cerys Townend, lead for autism, CYPS<br>Becky Allright, specialist commissioning assistant, PCU<br>Amanda Thompson, specialist commissioning assistant, PCU |
| How will you pay due regard? e.g. working group, individual officer | Autism Project Board (meets quarterly)   |
| When did the due regard process start?                              | During development of strategy from April 2014.  |
| Sign off by Assistant Director (or equivalent) and date             | Anne Marie Lubanski, Assistant Director Operations   |

**Section 1. Please describe briefly what this EIA is about.**

The development, publication and implementation of a new strategy for meeting the needs of all people with autism in North Yorkshire 2015-2020. This strategy will be published as an online document in October 2015.

The strategy is being developed by the lead officers for autism within Health and Adult Services, Children and Young People's Services and the Partnership Commissioning Unit on behalf of the four North Yorkshire Clinical Commissioning Groups. An Autism Project Board consisting of senior managers from the above organisations oversees the development of the strategy and monitors progress. Alongside the Autism Project Board is a 'virtual' reference group of people with autism, their families and organisations who work with people with autism who comment on the content and design of the strategy.

There will be a public consultation during Summer 2015 which will provide the opportunity for people to comment and feed back about the strategy. Following the consultation period the strategy will be amended and strengthened as necessary to reflect the input of respondents.

This is a draft EIA that will be updated post consultation to reflect the views provided during consultation.



**Section 2. Why is this being proposed?** Producing a local autism strategy is a requirement of the 2010 national strategy “Fulfilling and Rewarding Lives” which stemmed from the 2009 Autism Act, the first single-disability act of legislation in the UK. The requirement was reiterated in the refresh of the national strategy ‘Think Autism’ which was published in April 2014.

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

This strategy sets out plans to improve support, advice and guidance available for all people with autism in North Yorkshire.

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.

**Section 4. What impact will this proposal have on council resources (budgets)?**

**Cost neutral?** Yes. There are no plans to derive savings from this project and any incidental savings may be re-invested.

**Increased cost?** No

**Reduced cost?** No

Please explain briefly why this will be the result.

There is no new funding for work on autism and any expenditure has to be resourced from existing budgets.

| <b>Section 5. Will this proposal affect people with protected characteristics?</b> | <b>No impact</b> | <b>Make things better</b> | <b>Make things worse</b> | <b>Why will it have this effect? State any evidence you have for your thinking.</b>                      |
|--|------------------|---------------------------|--------------------------|--|
| Age  |                  | X                         |                          | Currently the majority of local provision is focused on children and young people, the strategy seeks to |

|                               |   |   |  |   |
|-------------------------------|---|---|--|---|
|                               |   |   |  | improve access for adults (including over 65s). However the strategy will also improve access and provision for children with autism.   |
| Disability                    |   | X |  | Autism is a recognised disability and the strategy aims to improve the experience of accessing services for people with autism, and reduce barriers to access   |
| Sex (Gender)                  |   | X |  | The strategy recognises that autism is often under-diagnosed in women and girls and will include a target to monitor the number of girls/women being diagnosed to identify whether numbers of girls and women are increasing. |
| Race                          | X |   |  | Limited evidence about the prevalence within BME groups, however it is anticipated that the strategy could have a positive effect in reducing stigma and improving awareness for everyone.                                    |
| Gender identity               | X |   |  | We are not aware of any issues covered by this strategy that will impact in any way on an individual's gender identity.   |
| Sexual orientation            | X |   |  | We are not aware of any issues covered by this strategy that will impact in any way on an individual's sexual orientation.  |
| Religion or belief            | X |   |  | Religious belief is not a factor in terms of prevalence but the strategy recognises that an individual's religious beliefs should be taken into account in ensuring culturally appropriate support is provided.               |
| Pregnancy or maternity        | X |   |  | We are not aware of any issues covered by this strategy that will impact in any way on an individual's pregnancy or maternity.  |
| Marriage or civil partnership | X |   |  | We are not aware of any issues covered by this strategy that will impact in any way on an individual's  |

|  |                  |                           |                          |   |
|--|------------------|---------------------------|--------------------------|---|
|  |                  |                           |                          | marriage or civil partnership.  |
| Looked After Children, children from military families and those from travelling communities |                  |                           |                          | It is recognised that Looked After Children, children from military families and those from travelling communities may be less likely to be referred for a diagnosis of autism. There may be a reluctance to engage with services either because of a lack of trust or a lack of knowledge of services available. The transient nature of these people's lives may mean that they are not settled in one place long enough to complete necessary assessments to receive a diagnosis. Data to evidence these statements is lacking, both nationally and locally. In recognition of this lack of data we have put an action in this strategy to improve the data collated in relation to these vulnerable groups. |
| <b>Section 6. Would this proposal affect people for the following reasons?</b>               | <b>No impact</b> | <b>Make things better</b> | <b>Make things worse</b> | <b>Why will it have this effect? Give any evidence you have.</b>  |
| Live in a rural area   |                  | X                         |                          | One of the aims of the strategy is to provide improved services and support/advice to all parts of North Yorkshire, regardless of rurality.   |
| Have a low income  |                  | X                         |                          | One of the strategy's priority targets is to get more people with autism into employment. Adults with autism are significantly under-represented in the labour market; only 15% of people with autism are in employment. This means that many adults with autism are dependent on benefits, and the under representation also indicates   |

|        |  |   |  |   |
|--------|--|---|--|---|
|        |  |   |  | that employers are not benefitting from the skills and talents adults with autism can offer in the workplace. The targets contained in the all-age strategy should make things better for people with autism who are currently reliant on benefits. |
| Carers |  | X |  | Support for carers and signposting to advice and guidance are part of the target to improve the diagnostic process. Carers are included in the virtual reference group to co-produce the new all-age strategy to be published in 2015.              |

**Section 7. Will the proposal affect anyone more because of a combination of protected characteristics? (e.g. older women or young gay men?) State where this is likely to happen and explain what you think the effect will be and why giving any evidence you have.**

Autism is classified as a disability and therefore it is more likely that individuals with autism may have a combination of protected characteristics, e.g. that they are a female with autism.

However, it is envisaged that the strategy will only affect people with autism in a positive way so that there will be no detrimental impact on anyone regardless of protected characteristic, or combination of protected characteristics.

**Section 8. Only complete this section if the proposal will make things worse for some people. Remember that we have an anticipatory duty to make reasonable adjustments so that disabled people can access services and work for us.**

**Can we change our proposal to reduce or remove these adverse impacts?**

**Can we achieve our aim in another way which will not make things worse for people?**

**If we need to achieve our aim and can't remove or reduce the adverse impacts get advice from legal services. Summarise the advice here. Make sure the advice is passed on to decision makers if the proposal proceeds.**

**Section 9. If the proposal is implemented how will you find out how it is really affecting people?** The virtual reference group comprising carers/parents and people with autism will monitor the implementation of the actions in the strategy to ensure that no individual or group of people with protected characteristics is adversely affected. This group will operate alongside the Autism Project Board, comprising senior officers within HAS, CYPS and Health who will also carry out a monitoring role.

One of the targets of the strategy is to carry out a longitudinal study of people, following their progress from the publication of the strategy in October 2015 to the end of the strategy in 2020. The aim of this study is to track people's outcomes at the start and end of the process and determine whether the actions put in place by the strategy have positively changed people's lives. We will therefore be able to compare outcomes for different groups, for example women and men.

**Section 10. List any actions you need to take which have been identified in this EIA**

| Action  | Lead          | By when      | Progress |
|---|---------------|--------------|----------|
| The strategy recognises that autism is often under-diagnosed in women and girls and will include a target to monitor the number of girls/women being diagnosed to identify whether numbers of girls and women are increasing. | Sally Ritchie | October 2015 |          |

## Appendix 5

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

#### Executive Summary

##### What is this strategy for?

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 to October 2020.

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.

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.

In April 2014 the Department of Health published 'Think Autism', its review of the national 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

##### What will this strategy do?

In North Yorkshire, health, social care and education share the above 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.

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

There is an estimated 7,000 people with autism across North Yorkshire. This is assuming a 1% prevalence.

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

There is a projected growth in demand for diagnostic assessment and support services.

### **How are we developing this strategy?**

In order to develop this strategy our first priority is to engage with children, young people and adults with autism and their families living in North Yorkshire.

A virtual reference group of people with autism, their families and organisations that work with people with autism has been established to jointly develop this strategy.

We will be holding a public consultation about the strategy in summer 2015 and will be asking for people's feedback so that the strategy can be improved and strengthened prior to its publication in October 2015.

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

As a result of the previous autism strategies 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. 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.

### **What will this strategy achieve?**

There are key themes within the actions for this strategy which include:

- Increasing awareness and understanding of autism
- Reducing any barriers to participation and inclusion
- Increasing the involvement of families in service planning
- Improving access to services for people with autism

These targets will be monitored and overseen by the joint strategic groups and the virtual reference group.

### **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.

We will monitor a small group of people with autism during the course of the strategy to determine whether their lives have improved as a result of the actions undertaken. We will report the results so that everyone can see the progress that has been made.



## APPENDIX 6

### Proposals for all-age autism strategy consultation events

- The virtual reference group will be asked for their thoughts on these proposals for consultation during March 2015.
- Consultation to take place for a 10-week period, between mid-May and late July 2015. This coincides with the end of the general election in early May and leads into the six-week school summer holiday, beginning late July.
- Consultation to take the form of an online questionnaire (to go live on designated date in mid-May) and three face-to-face events (to be held middle two weeks of June).
- Online questionnaire to be designed by editorial group and consultation specialist in the corporate Communications Unit. To be tested by the virtual reference group during April 2015.
- Five events to cover five CCG areas (including Airedale, Wharfedale and Craven CCG) to be held in Skipton, Harrogate, Northallerton, Selby and Scarborough.
- One evening event (6pm-8pm) and four afternoon events (12-2pm). Events may need to be longer than 2 hours.
- To encourage greater attendance the events will consist of workshops which will be led by subject specialists and designed to be participative and accessible for people with autism and their families. The workshops will be reflective of age phases:
  1. Early Years
  2. School
  3. Leaving school
  4. Adults
- There will be a short introduction by a senior manager, then participants will attend their preferred workshop. Part of the workshop will involve a discussion about the relevant section of the strategy. The remainder of the workshop will consist of practical discussion tailored to the theme of each workshop.
- The autism outreach team will be asking the pupils they work with to submit artwork, personal observations about autism, and these will be displayed

prominently throughout the consultation venues. Artwork, personal stories and anecdotes will also be sought from the virtual reference group. This will be displayed in the consultation venues and will also contribute to the design of the final strategy to encourage participation and to give people a sense of ownership.

- The consultation events will be designed with advice from the virtual reference group as to making the events as autism-friendly as possible, with quiet areas, a crèche and a TV area all possibilities.
- Personal invitations to the consultation events (and to participate in the consultation questionnaire) will be sent out to our existing autism networks. This will be supplemented by extensive publicity via existing NYCC social media channels. A communications plan has been developed by the corporate Communications team and the autism leads for CYPs and HAS. The PCU has agreed to distribute any publicity via its own networks.
- The invitations sent out by email will be accompanied by the draft strategy and executive summary so that people are familiar with the contents before they arrive at the consultation events.