

NORTH YORKSHIRE COUNTY COUNCIL**Care and Independence Overview and Scrutiny Committee****23 January 2014****Draft interim strategy for meeting the needs of adults with autism in North Yorkshire 2014-15****Report of the Corporate Director – Health and Adult Services****1. PURPOSE OF REPORT**

This report seeks to inform members of the Care and Independence Overview and Scrutiny Committee of the current status of the above strategy and to seek comments on the document, in particular the priority actions for 2014-15.

2. REPORT SUMMARY

This report provides some background information about the interim draft strategy for meeting the needs of adults with autism in North Yorkshire 2014-15. It describes the proposed consultation exercise for people with autism and their carers and makes recommendations to the Committee for further action.

3. BACKGROUND

The interim draft strategy has been produced in response to the requirements of the national autism strategy “Fulfilling and Rewarding Lives” (2010); the CYPS strategy for children and young people with autism (2012); and a consultation exercise in North Yorkshire commissioned from the National Autistic Society (NAS) in late 2012.

The consultation results laid out the main issues that people with autism in North Yorkshire and their carers were concerned about in relation to health and social care services.

This draft interim strategy, which has followed the format of the CYPS strategy, describes the situation in North Yorkshire as it is now, and how we intend to move forward, taking into account the drivers outlined above. It is an interim draft strategy because agreement has been reached with CYPS that we will work towards one strategy for all people with autism in North Yorkshire to be published in April 2015.

4. ISSUES AND DISCUSSIONS

Six consultation events will take place in January and February 2014 in the four main CCG areas, plus Whitby and Skipton. Senior representatives from Health and Adult Services and Health will attend all meetings.

Invitations to the events were widely distributed in in December 2013 via groups such as the National Autistic Society (NAS), PACT and the Flying High club.

Alongside the consultation events, the draft strategy, an Easy Read version and an online feedback form have been available on the NYCC and NY Partnerships websites since 12 December 2013 for people who are unable or unwilling to attend the events. The feedback form and the opportunity to make general comments have been made available until mid-February 2014.

After this time feedback will be collated and analysed. Changes will be made to the draft strategy as necessary and the final strategy will be published in April 2014.

5. RESOURCE IMPLICATIONS

No additional resources have been made available by the Government to implement the Autism Strategy, so any developments will need to be within existing resources. Knowledge and understanding of autism is still evolving; a prevalence rate of 1% has been used, but this is increasingly considered an underestimate. Data would indicate that the number of new diagnoses within Children and Young People's Services will have increased by between 15-30% by 2015. The needs of this group of people will be passed onto HAS as children move into adulthood.

6. CONSULTATION

In addition to discussion by this Care and Independence Overview and Scrutiny Committee the interim strategy was discussed at the following groups:

- HASMB - 23 October 2013
- Integrated Commissioning Board (ICB) – 14 November 2013
- LD Partnership Board – 6 December 2013
- CCG management meeting – 12 December 2013

Forthcoming discussions will also take place at:

- Health and Wellbeing Board – February 2014
- HAS Executive – February 2014

The above meetings are taking place at different points during the consultation period, with updates as necessary to inform groups about the progress of the consultation. The final strategy will be brought to the ICB for approval following the end of the consultation period, and will be signed off by the Health and Wellbeing Board before April 2014.

7 RECOMMENDATIONS

- Care and Independence Overview and Scrutiny Committee members are invited to comment on the draft interim strategy for meeting the needs of adults with autism in North Yorkshire 2014-15, in particular its priority actions.
- That Care and Independence Overview and Scrutiny Committee receive a further report at the conclusion of the consultation period.

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Interim strategy for
meeting the needs of
adults with autism in
North Yorkshire

2014 - 2015

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Chapter 1 - Introduction

This is a draft strategy for meeting the needs of adults with autism in North Yorkshire. There is also a strategy for meeting the needs of children and young people with autism in North Yorkshire. The strategy can be found by clicking on this link:

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

The draft strategy for adults with autism covers the period from April 2014 until March 2015. At that time a new long term joint strategy will be published that describes how the needs of children, young people, adults and older people with autism will be met.

Vision statement

The partner organisations in North Yorkshire that have collaborated to produce this strategy share the vision of 'Fulfilling and Rewarding Lives'¹, that:

'All adults with autism should be able to live fulfilling and rewarding lives within a society that accepts and understands them. That they are able to get a diagnosis and access support if they need it, and that they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.'

Why this strategy has been produced

For several years there has been a strong message from central government and people within the autism communities that there is a need for local services to meet the needs of young people and adults with autism.

The national strategy for adults with autism in England, 'Fulfilling and Rewarding Lives' (2010)², 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 set out a clear directive for change to ensure that those with autism are included in society and supported to lead full and rewarding lives.

It is essential to ensure that work continues to raise awareness of autism and improve services for adults with autism in North Yorkshire. This draft strategy responds to the requirements of the national strategy and describes the on-going and planned future work to develop local services for adults with autism.

(1) & (2) Department of Health (2010) Fulfilling and Rewarding Lives. The strategy for adults with autism in England
HMSO

Overall objective of strategy

The strategy will shape North Yorkshire's priorities in delivering improved services and outcomes for adults living with autism in the county.

This draft strategy for meeting the needs of adults with autism has been developed as a joint strategy between Health and Adult Services (HAS) and the Partnerships Commissioning Unit (PCU) on behalf of the four North Yorkshire Clinical Commissioning Groups (CCGs).

A joint strategy ensures that there is more effective, tangible support for adults with autism and reinforces the enormous potential benefits that can result from collaboration.

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 work together to improve services for adults with autism.

Signatures of Director of Health and Adult Services, Exec Member and Head of Mental Health and Vulnerable Adults, Partnerships Commissioning Unit

Draft paragraph from the NAS and signature

The National Autistic Society (NAS) is the UK's leading charity for people affected by autism and exists to champion the rights of all people living with autism in the UK.

We want a world where all people living with autism get to lead the life they choose.

Autism is a complex condition that requires a broad range of services and support to meet the individual needs of people affected by the condition. Good practice highlights the benefits of joint planning and commissioning of services and all services working together with a clear strategy that reflects the needs and priorities of the local area.

Good practice also sees people with autism, their carers and families at the heart of any strategy and it is essential that their views are obtained and used to assess the success of its implementation. This strategy demonstrates a commitment by North Yorkshire to improve the lives of people affected by autism. We are confident it will make a positive difference to the lives of people living with the condition across the county.

Scope of strategy

This strategy concerns adults with autism from 18 years of age, and their families and carers. It recognises that there is a range of severity of need.

The strategy has been informed by a number of national priorities and best-practice models. It links closely with the strategy for autism for children and young people with autism in North Yorkshire which was published in 2012.

Chapter 2 - Aims and principles

Our aims, in accordance with national recommendations, are to develop services in North Yorkshire by:

1. Increasing awareness and understanding of autism among frontline professionals
2. Developing a clear, consistent pathway for diagnosis in every area
3. Improving access for adults with autism to the services and support they need
4. Helping adults with autism into work
5. Enabling local partners to plan and develop appropriate services for adults with autism

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Chapter 3 - Knowing 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'³: 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'

The extent to which an individual is affected varies from person to person. People with autism can have a wide variety of support needs and each individual with autism can have areas where they function well and other areas where they may need support (we use the term autistic spectrum to describe this). Therefore some people are able to live independently, are able to interact well and be relatively unsupported while others may require specialist support.

Whilst people with autism vary greatly along this spectrum there are three main areas, known as the triad of impairments, which are common to all people with autism.

They are:

Social communication – problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.

Social interaction – problems in recognising and understanding other people's feelings and managing their own.

Social imagination – problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine.

Many people with autism prefer routine and structure and may find change exceptionally difficult to deal with. It is also possible for them to experience some form of sensory sensitivity either hypersensitivity or hyposensitivity, for example to sounds, touch, taste, smells, light or colour.

Asperger syndrome is often referred to as high functioning autism due to the fact that people with Asperger syndrome often have good verbal/language skills and are often of average or above average intelligence. Their ability to speak fluently often masks the substantial difficulties they have with communication, which can leave them highly vulnerable and at risk of social exclusion.

Autism is a disability which was recognised by the Equality Act of 2010. However, autism is not a mental health condition or a learning disability, although it is estimated that around 50% of those with autism also have a learning disability and 71% of those with autism may experience a mental health problem.

3) Department of Health (2010) Fulfilling and Rewarding Lives - the strategy for adults with autism in England HMSO

It is generally recognised that there are more males than females with autism (1.8% men compared to 0.2% women).

A number of theories have been put forward for these gender differences. Due to the male gender bias, girls are less likely to be identified with autism, even when their symptoms are equally severe. Many girls are never referred for diagnosis and are missed from the statistics. This may be due in part to the different manifestations of behaviour in autism as seen in girls and women compared with boys and men.

National context and prevalence

Autism is much more common than many people think. NAS estimates that there are 535,000 people in the UK with autism. If their families are included, autism touches the lives of over two million people every day.

NAS has reported a 61% increase in autism cases between 2005 and 2010. Recent studies have reported increased prevalence and the condition is now thought to occur in at least one per cent of people.

We also know that there is an increase in the numbers of people who have complex learning needs where autism co-exists with another difficulty. What remains unclear is whether the actual prevalence of autism is on the rise, or whether the increasing numbers of people with autism is the result of broadening or improved diagnosis. What is evident 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 these people.

Local context and prevalence

Knowledge and understanding of autism is still evolving. Therefore, the numbers of people with autism in North Yorkshire are not yet fully documented and knowledge and evidence of how to support people is still developing.

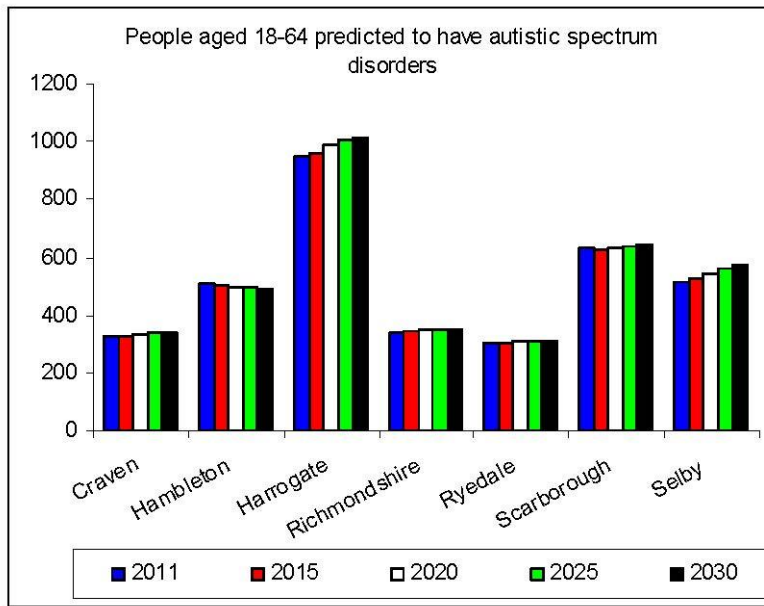
The 2005 Office of National Statistics survey found a prevalence rate of 0.9% for autism spectrum disorders. NAS recommends using a prevalence rate of one per cent, although this is increasingly considered an underestimate.

At a prevalence rate of one per cent, with a 0-19 years population of around 132,000, we would expect to see approximately 69 new diagnoses per annum from this age group in North Yorkshire. This puts huge pressure on all diagnostic, educational and support services. This is supported by data from Children and Young People Services who indicate an overall increase of between 15-30% of people being diagnosed with autism by 2015. The needs of this cohort of people will be passed on to adult services as children age.

Based on predicted adult population changes there is a small decrease in the number of people aged 18-64 predicted to have autistic spectrum disorders in North Yorkshire. The predicted

decrease is from 3,565 (3,213 male, 352 female) in 2012 to 3,499 (3,155 male, 344 female) in 2030, a 2% decrease⁴.

The overall prevalence might also be a slightly low estimate. The forecasts use a prevalence rate for autism of 1.0% of the adult population in England (men 1.8%, women 0.2%), based on studies published in 2007. A more recent study (2012) suggests the rates may be nearer 1.1 % (men 2%, women 0.3%)⁵.



4) Projecting Adult Needs and Service Information. Available at www.pansi.org.uk. Accessed 26/09/2013

5) The Health and Social Care Information Centre, 2012. Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey. Available at <http://www.ic.nhs.uk/statistics-and-data-collections/mentalhealth/mental-health-surveys/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults-extending-the-2007-adultpsychiatric-morbidity-survey>. Accessed 26/09/2013.

Some very able people with autism may never come to the attention of services because they have developed strategies to overcome difficulties with communication and social interaction, and found fulfilling employment that suits their particular talents. Other people with autism may be able intellectually, but have need of support from services, because the degree of impairment they experience hampers their chances of employment and achieving independence. Traditionally people with both a learning disability and autism have accessed and been well supported by both health and social care in North Yorkshire.

North Yorkshire has a relatively low incidence of diversity in population as the Black and Minority Ethnic (BME) communities amount to approximately 8% of the total population. This compares to the national average of 17%. The largest ethnic group in the county is of Asian or Asian British background.

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.

The NAS Black and Minority Ethnic Communities Project 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 point needs to be considered 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 treatment and support.

Religious belief is not a factor in terms of prevalence but should be taken into account in ensuring culturally appropriate support is provided.

Chapter 4 – Autism policy framework

National Context

The following documents are driving both the national and local work in relation to autism. They are presented in date order (earliest first) and their key messages are outlined briefly below.

✓ **I Exist: The Message from Adults with Autism in England (2008)**⁶

This report highlighted the problems experienced by adults with autism, in their own words, and examined the changes needed to transform their lives.

✓ **Valuing People Now: A New Three Year Strategy for People with Learning Disabilities (2009)**⁷

The document is a refresh of the Valuing People strategy and vision, which focused on rights, independence, choice and inclusion.

Following on from Valuing People Now, the Government published 'Valuing Employment Now' (2009). This strategy aims to redress the inequality of people with learning disabilities within the workplace. It set a clear target of 48% of people with learning disabilities in paid work by 2025.

✓ **Supporting people with autism through adulthood (2009)**⁸

This report identified the range of services available for adults with autism and their carers in England. The main findings indicated that people with autism may use a very wide range of public services, but that the data available on the number of people with autism using services is limited. Despite limitations the report stated that there are two key areas where the effectiveness of existing services can be improved. These are:

- Better strategy and planning, based on good information and raising levels of knowledge
- Awareness of the nature of autism and the potential needs of autistic people

The report also suggests that there is scope for better targeted support for people with high functioning autism and Asperger syndrome and indicated that, whilst financial investment in services would be necessary, identifying and supporting just 4% of those with high functioning autism in the population could result in them becoming cost neutral over time. The report goes on to suggest that increasing identification to 6% could result in potential savings of £38 million; an 8% identification rate could result in savings of £67 million.

6) National Autistic Society (2008) [I Exist: The Message from Adults with Autism in England](#) National Autistic Society, London

7) Department of Health (2009) [Valuing People Now: A New Three Year Strategy for People with Learning Disabilities](#) HMSO

8) National Audit Office (2009) [Supporting people with autism through adulthood](#) HMSO

✓The Autism Act (2009)⁹

The Autism Act was passed in 2009. This was a landmark document as it was the first single disability specific piece of legislation and it placed a number of obligations on a range of public bodies to improve opportunities for people with autism.

It also placed a duty on the Secretary of State to publish a strategy and also required them to issue guidance to NHS bodies, NHS foundation trusts and local authorities on implementing the strategy. The Act places a duty on local authorities and NHS bodies to act under the guidance.

✓Fulfilling and Rewarding Lives. The strategy for adults with autism in England (2010)¹⁰

Stemming from the Autism Act and published in 2010, the strategy sets out the vision for those with autism and gives a narrower range of areas and clear direction in terms of how public services must transform to better address the needs of adults with autism. It focuses on five outcomes of activity

- Outcome 1 Increase awareness and understanding of autism among frontline professionals
- Outcome 2 Developing a clear, consistent pathway for diagnosis in every area which is followed by the offer of a personalised needs assessment
- Outcome 3 Improving access to services and support which adults with autism need to live independently within the community
- Outcome 4 Helping adults with autism into work
- Outcome 5 Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

For individuals with autism this means:

- Having a right to receive an assessment of social care need from Health and Adult Services
- Getting the same opportunities for education and further education as everyone else
- Being supported to get a job and stay in work
- Being able to choose where to live just like anyone else
- Having relationships and social networks
- Having their health care needs properly met in a way which is appropriate for someone with autism

9) Department of Health (2009) Autism Act HMSO

10) Department of Health (2010) Fulfilling and Rewarding Lives. The strategy for adults with autism in England HMSO

- Being safe from hate crime and discrimination
- Living in a society where people understand, respect and accommodate difference, and
- Receiving support to live as independently as appropriate
(Fulfilling and Rewarding Lives, p13)

✓Implementing Fulfilling and Rewarding Lives. Statutory guidance for Local Authorities and NHS organisations to support implementation of the autism strategy (2010)¹¹

Following on from the strategy document, Fulfilling and Rewarding Lives, this document provides the statutory national guidance which NHS bodies and local authorities must follow.

The national guidance in support of the Autism Act covers the following key areas:

- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- Training of staff who provide services to adults with autism
- Planning in relation to the provision of services to people with autism as they move from being children to adults
- Local planning and leadership in relation to the provision of services for adults with autism

✓Improving access to social care for autism (2011)¹²

These guidelines from the Social Care Institute for Excellence (SCIE) give a number of key recommendations for practice, including:

- Greater understanding of autism among the social care workforce. Enabling individuals and their families to gain the most from personalisation. Better awareness of autism in the social care sector, enabling individuals to obtain a diagnosis of autism in a timely manner and also appropriate support when they are diagnosed.
- Staff supporting people with autism need to make adjustments in how they work, plan, and communicate with people with autism and with each other, so that universal services can be more accessible to people with autism
- Managers and commissioners of services also need to be flexible, creative and collaborative in how they meet the needs of people with autism. People with autism whose behaviour challenges services and those with Asperger syndrome or high functioning autism in particular need better access to services.
- Good support is vital when people with autism experience significant life changes.

11) Department of Health (2010) [Implementing Fulfilling and Rewarding Lives](#) HMSO

12) Social Care Institute for Excellence (2011) [Improving access to social care for adults with autism](#) SCIE

- Support with social interaction and practical everyday living tasks can address some of the needs people with autism commonly have at a relatively low cost.
- Multidisciplinary specialist autism services can provide good outcomes for people with autism.
- Professionals should offer carers support in their own right and work in partnership with them to provide the best possible assessment and service provision.

✓ **NICE Guideline 142, Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (2012)**¹³

This guideline covers the care provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning the care of, adults with autism.

✓ **NHS Standard Contract (2012/13)**¹⁴

The Standard Contract for Mental Health and Learning Disability Services contract requires service providers to describe the reasonable adjustments they are making for people with autism.

Local context

To ensure a consistent approach across health and social care this strategy for meeting the needs of adults with autism in North Yorkshire also needs to be linked to other local strategies including the following:

- One Council Vision
- North Yorkshire Health and Wellbeing Plan
- North Yorkshire Prevention Plan
- NHS North Yorkshire and York and North Yorkshire County Council Joint Strategic Needs Assessment
- Strategy for meeting the needs of children and young people with autism in North Yorkshire
- Getting a life not a service, Learning Disability Strategy
- Wellbeing in mind, Mental Health Strategy for working age adults

13) NICE clinical guidelines (2012) [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](http://www.guidance.nice.org.uk/cg142)

14) [NHS Standard Contract](http://www.commissioningboard.nhs.uk/nhs-standard-contract) www.commissioningboard.nhs.uk/nhs-standard-contract

- Equal Lives Physical Disability strategy
- Supporting People Five Year Strategy
- Adults Commissioning Strategy
- NHS North Yorkshire and York Transforming Primary and Community Services Strategy
- North Yorkshire Joint Carers Strategy
- North Yorkshire and York Dementia Strategy
- North Yorkshire Learning Disability Housing Plan

All of these strategies are available to view on the North Yorkshire County Council website at www.northyorks.gov.uk

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Chapter 5 - Engagement and consultation

In order to formulate this draft strategy, our first priority was to engage with adults and young people living in North Yorkshire who are affected by 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. The aim of engaging with people with autism and their families was to identify priority areas of development for this strategy.

NAS were commissioned to carry out four face to face engagement events across North Yorkshire and also to conduct an online questionnaire survey with individuals who have autism, their carers and families. The consultation was carried out in December 2012.

The engagement focused on the five key outcome areas described by Fulfilling and Rewarding Lives (2010):

- Increasing awareness and understanding of autism
- Developing a clear, consistent pathway for diagnosis of autism
- Improving access for adults with autism to the services and support they need to live independently within the community
- Helping adults with autism into work.
- Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities

It was important that to take into account the views of young adults who in time would be moving into using services for adults. Therefore the events were targeted at individuals aged 14+ years. Engagement events took place in Selby, Harrogate, Scarborough and Northallerton. A total of 72 individuals attended the engagement events and 62 online questionnaire surveys were completed.

The findings of this work are discussed within the section entitled 'Moving Forward' and are broken down into the five key outcome areas as detailed above. A full report with findings is available on request. Contact details can be found at the end of this document.

Chapter 6 - Current provision

It is important to note that North Yorkshire is already providing services and support to people with autism and their carers and this is described below using the five key outcome areas described in 'Fulfilling and Rewarding Lives'.

1. Increasing awareness and understanding of autism

A basic introductory e-learning package on autism is mandatory for North Yorkshire frontline social care staff. 85% of 2,184 staff have completed the course. The contract with the provider of this package is due to end in December 2013. Following feedback from frontline staff a bespoke online training course is currently being designed and tested by North Yorkshire staff. It will be in use by January 2014.

North Yorkshire County Council has engaged in further training and development of a group of assessment staff from around the County to become Autism Champions. These staff will cascade this training and knowledge to colleagues in their teams and provide advice and guidance to colleagues working with people with autism.

The Royal College of General Practitioners has a free e-learning package available to GPs, 'Autism in General Practice'. Currently, it is not known how many GPs in North Yorkshire have undertaken this training.

Providers of statutory health services are in the process of developing a training model which will be implemented across their services.

North Yorkshire County Council social care services currently have two provider in-house services in the Scarborough area both of which have achieved NAS accreditation status. This accreditation has been in place since 2001. Accreditation enables providers to deliver appropriate, quality services to individuals with autism within a base-line standard, with an acknowledgement of the services' excellence and best practice. A total of 17 North Yorkshire provider services have registered to work towards NAS accreditation by 2016.

We are aware that some independent sector providers have undertaken autism training, however, this training is currently not audited.

2. Developing a clear, consistent pathway for diagnosis of autism

The current health diagnostic pathway within North Yorkshire is limited and inconsistent across the county. The assessment of adults for autism is not currently commissioned by CCGs in North Yorkshire. This is an inherited situation from the previous Primary Care Trust.

If a diagnosis is required a request is made from the person's GP or Community Mental Health Trust to the Partnership Commissioning Unit to fund an assessment from available services, these include services in Sheffield and Teesside.

Tees Esk Wear Valleys Foundation Trust (TEWV) provide a limited diagnosis service in the Northallerton and Scarborough areas.

3. Improving access for adults with autism to the services and support they need to live independently within the community

In June 2009 a joint transition protocol supporting young adults with autism moving from Children and Young People's services to Health and Adult services was implemented. Assessments are now completed by a team of social care staff who specialise in carrying out this transition work. This was highlighted as an area where people experienced considerable difficulty. Work is on-going to improve this process.

Work began in 2012 on developing a housing strategy for North Yorkshire, by working together with all partners to increase and develop a flexible range of housing, care and support options.

North Yorkshire County Council provides services within a self-directed framework. This places people at the centre of assessing their own needs and deciding how they can be met. Self-directed support is available to all individuals who are eligible under current Fair Access to Care Services criteria for social care support.

4. Helping adults with autism into work

Jobcentre Plus (JCP) 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 Advisers (DEAs) are available to support people who have disabilities, including people with autism. DEAs will act as advocates for customers who experience difficulties in speaking / communicating with employers. Also, through its Flexible Support Fund, (geographical limits apply) or through Access to Work, JCP can procure additional specialist support for customers to help them in moving into employment as required. Clients can also get support through Access to Work if a mentor or support is required when they first start work.

DEAs can also provide advice on Work Choice, a programme aimed at helping severely disabled people to find and retain employment. Work Choice is tailored to meet the client's individual needs and focuses on helping them achieve their full potential and move towards being more independent. Work Choice also ensures employers get the support they need to employ more disabled people.

DEAs actively market their clients with local employers and encourage employers to apply for Disability Symbol status - showing positive approaches to recruiting clients with health or disability issues.

DEA training covers a wide range of conditions including autism and advisers undertake autism specific training. JCP Work Physiologists support advisers. Mental Health Co-ordinators also support the delivery and accessibility of services to people with experience of mental health problems. The national strategy for adults with autism states all new and existing Disability Employment Advisers (DEAs) will have autism training.

NYCC Health and Adult Services offer a Supported Employment service which includes support for people with autism. Staff within this service have training to enable them to support people with autism to gain and retain employment.

Supported Employment staff work with employers to advise on reasonable adjustments in the workplace. This service is undertaking the NAS Autism Accreditation process alongside 16 other North Yorkshire Health and Adult Services.

5. Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities

There is currently no commissioning plan focusing specifically on the needs of people with autism in North Yorkshire. As previously stated, the number of adults with autism living within North Yorkshire is based upon local prevalence data, which is extrapolated from national rates.

However, more accurate data is available for children, and with the implementation of the Child Autism Diagnostic pathway this will become increasingly accurate as time progresses.

In 2012, for the first time, the Joint Strategic Needs Assessment (JSNA) included a section on autism. This needs further development to enable us to collate comprehensive data on the local population of people with autism and their needs and will require regular updating.

The work of the North Yorkshire Steering Group for adults with autism

This group was established in 2012 in response to the guidance contained in **Implementing Fulfilling and Rewarding Lives. Statutory guidance for Local Authorities and NHS organisations to support implementation of the autism strategy (2010)**. This advised local authorities to put in place local planning and leadership in relation to the provision of services for adults with autism.

The North Yorkshire Steering Group is chaired jointly by senior managers from Health and Adult Services and Health. It reports to the North Yorkshire Health and Wellbeing Board. Members include senior managers from within Health and Adult Services, the Children and Young People's Service, Clinical Commissioning Groups and NHS Foundation Trusts. A representative from the National Autistic Society also sits on the group. The work of the group focuses on:

- The production of a North Yorkshire strategy for meeting the needs of adults with autism
- Mapping existing needs and services and linking these to the Joint Strategic Needs Assessment.
- Improved identification and diagnosis of autism in adults
- Training multi agency staff that provide services to adults with autism

The Steering Group has several sub groups which meet to work on various projects, such as training and the creation of a diagnostic pathway. The groups operate on a task and finish basis, reporting in to the Steering Group. The groups are disbanded on completion of projects.

Chapter 7 - Moving forward

This section of the North Yorkshire strategy for meeting the needs of adults with autism is divided into the five key outcomes of 'Fulfilling and Rewarding Lives' and outlines the following:

- The national view of the actions that need to take place in this specific area;
- The key messages from people who attended the North Yorkshire engagement events described on the following pages and from people who completed the online questionnaires;
- North Yorkshire's proposals for how we intend to fulfil the expectations of both the Government and people with autism and their families in the local area. We call these our 'priority actions'.

It should be noted that the priority actions in this document relate to this one year strategy (2014-15) for meeting the needs of adults with autism. From April 2015 new priority actions for children, young people, adults and older people will be produced within a joint strategy.

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Increasing awareness and understanding of autism

National view of actions that should take place in this area

Many of the difficulties that adults with autism experience are as a result of poor understanding of autism and its impact, both in the wider community and also amongst professional staff who work within the community, for example:

- Social care workers such as social care assessors, customer advisers and managers
- Health service practitioners such as GPs and community nurses
- Further education professionals such as lecturers and learning support staff
- Professionals who support people into work such as supported employment officers, Connexions and Job Centre Plus
- The criminal justice system, e.g. police officers and prison officers

The national strategy and guidance makes plain the need to ensure frontline staff are trained appropriately. This training should provide:

- General autism awareness training, which should ultimately be available for everyone working in health and social care
- Specialised training for staff working in key roles – such as GPs, those responsible for conducting community care assessments and those in leadership roles locally.
- Training should reflect the actual situations staff work in.

The core aims of training should be that staff are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services for people who have a diagnosis or display characteristics of autism.

Feedback on this issue from engagement events

1. Raising awareness amongst professionals working with people with autism

Findings within the NAS engagement report indicate that approximately 70% of those who took part either in the engagement events or the online survey felt that social care and health service staff did not have a good understanding of autism. Particular concern was raised about the lack of awareness amongst local GPs.

2. Women and girls with autism

A specific reference was made to the lack of awareness by GPs about the needs of women and girls on the autism spectrum. This lack of awareness is supported by national findings as discussed on page 6 of this strategy.

3. Health and social care staff

Individuals stated that they had experienced inflexible ways of working from health and social care staff, and that reasonable adjustment had not taken place to take account of their autism as a spectrum condition within both health and social care settings.

4. Training for frontline staff

The value and need for mandatory and standardised training for social care and health staff was identified. Respondents felt that if this could be developed and in part delivered by people who have autism which included real life stories, then this would be viewed as proactive and inclusive.

5. Provision of information

The desire for information for carers and family members post diagnosis and condition management information for newly diagnosed individuals was expressed as a need.

6. Training for other staff in the public sector

In addition to health and social care staff, the engagement events and online questionnaires highlighted the view that training would also be beneficial for other sector service providers, such as job centre staff, district council and housing providers, the criminal justice system, emergency services and universal services. This could be achieved with the rolling out of an online e-learning tool.

Increasing awareness and understanding of autism

Actions for 2014 – 2015

Raise awareness and understanding of autism amongst adult social care and health staff as well as other frontline staff in the public sector via the following actions:

- Rolling out a new online e-learning package designed to raise awareness of autism in January 2014. Initially this will be piloted and rolled out with North Yorkshire County Council staff, but it is anticipated that other public sector staff will be able to use the tool from April 2014.
- Exploring research around women and girls with autism to better understand the needs of this cohort. This research will be carried out in 2014 and the findings will inform the development of the joint strategy for children, young people, adults and older people with autism to be published in 2015.
- The Partnership Commissioning Unit will liaise with area teams in Autumn 2013 to promote the Royal College of General Practitioners' online autism awareness e-learning tool 'Autism in General Practice' to GP practices and to monitor uptake of this e-learning opportunity.
- Training for health and social care staff to include the necessity of making reasonable adjustments to take account of people's autism. This training will take place on a continuing basis throughout 2013/14.
- Working in partnership with people with autism, where possible, to develop and deliver appropriate training for frontline staff. This work will begin in 2014.
- An on-going piece of work is attempting to map the existing provision of information to people with autism and their families. This piece of work will be completed in 2014.
- Members of the Autism Steering Group to ensure multiagency training opportunities are actively pursued.

Developing a clear, consistent pathway for diagnosis of autism

National view of actions that should take place in this area

The Social Care Institute for Excellence guidance on autism acknowledges that getting a diagnosis of autism in adulthood, in some instances, can lead to discrimination. However, this guidance also identified the following key benefits:

- A diagnosis helps explain to the person, their family and friends and the wider public what has previously been unknown or misunderstood.
- A diagnosis can help shape an improved support package, as long as this is not done in a mechanistic way.
- A diagnosis avoids the problems of misdiagnosis, as faced by many people with autism, e.g. individuals wrongly thought to have a mental health problem.
- A diagnosis can assist with accessing services and benefits.

National guidance demonstrates a need for:

- A clear local pathway for diagnosis of autism, from initial referral through to assessment of needs, should be in place.
- A diagnosis alone is not enough: the fundamental change needed is that diagnosis leads to a person-centred assessment of need, in line with the NHS and Community Care Act 1990.
- A diagnosis of autism should be recognised as a reason for assessment; it should also be a catalyst for a carer's assessment.
- The end goal is that all NHS practitioners will be able to identify potential signs of autism, so they can refer for clinical diagnosis if necessary, but more importantly so they can understand how to adapt their behaviour, and particularly their communication, when a patient either has been diagnosed with autism or displays signs of autism.
- When a person has previously had a needs assessment, and is then diagnosed as having autism, this should be recognised as a potential reason for reassessment.

Feedback on this issue from engagement events

90% of those who took part in the engagement events had a formal diagnosis of autism, of these, 58% had received this diagnosis under the age of 18.

1. Lack of knowledge of diagnostic services

People who attended the events highlighted the lack of knowledge of GPs about how to access diagnostic services.

“GP was unable to find anyone who could diagnose me on the NHS so paid for myself privately (£1000).”

2. Location of diagnostic centres

People who attended the events expressed concerns about the distances needed to travel to access a diagnostic service.

“The whole process was horrific and it was a great problem to have to travel 60 miles each way to Sheffield”.

People were also worried about the length of time it took to get a diagnosis due to waiting lists.

“Initially I was told that I’d be ‘assessed’ in Harrogate and then probably be referred to somewhere like Sheffield....and that the process could take anything up to 4 years. Can you imagine how frustrating that is?”

3. Lack of post diagnostic support.

Approximately 43% of those who had received a diagnosis had received no post diagnostic support. Of those who had received support attendees commented that they found the most benefit having flexible access to a psychotherapist, and access to an Asperger support group.

4. Referring for a social care assessment.

The research also demonstrated a gap following diagnosis in then referring onto social care for an assessment of need, one attendee expressed the view that:

“Personalised needs assessments do not exist for adults with Asperger syndrome!”

5. Health Support

The research asked people to express what support provided by health would be most useful. 83% responded that having advice and information with signposting to other services would be the most useful. Other high scoring areas were counselling, support groups, psychology, occupational therapy, speech and language therapy and psychiatry.

Feedback evidenced that where a person had the need for support from psychological services, but had no formal diagnosis of a mental health condition or a learning disability,

then they frequently were not able to access support, until their mental health had deteriorated to such an extent that they then received support from mental health services.

Developing a clear, consistent pathway for diagnosis of autism

Actions for 2014/15

- The Partnership Commissioning Unit, via the Clinical Commissioning Groups will communicate the current correct diagnostic pathway to accessing services to GP practices by December 2013.
- The Partnership Commissioning Unit will examine setting minimum waiting times for a diagnosis of autism. The Unit will monitor current waiting times and will feed back the results by April 2014.
- The Partnership Commissioning Unit will review the current costs of out of area diagnostic services by December 2014.
- The Partnership Commissioning Unit will review the availability and accessibility of other health services such as counselling, psychology etc. for those with autism and make recommendations to the Clinical Commissioning Groups to improve access. Signposting to other services such as support for carers and advocacy will also be promoted at diagnosis. This work will take place in 2014.
- The CCGs and NYCC will ensure that any person with more complex needs will receive appropriate care in line with the recommendations and principles of the Winterbourne Concordat Action Plan. This work is on-going.

Improving access for adults with autism to the services and support they need to live independently within the community

National view of actions that should take place in this area

Improving access to services and support is a longer term goal as it will require a cultural change within public services and in the community.

This section of the national implementation strategy focuses on how local areas can better identify needs, and what structures and processes can best enable those needs to be met. In particular, it looks at the leadership structures locally, which will help drive change. Importantly, it does not pre-empt any decisions about what services should be made available, or how.

- Adults with autism should be able to access personal budgets and direct payments in line with the assessment of their needs.
- The commissioner/manager should participate in relevant local and regional strategic planning groups and partnership boards including the proposed Health and Wellbeing Board.
- Local partners may also want to consider establishing a local autism partnership board.
- The Standard Contract for Mental Health and Learning Disabilities explicitly requires service specifications, and therefore service providers, to demonstrate how reasonable adjustments for adults with autism are made.
- Around 70% of children with autism identified through the SEN system have statements and therefore transition planning must take place. Young people with autism who do not have a statement of SEN may instead have a Health Action Plan.
- Effective transition planning should include career preparation up to age 16 and plans for education, employment, training, transport, housing and leisure from 16 to 19 and beyond.
- Young people with autism and their families/carers should always be involved in transition planning. Plans should be individually tailored to the needs and wishes of the individual young person and reviewed and updated each year.

Feedback on this issue from engagement events

1. Social care assessments

The engagement events carried out by the National Autistic Society were also tasked with identifying what services were working well locally and where gaps in service provision exist. Just over 60% of those who completed the online survey had received an assessment from social care, with 80% of these going on to receive services.

Experiences of the social care assessment process varied:

'Due to my daughter having an IQ above 70 and no learning difficulties, there isn't any help or support available: this is not funded'

'Assessments have been done on our daughter over the last 2-3 years, but not very effectively initially due to poor understanding and assessment process'

'We eventually were allocated to a Transitions social worker who was much more helpful, on the third attempt at assessment my daughter was allocated a reasonable personal budget and now we are exploring ways of using it'

2. Housing

Living within the community and also in supported housing with personalised support was seen as very positive, with just under 70% of those who took part living in owner occupier properties. However, concerns were raised where people were living with older parents on what would happen when they passed away.

Attendees wanted a range of living arrangements to be available, and felt that to provide a better quality service housing providers would benefit from autism training. It was felt that this would enable them to identify and prevent potential problems for tenants. The research also identified that it would be

'It would be enormously helpful for N.Yorkshire to produce a clear housing strategy for autistic adults'

3. Reablement

Approximately 38% of respondents were receiving services from social care. START (Short Term Assessment and Reablement Team) was viewed very positively.

'START helps transition to independent living – it is working well and monitored too'

4. Personal budgets

Personal budgets were working well, and were being used to provide varied support. It was felt that providers were now more aware of personal budgets and were adapting their services accordingly. The report identified that personal budgets were not always accessible to those with Asperger syndrome or high functioning autism.

Personal health budgets have been piloted within Continuing Health Care but will be implemented more widely in 2014/15.

5. Transitions and advocacy

However, two areas which were highlighted which needed improvement were, the lack of advocacy and transitions.

'Transitions managers – useless, they hinder you and deny access to services, only fighters stand a chance – and I'm tired of fighting, I shouldn't need to do this.'

Improving access for adults with autism to the services and support they need to live independently within the community

Actions for 2014/15

- A new assessment tool, which will be used from 2014, will aid social care assessors by building an autism checklist into the standard assessment. This will enable the development of a personalised support plan to meet identified need.
- Lead commissioners from North Yorkshire County Council and the Partnership Commissioning Unit will link with District Councils on the development of appropriate accommodation for adults with autism.
- The reablement (START) service in North Yorkshire will monitor the number of people with autism who undertake the period of reablement, and the outcomes of this input.
- As part of the North Yorkshire Prevention Strategy, work will continue to maximise the use of personal budgets by adults with autism. North Yorkshire County Council will monitor the uptake of personal budgets by people with autism. Information will be made available on Personal Health Budgets as they are implemented.
- Health and Adult Services and Children and Young People's Services will continue to work together to improve the Transitions process for young people moving into adult services. There is a Transitions Steering Group, a multi agency protocol and action plan in place to aid this improvement.
- Advocacy service specifications will include the requirements for staff to have autism awareness training and have the skills to appropriately support people with autism.

Helping adults with autism into work

National view of actions that should take place in this area

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. It is clear that more needs to be done to help adults with autism into work.

The national strategy includes:

- ensuring adults with autism benefit from wider employment initiatives
- personalising welfare and engaging employers
- improving existing provision
- developing new approaches that will better support adults with autism.

Feedback on this issue from engagement events

1. Employment status

Completed online surveys confirmed that just over 70% of respondents were not currently employed. From those that were employed, just over 60% were in full time paid employment and 30% worked in paid part time employment. The remainder worked on a voluntary basis. From the 70% who were not employed, 50% said that they would like to be.

2. Supported Employment Service

Several comments from the research were very positive about the supported employment service

'Excellent support from NYCC Supported Employment service'

However, opinion was expressed that the rural geography of North Yorkshire along with difficulty in accessing transport was detrimental to people gaining employment.

3. Job centre

Individuals had also experienced negative experiences whilst attending the job centre.

'Job centre was a disaster to start with. In the end we had to go with him to make sure they had some understanding of his difficulties'

4. Information for employers

The need for employers to have information and awareness on autism was an additional point which was highlighted.

'Employers need training and awareness raising; so do careers advisors'

5. Transition from education to employment

There was a clear interest in the need for support to identify employment strengths and transition from education into employment. Looking at employment in its wider context was also seen as valuable.

'Self-employment needs to be explored, support to start your own business or social enterprise, and on-going support for issues you might face in your first year, a mentor or something like that'.

Helping adults with autism into work

Actions for 2014/15

- A key priority action of this strategy is to get more people with autism into paid employment.
- The North Yorkshire County Council Supported Employment team plays an important role in gaining paid or voluntary employment for people with autism around North Yorkshire. In order to improve the service further, the Supported Employment team have registered to work towards NAS accreditation status. The timescale for completion of this process is June 2016.
- The Supported Employment lead for North Yorkshire County Council will engage with the Department for Work and Pensions regionally to discuss their targets and objectives for supporting adults with autism into work. This engagement will take place in early 2014.
- The Supported Employment team will continue to work with employers to develop their skills and knowledge of the needs of employees with autism. This will improve the experience of people with autism in the workplace.
- Health and Adult Services and Children and Young People's Services will continue to work together to improve the Transitions process for young people moving into adulthood. This will include moving from education to employment. The Transitions Steering Group have this issue as a key priority and will monitor the outcomes of people with autism as they move into work.

Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities

National view of actions that should take place in this area

Developing appropriate services is a long term responsibility and sits locally. Local partners need to work together to develop relevant services and extend existing ones, to enable adults with autism to be included in society. Obviously this development must reflect the needs, available resources and priorities of the local area. Local partners include:

- Collaborative Commissioning Group
- Health and Well Being Board
- Children and Young People Services
- Elected members
- Police/Fire and Rescue
- Criminal justice system
- Job Centre Plus
- District / Borough Councils
- Social care providers
- Housing and support providers
- Voluntary sector
- Clinical Commissioning Groups
- Community Mental Health Service Providers
- General Hospital Acute Foundation Trusts
- Community health services
- Specialist Commissioning Group (NHS England)
- Opticians
- Dentists

The national strategy includes:

- Prioritising the needs of adults with autism in every area.
- Identifying and promoting service models that are proven to make a positive difference for adults with autism.
- Enabling adults with autism and their families to have greater choice and control over where and how they live.
- Local authorities should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of community care services for adults with autism.
- The development of commissioning plans could be led by the Health and Wellbeing Board under its proposed remit to lead the JSNA.
- Adults with autism should be able to access mainstream public services and to be fully included within society. However, specific services and support dedicated to adults with autism can play a pivotal role in enabling them to use mainstream services effectively.

Feedback on this issue from engagement events

1. Information and universal services

Having access to a *'one stop shop'* or *'shop for support type online information – like trip advisor'* would be seen as being beneficial, along with local *'preventative services not crisis led services'*. Attendees also expressed a view that they would like to see:

'An improvement in universal services so we can access everything just like everyone else.'

'I am not sure what we could have accessed'

2. Types of support

The types of support which were viewed as valuable, in ascending order, focused around

- one to one support
- social skills training, mentoring, befriending and social groups
- access to advice and information and advocacy
- daily living support
- day activities and employment services
- money management

- access to education
- respite care and support for carers and partners

Family support

70% of those who completed the online survey were receiving support from family members. This support came in the form of

- providing a home
- arranging and accompanying to appointments
- providing transport
- managing paperwork and finances
- ensuring that the person was kept safe and not taken advantage of due to their autism.

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Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities

Actions for 2014/15

The lead officer for adults with autism will improve the information available including:

- Co-ordinating information about voluntary and other sector organisations that offer support to people with autism and their families.
- Ensuring that people with autism and their families are made fully aware of the services available from Health and Adult Services.
- Ensuring information on autism is readily available and accessible through public networks such as libraries and via autism community channels.
This work will take place during 2014.
- Work will take place in 2014 to explore with people with autism how to co-produce options for the best support.
- A mapping exercise of current services which can support people with autism will take place in 2014.
- By December 2014 an online directory of support, advice and services that offer support to people with autism will be added to North Yorkshire County Council's website.
- This online directory will be shared with people with autism, their carers, the North Yorkshire County Council Customer Services Centre and key organisations such as GP practices and Carers Centres.

Chapter 8 - Accountability and Performance Framework

The implementation of the action plan relating to this strategy will be overseen by the North Yorkshire Autism Strategy Steering Group. It will be monitored by the Integrated Commissioning Group, Care and Independence Overview and Scrutiny Committee and Health and Wellbeing Board.

Reports and updates on work in progress will be taken regularly to the Learning Disability Partnership Board.

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