

The changing landscape of autism in North Yorkshire



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



Airedale, Wharfedale and Craven CCG

North Yorkshire Autism Strategy 2015-2020 Policy Framework



Autism Policy Framework

The national context

This document considers the legislation, policies and guidance relating to people with autism. This includes national and local reviews of current provision and key targets for the future. Many of the findings of these documents have informed "The changing landscape of autism in North Yorkshire - the North Yorkshire autism strategy 2015-2020."

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. This section is divided into legislation, statutory guidance, best practice and the local context.

Legislation

Disability Discrimination Act 2005 / Equalities Legislation/ Equalities Act (2010)

The Disability Discrimination Act 2005 requires all organisations that provide a service to the public to make reasonable adjustments to those services to ensure they are accessible for disabled people. This includes making reasonable adjustments for people with autism. Potential areas for consideration include environmental adjustments to take account of hypersensitivities, adjustments to processes, such as scheduling appointments at less busy times, and adjustments to communications, for example by ensuring essential documents and forms are available in accessible formats. All public sector services should make reasonable adjustments (December 2006, Disability Equality Duty).

Health Act 2009

This Act aims to improve the quality of NHS care and services and to improve public health.

The Autism Act 2009

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.

Health and Social Care Act 2013

The act looked at modernising the NHS by putting clinicians at the centre of commissioning, allowing there to be greater focus on innovation, patient empowerment and the role of public health.

There are six key policy areas of the Act:

- Clinically led commissioning
- Provider regulation to support innovative services
- Greater voice for patients
- New focus for public health
- Greater accountability locally and nationally
- Streamlined arms-length bodies

In addition to these there are nine crosscutting themes, which look at the role of the NHS and key areas for change.

Improving quality of care

- Tackling inequalities in healthcare
- Promoting better integration of health and care services
- Choice and competition
- The role of the Secretary of State
- Reconfiguration of services
- Establishing New Bodies
- Research
- Education and Training

Children and Families Act (2014)

The Children and Families Act states that as a fundamental requirement the local authority must follow four guiding principles:

- Listen to the views, wishes and feelings of children, young people and parents;
- Ensure children, young people and parents participate in decision-making;

- Provide the necessary information and support to help children, young people and parents participate in decision-making; and
- Support children, young people and parents in order that children and young people can achieve the best possible educational and other outcomes.

The Children and Families Act takes forward the government's commitments to improve services for vulnerable children and support strong families. It underpins wider reforms to ensure that all children and young people can succeed, no matter what their background. The Act will reform the systems for adoption, looked after children, family justice and special educational needs.

Statutory guidance about managing the transition to the new SEND support system is available for local authorities and related organisations.

The Care Act 2014

The Care Act represents the most significant reform of care and support in more than 60 years, putting people and their carers in control of their care and support. For the first time, the Act will put a limit on the amount anyone will have to pay towards the costs of their care.

To help make things clearer the Act has introduced a minimum eligibility threshold across the country – a set of criteria that makes it clear when local authorities will have to provide support to people. Until now, local authorities have been able to decide this threshold themselves, meaning decisions varied from place to place.

Statutory guidance and best practice

Aiming High for Disabled Children (2005)

This document follows the Government's objective to ensure that disabled children and their families are empowered and enabled to make a full contribution to society:

"By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society."

Inclusion: Does it matter where pupils are taught? OFSTED (2006)

This report outlines the key factors that lead to good progress in pupils with SEN.

These include: involvement of a specialist teacher; good assessment procedures; work tailored to the pupils' needs which also challenges; and inclusive ethos within school recognising that all children can progress and achieve.

Education for Pupils with Autism Spectrum Disorders, Report (HMIE 2006a)

A focused inspection of education for pupils with autism reported in 2006 by Her Majesty's Inspectorate of Education (HMIE). The report highlights the variety of provision and arrangements for meeting the needs of pupils with autism.

I Exist: The message from adults with autism in England 2008

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

Supporting People with Autism Through Adulthood (2009)

This review identified that people with autism may use a very wide range of public services. The report identified that the services available could be improved through better strategy and planning at a local and national level and a widespread awareness of autism within the workforce.

Valuing People Now (2009)

This was a three year strategy by the Department of Health for people with learning difficulties, including autism. It highlighted the need to improve referral, diagnosis and management processes. The document refers to:

"The vision for people with more complex needs is the same as for everyone: inclusion and participation in all areas of community life, including living independently and having paid work. To assume that people cannot, and will never, achieve these is to set a ceiling on what progress can be made, both by an individual and by society".

Following on from this the government published 'Valuing Employment Now' (2009). This strategy aimed 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.

Valuing People: A New Strategy for Learning Disability for the 21st Century (2010)

This strategy takes forward the recommendations of the 'Valuing People Now' (2009) document and looks to specifically address the complex needs of the most vulnerable within society. It emphasises the importance of developing person centred care when delivering health and social care services. The strategy includes a number of

key policy objectives for both the care given and received, as well as objectives for service management and organisation. It sets out a plan for improving people's lives and those of their families and carers, based on recognition of rights as citizens, social inclusion in local communities, choice in every daily lives and real opportunities to be independent.

Implementing Fulfilling and Rewarding Lives. Statutory guidance for Local Authorities and NHS organisations to support implementation of the autism strategy (2010) Fulfilling and Rewarding Lives. The strategy for adults with autism in England (2010)

This national strategy follows the Autism Act (2009) and sets out a vision for public service transformation to better address the needs of adults with autism. It focuses on:

- frontline professionals' awareness of autism,
- clear and consistent diagnostic and support pathways,
- living independently including developing social networks and relationships,

- support gaining employment and staying in work,
- appropriate adult support services in adulthood including services to meet health care needs.
- being safe from hate crime and discrimination
- National guidance has identified that to deliver this, local authorities need to consider:
- identification, diagnosis and support assessment pathways for people with autism of all ages
- training of staff who provide services to people with autism
- coordinated planning with professionals, young people and their families around key transition periods
- local planning and leadership in relation to the provision of services for adults with autism

NAS 'You Need to Know' Report (2010)

This report reviewed the services offered to children and young people with autism who also suffer with a mental health problem. The report showed that up to 71% of children and young people with autism have an additional mental health need. The report makes a number of recommendations for both national and local change.

'Great Expectations' report by the National Autistic Society (2011)

This report reviewed the experiences of children and young people with autism and their families in relation to education. They found that a third of parents were unhappy with their child's educational placement, and that over 50% felt they were not making good educational progress. A quarter of the children interviewed were unhappy at school and many felt their teachers did not understand them.

In trying to tackle these concerns and ensure the needs of these children are met, education authorities must make a wide range of provision available and ensure that the teaching methods used in schools meet the needs of each individual pupil. This provision

may be made in enhanced mainstream schools, mainstream schools, or by outreach, specialist support teams or special schools.

No Health without Mental Health: A Cross-Government Mental Health Outcomes Strategy for People of All ages (2011)

This documents sets out key objectives to improve the mental and physical wellbeing of people in the UK, including the objective for more people to have good mental health. Research from the NAS suggests that up to 70% of children and young people with autism may also have a clinically significant mental health need.

NICE Quality Standard 51 [QS51] (Jan 2014)

The National Institute for Health and Care Excellence (NICE) quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. They draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

This quality standard covers autism in children, young people and adults, including both health and social care services and is the overarching quality standard for autism. The most relevant clinical guidelines relating to work on autism in North Yorkshire are provided below.

Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum: NICE Clinical Guideline 128 (Sept 2011)

This report highlights the areas of difficulty faced by children and young people with autism during the diagnostic process. It recommends:

- a local pathway for recognition, referral and diagnosis of possible autism;
- a multi-disciplinary group of professionals to diagnose with multi-agency support;
- a case co-ordinator throughout the diagnosis process;
- specified diagnosis tools;
- a smooth transition to adult services.

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

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.

Autism: The Management and Support of Children and Young People on the Autism Spectrum, NICE Clinical Guideline 170 (2013)

This guidance for professionals working with children and young people with autism takes account of the variation in severity of autism, co-existing conditions and levels of cognitive ability. It identifies that the clinical (and educational) response for these children and young people should vary accordingly.

The importance of assessing the needs of families and carers and of creating comprehensive transitions plans for young people with severe and complex needs are also discussed.

NICE support for commissioning for autism (Jan 2014)

This report highlights the key actions that local authorities and clinical commissioning groups (CCGs) should take to improve the quality of care for people with autism.

Think Autism, Department of Health (April 2014)

This document provides an update on the previous strategy 'Fulfilling and Rewarding Lives' (2010). It recognises success in increasing awareness of autism and increased services, but it says that there is still considerable work to be done. In particular the document notes that there are still gaps in the autism provision and extensive waiting times for diagnosis and services in some areas. The report also recognises the difficulties people with autism have in the workplace and that many people with autism find they have difficulty gaining employment or reaching their potential. The report also looks at NHS services, the criminal justice system and benefits systems and identifies how access to these services could be improved for people with autism.

Mental Health Crisis Care Concordat 2014

This sets out national objectives to ensure that there is an effective response from services to people who require assistance urgently, including those with mental health problems and other co-occurring conditions, including autism.

NHS Standard Contract 2014/15

The Standard Contract requires that all service providers must demonstrate how they are making reasonable adjustments for people with autism.

Autism Education Trust Standards and Competency Framework

The Autism Education Trust (AET) have developed a set of standards and a competency framework for early years settings, schools and post 16 establishments. The standards allow for educational settings to evaluate their practice in addressing the needs of pupils on the autism spectrum. The competency framework is for staff to audit their skills and knowledge in respect of autism.

The Autism Education Trust Quality **Standards and Competency Frameworks**

Three competency frameworks for people working with children and young people from 5 to 25 years on the autism spectrum.

The frameworks are presented as selfevaluation tools that practitioners can use to rate their current practice and understanding against a set of descriptors (knowledge, skills, personal qualities). Feedback should inform practitioners' professional development plans and content of any future training.

Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (March 2015)

This statutory guidance shows how local authorities and NHS organisations should carry out their responsibilities under the Autism Act 2009 to develop services that support and meet the needs of people with autism, and their families and carers. It also explains what support people with autism can expect to receive from local authorities and NHS organisations.

The guidance was revised to take account of responses to a related consultation, and reflects changes to support the implementation of 'Think Autism', the update to the 2010 autism strategy for adults with autism in England.

Supporting people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges – draft service model (July 2015)

A draft national framework from NHS England, the Local Government Association (LGA), and the Association of Directors of Adult Social Services (ADASS) designed to improve the care of people with learning disabilities, shifting services away from hospital care and towards community-based settings. The service model sets out nine overarching principles which define what 'good' services for people with learning disabilities and/or autism whose behaviour challenges should look like.

These principles will underpin how local services are redesigned over the coming months and years – allowing for local innovation and differing local needs and circumstances, while ensuring consistency in terms of what patients and their families should be able to expect from local decision-makers.

0-25 Special Educational Needs and Disability (SEND) Code of Practice for England (2015).

This document provides guidance on part three of the Children and Families Act (2014). It divides special educational needs into four areas; communication and interaction, cognition and learning, social, emotional and mental health and sensory and physical needs. The guidance recognises that children and young people with autism may have needs in one or more of these categories. The document informs Early Years settings, schools and Post 16 establishments of their statutory requirements in relation to children and young people with SEND and sets out the statutory process for Education, Health and Care plans (EHCP) for those children whose needs cannot be met within the school's delegated SEND resources. It also provides information in relation to the Local offer and Preparation for adulthood.

The local context

This section considers existing strategies, reviews and publications relevant to people with autism in North Yorkshire.

Hope, control and choice, North Yorkshire Mental Health Strategy

This strategy, published Autumn 2015 sets out a new vision and new priorities for mental health services as well as a series of commitments for the next 5 years. It signals a new determination for agencies to improve services and outcomes for people, to promote well-being and resilience in communities to tackle head on the issue of the stigma that still too often surround mental illness.

North Yorkshire Health and Wellbeing strategy – updated Autumn 2015

This strategy was first published in 2013 and has now been updated and revised with the latest evidence from North Yorkshire Joint Strategic Needs Assessment. It reflects national changes in policy and includes four key themes:

- Connected communities
- Start well
- Live well
- Age well

The strategy states what people can expect to see in terms of work on health and wellbeing by 2018.

Young and Yorkshire, Children and Young People's Plan 2014-2017

The plan sets out the vision North Yorkshire County Council has for children and young people. It celebrates current successes and identifies principles and priorities for the next three years. Our three particular priorities for 2014-17 are:

- Ensuring that education is our greatest liberator, with a greater proportion of pupils attending a good or outstanding school or setting;
- Helping all children enjoy a happy family life, with a safe reduction in the looked after child population;
- Ensuring a healthy start to life, with more children and young people leading healthy lifestyles.

North Yorkshire Special Educational Needs and Disability Strategy 2014 – 2018

This sets out the local authority's strategy for developing services for children and young people with special educational needs and disability. It emphasises that involving partner agencies including Health and the Voluntary Sector and working with parents is the key to success.

North Yorkshire Children's Trust: Emotional and Mental Health Strategy (2014-2017)

The strategy aims to improve the mental health of children and young people in North Yorkshire. It is in line with the national 'No Health without Mental Health' strategy. CYPS seeks to ensure that 'our services are coordinated, integrated, deliver quality outcomes and value the voice of the child, young person and family'. The document looks at prevalence and risk and protective factors and service provision in response to this need. It is identified that children with disabilities (including learning disabilities) are at a greater risk of developing a mental health condition.

North Yorkshire's 2014-19 Education and Skills Plan

This document discusses the position statement for North Yorkshire and contains key priorities for 2014-15.

- Ensure the attainment gap between vulnerable learners and the wider cohort is minimised;
- Ensure all young people have access to good quality and appropriate education and training;
- Increase the number of pupils attending a good or outstanding school so more young people can benefit from a high quality education;
- Increase young people's participation in education and training and thereby reduce the number of young people Not in Education, Training or Employment (NEET);
- Ensure young people leave training and education with the employability skills they need to succeed.

Clinical Commissioning Group (CCG) strategic plans

Harrogate and Rural District CCG

Hambleton, Richmondshire and Whitby CCG

Scarborough and Ryedale CCG

Vale of York CCG

Airedale, Wharfedale and Craven CCG

North Yorkshire SEN Specialist Support Autism, Mental Health and Emotional Wellbeing Prevalence Study, 2014.

NYCC undertook a study to better understand the prevalence and needs of children and young people aged 5-16 in North Yorkshire schools who have a diagnosis of autism and may also have emotional well-being and mental health needs. Due to the low number of data returns and reliance on electronic questionnaires it is thought this survey underestimates the prevalence of co-occurring mental health condition in children and young people with autism in North Yorkshire. National predictions by the NAS suggest that up to 70% of young people with autism in

North Yorkshire have a co-occurring mental health condition. Despite this, the study did suggest that there are a number of concerns in relation to supporting the mental health and emotional well-bring needs of pupils with autism within schools in North Yorkshire.

2020 North Yorkshire (2014)

This document sets out a vision for change and how North Yorkshire County Council will work together to achieve it. There will be positive opportunities to be more efficient, to do many things better and smarter than we have before and ways of working that are better for our service areas.

In addition the following documents inform and relate to work on autism in North Yorkshire:

- 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

- Interim strategy for meeting the needs of adults with autism in North Yorksahire 2014-2015
- Getting a life not a service, Learning Disability Strategy
- 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

Contact us North Yorkshire County Council, County Hall, Northallerton, North Yorkshire, DL7 8AD Our Customer Service Centre is open Monday to Friday 8.00am - 5.30pm (closed weekends and bank holidays). Tel: 01609 780 780 email: customer.services@northyorks.gov.uk web: www.northyorks.gov.uk

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