

NORTH YORKSHIRE COUNTY COUNCIL**SCRUTINY OF HEALTH COMMITTEE****4 September 2015****Joint All Age Autism Strategy****Purpose of Report**

1. To update the Scrutiny of Health Committee on progress of the Joint All Age Autism Strategy and to give the Committee an opportunity to influence the content of the final version of the strategy.

Introduction

2. The Joint All Age Autism Strategy for meeting the needs of children, families and adults with autism in North Yorkshire 2015-2020 is being developed by North Yorkshire County Council (NYCC) and NHS Partnership Commissioning Unit (PCU) on behalf of the 4 North Yorkshire and York Clinical Commissioning Groups (CCG) with input from neighbouring CCG representatives.
3. Joint working is not confined to the local authority and the NHS but to other public and independent sector organisations. As part of the consultation phase for the strategy, other public and independent sector organisations are being asked for their views on the strategy's proposed aims and outcomes, and invited to formally endorse the strategy.
4. Members will recall that this Committee at its meeting in January contributed to the development of the consultation document shown in Appendix 1.
5. An on-line consultation was launched in June 2015 and closes on Friday 11 September 2015.
6. Consultation events have been held during the summer, the last of which is on Friday 11 September 2015, 2.30pm - 4.30pm, Golden Lion Hotel, 114 High Street, Northallerton, DL7 8PP.
7. This report will provide the Committee with assurances that the consultation is on schedule, and provide an opportunity to comment and influence thinking before the final strategy is signed off by the Health and Wellbeing Board at its meeting on 30 September 2015.
8. Janet Probert (Director of Partnership Commissioning) will be attending the meeting to summarise the emerging themes received to date as part of the consultation. A summary of the themes is attached as Appendix 2.

Recommendation

9. Members note the progress being made on the Joint All Age Autism Strategy and to offer advice and comment to be taken into account in the final version of the strategy.

25 August 2015

Bryon Hunter
Scrutiny Team Leader

County Hall
NORTHALLERTON

25 August 2015

Background Documents: None



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



North Yorkshire
County Council

**Strategy for meeting the needs of children, families
and adults with autism in North Yorkshire 2015-2018**

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Strategy for meeting the needs of children, families and adults with autism in North Yorkshire 2015-2018

Foreword: A message from North Yorkshire's autism leads

It is likely that there are around 7,000 people with autism who live in North Yorkshire. 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. It is important to note that people with autism 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.

The benefits of developing one strategy that meets the needs of all children, young people and adults with autism across North Yorkshire is that it will enable a more integrated coordinated approach across partner organisations. It means we can plan more efficiently and support people more effectively. 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. Their views have enabled us to identify joint priorities, which will have benefits for all people living with autism in North Yorkshire. This strategy has been developed 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 NHS Cumbria CCG (representing the town of Bentham). Senior colleagues from these two organisations have given their support to the development of this strategy.

This strategy is endorsed by a number of organisations that work with people with autism in the North Yorkshire area. These include North Yorkshire Police, Richmondshire District Council, Hambleton District Council, Craven District Council, Selby District Council, Ryedale District Council and Scarborough District Council

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

Chief Executive Hambleton, Richmondshire and Whitby Clinical Commissioning Group
Chief Executive Harrogate and Rural District Clinical Commissioning Group
Chief Executive Scarborough and Ryedale Clinical Commissioning Group
Chief Executive Vale of York Clinical Commissioning Group
Chief Executive Airedale, Wharfedale and Craven Clinical Commissioning Group

Deputy Chief Constable, North Yorkshire Police

Chief Executive Hambleton District Council

Chief Executive Harrogate Borough Council

Chief Executive Selby District Council

Chief Executive Craven District Council

Chief Executive Scarborough Borough Council

Chief Executive Richmondshire District Council

Chief Executive Ryedale District Council

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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 three-year period from October 2015 to October 2018.

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 know that they can depend on mainstream public services to accept, 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 line with current national policy e.g. Think Autism (2014).

What will this strategy do?

Engagement with children, young people and adults with autism and their families has highlighted a number of local themes. This strategy will consider these emerging themes and identify priority actions.

- **Raising awareness of autism**

People with autism and their families would like to access mainstream services and find suitable “reasonable adjustments” have been made to ensure provision is “autism friendly”.

- **Assessment and diagnosis**

People with autism and their families would like to be able to receive a diagnosis closer to home, without waiting for long periods of time.

- **Information and signposting**

We know that navigating services is difficult for people with autism and their families and it can be difficult to understand different access criteria.

- **Employment and education**

Many young people find school difficult and understanding of autism varies significantly across educational settings. We also know not enough people with autism are supported to gain or maintain employment.

- **Family Support**

It can be challenging for people with autism and their families or carers to know where to go in a crisis.

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

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

How have we developed this strategy?

We have developed this strategy with direction from a virtual reference group of people with autism, their families and organisations that work with people with autism. We 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 final publication in October 2015.

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

As a result of previous autism strategies in North Yorkshire there have been a number of achievements, including the establishment of joint strategic groups consisting of senior managers from the NHS and North Yorkshire County Council. 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. The work that has been undertaken so far is summarised in Chapter 5.

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.

Plan on a page

This strategy achieves the following objectives:

- One strategy across children, young people and adults services in the county
- Agreement with local NHS commissioners
- Highlights the key priorities of local people
- Considers national policy and guidance

The strategy highlights additional issues in accessing services for people with autism in relation to

- Gender
- Age
- Disability
- Looked after children
- Disability

The strategy identifies some key themes for implementation:

- Diagnosis
- Raising awareness
- Information and signposting
- Employment and education
- Support for people in crisis
- Working together

Chapter 1 – Introduction

Why has this strategy been produced?

The overall objective of a strategy for autism is to ensure that services are identified, commissioned and improved to meet current and future needs and improve services for people with autism. The Autism Act (2009) statutory guidance places a duty on all local authorities to produce an autism strategy. North Yorkshire's strategy is written with due regard for all relevant UK legislation and statutory guidance. A summary of this can be found in Appendix 1, "Autism Policy Framework".

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

This strategy outlines a shared vision that people with autism will receive an assessment in line with NICE guidance and diagnosis as early as possible, access additional support if they need it and know that they can depend on mainstream public services to accept, understand them and treat them fairly as individuals.

What is the scope of this strategy?

This strategy is for people with autism and their families and carers. It recognises that there is a range and severity of need. The strategy has been informed by national priorities and best-practice models. It reflects upon the work that has been carried out in the previous children's and adults' autism strategies and extends this work to set new longer-term objectives.

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

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

autism and their families locally and aim to ensure the services available meet the needs of those who access them.

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Chapter 2 - What do people with autism tell us?

So far we have identified some key themes in North Yorkshire that are important to people with autism and their families.

How have we learnt this?

- 2011-12 children's autism strategy development and consultation
- 2012 National Autism Society consultation for adults with autism, commissioned by NYCC
- 2013-2014 adults' autism strategy development and consultation
- 2014-2015 development of commissioning plan for NHS assessment and diagnosis service
- Feedback from virtual reference group from June 2014

What are the themes that have come up so far?

1. *Raising awareness of autism:* we know people with autism and their families would like to access mainstream services and find suitable "reasonable adjustments" have been made to ensure provision is "autism friendly"
2. *Assessment and diagnosis:* we know families and people with autism would like to be able to receive a diagnosis closer to home, without waiting for long periods of time
3. *Information and signposting:* we know that navigating services is difficult for people with autism and their families and it can be difficult to understand different access criteria
4. *Employment and education:* we know that many young people find school difficult and understanding of autism varies significantly across educational settings. We also know that not enough people with autism are able to find or maintain work
5. *Support for people with autism in crisis:* we know that it can be challenging for people with autism and their carers to know where to go in a crisis

In order to respond to the needs of local people, we will consider these themes when considering the priorities for action for 2015-2018. The views of children, young people and adults with autism and their families are central to the development of services. We want to gather people's views, opinions and experience further to help us understand what works well and what needs to improve locally.

In the summer of 2015 we will consult through existing autism networks across partnership agencies and invite people with autism, their families and other interested parties to attend events in their local area. We will hold additional focus groups for children and adults with autism via the Enhanced Mainstream Schools and the Flying High group and ask our existing adult Partnership Boards for their feedback.

We are also giving people the opportunity to comment via an online questionnaire 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. We will post out questionnaires to individuals on request 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.

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Chapter 3 - What's the bigger picture?

How does national policy influence this strategy?

The National Autism Plan for children was published in 2003. This was followed by the Autism Act which was passed in 2009. The Autism Act placed a number of obligations on a range of public bodies to improve opportunities for people with autism. The strategy for adults with autism in England 'Fulfilling and Rewarding Lives' followed in 2010 and provided clear direction in terms of how public services must transform to better address the needs of adults with autism. More recently 'Think Autism', published in April 2014 shared detailed consultation and research into the views of people with autism and their families on how progress has been taken forward in implementing the 2009 Autism Act. In March 2015 "Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy" was also published. The policy framework governing our work on autism is extensive. An overview of this can be seen at Appendix 1.

What is the national prevalence of autism?

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

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

What about people with protected characteristics and autism?

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

There is strong evidence to suggest that there are more males with autism than females. However, females are less likely to be identified with autism even when their symptoms are equally severe. This is because their traits can be more subtle and females may be more able to mask their difficulties by modelling their behaviour on others. In addition autism diagnostic criteria has historically been developed using the behaviours that males display. Many females are never referred for diagnosis and are missed from the statistics.

Autism is a development disorder, which is also considered a disability, recognised by the Equality Act of 2010. Although autism is not a mental health condition or a learning disability, it is estimated that between 44% - 52% of people with autism may have a learning disability and an estimated 71% of people with autism are likely to have a mental health condition.

There is limited research around ethnicity and autism which has given an inconsistent picture as to whether autism is more prevalent or frequently diagnosed in particular ethnic groups. Some minority ethnic communities have a limited understanding of autism and the condition is perceived differently by some communities. This is important as it is likely to have implications for how families, carers and professionals respond to autism and how likely and easy an individual may find it to access appropriate support.

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

Using the 1% prevalence rate it is expected that there are around 1,272 adults over the age of 65 with autism in North Yorkshire. As the older adult population grows it is estimated that this figure will increase by over 500 people by 2030. Older people are less likely to have received a diagnosis.

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

What is the local prevalence of autism in North Yorkshire?

Between April 2014 and March 2015 in the areas covered by the four North Yorkshire and York CCGs, there were 239 children diagnosed with autism. As at March 2015 there are 1,721 children and young people with autism up to the age of 25 in North Yorkshire known to service providers. There are 154 children and young people who have a statement of SEN or an Education Health Care plan with autism identified as their primary need. This reflects 23% of all statements.

There has been a 25% increase in the number of children and young people with autism who require additional support from the Inclusive Education Service since 2010 and as of April 2015 there are 489 supported by the service, equivalent to 28% receiving educational support. Projection figures for 2015 suggest a further increase in requests for assessment and diagnosis services and the involvement of the Inclusive Education Service of approximately 30%. This puts a huge pressure on all diagnostic, educational, and social care services.

In 2015, 50 young people with autism transitioned from school to Post-16 provision. Consideration needs to be given to increasing the number of people with autism being supported in higher and further education and to gain or maintain employment.

In 2014, 17 adults per month were referred for diagnosis of autism and/or ADHD 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 autism. The average age of patients referred in 2014 was 28 years old.

There are 270 adults with autism supported by Health and Adult Services (as at February 2015). There are many more people with autism who may never come to the attention of services. This is because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents.

Chapter 4 - What is on offer in North Yorkshire?

This strategy reflects the 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. Further information on all North Yorkshire services can be found on our [local offer](#).

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

What health provision is available for people with autism?

The majority of healthcare for people with autism will be provided through primary care, and the key coordinator will be the person's GP.

How do I get a diagnosis of autism?

A health professional will make the referral for an autism diagnostic assessment. For children and young people, a health professional will carry out an initial assessment, and then make the decision to refer on to the autism diagnostic assessment team. A health professional could include a paediatrician, child psychiatrist, clinical psychologist or speech and language therapist. For adults over 18 years of age, a GP will refer on their behalf, or another health professional involved in their care.

There is a local service provider in each locality for children and young people (Harrogate, York, Scarborough and Northallerton). Currently adult services are provided outside of the county, so people may have to travel out of the area for their assessment. The service patients are invited to attend will also vary on their location and individual needs.

The autism diagnostic assessment teams are multidisciplinary in line with NICE guidance QS51. For children and young people the team may consist of a paediatrician, psychiatrist, speech and language therapist, clinical psychologist, and specialist CAMHS consultant. The adult autism diagnostic team could include a psychologist, psychiatrist or other mental health professional. These teams have specialist skills in autism diagnostic assessments. They can advise other professionals involved in the patient's care about the impact of a diagnosis or treatment, education or social support. The diagnostic process can be complex and challenging for some families and individuals. Professionals working in this area are sensitive to the emotional impact of this process and work within the most up to date NICE guidance and diagnostic tools e.g. ICD 10 or DSM-V for children and young people.

Following an assessment, support will be offered dependent on the presenting healthcare needs of the patient. This may include further signposting and support to access relevant services for people who have not received a diagnosis. For those who do receive a diagnosis, post diagnostic support for children and young people includes a parent information pack and access to autism specific parent training programmes which is offered jointly by the NHS and CYPS. Post diagnostic support is provided on an individual basis for adults and may include carer support, information, signposting or attending a group.

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

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

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

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

In line with the 2014 SEN Code of Practice, local authorities have a duty to ensure that they provide adequate and efficient educational provision for any child or young person with additional support needs including children and young people with autism. The code emphasises that having an SEN is not a reason for poor educational attainment. North Yorkshire promotes the personalisation of learning for children and young people with autism. The local authority pattern of provision aims to develop the capacity of local education provision, by sharing expertise in autism. Some children and young people will require specialist educational provision. Further information on the specialist educational provision available can be found [here](#).

What provision is available for families with autism?

Parents of, or professionals working with children and young people with autism may consider a referral to access services provided by children's social care (higher functioning conditions) or disabled children's services (for children with a learning disability). They can request that a Child in Need Assessment is carried out to see if their child is eligible to receive support or short breaks, either from social care or from 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 [here](#).

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

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

How do we prepare young people with autism for adulthood?

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

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

Significant work has been undertaken to improve the process of transition for young people. In 2008 the National Transitions Support Programme was introduced by the government to develop systems which would improve the experience of young people including those with autism. North Yorkshire is committed to improving local provision for post-16 learning opportunities, including the development of flexible and personalised packages of support to continue in education or training. It will also ensure integrated person-centred planning and assessment approaches through the transition period, using the Preparing for Adulthood section of the Education, Health and Care plan.

What support is available for adults with autism?

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

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

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

In addition, North Yorkshire County Council's Health and Adult Services offer a Supported Employment Service which includes support for people with autism. They are able to support people with autism to gain and retain employment. Supported Employment staff also work with employers to advise on reasonable adjustments in the workplace.

What provision is available in my community?

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

There are a range of local community groups and support available for people with autism and their families. These include leisure and sport activities, youth provision, after school clubs, parent support groups and peer support groups.

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

Themes

In the following pages each theme identified by people with autism and their families will be considered and joint priorities identified. An implementation plan containing Specific, Measurable, Achievable, Realistic and Timely (SMART) targets will be written following the publication of the strategy. Under each theme we have listed:

- What are the priorities going to be?
- What is the progress so far?
- What next?
- How will we know if it's working?

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Theme 1 - Diagnosis

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

What are the priorities going to be?

- To review and improve local pathways for assessment and diagnosis
- Improve transitions for young people
- Provide diagnostic services close to home

What is the progress so far?

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

What next?

- Improve and develop local autism assessment and diagnostic services within North Yorkshire as identified through on-going reviews of service availability and quality

- Review and improve existing post diagnostic support pathway with local partners to support assessment and diagnosis
- Build on existing established baseline data within children's services to monitor activity across all ages
- Monitor data on how assessment services are accessed by groups with protected characteristics e.g. Looked After Children, older people, women, Black and Minority Ethnic (BME) and Lesbian, Gay, Bisexual and Transgender (LGBT) communities
- Joint working across all CCG partners within NYCC area, including NHS Airedale, Wharfedale and Craven to agree shared pathways for patients
- Developing a pathway for young people in transition
- Implement any new international criteria for diagnosis (ICD) once published, relevant statutory guidance and NICE Quality standards
- Explore tools for identifying and supporting differential diagnosis in children that are looked after and develop service specifications to ensure that LAC receive the opportunity for assessments as required
- Ensure that the diagnosis and assessment services have clear pathways into mainstream provision for people with autism e.g. speech and language therapy/paediatricians for children and mental health/learning disability services for adults
- People with autism are more likely to have mental health issues. An on-going review of the NHS mental health provision currently commissioned in the four CCG areas aims to improve access to services for children, young people and adults with autism who require specialist mental health support and services in 2015.

How will we know if it's working?

- Referral pathways are working efficiently
- Patient's first appointment for an autism assessment is within three months of initial referral (in line with NICE guidance)
- Local outreach as part of the provider pathway for assessment and diagnosis in each CCG area
- Increased number of Education, Health and Care plans developed jointly for young people with autism (SEND)
- Increased number of people receiving a diagnosis in North Yorkshire
- Staff working with people with autism are appropriately trained e.g. GPs, psychiatrists, and counsellors
- Increase in the positive outcomes reported by patients and families, through the commissioning process e.g. provider and PALS feedback

Theme 2 - Awareness raising and training

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

What are the priorities going to be?

- Map current training on autism throughout public sector agencies in North Yorkshire and identify training pathways for professionals who work with people who have autism
- Support the development of universal, targeted and specialist training opportunities available to all public sector agencies
- Increase the number of autism champions across a range of local services. Autism champions are existing staff who undertake enhanced training modules in elements of autism in order to improve their knowledge and experience

What is the progress so far?

- 1,593 of North Yorkshire County Council's workforce have undertaken online autism awareness training; 159 non-local authority staff have also undertaken this training as at May 2015
- North Yorkshire has been awarded the position of Yorkshire and Humber Autism Education Trust Early Years and Post 16 training hub, it also offers the school programme through a reciprocal arrangement with Leeds STARS
- North Yorkshire Police Community Support Officer 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

What next?

- Improve knowledge, understanding and inclusive practice in educational settings
- Contribute to the development of skills, knowledge and understanding of the workforce, across NYCC, the NHS

- Partnership Commissioning Unit (PCU) to liaise with Education Yorkshire and Humber to identify new opportunities for commissioning training on autism for the local NHS
- NHS, public health and social care commissioners to include reference to autism in service specifications for commissioned services where relevant e.g. Looked After Children, Mental Health, CAMHS, Healthy Child Programme
- Encourage front line services to become “autism friendly” e.g. promoting the National Autism Society accredited status and the Autism Education trust Standards and Competency framework

How will we know if it's working?

- Clear pathway to access training and development in autism across partner agencies
- Increased awareness and knowledge across universal, targeted and specialist services workforce in supporting children, young people and adults with autism
- People with autism and their families report better experience of accessing services
- Local services gain NAS accredited status

Theme 3 - Information and signposting

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

What are the priorities going to be?

- Public sector agencies will provide information that is “autism friendly” i.e. use clear and straightforward language
- Web-based information will be maintained regularly
- A wide range of communication methods will be used to interact with people with autism
- Services will be tailored to people’s individual needs
- Communication that is written by NYCC or the PCU and is designed for people with autism will be developed in partnership with people with autism.

What is the progress so far?

- An information pack for parents was developed in 2012 jointly between parents, the NHS and NYCC, for assessment and diagnostic teams to share with parent
- Autism specific parent training is available for parents of children and young people who receive a diagnosis of autism
- The local offer has been developed
- NYCC and NY Police are jointly developing Safe Places with third party, voluntary sector and statutory bodies. Safe Places have been created so that people are able to travel independently and safely in their own communities
- NYCC’s Customer Service Centre staff have undertaken basic autism awareness training in order to better understand the needs of people who ring up requesting advice and guidance
- A member of staff in NYCC’s customer service centre is an autism champion and has undertaken five enhanced training modules in different issues around autism, enabling a greater level of knowledge of autism within the customer service centre
- NYCC has developed a guide to developing accessible information

What next?

- Adult assessment and diagnosis services commissioned will be required to provide information and signposting as part of the post diagnostic support planning
- Inform and involve people with autism and their carers in changes resulting from the Care Act
- Single point of referral for the Inclusive Education Service
- Advice and support for GPs on referral criteria
- Local information and signposting resources to be developed to support implementation of adult assessment and diagnosis service
- Liaise with public health teams to ensure information is widely available for people with autism
- Develop appropriate peer support
- Ensure that the NYCC and North Yorkshire Partnerships websites are useful local sources of information for people with autism and their families

How will we know if it's working?

- People with autism report that information is easily accessible and useful
- People with autism and their families feel confident that they will receive appropriate advice and guidance when contacting public sector agencies
- People with autism report that information is easy to understand

Theme 4 - Employment and education opportunities for people with autism

What are the priorities going to be?

- Improve the knowledge, understanding and inclusive practice in educational settings (0-25) through implementing excellent continuing professional development opportunities for staff
- Increase access to intensive support for reintegration of children and young people with autism that are excluded or at risk of exclusion to reduce breakdowns in educational placements
- Continue to improve the support offered to people with autism and potential employers through NYCC's Supported Employment service

What is the progress so far?

- A "Review of Evidence Based Educational Interventions for Autism in North Yorkshire" has been written to highlight the national recommendations and best practice guidelines; leading to an NYCC statement regarding autism and evidence based intervention
- A range of training and development opportunities have been made available for schools and settings to access
- The inclusive education service commission specialist services to provide outreach support for schools and settings requiring support to improve inclusive provision
- North Yorkshire County Council's Supported Employment service works with a number of people with autism to find suitable work
- The Supported Employment service supports potential employers to provide job opportunities for people with autism. This service also offers advice to employers and employees about making reasonable adjustments within the workplace to enable people to stay in their job

What's next?

- Support schools in developing their knowledge of therapeutic and educational autism interventions and their implementation through the "assess, plan, do, review" model
- Introduce the Autism Education Standards and Competency framework across educational establishments to support them in improving their offer to children and young people with autism.
- Improve transition to Further Education (FE) by developing relationships with independent providers, offering training and tracking pupils at the transition phase
- Include support for employers within the post diagnostic pathway for adults with autism e.g. advice on reasonable adjustments within the workplace

- Link with the Department for Work and Pensions regionally to discuss their targets and objectives for supported adults with autism into employment
- Adjustments in education settings, such as providing quiet or low-light areas, can benefit people with autism. The Disabled Student Allowance supports people with autism with the academic aspects of university life. This includes funding a note-taker for lectures, electronic equipment and software, social skills training, travel training, and 1:1 support

How will we know if it's working?

- Educational outcomes for people with autism are improved and the attainment gap is reduced
- Increased teacher confidence in supporting children and young people with autism within Early Years settings, schools and post 16 establishments
- Children, young people and their families report better school experience
- The number of schools and settings using the AET competency framework and national standards increases
- Reduction in school exclusion, family breakdown and out of authority placement
- More people working with the Supported Employment service to achieve employment are successful in finding and maintaining a job
- Employers feel more confident in making reasonable adjustments in the workplace so that people with autism can keep their job
- The Department of Work and Pensions, on a regional level, become involved in the work of the Steering Group

Theme 5 - Support for people with autism in crisis

Crisis can mean different things to different people. Different situations can prompt a crisis at different times. The aspiration of this strategy is that services respond in a personalised way to individuals, regardless of the scale of the crisis.

What are the priorities going to be?

- Improve support for families and carers to avoid breakdown of social support
- Support for people with autism to self-care and manage day to day life
- Appropriate advice and urgent response from a trained professional in high risk situations

What is the progress so far?

- Local Crisis Care Concordat agreed for mental health services includes developments for people with autism
- Mental health staff employed by NYCC's Health and Adult Services (HAS) have received specialist training on how autism can affect a person's mental health
- Three mental health staff are autism champions within HAS and have completed five enhanced training modules around specific issues for people with autism

What next?

- Review CAMHS pathways for children in crisis
- Review the urgent care pathway for adults with autism and mental health needs
- To review support for people with autism/complex needs in a crisis
- Increase access to intensive support for the most vulnerable children and young people with autism to ensure success in educational placements
- Ensure that all mental health staff can identify the mental health needs of people with autism effectively particularly during a point of crisis.
- Support parents and families by delivering effective, and timely, autism specific parent programmes
- Contribute to the development of the skills, knowledge and understanding the workforce requires, across CYPS including children's social care, through creating autism champions

How will we know if it's working?

- Reduction in school exclusion, family breakdown and out of authority placement
- Parental confidence in meeting the needs of their child or young person increase.

- Families of children with autism report improved experience of social care support
- Increased knowledge and understanding of autism reported by social care staff.

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Theme 6 - Working together

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

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

What are the priorities going to be?

- Continuing to hold discussions with public and voluntary sector agencies that have not, to date, been part of the development of the all-age strategy to bring them on board
- Ensuring that all public and voluntary sector agencies have representation on the York and North Yorkshire Steering Group (Autism)
- Encouraging representation on the Steering Group from people with autism and their families
- Enabling people who cannot or do not wish to attend the Steering Group to have their say using a wide variety of resources, such as email and social media
- Being transparent and honest about progress by regularly sharing progress against the priorities in the strategy to as wide an audience as possible

What is the progress so far?

- Governance structures have been set up to review and implement this strategy across CYPS and HAS (see structure below)
- A ‘virtual reference group’ has been created in order to involve people with autism, their families and interested groups in the development of autism provision across the county. People expressed a preference to be proactively engaged and involved in producing this strategy and the group operates mainly by email to reflect that not everybody is able, or wishes to attend meetings

- Initial engagement has taken place with North Yorkshire Police and the seven district and borough councils in North Yorkshire to inform them of the strategy, request their endorsement and discuss future involvement

What next?

- Work together to improve pathways and better manage expectations for young people moving from being a child to an adult;
- Support the development of autism friendly communities through the NYCC community delivery managers
- Work with universal services to raise awareness of how people with autism may present differently (GP's, hospitals, schools, youth centres etc.)
- Explore community development opportunities to support people with autism (e.g. sports and leisure)
- Improve preparation to adulthood through enhanced partnership with further education providers
- Explore community development opportunities to ensure people with autism have local access and involvement
- Develop personalised pathways of support for people with autism

How will we know if it is working?

- There is endorsement from all local public sector agencies for the priorities in this strategy
- People with autism, their families and public sector agencies will be centrally involved in the work of the Steering Group
- Universal services are aware of the potential needs of people with autism, and these are considered when producing strategies, policies and procedures

Chapter 6 – How will we bring the strategy to life?

The monitoring of the implementation plan for 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. Membership will comprise representation from NYCC Health and Adult Services, Children and Young People's Service, NHS Partnership Commissioning Unit, NHS Foundation Trust service providers and a senior representative from Airedale, Wharfedale and Craven CCG. Other public sector agency members will be sought. The virtual reference group members will also be active in the development of plans and actions

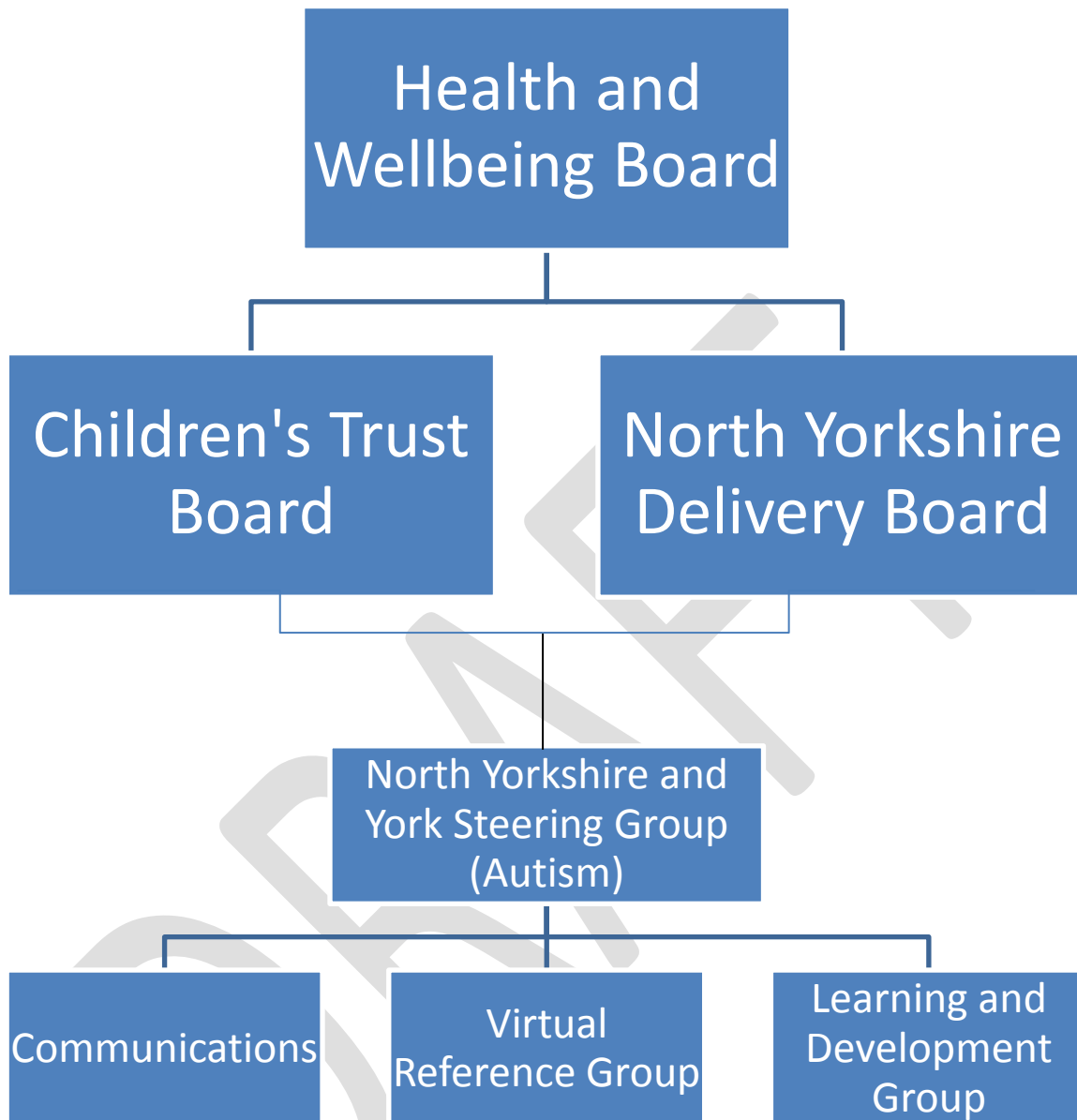
The Steering Group will receive regular reports on progress against the priorities and planned improvements, and will monitor progress against these priorities and improvements. An annual summary will be published demonstrating progress against the commitments made within this strategy.

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

North Yorkshire Health and Wellbeing Board
Children's Trust Board
North Yorkshire Delivery Board
Care and Independence Overview and Scrutiny Committee
Scrutiny of Health Committee
Partnership Commissioning Unit Management Board
CYP Leadership Team
HAS Leadership Team
North Yorkshire learning disability partnership board

The success of the strategy will be measured against the themes presented in chapter 5. 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



Autism Strategy consultation events Main feedback by theme

Diagnosis

- Improve diagnosis for girls with autism
- Improve post diagnostic services from health to include supporting young people in understanding the diagnosis, sleep difficulties, eating difficulties, sensory needs
- The diagnostic process does not always consider behaviour within the home
- There is not always a key worker – this would be helpful
- The links between diagnostic services and schools are not good
- Diagnosis is not open or transparent enough
- There needs to be a follow up visit after families have had time to digest the diagnosis information.
- An information booklet or website would be useful that explained what to expect in relation to a diagnosis and what to do next.
- Late diagnosis impacts on education
- Service feedback needs to inform the services that are being commissioned and the way that services are delivered.

Awareness raising (Should this be called awareness raising and training?)

- Needs to be about awareness, knowledge and understanding – awareness is not enough.
- Knowledgeable teachers, support staff, GP's, social care staff, hospital staff, mental health services, provider services are needed that really understand autism and know how to work effectively with children, young people and adults with autism. Knowledge of autism needs to be across all agencies and all communities and everybody needs to be aware of what services are available.
- GP's need to know about the referral pathway
- There is a need for parent training/support at different stages through the child/young person or adults journey.
- There needs to be increased understanding around girls with autism and children with autism who are looked after or adopted and those with PDA.
- More needs to be done to raise awareness of higher functioning children with autism and the subtle difficulties that they are experiencing.
- Provider services need training in autism as they are not always aware of autism and the needs of those with autism.

- Autism champions should be expanded across different agencies NHS, police housing, district councils the START team
- ESW's need a good understanding of autism
- There is a need to raise awareness of autism within communities

Information and signposting

- An online hub would be useful that contained information and a chat forum
- A single database of children, young people and adults with autism would be helpful for informing people of events and activities.
- Information on interventions and strategies need to be available to families as well as schools.
- An information pack post diagnosis is not enough
- A single point of contact would be helpful for advice, guidance and signposting "A one stop shop"
- Clear support plans need to be developed and maintained for children, young people and adults with autism to support information sharing.
- Literature is needed for children, young people and adults with autism, their siblings and the extended family. Library hubs would be good that include fiction and reference books.
- There is a lack of information for services about how to support children, young people and adults with autism.
- The NYCC website needs to be more user friendly for those with autism
- Consideration needs to be given as to how we communicate services for autism through social media and apps to make it accessible for young people with autism.
- Professionals on the frontline do not always know what services and support is available.
- An online chat facility for local people would be helpful for information and signposting.

Employment and education

- Primary to secondary transition is difficult for many families
- Schools need to make more reasonable adjustments to make the environment and curriculum work for children and young people with autism.
- Transition from education to employment and careers advice for young people with autism is poor
- Peers need to be better informed in relation to autism
- There is a need to measure the number of people with autism in paid employment.

- Employers need to be better informed about autism and there needs to be job coaching and employment support for young people with HFA.
- There needs to be more of an incentive for employers to recruit people with autism.
- NYCC and the NHS should provide supported internships for people with autism and lead by example
- Schools need more knowledge of autism interventions
- Job centre plus need a better understanding of autism
- Schools should be more accountable and transparent in demonstrating how they are using SEN funding to support individuals.
- Schools need to value the parents knowledge of their child and of autism and work with the family not against them.
- Schools need to develop their knowledge of the C&FA and the EHCP process.
- Consideration needs to be given to how the LA can achieve engagement from all schools even those that are resistant.
- There is a need for autism champions in every school
- The strategy needs to consider how best to support parents seeking a good education establishment for their child.
- There need to be better links between schools, the LA and OFSTED to ensure that all schools improve their autism knowledge and provision
- The LA need better links with local employers
- Support needs to be available when leaving school and transitioning into college or work.
- Residential placement specifications need to consider access to work opportunities
- Parents need effective signposting and guidance when choosing a school
- Bullying is a big issue for children with autism attending mainstream schools

Support for people with autism in crisis (this needs to be called something else supporting families/ social support?)

- Parent support needs to be strengthened this could be facilitated by parents for parents. It is as important to provide support for parents as it is to support the individual with autism.
- There is a lack of social activities for children, young people and adults with autism.
- There is a need for positive handling training for parents of children with autism.
- Families need support with planning for the future as they get older.
- When a person disengages with services the family still require support
- Families do not feel well supported

- The LA need to ensure that carers assessments are available for parents of children and young people with autism
- There is a need to develop safe environments within the community for people with autism
- Crisis support needs to be available 24 hours a day, 7 days a week
- The emphasis needs to change from supporting children and families at crisis point to early intervention and better understanding and acceptance
- A single point of contact would be helpful for advice, guidance and signposting,
- There need to be courses available to ensure emotional wellbeing, to reduce anxiety, stress and isolation. Some people with autism may never work but there needs to be access to activity and occupation.
- Families need support to adapt when children become adults and leave home and when planning for the future of their adult with autism as they become older
- There need to be different levels of support available at different times depending on the needs of the family at that time, families should not be in crisis before support is available
- Family support needs to be in the right venue and at the right time for the family
- It is not clear who undertakes carers assessments in children's services
- The Mental capacity act is not fit for purpose for those with HFA.
- Carers need support when their child becomes an adult
- Families would rather one service that supports the family rather than numerous different services all offering different aspects of support.

Transition

- Transition is not considered sufficiently within the strategy and this is a major difficulty for young people with HFA moving into adulthood.
- There are no specific transitions roles within NYCC and parents have to find things out for themselves.
- The strategy needs to address those that fall through the cracks during transition from education.
- There is a lack of resources for supporting those with HFA transitioning into adulthood.
- Additional support is required for transitions from primary to secondary school many children can cope in primary school but don't manage the transition to secondary school.
- There are too many people with HFA who are supported through education who then become reclusive and stay in their flats with no support to seek employment or continue their education. Support for this group is limited.

- There is a gap in for young people with autism who transition into adult-hood. They need support with confidence, self-esteem, making choices about their future, applying for courses or work and support undertaking the chosen activity.

Working together

- There needs to be collaboration with the police and district councils to develop skills in children with autism in relation to stranger danger, road safety, health eating etc.
- There need to be better links and collaboration with the voluntary sector
- Feedback relating to the strategy needs to be circulated with a range of organisations (job centre, district councils, schools, care providers etc.)
- Agencies need to understand each others roles and how these interlink
- Resources across health, social care and education need to be pooled to ensure that there are no gaps in service provision and that there is a reduction in the number of separate services that become involved with a person with autism.
- Parents do not want to fight to get what they need.