

# Improvement and Integration

## **Strategy for meeting the needs of Children and Young People with Autism in North Yorkshire**



***North Yorkshire and York***

Children and Young People's Service

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<sup>†</sup> 'Related Documents' referenced in section 4 set out in the Appendix and can be accessed via the Council's website.

## 1. Introduction

*“Once you have met one person with autism, you’ve met one person with autism ...”*

*Lorna Wing in Happe, Rosalind Frank Lecture, Oct 2011*

All children and young people deserve a fair start in life and opportunities which help them to meet their aspirations and to become independent and fulfilled as they move into adulthood.

It is essential to ensure that work continues to raise awareness of autism and improve services for children and young people with autism in North Yorkshire. To this end, the need for a cross-cutting, joint strategy for autism which covers the age range (0-25) was identified in the strategy for Special Educational Needs and Disability (SEND) ‘Improvement and Integration’ which was adopted by the Council in February 2012.

New national guidance has prompted a review of current service provision across health and education which has helped us to identify areas for improvement.

The overall objective of a strategy for autism is to ensure that services are identified, commissioned and provided to meet current and future needs. We want children and young people with autism to receive the right assessment and diagnosis as early as possible, to be able to access additional support if they need it and to know that they can depend on professionals and agencies to treat them fairly as individuals.

This strategy for meeting the needs of children and young people with autism has been developed as a joint strategy between the Children and Young People’s Service (CYPS) and North Yorkshire and York NHS.

Crucially, a coherent strategy will ensure that there is more effective, tangible support for children, young people and young adults with autism and will underline the enormous potential benefits that can result from collaboration.

We aim to:

- promote positive outcomes for young people with autism;
- provide earlier, better integrated support for families;
- enable families to stay together through access to local services and support;
- promote active engagement of children, young people and their families in shaping services;
- prepare young people with autism well for future life;
- ensure consistency across the county in service provision;
- improve practice and be attentive to national guidelines.

We stand a much better chance of succeeding in our ambitions if we work together as agencies, with parents and with the voluntary and community sector, which is why this is a joint strategy. Together, we are determined to improve services for children and young people with autism and greater integration is key to this.

Cynthia Welbourn.

Cynthia Welbourn  
Corporate Director -Children  
and Young People's Service

Tony Hall

Tony Hall  
Lead Executive Member  
for Children's Services

Julie Bolus

Julie Bolus  
Director of Nursing  
North Yorkshire & York PCT



The National Autistic Society (NAS) is the UK's leading charity for people affected by autism and exists to champion the rights of all people living with autism in the UK. We want a world where all people living with autism get to lead the life they choose. Autism is a complex condition that requires a broad range of services and supports to meet the individual needs of people affected by the condition. Good practice highlights the benefits of joint planning and commissioning of services and all services working together with a clear strategy that reflects the needs and priorities of the local area. Good practice also sees people with autism and their parent's carers at the heart of any strategy and it is essential that their views are obtained and used to assess the success of its implementation. This strategy demonstrates a commitment by North Yorkshire in improving the lives of people affected by autism. We hope it will make a positive difference to the lives of people living with the condition across the County.

Lisa Pitkeathley

NAS Area Development  
Coordinator – North

## **Scope of the Strategy**

This strategy concerns children and young people with autism from 0-25 years of age, and their families. It recognises that there is a range and severity of need.

The strategy has been informed by a number of national priorities and best-practice models. It will link closely with the strategy for autism that is being developed in the council's Health and Adult Services Directorate.

The strategy does not cover details of interventions for autism. Autism means many different things to each individual child, family and school/setting, and can present very different challenges. Every child is an individual and, as such, pathways and interventions need to be individualised. It is anticipated that the National Institute for Health and Clinical Excellence (NICE) will be issuing guidance on interventions in the near future and any implications will be considered.

## 2. Aims and Principles

The following principles have informed the proposals for change for children with SEND. They are intended as general principles to inform decisions and ways of working:

1. Keeping the child and family at the centre of our work.
2. So far as is reasonable and practicable, the preferences of the parents or young person should be followed by decisions on service provision, giving greater control and influence.
3. Integrating our approach to assessment and decision making at key points in a child's life, with shared standards and core competencies for staff.
4. Ensuring interfaces with partner agencies are managed to improve the experience for families.
5. Ensuring our services provide the best value for money through being both effective and efficient.
6. Take account of national policy and evidence-based practice in shaping services and decision-making around individuals.

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

- increase awareness and understanding of autism across all services and professionals;
- improve access to autism diagnosis services by developing a clear, consistent pathway for diagnosis and post-diagnostic support, including early intervention;
- improve equality of access for children and young people with autism to services, support and provision;
- raise expectations and achievement by delivering improvements in partnership working;
- increase the involvement of parents / carers and children and young people with autism in service planning and delivery and involve young people and their parents / carers in making decisions that affect them;
- remove any barriers to the participation and inclusion of children and young people with autism particularly at stages of transition;
- provides a flexible package of support using the best aspects of evidence-based interventions;
- ensure good quality, clear and accurate information on the range of services available;
- enable smoother transition for young people with autism into adult services;
- ensure multi agencies work together;
- provide sustainable services;
- enable provision to be managed within available resources.

### 3. Knowing about Autism

Until recently, individuals and groups have used a variety of terms for autism including: Autistic Spectrum Condition (ASC); Autism Spectrum Disorder (ASD); Autistic Spectrum Difference; Asperger syndrome.

In line with the NICE clinical guideline 2011, we have decided to use the term 'autism' throughout this strategy document to signify children and young people with a diagnosis of autism including, high functioning autism, Asperger syndrome and other autistic conditions as described in ICD 10 (World Health Organization, 1992) - to date the most commonly used diagnostic criteria. In this context the term 'autism' is used as an umbrella term synonymous with all diagnosed autism spectrum disorders. Work is underway on revising DSM–IV and ICD–10 with plans for DSM–V to be published in 2012 and for ICD–11 to be completed by 2014.

*“Reality to a person with autism is a confusing, interacting mass of events, people, places, sounds and sights .... A large part of my life is spent just trying to work out the pattern behind everything.”*

*Annabel Stehli, 1991*

It is essential to build a relationship with and to develop personal knowledge of the individual child or young person with autism. In this way it is possible to begin to appreciate that autism is part of the story of who the child is i.e. a person with a unique profile that includes their personality, strengths, challenges, likes and dislikes. Each person with autism is unique and provision needs to be sensitive, flexible and personalised to meet their needs.

*“All children with autism are individuals and their areas of strength will vary. Many children with autism will have an ability to focus on detail and they may be able to concentrate for long periods on a single activity if it is of interest to them. They can give their sole attention to a task and therefore can often achieve a high level of skill.”*

*Adapted from Autistic Spectrum Disorders – Good Practice Guidance*

Autism is a lifelong condition that has a great impact on children, young people and their families or carers. It can affect how they make sense of the world around them. Usually, difficulties are present in early childhood although sometimes they are not evident or significant until a time of change or transition. Autism is considered to be a neuro-developmental condition and, as such, health services have a key role in recognising and diagnosing autism.

Currently all children with autism are said to share a triad of impairments, however when the DSM-V and the ICD 11 are released, the triad of impairments will be reduced to two main areas:

1. social communication and interaction.
2. Restricted, repetitive patterns of behaviour, interests, or activities.

Sensory behaviours will be included in the criteria for the first time, under restricted, repetitive patterns of behaviours descriptors. The emphasis during diagnosis will change from giving a name to the condition to identifying all the needs someone has and how these affect their life.

There is a wide range of cognitive, social and communicative ability within the autism spectrum which can include children with profound learning difficulties, with little or no verbal communication through to those with average or high levels of functioning.

Children and young people with autism and more severe learning disability may exhibit more extreme social impairments, less verbal ability and increased repetitive, self-injurious and aggressive behaviours than children and young people with no, or only mild, learning disability.

In addition to learning disability, autism often occurs alongside other developmental differences such as sensory impairment, Down syndrome, gastrointestinal disorders, epilepsy, or other related genetic conditions. Coexisting conditions e.g. specific learning difficulty such as dyslexia may compromise the effectiveness of accepted educational approaches for students with autism, and increase the need for a more personalised teaching approach and individualised learning strategies. Table 5 in the NICE parental guide details more information. Some individuals with autism may also go on to develop mental health problems.

As well as coming to terms with, and learning about, their child's difficulties many parents also have to grapple with aspects of how the condition affects all aspects of their life. It is easy to be confused and overwhelmed by the processes and systems, the technical language, the various approaches, roles of different professionals and the complexities of inter-professional working. They may take time to understand the complex nature of their child's difficulties, particularly in the early days following diagnosis.

Children and young people with autism may show behaviours and characteristics including, but not limited to:

- rigidity and flexibility of thought, resistance to change, high levels of anxiety;
- ritualistic/repetitive behaviours, stereotypical mannerisms and obsessive interest in specific items or information;
- speech, language and communication needs;
- developmental coordination difficulties and/or delay in motor skills;
- sensory sensitivities which affect their response and ability to understand and make sense of their world;
- lack of skill in interacting with others;
- little understanding of the abstract uses of language, e.g. humour;
- lack of ability to infer what others are thinking and experiencing;
- difference in emotional reactions to environmental cues;
- difficulty with thinking and play which is creative, imaginative and social;
- disrupted or unusual sleep patterns.



Children and young people with autism also exhibit positive traits such as exceptional visual and/or auditory memory.

Appendix A (Signs and symptoms of possible autism) contains more detailed information regarding the signs and symptoms of possible autism taken from the NICE Clinical Guideline128.

### **Girls with Autism / Asperger syndrome**

Girls are less likely to be identified with autism even when their symptoms are equally severe as those of boys. Many girls are never referred for diagnosis because of the different manifestations of behaviour seen in girls and they are therefore missed from the statistics

- Girls are more able to follow social actions by delayed imitation because they observe other children and copy them, perhaps masking the symptoms of Asperger syndrome (Attwood, 2007).
- Girls are often more aware of and feel a need to interact socially. They are involved in social play, but are often led by their peers rather than initiating social contact. Girls are more socially inclined and many have one special friend.
- In our society, girls are expected to be social in their communication. Girls on the spectrum do not 'do social chit chat' or make 'meaningless' comments in order to facilitate social communication. The idea of a social hierarchy and how one communicates with people of different status can be problematic and get girls into trouble with teachers.
- Evidence suggests that girls have better imagination and more pretend play (Knickmeyer et al, 2008). Many have a very rich and elaborate fantasy world with imaginary friends. Girls escape into fiction, and some live in another world with, for example, fairies and witches.
- The interests of girls in the spectrum are very often similar to those of other girls – animals, horses, classical literature – and therefore are not seen as unusual. It is not the special interests that differentiate them from their peers but it is the quality and intensity of these interests. Many obsessively watch soap operas and have an intense interest in celebrities.

Dr Judith Gould and Dr Jacqui Ashton Smith  
Good Autism Practice, May 2011

### **National context and prevalence**

Autism is much more common than many people think and is recognised as the second most common primary special educational need according to Pupil Level Annual Schools Census (PLASC). The NAS estimates that there are 535,000 people in the UK with autism. If their families are included, autism touches the lives of over two million people every day.

The NAS has reported a 61% increase in autism cases between 2005 and 2010. Recent studies have reported increased prevalence and the condition is now thought to occur in at least 1% of children.

We also know that there is an increase in the numbers of children and young people who have complex learning needs where autism co-exists with another difficulty.

What remains unclear is whether the actual prevalence of autism is on the rise, or whether the increasing numbers of children and young people with autism is the result of broadening or improved diagnosis. What is evident is an increasing demand for diagnostic services for children and young people of all ages in the health services and an increase in the overall volume of referrals to the teams that support these children and young people.

More children and young people have autism than ever before and most teachers will teach a pupil with autism at some point during their career. In fact 1 in 3 children in special schools now have an educational need related to autism which highlights the need for an effective educational approach to meet the needs of this complex population of students. It is essential that all staff have an awareness and understanding of autism and how to implement strategies to enable these children and young people to access all aspects of school life and to reach their full potential.

Autism is far more prevalent in boys than in girls (by approximately four to one). The potential reasons for this are highlighted above.

### **North Yorkshire prevalence**

There are approximately 155,000 children and young people aged 0-19 in North Yorkshire, including around 84,000 school age children (January 2011, Schools' Census). Taking the national prevalence for autism of about 1 in 100, which is in line with the North Yorkshire health prevalence, this suggests that we could expect around 1,550 children and young people in the county to have a diagnosis of autism. However, some families may choose not to seek a diagnosis or to access support services.

- Nationally, around 20.8% of statements of SEN are for autism. In North Yorkshire, this figure has risen over the last 2 years and in 2012 was 23.3%. Autism is the most common primary need among pupils with a statement of SEN in North Yorkshire.
- According to the SEN Code of Practice, the proportion of children at School Action Plus (SA+) for autism in North Yorkshire is higher than that observed nationally. Children with autism at SA+ account for 4.8% of the SA+ population in North Yorkshire (4.6% observed nationally).
- The current age profile for children with a statement for autism shows peaks around the age of 6 to 7 years old, 10 to 11 years old and 13 to 14. This may indicate that transition to Year 1 and from Key Stage 2 to Key Stage 3 is a focal point when schools, and parents, may become concerned at a child's progress.

## 4. Autism Policy Framework

### The National Context

The overarching strategy for SEND, Improvement and Integration sets out the legislative framework and statutory guidance.

In the past few years there has been a national impetus to improve provision and support for children with SEND, with a number of key reviews and initiatives centring on autism.

Many of the findings of these key documents have informed this strategy.

[Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum: NICE Clinical Guideline128 \(Sept 2011\) – Appendix B](#)

This report highlights the areas of difficulty faced by children and young people with autism. 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.

[Support and Aspiration Green Paper 2011 – Appendix C](#)

The paper proposes:

- a single assessment process and an 'Education, Health and Care Plan';
- to remove the current SEN identification levels of School Action and School Action Plus;
- a discussion of the diagnosis, which includes a sensitive framework for sharing information;
- easy access to information and support in relating it to their needs;
- multi-agency, multi-disciplinary assessment and working;
- appropriate intervention.

The document recommends improved strategic planning and co-ordination of services.

[Autism Good Practice Guidance \(2002\) – Appendix D](#)

The Autism Good Practice Guidance (Department of Health), written by the Autism Working Group within the Department for Education and Skills, highlights and shares examples of best practice from around the country when reviewing educational services and support for children with autism. It provides a useful overview, including information regarding the impact upon development and functioning. It seeks to establish the key principles relating to best practice.

These include:

- the need for those working with children with autism to have a well developed working knowledge and understanding of autism, in order to ensure individual learning styles and needs are met and environments are structured to support all children;
- a need for the local authority to regularly complete audits which evaluate the knowledge and skills of their workforce in order to assess training needs and then take appropriate action;
- having a clear, agreed referral pathway when autism is suspected;
- a priority to support early identification and intervention;
- joined up working within local authority/regional/strategic levels across health and social care services with a clear inter-agency policy on provision communicated widely;
- families, including siblings, to be supported within a partnership working model;
- regular consultation with children and young people with autism regarding their educational provision.

#### [NAS 'You Need to Know' Report \(2010\) – Appendix E](#)

This report reviewed the services offered to children and young people with autism who also suffer with a mental health problem. The report makes a number of recommendations for both national and local change.

#### ['Great Expectations' report by the National Autistic Society \(2011\) – Appendix F](#)

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 fifty percent felt they were not making good educational progress. Worryingly, 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 also make a wide range of provision available and ensure that the teaching methods used in schools meets the needs of each individual pupil. This provision may be made in enhanced mainstream schools, mainstream schools, or by outreach, or peripatetic support teams. Provision may also be made in special schools.

The 'Great Expectations' Report (NAS 2011) summarises what parents of children or young people with autism expect and need:

- *"to have robust, simple ways to challenge the system if their child doesn't get the support they need"*
- *"local authorities to have a thorough understanding of the needs of children with autism in their area, and to plan provision accordingly"*
- *"to be equal partners in the system and genuinely involved in decisions about their child's education and the planning of local services"*
- *"local information that empowers them to make the right decisions for their child"*

*(Executive Summary, page 3)*

### Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century (2010) – Appendix G

This strategy takes forward the recommendations of the 'Valuing People Now' (2001) 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.

### Disability Discrimination Act 2005 / Equalities Legislation/ Equalities Act (2010) – Appendices H & I

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 adjustments to premises 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 (Dec 06, disability equality duty).

### Valuing People Now (2009) – Appendix J

This is a collation of data on prevalence of autism and learning disability highlighting 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".

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

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

[Education for Pupils with Autism Spectrum Disorders, Report \(HMIE 2006a\) – Appendix K](#)

A focused inspection of education for pupils with autism reported in 2006 by HM Inspectorate of Education.

*“Autism spectrum disorders, as the name suggests, do not represent a single nor straightforward set of needs to be met. The challenges facing education and other professionals, and the young people whose needs are being addressed, are considerable. The key is to see past the presenting issues, often behavioural in nature, to the communication disorders beyond that and to find what works for each individual concerned.”*

HM Senior Chief Inspector Graham Donaldson

The report highlights the variety of provision and arrangements for meeting the needs of pupils with autism.

[Inclusion: Does it matter where pupils are taught? OFSTED \(2006\) – Appendix L](#)

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.

[Aiming High for Disabled Children \(2005\) – Appendix M](#)

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.”*

Both the Strategy for SEND and this Strategy will be refreshed to include other duties.

## **The Local Context**

[Children and Young People's Plan 2011-2014](#)

The Children and Young People's Plan 2011-2014 provides the detail of how the CYPS will contribute to the County Council's priorities through helping all children and young people to develop their full potential and to protect and support vulnerable children and young people. The plan can be found on the local authority website [www.northyorks.gov.uk](http://www.northyorks.gov.uk)

[North Yorkshire Special Educational Needs and Disability Strategy 2011 - 2014](#)

This sets out the local authority's plan 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. The SEND strategy 'Improvement and Integration' is closely aligned to The SEND provisions in the Children and Families Bill.

#### [NHS North Yorkshire and York Strategic Plan – Healthier Lives](#)

The PCT's related strategic priorities, as expressed in Healthier Lives, include:

Goal 5 – Highest quality of care in the right settings

Goal 6 – Strong partnership working focussed on the individual.

Strategic Initiative1 – Community Systems, focuses on improving services for children with complex needs and disabilities.



## 5. Engagement and Consultation

### Joint Engagement in Preparing the Strategy

In developing this strategy, we have listened to and taken account of feedback from a range of professionals, parents / carers, voluntary sector organisations and young people with autism.

As part of this engagement process, a representative parents' group was established including representation from North Yorkshire Participation, Advocacy, Cooperation and Trust (NYPACT). The group identified the following areas they would like to see to improve support for families:

- information pack post diagnosis, including where to go for local support, what type of support is available, and details of any statutory entitlements;
- an appropriate parent support package for very young children with autism e.g. ASCEND (Selby and York), EarlyBird (Craven area);
- a programme for parents of children in Early Years;
- information about schools and settings to provide confidence that teachers and support workers understand autism, that schools and settings are suitably skilled up, and that they have experience of good autism practice;
- improved dialogue between schools/settings and parents;
- improved multi-agency working including consistent support and advice from professionals;
- social skills programmes / independence skills programmes;
- for older young people – a 'social mentor'.

The parents also highlighted the following areas that their children find stressful:

- moving around the school;
- break times / lunch times/any unstructured time;
- after school activities;
- the environment of the school, particularly where it's not autism-friendly;
- not feeling part of their peer group and lack of support to build relationships;
- lack of a quiet, safe space or not being able to have time out;
- exams;
- school trips;
- homework;
- lack of effective home-school communication;
- challenges in the sensory environment;
- changes in the daily routine;
- coping with transition.

The information gathered from this representative parent's group has helped shape the strategy and will inform our work with schools and settings.



## **North Yorkshire and York Strategic Steering Group for Autism**

A multi-agency, multi-professional strategic partnership group focusing on autism has been established in North Yorkshire and York. The steering group includes: commissioners, managers and clinicians from health; senior officers from the CYPS; parents and representatives from the voluntary sector. This group has contributed to the development of the strategy and will support the implementation of the action plan.

### **Consultation with Parents**

There was public consultation between 4<sup>th</sup> May 2012 and 27<sup>th</sup> July 2012. Local meetings were held with parents and carers of children with autism. The consultation also included young people through the Flying High Group, Health commissioners and providers, local authority staff, Health and Adult Services, the Children's Trust Board, and Professional Associations. The consultation document was posted on the Council's website. It was also promoted on the NYPACT and NHS NYY websites.

The strategy has taken the consultation responses into account. A detailed implementation plan will be developed which will be monitored by the Children's Trust Board through its SEND Change and Integration steering group.

The local authority has undertaken an Equality Impact Assessment (EIA) in developing this strategy and reviewing services. This is available at <http://www.northyorks.gov.uk/index.aspx?articleid=20203>

## 6. Current Provision

### Autism Diagnosis by Health Services

It is important that a child's individual needs are identified as soon as possible so that they can be met in the most appropriate way. The assessment over time may indicate autism, but early intervention appropriate to the child's identified needs should not be dependant on a diagnosis of autism. However, it is recognised, that a diagnosis may help to guide families and professionals to the most appropriate source of information and support. A diagnosis can point the way to the type of difficulties that a child may have, but effective support can only be based on identification of the particular profile of individual needs and strengths, working in partnership with other agencies.

Provision of autism diagnosis is offered by local health services in partnership with the local authority across the county. Due to increasing demand in referrals and the complexity of the diagnosis pathway, capacity issues have resulted in waiting lists in some areas. Some of the services have therefore targeted their resources at younger children for earlier intervention. A review of the diagnostic process to bring it in line with the NICE Guideline highlighted some areas of excellent practice and some areas for improvement; work is on-going to improve these diagnosis services.

Local health led multi-agency groups within North Yorkshire have an autism diagnostic team with core membership of a paediatrician and/or child and adolescent psychiatrist, a speech and language therapist, and a clinical and/or educational psychologist. These teams have specialist skills in completing autism diagnostic assessments and will inform and advise parents and colleagues of their findings. Child and Adolescent Mental Health Services (CAMHS) have a role in supporting children and young people with autism where the condition overlaps with other conditions.

For most, the recognition and diagnosis of autism leads to a framework pathway of care and service provision being put into place which is autism-supportive and needs led. This in turn impacts positively and significantly for the child and young person involved, and helps ensure the best possible outcome for that individual.

*"Any diagnosis should engage the parents and carers in such a way that it leads to a better understanding of their child and is inextricably linked to appropriate educational and other interventions."*

*Phil Christo NAS Conference 2012*

The diagnostic process can be complex and distressing for some families and individuals; professionals working in this area must be sensitive to the emotional impact of this process. It is also important that the correct diagnosis is given; therefore this process can sometimes necessarily be quite lengthy. If there is uncertainty regarding the diagnosis, in some instances, professional clinical judgement may indicate the need for 'watchful waiting' to take into account any new information. Children and young people in this category will be monitored over a period of time.

There may be instances where the complexity of a case makes diagnosis difficult and therefore may require an additional referral for assessment at a specialist (i.e. Tertiary, Tier 4) centre.

### **Supporting parents and families**

Schools, health and early years' settings have a major role to play in supporting families by expanding opportunities, widening access to education, as well as increasing the opportunities available to, and the achievements of, children and young people with autism.

Schools and settings sometimes work with children using autism friendly approaches prior to diagnosis - perhaps when a process of assessment and diagnosis is underway, or when behaviours strongly suggest that such approaches will be helpful to the individual concerned.

*"To be in a position where he understands that he's autistic and that with autism there comes difficulties that he'd find magnified compared to other children...and then sort of learn how to manage them and to cope with them... and maybe use it to his advantage"*

*Mother of 3 year old boy with autism*

Following diagnosis, a parent information pack is made available and appropriate arrangements are made if a child needs access to additional health services such as occupational therapy, speech and language therapy, and physiotherapy.

Children's Centres and voluntary sector organisations also provide a wide range of services and support for children, young people who have special educational needs, some specifically autism. and their families

Active parental engagement and participation is encouraged to better enable the child to gain the best possible outcomes. Parents/carers are given the opportunity to attend a programme for families. Depending upon which area of the County they live in these joint health / education, parenting support programmes for parents of children aged 0-19 years of age with a diagnosis of autism are:

- the CYGNET programme, developed by Barnardo's which takes a psycho-educational approach.
- the EarlyBird and EarlyBird Plus programme, developed by the National Autistic Society.
- the ASCEND programme, developed by CAMHS in York which is a therapeutic programme.

The training programmes are designed to raise awareness of autism and offer a range of strategies and approaches. They enable parents to discuss their issues within a supportive environment. The training also gives families the opportunity to meet others who are in a similar situation and may have shared experiences.

The PCT has extended the Training and Education for Short breaks Service (TESS) to age 25 years as a pilot, to support those going into employment. The service is

accessible to disabled children and young people and the TESS team provide training and mentoring for carers, family members and short break providers.

These programmes are thoroughly evaluated and proven to be effective. They support parents to be better informed and to have knowledge of a wide range of strategies to support their child.

### Approach to meeting need

*“Children expect an education that sets them up for life. Parents expect a system that works with, not against, them.”*

*The Great Expectations Report 2011*

It is important to remember that autism can mean many different things to each child, family and school/setting, and can present very different challenges. The level and type of support required will vary greatly in relation to the characteristics presented due to autism, other additional needs, the circumstances of the family and the experience of the school/setting.

The local authority's approach is not to specify particular 'off the shelf' packages but to design programmes based on appropriate assessment and identification of needs. The local authority use an enquiry based approach to information gathering and a scientist-practitioner approach to intervention.

This approach offers a systematic and structured method of assessing need, developing targets and measuring and evaluating outcomes for children and young people with autism.

*“Recognise that autism isn't just about deficits, but represents a different cognitive style. People with autism can excel in certain tasks that play to their strength of being focused on detail”.*

*The Psychologist Vol. 24 No 12 Dec 2011*

We consider each child individually and aim to design a supportive package around them, rather than apply a blanket approach to all children just because they have a diagnosis. The Autism Education Trust concurs with this view.

### Early Intervention

Families are the most valuable asset a child with autism has and it is important to recognise the knowledge they have of their own child as an individual. It is very important that parents / carers feel supported and that they are listened to when designing any intervention that will take place for their child, either in the school/setting or in the home environment, if they have not yet begun to access a school/setting.

## Personalised Intervention Programme (PIP) for children in the early years

The North Yorkshire Personalised Intervention Programme (PIP) for early years is an educational intervention which has been developed in response to an identified need in terms of supporting children who have a diagnosis of autism and who require a more robust start to their education. The need has been identified by the local authority, to address the challenge of providing a more equitable service across the county i.e. to ensure that all children have access to appropriate levels of support, following a diagnosis of autism, regardless of where they live and where they are educated.

There are similar PIPs for primary school children and young people in secondary school. The programmes will be introduced for learners who require this type of approach, but not for all children and young people with autism.

## Provision for children of school age

Education authorities have a duty to ensure that they provide adequate and efficient educational provision for any child or young person with additional support needs and this of course includes children and young people with autism. In ensuring these duties are met, North Yorkshire makes a wide range of provision available and ensures that the teaching methods used in schools meet the needs of each individual pupil.

All children and young people will benefit from excellent classroom practice and skilled teachers. Some will require additional specialist support from Outreach Services e.g. Autism Outreach Support Services (ASCOS), others will need a personalised, or in some cases profoundly personalised, approach to teaching and learning. Many young people will move into adulthood requiring additional support throughout their transition to adult services.

To improve local provision we have recognised the need to have the right specialist support in place and the right pattern of provision to meet the needs of children with autism and their families. We promote a mixed economy of provision, some provided directly through centrally based local authority staff and other services are procured on its behalf e.g. EMS, special schools and some out of area services.

These services, regardless of who they are delivered by:

- deliver the appropriate support to help children fulfil their potential;
- place the child and the family at the centre;
- safeguard children and young people;
- are of high quality, demonstrated by evidence of impact;
- provide the best value for money through being effective and efficient.

North Yorkshire offers a wide range of pre-school and educational provision including:

- Early Years Service / Portage Home Visitors;
- ASCOS Early Intervention pre-school;

- mainstream schools;
- special schools;
- enhanced mainstream schools, primary and secondary;
- specialist support and advisory support services, centrally-based and from special schools. These services support mainstream settings and schools that have children and young people with a diagnosis of autism on roll;
- Sixth Form provision e.g. Springwater.

Collectively the above provision ensures a flexible continuum of provision available at a local level. The local authority's primary aim is to support children and young people within their local mainstream community school, wherever possible, having regard for parental preference.

The local authority pattern of provision aims to develop the capacity of local schools, by sharing expertise in autism and, in the case of the primary Enhanced Mainstream Schools (EMS), speech, language and communication needs. For a small number of children who have highly complex needs, which cannot be met locally, the local authority may consider access to appropriate provision outside the County.

### Mainstream Schools

The majority of young people with autism will attend their local maintained mainstream school or academy and will have their needs met within the mainstream from delegated funding. Resources are delegated to schools to enable them to meet the needs of pupils with SEND at lower levels of need. For children with higher levels of need, the local authority may provide resources through a Statement of Special Educational Needs.

The local authority provides support to all schools to develop their knowledge, skills and competencies to meet a wide range of needs and to be more inclusive.

Important considerations include:

- promoting autism-friendly learning environments, with particular emphasis on the sensory aspects of the school, classroom and social environment;
- facilitating a social education for children and young people with autism. Socialising provides the platform required for interaction and communication to develop and social interaction skills to be learnt;
- consideration of the individual's preferred learning style and the need to adapt approaches to teaching to take account of this. Research suggests that learners with autism can be described as 90% visual and 10% auditory learners but also benefit from opportunities for kinaesthetic learning (learning through doing).

### Enhanced Mainstream Schools

The EMS form part of the SEND Support and Outreach Service. The provision is commissioned by the local authority and is led and coordinated by the Children and Young People's Service, through the Access and Inclusion service. Between 2010 and September 2011, ten Enhanced Mainstream Schools (EMS) were opened. Five

schools are primary EMS for learners with communication and interaction needs, which embrace speech, language and communication and needs relating to autism, but not necessarily a formal diagnosis of autism. Five secondary schools have been enhanced for students with a diagnosis of autism.

The five enhanced mainstream primary schools for communication and interaction:

- Embsay Church of England VA Primary School, Skipton
- Kirkbymoorside Community Primary School, Kirkbymoorside
- Thorpe Willoughby Community Primary School, Thorpe Willoughby, Selby
- Mill Hill Community Primary School, Northallerton
- Hookstone Chase Community Primary School, Harrogate

The enhanced mainstream secondary schools for young people with autism

- King James's School, Knaresborough
- Filey School, a Technology College, Filey
- Bedale High School, Bedale
- Holy Family Catholic High School, Carlton, Selby
- South Craven (Academy)

### Special School provision

*"Expert enlightened education with understanding really works – there are miracles happening every day in our special schools and 'units' around the country."*

*Happe 2011*

Special schools form part of a pattern of provision that is autism capable and focussed on higher levels of need. These include schools for children and young people with:

- profound multiple learning difficulties (PMLD) and severe learning difficulties (SLD);
- learning needs and communication difficulties.

North Yorkshire's special schools are highly regarded by the local authority and Ofsted. Appropriate provision is made based on individual needs – this may be within a generic class group or may involve a more bespoke response.

### Out of Area provision

In a small number of cases where the needs of young people with a statement of special educational needs are unable to be met through local provision, it may be necessary for the local authority to consider out of authority provision. These cases will arise through a review of the young person's statement of SEN and decisions regarding placement will be made through a local authority multi-agency panel.



## **SEND Support and Outreach Services**

These services assist local mainstream provision to support children and young people with autism.

### **Autism Outreach Support Service (ASCROSS)**

The ASCROSS team operates across North Yorkshire to provide support for children, schools and families. The service, which is primarily a teaching service, is designed to enable local access through a network of support provided by area teams, with access to professional support from specialist educational psychologists.

The ASCROSS team are alerted following a diagnosis by the health diagnosis assessment team. An initial visit to the school is arranged in order to gather information about the child, discuss their needs and build a picture of what interventions may be useful. A range of interventions and support options will be considered based on individual need.

The team consists of staff from a range of professional backgrounds; they provide specialist support, advice and training to improve provision to children and young people with a diagnosis of autism who are educated in mainstream schools. This support is designed to enhance learning, achievement and social inclusion and comes in a variety of formats. This includes advice on curriculum content, the optimum learning environment, support with provision mapping and target setting. The team also provides modelling and coaching on appropriate support strategies as well as a range of autism awareness training for leadership teams, staff and parents.

Additionally, three special schools (Mowbray School, Bedale; The Forest School, Knaresborough; The Woodlands School, Scarborough) are commissioned to support local mainstream schools and settings that have children and young people with autism on roll.

### **North Yorkshire Communication Aids Partnership (NYCAP) and Alternative and Augmentative Communication (AAC)**

The use of low tech aids e.g. paper based visual supports for children with autism is now widespread. North Yorkshire has produced a guidance document to ensure consistency of approaches in using visual supports.

However, there is growing evidence that the particular needs of some children and young people with autism can be met by capitalising on their strengths and using high tech communication aids as appropriate in order to:

- support the development of language, communication;
- encourage day to day interaction;
- promote the development and use of higher level language and literacy skills;
- include visual support tools to increase learning, support understanding and act as positive behaviour supports.



Communication aids are able to support all these areas effectively, and also promote both joint attention and the development of pretend play skills through a technology medium.

NYCAP is available to take referrals from schools and specialist staff to support assessments for high tech AAC systems, and to make funding requests for this equipment. This is, however, a potential growth area for the use of AAC, which could easily overtake the existing joint funded Health and Education budget. Provision will need to be made for this into the future if children and young people with autism are to benefit from these advances in communications technology.

### **Parent Partnership Service**

The Parent Partnership Service offers confidential and impartial advice and support to any parent who has concerns about their child's special educational needs. Parents can contact the parent partnership coordinator for their area directly to discuss their child in confidence including arranging a home visit if preferred. No information is shared with other people without the parent's consent (except in rare safeguarding situations).

The Parent Partnership Service also provides information sheets and useful links on the Council's SEND web pages: [www.northyorks.gov.uk/parentpartnershipservice](http://www.northyorks.gov.uk/parentpartnershipservice) An Enquiry Line is available all year round during office hours 0845 034 9469.

### **Educational Psychology and Early Years Service**

The Educational Psychology and Early Years Service supports a multi-agency approach to identifying and meeting the needs of children and young people with communication and interaction needs, including those that have an autism diagnosis. As part of this they may:

- work with schools and settings, parents and carers, prior to a diagnostic referral, to better meet the needs of children with complex communication difficulties;
- support the multi-agency approach to gathering evidence for the autism diagnostic process through:
  - helping schools and settings to gather evidence for the multi-agency autism forum to check against diagnostic criteria
  - completing a psychological assessment, to include evidence of the child or young person's cognitive ability
  - being the educational representative at the multi agency diagnostic forum
  - providing input into the educational home plan and working with schools and settings and ASCOSS to support those children in their 'settings';
- additionally they will support ASCOSS with complex casework after diagnosis;
- and provide direct input into parent programmes such as Cygnet.

Information on arrangements for early support can be found on the local authority website [www.northyorks.gov.uk](http://www.northyorks.gov.uk)

## **Portage Home Visiting Team**

The North Yorkshire Portage Team is registered with the National Portage Association. Portage is a home visiting educational and support service for young children with additional needs and their families. The Portage Model, as a model of support for pre-school children with additional needs and their families, is characterised by:

- regular home visiting;
- supporting the development of play, communication, relationships and learning for young children within the family;
- working together with parents/carers within the family, with them taking the lead role in the partnership that is established;
- helping parents/carers to identify what is important to them and their child and plan goals for learning and participation;
- keeping a shared record of the child's progress and other issues raised by the family;
- responding flexibly to the needs of the child and family when providing support;
- Portage Home Visitors accessing support through regular team meetings, on behalf of the family they work with;
- working closely with other agencies.

Parents and professionals can access Portage services through an open referral system, by completing a 'Request for Involvement'. Children can be eligible for services from a very young age, even a few months old. Portage input would continue until there is no longer a need for support or until the child enters an early years setting, at which time involvement would be phased out through an agreed transition process.

Portage Home Visitors may work with children with communication and interaction needs, usually as one of a cluster of needs, up to the child receiving a diagnosis of autism. Following a diagnosis of autism individual children will transfer to ASCOSS. Transition will be carefully planned to ensure smooth transfer.

## **Short Breaks**

Children and young people with autism whose parents feel that they need additional advice and support can seek a referral to the Disabled Children's Team in the SEND Service. Depending on the child's level of need parents/carers could be directed to Integrated Services or, in more complex cases, to the Disabled Children's Service.

If a family are in need of a break from their caring responsibilities, their short break requirements can be assessed to see what might help them most. This might include work on parenting, one-to-one work with the young person, advice for the parents and liaison with other agencies to develop consistent strategies.

Training and education for short break services (TESS) delivers individual training to short break providers to enable disabled children to access activities out of school.

Information on Short Breaks provision can be found on the local authority website [www.northyorks.gov.uk/SEND](http://www.northyorks.gov.uk/SEND).

## Transition to Adulthood

Making the transition from childhood, through adolescence and into adulthood is challenging for any young person. Young people with SEND generally and those with autism can face significant additional barriers, including a lack of local post-16 or post-19 learning opportunities, limited access to paid work and changes to health and care provision. This period of time, often referred to as 'Transition' can be both daunting and frustrating for young people and their parents.

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

Significant work has been done over the past three years, through the Transitions Support Programme, to develop systems which will improve the experience of young people including those with autism in North Yorkshire but there is much more to do. This focus area will include:

- improving local provision for post-16 learning opportunities, including the development of flexible and personalised packages of support to continue in education or training;
- integrated and person-centred assessment approaches through the transition period, using the Learning for Living and Work Framework;
- close working with colleagues in HAS and with NHS providers and commissioners to improve the pathway from children's services to adult services;
- improving information, advice and support to families.

## Provision in the Local Community

*"To get any kind of all-round service, people with autism don't need a High Street full of competing shops; they need a department store where each department is aware of what the others offer and points people in the direction of other services which complement their own"*

*Donna Williams, 1996*

There are a range of community groups and support available in the local community for children and young people with autism and their families. These include leisure and sport activities, youth provision and after school clubs. As part of developing the strategy we have liaised with, and will continue to work with, a number of voluntary organisations to map activities available and signpost families to opportunities.

This information will be included in the local authority's Local Offer to be published in April 2013.

## **Transport**

Parents and carers are sometimes eligible for home to school transport for their child. In the procurement of transport, we ensure that staff are autism aware and attention is drawn to the needs of the individual when arrangements are made. Training, where necessary, is provided for the operator's staff and they are made aware of the pupil's specific needs.

A programme of specific training for taxi drivers and escorts in understanding disability and autism is being developed and will become part of the training programme.

The local authority offers support for young people with disabilities to develop the necessary skills and confidence to enable them to travel independently. An Independent Travel Scheme has been commenced and will be further developed.

## 7. Moving forward

### **Focus Area 1: Raising awareness of autism**

*Parents and young people agree that knowledge of autism, more than anything, helps children's needs to be met*

*Great Expectations 2011*

Raising awareness of autism via multi-professional training of the workforce is beneficial to increasing early identification of need and related assessment and diagnosis. Additionally, a workforce that is skilled in autism can help identify particular 'at-risk' groups for which autism is currently under-diagnosed (including individuals who have English as an additional language and those with an intellectual or sensory impairment).

Through increasing understanding and awareness of autism it is envisaged that this will help identify children who may potentially have autism at an earlier stage. This should enable early intervention.

#### **Priority Actions:**

- **Improve the skills of the workforce in meeting the needs of children and young people with autism through a targeted programme of competency-based training (universal, targeted and specialist)**
- **Raise awareness of the specific needs of girls with autism, those with Asperger syndrome and other lower incidence groups**
- **Work with the Voluntary Sector in increasing awareness of autism e.g. through TESS**
- **Increase the number of professionals able to deliver a range of parent support training courses for autism**
- **Increase provision of parental support programmes e.g. Cygnet, Ascend, EarlyBird, EarlyBird Plus**

### **Focus Area 2: Identification, assessment and diagnosis**

*"The identification of autistic spectrum disorders requires expertise, experience and time."*

*Wing, 1996*

When autism is suspected the assessment process can be detailed and complex, and usually involves a range of professionals. The North Yorkshire diagnostic pathway agreed between health commissioners and providers is set out in Section 10.

#### **Priority Actions:**

- **Ensure the pathway for assessment and diagnosis of autism is consistent across the County, is NICE compliant and leads to identification of need for services**

- Establish multi-agency diagnostic teams for autism in all areas of North Yorkshire including the allocation by health of a Diagnosis Assessment Pathway Coordinator
- Ensure joint planning for children with autism post diagnosis is coordinated across health, education and social care
- Establish a mechanism for data collection and monitoring of the diagnostic process relating to autism
- Ensure that future health commissioning arrangements include full engagement with the strategy for autism

### **Focus Area 3: Give parents greater control and influence**

*“Parents want professionals to work in partnership with them, to recognise that their knowledge of their own child is valuable, to listen when they have concerns, and to communicate with them so they feel fully involved.”*

*Great Expectations 2011*

For partnership working to be effective, sharing and collaboration are essential - between parents, between professionals and between parents and professionals.

#### **Priority Actions:**

- Ensure the local authority Local Offer includes comprehensive information on the full range of support available
- Improve data collection and analysis to identify whether pupils with autism are making progress in line with expectations
- Improve signposting to Voluntary Sector organisations that offer support to children and young people with autism and their families, including opportunities for short breaks and leisure activities
- Ensure that families of children 0-5 with a diagnosis of autism are made aware of the full range of services available from their local Children’s Centre
- Conduct annual service user satisfaction surveys to monitor parental and service user feedback
- Provide an information pack for each family post diagnosis to include relevant information and support
- Ensure autism information is readily available and accessible through Family Information Services and libraries
- Increase the number of training events and availability of autism awareness sessions for parents and professionals
- Investigate the possibility of training in positive handling for parents and carers.

### **Focus Area 4: Improve local provision**

We have a good pattern of provision and specialist services in place for children and young people with autism but there is still room for improvement.

**Priority Actions:**

- **Identify a clear model of specialist support for children and young people with autism, their families and schools.**
- **Map the autism pathway of services to identify gaps in provision and encourage greater integration of services**
- **Improve targeting and efficiency by reviewing ways in which individual need is identified and provision is made by specialists, with a greater emphasis on planned outcomes**
- **Ensure the needs of children with autism are included in the local authority's strategy for Narrowing the Gap**
- **Achieve National Autistic Society accreditation for autism support and outreach providers**
- **Improve and integrate specialist support e.g. by training and skilling up Family Support Workers in the Disabled Children's Team to extend their role to provide support for parents in crisis, without the necessity for additional assessment**
- **Ensure that related strategies take into account the needs of children and young people with autism e.g. the strategies for meeting the needs of children and young people with speech, language and communication needs, and those with mental health difficulties**

**Focus Area 5: Transitions**

It is important to ensure that the transition planning and process is well planned and coordinated at every stage for children and young people with autism. All providers and partners must work closely with the child and their family to ensure that these stages of the individual's life are well coordinated. This will ensure that services are tailored to meet the individual needs of the young person.

The goal is to deliver personalised services that give each individual the right support to have more choice and control over their own lives.

Transition should not be a one off event and preparation should start early and can be supported by a health transition plan. It is important that we improve multi-agency working for young people with autism going through transition.

The strategy reflects the work within HAS to meet the requirements of the Autism Strategy 'Rewarding and Fulfilling Lives' (March 2010) and related statutory guidance.

**Priority Actions:**

- **Monitor and track destinations post 16 for young people with autism**
- **Continue to improve local personalised pathways for Post 16 and Post 19 learning opportunities, to enable more young people with autism to be educated and to live locally**
- **Ensure that this strategy helps to inform the strategy for young adults with autism and leads to improved pathways and better managed expectations for young people moving from being a child to adulthood**
- **Young people with autism moving into adult services will have an individual assessment of need and transition plan, including plans for education, employment and training developed jointly across CYPS and HAS**

## **8. Accountability and Performance Framework**

### **Accountability Framework**

The implementation of the action plan relating to this strategy will be overseen by the North Yorkshire and York Strategic Steering Group (Autism) and monitored by the Children's Trust Board through its SEND Change and Integration steering group.

### **Measures of Success**

The success of this strategy will be measured against the outcomes and aims we plan to deliver. This will include:

- a) Implementation of the Priority Actions in section 7 and progress against these (progress)
- b) Improved progress against performance indicators in the over-arching SEND Strategy (impact/process)
- c) Responding to feedback from professionals, service users, young people and families (impact)
- d) An annual report on the effectiveness of autism specialist services and implementation of any actions arising.



## 9. Resourcing the Strategy

### Children and Young People's Service

Details of Budgets	Estimated Gross Expenditure £'
<b>Early Years Providers - (Maintained Schools and Private Voluntary &amp; Independent Providers)</b>	
Allocated to Early Years Provision to support SEN	15,230
<b>Mainstream Schools</b>	
Allocated to Schools to support High Need Statements	2,116,741
<b>Special Schools</b>	
Day Provision	2,267,328
Residential Provision	190,497
	<b>2,457,825</b>
<b>Outreach Services</b>	
Severe Learning Difficulties	#
Autistic Spectrum Disorder	67,400
North Yorkshire Communication Aids Partnership	#
	<b>67,400</b>
<b>Enhanced Mainstream Schools</b>	
Schools for High Functioning Autism	548,010
Schools for Specific Learning Difficulties	#
Schools for Communication & Interaction	309,428
	<b>857,438</b>
<b>Independent Special Schools</b>	
Fees and Support	798,423
<b>Recoupment with Other Local Authorities</b>	
Payments / income to & from other local authorities	276,550
<b>Commissioning Budgets for Disabled Children's Services</b>	
Commissioning and Placements	2,699,256
<b>Residential Short Break Budgets</b>	
May Lodge	44,803
Morton-on Swale Children's Resource Centre	168,547
Nidderdale Children's Resource Centre	231,750
Beck House Children's Resource Centre	18,200
The Ghyll Children's Resource Centre	145,857
	<b>609,157</b>

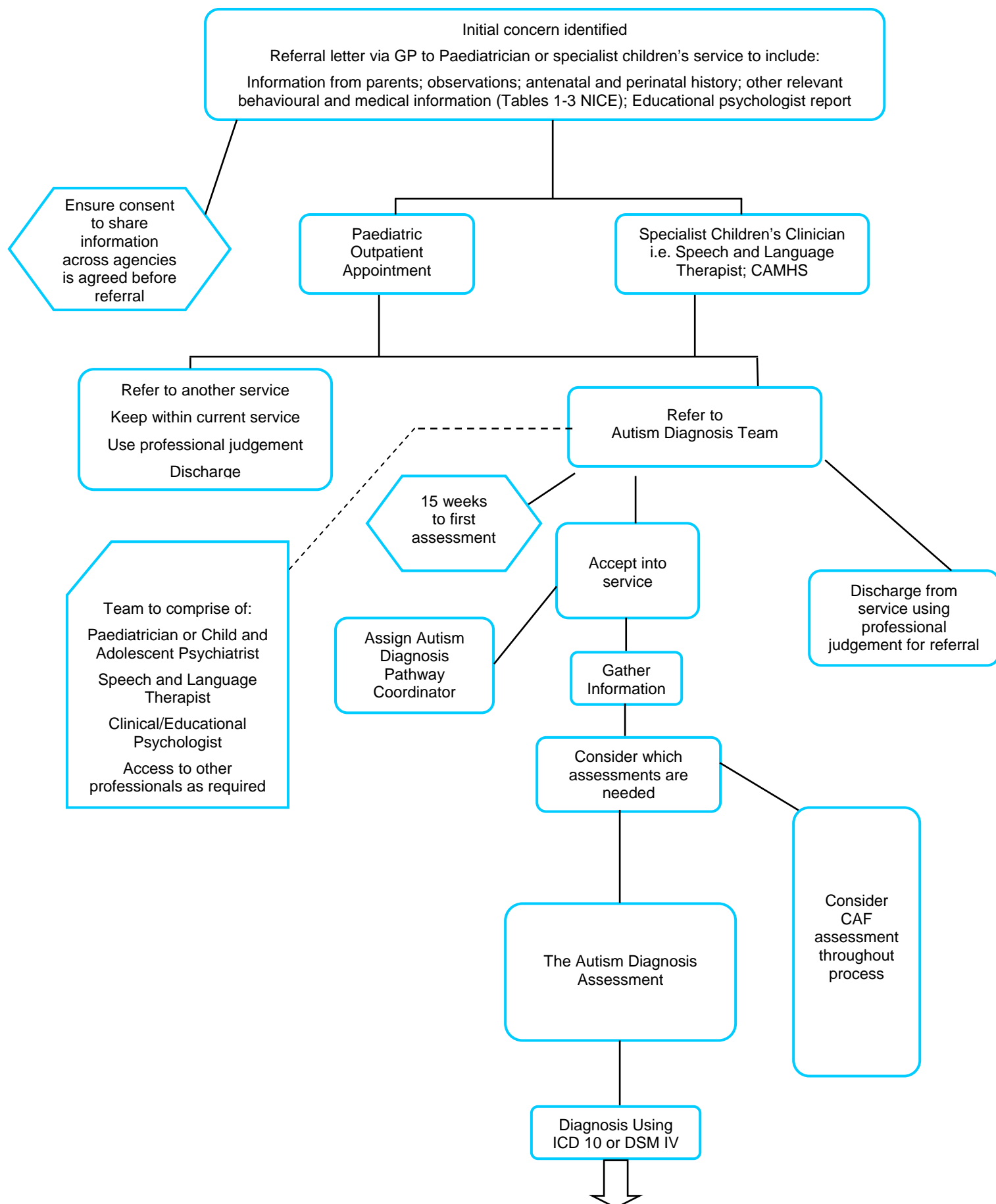
**Retained Staffing Supporting SEND**

SEN Support & Outreach to Schools	412,410
Personalisation & Transition	#
Education Psychology (inc Early Years SEN and Portage)	#
Integrated Support	#
Other Retained Staffing budgets	19,720
	<b>432,130</b>
<b>TOTAL HIGH NEED SEND BUDGET FOR AUTISM</b>	<b>£10,330,150</b>

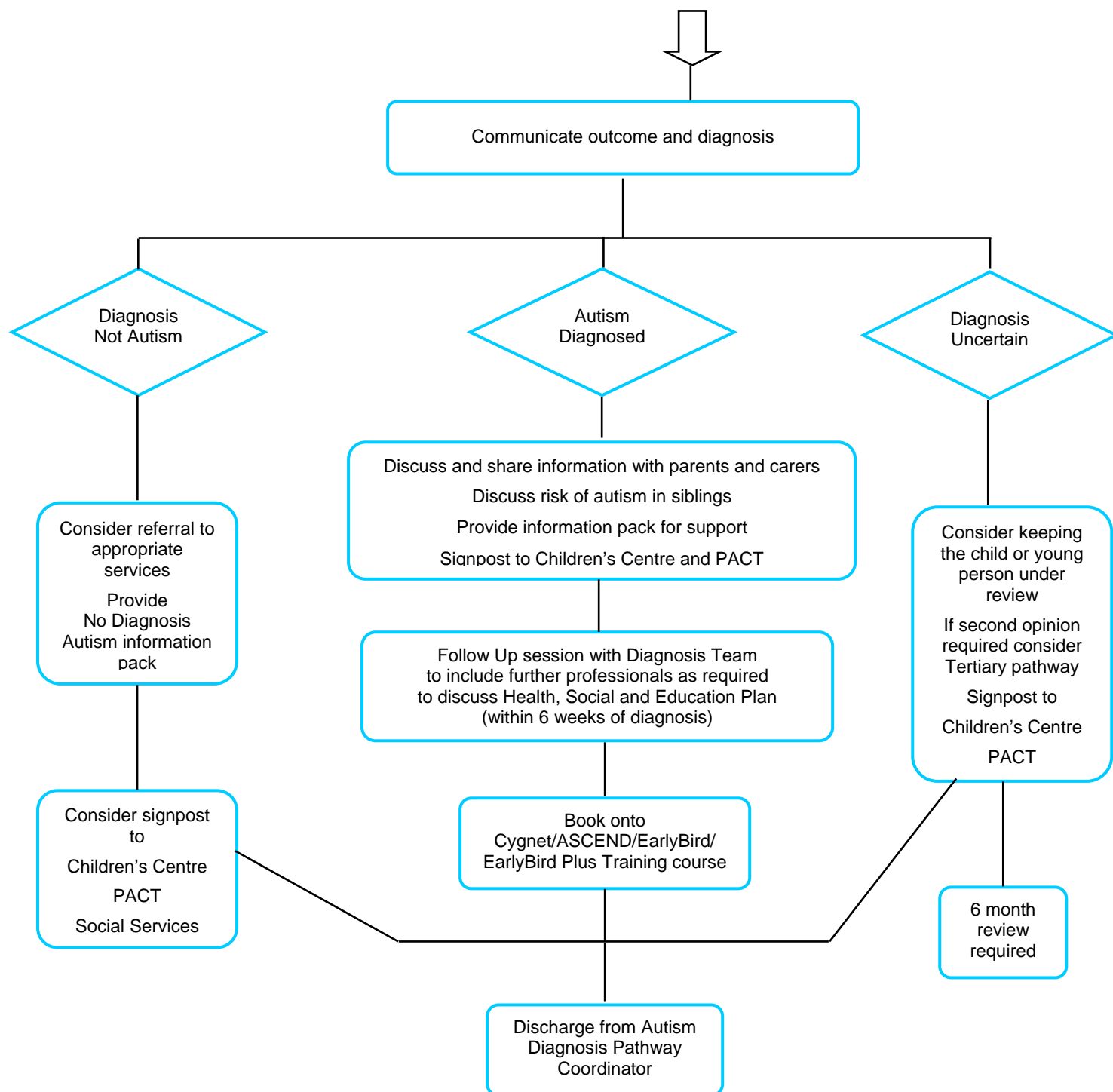
**Health**

Health spending on autism services is included in the budgets for children's services and is not identified separately.

## 10. North Yorkshire Referral Pathway



## North Yorkshire Referral Pathway continued



## The Referral Process

- the referral route into the diagnosis assessment pathway is firstly via the General Practitioner (GP) who will refer to either the Paediatrician or another specialist Children's Community Service e.g. Speech and Language Therapy Service, Child and Adolescent Mental Health Service (CAMHS);
- parental consent will be requested at the point of referral to share information with key professionals, such as those within education and social care, involved in the care of the child or young person;
- the first assessment will commence within 15 weeks of acceptance into the autism diagnosis pathway;
- a pathway coordinator will be allocated from within the autism diagnosis team. Their responsibilities include communication and liaison with parents or carers as a single point of contact during the assessment process;
- following assessment the diagnosis will be communicated to the family, and where appropriate the child or young person, swiftly and sensitively;
- where a diagnosis of autism has been made, an information pack will be given to the family;
- the family will be provided with a written report of the assessment findings and the conclusions drawn. These findings will be shared with the child's GP;
- once a diagnosis has been given, the autism diagnosis team will offer a follow-up appointment for the family within six weeks of the diagnosis to further discuss any concerns;
- after diagnosis, if required, a health, social and education plan will be developed in conjunction with the family;
- parents will be signposted to appropriate support organisations and professionals e.g. Children's Centre, NY PACT, Carers Resource, NAS, local support groups e.g. Sparkle, Ryedale Special Families, Acorns.

An accurate diagnosis can often bring clarity of what is needed to help the child or young person progress, and relief to those involved that they now have an explanation for the symptoms they have. We acknowledge that not all parents want to go down the diagnosis route. This may be for a number of reasons; however clinical support will still be available without formal diagnosis.

During the critical period around diagnosis school remains a constant in the child's life, providing regular structure and stability whilst parents and families begin to understand the lifelong implications of such a diagnosis. School provides a sense of structure and stability for the child and family, particularly throughout the diagnostic period. Parents will seek reassurance and evidence that their child's school is, at the very least, autism aware. They may also seek information on the skill level of their child's teacher in relation to autism.

Educational professionals e.g. Educational Psychologist will have been involved with the child and parents during the assessment period, or perhaps been part of the diagnostic process and therefore already have an understanding of the parents and extended family. This relationship can be pivotal in helping parents understand how autism affects their child and impacts on their learning as well as developing strategies that will help.

## **Appendix – Related Documents**

**A** - NICE 2011 – Signs and symptoms of possible autism

**B** - NICE clinical guideline 2011 – Autism

**C** - Support and Aspiration Green Paper 2011

**D** - Autism Good Practice guidance 2010

**E** - NAS report 2010 – You Need to Know

**F** - NAS 2011 – Great Expectations

**G** - Department of Health 2001 - Valuing People Now

**H** - Disability and Discrimination Act 2005

**I** - Equalities Act 2010

**J** - Department of Health 2009 – Valuing People Now

**K** - HMIE 2006 – Education for Pupils with Autism Spectrum Disorders

**L** - Ofsted 2006 – Inclusion: Does it matter where pupils are taught

**M** - Aiming High for Disabled Children 2005

All documents available at:

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