North
Yorkshire County Council

Improvement and Integration

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

Guide for Parents

NHS
North Yorkshire and York

Children and Young People's Service

A responsive County Council providing excellent and efficient local services

Contents

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† 'Related Documents' referenced in section 3 are available on the local authority website, see p32

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 (0-19) was identified in the SEND Strategy '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 the right 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.

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
Corporate Director -Children and Young People's Service

Carl Les
Lead Executive Member for Children's Services

Julie Bolus
Director of Nursing
North Yorkshire & York PCT

2. Knowing about Autism

We have used the term ‘autism’ throughout the strategy to signify children and young people with a diagnosis of autism including those with high functioning autism, Asperger syndrome and other autistic conditions.

Autism is part of the story of who the child is - an individual with a unique profile that includes their personality, strengths, challenges, likes and dislikes. We aim to build a relationship with and develop personal knowledge of the individual child or young person and put in place provision that is 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.

All children with autism share a triad of impairments. Your child may present with the following:

Non-verbal and verbal communication

We often do not mean exactly what we say. Children with autism find this very confusing and may take us literally. If you say, ‘Can you get your coat?’ your child may simply answer ‘Yes’, but then not act on this. When reading or listening to a story, a child may have an excellent memory for the details, but have problems with understanding the main points.

Children with autism may repeat what you say (echolalia) - this may serve a function in helping them to work out the meaning or to reduce their anxiety. They may have little understanding of the abstract uses of language, e.g. humour.

Many children with autism are delayed in learning to speak and some do not develop speech. Others with speech have difficulties in using this effectively to communicate.

Social understanding and social behaviour

Your child may have difficulty in understanding your behaviour and ‘reading’ your intentions.

Our behaviour is very much influenced by what we think others might think of us. For the child with autism though, other people's opinions may have little or no influence and he/she may say and do exactly as he/she wants.

Children with autism find it hard to play and communicate effectively with other children who, in turn, may be confused by your child's behaviour and avoid or tease him/her.

Adults who do not know your child or who do not understand autism, may misunderstand their behaviour and view it as naughty, difficult or lazy, when in fact, the child with autism may not understand the situation or task or read the adult's intentions or mood correctly.
their anxiety.

Many children with autism are delayed in learning to speak and some do not develop speech. Others with speech have difficulties in using this effectively to communicate.

Thinking and behaving flexibly according to the situation

Children with autism often do not play with toys in a conventional way, but instead spin or flap objects or watch moving parts of toys or machinery for long periods and with intense interest. Play tends to be isolated or alongside others.

They may initiate certain scenes they have observed and more able children do play imaginatively, but they may not share in imaginative play with others (e.g. they may play at being a TV character)

Some children with autism develop an obsessional interest in a topic or hobby. They may also show an extreme reaction to change in routines which have become familiar to them or when something they rely on is changed.

Many children with autism are delayed in learning to speak and some do not develop speech. Others with speech have difficulties in using this effectively to communicate.

In addition to this, it is generally accepted that sensory sensitivities and responses are a significant area of need.

Sensory perception and responses

Your child may be over-sensitive to certain sounds, sights and textures. This has implications for your child's home and school environment and may explain their response to changing clothes or food, and their response to noise. In addition, your child may be uncomfortable making direct eye contact and may look too briefly or stare at others.

Recent research estimates that as many as 70% of individuals with autism may also have other difficulties which impact upon their functioning and wellbeing.

As professionals, we are sensitive to the fact that as well as coming to terms with, and learning about, their child's difficulties many parents also have to come to terms with how the condition affects all aspects of their daily 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.

Your child with autism may have strengths in one or more areas, including the ability to:

- focus on details or to see the world in unusual (and often enriching) ways (in art, music or poetry, for example);
- concentrate for long periods on a single activity, if it is of interest to them;
- process visual information better than that given purely in spoken form;
- give their sole attention to a task and therefore achieve a high level of skill or work on tasks way beyond the point at which we as adults would have tired of it;
- succeed, if they are more able, in academic areas that do not require high degrees of social understanding and where the language used is technical or mathematical (e.g. science, engineering, music, information technology).

Your child with autism may present with other behaviours and characteristics including:

- rigidity and flexibility of thought, resistance to change, high levels of anxiety;
- developmental coordination difficulties and/or delay in motor skills;
- 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.

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, then 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 an increase in the numbers of children and young people with autism and the condition is now thought to affect at least 1 in 100 children. We are also aware that 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.

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 (Barnard et al, 2002), 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 children and young people with autism to access all aspects of school life and to reach their potential.

Autism is more prevalent in boys than in girls (by approximately four to one). Happe (2011) suggests that this may be because of diagnostic practices and that, perhaps, females tend to cope better with their autistic traits.

3. Autism Policy Framework

The National Context and Legislative Guidance

In the past few years there has been a national move towards improving provision and support for children with Special Educational Needs and Disabilities (SEND), with a number of key reviews and initiatives focusing on autism.

A number of key documents have been referred to in the strategy and used to help shape and inform future service development and delivery for those working with and affected by autism.

Some, but not all are referenced below:

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

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

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

Autism Good Practice Guidance (2010) – Appendix B

This Department of Health document, written by the Autism Working Group within the Department for Education and Skills, looks at highlighting and sharing 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 LA to regularly complete audits which evaluate the knowledge and skills of their workforce in order to assess training needs and then take appropriate action;
- to have a clear, agreed referral pathway when autism is suspected;
- a priority to support early identification and intervention;
- joined up working within LA/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.

The NAS ‘You Need to Know’ Report (2010) – Appendix C

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 D

This report reviewed the experiences of children and young people with autism and their families in relation to education. The NAS 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)

The North Yorkshire Context

Children and Young People's Plan 2011-2014 – Integrated Plan

The Children and Young People's Plan 2011-2014 provides the detail of how the Children and Young People's Service 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

North Yorkshire Special Educational Needs and Disability Strategy 2011 - 2014

This sets out the local authority plan for developing services for children and young people with special educational needs and disability. It stresses the point that involving partner agencies including Health and the Voluntary Sector and working with parents is the key to success. The SEND strategy forms part of the local authority's Change and Integration Programme which is closely aligned to the government's Green Paper 'Support and Aspiration: A new approach to special educational needs and disability'.

4. Engagement

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 Teamwork group (NY PACT). The group identified the following areas they would like to see to improve support for families:

- an 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. EarlyBird and ASCEND (available in Selby and York 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'.

Our parents group 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.

5. Aims and Principles

The following general principles have been adopted by the local authority to inform decisions, ways of working and change:

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 and/or young person should be followed by decisions on service provision, giving them 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.

6. Autism Diagnosis by Health Services

It is important that your child's individual needs are identified as soon as possible so that they can be met in the most appropriate way.

If you or a healthcare professional or teacher has concerns about your child's development or behaviour, you (and your child if appropriate) should discuss these with your child's health professional (e.g. GP/ Speech and Language Therapist).

They will ask you about your child's development, behaviour and about how they talk with and relate to others. Any professional should do this sensitively, take any concerns you have seriously, and take time to listen to you and your child. You should be given time to consider the concerns, especially if you had not previously suspected a problem.

The professional (GP) will discuss with you how these signs are affecting your child and the rest of your family. They will also discuss your concerns, the possibility of a different cause of the signs, and whether there are any other factors that would make autism more likely (such as a brother or sister with autism). You can together decide whether your child should be referred for specialist assessment. If the concerns are not strong and you prefer to wait for a while before referral, you and the professional can decide to review the situation after a period of time.

The professional should explain what should happen after your child has been referred. They should also put all the information they have gathered so far into a letter for the specialist team.

If your child is referred for assessment for possible autism, they will see someone from a team known as the Autism Diagnosis Team. After reading the referral letter, the Autism Diagnosis Team may gather more information (for example, from your child's school, if you agree). This will help them decide what to offer your child next – this may be an autism assessment, and/or an assessment for a different kind of condition if they think this would be helpful. If they think an autism assessment is appropriate, this will start within 15 weeks of the referral. One of the members of this team should be your child's case coordinator (Autism Diagnosis Pathway Coordinator), who will be your point of contact. The Coordinator will explain the assessment to you and your child, and make sure you can get relevant information and support.

If there is not enough information to decide whether an autism assessment is appropriate, you and your child may be offered a consultation with someone from the autism team before deciding whether a full assessment is needed.

The Autism Diagnosis Team will include the following professionals:

- Paediatrician;
- Clinical Psychologist;
- Educational Psychologist;
- Speech and Language Therapist.

The team may call on the services of other professionals, as appropriate e.g. developmental psychiatrist, occupational therapist, child and adolescent psychiatrist (CAMHS).

What happens at an autism assessment?

The assessment will involve members of the Autism Diagnosis Team talking with you and talking with and observing your child, and finding out about:

- your concerns, and those of your child if appropriate;
- how your child has been getting on at home, in nursery or school, or in care;
- your child's past and present health, and that of the family;
- your child's behaviour and development.

The kind of behaviours professionals look for in diagnosing autism:

- delay or absence of spoken language (but not true for all children);
- unusual uses of language (e.g. pronoun reversal saying 'you' instead of 'I') prolonged echolalia (i.e. repeating others' words beyond the usual age) or 'playing' with sounds;
- difficulties in playing with other children;
- inappropriate eye contact with others;
- unusual play activities and interests;
- failure to point with their index finger to communicate;
- failure to share interests with others; unusual response to certain sounds, sights and textures;
- resistance to changes in familiar routines.

After the assessment

The autism team will use all the information from the assessment, the information you have given them and any information from your child's school or healthcare professionals to help them come to a decision about whether your child has autism. They will write down and keep a record of the assessment and all the information gathered so far, taking into account your family and your family's needs. This record will include your child's strengths, skills, difficulties and needs, and what help your child may need in terms of learning, communication, day-to-day care, sensory issues and behavioural and emotional health. The Autism Diagnosis Team will share information from the assessment with your child's GP, and if you agree, with other professions such as your child's school, the local authority Autism Outreach Service or social services if appropriate, to help them offer you the support you need.

A member of the team will talk to you (and your child, if appropriate) about all of this, soon after the assessment, and give you a written report explaining the findings of the assessment.

If your child is diagnosed with autism

You will be offered another appointment with a member of the Autism Diagnostic Team within 6 weeks of the end of the assessment so you can talk more and ask any questions you may have. They will explain more about autism and how it might affect your child.

You will also be given an information pack which will outline the support you and your child can get in your local area. For example, you may be given contact details for parent awareness raising sessions and support groups such as Cygnet, Early Bird, TESS. These can give you the opportunity to meet other families with experience of autism, and advice about where to find out about welfare benefits and other services that are available. Your child's healthcare professional will also talk to you about the possibility of siblings and future children having autism.

If the diagnosis is uncertain

Sometimes there can be uncertainties when diagnosing autism. The autism team may offer to see your child again or they may offer to refer your child to another team that can help, for example an autism team in specialist care.

If your child does not have autism

Your healthcare professional may offer to refer to you to other specialists (for example, child health services or child and adolescent mental health services, also known as CAMHS), if they think they may be able to help.

7. Current Provision

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, or physiotherapy.

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

Parents/carers are given the opportunity to attend a programme for families. Depending upon which area of the County they live, these joint health / education run 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 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 is a therapeutic programme.

All three 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.

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 proper assessment and identification of needs.

> *"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 for professionals to recognise the knowledge you have of your own child as an individual. As parents/carers we want you to feel supported and listened to when designing any intervention that will take place for your child, either in the school/setting or in the home environment, if your child has not yet begun to access a school/setting.

Pre-school children

It is important that you and your family receive information and advice early on to make sense of how your child behaves and so that your child is helped to understand others and to communicate. This information and advice will immediately follow diagnosis.

In spite of publicity for different interventions, no single approach has been found to be the most effective, although there is evidence that early intervention, working on communication and involving parents are beneficial.

Provision for children of school age

Your child may attend an ordinary mainstream school, an Enhanced Mainstream School (EMS) or a Special School for children with learning disabilities or autism.

The specific educational needs of children with autism are different, so a detailed assessment of the individual child is necessary to determine which school is most appropriate.

The majority of children will be recognised within the school as having additional or different needs from their peer group and they should have an individualised plan e.g. an Inclusion Passport and/or a provision map.

Some may require more support than is usually provided from within a school’s resources and may need a formal statutory assessment, leading to a Statement of Special Educational Needs, which will specify their main needs and the provision to meet these.

Whatever school your child attends, it should be possible for the staff to meet his/her needs, in collaboration with you and other professionals.

Staff will need to gain knowledge on the implications of autism for teaching and learning and be willing to modify the school environment and how the curriculum is delivered, for the placement to succeed.

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. the Autism Outreach Support Services, others will need a personalised, or in some cases profoundly personalised, approach to teaching and learning.

Many young people progress into adulthood requiring additional support throughout their transition from children to adult services.

To improve local provision we have recognised the need to have the right services in the right 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 provided 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;
- Autism Outreach Early Intervention pre-school, primary and secondary;
- 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 range 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 your preference as parents.

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 funding provided to the school to enable them to meet the needs of pupils with autism 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 enhanced mainstream schools form part of the Special Educational Needs and Disabilities Support and Outreach Service. 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.

These enhanced mainstream schools are:

- Bedale High School, Bedale
- Embsay Church of England VA Primary School, Skipton
- Filey School, a Technology College, Filey
- Holy Family Catholic High School, Carlton, Selby
- Hookstone Chase Community Primary School School, Harrogate
- King James's School, Knaresborough
- Kirkbymoorside Community Primary School School, Kirkbymoorside
- Mill Hill Community Primary School School, Northallerton
- South Craven (Academy), Keighley
- Thorpe Willoughby Community Primary School, Thorpe Willoughby, Selby

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 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.

Specialist Support

The function of these services is to enable local mainstream provision to support children and young people with autism.

Autism Outreach Support Team

The Autism Outreach 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 Autism Outreach team are alerted following a diagnosis by the health diagnosis assessment team. Autism Outreach then contacts the school / setting (within two working weeks) to offer support. An initial visit 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; 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 (high tech AAC) 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.

North Yorkshire's Communication Aids Partnership Team (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 (PPC) 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 its website: www.northyorks.gov.uk/parentpartnershipservice An Enquiry Line is available all year round during office hours 0845 034 9469.

Educational Psychology and Early Years Team

The Educational Psychology and Early Years Team 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 Autism Outreach to support those children in their 'settings';
- additionally they will support Autism Outreach 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

Portage Home Visiting Team

The North Yorkshire Portage Team is registered with the National Portage Association (NPA). 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 Autism Outreach. 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 Disabled Children’s Services.

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

Transition

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.

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 health providers and commissioners to improve the pathway from children’s services to adult services;
- improving information, advice and support to families.

Health and Adult Services, Children and Young People’s Service and Health work in close collaboration to ensure transition to adulthood is as smooth as possible. Planning for young people leaving school takes place in local multi-agency strategic groups and senior managers from the key agencies identify commission actions.

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.

The local authority will work towards publishing a local offer as referenced in the Support and Aspiration Green Paper 2011.

Transport

In some cases parents will be eligible for home to school transport for their child. In the procurement of transport, we ensure that staff are autism aware and attention is made 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.

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 is being developed.

8. Moving forward

Focus Area 1: Early Identification and Awareness Raising

> *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 assessment of need and related 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:

- **Increase autism awareness across the workforce through a targeted programme of competency-based training (universal, targeted and specialist)**
- **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: Integrated Assessment

> *"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 the appendix.

- 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, education and care 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.

Priority Actions:

- **Ensure the pathway for assessment and diagnosis of autism is consistent across the County and that it is NICE compliant**
- **Establish multi-agency diagnostic teams for autism in all areas of North Yorkshire including the allocation by health of a Diagnosis Assessment Pathway Coordinator**
- **Provide joint health / education / social care plans post diagnosis, for children with autism, linked to the work of the Local Pathfinder**
- **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.

We will engage with young people, their parents/carers and those representing support organisations e.g. Flying High, in developing the information pack for parents and families. Once the strategy is finalised we will work with a group of young people from the enhanced mainstream schools for autism to develop a young-person friendly version.

Priority Actions:

- **Work through NY PACT to ensure comprehensive awareness of local groups that operate for children with autism**
- **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 aware of and registered with their local Children's Centre**
- **Increase the number of training events and availability of autism awareness sessions for parents and professionals**
- **Conduct annual service user satisfaction surveys to monitor parental and service user feedback**
- **Ensure information packs are available for families post diagnosis to provide relevant information and support**
- **Ensure autism information is readily available and accessible through Family Information Services and libraries**

Focus Area 4: Enhance local provision

North Yorkshire is a Local Pathfinder for SEND and is therefore taking the opportunity to review and improve provision pathways and children's journeys.

Priority Actions:

- **Map the autism pathway of services to identify gaps in provision and encourage greater integration of services**
- **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 our central autism team**
- **Further develop central autism team to support pre-school children through early intervention**
- **Ensure that the full range and extent of provision for families of children with autism is identified and included in the published Local Offer**
- **Address the development issues identified in the first annual evaluation of the Enhanced Mainstream Schools**

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**
- **Take a ‘One Council’ approach to planning for autism, working closely with the Health economy**

9. Accountability and Performance Framework

Accountability Framework

The implementation of this strategy will be overseen by the North Yorkshire and York Strategic Steering Group (Autism) and monitored by the SEND Change and Integration Board on behalf of the Children’s Trust.

Key Performance Indicators

The success of this strategy will be measured against the outcomes and aims we want 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) Feedback from professionals, service users, young people and families (impact)

10. Resourcing the Strategy

Children and Young People’s Service

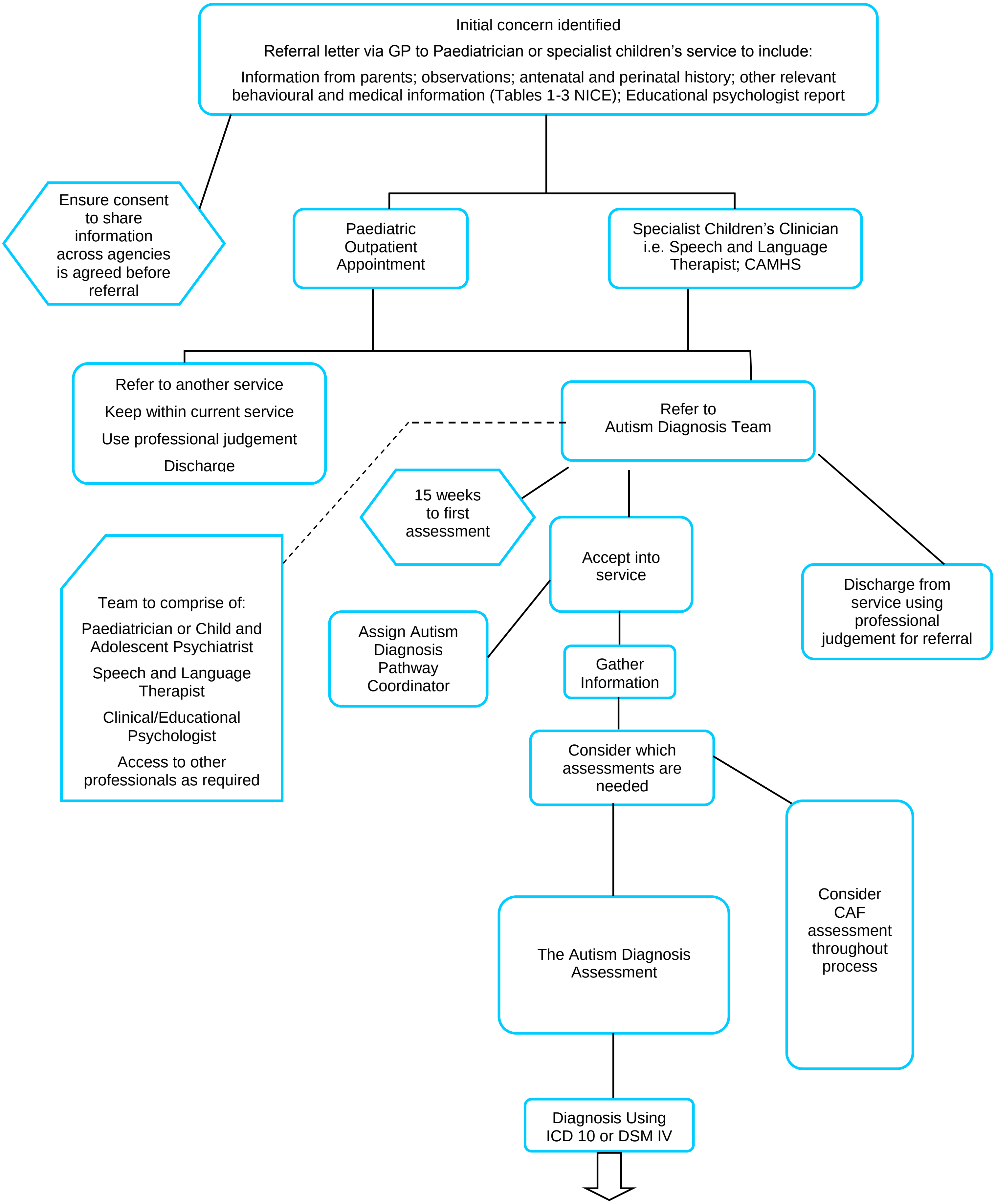
Details of Budgets	Estimated Gross Expenditure £'
Early Years Providers - (Maintained Schools and Private Voluntary & Independent Providers)	
Allocated to Early Years Provision to support SEN	15,230
Mainstream Schools	
Allocated to Schools to support High Need Statements	2,116,741
Special Schools	
Day Provision	2,267,328
Residential Provision	190,497
	2,457,825
Outreach Services	
Severe Learning Difficulties	#
Autistic Spectrum Disorder	67,400
North Yorkshire Communication Aids Partnership	#
	67,400
Enhanced Mainstream Schools	
Schools for High Functioning Autism	548,010
Schools for Specific Learning Difficulties	#
Schools for Communication & Interaction	309,428
	857,438
Independent Special Schools	
Fees and Support	**798,423**
Recoupment with Other Local Authorities	
Payments / income to & from other local authorities	**276,550**
Commissioning Budgets for Disabled Children's Services	
Commissioning and Placements	**2,699,256**
Residential Short Break Budgets	
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
	609,157

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 Stafffing budgets	19,720
	432,130
TOTAL HIGH NEED SEND BUDGET FOR AUTISM	**£10,330,150**

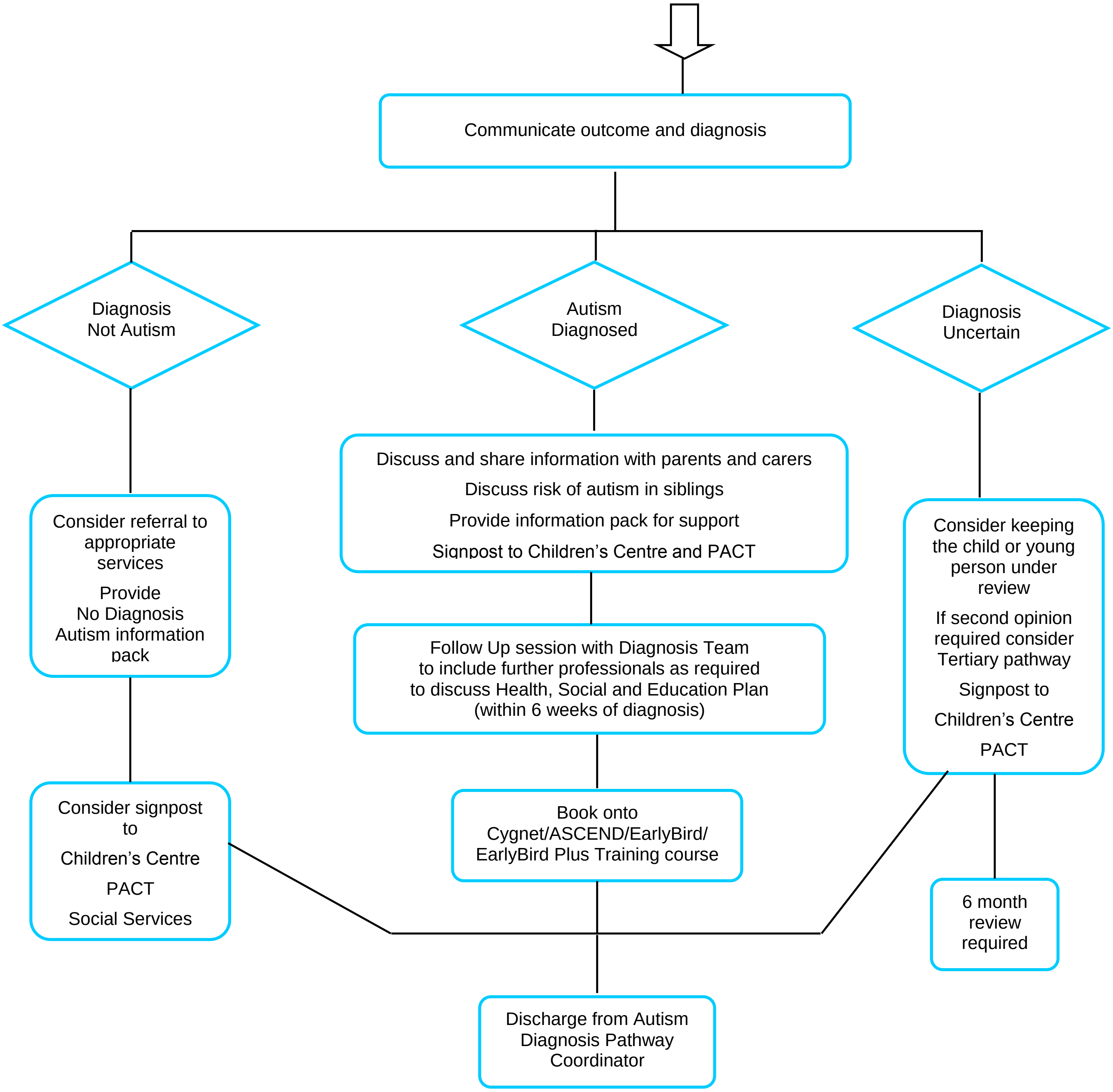
Health

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

11. North Yorkshire Referral Pathway



North Yorkshire Referral Pathway continued



North Yorkshire Referral Pathway is based on the NICE Guidance 2011

12. Appendices – Related Documents -

A - NICE clinical guideline 2011 – Autism

B - Autism Good Practice guidance 2010

C - NAS report 2010 – You Need to Know

D - NAS 2011 – Great Expectations

All documents available at:
http://cyps.northyorks.gov.uk/index.aspx?articleid=15825