

# **Sections**



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Your health professional will provide you with information to add to your pack which will include local and national services, contacts and networks.



# Introduction



In 2011, the North Yorkshire and York Autism Diagnosis Strategic Partnership Group decided that they should look to improving the information available for families when a child or young person has received a diagnosis of autism.

Parents, Local Authority colleagues, health professionals and young people were involved in this project.

We looked at a range of information already on offer and available. We decided to produce a booklet with a range of topics and signposting which we thought would be helpful for you, your family and friends in these first few weeks and months.

During your journey you may have questions that you might like to ask, we have provided some space below for you to take along to your follow up meeting.



# Questions I've thought about to ask at my follow up meeting:

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# What is autism?



Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.



Autism means many different things to each individual child, family and school /setting. Every child is an individual and, as such, pathways and support need to be individualised. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support.

In recent years people with autism were said to share three main areas of difficulty known as the 'triad of impairments', made up of social communication, social interaction and social imagination. People with autism may also experience over or under sensitivity to sounds, touch, tastes, smells, light or colours. Asperger syndrome is recognised as a form of autism, within the spectrum of autism. People with

Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

In 2013/14, the international diagnostic criteria for autism diagnosis i.e. ICD10 and DSM-V were revised to include all forms of autism. The triad of impairments was reduced to two main areas:

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

Sensory behaviours are included within the descriptor 'restricted, repetitive patterns of behaviour'.

The descriptors below are not intended to be used as a check list, but to help parents recognise and better understand the pattern of behaviours associated with autism.

# Social communication and interaction

People with autism have difficulties with both verbal and non-verbal language. Many have a very literal understanding of language, and think people always mean exactly what they say.

Spoken language may be unusual in several ways:

- very limited use
- talking 'at' others rather than sharing a two-way conversation

- unusual tone of voice
- repetitive speech, use of learnt phrases and information on topics of own interest
- responses to others may be viewed as rude or inappropriate e.g. because of literal understanding.

# Responding to others

- reduced or absent response to other people's facial expression or body language
- reduced or delayed response to name being called, despite normal hearing
- subtle difficulties in understanding other's intentions, may take things literally and misunderstand jokes, sarcasm and common phrases and sayings; an example might be the phrase 'It's cool', which people often say when they think that something is good, but strictly speaking, means that it's a bit cold
- unusually resistant response to the requests of others (demand avoidance).

# Interacting with others

People with autism often have difficulty recognising or understanding other people's emotions and feelings, and expressing their own, which can make it more difficult for them to fit in socially. They may:

- not understand the unwritten social rules which most of us pick up without thinking: they may stand too close to another person for example, or start an inappropriate subject of conversation
- not use 'hello' or 'goodbye'
- appear to be insensitive because they have not recognised how someone else is feeling
- prefer to spend time alone rather than seeking out the company of other people and not share in social play
- not seek comfort from other people
- behave in an unexpected or inappropriate manner, as it is not always easy for them to express feelings, emotions or needs.

Some people with autism may not speak or have very limited speech. Some may have a good understanding of language but have difficulty using spoken language and for these children/people alternative methods of communication are useful e.g. signing or symbols. Others may have significant difficulties in both understanding language and using spoken language and the use of signs and symbols is helpful for this group too.



Others will have good language skills, but they may still find it hard to understand the give-and-take nature of conversations, perhaps repeating what the other person has just said (this is known as echolalia) or talking at length about their own interests.

It helps if other people speak in a clear, consistent way and give people with autism time to process what has been said to them.

Difficulties with social interaction can mean that people with autism find it hard to form friendships; some may want to interact with other people and make friends, but may be unsure how to go about this.

# Ideas and imagination

Social imagination allows us to understand and predict other people's behaviour, make sense of abstract ideas, and to imagine situations outside our immediate daily routine. Difficulties with social imagination mean that people with autism find it hard to:

- engage in flexible imaginative play or creativity (it may be reduced or absent), although scenes from television or films may be re-enacted
- understand social niceties and may make comments or appear to address adults inappropriately
- predict what will happen next, or what could happen next
- understand the concept of danger, for example that running on to a busy road poses a threat to them
- engage in imaginative play and activities; children with autism may enjoy some imaginative play but prefer to act out the same scenes each time
- prepare for change and plan for the future
- cope in new or unfamiliar situations.

Difficulties with social imagination should not be confused with a lack of imagination. Many people with autism are very creative and may be, for example, accomplished artists, musicians or writers.

# Unusual or restricted interests and/or rigid behaviours

These may include any of the following:

- repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking
- play is repetitive and focused towards objects rather than people
- unusual or over focused interests
- rigid expectation that other children should follow the rules of play
- insistence on following own agenda
- strong preference for familiar routines and things being 'just right'
- dislike of change, which often leads to anxiety or other forms of stress (including aggression)
- over or under reaction to sensory stimuli e.g. textures, sounds, smells
- reaction to taste, smell, texture or appearance of food or food fads.

Young people with autism may also have an unusual profile of skills or difficulties, for example poorly developed motor skills, while particular areas of knowledge, reading or vocabulary skills are advanced for their age.

Social and emotional development may be more immature than other areas of development, excessive trusting (stranger danger), lack of common sense, less independent than their peers.

#### References

- 1. www.nice.org.uk/guidance/CG128
- 2. <a href="http://www.autism.org.uk/About-autism/Autism-and-Asperger-syndrome-an-introduction/What-is-autism.aspx">http://www.autism.org.uk/About-autism/Autism-and-Asperger-syndrome-an-introduction/What-is-autism.aspx</a>



# Which professionals might be involved?



The range of professionals you may meet will vary according to your child's needs and their roles may differ in different localities.

# **Audiologist**

An audiologist can work with children who have hearing difficulties and will be able to give advice on aids to improving hearing.

# Behaviour support team

These are teams who support families by assessing behaviour and who then may introduce behaviour management programmes. Services may differ in different localities.

## Child and Adolescent Mental Health (CAMHs) Teams

These can include clinical psychologists, Child and Adolescent Psychiatrists, Nurse Therapists, Occupational Therapists and Mental Health Workers working in partnership with Social Work, Education and Health teams to promote mental health awareness. CAMHs provide assessment and intervention for children and adolescents with mental health problems.

### **Children's Centre**

Children's Centre offer a range of services and activities for Children, Young People and their families throughout the 0-19 age range. Children's centre aims to provide services that are balanced to their community's needs and offer the following -

- early learning opportunities for you and your child including play and development sessions
- · advice, support and learning opportunities for parents and carers
- child and family health services
- youth activities and support

For our current 'What's On' guide please visit <a href="www.northyorks.gov.uk">www.northyorks.gov.uk</a> and search for Children's Centres. You will be able to see the full programme for your area. Please do not hesitate to contact your local Children's Centre to discuss what services are available for you and your family, we will be happy to help.

#### \*Clinical Psychologist

Clinical psychologists may contribute to the diagnostic process and may offer a follow-up service.

# Community Children's Nurse, Community Psychiatric Nurse and Learning Disability Nurse

They can provide help and advice on a range of needs. Their roles may differ in different localities.

# **Counsellors and psychotherapists**

Counselling and psychotherapy are umbrella terms that cover a range of talking therapies. They are delivered by trained practitioners who work with people over a short or long term to help them bring about effective change or enhance their wellbeing. These services are provided by services such as the Child and Adolescent Mental Health Service (CAMHS) and Compass Reach. (Definition from the BACP – British Association for counselling and psychotherapy)

# **Dentist**

Dental health and regular checks are important. Ask your dentist for advice and how to prepare for a visit to the dentists. The National Autistic Society (NAS) web site has lots of useful resources.

# **Dietician**

Dieticians work with people who have special dietary needs.

# **Early Years Advisory and Portage Team (NYCC)**

The Early Years Advisory and Portage Teams work closely with other services, in particular with educational psychologists to meet the needs of pre-school children with additional support needs. They also work with the Autism Outreach Support Service and the Sensory, Physical and Medical Network.

# \*Educational Psychologist

Educational psychologists may contribute to the diagnostic process and can be involved in assessing children's educational needs and in the process of requesting an assessment for an Educational Health and Care Plan (EHCP).

## **Family Support**

SENDIASS (Special Educational Needs, Information, Advice and Support Service) offer support for parents/carers/professionals as well as for young people with SEND aged 16 to 25 years old. Free advice, information and support can be accessed in relation to the legal requirements relating to SEND. SENDIASS also support families where decisions made by the Local Authority or health service do not adhere to a relevant law and are being challenged. A parent/ carer, professional or young person aged 16 -25 years old can contact the enquiry line which is staffed Tuesday and Thursday from 9:30-1pm (including school holidays) on 01609 536923.

#### **GP – General Practitioner**

A GP is responsible for the general health of their patients and can make referrals to relevant professionals.

### **Health visitor**

A health visitor is a specially trained nurse who works with families with young children in the community. A health visitor may refer on to other professionals.

Health visiting teams are based in the community and provide services for all preschool children. Teams can vary and may comprise Health Visitors (qualified nurses who have undergone additional specialist training), Community Staff Nurses and Community Nursery Nurses (sometimes called Assistant Practitioners or Child Development workers)

Teams are able to offer ongoing support to the whole family if needed. As part of this they may refer to and liaise with a wide range of other professionals as well as assess and plan care to help ensure needs of the child and family are met.

Health visiting teams work closely with Children's Centres and together they offer a rich source of local information offering advice and signposting around a range of local services and community resources.

# **Healthy Child Team**

Harrogate & District NHS Foundation Trust 5-19 Healthy Child Service (HCP) is an evidence-based universal service offered to all Children Young People and Families aged 5-19 or those aged 25 Years where they have a Special Educational Need or Disability (SEND) to ensure that they lead safe, healthy lives and grow into healthy adults. We work closely with children, Young People, Families and in partnership with other agencies to promote and support health and wellbeing to ensure positive outcomes are achieved. The Healthy Child team have particular skills which makes them the ideal bridge between education, health and home and offer a caring, non-judgmental and confidential service for CYP and families.

We work both in and out of school providing support, advice and intervention around many aspects of children and young people's health and wellbeing which includes:

- Resilience and emotional wellbeing
- Healthy Eating and Growth Development
- Chronic & Complex Health Needs Asthma, Diabetes etc.
- Toileting issues
- Childhood Illnesses
- Dental Health
- Immunisation advice
- Sexual health advice and guidance
- Risk Taking behaviors
- Young Carers
- Youth Justice
- Support with School Transition
- Healthy Child Team Drop-ins in school and community venues
- Support for Looked After Children & Young People
- Support for Children and Young People who have been abused and/or exploited
- Safeguarding of Young People

If at any time you would like more information or contact with your Healthy Child Team please visit www.HDFT.nhs.uk community services

### **Occupational therapist**

Occupational therapists may contribute to the diagnostic process. They are often concerned with the addressing the needs people have in relation to carrying out everyday activities.

# Optician

Opticians are able to assess visual difficulties. Ask your optician for advice and how to prepare for a visit to the opticians.

# \*Paediatrician (Community)

Paediatricians may contribute to the diagnostic process and offer follow-up support in some cases.

# **Physiotherapist**

Physiotherapy helps with movement and function when someone is affected by injury, illness or by developmental or other disability.

## \*Psychiatrist/Child and Adolescent Psychiatrist

Psychiatrists may contribute to the diagnostic process and may offer a follow-up service. Psychiatrists are often involved where there are behavioural or mental health difficulties, and are able to prescribe and monitor medication.

# **School Nurse**

School nurses aim to promote the health and well-being of children and young people aged 5-19 years. They can offer a variety of advice, support and information.

### **Social Worker**

Social workers work with individuals and families to help improve outcomes in their lives. Social workers support people, act as advocates and direct people to the services they may require. Social workers often work in multi-disciplinary teams alongside health and education professionals.

# Special Educational Needs and Disabilities Co-ordinator (SENDCO/SENCo)

The SENDCO is the teacher in the school/college/early years setting with responsibility for the day-to-day operation of the setting's special educational needs policy. This involves making sure that the setting meets the needs of children or young people with a special educational need or disability where lawful.

## **Specialist Teacher**

Specialist teachers may be involved to support the teaching of specific skills.

# \*Speech and Language Therapist

Speech and language therapists may contribute to the diagnostic process, working as part of a multi-disciplinary team.

Speech and language therapy is concerned with the management of disorders of speech, language, communication in children and adults.

#### **Teacher**

Teachers have responsibility for teaching according to the national curriculum to suit your child's learning needs.

\* These people from the team could be involved in the diagnosis process

# Space for you to add your own contact details

Name: Key Contact	Tel:
Name:	Tel:

# How can I help my child?



- Autism is a lifelong condition A child with autism becomes an adult with autism. However, with support and appropriate strategies, individuals and families can lead full lives.
- There is a wide range of cognitive, social and communicative ability within the autism spectrum - your child may have some or all of the traits to varying degrees. There is no such thing as a typical autistic person.
- Don't blame yourself; it's not your fault.

# People with autism may:

- -take things literally
- -speak the truth as they see it this is not being rude, just honest
- -have obsessions, which can be quite specific, and may seem unusual
- -have difficulty with making eye contact
- -have huge meltdowns
- -fail to comprehend social situations
- -not like being touched
- -be very routine based. Structure is very important
- -find changes in routine difficult, without planning
- -also have other conditions such as dyspraxia, downs syndrome, dyslexia, ADHD etc.

#### People with autism may not:

- -understand sarcasm
- -read body language
- -read facial expressions
- -understand jokes
- -be able to express emotions, this does not mean that they do not feel them.

### Tips for you:

- Attend an Early Bird/Cygnet/ASCEND course (offer may vary locally) these are all courses for parents designed to increase understanding of autism and parental confidence in supporting your child effectively. They also offer an opportunity to meet other parents.
- Join an autism support group. There is support and strength in numbers, as well as lots of advice and information.
- Social skills training for your child is essential and it works. It needs to be constant, structured and ideally in social settings.
- Be aware that people with autism take longer to process information than others. Give them time to process and then to respond. (The 6 second rule)
- Be positive. Provide experiences and situations where the person can excel.

- Accept that certain tasks may need to be specifically taught and learnt. They
  may need to be broken down into smaller steps and then taught again.
- Your behaviour and your response to their behaviour is very important. Keep calm and be consistent.
- Take time out for both of you Reassess the situation try to get a different perspective on things
- Be patient and tolerant
- Remember to say what you mean and mean what you say. Don't tell your child lies (not even little white ones)
- Keep your tone of voice calm and level. If necessary, repeat the instructions or request.

## When things go wrong:

- An autistic person in meltdown is in severe distress. They are not intentionally being disruptive, destructive or naughty.
- Ensure your child feels safe, and is in a safe environment.
- It does not matter what other people think, don't waste your energy being embarrassed by your child's behaviour.
- Be calm. There is no point trying to engage your child while they are in meltdown. Wait until they have calmed down. Back off—give them time and space to allow the situation to calm down
- Don't raise your voice; this will only make the situation worse. Take a deep breath and keep your voice at a level tone
- Don't insist upon eye contact. When an autistic person is stressed, eye contact is hard work.
- Take a few deep breaths!! Do not take things personally but realise that you may need to reframe the way that you think.

You are a Carer and as such, parents/carers can request a carer's assessment via the National Carer resource centres with a view to being put on the Carers Register. Siblings may also need to be assessed as carers in order to give them access to support for young carers. Contact your local Carers Support group.

Benefits: your child may be entitled to Disability Living Allowance and you may be entitled to Carers Allowance. Get help claiming these as the forms are very difficult. Carers Resource and the Citizens Advice Bureau (CAB) are very good at this.

Short Breaks: Short Breaks is a service offered to families to provide a break from caring for a disabled child and for the child to have a break from their carers; these can be good for everyone. Contact your local authority for further details.

Remember every child is an individual and not every rule / piece of advice will apply. You know your child best, better than the professionals, DO NOT forget that and don't let them forget it either.

Remember that autism is part of your child – without it, they would not be the same person and they would not have the same positive points either.

# Money, Benefits, Allowances, Concessions



You could be eligible for certain benefits and allowances but the amount of information available can be quite daunting. We want to help you in the best way possible by giving you a brief overview of what might be available. This information signposts you to those who can offer advice and guidance which will then be tailored to you and your family's particular needs.

Once your child reaches 16, benefits will be given to them, however the benefits agency should contact you to see if they are able to manage their own finances. If they are not, the benefits agency should guide you through the process to allow you to continue to manage them.

Below we have included a range of benefits which you may be able to apply for, we would advise that you seek specialist advice to help you.

- The National Autistic Society has a helpline, 0945 070 4004 or 020 7903 3555
  where you can make an appointment to talk to a Welfare Rights Advisor who
  can help you with the benefits process.
- An online benefits advisor is also available at www.direct.gov.uk/en/Diol1/DoltOnline/DoltOnlineByCategory/DG\_172666
- Or you can contact your local Citizens Advice Bureau at <a href="http://www.citizensadvice.org.uk/index/getadvice">http://www.citizensadvice.org.uk/index/getadvice</a>

### **April 2013 Addendum – Benefits and Allowances**

Due to welfare reforms commencing April 2013, with a gradual rollout across the country, it is advisable that you seek advice for the most up to date information for your area.

### **Disability Living Allowance**

Disability Living Allowance (DLA) is a tax-free, non means-tested benefit for disabled children and adults to help with extra costs you may have. It comes in two parts; mobility and care components. From 16 years old, this benefit is moved to Personal Independence Payment (PIP).

The claim form for Disability Living Allowance is long and you can get help completing it.

- Local support may also be available to help you with the claims process for a child DLA application from: Help in Hand, Welfare benefits Unit, 17 Priory Street, York YO1 6ET Telephone 01904 646058
- You can use the forms completion service offered by the Benefit Enquiry Line
  - 1. Call on Freephone 0800 882 200

- 2. Go to their web site at <a href="http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/index.htm">http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/index.htm</a>
- 3. Email them at: BEL-Customer-Services@dwp.gsi.gov.uk
- You could consult an experienced adviser, for example, at a Citizens Advice Bureau. To search for details of your nearest CAB, including those that can give advice by email, click on □ nearest CAB. <a href="http://www.citizensadvice.org.uk/index/getadvice">http://www.citizensadvice.org.uk/index/getadvice</a>
- You could consult your local Carers Resource Office http://www.carers.org/carers-services/find-your-local-service

### Top tips:

- Describe your child and the care you give them on their worst day as that is what you are expected to do.
- Don't understate the problems and be very clear if there are night time problems
- Keep a diary, it will help you when you are filling out your form
- Take a photocopy of any forms you fill in just in case there is a query

 $\frac{http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Disabledpeople/DG\_10018702}{ort/Disabledpeople/DG\_10018702}$ 

# **Carer's Allowance**

This is paid to a carer who looks after a child or young person for more than 35 hours a week and earns less than a certain threshold. This is not available to everyone. Visit the web site for more details.

http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupp ort/Caringforsomeone/DG\_10018705

# **Employment and Support Allowance**

Employment and Support Allowance provides financial help to people who are unable to work because of illness or disability. It also provides personalised support to those who are able to work. This allowance may be available for young people from the age of 16. Certain rules and conditions apply. Details can be found on the Directgov website.

http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Illorinjured/DG\_171894

# **Income Support**

Income Support is a means-tested benefit payable to certain people on a low income. It is designed to bring an applicants income up to a minimum level to cover their basic living expenses. You may be able to access this benefit.

<a href="http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/On\_a\_low\_income/DG\_10018708">http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/On\_a\_low\_income/DG\_10018708</a>

# **Child Tax Credit and Working Tax Credit**

To find out more about Child Tax Credit, visit <a href="http://www.direct.gov.uk/en/MoneyTaxAndBenefits/TaxCredits/Gettingstarted/whoqualifies/Childrenandtaxcredits/index.htm">http://www.direct.gov.uk/en/MoneyTaxAndBenefits/TaxCredits/Gettingstarted/whoqualifies/Childrenandtaxcredits/index.htm</a>

For all you need to know about Working Tax Credit visit <a href="http://www.direct.gov.uk/en/MoneyTaxAndBenefits/TaxCredits/Gettingstarted/whoqu">http://www.direct.gov.uk/en/MoneyTaxAndBenefits/TaxCredits/Gettingstarted/whoqu</a> alifies/WorkingTaxCreditthebasics/index.htm



# **Social Fund Payments**

A guide to The Social Fund can be found at <a href="http://www.dwp.gov.uk/publications/specialist-guides/technical-guidance/sb16-a-guide-to-the-social/">http://www.dwp.gov.uk/publications/specialist-guides/technical-guidance/sb16-a-guide-to-the-social/</a>

# **The Family Fund Trust**

The Family Fund Trust is the UK's largest provider of grants to low-income families raising disabled and seriously ill children and young people. They help ease the additional pressures families face. They can help with essential items such as washing machines, fridges and clothing but can also consider grants for sensory toys, computers and much needed family breaks together.

http://www.familyfund.org.uk/

# **Disabled Facilities Grant**

A Disabled Facilities Grant is a local council grant. It helps towards the cost of adapting your home to enable you to continue to live there. A grant is paid when the council considers that changes are necessary to meet your needs, and that the work is reasonable and practical.

 $\frac{http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/YourHome/D}{G\_4000642}$ 

# **Disabled Students Allowance**

As a higher education student living in England, you can apply for a Disabled Students' Allowance (DSA) if you have a; disability, long-term health condition, mental health condition or specific learning difficulty such as dyslexia. To find out more visit the web site below

https://www.gov.uk/disabled-students-allowances-dsas

#### Concessions

 The Carers Trust web site is worth a visit to see if any national concessions are advertised as well as directing you to your local Carers Resource group.
 <a href="http://www.carers.org/">http://www.carers.org/</a> Disabled **Parking Badge** allows certain parking privileges and allowances. Certain terms and conditions apply. For information on how to apply, visit <a href="https://www.gov.uk/apply-blue-badge">https://www.gov.uk/apply-blue-badge</a> or contact your Local Authority Customer Services Centre: North Yorkshire County Council Tel: 0845 872 7374: <a href="http://www.northyorks.gov.uk/">http://www.northyorks.gov.uk/</a> or City of York Tel: 01904 551550; <a href="http://www.york.gov.uk/">http://www.york.gov.uk/</a>

- You may be entitled to road tax exemption. For further details you can go to <a href="http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/Yourvehicleondollows.">http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/Yourvehicleondollows.</a>
   eandlicence/DG\_10028003
- You may be able to get financial help from the Healthcare Travel Costs
   Scheme. To see if you would qualify for this support go to:
   <a href="http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx">http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx</a>
- Motability is a scheme where you can exchange your higher rate mobility allowance to buy or hire a car. To find out if you could qualify go to <a href="http://www.motability.co.uk/main.cfm?Type=IDX">http://www.motability.co.uk/main.cfm?Type=IDX</a>
- Disabled Person's Railcard further information is available at http://www.disabledpersons-railcard.co.uk/
- National Key Scheme (RADAR) public toilet keys are available at <a href="https://crm.disabilityrightsuk.org/radar-nks-key">https://crm.disabilityrightsuk.org/radar-nks-key</a>
- The Disabled Person's Bus Pass entitles eligible disabled people to free off peak travel on local buses anywhere in England. Full details can be found at <a href="http://www.northyorks.gov.uk/index.aspx?articleid=14301">http://www.northyorks.gov.uk/index.aspx?articleid=14301</a> for North Yorkshire or for York:

https://www.york.gov.uk/info/20103/travel\_passes\_and\_concession/1500/appl y\_for\_disabled\_persons\_bus\_pass\_

# **Social Care/Short breaks**

A Short Break (sometimes known as "respite care") is an opportunity for parents and carers of a disabled child to have a break from their caring arrangements and for their disabled child to have a positive enjoyable experience. A short break could be a session at a club, an activity or, if needs are more complex, a service lasting a day or even overnight. The short break is matched to meet the child's needs, interests and preferences.

Short Breaks information in North Yorkshire is available at:

http://www.northyorks.gov.uk/index.aspx?articleid=3202

For more information on Short Breaks in York:

http://www.yor-ok.org.uk/families/Local%20Offer/short-breaks-2.htm

# What is available from education?



All parents want the best possible education for their child. If your child has a diagnosis of autism it can sometimes seem difficult to know what the best options are. Knowing how or where they should be taught can be a big worry. The key to success is to ensure any barriers to learning are removed so that all children achieve their potential.

Some children with autism make progress very successfully within their local mainstream school, with support from specialist support and outreach services. Others may need additional support perhaps through an Education and Health Care Plan (EHCP), and some may be educated in a Special School depending on the type and severity of their special educational need.



All children deserve a fair start in life as well as an education that enables them to flourish and develop to their full potential. Each child with autism is an individual and will require an autism friendly environment that has teaching tailored to their individual needs and learning styles.

In North Yorkshire the Inclusive Education Service provides this support through Enhanced Mainstream Schools (EMS), and the Communication and Interaction (Autism) team.

Across the county there are 5 Primary/Pre-School Enhanced Mainstream Schools for Communication and Interaction and 5 Secondary Enhanced Mainstream Schools for Autism, as well as 11 Special Schools where high need specialist provision is available. EMS have additional resources, staffing, funding and physical provision to support the education of children and young people who need additional and different support to make progress in a mainstream school environment.

### **Supporting Children, Parents and Families**

Schools and early years' settings have a major role to play in supporting the educational development of children and young people with autism. They provide a range of learning opportunities, where children and young people's needs are met locally in most instances. The Local Authority strives to support children and young people within their local mainstream community school, wherever possible, taking account of the views and wishes of the parents.

North Yorkshire has a wide range of pre-school and school age educational support for children in mainstream settings which include:

- Portage Home Visiting and Early Years Support
- Autism Early Intervention Support
- Support and Outreach services (including outreach from Enhanced Mainstream Schools and Special Schools).

Specialist settings are available for those children and young people whose needs cannot be met in a mainstream setting, these include:

- Enhanced Mainstream Schools (primary and secondary)
- Special Schools
- Specialist 6<sup>th</sup> form provision.

Educational provision may vary in other areas. To find out more about which specialist services are available locally in your area, you can contact the school or setting your child attends. For families living in North Yorkshire you can also get in touch with the Specialist SEN Support Service via the Customer Services Centre on 0845 872 7374. Families in York should contact the SEN Service on 01904 554302.

The DFES (2002) guidelines for schools include a description of how a school can become "autism friendly" and this is something that you can consider when looking for the right setting for your child or young person's education. A summary of these 'pointers for good practice' can be found on the NAS website at: <a href="http://www.autism.org.uk/">http://www.autism.org.uk/</a>

## **CHILDREN IN THE EARLY YEARS**

Early education provides an opportunity for all children to receive a period of free preschool education before they are of compulsory school age. Early education enables children to enjoy playing and learning before they go to school and to acquire the skills which will help them once they start school.



The majority of pre-school children with autism will attend their local, private or voluntary independent nursery settings. A graduated approach to meeting their needs is provided and, for those children who have a high level of need, Early Years settings are able to apply for additional support via Element 2 Inclusion Funding as appropriate.

When children's needs are at a level where specialist educational support/advice is appropriate, a Request for Involvement (Rfl) can be made via the Inclusive Education Service Single Point of Access (SPA) process. Following the weekly SPA panel an individual child can be allocated to the appropriate team within Inclusive Education.

The Early Years Team (which is part of the Educational Psychology and Early Years Service) is made up of Early Years Advisory Teachers (EYATs) and Portage Home Visitors (PHVs)

The Early Years Advisory Teachers (EYATs) and Portage Home Visitors (PHVs) work together to provide a continuum of specialist support for children under 5 years old with a wide range of Special Educational Needs and disabilities (SEND). The EYATs are a small team of specialist teachers with high levels of expertise and training in working with children with a wide range of SEND in the Early Years Foundation Stage (EYFS). They offer support, advice and training to parents/carers and practitioners in settings to help them meet children's additional needs. The team is committed to early intervention and inclusion.

Portage is primarily a home visiting educational service for pre-school children with additional needs and their families. The Portage Home Visitors (PHV's) are qualified early years practitioners who have additional training and experience in working with children with SEND (Special Educational Needs and Disabilities). Portage Home Visitors access supervision from the Early Years Advisory Teachers (EYATs) and all the children receiving Portage are also on the caseloads of the EYATs as part of a 'seamless' provision. As it is largely home-based, there are criteria for allocating and ending Portage which include taking into consideration the number of hours a child is attending a funded place in an Early Years setting.

#### The team works with:

- individual children with a high level of Special Educational Needs. These are the children who, after a period of universal and targeted support and intervention, have not made adequate progress and will require further specialist support. (Special Educational Needs Code of Practice, 2015).
- children who have been identified with a high level of on-going complex needs in early childhood by health professionals.

# Early Years Advisory Teachers (EYATs) provide:

- observation and assessment of individual children in order to make specific recommendations for differentiation and target-setting
- written advice for individual children which can inform day-to-day practice and be utilised to support funding and statutory processes if appropriate
- facilitation of and participation in multi-agency working
- guidance on accessing appropriate resources and information for individual children
- a range of relevant training
- support and advice regarding transition of individual children from home to setting and between settings
- facilitation of the communication between parents/carers and settings

## **Portage Home Visitors provide:**

- regular home visits to a child and family to deliver a step-by-step play-based educational programme in liaison with the Early Years Advisory Teachers (EYATs) and other agencies involved
- support and written information during the transition of individual children into Early Years settings in liaison with the EYATs.

# **Inclusive Education Service – Communication and Interaction (Autism)**

Where support is required for a young person with autism, a setting or professional may submit a request for involvement (RFI) to the Single Point of Access (SPA). This request will detail the needs of the child as well as any diagnoses they may have. The case will then be allocated to a team within the Inclusive Education Service depending on the child's needs rather than their diagnosis. These services include:

- Communication and Interaction (including Autism)
- Social, Emotional and Mental Health
- Early Years Advisory Team
- Cognition and Learning
- Severe Learning
- Physical and Medical

The needs of a child with Autism may be best met by the Communication and Interaction – Autism (C&I - Autism) team. However, they might be better met by another team and as such may be allocated to that service.

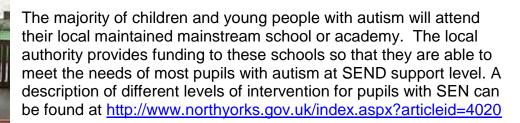
The C&I team is divided into local area teams to ensure local access for all families across North Yorkshire. The team provides training, specialist support and intervention to improve provision for children and young people with needs relating to communication or interaction including those with a diagnosis of autism. Support is designed to enhance learning, achievement and social inclusion and is personalised to meet the individual needs of the child or young person.

Where support is offered by C&I – Autism, this may include:

- Advice and recommendations to the Early Years setting
- Opportunity to attend a parent/carer support and training programme
- Discussion with parents to identify priorities and plan goals for their child's learning and participation
- Creation of a support plan for children and their families
- Empowering parents to lead appropriate support for their child
- A flexible approach to responding to the needs of the child and the family
- Access to an early years personalised intervention plan if appropriate
- Transition support into an Early Years setting
- Ongoing support within the setting to support the implementation of autism specific strategies and interventions, plan goals and evidence progress.

#### SCHOOL AGED CHILDREN AND YOUNG PEOPLE





Delegated funding enables schools to make their own decisions about how pupils can be best supported at a local level, in partnership with families. Some children with the most complex needs may receive an Education and Health Care Plan (EHCP) from the local authority if they need additional adjustments that cannot be reasonably expected of the mainstream school or setting.

# **Inclusive Education Service – Communication and Interaction (Autism)**

Where support is required for a young person with autism to access education, a setting may submit a request for involvement (RFI) to the Single Point of Access (SPA). This request will detail the needs of the child as well as any diagnoses they may have. The case will then be allocated to a team within the Inclusive Education Service depending on the child's needs rather than their diagnosis. These teams include:

- Communication and Interaction (including Autism)
- Social, Emotional and Mental Health
- Cognition and Learning
- Severe Learning

Physical and Medical

The needs of a child with Autism may be best met by the Communication and Interaction – Autism (C&I - Autism) team. However, they might be better met by another team and as such may be allocated to that service.

The C&I team is divided into local area teams to ensure local access for all families across North Yorkshire. The team provides training, specialist support and intervention to improve provision for children and young people with needs relating to communication or interaction or with a diagnosis of autism. Support is designed to enhance learning, achievement and social inclusion and is personalised to meet the individual needs of the child or young person.

Where support is offered by C&I – Autism, this may include:

- Advice and recommendations to the setting
- Opportunity to attend a parent/carer support and training programme
- Discussion with parents to identify priorities and plan goals for their child's learning and participation
- advice on curriculum content and delivery
- advice on creating an optimum learning environment
- support with provision mapping and target setting
- building the capacity of schools to implement autism interventions
- modelling and coaching on appropriate support strategies
- a range of bespoke training
- a Personalised Intervention Programme if appropriate

# **Enhanced Mainstream Schools (EMS)**

In North Yorkshire, there are five primary enhanced mainstream schools for learners with communication and interaction needs. These following schools also offer outreach support to other mainstream, settings where pupils are aged 5-16 years old:

- 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
- Alverton Pre-School, Northallerton
- Hookstone Chase Community Primary School, Harrogate

There are five enhanced secondary schools for students with a diagnosis of autism that provide both outreach and inreach support:

- King James School, Knaresborough
- Filey School and Technology College, Filey
- Bedale High School, Bedale
- · Holy Family Catholic High School, Carlton, Selby
- South Craven (academy)

(adapted from the Strategy for meeting the needs of Children and Young People with Autism in North Yorkshire 2012). In the York area, City of York Council's Specialist Teaching Team works with schools to provide specialist advice, support and teaching for children and young people with special or additional needs.

**FAMILY SUPPORT:** support for parents/carers/professionals as well as for young people with SEND aged 16 to 25 years old.

# SENDIASS (Special Educational Needs, Information, Advice and Support Service)

Each Local Authority must provide an arm's length, impartial service that remains confidential unless consent is given to share information. North Yorkshire Local Authority funds SENDIASS, a service for children and young people, 0-25 years old who have special educational needs or disability (SEND). A parent/ carer, professional or young person aged 16 -25 years old can contact the enquiry line which is staffed Tuesday and Thursday from 9:30-1pm (including school holidays) on **01609 536923**.

If the line is busy, a short message can be left along with your contact details and someone will return your call within a week. Alternatively, your local SENDIASS coordinator can be contacted directly, see link below for contact details. Please understand that all coordinators are part time, so you may need to leave a message to be contacted as soon as practicable.

http://www.northyorks.gov.uk/article/31690/SENDIASS---information-advice-and-support

SENDIASS can offer free information, advice or support to ensure babies, children and young people with SEND are having their educational or training needs met appropriately. Needs range widely from such issues as a medical need that impacts upon education or training, to a child who is struggling at school but does not necessarily need a statutory plan. Alternatively a 0-25 year old student may need an assessment for an EHC plan but parents/carers require support from SENDIASS within this process if there are difficulties. SENDIASS remains impartial and confidential (except safeguarding) which means anyone can make contact to gain clear information or advice about anything connected to education and SEND. Our aim is to encourage communication and clear planning alongside relevant services in order to ensure the child or young person's education or training is being accessed as fully as possible. We also have a statutory duty to support parents/carers or young people when challenging actions decided upon by the local authority or health services if they are not adhering to the relevant law.

# **Parent/Carer Support Programmes**

Parents and carers of children and young people diagnosed with autism will be given the opportunity to attend a support programme for families which are run jointly between health and education. These may include Early Bird, Cygnet or ASCEND (offer varies locally).



Where possible, training will be available locally, however parents have the flexibility to travel to a different part of the authority area to receive training if this suits their circumstances better.

The training programmes are awareness raising programmes and introduce a range of strategies and

approaches that may be helpful. They enable parents to discuss individual issues within a supportive environment. The programmes also give families the opportunity to meet others who are in a similar situation and time to discuss experiences between themselves.

A calendar of forthcoming parent support programmes can be found on the NYCC website at <a href="http://cyps.northyorks.gov.uk/autism">http://cyps.northyorks.gov.uk/autism</a>



# Helping to prepare for transitions



Transitions are defined as the "passing from one place, stage or activity to another". During the journey through childhood and into adulthood an individual will pass through a number of informal and formal transitions.

#### Education

Often many of the major (formal) transitions in childhood relate to moving from nursery to school, primary to secondary and secondary school to further education. There are also a number of other transitions that your child will experience, sometimes on a daily basis, such as moving from class to class or simply informal transitions within a school or classroom which can be difficult to manage.

It is commonly found that children and young people with autism find it difficult to manage transitions. This is partly due to their desire for sameness, predictability and routine as well as their cognitive processing difficulties in understanding the reasons behind these changes.



Transitions need to be considered and planned for where possible, and coping with transition needs to be recognised as a potential area of stress for pupils and their families.

Some children with autism struggle with everyday changes and need support and strategies to help them deal with these successfully. For example, TEACCH (2006) recommend that children are prepared for changes within school by being informed about:

- Where they have to be at a set time
- Who might be present
- What they will/should be doing during the lesson
- What behaviour is expected of them
- How much work they will have to do
- How they will know when they have finished their work
- What they will be doing next.

Key areas of challenge for children and young people with autism can occur:

- When moving from one educational placement to another (new buildings, new people, new structures/routines)
- When moving between different areas of a school, including moving from one base to another such as in key stage changes
- When moving between home and school
- When new or different staff become involved in a child or young person's care
- If there are changes within the home (such as moving house, a new baby in the family, loss or bereavement of someone close, holidays)

 During personal transitions as a result of puberty, maturation and development.

#### Transition to adulthood

For many adolescents with autism, the transition from school to adulthood can be particularly difficult. Although some individuals with autism are able to make this transition successfully, additional support may be required to help the young person and their family to plan the most appropriate next step for them to take. This support will enable them to overcome any difficulties or obstacles that may arise as they attempt to negotiate their way into further education, training, work, community participation and independent living.



Most children's services finish when a young person reaches 18 and/or finishes in full time education. In some instances, where a young person continues to access education, they may continue to access support from some teams within the Inclusive Education Service until they are 25 years old. Other teams are available on a traded basis and settings would need to purchase support. The move from children's services to adult focused services will involve building new relationships with different professionals. The needs of the young person as a developing adult will need to be considered and an appropriate programme of support provided.

The choices available to young people with special educational needs and disabilities (SEND) when leaving school has a significant impact on their experience of moving into adulthood. Discussions focusing on the aspirations of young people with SEND and the support they need to make a successful transition to adulthood are important and should begin during year 9 where possible, to allow time for all those working with the young person to develop an effective transition plan.

Transition planning must begin by Year 9 for young people with an Education, Health and Care Plan. A range of professionals may be involved in supporting this transition, including the SEN coordinator within a mainstream setting or possibly the ARO (Area Reviewing Officer) who holds responsibility for a child or young person's EHCP, a specialist careers adviser and/or travel trainer. If the CYP is open to the Social Care Team, their Social worker would also be involved in this process. The specialist careers advisers are aware of the full range of post-16 options open to young people with SEND and will be able to discuss these options with them and their parents or carers. The specialist careers adviser service is a traded service and can be purchased by the school or college.

The level of support available may vary in mainstream schools. Young people and parents/carers can also contact the Special Educational Needs and Disabilities Information Advice and Support Service to discuss their needs in transition. They can be contacted on 0845 034 9469, or visit their website at <a href="https://www.northyorks.gov.uk/parentpartnershipservice">www.northyorks.gov.uk/parentpartnershipservice</a>

# Post 16 opportunities

- School 6<sup>th</sup> Form offers a wide range of learning opportunities which will support learners to develop skills in areas of personal progress, independent living and employment.
- Further Education Colleges can offer both full and part time courses, including supported vocational courses where learners have the chance to try out a range of different career ideas.
- Apprenticeships are an excellent way of gaining qualifications and workplace experience. As an employee the young person can earn as they learn and gain practical skills from the workplace.
- Personalised Learning Pathway (also known as specialist non-standard mainstream provision) is a person centred programme which supports the young person to develop and progress. It is based on a clear understanding of how the individual person learns best, using strategies that help them achieve their goals and giving the support they require to succeed within the learning environment.
- Independent Specialist Providers can provide both day and residential educational programmes for young people with complex learning difficulties and or disabilities who require a high level of expertise and support in making their transition to adult life.

#### Resources

There is a range of resources which can be invaluable in supporting children and young people with autism through major transition points in their lives. A key resource is the 'Transition Tool Kit' (Autism Education Trust) which provides a wealth of practical strategies and advice across various stages of transition. The ideas and strategies suggested in the toolkit will need to be adapted to be applicable in different situations and with different ages and levels of understanding.

# The Transition into an Early Years Placement

- Attending programmes for parents such as NAS Help! or Early Bird; also helpful for nursery staff/ 1:1 support staff to attend with parents
- Inclusion Development Programme materials
- Home visits
- Visits to nursery with parents/carers to sample various different sessions and activities e.g. Circle Time etc.
- Develop a photo book with relevant staff pictures, photos of activities and different areas in the setting e.g. sandpit, lunch table etc.
- Autism specific training provided for staff
- Pen portrait of child to be drawn up with parents

'Transition Tool Kit' (Autism Education Trust)

# The Transition from Early years to Primary School

- Attending parent programmes, including NAS Help! and Early Bird
- Inclusion Development Programme materials
- Transition visits into new school, child to be accompanied by a familiar adult, to sample various settings and activities e.g. assembly, structured lessons and play
- Transition pack to be developed which includes photos and information about the new school
- Opportunities to meet key staff, e.g. teacher/teaching assistant; two way transition visits (primary staff to visit child in Early Years setting)
- Transition planning with parents and Early Years staff including pupil pen portrait to be drawn up
- Focus upon 'learning to learn behaviours' e.g. listening to teacher
- Consideration of the transition issues between the yearly class changes e.g. information transfers, personal introductions etc.

'Transition Tool Kit' (Autism Education Trust)

# The Transition from Primary to Secondary School

- Map of new school building, highlighting important areas e.g. form room, locker, dining hall
- Easy to use timetable suited to the individual / colour coded subjects
- Create daily checklists to ensure correct items are taken to correct lessons/school activities
- User friendly homework diary
- Use of a buddy system with designated peer/group
- Staff member to act as a mentor to help in times of 'crisis' e.g. if pupil becomes anxious over losing dinner money/forgetting PE kit
- Plan for a consistent approach across lessons through an effective staff communication system
- Inclusion Development Programme materials
- Provision for a 'chill out' area for child/young person to withdraw to
- Consider procedures to manage unstructured as well as structured settings lunchtimes can be the most stressful part of the day. Options include a 'circle of friends' or a lunch club.
- Attending parent programmes, including NAS Help!, Cygnet/ASCEND

'Transition Tool Kit' (Autism Education Trust)

Other important resources provide a range of practical strategies to support transitions. These include the Mencap Transition Guide, and the Transition Information Network.

# **Publications, Websites and Apps**



#### **Publications**

Publications	
A Practical Approach at Home for Parents and Carers - Autistic Spectrum Disorder. Falkirk Council	https://www.falkirk.gov.uk/services/social-care/disabilities/docs/young-people/Autistic%20Spectrum%20Disorder.pdf?v=201507131117
A Practical Approach at Home for Parents and Carers – Aspergers Syndrome (Teenagers). Falkirk Council	https://www.falkirk.gov.uk/services/social-care/disabilities/docs/young-people/Aspergers%20Syndrome%20- %20Teenagers.pdf?v=201507131117
Autism and Asperger Syndrome: Social and Communication Disorders. An Information Pack. Produced by parent members of the Richmond upon Thames branch of The National Autistic Society.  Contains many useful publications and web site links.	http://www.richmondnas.org/information-pack.html



# **Websites**

The National Autistic Society	http://www.autism.org.uk/
The NAS After diagnosis. Information	
for parents and carers of children with	http://www.autism.org.uk/products/leaflets/after-diagnosis.aspx
autism	

Contact a Family – For families with	http://www.cafamily.org.uk/
disabled children.	
National Children's Bureau	http://www.ncb.org.uk/
Mencap – The Voice of learning disability	http://www.mencap.org.uk/
Listening Books	http://www.listening-books.org.uk/
British Institute of Learning Disabilities	http://www.bild.org.uk/
Autism Education Trust – Supporting	http://www.autismeducationtrust.org.uk/
supportive education practice.	
The National Autistic Society Local	http://www.autism.org.uk/directory.aspx
Services Directory	
Help, support and information regarding	http://www.asperger-syndrome.me.uk/
aspergers syndrome	
The Autism Directory	http://www.theautismdirectory.com/
United Response- Supports people with	http://www.unitedresponse.org.uk/
learning disabilities	
Dimensions-Support people with learning	http://www.dimensions-uk.org/
disabilities and autism	
Citizens Advice Bureau	http://www.citizensadvice.org.uk/
Transition	
Transitions Information Network	http://www.transitioninfonetwork.org.uk/home1.aspx
Carers	
The Princess Royal Trust for Carers –	http://www.carers.org/carers-services/find-your-local-service
Carers Trust	
Siblings	
Sibs for brothers and sisters of disabled	http://www.sibs.org.uk/
children and adults	
KIDS Working with disabled children,	https://www.kids.org.uk/
young people and their families	http://www.autism.org.uk/about/family-life/siblings.aspx
NAS Support for siblings	nttp://www.autism.org.uk/about/ramily-lile/siblings.aspx
Communication	
Association for all speech impaired	http://www.afasicengland.org.uk/
children - AFASIC	http://www.ican.org.uk/
I can – helps children communicate	
The Communication Trust	http://www.thecommunicationtrust.org.uk/
Education	

Portage- home visiting educational service	http://www.portage.org.uk/
Pre school learning alliance	https://www.pre-school.org.uk/
Health	The second secon
Dyspraxia Foundation	http://www.dyspraxiafoundation.org.uk/index.php
Talking Point	http://www.talkingpoint.org.uk/Parent.aspx
Clinical Commissioning Group Websites	http://www.valeofyorkccg.nhs.uk/
Clinical Commissioning Group Websites	http://www.hambletonrichmondshireandwhitbyccg.nhs.uk/
	http://www.harrogateandruraldistrictccg.nhs.uk/
	http://www.scarboroughryedaleccg.nhs.uk/
	http://www.airedalewharfedalecravenccg.nhs.uk/
Local Websites	
NAS Harrogate and District Branch –	http://www.autism.org.uk/directory/resources/11229.aspx
Harrogate, Richmondshire and Craven	
NAS North Yorkshire Central Branch –	http://www.autism.org.uk/directory/resources/6031.aspx
York Selby and Hambleton	
Special Educational Needs – Information	http://www.northyorks.gov.uk/send
for Parents	
Family support: SENDIASS	http://www.northyorks.gov.uk/article/31744/SENDfree-and-impartial-information-advice-and-support
Children's Centres	https://www.northyorks.gov.uk/childrens-centres
Web links for North Yorkshire & York	http://www.yor-ok.org.uk/Parents/Childrens%20Centres
North Yorkshire PACT – partnership,	http://www.nypact.org.uk/
advocacy, co-operation and teamwork	
Parent/carer forum	
York Parent Carer Forum (YPCF)	https://yorkparentcarerforum.org.uk/
Ryedale Special Families	http://www.ryedalespecialfamilies.org.uk/
Ohana	http://ohanacharity.co.uk//
Carers Resource Harrogate, Ripon,	http://carersresource.org/
Bradford, Craven and Airedale	
Hambleton & Richmondshire Carers	www.hrcarers.org.uk
Centre	
Scarborough & Ryedale Carers	http://www.carersresource.net/
Resource	
AWARE – Airedale & Wharfedale Autism	http://awareuk.homestead.com/

Resource	
Parent groups & networks – various	http://www.northyorks.gov.uk/article/29826/SENDgroups-and-networks
across NYCC, see contacts in link	
SUNBEAMS	http://www.sunbeamsbentham.co.uk/
WHISH (Whitby Hidden Impairment	http://www.whishgroup.co.uk/
Support & Help	

# Apps

Autism and Asperger Syndrome: Social and Communication Disorders. An Information Pack.  See pages 108-110 for a list of useful apps	http://www.richmondnas.org/information-pack.html
The National Key Scheme (RADAR) public toilet keys. App available	https://www.disabilityrightsuk.org/shop/radar-key

**Disclaimer:** The documents and links are being provided as examples of useful resources only. Listing these resources should not be considered an endorsement of the particular organisation by NHS North Yorkshire and York, nor is the PCT responsible for the content of external websites.

# What is it like to have autism?



"Once you have met one person with autism, you've met one person with autism...." Lorna Wing, October 2011

In this section you will find some thoughts from two young people with autism.

They are both very different even though they both have autism. They wanted to share the following. You might be able to relate to some things and not others. You are your own person too everyone is different in some way to others, over time; you will collect your own experiences and thoughts.

They hope that this will help you in some way, in these first few weeks and months, to help you understand what it might feel like to have autism.

#### About me

- Because it depends on where you are on the spectrum, everyone is different and that's ok
- It's a matter of choice what you like to call autism. Let people know what you prefer
- Don't keep acting in a way to look normal, it's better to be who you are
- People might make assumptions about what they think you can or cannot do and you have to keep explaining. But if they take the time to find out about you then it will become easier
- It always helps to know someone who you can talk to
- You can try new things with support to get you out of your comfort zone if that's what you want
- There is a bright side
- Don't be afraid to take control
- Be inspired
- It is sometimes hard to fit in
- You can achieve

## Friends and Family

- If you are anxious or worried you; might want to talk to your parents, friends or someone else you trust
- You might want to be alone, you might want some space
- You might find it hard to talk to people
- Friends and family are important to you
- Everyone needs to be aware of the sensory affect autism can have. Let people know what makes you feel uncomfortable
- Sharing things with family and friends can help
- Making friends can be hard
- It can feel lonely having autism, friends can help
- If you want to make some new friends and do something interesting, you can join groups like the Flying High Group. See what is happening in your local area when you are ready to explore

#### **Role Models**

- A person around you can inspire you and it might not even be who you expected it to be
- Einstein
- Rory Hoy <u>http://www.youtube.com/watch?v=P</u>
   OIJG3qmV9Q

http://www.roryhoy.com/

 You might see talents that others have and they might not realise. They might like to know

#### School

- Making friends can be hard. Finding someone who has a similar interest may help. Joining a school club may be a good place to do this
- If you make friends at clubs then joining them at break times and dinner time could help if you are finding those times difficult
- At school the learning support team can help you with school work and sometimes just to talk to
- At school, other people who go to learning support can really help because they know how it feels
- School planners are great, put everything in them so that you know where to go and what needs handing in and when.

#### **Transitions**

- This is an important time when you move schools, university or become an adult
- It can help if you know some people who are moving on too and you can do it together
- If you like Blogs they can be great when you are older
- If you don't know what is going on or things are not happening, you can ask for additional support and help to make sure things do happen

Inspired by and produced with the help of our friends at Barnardo's 'The Flying High Group' who wanted to share with you their experiences.