



Greater Manchester
Autism Consortium



The National
Autistic Society

The National Autistic Society
Family Services Development Project

AS INFORM

Greater Manchester



An information resource for **Children**
with Asperger Syndrome in Greater Manchester
and their parents and carers

Last updated 01/01/2012

Your autism charity

ACKNOWLEDGMENTS

Thanks to all those who offered their advice and information for this resource.

Introduction

This information resource is designed to give information to parents with children who have Asperger syndrome or who are "able autistic". It is also hoped to be of use to people with Asperger syndrome and professionals working alongside them.

It is an attempt to 'map' services in the areas of Care, education, family support, diagnosis, counselling, benefits and social support/ leisure.

Updates

This document is the children's version of Greater Manchester AS INFORM. The original Greater Manchester publication aimed at teenagers and adults was launched in 2004, and is regularly updated. This version was last updated on the date shown on the frontsheet. The original version of AS INFORM was produced by Andrew Powell in Avon in 2001.

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Please contact the **Family Services Development Project on 0161 998 4667** if you have new information which you think we should add, or out-of-date information we should remove.

Important numbers and websites for further information!

Although this resource covers many areas relating to young people and adults with Asperger syndrome or who are able autistic it does not pretend to cover all. For any information not detailed in the resource please contact:

National Autistic Society Family Services Development Project – 0161 998 4667

National Autistic Society Helpline - 0808 800 4104

National Autistic Society - Education Rights Service (Education Advice Line and Tribunal Support Scheme 0808 800 4102)

National Autistic Society – Parent To Parent Line - 0808 800 4106

National Autistic Society general information website www.autism.org.uk

National Autistic Society Directory of Services website www.autismdirectory.org.uk

Asperger syndrome is an autism spectrum disorder

For the purposes of this resource, wherever it says Asperger syndrome read 'able autistic', or 'high-functioning autism'. This resource may also be of use to people with semantic pragmatic disorder, dyspraxia and other similar conditions.

Gender of people with Asperger syndrome

Most reference to people with Asperger syndrome in this resource use the male pronoun. This is for economy of style.

Although there are more males than females with Asperger syndrome, and we do not know the exact male to female ratio, it is important to remember many people with Asperger syndrome are female.

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How to use this resource

This resource is aimed at parents and professionals who assist and support children with Asperger syndrome and those who are 'able-autistic'.

Getting support for someone with Asperger syndrome is often far from straightforward. This is because people with Asperger syndrome do not fit the traditional idea of disability. As many parents already know this causes frustration. This resource is an attempt to at least clarify some of the processes involved in trying to get the best out of existing services.

It covers the 10 local authorities that make up Greater Manchester. These are:-

- **Bolton**
- **Bury**
- **City Of Manchester**
- **Oldham**
- **Rochdale**
- **City Of Salford**
- **Stockport**
- **Tameside**
- **Trafford**
- **Wigan**

The resource gives information on the planning required to assist a child both in education, covering pre-school through to secondary education and sources of support for parents and carers of children in many areas.

There is some information about helping children with everyday aspects of life which they and their parents find difficult including sensory and behavioural issues and help with siblings.

There are also pages on getting a diagnosis, counselling, Benefits, legal issues and other contacts.

There is a quick Who To Contact Guide that provides an overview of the professionals a child with Asperger syndrome (aged 14 and older) is likely to need to contact for support.

The Who To Contact Guide gives basic information on which professionals to contact, for what purpose and when.

DIAGNOSIS

Could my child have an Autism Spectrum Disorder (ASD) ?

You may be concerned about your child's development and suspect that it could be Asperger Syndrome or another Autism Spectrum Disorder. If you only know a little about the condition, it will also be helpful to read the NAS leaflets *What is autism?* and *What is Asperger syndrome*. They are available from the NAS Helpline (0808 800 4104) and from the following website links:

Autism: www.autism.org.uk/autism

Asperger syndrome: www.autism.org.uk/asperger

One of the most important indicators that an ASD could be present in a child is the absence or very delayed development of drawing parents' and others' attention to objects or events. Other key signs that usually emerge in the first few years of life are three areas of difficulty all people with an autism spectrum disorder share difficulty with: social interaction, social communication, and social imagination. These are usually called the 'triad of impairments'. These often combine with a repetitive pattern of activities and sometimes challenging behaviour.

Although a child may show signs of ASD early in life, the condition can go undetected for some years, especially in those who are at the more able end of the spectrum where the signs are more subtle.

What you have read may seem to reflect at least some of what you see in your child. Who do you take your concerns to and how can your child be assessed?

Getting a referral to somebody who can perform a diagnosis

The first person to approach will be your GP, though for young children your health visitor may also pick up that your child is experiencing difficulties. Choose to see a practice doctor who you think knows your child well and is likely to listen to and act on your concerns. Don't 'tag' on discussing ASD at the end of a doctor's appointment when other health difficulties are being discussed, but arrange an appointment specifically to discuss your concerns.

Don't assume the GP will or won't know about the condition. Although many GPs are short of knowledge there are a growing number who have some awareness. So take along some literature about Asperger syndrome if you have some, to offer to the doctor if necessary.

It can also help to take along to your GP a list of behaviours and characteristics that make you suspect your child has an ASD, as this can help as a good prompt during your appointment.

If your child is pre-school your health visitor or GP may carry out a screening interview called CHAT (Checklist for Autism in Toddlers). You can see a copy of this on our website:

www.autism.org.uk/chat

This is not a diagnostic interview but can help to identify behaviours that indicate your child may have an ASD.

Once your GP is convinced of your child's difficulties, whatever age your child is, s/he should refer you for an assessment appropriate for any child with a possible developmental problem.

Ideally, then, the next stage will be a multi-agency assessment – an assessment by a team of professionals from different disciplines. Your GP may refer you to the early support or child development unit in your area.

Child Development Units (CDUs)

<p>Bury Child Development Centre Fairfield General Hospital Rochdale Old Road Bury BL9 7TD Tel: 0161 778 3031 janet_hardman@pat.nhs.uk</p>	<p>Bolton Bolton PCT Halliwell Health & Child Development Centre Aylesford Walk Halliwell Bolton BL1 2UT. Tel: 01204 463500</p>
<p>Manchester Manchester Contact Centre for Social Care Services Tel: 0161 255 8250 (initial contact) Referrals will be forwarded to a local specialist resource team.</p>	<p>Oldham Children with Disabilities Team Woodfield, Manchester Road Oldham OL8 4ET. Tel: 0161 627 1749</p>
<p>Rochdale Child Development Unit Wardleworth and Hamer Health Centre Belfield Road Rochdale OL16 2UYF</p>	<p>Salford Lynne Moody Early Support Team Larkhill Children's Centre Sedgefield Close Salford M5 4JL Tel: 0161 921 1382 lynn.moody@salford.gov.uk</p>
<p>Stockport Julie Dempsey Senior Nurse Practitioner Child Development Unit Ground Floor Tree House Children's Centre Stepping Hill Hospital Poplar Grove Stockport, SK2 7JE. Tel: 0161 419 2063</p>	<p>Tameside Child Development Unit Rowan House Grange Road South Hyde SK14 5NY</p>
<p>Trafford Trafford Early Development Service (TEDS) 70 Chapel Road Sale M33 7EG Tel: 0161 872 4333</p>	<p>Wigan Mary Sheridan Centre Leigh Infirmary Leigh WN7 1HS</p>

If your child is referred to an individual professional, it is important that the professional is experienced in diagnosing ASD. The GP should try to refer you to someone who can help establish what is causing your child's difficulties, whether an ASD or something else. A formal diagnosis is the way to access the provision that your child needs. The NAS Helpline has written an information sheet explaining how to complain if you are unable to get a referral to a professional able to diagnose ASD. Please contact us if you would like a copy.

Private assessments

Some parents feel that they would rather pay to see someone privately. This can reduce the amount of time that the family have to wait for the assessment to take place. Parents often ask how much a private assessment will cost. This can vary. It is a good idea to phone a number of services to ask about costs, what this pays for and whether any follow up service is offered.

There are occasions where local authorities such as the social services department and local education authority has not recognised a private diagnosis. We suggest that you try to get a referral through the statutory authorities and stay on the waiting list for an assessment even if you do decide to pay privately to avoid any future disputes.

What to expect on the day

It is important to emphasise that local professionals will have different procedures for assessment after the referral by a GP. In the areas where a multi-disciplinary team carries out separate assessments, these are then brought together by the team leader who may be any member of the team. In some areas, you may only see one relevant professional. The whole assessment may be carried out in a variety of ways – it depends on the service. Assessors may use a variety of diagnostic tools, checklists and observations in order to make their diagnosis.

The *National autism plan for children (NAPC)* recommends that other assessments as well as a developmental history are carried out at the time of diagnosis.

The diagnostic report

It is hoped that a diagnostician or diagnostic service would provide you with a detailed report containing both findings and recommendations for support. It is important that the diagnosis is clearly stated. Phrases such as 'has autistic tendencies' are not very helpful because they imply that the child does not have an Asperger Syndrome or another ASD. This can cause problems when trying to access ASD-specific support. Sometimes the report is given at the end of the assessment, at other times it is typed up and sent later.

The professionals should give you plenty of time to ask questions. If you do not understand any part of the report or anything that the professionals say to you during the whole assessment do not be afraid to ask for clarification. This may even mean phoning back a few days later. Medical professionals can sometimes presume patients understand the medical jargon that they use. The NAS Helpline often receives calls from parents who do not understand parts of their child's report. However, as they are not qualified diagnosticians they are often unable to clarify the content of any professional reports. It is therefore important to ring the diagnostician's office if you require further explanation.

If you are unclear about what you read in the report you receive, you may also find it helpful to read the article that Lorna Wing has written which helps to explain diagnostic labels. It can be accessed using the following link www.autism.org.uk/labels or by contacting the NAS Helpline: Some professionals offer follow-up. What this includes varies, depending on the service. Sometimes it can be regular visits to monitor progress, while with others it is simply telephone advice.

Further Information

National Autistic Society Helpline Information Sheet 'Diagnosis; What To Expect'

The NAS Autism Services Directory: www.autismdirectory.org.uk lists professionals who have given their details as being experienced in diagnosis. Many of these diagnose as a member of a team, but some practise as individual diagnosticians.

Under the **NHS Patients Charter** you are entitled to seek a second opinion regarding your child's care. This might include asking to see another professional for diagnosis. Telephone free on NHS Information line 0800 665544 for advice.

If the GP decides not to refer on, you may wish to discuss with the **National Autistic Society**
Autism Helpline Tel: 0808 800 4104

Why opportunity for diagnosis is important

Asperger syndrome is a recognised condition, and is described in both ICD-10, and DSM-IV international classification systems. If someone meets the criteria they should have the opportunity to be diagnosed.

Diagnosis enables parents and the child to make sense of their history, often marked by experience of disadvantage and others' misunderstanding.

Diagnosis enables parents make necessary adjustments for their future of their child.

Diagnosis can help others - families, friends, siblings, and school staff to better understand and cope with the child's needs, and behaviour.

Diagnosis can help parents locate local support groups, and get more appropriate support from schools, educational authorities, leisure and other organisations.

If you or someone you care for is experiencing difficulty getting a diagnosis please contact **The National Autistic Society Family Services Development Project**
Tel: 0161 998 4667.

Other people who may be able to assist with assessment for diagnosis:

There is a free diagnostic service based in London at the **Behavioural/Genetics Clinic** Tel: **0203 228 4847** website www.national.slam.nhs.uk/bgc

Dr Lorna Wing and Dr Judith Gould
Centre for Social and Communication Disorders,
Elliot House
113 Masons Hill
Bromley
Kent BR2 9HT
Tel: 0208 466 0098

Professor Pat Howlin
St Georges Hospital
London
Tel: 0208 725 5604

Michael Rutter Centre for Children and Young People
London Tel: 0207 919 2535

Dr Meera Roy, Birmingham-based
Tel: 0121 255 8000

Vicky Bliss
The Missing Link
Clarks Cottage
Union Lane
Pilling

Lancashire PR3 6SS
Tel: 07971 569042
Email: feedback@missinglinkssupportservices.co.uk

Mr. Barry G Holland St. Helens based
Consulting Psychologist in ASD
Telephone number: 0784 597 8760
Email: asdpsych@btinternet.com

National Autistic Society Directory of Services website www.autismdirectory.org.uk contains an up to date list of qualified clinicians who offer a diagnostic service.

What If Your Child Is Refused A Diagnosis

If you feel your child has an autism spectrum disorder (ASD) and:

- they have been refused a referral to a diagnostician by your GP
- they have been refused a referral to a diagnostician of your choice
- a diagnostician has refused to assess your child.

You have the right to make a complaint to the NHS. (If you have complaints about private diagnosticians they should have their own complaints procedure as required by the *Care Standards Act 2000*.)

Time limits for making a complaint

You should make your complaint as soon as possible. The time limit for complaints is usually six months from the date the matter you are complaining about happened, or six months from the date that you first became aware of the problem.

These time limits can be overlooked if it would be unreasonable to expect you to have complained within six months, for example because of grief or trauma. However, it must still be possible to investigate the complaint.

You cannot use the NHS complaints system to get any financial compensation. If you are seeking financial compensation you will need to get independent legal advice

Complaints Procedure

Local Resolution

Complaints about any service provided by the NHS should first be addressed to the practitioner concerned.

Firstly, contact the practice, hospital or health trust concerned and ask for a copy of their complaints procedure. You should also ask why you have been refused a referral or assessment and whether the decision is based on clinical or financial grounds. You could request this information over the phone or in writing. Additionally it might be useful to ask for access to your medical records, under the *Access to Health Records Act 1990*.

A large service will probably have a designated person who deals with complaints while smaller ones may not. However, every NHS service will have a complaints procedure and someone who is responsible for it.

State that you expect acknowledgement of your letter within two working days and a response within ten working days. Hopefully your complaint will be resolved at this level.

If, after ten working days, you have not received a reply from the service concerned you should write to remind them that you requested a response and ask them to explain the delay.

If, after 10 working days, you still do not receive a response or you are not happy with the response you received, you could write a letter to the chief executive of the local health authority. Your local NHS trust's Patient Advice Liaison Service (PALS) should be able to supply you with this person's name and address as well as providing general advice on making complaints about NHS services. You should explain in your letter to the chief executive that your child has been refused a referral or assessment and that you feel that your child has an ASD. You should also explain that you have not received a satisfactory reply from the service involved and that if the matter is not resolved you will have no option but to request that the matter is investigated independently.

Independent investigation

If you do not receive a reply to your first letter of complaint within twenty working days, or you are not happy with the response you did receive, you could ask the Parliamentary and Health Service Ombudsman to investigate the matter.

Further Information

National Autistic Society Helpline Information Sheet 'Complaints about the NHS- children's procedure'

After Diagnosis What next?

Receiving a diagnosis of Asperger Syndrome can be a relief for some parents, but for others it is a big shock. In either case moving on from a diagnosis can seem daunting and many people wonder what to do next.

NAS brochures:

- ‘**After Diagnosis**’ outlines the services and support for children with a diagnosis of autism and their parents and carers.
- ‘**Asperger’s Syndrome – from diagnosis to solution – a guide for parents**. A cheerful introduction to the condition, with lots of helpful strategies and advice. A really good starting point for parents and carers of children who have just had a diagnosis, with helpful pointers to moving on.

This document (AS Inform) contains details of known services and support in the Greater Manchester area.

The NAS also provide an online service called **Signpost** (www.autism.org.uk/signpost). After you have entered some basic information about your child and their diagnosis you will be presented with personalised information relevant to your child’s age, diagnosis and the area that you live in. This can be a starting point for accessing support from the local authorities and for meeting others in your area with a child with an ASD.

EarlyBird and Help!

The NAS run four post diagnostic programmes: EarlyBird (for parents of children under school age), EarlyBird Plus (for parents of children aged 4-8 with a later diagnosis), *help!* (for parents of children of school age and above) and *help!2* (a series of seminars focusing on ASD-related topics). See separate section elsewhere in this document.

Parent Support Groups

You may find it useful to attend a parent support group. This will give the opportunity for you to talk to other parents who have children diagnosed and can offer and share advice based on their own experiences. Many also have a telephone help line. See separate section for details.

Telling A Child About Their Diagnosis

When should I tell my child they have an Asperger Syndrome

It is a very personal decision as to when families decide to tell a child about their diagnosis – it all depends on personal circumstances. Some children are told when they are young as they become aware of their differences. In other cases parents/carers feel they should wait until their child is a little older so they will understand the diagnosis better.

How should I tell my child about their diagnosis?

There is no one right way of telling a child. However, there are some points you may want to consider. Firstly, who is the best person in the family to help bring up the subject? If your child is comfortable with a grandparent or aunt, they may be a good person to get involved, too. Secondly, make sure that when you do tell your child, you are both in calm moods and in a place where you both feel comfortable as children with an ASD can find it difficult to process new information. Their ability to process is even lower when they have high levels of stress. As a result, they may find it difficult to take in and understand what you are trying to tell them.

It is also important to ensure you will not be interrupted because your child may need extra processing time to think or to ask questions about what you have told them. Siblings interrupting in the middle of this could lead to unnecessary frustration.

What if my child wants to meet other children with an Asperger Syndrome?

Some children find it helpful to meet other children with similar difficulties and to learn that they are not alone. There are a number of social groups around the country. The NAS runs social programmes for the over 16s and there may also be an NAS branch or other parent support group near to you where you can meet other families. Details of these can be found in the NAS our directory www.autismdirectory.org.uk. Alternatively, you can contact the Autism Helpline on 0800 800 4104 for details of services.

Are there any books or resources that could help explain Asperger Syndrome to my child?

After your first talk, your child may have some ongoing questions. They may benefit from reading some books on the subject. There are now accounts written for children of varying ages:

4-9 years

- **I am utterly unique: celebrating the strengths of children with Asperger syndrome and high functioning autism** by Elaine Marie Larson

8-12 years

- **Different like me. My book of autism heroes** by Jennifer Elder This book is about famous people who may have had an ASD. It talks about the achievements of people such as Albert Einstein, Kandinsky etc.
- **What is Asperger syndrome and how will it affect me?** A guide for young people. Written by members of the NAS Helpline, this booklet explains Asperger syndrome in simple jargon-free language. It also offers helpful contacts and strategies for making life more comfortable.
- **I am special: introducing children and young people to their autistic spectrum disorder** by Peter Vermeulen. Aimed at young people over the age of ten with autism spectrum disorder, this workbook is designed to be worked through with an adult - parent, teacher or other professional. The content and layout are devised especially for children who process information differently.
- **Finding out about Asperger syndrome, high-functioning autism and PDD** by Gunilla Gerland, published by Jessica Kingsley Publishers. Gunilla's book can be helpful to all young people who receive a diagnosis of Asperger syndrome, PDD or high functioning autism. It will also be of interest to their peers in school, siblings, and other children.
- **Asperger Syndrome, the universe and everything** by Kenneth Hall. Written by a 10 year old with Asperger Syndrome, Gives a first hand account of what it's like to have A.S.
- **I Have Autism – What's That** by Kate Doherty, Paddy McNally and Eileen Sherrard

What else could I do if my child feels anxious about the diagnosis?

It is important to keep lines of communication open. Some children may have further questions but not want to ask them face to face. Having a question box, diary or email system can make it easier for some children to ask personal questions. It also gives them more time to process the answer or think of more questions.

Further Information

National Autistic Society Helpline Information Sheet 'How To Tell Your Child'

Pike, R. (2008). *Talking together about an autism diagnosis: a guide for parents and carers of children with an autism spectrum disorder*. London: The National Autistic Society

Getting Help - NAS Programmes

Following a diagnosis of an autism spectrum disorder, many parents and carers feel isolated and unaware of what to do next. By providing information on communication, behaviour strategies, education, and accessing services and benefits, parents are able to see the most effective ways to support and advocate for their child now and in the future.

- **EarlyBird (pre school children)**
- **EarlyBird Plus (4-8 year olds)**

EarlyBird is a programme developed specifically for parents and carers of pre-school age children with autism spectrum disorders. EarlyBird is a three-month programme which combines group training sessions for parents with individual home visits when video feedback is used to help parents apply what they learn, whilst working with their child.

Parents have a weekly commitment - to a two-and-a-half hour training session or a home visit, and to ongoing work with their child at home - during the three-month programme.

The EarlyBird programme aims:

- to support parents in the period between diagnosis and school placement
- to empower parents and help them facilitate their child's social communication and appropriate behaviour within the child's natural environment
- to help parents establish good practice in handling their child at an early age so as to pre-empt the development of inappropriate behaviours.

The EarlyBird programme draws from well-established practice in the field of autism. The approaches used include:

- the NAS SPELL approach
- techniques from the TEACCH approach
- Picture Exchange Communication System (PECS).

EarlyBird Plus is similar to EarlyBird but is for parents and carers of children aged 4 to 8.

Contact

For further information on local programmes contact EarlyBird (details below) visit www.info.autism.org.uk or contact your local authority.

Many of our local authorities including Bolton, Oldham, Salford, Tameside, Trafford and Wigan have teams trained on delivering EarlyBird programmes.

Jo Stevens
Director
NAS EarlyBird Centre
Barnsley Road
Dodworth
Barnsley S75 3JT

Tel: 01226 779 218
Fax: 01226 771 014
E-mail: earlybird@nas.org.uk

- **Help! (for children 5 and over)**

The NAS *help!* programme (including the *help!* 2 seminars) provides parents and full-time carers with information, advice and support. It helps develop an understanding of autism spectrum disorders and positive strategies, as well as knowledge of rights, benefits and local support services. It is run by locally based trained NAS staff.

The *help!* programme is about sharing of information, experiences enabling learning together to reduce parental isolation. The programme uses the most up to date information, delivered simply and clearly by a dedicated and experienced team of ASD knowledgeable practitioners.

The information provided on *help!* programmes is well researched, and evidence based. Over 10000 parents have attended and helped shape the programme by contributing material and ideas themselves, making sure *help!* tips and strategies remain relevant, practical and easy to use. All material is continuously monitored and reviewed to ensure it is up to date and clearly expressed.

The NAS *help!* programme was developed to run alongside the NAS EarlyBird programme with the additional emphasis on helping parents understand their rights to services and how to access support from local professionals. It is also aimed at parents of school aged children and older. It is not about training parents – it is a structured programme of information, support and advice to parents.

The NAS also offer the *help!* seminars for parents and carers of children and young people with ASDs who already have some basic knowledge of autism. The seminars offer practical advice on issues such as managing anger, bullying, supporting siblings and using visual supports.

Up to fifteen families can attend each *help!* seminar. The seminar include presentations, group discussions, DVD material and practical activities.

All the programmes and seminars can be purchased by a local authority or NHS trust.

Applying for a place on a help! programme

For more details of seminars coming up, and to book a place, contact

The Family Support Seminars
Tel: 07425 624 592 (normal call charges apply)
Family Service Seminars Administrator
EarlyBird Centre
Barnsley Road
Dodworth
Barnsley S75 3JT Email: help@nas.org.uk

If you telephone and get a voice mail message, please leave your contact details with your name and telephone number, spelling any difficult words. The *help!* administrator will get back to you.

Commissioned seminars

The NAS can be commissioned to deliver a seminar for parents in your local area for up to fifteen families. Contact the Family Support Seminars team (number above) for more details.

Further Information

National Autistic Society Helpline Information Sheet 'National Autistic Society *!help* programme.'

MEDICAL

What Is Asperger Syndrome?

Asperger Syndrome is a form of autism, which is a lifelong disability that affects how a person makes sense of the world, processes information and relates to other people.

Autism is often described as a 'spectrum disorder' because the condition affects people in many different ways and to varying degrees.

Asperger Syndrome is mostly a 'hidden disability'. This means that you can't tell that someone has the condition from their outward appearance. People with the condition have difficulties in three main areas. They are:

- **Social Communication**

People with Asperger syndrome sometimes find it difficult to know what to say to other people and what they are saying to you

- **Social Integration**

Knowing what to do when you are with other people

- **Social Imagination**

People with Asperger syndrome can be imaginative, for example, many are accomplished writers artists and musicians. However they can have trouble with pretend play, make believe and fantasy

These are often referred to as 'the triad of impairments'.

While there are similarities with autism, people with Asperger syndrome have fewer problems with speaking and are often of average or above average intelligence. They do not usually have the accompanying learning disabilities associated with autism, but they may have specific learning difficulties. These may include dyslexia and dyspraxia or other conditions such as attention deficit hyperactivity disorder (ADHD) and epilepsy.

With the right support and encouragement people with Asperger syndrome can lead full and independent lives.

Further Information

National Autistic Society Helpline Information Sheet 'What is Asperger Syndrome and How Will It Affect Me' A Guide for Young People

Associated Difficulties often seen in Children with Asperger Syndrome

Sensory Difficulties

Children with Asperger Syndrome may have sensory difficulties. These may occur in all or one of the senses (sight, sound, smell, touch or taste). The degree of difficulty varies from one individual to another. Most commonly, an individual's senses are either intensified (over sensitive) or under

developed (under sensitive). For example, bright lights, loud noises, overpowering smells, particular food textures and the feel of certain materials can be a cause of anxiety and pain.

If you think your child is particularly sensitive to noise you should take them for a hearing test.

Further Information

National Autistic Society Information Sheets

The Sensory World Of The Autism Spectrum – A Greater Understanding Autism Spectrum Disorders and hearing impairments

**Book : K. Wilkes (2005) *The sensory world of the autistic spectrum: A greater understanding*
(NAS: London)**

Motor Coordination

Some children have difficulties with motor imitation and control. For example, they may have an odd posture or springy tiptoe walk. Some children may appear clumsy and have difficulty differentiating between left and right and up and down.

Also they may also find it harder to carry out fine motor skills such as tying shoelaces or have poor hand –eye coordination.

What Causes Asperger Syndrome?

The exact cause of Asperger Syndrome is still being investigated. However, research suggests that a combination of factors – **mostly genetic but with some environmental factors** – may account for changes in brain development.

Asperger syndrome is not caused by a person's upbringing, their social circumstances and is not the fault of the individual with the condition.

Vaccinations

Substantial scientific evidence indicates that there is no statistically significant link between the MMR vaccine, or any other vaccine, and Asperger syndrome.

Further Information

National Autistic Society Helpline Information Sheet 'Autism and Genetics'

Is there a cure?

There is currently no cure and no specific treatment for asperger syndrome. Children with Asperger syndrome become adults with Asperger syndrome. However, as our understanding of the condition improves and services continue to develop, people with Asperger syndrome have more opportunity than ever of reaching their full potential.

Related/Associated Medical Conditions

There are some other medical conditions which appear to affect the same parts of the brain as Asperger Syndrome, and are often diagnosed alongside Asperger Syndrome in younger children. Your child's diagnosis may include reference to these conditions.

There are others which although separate conditions, appear to have a higher incidence in people with Asperger syndrome than in the general population.

Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD)

ADHD is a sub-category of the condition ADD, which is an emotional and behavioural difficulty characterised by extreme inattentiveness, impulsiveness and motor activity.

Many children with ADHD often experience associated problems with reading and writing abilities and sometimes coordination difficulties.

Many children with Asperger syndrome display signs of hyperactivity and inattention when they start school. However, experts are very clear that as the child becomes older the apparent similarities between the two conditions will separate out. The child with autism may become more withdrawn and given the right environment their hyperactivity should wane and their difficulties with social skills will emerge. Children with ADHD on the other hand are unlikely to become calmer with age unless they receive medication or high quality therapeutic interventions. They still develop social and communication skills and are unlikely to have the anxiety levels of a child with autism.

Dyspraxia

Dyspraxia is a lifelong condition in which a person's movement and co-ordination are affected so that both are difficult. This can include co-ordination of both fine and gross motor skills. For example, the co-ordination of fine movements for fiddly tasks such as tying shoelaces or the co-ordination of big movements of the limbs such as running, hopping or throwing and catching.

Someone who has dyspraxia will often also show difficulties with sequencing and language, and maintaining attention.

Dyspraxia is a separate condition to an ASD, however it is possible for a child to be diagnosed with both conditions. For both conditions, early recognition and intervention are important to provide the best support for the child.

Pathological Demand Avoidance (PDA)

Pathological Demand Avoidance syndrome (PDA) is a pervasive developmental disorder. PDA is related to, but separate from, what is currently termed the autistic spectrum, namely autism and Asperger syndrome. Individuals with PDA are typically socially manipulative with people, and are thus superficially socially skilled, which sets them apart from autism and Asperger syndrome.

Pervasive Developmental Disorder (PDD)

This term originally was used by the American Psychiatric Association. PDD, like ASD is an umbrella term that covers autism and Asperger Syndrome, but also covers related conditions such as Rett's syndrome and Fragile X syndrome.

Semantic Pragmatic Disorder (SPD)

SPD is a language disorder that affects semantic processing and the pragmatics of language use. Pragmatics refers to the use of language in a social context (knowing what to say and when to say it to people). Semantics refers to the meanings of words and phrases.

Further information:

- **NAS Dyspraxia and Autism Spectrum Disorders fact sheet**
- **NAS Pathological Demand Avoidance (PDA) fact sheet**
- **NAS Pervasive Developmental Disorder (PDD) fact sheet**
- **NAS Semantic Pragmatic Disorder (SPD) fact sheet**
- **Jargon used around Autistic Spectrum Disorders fact sheet**

These fact sheets are available from the Autism Helpline.

Other Medical Conditions

There are other medical conditions which although separate unrelated conditions, appear to have a higher incidence in people with Asperger syndrome than in the general population. The relationship between these conditions and the autism spectrum are not yet fully understood. These include:

- Epilepsy
- Downs Syndrome
- Tourettes Syndrome

Further Information

The NAS produce fact sheets on these and a number of other rarer associated disorders. Contact the NAS Helpline.

LIVING WITH A CHILD WITH ASPERGER SYNDROME

Behaviour Management

Some children with autism spectrum disorders exhibit challenging behaviour. This is a complex issue and it would be helpful to consult books in the recommended reading section for an in-depth look at the subject. Most behaviour problems are as a result of the communication difficulties experienced by those on the autism spectrum, and therefore it is important to consider what the function of the behaviour is and look at ways to enable the child to communicate this appropriately through words or signs as an alternative to the behaviour. Below are some very general guidelines.

- Try to incorporate some sort of routine and structure in to your child's day. Make sure your child understands what is happening next. The use of photographs or picture symbols can be particularly effective for this.
- Keep to your word. Once you have agreed to something with your child it is important to try to keep to it. Extreme anxiety can occur when something they expect to happen does not.
- Try preventative measures. For example think of things to distract the child from whatever may be upsetting them.
- Encourage your child to go out in to the garden or somewhere safe when they are becoming angry or upset. Make sure that they can get there easily without encountering too many obstacles on the way.
- Channel behaviour positively.
- Listen to your child. Children with Asperger syndrome are often able to express in some way to you what is upsetting them. This may occur at the time or in many cases hours or even days later. Observe your child's behaviour and see if you can notice any patterns. What are they trying to tell you?
- Consider the iceberg effect. You may see a particular behaviour, but the underlying reason may not be clear. When a child starts behaving differently assess if there have been any changes in the child's routine or environment at all.
- Choose the right incentives. Think of things to motivate your child to behave. What things do they enjoy? What will they find rewarding? For some children using whatever their obsessional interest is can be particularly rewarding. So for example if your child really enjoys watching Thomas the Tank Engine videos allow him or her to watch this after they have done something good or behaved well.
- Be consistent. Whatever strategy you choose to use with your child it is essential that you are consistent. To be successful, all those involved with your child should use the same strategy and language in response to your child's behaviour. It is very important that children with autism have clear boundaries.

Further Information

National Autistic Society Helpline Information Sheet 'Understanding Behaviour'

Books

The Red Beast: controlling anger in children with Asperger Syndrome by K.I Al-Ghani. Offers a range of anger management strategies for primary age children.

When My Autism gets too big! by Brenda Smith Myles and Kari Dunn Buron. Helps children understand their Autism and what to do when overloaded with stress.

Autism: Understanding and Managing Anger by Andrew Powell. Aimed at parents and carers of children with Asperger syndrome and high-functioning autism - talks about why children with autism become angry and some practical ways in which you can help, including preventing and managing anger; coping with meltdowns; and helping your child to manage their feelings.

Communicating

Certain styles of communication seem to be particularly effective with children with Asperger syndrome

- Have your child's full attention when you speak to them. Use their name so they know you are talking to them. Try to reduce any background noise for example the TV or radio when speaking to your child so they can focus on your words.
- Keep language simple. Only use necessary words. For example instead of saying *'would you please come over here and sit down on the chair'* try saying *'Jack, sit down'*
- Don't make promises you may not be able to keep.
- Children with autism often have a very literal understanding of language, and therefore can become very confused and sometimes distressed if sarcasm or irony is used. You should also try to avoid using phrases such as *'frog in your throat'* *'I laughed my head off'* *'give me a hand'* etc.
- Use concrete terms, particularly with reference to time. For example instead of saying *'we will go to the shops later'* try saying *'we will go to the shops at 3pm'*, or if the child can not tell the time say *'we shall go to the shops after lunch'*.
- Be positive, don't just tell your child what they shouldn't be doing but instead tell them what they should be doing. For example instead of saying *'don't throw your toys all over the floor'* say *'put your toys in the toy box'*
- Provide extra thinking time for information to be processed. Some people with autism may process auditory information differently or more slowly than other people. Therefore it may be necessary to allow extra time for a person with autism to respond to a request or question.
- Use visual supports. Some people with autism appear to have particularly strong visual skills and may understand information that is presented visually to them better than information processed through spoken language. There are a variety of options that can be used to help children to communicate in this way. For example you can use photographs or symbols to communicate what is happening next to ease anxiety. (The following web site has over 300 picture cards which can be printed off <http://www.dotolearn.com>)

Disciplining the Child with Asperger Syndrome

Children with Asperger Syndrome may need guidance on appropriate behaviour.

- **Does your child understand what they have done wrong?** Make sure they know what they have done is wrong and why. So for example instead of saying *'You have been naughty today'* say *'You took your sisters sweets, they are not yours'*
- **Focus on behaviour not the child.** Tell your child if you are unhappy with what they have done, not what they are. So for example don't say *'You are naughty'* but make it clear that what they did was wrong.
- **Be aware that your child may not learn from experience.** They often have great difficulty applying what they have learnt in one situation to another. Your child may require very clear and consistent instructions.
- **Reinforce good behaviour.** Try to reward good behaviour and where possible ignore the bad behaviour. Any attention, even being told off can be rewarding for a child.

- **Special circumstances.** There may well be times, no matter how well behaved your child is, when they misbehave. A deterioration in behaviour may well be seen in times of anxiety, for example if there is a change in routine or in the environment no matter how small.

Getting Help

- **EarlyBird.** Courses for parents of pre-school aged children with a diagnosis. See details in earlier part of this document
- **HELP! A** training programme for parents of recently diagnosed school aged children, See details in earlier part of this document
- **Local support groups** for details contact the NAS Autism Help Line or look at the NAS online database at www.info.autism.org.uk)
- **NAS Autism Help Line**, call 0808 800 4104 (Mon- Fri, 10am – 4pm) or email autismhelpline@nas.org.uk

Creating A Friendly Environment

- Some children on the autism spectrum are hypersensitive. Where possible use soft lighting and avoid fluorescent and harsh lighting which may be distracting. Children with autism may also be hypersensitive to noise, whilst being quite noisy themselves. Furnishings can help reduce noise levels in your home, for example carpet may be better than laminate flooring.
- It has been suggested that people with autism find it helpful if furniture is kept to the peripheries of the room, and the middle space kept clear. Using colours that distinguish walls, floors and furniture make rooms easier to navigate for children with autism. Furnishings should be plain in colour, as patterns can be confusing to walk across and may increase anxiety.
- Cosy chairs, dens, bean bags and duvets can all help to make children feel calmer and safer.
- Make sure your house is safe. Some children may try climbing out of windows or running out of the front door into the road as they often have very little sense of danger. If your child does have a tendency to run out of the door there are alarm systems available. For details contact the NAS Autism Helpline.
- Don't have any poisonous substances in the house, including plants.
- Have locks on cupboards
- A child with autism can need their own privacy and personal space like any other child. Try to ensure that there is a safe place for them to be alone.
- If possible, create space to exercise both inside and out the house. Trampolines in particular are very popular with children with autism.
- It may be helpful to have visual supports for your child around the house. For example a picture timetable of what is happening during the day. For further information see the NAS fact sheets listed below

Preparing A Child with Asperger Syndrome for Change

A child with Asperger Syndrome thrives from being in a familiar environment with routine and structure. However some changes in life such as going to a new school are inevitable. As soon as you know what the change involves, start to prepare them. This may mean that, as parent or carer, you have to be proactive in finding out what is involved in a specific change. For example, if you know your child finds certain changes at school difficult such as changes to PE lessons, you may need to talk to the school. If possible, find out when exactly changes are going to take place, what is involved and if a different PE kit will be needed.

If the child is going to a new school, or on a holiday, perhaps flying abroad, it's important that you prepare and brief staff about the things that the person finds difficult or may become anxious about

Further Information

National Autistic Society Helpline Information Sheet: Change: Preparing a person with an autism spectrum disorder for change

National Autistic Society Booklet 'Environment and Surroundings – How to make them autism friendly' by Anh Nguyen

Obsessions, Repetitive Behaviours And Routines

Obsessions, repetitive behaviours and routines are key features of autism spectrum disorders. The way these characteristics present will vary substantially from person to person and will be influenced by the individual's level of development and functioning, and their particular areas of interest.

Obsessions

Obsessions can cover a diverse range of topics dependent on the individual's particular areas of interest and level of ability. Thomas the Tank Engine, dinosaurs or cartoon characters can be common obsessions for younger children with autism spectrum disorders. Other topics may include computers, trains, historical dates or events, pop or movie stars, the military, sports or science. Sometimes an individual may develop obsessions in unusual subject areas such as car registration numbers, bus or train timetables, postal codes, traffic lights, numbers, shapes or particular body parts such as feet or elbows. Some people will remain interested in one area for their entire lives; others develop interests in new areas after particular time periods. Obsessions generally differ from other interests in their intensity (i.e. how much an individual will learn about a particular area and how strongly they feel about it) and their frequency and duration (i.e. how long a person will spend on their area of interest). Obsessions can be very intrusive in an individual's life and limit the person's involvement in other activities.

Another common characteristic of autism spectrum disorders is an attachment to particular objects. These may be particular toys such as figurines or model cars, or more unusual objects such as milk bottle tops, stones, shoes or bath plugs as described in the above example. Other individuals develop an interest in collecting items. These may vary from Star Trek videos and travel brochures to insects, leaves or bus tickets. As with other obsessions it is the intensity, frequency and duration of an individual's interest in a particular object or collection that distinguishes it.

Repetitive Behaviours

Repetitive behaviours are often observed in children who have more severe autism diagnoses, but do occur in children with Asperger syndrome.

Such behaviours may include arm or hand flapping, finger flicking, rocking, jumping, spinning or twirling, head banging and complex body movements. They may also include a preoccupation with parts of objects (such as the spinning wheels of toy cars), repetitive use of a particular object, such as the flicking of a rubber band or the twirling of string, or repetitive activities involving the senses (such as repetitive smelling, feeling of particular textures, and listening to different noises).

Routines

Many people with an autism spectrum disorder, of all ages and levels of ability, have a strong preference for routines and sameness. The individual may have a need for routine around particular daily activities such as mealtimes or bedtime, and may experience great distress if the routine is disrupted. Routines can become almost ritualistic in nature needing to be followed very precisely, with attention paid to the tiniest details. There may be a need to engage in a series of behaviours in an exact and almost compulsive way and the individual may become extremely distressed if interrupted before the completion of the ritualistic routine. Some individuals may develop compulsive behaviours such as constantly washing their hands or checking locks, others may have obsessional thoughts regarding distressing topics such as death, illness or making mistakes (Howlin, 1998). Rituals may also be verbal in nature, and may involve the individual repeatedly asking the same question and requiring a specific answer.

The individual may find changes to their physical environment (such as the layout of furniture in a room) or the presence of new people/absence of familiar ones very difficult to manage. Even those changes to routine that others may enjoy such as holidays or birthdays can cause anxiety for a person with an autism spectrum disorder. Sometimes minor changes such as transitions between two activities can be distressing, for others unexpected changes are the most difficult to manage. Some individuals can have very specific and rigid preferences when it comes to the food they eat (such as only eating foods of a particular colour), the clothes they wear (e.g. only wearing clothes made from specific fabrics) or objects used on a day-to-day basis (such as the type of soap or brand of toilet paper they will use).

An individual's dependence on particular routines can increase during times of change, stress or illness and may even become more dominant or elaborate at these times (Attwood, 1998).

Routines can be highly intrusive in the lives of the individual, their family and carers. They can also cause extreme distress and limit the individual's experience and opportunities. However, it is important to remember that these behaviours often serve a very important function for the individual – to introduce order, structure and predictability and to assist the person to manage anxiety levels.

Responding to Obsessions, Routines and Repetitive Behaviours

- Does the obsession, routine or repetitive behaviour restrict the person's opportunities, cause distress or discomfort or impact on the individual's learning? If not, is it really necessary to intervene?
- What function does the repetitive behaviour, routine or obsession have for the individual? (i.e. what does the person get out of the behaviour?).
- Intervene early by setting boundaries around repetitive behaviours and obsessions from a young age and as they emerge.
- Increase environmental structure by using visual cues (e.g. timetables, daily planners), social stories, and pre-planning strategies to prepare for stressful events or change.
- Provide skill development opportunities including social skills training, relaxation and emotions identification training and skills to assist the individual better cope with change.

- Increase social, recreational and vocational opportunities for the person.
- Set clear and consistent boundaries around the behaviour by rationing the object, the time or the place – remember to start small and go slowly.
- Explore alternative, more appropriate activities that have the same function as the repetitive behaviour.
- Use obsessions to motivate and reward, develop skills, increase social opportunities and improve self-esteem.

Further Information

National Autistic Society Helpline Information Sheet ‘Obsessions, Repetitive Behaviours and Routines’

When and where to get extra help

Sometimes an individual’s repetitive behaviour, routine or obsession can present significant risks to the person or those around them. In these instances it is important to get specialist help to deal with the behaviour.

For further information about where and how to get extra help contact the **Children’s And Adolescents Mental Health Service (CAMHS)** in your area. Local contact numbers are found later in this document.

Sleep Issues

Learning to sleep through the night is something all children have to do. It may take a little longer for some more than others, but sleepless nights when a child is young are an almost universal problem. However, for some children learning to sleep through the night is a difficult and seemingly impossible process. This, in turn, can have an enormous impact on their families.

We must stress that helping your child to overcome their sleep disorder will not be easy. Most experts would recommend you ask for advice and support from somebody outside your immediate family. An ideal person would be an expert in sleep disorders: this might be a child psychiatrist or a paediatrician. However, getting a referral to a suitable professional can be difficult. You could approach your GP or social worker first and you might also be able to get support from your local Family or Child Development Centre.

It’s also worth talking to your child’s teachers so that they’re aware of the problems and also that they can support your child adequately. They may be able to contribute to keeping a sleep diary (see below) and you can also ask them to let you know how alert your child is during the day.

How do you define a sleep disorder?

By the age of one year most children should be sleeping through the night. If after that time your child is regularly unable to sleep or if they have a period of good sleep which is disrupted then this constitutes a sleep disorder. It’s important to be aware that all children are likely to have brief periods of poor sleep after illness, during holidays and festivals like Christmas or during periods of particular stress such as exams or if somebody close to them is ill. After events such as these a normal sleep pattern should be established again within a few days.

It’s also important to consider your own expectations: children can’t simply go to bed early and wake up late. They won’t remain asleep for more than a certain period of time. There are no guidelines on how long a child should sleep; how much sleep a person needs can vary considerably. On average the amount of sleep a child needs per night decreases by a quarter of an hour per year until the age of sixteen. So a five-year-old needs an average of eleven hours sleep a night and a sixteen-year-old needs an average of eight and a half hours a night. But these aren’t

hard and fast figures and you may have a sixteen-year-old who needs ten hours sleep a night or a five-year-old who only needs seven.

What can we do?

Establishing a routine

Children with Asperger Syndrome respond well to routine and structure because it allows them to feel safe and in control. Although sticking to routines can be frustrating during the day, setting up a routine that fits in with your family's needs and helps your child feel calm by the time they go to bed could be very helpful. To do this effectively you will need to look carefully at the routine your family follows at the moment. Things to look for include:

- Is it possible for you to eat dinner at the same time each night? Do you do this already? Is this quite late in the evening or quite early?
- Is it possible for your child to have a bath at the same time each night?
- Is there anything about your child's routine that can only be done in your home? This could be something like playing on a particular climbing frame or having their own space for 'time out' in the evenings.

Essentially an evening routine needs to be fairly simple, with scope for flexibility. This means if you go away for a break, or your child does, then the bare bones of it can still be preserved.

Whatever routine you try to impose needs to be something you feel comfortable implementing, and that your family can agree on. It may take several weeks for it to alter your child's sleep patterns. It can help to present this routine visually, using a timetable for instance, so your child knows exactly what to expect, including getting up in the morning. Also if the routine needs to be altered, it can be explained visually. It may be that your child's timetable needs to be more detailed so that they are told exactly what to do when going to bed, for instance, drawing the curtains, get in to bed, turn light off, lie down, pull cover over. It may also be worth setting aside time to prepare for the next day in the routine. This could include getting the school bag ready or making a list/timetable of things that need to be done the next day.

Removing stimulants from the diet

If you're already keeping a sleep diary then monitoring this should not be a problem. If you aren't, then it's advisable that you at least start keeping note of when your child sleeps so that you can monitor any improvements.

Using relaxation techniques

We all have difficulty sleeping if we're feeling wound up when we go to bed. Settling down when a lot has been happening or when we're feeling emotional can be very difficult. Children with autism may not be able to articulate their need to unwind and relax. Additionally, they may feel more anxious and confused around bedtime.

Further Information

National Autistic Society Helpline Information Sheet 'Sleep And Autism; Helping Your Child'

Cerebra Sleep Service

Cerebra is an organisation for brain-injured children and young people. They can provide information and advice on a range of sleep issues for parents of children with sleep problems from a sleep nurse. Advice can be given by telephone, post, home visits or email; this can be arranged to suit the family and the level of input required. The advice about their sleep service is located in the parent support section of their website.

Cerebra Sleep Service
Freepost SWC3360
Carmarthen SA31 1ZY
Tel: 0800 32 81 159
Email: sleep@cerebra.org.uk Website: www.cerebra.org.uk

Together Trust – Sleep Clinic

Together Trust have sleep counsellors who can help children with autism conditions and their parents deal with disturbed sleep patterns. They are hoping to establish a dedicated Sleep Clinic service.

Together Trust
Inscape House
Schools Hill
Cheadle SK8 4JE
Tel: 0161 283 4750
Email: enquiries@togethertrust.org.uk Website : www.togethertrust.org.uk

Books

Douglas, J. and Richman, N. (1984). My child won't sleep – practical advice and guidance on the common sleeping problems of young children.

Dunn Buron, K. (2003). When my worries get too big: a relaxation book for children with autistic spectrum disorders.

Toilet Training

There are many factors you need to take into consideration when deciding when it's right to start toilet-training with your child. Choose a time when you have few social commitments and are feeling relatively stress-free. Concentrate on one aspect of toilet training at a time as this is likely to be less confusing and lead to quicker success in each step.

Ideally, everyone working with your child will start toilet-training at the same time and follow your agreed approach, so make sure school, his childminder, family members and any other carers are all aware of when you're going to begin the routine, the steps to be followed and the equipment needed. Your child's behaviour may be different from usual during this time, especially when the change of routine first takes place, so it's a good idea to let everyone know why a behavioural change could occur.

Remember that the ultimate aim for your child is that he will go to the toilet independently. This may take many months but there will be many small steps and successes along the way.

Developing a toilet-training routine

Children with an autism spectrum disorder often like routine. You can build upon this desire for predictability to develop a successful toilet-training routine. Teach this as a whole routine from communicating a need to use the toilet to drying hands, rather than just sitting on the toilet. Keep the sequence of behaviours the same every time and use visual cues to support the routine. Often when a child sees that an activity is anticipated, there may be less resistance to it.

Dressing and undressing

It's important that children wear clothes that they can manage themselves while they're being toilet-trained. Trousers or shorts with elastic waistbands and skirts or dresses that aren't too long are usually the most manageable. Clothing needs to be comfortable, so beware of labels, tags or

seams that may rub. Thomas the tank engine, Barbie or other favourite brand underwear could be a great motivator for some children to begin toilet training.

Hand washing

Teach hand washing as part of the whole toileting routine. Follow the same steps each time: sleeves up, tap on, wet hands, squirt soap, rub hands together, rinse hands, turn off tap, shake hands, dry hands.

Top tips

- Giving a drink 10 – 15 minutes before toileting can help increase the chances of your child successfully doing a wee in the toilet but avoid giving too much as this creates an unnatural routine.
- You need to decide if you are going to teach your child to shut the door as part of the whole toileting routine or only in certain situations.
- Avoid using childlike terms for toileting as your child may find it difficult to change language later in life. It is not appropriate for a 20-year-old to say he is going for a pee pee.
- When your child first learns to poo on the toilet it may be easier for him to wipe himself with wet wipes rather than toilet paper.
- If your child has a fear of flushing the toilet you may wish to remove this from the visual sequence and leave it until the end of the routine – after your child has dried his hands. He then may need to stand in the door way while you flush the toilet and then gradually stand closer each time until he's able to flush it himself. Playing calming music to drown out the noise of the flush or explaining with pictures what makes the noise when the toilet is flushed may also help.
- When your child is in a car ensure he has a seat protector to sit on so that the car seat isn't soiled by accidents. Avoid drinks before long car journeys.
- Be aware that some children will hold onto their wee/poo until they have their nappy put on. For example if they know they always have a nappy on before going in the car they may wait until it is put back to release their bowel/bladder.
- There is a range of absorbent pants and swimwear for older children available
- While toilet-training you will spend more time than usual focusing on your child with autism. If you have other children you may need to put aside some extra time just for them.
- Once your child is toilet-trained at home you will want to teach him to use toilets when out in the community. When visiting new places show him where the toilets are and use the same routine as you do at home. Use the same picture and toy or book he may have for toileting at home.
- Some children smear their poo. This is a very challenging behaviour to come to terms with. There are a number of reasons your child may do this. Firstly take him to your GP to make sure there are no physical factors as to why this is happening (being in pain). He may not have understood the process of wiping and you may need to teach him 'hand over hand'.
- The toilet paper could be too harsh for sensitive skin so using wet wipes may be easier. Some children enjoy the feel of smearing: in this case provide other acceptable activities which give the same feeling such as finger painting, gloop (cornflour and water) or playdough

- Some children may see clearing up after they have smeared as a reward particularly if they like water or receive lots of attention from their carer. Even if the carer is reprimanding them it can still be seen a reinforcement. Use minimal interaction and alternative clean up methods such as baby wipes or a tepid shower.
- If your child is learning to use the toilet in another setting as well as at home, e.g. school, send in any equipment you use at home, for example a toilet seat he may use to make the seat smaller. Also remember to send spare clothes, plastic bags to put any wet clothes in and wet wipes. It is important that you have clear lines of communication during this time, so having a home/school book to share concerns and successes is vital.

Further Information

National Autistic Society Helpline Information Sheet 'Toilet Training'

ERIC (Education and Resources for Improving Childhood Continence)

Helpline providing advice and information to children, parents and health professionals on all aspects of toileting 0845 370 8008 (Monday – Friday 10.00am – 4.00pm)

Specialist ASD adviser available Thursday and Friday) www.eric.org.uk

36 Old School House,
Britannia Road
Kingswood,
Bristol BS15 8DB
Tel: 0117 960 3060

Specialist Resources

ERIC sells a range of bedding protection, swimwear, absorbent pants and vibrating watches.

Webshop tel: 01173 012 101

Email: sales@webshop.org.uk

Website: www.ericshop.org.uk

Fledglings is a charity which helps parents and carers of a child with special needs of any kind to find simple, affordable solutions to practical problems.

Telephone number: 0845 458 1124

Email: enquiries@fledglings.org.uk

Website: www.fledglings.org.uk

PROMOCON (Promoting Continence and Product Awareness) has links to various organisations who sell toilet related products including swimwear, absorbent pants and toilet seats for older children.

Website: www.promocon.co.uk

TINKLETUNES have musical sensors in potties and musical sensors which can be used in underwear, nappies and pull ups designed to alert the child or the parent that the child has 'gone' in his potty or pants. http://www.tinkletoonz.com/special_needs.html

Dental Hygiene

As parents and carers of children with autism conditions are aware, maintaining their oral hygiene and dental health can be challenging. Sensory issues and other characteristics associated with autism can make it difficult for children to accept regular tooth brushing.

The Dental Booklet, produced by Sheffield University, is full of information and tips on how to help maintain oral health and help reduce the risk of dental problems. The booklet includes lovely illustrations which will appeal to children and includes information on:

- Tooth brushing
- Tooth decay
- Acid erosion
- Trauma
- Grinding and tooth wear
- Dry mouth
- Preparing for a dental visit
- There is also a tooth brushing chart that can be laminated and put on the bathroom wall to be completed each month.

As every child varies widely in terms of their needs, sensory issues and abilities, parents and carers can take certain tips and adapt them to their individual needs.

The booklet and tooth brushing chart are available for download from our website at www.autismgm.org.uk

Further Information

NAS Information Sheet: Dentist- Preparing For A Visit

Sex Education and Personal Hygiene

“Children learn about sex from a very young age even if we don’t talk with them about it. Many of the things they learn are incorrect, confusing and frightening. In a world where sex is used to sell cars and ice creams, and celebrities’ private lives become everybody’s business, we cannot afford not to talk to our children about sex and relationships if we’re going to help them make sense of it all.” (National Children’s Bureau, Sex Education Forum, 2003)

The above quotation is from a parent support guide that is not autism specific. It describes how important it is to speak to any child about sex education so they do not become confused and anxious. The unique difficulties of a child with an autism spectrum disorder (ASD) mean that ordinary, everyday conversation and social interaction can lead to many misunderstandings, bewilderment or upset.

Consequently, parents, like you, spend a lot of time trying to explain this chaotic and scary world to your children. Your explanations and support are even more important when talking to your child about puberty, sex and relationships.

The NAS have written an information sheet to help in this difficult area. Note that the information is aimed at the whole autism spectrum, and a variety of ages, and therefore some adjustments may have to be made for your particular child.

National Autistic Society Helpline Information Sheet ‘Sex Education and Children and Young People with Autism Spectrum Disorders’

The Information Sheet covers:

- Puberty (including menstruation and masturbation)
- ‘Private’ and ‘Public’ behaviour
- Keeping safe
- Personal Hygiene
- Sensory Issues
- Relationships
- Inappropriate Behaviour

Further Information

Crissey, P (2004). *Personal hygiene? What’s that got to do with me?*. London: Jessica Kingsley Publishers

Jackson, L (2002). *Freaks, geeks and Asperger syndrome*. London: Jessica Kingsley Publishers

Wrobel, M (2003). *Taking care of myself. A hygiene, puberty and personal curriculum for young people with Autism*. Arlington, Texas: Future Horizons Inc

Henault, I (2006) *Asperger Syndrome and Sexuality*, JKP

Attwood,S (2008) *Making Sense Of Sex*, JKP

Nichols, S (2009) *Girls Growing Up On The Autism Spectrum*, JKP

C.Gast and J Krug (2008) *Caring For Myself* JKP

MEDICATIONS AND THERAPIES

Medications

The National Autistic Society is not a medical based charity. NAS staff are not medically trained and are therefore unable to give medical feedback on any prescribed medication. We recommend that people seeking information regarding medication should consult with a medical professional, preferably one with knowledge of ASD's and where possible a professional who has a relationship with the client so they are fully aware of the individuals needs.

At present there is no specific medication that is known to be a cure or to alter the core social and linguistic features of impairment in ASD. Medication may however be prescribed for additional behavioural or mental health difficulties where behavioural intervention on its own has not been effective.

Difficulties that may be responsive to medication in conjunction with behavioural intervention

- Aggression
- Anxiety
- Depression
- Impulsivity

Difficulties that may be responsive to medication

- Hyperactivity
- Sleep disorders
- Ritualistic behaviours
- Tics/ Tourette's syndrome

Successful medication requires good communication between the prescriber and the client and the client's representative. Clients and their representative should always be clear of the benefits and potential hazards of the medication prescribed. Consistent monitoring of the client is needed with all medication prescribed. Clients should always consult with the prescriber whenever possible. If you are unable to consult with the prescriber and are in need of medication advice the following sources may be able to offer advice.

Further Information

National Autistic Society Helpline Information Sheets

- 'Medication and autism spectrum disorders'
- 'Secretin and Autistic Spectrum Disorders'
- 'Serotonin'

Tsai, L. (2001). Taking the Mystery Out of Medications in Autism/Asperger syndromes. Arlington: Future Horizons Inc.

Dietary Therapies

Diet/Vitamins

Interest in the use of diet and vitamins as a therapeutic approach for autism spectrum disorders is high. However, there is a lack of evidence to support the use of diet as an effective treatment for autism. Even where evidence is available, it is important to note that dietary approaches cannot be expected to help all individuals with a particular diagnosis: they should be viewed as complementary to other methods of management, rather than as a primary or stand alone treatment.

Safety

Before embarking on any change of diet or use of supplements, **consultation with a general practitioner (GP) or registered dietician is strongly recommended.**

Vitamins and supplements can be toxic in high doses.

The Food Standards Agency website

www.eatwell.gov.uk/healthydiet/nutritionessentials/vitaminsandminerals/

and The British National Formulary website: www.bnf.org.uk/bnf/

give further information on vitamins and supplements, including safe upper levels for supplementation.

The British Dietetic Association (BDA) warn against excluding foods without making sure that the diet remains balanced as this may lead to dietary deficiencies, weight loss and poor growth.

Some of the approaches currently being researched are described below.

These have been included to provide information on particular intervention/approach and any research connected with it, not as a recommendation. The outcome of any approach will depend on the needs of the individual, which vary greatly, and the appropriate application of the intervention. An intervention that may help one individual may not be effective for another. It would therefore not be appropriate for the NAS to recommend any one particular practice or therapy.

- **Vitamin B6 (pyridoxine) and magnesium**

Researchers have noted some children with pervasive developmental disorders (PDDs) such as autism resemble children with pyridoxine-dependent epilepsy, an impairment of vitamin B6 metabolism treated with high doses of the vitamin.

A report (Nye and Bryce 2005) concluded that use of vitamin B6 for improving the behaviour of people with autism cannot currently be supported, but more research is needed.

- **Fatty acids**

Omega-3 and omega-6 fatty acids play key roles in brain development and function. Research suggests that imbalances or deficiencies in highly unsaturated fatty acids (HUFA) of the omega-3 and omega-6 series **may** contribute to a range of behavioural and learning difficulties, and neurodevelopmental disorders including autism spectrum disorders.

Current expert opinion is that while research concerning fatty acid supplementation for other related conditions or those with some similarities to autism is interesting, further autism-specific research is required to add to our knowledge in this area.

- **Gluten-free and casein-free diet (GFCF)**

It has been suggested that peptides (compounds of amino acids linked in a chain) from gluten (present in grains and cereals) and casein (present in milk and milk products) may play a role in

autism. Abnormal levels of peptides in the urine of some people with autism have been reported in a study. This suggests that people with autism may have a condition which is causing peptides to flow directly into the bloodstream. This is often referred to as leaky gut syndrome. The peptides containing high level opioids, similar to heroin or morphine, cross the blood-brain barrier and cause problems with the nervous system. It is therefore proposed that by eliminating foods containing gluten and casein from the diet, e.g. bread, dairy, etc autistic behaviours may be reduced.

Research currently is of the opinion (Millward et al (2008)) that a GFCF diet cannot be recommended as a standard treatment for autism due to the limited data available. They recommend further randomised controlled trials in this area.

Further Information

National Autistic Society Helpline Information Sheet 'Diet and vitamins: therapeutic approaches for autism'

Dietary Management –Restricted Diet and Over Eating

Some individuals with Autistic Spectrum Disorders (ASD) can have problems relating to feeding and difficulties surrounding their diet. These dietary problems can relate to both over and under eating.

Please note that all of the following points are general and therefore we would always advise individuals or their carer's to consult with a G.P or a medical professional if they have any dietary issues.

The first step if you are concerned about the restricted diet of an individual should be to create a food diary. A food diary will hopefully be able to show possible reasons for the restricted or rigid diet. By regularly recording an individual's eating habits you will be provided with useful information about their eating pattern. In many situations it can act as a reassurance that the individual has a better and more stable diet than originally thought. Possible sample questions for the food diary could be:

- What time of the day did they eat? – *11: 05*
- What did they eat? – *Walker's Salt & Vinegar crisps*
- Where did they eat? – *In the living room*
- How much did they eat? – *Half a bag*
- Who was there? – *Mum, brother*
- Were there any environmental factors? - *Radio was on in the background*

Further Information

- **Restricted Diet**

NAS Helpline Information Sheet 'Dietary Management for Children and Adolescents with Autistic Spectrum Disorders – Restricted Diet'

This information sheet intends to provide an insight into the possible reasons for a restricted diet and basic strategies to try and overcome this problem.

- **Over Eating**

NAS Helpline Information Sheet 'Dietary Management for Children and Adolescents with Autistic Spectrum Disorders – Over Eating'

This information sheet intends to provide an insight into the possible reasons for over eating and basic strategies to try and overcome this problem.

Speech and Language Therapy

Children who have an ASD tend to have language which may be delayed or different from the language children typically develop, and parents are understandably often concerned about this.

Many children with an ASD have some degree of difficulty in all three areas of language, namely:

- **The form of language – understanding how ‘sounds’ make up words and phrases**
- **The content of language – understanding the meaning of words**
- **The use of language - the ability and intent to communicate**

Speech and language is used to communicate with others in a social interaction. Communication involves more than just saying words. Communication also includes non-verbal factors such as body language, gesture and eye-contact. People communicate in order to convey information, share feelings, point out observations or to bring about changes in the immediate environment.

Common areas of difficulty that children with an ASD have in the use of language for communicative purposes include

- **Eye contact**
- **Attention and listening**
- **Copying**
- **Turn-taking**
- **Echolalia (repeating what’s just been said)**
- **Idiosyncratic language**
- **Verbal social communication skills including**
 - how to initiate a conversation, e.g., making a comment about something of interest
 - how to maintain a conversation, e.g., adding new information to a conversation
 - how to end a conversation e.g., saying, “Anyway, it was good to see you, I’ve got to go now”
 - how to greet
 - how to turn-taking in a conversation
 - how to ask for clarification
 - how to ask and answer questions.

Children who have an ASD may need direct teaching to acquire these skills.

- **Non-verbal social communication skills**

Children with an ASD have difficulty in conveying non-verbal features of communication and identifying and understanding these features in others. These features include facial expression; body language; eye gaze; gestures; tone of voice and volume. For example, some children with an ASD may have difficulty regulating the volume of their voice, others may have difficulty interpreting an “angry” tone of voice.

- **Incessant question asking/preservative speech**

Some children with an ASD may ask the same question over and over or talk constantly about one topic.

- **Figurative language**

Children with an ASD may find it difficult to understand language with implied or double meaning. For example, if a child with an ASD is told to “pull your socks up” or that it’s “raining cats and dogs”, it is likely that he will take that phrase very literally.

- **Verbal reasoning skills and communicating about past/future events**

The role of the speech and language therapist (SALT) when working with people with an ASD

Speech and language therapists work to assess, diagnose and develop a programme of care to maximize the communication potential of the people under their care. Working on the development of speech and language in a child with an ASD can take place over months or years.

How to contact a speech and language therapist

There is no common procedure for referral to a SALT. For an NHS appointment you can either contact the speech and language therapist yourself or your GP, Health Visitor, School or Nursery may be able to make a referral for you. If you would like to contact a SALT in your area directly, contact your local NHS Primary Care Trust (PCT) or the Royal College of Speech and Language Therapy and they will give you the contact details of the appropriate person in your area. Also, you can find contact details of local NHS Speech and Language Therapy Departments through the NHS website.

For a private speech and language therapy appointment you can contact the Association of Speech and Language Therapists in Independent Practice, who will be able to supply you with the SALTs who are working in your area.

Access to speech and language therapy can also be gained through a Statement of Special Educational Needs. If the Local Educational Authority recognises that the child needs the input of a speech and language therapist as an educational need, this should be written in part 3 of the child’s statement.

Further Information

NAS Helpline Information Sheet ‘Speech and Language Therapy’

Royal College of Speech and Language Therapists www.rcslt.org.uk

Serious Illness And Bereavement

Serious Illness, Death and bereavement are subjects none of us find easy to discuss or cope with, and this is particularly so for children with Autism Spectrum Disorders.

Clearly every child is different, and their level of understanding differs too. As with most life experiences, a child with an ASD will understand and adjust better if they are involved in the situation and prepared as much as possible. If someone in the family is ill, it is better to explain what is occurring and why Grandma, for example, keeps going to the doctor's or spending time in hospital. (As a family you will need to decide how much detail will be appropriate, however please remember to explain any possible change in the person's appearance.) This is because it is often unexplained occasions and the unknown that scares children with ASD, and therefore can produce anxiety and challenging behaviour.

You may be concerned that you will make them anxious by telling them about the illness. However feeling worried is a natural response to such a situation, and you may upset and confuse them by not telling them. For example, the child may be aware that the routines and atmosphere of the household have changed, and may display challenging behaviour because of this. Hopefully by providing your child with an explanation, and changing as little as possible, their anxiety will be kept to a minimum.

You could also add any routine changes, such as who will pick them up from school. This is particularly important if this role is normally fulfilled by the family member who is ill. This will help the person with the ASD to see the situation in a more general context within their life. Also as any change is difficult for a person with an ASD, this will remind your child about those things in their life which will remain the same, for example attending school everyday.

If the person's illness becomes more serious, you may feel that you need to prepare the child for this individual's possible death. Actually explaining what death is will be determined by your own beliefs and values. One suggested approach is to explain death within a life cycle, possibly using insects, plants or animals to demonstrate this. This biological approach is practical, clear, and could be presented visually; many individuals on the autism spectrum respond well to visual descriptions.

Remember to be careful about the language you use, especially if your child is literal in their understanding and interpretation, for example if you describe death as: "like going to sleep" you may make the individual terrified of going to sleep at night. Something simple such as "sometimes people's bodies become worn out" may be appropriate. If they want to know what this means, or how it will affect their lives, you could say that they "will not see Grandma again".

A sudden death may cause more extreme forms of upset and confusion. But this reaction is natural and will probably be experienced by everyone within the family. In your explanation for why that person died, you may need to reassure the child with an ASD that this will not happen to them. You may like to set a boundary on age, for example: "usually only people over seventy years of age die, it is rare for children or people younger than that to die". However if you do use this, please think very carefully about the possibilities of your child experiencing a younger person's death.

In Summary:

- Prepare your child as much as possible
- Keep routine changes to a minimum
- Use clear, simple language
- Use visual supports where appropriate
- Show understanding for unfamiliar displays of grief, for example challenging or obsessive behaviour or an increased reliance on routines. Any reactions may be delayed

Further Information

National Autistic Society Helpline Information Sheet 'Death And Bereavement'

MENTAL HEALTH

It is not unusual for children with Asperger syndrome to feel anxious or depressed. The daily stresses of coping with what can seem a confused and puzzling world, and the difficulties relating to education and friendships sometimes makes children feel bad about themselves. This can lead to our inability to cope or function on a day to day basis and may need some professional assistance and guidance to overcome.

The first course of action should normally be to see one's own doctor (General Practitioner) to talk things over. If the doctor feels that a visit to a more specialist help is needed, then they will refer to the local **Children and Adolescents Mental Health Service (CAMHS)** for an assessment.

CAMHS is the part of the NHS which looks after the mental health of youngsters.

Children and Adolescents Mental Health Services (CAMHS)

Separate CAMHS (Children and Adolescents Mental Health Services) teams look after the Mental Health for those under 18.

CAMHS normally do not normally accept referrals directly from children or their families. If you have any concerns, please contact any of the following first:

- Your GP/Family Doctor
- School
- Social Worker
- Community Health Professional

With regard to behaviour you may notice that your child becomes very distressed if routines are changed. They may be interested in a special subject and want to talk about this or play with it all the time.

Please note that, CAMHS staff in your area may have a low understanding of autism with a lack of basic training. The National Autistic Society campaign 'You Need To Know' aims to address this issue.

What can help?

Many parents find their child may need specialist help in school and until they have a diagnosis this can be difficult to access. In order to get a diagnosis, a number of professionals need to assess your child. These may be a Paediatrician, Psychiatrist, Psychologist, Speech and Language Therapist or Occupational Therapist. Often there are specialist clinics to assess young people who may have autism.

What can I do?

- Go to your GP and ask them to put you in touch with your local CAMHS service.
- Talk to your child's teacher, ask if they have similar concerns, and if there is a social communications group your child can access.
- When changes in routine upset your child, try to be sensitive, even if you find it hard to understand what is going on for them.
- It is best to try and stick to routines with your child in order to avoid problems happening in the first place.
- Occasionally medication can help. Raise this in discussions with professionals.

- Having a child with autism can be stressful. Try to access any local support groups listed above.

Mental Health contacts for people aged under 18

<p>Bolton</p> <p>Bolton CAMHS Royal Bolton Hospital Minerva Road Failsworth Bolton BL4 0JR Tel: 01204 390659</p>	<p>Rochdale</p> <p>Rochdale CAMHS Birch Hill Hospital Rochdale OL12 9QB Tel: 01706 754349</p>
<p>Bury</p> <p>Bury CAMHS Fairfield Hospital Rochdale Old Road Bury BL9 7TD Tel: 0161 778 3784</p>	<p>Salford</p> <p>Salford District Child Psychiatry Service Pendleton Gateway Centre 1 Broadwalk Pendleton Salford M6 5FX Tel: 0161 211 7260</p>
<p>Manchester (South) Carol Kendrick Unit Stratus House Wythenshawe Hospital Southmoor Road Manchester M23 9LT Tel 0161 902 3400</p> <p>Manchester (Central) The Winnicott Centre Hathersage Road Manchester M13 0JE Tel 0161 248 9494</p> <p>Manchester (North) Child Clinical Psychology Department The Bridge Madison Place Newton Heath Manchester Tel : 0161 203 3250</p>	<p>Stockport</p> <p>Stockport CAMHS The Tree House Stepping Hill Hospital Poplar Grove Stockport SK2 7JE Tel: 0161 419 2053</p>
<p>Oldham</p> <p>Oldham CAMHS The Royal Oldham Hospital Parkland House Rochdale Road Oldham OL1 2JH Tel: 0161 770 1173</p>	<p>Tameside</p> <p>Children & Family Psychotherapy Service Springleigh Waterloo Road Stalybridge SK15 2AU Tel 0161 303 4902</p>
<p>Trafford</p> <p>Trafford CAMHS 226 Seymour Grove Old Trafford Manchester M16 0DU Telephone: 0161 860 5157</p>	<p>Wigan</p> <p>Wigan CAMHS 155/157 Manchester Road Higher Ince Wigan WN2 2JA Tel: 01942 775400</p>

Another approach is to talk to the local **PALS (Patient Advice And Liaison Service)** who can provide advice and suggest who can help. Further details below.

PALS (Patient Advice And Liaison Service)

As a patient, relative or carer sometimes you may need to turn to someone for on-the-spot help, advice and support. This is where the Patient Advice and Liaison Service comes in. PALS is a patient focused confidential service helping you to sort out any concerns you may have about the care we provide, guiding you through the different services available from the NHS.

PALS provide:

- Confidential advice and support to patients, families and their carers
- Information on the NHS and health related matters
- Confidential assistance in resolving problems and concerns quickly
- A focal point for complaints and feedback

PALS Mental Health contact information for our area.

<p>Bury, Oldham, Rochdale, Stockport Tameside</p> <p>PALS Pennine Care NHS Trust Headquarters 225 Old Street Ashton-under-Lyne OL6 7SR. Tel: 0161 716 3178 (24 hour answer phone) Email: pals.penninecare@nhs.net</p>	<p>Bolton, Salford and Trafford</p> <p>Greater Manchester West PCT PALS Harrop House Bury New Road Prestwich Manchester M25 3BL Tel 0161 772 3642 Email: pals@gmw.nhs.uk</p>
<p>Manchester</p> <p>CMHT Reception Park House North Manchester General Hospital Delaunays Road Crumpsall Manchester M8 5RB Tel: 0161 918 4047</p>	<p>Wigan and Leigh</p> <p>PALS 5 Boroughs Partnership Hollins Park Hospital, Hollins Lane, Winwick, Warrington WA2 8WA Tel: 01925 664450 Email: dennis.dewar@5bp.nhs.uk Email: katherine.fitzpatrick@5bp.nhs.uk</p>

Further Information

The National Autistic Society have produced a useful information sheet called **Mental Health and Asperger syndrome**. You can get a copy from the NAS Autism Helpline or from the Family Services Development Project.

The NAS have also written a guide for health professionals about mental health in people with autism and Asperger syndrome which costs £1.50.

Book: Mental health and autism - A guide for child and adolescent mental health practitioners by Patrick Sims

NAS Autism Helpline –Tel: 0808 800 4104
Family Services Development Project –Tel: 0161 998 4667

More details on the NAS ‘You Need To Know’ campaign are available on the NAS website www.autism.org.uk/youneedtoknow

Mental Health Act 1983

In a very small number of situations, if someone is putting their own health at risk, there may be times when the Mental Health Act 1983 is the most appropriate legislation to use in order to provide the necessary medical care.

For advice on serious mental health disturbance as it affects people with Asperger syndrome contact National Autistic Society Hayes Unit Tel: 01454 632 311.

What if Your Child Is refused a Mental Health Assessment

If you feel your child has an autism spectrum disorder (ASD) and they have been refused a mental health assessment or services, **you have the right to make a complaint to the NHS.**

See earlier section on ‘What If Your Child Is Refused a Diagnosis’ on how to go about making your complaint.

Help and Counselling for Older Children

Many youngsters with Asperger syndrome develop emotional difficulties. These can be due to living in a world that generally does not understanding the way people with autism think.

Sometimes it can help to have someone to talk to who is trained to counsel people but also has an understanding of Asperger syndrome.

There is little information at present on how best to provide counselling to young people with Asperger syndrome but there is general agreement that ‘solution-based approaches’ (such as cognitive-behavioural therapy) are more likely to be fruitful than approaches that dwell on past events and involve considerable interpretation of feelings.

Making as sure as possible that the person has a good understanding of their differences is important. For basic information **‘What is Asperger syndrome and how does it affect me?’** produced by the NAS Autism Helpline is a good overview which parents can read if they wish for advice about how best to explain Asperger syndrome to their son or daughter. They may wish to pass the booklet on to their son or daughter depending on age and interest etc.

Finding out about Asperger syndrome, high functioning autism and PDD by Gunilla Gerland, Jessica Kingsley publishers (short book – useful for teenagers)

‘I am special’ by Peter Vermeulen, Jessica Kingsley Publishers is also good source of ideas for explaining Asperger syndrome to children.

For more in-depth understanding, it may be better for someone outside the family to explain what Asperger syndrome means for the individual. This is called post-diagnostic counselling.

The best route for someone with an emotional difficulty is to see their GP to discuss what support may be available. Sometimes the GP may prescribe medication to assist with the difficulties. Sometimes GP surgeries have counsellors available who can offer free counselling.

If the person is unable to get free counselling he or she may wish to pay for some sessions of private counselling.

Below is a list of counsellors who offer private practice to people with Asperger syndrome. Most of the counsellors charge in the region of £20 and £40 an hour, but there may occasionally be slightly cheaper rates.

Some of the counsellors on this list are happy to visit the person with Asperger syndrome at their home but usually sessions take place at the counsellor's home.

The list is of counsellors who have varied experience and few would claim to be experts in Asperger syndrome. If a counsellor wishes to know more about Asperger syndrome before starting to see the person please ask the counsellor to contact the National Autistic Society Tel: 0207 9033 500 ask for Information centre.

If anyone has Asperger syndrome and wishes to consider counselling but is unsure they can contact the **National Autistic Society Helpline on 0808 800 4104**. The helpline keep a national list of counsellors with experience of Asperger Syndrome.

The British Association of Counselling and Psychotherapy Tel: 0870 443 5252

For a list of accredited counsellors working in each region.

Email www.bacp.uk

UK Council for Psychotherapy (UKCP) 0207 014 9955 for a list of psychotherapists in each region.

Email: www.psychotherapy.org.uk

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

Tel: 01254 875 277.

Email www.babcp.com

British Psychological Society (BPS) Tel: 0116 254 9568

Email: www.bps.org.uk

Local counsellors with experience of Asperger syndrome:

Dr Lynn Jones

19 Anshaw Close

Bolton BL7 8BS

Tel No: 01204 811116

Service offered:

Cognitive Behaviour therapy and counselling to children and adults with ASD, as well as siblings and parents.

Experience with ASD

Has been involved in family support and behaviour management in the past with people with ASD.

Referral Process:

Private self-referral from North West area only.

Jan Maguire

Tel No: 01706 214994

Based in the Rossendale Area

Service offered:

Counselling for children and adults with AS/High-functioning autism and their parents.
Experience with ASD
Has several clients with the condition as well as having a son with AS. Has attended
Many conferences.
Referral Procedures
National NHS or private referrals. Does not travel.

Alix Otten

30 Kirkmanshulme Lane
Longsight
Manchester M12 4WA
Tel: 0161 256 2201

Service offered:
Counselling for children aged 12+ and adults with ASD and parents
Experience with ASD
Has worked as a support worker and trainer for people with ASD in past.
Referral procedure
NHS and private referrals in Greater Manchester area. GP or self referral

Respect For All Counselling

12 Stroud Close
Middleton
Manchester
Manchester M24 1RA
Contact: Gill Linden 07902 223743
Email: glinden@ntlworld.com www.respectforallcounselling.org.uk

Service offered:
A counselling service for people with learning disabilities, their parents or carers. We work in the Greater Manchester area. All nine counsellors are qualified and have experience of learning disabilities. We offer home visits and also have two counselling rooms.
Experience with ASD
Has worked with families and staff and 10 years experience working with people with learning disabilities
Referral procedure
Self referral. Appointment required or referral through other agencies (any agency dealing with learning disabilities, carers' forums, support workers etc.)

Disability Database

Local councils are required in accordance with the Children's Act to keep records of the number of children with disabilities who live in their area. They collect vital information about the needs of these children usually in the form of a computer database. The purpose of the database is to help the councils, local health services and voluntary organisations plan the right kind of support the children and their families need. Registration on the database is voluntary but strongly recommended.

The purpose of the database is to providing information on local services and funding to which children may be entitled.

The Disability Database co-ordinators for our area meet regularly to discuss issues and trends in their area and to coordinate messages they are feeding back through local authority social services and education departments and through NHS Primary Care Trusts in their areas.

The Disability Database Coordinators for our area are shown in the following table.

AUTHORITY	CONTACT NAME	TITLE	ADDRESS	CONTACT
Bolton	Claire Rurherford	Disability Database Coordinator	The Record Children with Disabilities Services Bolton Social Services Crescent House Lever Street Bolton BL3 6NN	01204 337102 TheRecord@bolton.gov.uk
Bury		Coordinator, Bury Children's Disability Database	Red Centre Morley Street Bury BL9 9JQ	0161 763 3939 cds@bury.gov.uk
Manchester		Family Information Service	Family Information Service Overseas House Quay Street Manchester M33BB	0800 0837972 Email: Fisinfo@manchester.gov.uk
Oldham	Julie Hawkins	Additional Needs Database Coordinator	Additional Needs Database Coordinator Woodfield Centre Netherfield Close Manchester Road Oldham OL8 4ET	0161 627 1749 Julie.hawkins@oldham.gov.uk
Rochdale	Christine Taylor	Link Up Coordinator	Rochdale Register for Children with Disabilities Floor 10, Municipal Offices Smith Street PO Box 67 Rochdale OL16 1XQ	01706 865209 Christine.taylor@rochdale.gov.uk
Salford	Alison Wickham	Database Coordinator	Salford Families Project 222 Eccles Old Road Salford M6 8AL	0161 707 0222 Alison.wickham@salford.gov.uk
Stockport	Elaine Mounter	Disability Database Coordinator	Floor 4 Beckwith House Wellington Road South Stockport SK4 1AF	0161 426 5514 Elaine.mounter@stockport-pct.nhs.uk
Tameside	Sheena Wooding	Disability Database Coordinator	Tameside Social services Jubilee Garden Gardenfold Way Droylsden M43 7XU	0161 371 2060 Sheena.wooding@tameside.gov.uk
Trafford	Christine Baker	Disability Database Coordinator	Trafford Social Services 4 th Floor, Waterside House Waterside Sale M33 7ZF	0161 912 5777 cypis@trafford.gov.uk
Wigan	Allana Mitchell	CWD Datahub Coordinator	Acting Monitoring & Evaluation Officer Children's Preventative Services Town Hall Market Street Leigh WN7 1DY	01942 404151 shortbreaksteam@wigan.gov.uk

EDUCATION

Preschool - Nursery

Introductions

Any child is likely to be overwhelmed by the noise, light, number of children present on the first visit to nursery school. This is particularly true of the child with autism who may be hypersensitive to these things.

It could be useful to introduce a child to the nursery gradually. Prior to a first visit, photographs of the nursery could be taken and shown to the child in the form of a picture book, and nursery staff could visit the child at home. A preparatory visit to the nursery when no other children were present could be made with introductions to staff and the activities.

Introductions to the other children, could be made gradually by increasing the amount of the time spent at the nursery. The book of photographs could be used to explain that it is a 'nursery day'.

It may also be useful for staff to have a photograph and name on a badge so that the child begins to recognise them and their name. For children who don't like change, it might be useful to have a display board with photos showing which staff are in that particular day.

Use Of Pictures

Picture timetables give children a sense of structure to their day and make them feel more secure. A variety of types of pictures can be used – photographs, drawings, symbols etc. – depending on the child's understanding. Older and more able children may prefer words. What is important is that the timetable is clear, unambiguous and does not give too much information at once. Visual timetables can also be used to break an activity down into steps.

Some children have tantrums because they are unable to communicate what they want or express their feelings in any other way. Furthermore, they may have difficulty in understanding what they are being told. The use of picture cards may help overcome some of these problems. It is also essential to keep your language clear and brief and to emphasis important words.

Problems with eating

Lunch time can be particularly difficult for children at nursery. Some are very sensitive to certain textures or flavours, or are frightened of trying new foods. Many are overactive and find it hard to sit down and eat at a table. It is therefore important to take things in small steps and praise the child for their progress. They may find eating as part of a group overwhelming – sitting the child at their own table and gradually introducing other children may help.

Lunch time must be a very consistent routine with, perhaps, a personal table mat so that the child knows that it is time to sit down and eat. Encourage the child only to eat when sitting. Keep returning him to his chair to sit for a few minutes to eat. Be very clear what you are working on, e.g. favourite foods, so that the child wants to sit down and eat.

Obsessions

Many children will have one or more obsessions e.g. Thomas the Tank Engine or dinosaurs. A child may talk repeatedly about the object. It may be necessary to have rules such as he can only bring one engine to nursery (or none if you have a rule about not bringing toys to nursery) and that he can only talk about Thomas at certain times. The visual timetable can be used to implement this.

However, a child's special interest can be used as a tool. For example, Thomas and the other engines can be used to teach numbers and colours.

Choice of activity

During free-time, the child may find it very difficult to choose what to do. Slowly build up the choices that are available to the child – initially offer him a favourite activity together with something he does not enjoy. Gradually build up to two desired activities. Alternatively, he may always choose the same activity, such as playing with the toy train. A picture timetable can be used, alternating the train play with other activities.

Further Information

National Autistic Society Helpline Information Sheet 'Early Years And Autism'

Book: My Friend Sam; introducing a child with autism to a nursery school by Liz Hannah and Steve Lockett. Uses simple wording and colour pictures to describe some of the difficulties young children with autism may have, and some things they are good at (NAS)

Local Special Education Needs Teams

If you think your child has a special education need, then it is recommended you contact your local authority's Special Education Needs team. They should arrange to assess your child's needs.

Bury Children's Advice and Assessment Team Grey Block Seedfield Parkinson Street Bury BL9 6NY Tel: 0161 253 5692 senteam@bury.gov.uk	Bolton Inclusion And Statutory Assessment Service Children's Services P.O Box 53 Paderborn House Bolton BL1 1JW Tel: 01204 338653
Manchester Children's Services SEN & Inclusion Strategy Team 5 th Floor Overseas House Quay Street Manchester M3 3BB Tel: 0161 234 7590. Email: m.leatherbarrow@manchester.gov.uk	Oldham Additional Educational Needs Service Greenbank Firbank Road Royton Oldham OL2 6TU Tel: 0161 770 3110 Email: julie.sweeting@oldham.gov.uk
Rochdale SEN Assessment Team P.O. Box 70 Municipal Offices Smith Street Rochdale OL16 1YD Tel: 01706 925140	Salford Special Education Needs Team Children's Services Directorate Minerva House Pendlebury Road Swinton M27 4EQ Tel: 0161 778 0410
Stockport Special Education Needs Department 3 rd Floor Stopford House Town Hall Stockport, SK1 3XE. Tel: 0161 249 4453 Email: specialeducation@stockport.gov.uk	Tameside Special Educational Needs Tameside MBC Council Offices Wellington Road Ashton Under Lyne OL6 6DL
Trafford Children's Multi Agency Referral and Assessment Team (MARAT) Trafford Town Hall Talbot Road Stretford M32 0TH Tel: 0161 912 5125	Wigan Children's And Young Peoples Services Wigan MBC Progress House Westwood Park Drive Wigan WN3 4HH Tel: 01942 486145 or 01942 486136

Starting School

Most children with Asperger Syndrome will not have a diagnosis before starting school, although parents are likely to be aware that their child has a problem. This may have also been also brought to their attention by nursery school staff.

It is a good idea to make teaching staff, in particular the school's Special Education Needs teacher (SENCO), aware that the child may have difficulties so that they can monitor the child's progress in settling into school.

Getting Extra Help In School

Identifying Special Education Needs (SEN)

The school has a duty to inform you if:

- the school thinks your child has difficulties
- the school thinks your child has special educational needs
- your child is able to work at the same level as other children of a similar age
- your child is already getting some extra help
- you can help your child.

How a child with Asperger Syndrome settles into school will vary significantly from child to child. If early difficulties do arise, the school has a duty to address those difficulties in the same way as it would for other types of special needs. Early education settings and schools place great importance on identifying special educational needs early so that they can help children as quickly as possible. Once it has been decided that your child has Special Education Needs (SEN), your child's teachers should take account of the guidance in the SEN Code of Practice.

The graduated approach outlined in the Code Of Practice recognises that children learn in different ways and can have different kinds or levels of SEN. So increasingly, step by step, specialist expertise can be brought in to help the school with the difficulties that a child may have. The school must tell you when they first start giving extra or different help for your child because your child has special educational needs. The extra or different help could be a different way of teaching certain things, some help from an extra adult, perhaps in a small group, or use of particular equipment like a computer or a desk with a sloping top. This help is called **School Action**.

School Action

Your child's teacher is responsible for working with your child will monitor your child's progress on a day-to-day basis. They may decide to write down the actions or help for your child in an Individual Education Plan (IEP).

The IEP should say:

- what special help is being given
- how often your child will receive the help
- who will provide the help
- what the targets for your child are
- how and when your child's progress will be checked
- what help you can give your child at home.

Your child's teacher should discuss the IEP with you and your child if possible. The IEP will be different for each child and should focus on the key areas where the child needs help. For a child with Asperger Syndrome these are likely to focus on communication, social inclusion and flexibility. Schools may use an IEP before going ahead with School Action, or as part of School Action.

School Action Plus

If your child does not make enough progress, the teacher or the SENCO should then talk to you about asking for advice from other people outside the school. They might want to ask for help from, for example, a specialist teacher, an educational psychologist, a speech and language therapist or other health professionals. This kind of help is called **School Action Plus**.

The SENCO should try to include you in any discussions, and should consider your views in making any decisions about how best to help your child. They should keep you informed about your child's progress. If the child has an IEP, this should be reviewed when moving to School Action Plus.

Most children's needs can be met by their school, sometimes with the help of outside specialists, through school-based 'Action' or 'Action Plus' as described above.

However, in some cases the local authority will be asked to make a statutory assessment of a child's educational needs. If you need to contact your local Special Education Needs team, the above table contains relevant addresses and telephone numbers.

Further Information

Department for Children, Schools and Families publications

Special Educational Needs (SEN) - A Guide for Parents and Carers
Special Educational Needs (SEN) – Code Of Practice

These are available free or can be downloaded from www.teachernet.gov.uk

Statutory Assessment

Most children's needs can be met by their school, sometimes with the help of outside specialists. through school-based 'Action' or 'Action Plus' as described above.

However, in some cases the local authority will be asked to make a statutory assessment of a child's educational needs.

A statutory assessment is a detailed investigation to find out what your child's special educational needs are and what provision is needed to meet those needs.

After the assessment, if the authority decides that a child needs special help which is greater than can be provided by the school's resources, they must write a **statement of special educational needs**. This describes all the child's needs and details the specialist help and provision required to meet those needs.

Assessment Process

You've heard from your child's school that a statutory assessment has been requested for your son or daughter, or you may have thought about requesting one yourself, as you think they need more help than the school can give at present. But what exactly is the assessment process?

An assessment is the step before a statement of special educational needs (often known simply as a statement), but doesn't always lead to a statement being written.

The local authority must, by law, comply with a request for a statutory assessment unless:

- a statutory assessment has been made within the last six months
- it believes upon examining evidence that a statutory assessment is not necessary. The local authority will only carry out a statutory assessment if they believe your child probably has special educational needs and that they need, or probably need, to determine the level of your child's special educational provision by writing a statement.

It's important to remember that a statutory assessment is different from assessments that your child's school may carry out. It is also different from tests or visits by educational psychologists, specialist teachers or speech and language therapists.

Only a local authority can carry out a statutory assessment, and this is the only kind of assessment that can lead to a statement of special educational needs.

Who can request a statutory assessment?

A request for a statutory assessment can be made by a head teacher or a professional working with your child, such as an educational psychologist. Schools should consult with you before requesting an assessment.

As a parent, you can request an assessment if you believe that your child's needs are either not being met through Action or Action Plus (support programmes which are funded by schools); or are so substantial that a school could not meet them from within their own resources.

The local authority doesn't need your consent to carry out an assessment of a child, but it does need to keep you informed. If a child is under the age of two, an assessment can still be carried out but local authorities need parents' consent to do this.

Before making a request, you should discuss your concerns with the school's special educational needs co-coordinator (SENCO), or the manager of the nursery or pre-school. If they're unable to offer any further support and your concerns remain, you can make a request for a statutory

assessment directly to the local authority. Clearly set out the reasons for making the request and provide information about the help that your child has already received.

The request should be made in writing to the either the Director of Education, or Director of Children's Services of the local authority where your child lives. Send a copy of the letter to the school or early years setting.

Sample letter requesting a Statutory Assessment

If you're thinking of requesting a statutory assessment for your son or daughter, you may like to use or adapt the following sample letter. Even if the school is asking for a statutory assessment it can be a good idea for you to send your own letter making a request for assessment, too. This then means that you can be sure of the exact date that the request was made; that it is a statutory assessment that has been requested; and that your legal rights are not compromised in any way.

If a professional associated with your child's school, such as an educational psychologist, is the person making the request for a statutory assessment, it is especially important that you also make your own request (see the special note in the section 'The decision to assess or not').

Dear Sir/Madam,

Child's name and date of birth

I am writing as the parent of the above child to request an assessment of his/her special educational needs under section 323 of the *1996 Education Act*. [Insert child's name] attends [insert name of school/early years setting].

I believe that my child needs more help than the school/setting is able to provide. His/her special educational needs are as follows:

[Here you could outline the difficulties your child is having at school/setting and at home, send information about any diagnosis, outline any support your child has been receiving and who (if anyone) outside the school/setting has been involved]

My reasons for believing that the school cannot on their own make the provision required to meet my child's needs are:

[Here you could outline your continuing concerns about your child's progress in relation to peers, any increased behavioural difficulties, progress through an Action or Action Plus programme, etc]

I would like you to seek advice from the following people, who are involved with my child.

[List the people involved, giving addresses where necessary]

I understand that you are required by law to reply to this request within six weeks and that if you refuse to carry out an assessment, I will be able to appeal to tribunal.

Yours sincerely,

[Your name and signature]

Considering the request for an assessment

As soon as the local authority starts looking at the request for a statutory assessment they should write to you and:

- tell you that they are **considering** whether to carry out a statutory assessment
- tell you how they will carry out a statutory assessment
- explain the timescales (no longer than six months in all)

- give you the name of the person at the local authority who will be your point of contact – your ‘named officer’
- ask you to give written or spoken reasons, called ‘evidence’, about why you think your child should or should not be assessed (you have 29 days to do this)
- tell you about sources of support and advice
- ask if there is anyone else you would particularly like the local authority to talk to about your child
- ask you for any evidence or opinions you have collected or intend to get.

The local authority must inform your child’s head teacher when you make a request for a statutory assessment. The local authority should ask for written evidence about your child, in particular the school’s assessment of his or her learning difficulty and the school’s account of any special educational provision that has been made.

At the same time the local authority must notify the educational psychology department and the health authority and any other agencies that later **may** be asked for advice.

In **considering** whether a statutory assessment is necessary local authorities will seek:

- evidence that your child’s school has responded appropriately to the requirements of the national curriculum
- evidence provided by your child’s school or early years setting, by you and by any other professionals who have been involved with **your** child, about the nature, extent and cause of his or her learning difficulties
- evidence of the rate and style of your child’s progress
- evidence that where some progress has been made it has only been as the result of a lot of additional effort.

As well as evidence of attainment the local authority should seek evidence of any other factors that could impact on learning. For example:

- evidence of clumsiness, marked difficulties with understanding the order or arrangement of things (sequencing), lack of working memory or delays in language
- evidence of difficulties with social interaction or communication, or restricted imagination and a limited interest in activities or particular topics
- evidence of significant emotional or behavioural difficulties.

The local authority has **six weeks** to decide whether or not to carry out a statutory assessment from the date that they first receive the request.

The decision to assess or not

If the local authority refuses to agree to a request for a statutory assessment, parents have a legal right to appeal to the Special Educational Needs and Disability Tribunal (SEND) in England or Special Educational Needs and Disability Tribunal Wales (SENTW). You can appeal whether you made the request for a statutory assessment, or whether the school did.

Special note: if the request for a statutory assessment has been made independently of the school by an educational psychologist or another professional, such as a speech and language therapist, and the local authority refuses to undertake an assessment, parents **do not** have the right to appeal. Therefore, if an independent professional is making a request for your child to be assessed, we suggest that you make your own request at the same time.

If the local authority agrees to conduct the assessment they will ask you and a number of professionals to give views on your child, including:

- your child’s school or early education setting
- an educational psychologist
- a doctor
- social services (who will only give advice if they know your child)

- anyone else whose advice the local authority considers appropriate.

As parents you:

- have the right to be present at any interview, medical or any other test during the statutory assessment process
- can suggest any other people or organisations whose views may be helpful to the assessment of your child
- may send the local authority any private advice or opinions you have collected. The local authority should take these into account.

The assessment process should take **ten weeks**, after which the local authority will decide whether or not to issue a statement of special educational needs.

It is only the local authority which can issue a statement and they must do so if your child has complex and significant special educational needs which need more help than can be given from the school's or early years resources.

If the local authority decides not to issue a statement (because they determine your child does not have special educational needs for which they must make provision) they must inform you, as parents, of your right to appeal to SEND or SENTW.

If the local authority decides to make a statement, they have **two weeks** to issue a proposed statement.

Timescales from statutory assessment to statement

- Local authority receives request for statutory assessment – **six weeks** to make decision about whether to carry out an assessment.
- Local authority decides **not** to assess – writes to parents with information about their right to appeal.
- Or... local authority decides to assess.
- Local authority seeks advice from parents and a range of professionals within **ten weeks** (unless in exceptional circumstances).
- Local authority decides whether or not to make a statement within **two weeks** of receiving all the advice.
- Local authority decides **not** to make a statement and writes to parents telling them that they have the right to appeal.
- Or... local authority decides to make a statement and issues a proposed statement within **two weeks**.
- Local authority has **eight weeks** to make a final statement.
- **Total time: 26 weeks.**

Local Special Education Needs teams details, including relevant addresses and telephone numbers are in the table in this document near the beginning of the section on Education.

Timescales from statutory assessment to statement

The local authority receives request for a statutory assessment from parents, a school or early education setting, or a professional who works with a child

The local authority writes to say it is considering whether to make an assessment and asks parents to send their views within 29 days. The local authority has **six weeks** in total to decide whether to undertake a statutory assessment (although there are some exceptions)

Refused
If the local authority decides not to carry out a statutory assessment, a letter should be sent to parents informing them of the reasons for this. If the request has been made by the school, early education setting or parent, the LA should also inform parents of their right of appeal to tribunal.

Agreed
If the local authority says it will carry out a statutory assessment, advice will be sought from parents, the school or early education setting, an educational psychologist, the health authority and social services. The local authority has **ten weeks** to complete the assessment (although there are some exceptions).

The LA then has **2 weeks** to decide whether they will issue a statement.

Statement refused
The local authority writes to inform parents that they are not issuing a statement and informs them of their right of appeal to tribunal.

Statement agreed
The local authority issues a proposed statement and copies of all the reports/advice gathered during the assessment. Parents have **15 days** to comment on the proposed statement.

The local authority must issue a final statement within **eight weeks** of issuing the proposed statement (although there are some exceptions).

Statements of Special Educational Needs

After the statutory assessment, if the Local Authority (LA) then decides your child needs special help, they must write a statement of special educational needs. This describes all your child's needs and all the specialist help and provision to meet those needs.

When the LA issues a statement they send you, as parents a copy of the draft, or proposed statement. They will also send you copies of all the professional reports, e.g. from the school or early years setting, educational psychologist, health authority etc., which were prepared during the statutory assessment. You have the right to ask the LA to arrange a meeting with a relevant professional to discuss this 'advice'. You also have the right to ask for a meeting with an officer of the LA to discuss the contents of the proposed statement.

The letter sent with the statement should inform you that you have **15 days** to 'make representations', which is to write comments or request a meeting with an LA officer. The meeting may take place after the 15 day period.

Meetings with LA officers can be repeated. Following the meeting, an 'amended proposed statement' may be produced, or the LA may finalise the statement. In that case, the LA will send the final statement to you with a letter explaining your right of appeal to the Special Education Needs and Disability Tribunal (SENDIST) or the SEN Tribunal Wales (SENTW) if you disagree with the statement. (see later section for details on how to appeal).

If when you first receive the proposed statement you either do nothing or write back accepting it, the LA will then send you a final statement and inform you of your right of appeal.

What should the statement contain?

The statement must contain six parts:

Part 1

Part 1 of a statement is a standard introduction that provides you and your child's details. It will often also list the details of the reports gathered during the statutory assessment process that are appended to the statement.

Part 2

Part 2 of a statement should describe your child's educational needs and current difficulties clearly and thoroughly. It should set out the nature and severity of your child's difficulties and how they might affect your child's ability to learn in the classroom. Part 2 should be set out so that it relates directly to the description of provision in Part 3.

You might wish to look at this document to ensure that **all** your child's educational needs are identified in Part 2 of the statement. You can do this by looking closely at all the professional reports or advices which formed part of the statutory assessment. Make sure that all the needs mentioned in them appear in the statement. It can be useful to make a copy of each report and highlight the educational needs mentioned and then check that these are in Part 2 of the statement.

It is important to try and avoid any vague descriptions in the statement. For example 'Autistic tendencies' can be a description that makes it difficult to pin down appropriate provision.

Children with Asperger syndrome often have additional overlying conditions such as attention deficit hyperactivity disorder (ADHD) and Dyspraxia. These also need to be identified in Part 2 of the Statement.

Children with ASD are likely to have needs that fall into the following categories:

- **Difficulties with communication**
- **Difficulties with social interaction**
- **Difficulties with sequencing and planning**

Look for the following points in the professional advices or reports and ensure they appear in Part 2 of your child's statement where appropriate

Communication Needs

Your child may have difficulty with:

- Processing, understanding or using language (receptive and expressive language)
- Interpreting instructions literally

Social Needs

Your child may:

- Have impulsive behaviour
- Act inappropriately with peers

Information Processing

Your child may experience difficulties including:

- Planning and organising information
- Forming concepts and understanding abstract ideas
- Predicting and anticipating events
- Processing spoken information
- Differentiating between relevant and background information
- Finding noisy and/or busy environments distressing
- Finding changes between activities difficult and so they need a lot of structure where activities must have a clear beginning, middle and ending.

Behaviour Difficulties

Your child may have difficulties in managing their behaviour due to:

- Lack of understanding of social rules,
- Confusion and fear of unexpected events,
- Interference with repetitive activities
- Inappropriate attempts to control environment.

Other difficulties

If your child has attention deficit disorder (ADD) or ADHD they will have great difficulty staying on task. If they have Dyspraxia they may also have difficulties with co-ordination from catching a ball (gross motor skills) to holding a pen (fine motor skills).

This is not an exhaustive list of the difficulties children with ASD may have, so it is important to read Part 2 carefully to make sure that all *your* child's needs are mentioned.

Part 3

Part 3 of a statement must specify all the educational provision to be made by the local authority to meet your child's special educational needs. Part 3 of the statement is in three sections.

Objectives

The first section within Part 3 sets out the main educational and developmental long-term objectives to be achieved by the special educational provision. Objectives should directly relate to the learning needs described in Part 2.

Educational provision

This is the most important section of Part 3 and it should specify all the special educational provision that the LA considers appropriate for **all** the learning difficulties detailed in Part 2. The provision in this part of the statement should be specific, detailed and quantified. In particular it should specify:

- Any appropriate facilities and equipment, staffing arrangements and curriculum
- Any appropriate modifications to the National Curriculum, or any appropriate exclusions from the National Curriculum in detail and the provision that will substitute any exclusions in order to maintain a balanced and broadly based curriculum

Where residential placement is appropriate this should also be recorded here.

Using all the advice received and what has been outlined in Part 2 of the statement, you should check whether the following have been included in Part 3 if appropriate:

- Frequent supervised small group activities
- A programme for personal and social development
- A behaviour management programme
- Additional supervision to help your child stay on task (for example a learning support assistant or teaching assistant)
- Access to additional special needs support to cover unstructured times of the school day
- A language programme to be developed by a speech and language therapist or direct input from a speech and language therapist
- A teacher and/or learning support assistant with a specific qualification and/or experience in teaching and supporting children with autism
- A learning support assistant to help in differentiating and delivering a modified curriculum
- Opportunities to develop social skills
- A low level distraction free environment
- An individualised programme to develop language and communication skills
- An individualised programme to develop social skills
- Structured tasks and routines
- Visual prompts and a visual timetable
- Clear unambiguous instructions at all times

This list is not definitive but gives an indication of the kinds of provision your child might need. Always try and get this provision as specific, detailed and quantified as possible. Ask yourself:

- Who will provide it?
- How will it be provided?
- When will it be provided?
- For how long?

In summary, this section should be comprehensive and specify all the educational provision to meet each need. Some of the provision will be made by direct intervention of the local authority, some will be made by the child's school from within its own resources and some may be made by the health authority. The LA has a legal duty to make sure that the provision in the statement is made irrespective of who actually delivers it, unless the LA is satisfied the parents have themselves made suitable arrangements.

Monitoring

The final section in Part 3 sets out the arrangements to be made to monitor and review your child's progress. It is helpful to ensure that this section specifies who will be involved in monitoring and

reviewing process. This section should also specify how often the statement will be reviewed, which should be at least annually.

Part 4

Part 4 details the placement. That is the type of school, the name of a school or early education setting, or any provision for home education (also known as 'education otherwise').

Once you receive a proposed statement, you can ask for a particular school or setting, including one that may be out of the area, if you believe it will best meet your child's needs. Requesting a placement is not a guarantee that your child will be placed there.

Part 5

Part 5 of the statement describes non-educational needs your child has, as agreed between the LA, health services, social services and other agencies. This part of the statement is not legally binding on the LA and it is not possible to appeal to SENDIST or SENTW about its contents.

Part 6

The last part of the statement describes how your child will get help to meet the non-educational needs in Part 5 of the statement.

While the LA must arrange all the special educational provision that it outlined in Part 3 of the statement, the provision outlined in Part 6 is described as non-educational. This is normally provided by the health authority or social services in response to a request from the LA. However, no-one has a legal duty to put the provision outlined in Part 6 in place. It is therefore important that **all** educational needs are described in Part 2 with the provision stated in Part 3. This would normally include therapies such as speech and language and occupational therapy.

If on receipt of the final statement you are still unhappy with its contents you have a right of appeal to SENDIST or SENTW within two months of the receipt of the letter accompanying it.

Further Information

- **Special Educational Needs Code of Practice published by Department for Education and Skills (Ref: DFES/581/2001)**
- **NAS Education Rights Service** 0808 800 4102
- **IPSEA Tribunal Helpline** 0845 602 9579 Daytime hours: Mon, Tues, Weds 10-1 and Thurs 10-4. Evening hours: Wednesday 7-9
- **NAS Information Sheet - Making A Complaint: Useful Tips**
- **Contact A Family – SEN National Advice Service.** Contact a Family run a Special Educational Needs advisory service covering all education issues. Contact their helpline 0808 808 3555 [email helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

School options for a child with Asperger Syndrome.

Many parents of children with an autism spectrum disorder (ASD) have difficulties finding the right school. This can happen for several reasons:

- your local authority may not provide the type of educational provision you would like for your child
- you may disagree with your local authority about which is the best school for your child
- your child may not have, or need, a statement of special educational needs. Children usually need a statement to access a placement at a special school, so those without statements may find that their choices are more limited. See the 'Statements' section for more information.

Your local authority (LA) only has a duty to provide an 'adequate' education for your child – it does not have to provide the best education. However, they are obliged to offer you other information about schools which are available locally and to explain their decision about where to place your child if necessary.

The following information is a guide to the different types of school available and how you can decide which is the most appropriate for your child. Everyone with autism is different and each family's circumstances will be different, so this information is not intended to be a definitive guide to making the right decision.

What different types of schools are there?

The following are different types of schools are available (although not all these types of school will necessarily be available in your local area).

- **Mainstream schools**

Most children with Aspergers are educated in mainstream primary and secondary schools. If your child has a statement of special educational needs, they may have extra support in school for a set number of hours a week. It is unlawful under the *Disability Discrimination Act 1995* (as amended by the *Special Educational Needs Disability Act 2001*) for schools in England and Wales to discriminate against children or young people with a disability with regard to admissions, education and associated services, and exclusions. See the 'Disability Discrimination Act' section for more information.

- **A base within a mainstream school**

Some mainstream primary and secondary schools have classes for pupils with an ASD within them. The pupils access the mainstream school when appropriate and are educated in the base during the other times. This is more likely to be an option for secondary school education.

- **Special And Residential Schools**

These are schools specifically for children with special educational needs. For a placement in a special school, pupils usually need a statement.

- **Independent or non-maintained schools**

These schools can be mainstream, special or residential, but none of them will be maintained by the local authority. Parents can choose to place their child at their own expense **or** to make representation to their local authority for a placement at an independent or non-maintained school (see the 'Parental preference section for more details).

Choosing a school for a child with a statement

Most children with Aspergers will not have a statement of special education needs before they start school. Some will go through the statementing process described above once they're in school but many will not have, or need, a statement at all.

For a placement in a special school or a residential school, pupils usually need a statement.

Once a child receives a final statement, part 4 of the document will name a school for them to attend. However, part 4 of a *proposed* statement (a copy of the statement sent out before the document is finalised) will be blank. Before the local authority names a school in the statement they need to check that the school is willing to accept your child.

If the local authority refuses to name the school of your choice, you are entitled to know why and to ask for a review of the decision. If you are having problems in any of these areas we would recommend seeking specialist advice from your local Parent Partnership Service or from one of the helplines listed in the 'Useful contacts' section before you sign the final statement. However, please be aware of the time limits involved in preparing and finalising statements; you may not have long to seek advice and follow up with your local authority.

A statement is issued by local authorities when the needs of a pupil are above those which a mainstream school could support in terms of funding for specialist support. It is a legally binding document which outlines a child's needs and how their local authority is going to meet those needs.

- **Mainstream Schools and a base within a Mainstream School**

The statement may decide your child's needs are best met within a mainstream school environment with specially funded appropriate support. The needs of the child and the extra support required to meet those needs should be specified in the statement. Mainstream schools vary considerably in their understanding and provision for a child with Asperger Syndrome.

- **Special schools**

These are schools specifically for children with special educational needs. For a placement in a special school, pupils usually need a statement.

The pupils special schools cater for vary: some are just for pupils with an ASD while others are for pupils with moderate or severe learning difficulties, pupils with physical difficulties, or a mixture of the two. **Be aware that local authorities may offer a place in a special school which may have no special provisions for a child with Asperger syndrome.**

- **Residential schools**

These schools can be for children with varying needs or specific needs, but are more likely to be relevant for children with more severe autism conditions. For a placement in a residential school, pupils usually need a statement. Pupils stay overnight and have a 24-hour curriculum – meaning there is support available 24 hours a day. Some have a 52-week placement, others will go home at weekends or during the holidays. A multi-agency plan should be put into place that establishes tripartite funding, but it remains the responsibility of the local authority to be legally responsible for ensuring education. Parents and local authorities should agree any arrangements for contact with the family and for any special help such as transport.

- **Independent or non-maintained schools**

These schools can be mainstream, special or residential, but none of them will be maintained by the local authority. Parents can choose to place their child at their own expense **or** to make representation to their local authority for a placement at an independent or non-maintained school..

Visiting schools

You don't need to visit every school you hear about but it's a good idea to visit a variety of schools. This will give you a better idea of what is available and which features you think are important. You may find that a type of school you wouldn't have considered may, in fact, be right for your child. For example, one parent was told by her son's educational psychologist that he would not be able to cope in a mainstream school. However, when she visited her local primary school she decided that it was actually suitable because it was quite small and had a very calm and caring ethos.

You may not think that some schools are suitable for your child, but find that they still have elements which appeal to you. For example, a speech and language therapy unit in a mainstream school might not suit your child, but the fact that the children there spend a lot of time in mainstream classes could be something that they would benefit from. As a result, you might choose to look at the arrangements which are made for inclusion of pupils with disabilities in mainstream classes at the other schools you visit.

Decide which features are crucial to you

Although children's and families' needs will vary, there are a few features which are likely to be important for all families affected by autism.

- Parents should feel they are able to feedback any concerns they have to the school and vice versa, so it is important that the staff seem approachable and open.
- Schools should be able to respond to the varying needs of children with autism. They should be aware that the approaches which work for one child may not work for another and that flexibility is crucial.
- Children with special educational needs are statistically more likely to be involved in bullying than those without. They may be the perpetrators or victims of bullying; either way, it is crucial that all schools have a clear policy on bullying.
- Careful and consistent planning is vital for children with an ASD, as mixed messages can cause them acute anxiety. Communication between staff, which can ensure a consistent approach to teaching and supporting pupils with autism, is as important as the school communicating effectively with parents. Ask about arrangements for staff meetings and how often teachers and learning support staff are able to meet to discuss children's progress.

There are many more features of a school which will be equally important, but perhaps specific to your child. You could ask family and friends to help draw up a list of such features. This may prove very helpful, as people outside the immediate family may see your child's needs very differently to you.

The Disability Discrimination Act

The Disability Discrimination Act 1995 was extended in 2002 to cover every aspect of education.

The Special Educational Needs Disability Act 2001 amends the Disability Discrimination Act part 4 to prevent discrimination against disabled people in education, including during the admissions process.

The Act defines a disability as 'a physical or mental impairment which has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities.'

The Act has made it unlawful for all schools – independent, maintained, mainstream and special, non-maintained, pupil referral units, nursery, primary and secondary schools – to discriminate against a pupil with a disability with regard to admissions. A school cannot refuse or deliberately omit an application for admission from a prospective pupil due to their

disability, unless it would be detrimental to the education of the pupil or the other pupils in the school.

The full *Disability Discrimination Act 1995* can be found at:
www.opsi.gov.uk/acts/acts1995/1995050.htm

Further Information

Book: A Parent's Guide To Disability Discrimination by Geraldine Hill. It can be downloaded free of charge from www.inclusivechoice.com.

Transport From Home To School

Local authority duties- 'Eligible Children'

All local authorities have a legal duty to make suitable travel arrangements free of charge for some children (called 'eligible children'- see below), where it is needed, so that they can attend school.

Eligible children are those with special educational needs (SEN), disabilities or mobility problems who cannot reasonably be expected to walk to their school (even though it is within the statutory walking distance from home - 2 miles for under eight year olds. 3 miles for eight years of age or more), and no suitable arrangements have been made by the local authority for them to attend a school nearer to their home.

Suitable arrangements

The local authority has a duty to make sure that travel arrangements are 'suitable'. This term is not fully explained in law. However, case law (*R v Hereford and Worcester CC ex parte P (1992)*) has judged that home to school transport should not cause the child undue stress, strain or difficulty that would prevent him/her from benefiting from the education the school has to offer.

Suitable transport arrangements may therefore depend on a number of things:

- the child must reach school without such stress, strain, or difficulty that would prevent them from being able to benefit from the education being provided
- the child must also travel in reasonable safety and in reasonable comfort.

Guidance issued by the Department for Children, Schools and Families (DCSF) in May 2007 states that it would **not** be considered suitable for a child to make several changes of public transport which results in an unreasonably long journey.

If your child has a statement of special educational needs (SEN)

For children with statements of special educational needs, transport is usually recorded in Part 6 of the statement. This part of the statement is not legally binding. However, there is a general expectation that local authorities will make suitable arrangements for transport if this is mentioned.

Local authorities may also provide transport for children with statements whose parents have not made 'suitable arrangements' themselves. This may be because the school is difficult to access by public transport and parents don't drive. DCSF guidance advises that any decisions about transport should be based on a child's individual needs.

As a parent, you can make a request for your child to attend a particular school. The local authority does not have to name your preferred school on your child's statement if they believe that another (nearer) school would be able to meet your child's needs. Sometimes a local authority will name your preferred school on the condition that you meet all or part of the transport costs. This arrangement should be written into your child's statement.

Residential schools

If your local authority names a residential school in your child's statement, which is some distance from your home, they should provide transport or transport assistance.

The authority should also talk to you and make arrangements for you to visit your child and attend any important meetings, such as annual reviews.

Under certain circumstances, if you do not agree with your local authority about the school that they have named in your child's statement, you can appeal to Special Educational Needs and Disability Tribunal (SENDIST). However, you are not able to go to tribunal if your choice of school is named in the statement.

Local authority duties- 'Other Children'

Discretionary arrangements

If a child is not eligible for free home to school transport, the local authority may still make transport arrangements for them. Such arrangements do not have to be free of charge. However, if there is a chance that the authority will make a charge, this should be made clear in their school travel policy. Good practice suggests that low income families should not be charged. However, local authorities can **choose** to make travel arrangements for any pupil, so your child may still be able to get transport even if they don't meet the criteria for 'Eligible children'.

Drivers and escorts

Local authorities should make sure that drivers and escorts have enhanced Criminal Record Bureau checks and receive disability equality training.

How to challenge decisions about transport

If you, as a parent, have a complaint or disagreement about the eligibility of your child for home to school travel support, there may be action you can take. Guidance from the DCSF suggests that local authorities should have an appeals procedure in place for parents to follow. This should be published alongside the authority's home to school travel policy.

Useful documents and reading

National Autistic Society Helpline Information Sheet 'Education: transport from home to school (England)'

The Department for Children, Schools and Families has issued guidance to local authorities about home to school transport. You can download copies of this guidance from the teachernet website.

- Home to school travel for pupils requiring special arrangements (November 2004)
www.teachernet.gov.uk/wholeschool/sen/sentransport
- Home to school travel and transport guidance (May 2007)
<http://publications.teachernet.gov.uk/eOrderingDownload/DFES-00373-2007.pdf>

Further help for parents trying to obtain an appropriate education for their child is available from our Education Advice Line on 0808 800 4102.

Home Education

Why some parents choose home education?

As a parent you may be wondering whether your child will benefit from being educated at home. Educating your child yourself is a huge responsibility, but you do have the right to choose to home educate your child. Parents choose to educate a child with autism at home for a number of reasons.

For example:

- your child may have sensory sensitivities, which makes a school environment noisy, distracting or even painful to them. They may therefore find it hard to concentrate or behave well, which may then stop them from reaching their full potential.
- you may feel your child's needs are not being recognised or properly supported at school. Although many children with autism do succeed in school and benefit from the support of dedicated staff, such as learning support assistants, your child may find the school environment difficult, with its emphasis on social interaction and group learning.
- you may feel you can provide a more appropriate education for your child than a school that follows the National Curriculum. This may depend on the educational options for children and young people with autism in your area.

Choosing to home educate your child may mean that you have to fulfill the role of teacher and you may therefore get no break from childcare as you will be spending most of your time with your child.

You may also feel overwhelmed by all the decisions you will need to make about your child's home education, especially if you have no previous knowledge about teaching or the education system. A number of organisations can help you. See *Further information*

What does the law say about home education?

Legally, you do not need to have any teaching qualifications to home educate your child. And you have the right to educate your child at home, as stated under section 7 of the Education Act 1996 (England and Wales):

“The parent of every child of compulsory school age shall cause him to receive efficient full-time education suitable – (a) to his age, ability and aptitude, and (b) to any special educational needs he may have, either by regular attendance at school or otherwise.”

How should you home educate?

The law does not define how you should home educate, and you do not have to follow the National Curriculum. Some children with autism can find this way of teaching too rigid. However, when you design your child's education, you will be able to concentrate more on the particular needs and interests of your child. If your child shows a particular talent for maths or music, for example, you could spend more time on these subjects. Your child could also go to classes that specialise in teaching these subjects.

You may decide that you should spend more time on subjects that your child does not do well in. We use the term 'subjects' loosely in this information sheet. It does not necessarily refer to the areas covered by the National Curriculum.

Although the term 'home education' is commonly used, a child may be taught at home for just part of the time, while also going to colleges or other establishments as well as taking part in community-based learning activities. You are not confined by the classroom and you don't have to teach a large number of children of different abilities. You are able to combine 'academic' lessons with less conventional ways to educate such as visits to leisure centres, classes at colleges or other

establishments as well as trips to, for example, historical places, botanical gardens, art galleries or zoos, which can all help a child to learn a particular subject.

In addition, you don't need to follow the hours of the standard school day. If, for example, your child is tired in the morning, but is energetic and has better concentration in the afternoon, you can plan things around this. It can also mean that if your child needs to go to hospital or keep appointments for therapy, they don't have to miss out on their education as these can be taken into account in advance.

Whatever 'timetable' you finally choose, you will need to make some specific decisions. For example, you will need to decide whether to home educate your child throughout their school career or just for a short time. You may feel that your child will benefit from a period of home education, but go back to formal education at a later date or at another level, for example when they reach secondary school or are of college age.

Helping your child to socialise

Home education can suit children and young people with autism, and children with autism may find being home educated an advantage. However, you may be worried about the lack of opportunity to socialise, as home educated children are often taught alone or in a small group.

Depending on your child's existing social skills and needs, social interaction may be less stressful if you plan and watch carefully. For example, you can help your child's social learning if you and your family act out or role play situations with them, explaining how and why people acted in a particular way. Your child may also be able to socialise with other children who are educated at home, or visit a local youth group or other clubs where they can practise their social skills in a relatively controlled environment. Or, they might like to go to more classes that teach social skills. A combination of any number of these suggestions may help your child to socialise better.

Telling others about your decision to home educate

If you decide to educate your child at home, you will need to follow some procedures. These may vary depending on the age of your child, the type of school they go to (if they already go to school) and whether they have a statement of special educational needs.

Children with a statement of special educational needs

If your child has a statement of special educational needs, it remains the local authority's (LA) duty to ensure that the child's needs are met. The statement must remain in force and the LA must ensure that parents can make suitable provision, including provision for the child's special educational needs. If the parent's arrangements are suitable the LA are relieved of their duty to arrange the provision specified in the statement. If, however, the parents' attempt to educate the child at home results in provision which falls short of meeting the child's needs, then the parents are not making 'suitable arrangements' and the LA could not conclude that they were absolved of their responsibility to arrange the provision in the statement. Even if the LA is satisfied, the LEA remains under a duty to maintain the child's statement and to review it annually. (SEN Code of Practice 2001, section 8:95)

Children who go to a state school

If your child does not have a statement and goes to a state school, tell the school, in writing, that you wish your child's name to be removed from the school register. This will stop any misunderstanding about your child's non-attendance at school. You don't need to let your LA know. However, if you do, they may be able to give you some appropriate guidance and educational materials. They are unlikely to be able to provide any financial help.

Children who go to a special school

If your child goes to a special school, you will need permission from your LA to withdraw your child's name from the school register. If your LA does not agree, you can apply to the Secretary of State for Education. However, you may wish to get legal advice before doing this.

Children who are not yet of school age

If your child is not yet of school age and you decide to home educate them, then you don't need to tell your LA. However, if your LA becomes aware of your child's existence, they may need to be assured that you are providing an 'efficient full-time education' for them. If your LEA is not satisfied that your child is getting an 'efficient full-time education', they may ask you to show how you are meeting your child's educational needs. If you are unable to fulfil this request, then a school attendance order can be served. This will mean that your child has to become a pupil at a school named by your LA.

This should not happen if you can produce, on request, workbooks, projects and certificates that demonstrate your child's progress.

Private Tutors

We advise you to check that tutors have experience of teaching someone with autism. You should also make sure that tutors are CRB (Criminal Records Bureau) checked and have references.

Sarah Freck offers private tuition to students with autism, and covers all core subjects at primary level including helping students prepare for 11+ and independent school entry exams. She also supports students with maths and science tuition up to GCSE and with special needs literacy at secondary level.

Sarah is Salford based and can be contacted on 0161 707 0346

Further Information

NAS Education Rights Service Line 0808 800 4102

National Autistic Society Helpline Information Sheet 'Home Education'

Book, *Home educating our autistic spectrum children: paths are made by walking*, Dowty and Cowlshaw. This clearly explains the legal requirements of home educating your child.

Home Education Advisory Service (HEAS) Tel: 01707 371 854

Department for Children, Schools and Families (DCSF) (2007). *Home Education*. London: DCSF

Department for Children, Schools and Families (DCSF) (2001). *Special Education Needs: Code of Practice*. London: DCSF

What if your child refuses to go to school?

Some children find school difficult to cope with. This can be for many reasons. For children with Asperger syndrome the difficulty is often social in origin. It could be that they are being teased or bullied. It could be that they are aware of feeling/ being different and find other children hard to get along with.

If the person is starting to find school more of a strain talk to the schoolteacher, or school Special Educational Needs Co-ordinator - SENCO. Try to find out if there have been any changes at school to upset the person or if the schoolwork is proving difficult.

If someone is beginning to miss days at school the Education Welfare Officer must become involved. The school SENCO will know who the Education Welfare Officer is.

For independent advice IPSEA is an excellent source of information and support for parents of children with special educational needs. Their contact details follow:

IPSEA (Independent Parental Special Education Advice)

Hunters Court
Debden Road
Saffron Walden
CB11 4AA
Advice Line: 0800 0184016
General Enquiries: 01799 582030
Website: www.ipsea.org.uk

Advisory Centre for Education

General advice line (Mon-Fri 10am-5pm): 0808 800 5793
<http://www.ace-ed.org.uk/>

The National Autistic Society also runs an Education Advice Line Tel: 0808 800 4102.

Sometimes making a few adjustments can work to make school more comfortable for the person. For example, moving the child who makes stupid comments away from the person, or having a quiet room designated for the person to use at lunchtimes.

Sometimes it is necessary to negotiate a return to school on a gradual basis. The school needs to think carefully about how they can make the school environment more comfortable for someone with Asperger syndrome.

It is also important to check there are not 'sensitivities' that are being missed. For example, it may be that one classroom is always perceived as too warm and this makes it impossible to concentrate for the person. Or it could be that PE involves touching other people and this causes anxiety.

There are usually good reasons why a child with Asperger syndrome is refusing school – no one should be forced to go back unless the difficulties have been resolved. The negative effects of bullying should not be under-estimated.

Book

'Asperger syndrome and Difficult Moments' by Brenda Smith Myles and Jack Southwick is a good book for managing difficult behaviour at school.

General Tips if there is a problem at school

Here are some tips to note where there is a problem at school for your child with Asperger syndrome.

- Raise any concerns you have as early as possible with the class teacher.
- Find out who the SENCO (special educational needs co-ordinator) is at school.
- Find out who the school/college's special educational needs (SEN) governor is.
- Obtain a copy of the school/college's SEN policy.
- Obtain a copy of the *Special educational needs code of practice* (see the section 'Useful documents and reading for details).
- Ask to see local authority's guidance/policy relating to special educational needs.
- Keep records of discussions and meetings and a diary of events.
- Keep a diary about your child's difficulties
- Keep copies of all letters.
- Send letters recorded delivery.
- Make sure that any deadlines are strictly adhered to. For example, the school or local authority may be obliged to give you information or take action within a certain time limit, and vice versa.
- Always keep the original versions of any documents you send to the school or local authority – send photocopies.
- Read through all documents – highlight or make a list of things you agree or disagree with.

Preparing for meetings

- Request copies of your child's school or college record before the meeting.
- Read any reports that have been written and highlight any areas that need clarification or are of concern.
- Make a list of your views/concerns and any questions you want to ask.
- Use this list during the meeting and tick off points as they are discussed.
- If you would like another, relevant person (or persons) to attend the meeting, ask if they can be invited (**see section below on Education Advocacy**).
- Ask someone to go with you to the meeting, if possible, and let the school or local authority know that this is happening.
- Don't feel pressured to agree to anything in the meeting.
- Make notes of what is said and, if someone has accompanied you, ask them to take notes as well.
- If anything is not clear ask for it to be explained again.
- Make sure that everything you wanted to discuss has been dealt with; discuss some points again if necessary.

Grievances and Complaints Procedures

It is recommended to use the school or local authority's grievance and complaints procedures first to try and resolve disputes.

In particular think about your grievance and whether you want:

- An apology or acknowledgement for a problem
- Resolution of the problem
- Compensation
- A mixture of the above

Further Information

- **NAS Education Rights Service** 0808 800 4102
- **NAS Information Sheet - Making A Complaint: Useful Tips**

School Exclusion

Government Statistics suggest that children with identified special needs (SEN) are at higher risk of exclusion than children who do not have such needs.

As a result, it is not uncommon for parents to contact the NAS Helpline asking for advice on what to do when their child has been threatened with exclusion.

According to the most recent government guidance on exclusion, schools should only exclude pupils 'in response to serious breaches of the schools discipline policy; once a range of alternative strategies have been tried and have failed; and if allowing the pupils to remain in school would seriously harm the education or welfare of other pupils.'

An exclusion can only be made by:

- the head teacher of a maintained school
- the teacher in charge of a pupil referral unit (PRU)
- a person acting in either of the above roles.

When a child is excluded, either for a fixed term or permanently, the parents should be notified of the reasons for the exclusion and are entitled to appeal against this.

Fixed Term and Permanent Exclusions

Fixed Term Exclusions

A fixed term exclusion lasts for a fixed period of time which is decided before the exclusion begins. Some schools describe fixed term exclusions as suspensions. Schools are not allowed to exclude a pupil for more than 45 days in each school year.

A fixed term exclusion does not need to be for the whole school day, it may be deemed necessary for certain lessons or for lunch hours only. Where this occurs, the guidance mentioned above states that it should not last for more than 5 days. In that time the school should establish whether extra support is needed to meet the child's needs or make a decision whether the school placement is right for the child in the long term.

Permanent Exclusions

A permanent exclusion means that the child will not be allowed to return to the school they have been excluded from unless they manage to overturn the exclusion decision on appeal, or the schools Disciplinary Committee decide the child should be reinstated. Permanent exclusions should only be used as a last resort, where other approaches have failed and where serious breaches of the schools disciplinary code have occurred.

If the head teacher decides to permanently exclude a child the school's governing body must meet to consider the exclusion.

Children with Statements Pupil support guidance (social inclusion) specifies that for children with statements, permanent exclusion should be avoided and instead, when schools are at the end of their tethers they should arrange an interim review of the statement which might lead to more support being provided or a different placement being suggested.

What if your child is excluded?

Parents should be informed in writing by the head teacher of the decision to exclude. This should explain how long the exclusion will last for and the reasons for exclusion. Parents should be informed of their right to state their case to the school's discipline committee and the practical information needed to do this. including the telephone number of a contact within the local authority

who can advise on the exclusions process. For permanent exclusions parents also need to be notified of the day in which exclusion takes effect and details of any earlier warnings, exclusions or other disciplinary measures taken.

Arrangements should be made for your child to continue his or her education, including setting and marking school work. For the first five days of a permanent exclusion the school is responsible for arranging education. The local authority is responsible for providing full-time education from the sixth day). It is parents' responsibility to make sure that work sent home is completed and returned to school.

In most cases involving children with autism, parents should consider whether the following conditions apply:-

- **If exclusion has occurred as a result of an unmet special educational need**

Providing additional support on the school based stages on the school based changes of the code of practice or requesting a statutory assessment would be the appropriate way forward

- **The child has a special educational need which has been identified, they have a statement but the provision specified on the statement does not meet their needs**

Parents or the school can request an early statement review. Amendments to the statement resulting from the review can be processed in 16 days, allowing 15 days for the parents to make representations if they are unhappy with the proposed arrangements. This is generally the most appropriate action to take when a child with a statement is threatened with exclusion.

- **The child has a special educational need and a statement, but the school named in Part 4 of the statement does not feel able to meet the child's needs**

Instead of exclusion, the school should talk with parents and possibly request an early review aimed at identifying a more suitable placement. If parents are unhappy about a decision to change the named school in Part 4 and want their child to remain at the current school, they have the right to appeal to the SEN tribunal over this (see below).

- **The exclusion is for lunchtimes only and is happening because the school does not feel able to support the child appropriately during these periods**

Appeals Against Exclusion

As a parent, you have the right to put your case in person and/or in writing to the chair of the governing body of your child's school.

For permanent exclusions, the governors must meet within 15 school days of the exclusion. For fixed term exclusions of less than 5 days, the governors do not have to meet, but should if requested.

It is advisable to take somebody for support at the governors' meeting and to prepare anything you wish to say beforehand. The governors must consider all the evidence and decide whether the head teacher was justified in excluding your child. For fixed term exclusions, if your child is still out of school at the time of the meeting, the governors must also decide whether to direct reinstatement.

The governing body must inform you, in writing, of its decision (and the reasons for its decision) within one school day of the hearing. They must also inform the head teacher and the local authority.

If a permanent exclusion is upheld, parents can appeal to the Independent Appeal Panel (IAP). Your child will remain at school until the IAP hear the appeal.

Further Information

NAS Information Sheets

Education; fixed term exclusion (England and Wales)

Education: permanent exclusion (England and Wales)

If your child has been excluded and you need help or advice contact:

NAS Education Rights Service Line 0808 800 4102

ACE (Advice Centre For Education)

Exclusion information line (24hr answer phone): 020 7704 9822

Exclusion advice line (Mon-Fri 10am-5pm): 0808 800 0327

IPSEA Tribunal Helpline 0845 602 9579 (Daytime hours: Mon, Tues, Weds 10-1 and Thurs 10-4. Evening hours: Wednesday 7-9)

Education Advocacy

The aim of advocacy is to speak and act on behalf of a person or a person's family and carers, including those with Asperger Syndrome, who sometimes cannot fully plead their cause themselves.

The aim is to ensure the person's needs are fully heard and to secure the rights and services the person believes they are entitled to.

Advocacy is often used for education provision problems, although it is useful to be clear on what you want to achieve. See note above on general tips if there is a problem at school.

If you need help with a tribunal appeal contact the following

NAS Education Rights Service Line 0808 800 4102

ACE (Advice Centre For Education) Information line (24hr answer phone): 020 7704 9822

Contact A Family – SEN National Advice Service. Contact a Family run a Special Educational Needs advisory service covering all education issues. Contact their helpline 0808 808 3555 [email helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

IPSEA Tribunal Helpline 0845 602 9579 (Mon, Tues, Weds 10-1 and Thurs 10-4 Evening hours: Wednesday 7-9)

Pannone Solicitors 0800 0384 384 (see below)

Education Advocacy Workers

Victor Staley

SEN Action & Support Group for parents & children with SEN's
C/o Fraser Street
Pendlebury
Salford M27 4DH
Tel: 0161 727 9065

A parent let us know about Victor who provides advocacy support at Tribunals.

Leah Burman

Fairlawns House
1 Thorn Road
Bramhall SK7 1HG
Tel: 0161 612 8808

Website; leah.burman.com

Parent who contacted the project has had involvement from Leah and found her very helpful. Not a specialist in ASD but has a wealth of experience in the field of education psychology.

Educational Law Solicitors

If you feel you need specialist legal advice in educational law issue for a child or adult with Asperger Syndrome, **Pannone**, based in Manchester have specialists in Educational Law. You may be entitled to legal aid depending on your means. Telephone 0800 0384 384.

The organisations listed in the 'Advocacy' section may also be able to assist with education tribunals.

Further Information

NAS Information Sheet

Education: advocacy tips for parents (England and Wales)

Appeals to Special Educational Needs and Disability Tribunal (SEND)

If parents cannot reach agreement with the LEA regarding their child's special educational needs, they can appeal.

Appeals are made to **The Special Educational Needs & Disability Tribunal (SEND)** set up by the Education Act 1993. The tribunal is independent and has no connection with any LEA. It covers children at school and in a sixth form which is part of a school run by an LEA.

The tribunal has powers to consider appeals in the following areas:-

- Should your child be assessed?
- Should your child have a statement?
- What should your child's statement say?
- Disability discrimination claims

SEND Contact Numbers

- **SEN Helpline** 0870 241 2555
- **Discrimination helpline** 0870 606 5750

Website <http://www.sendist.gov.uk/>

SEND also produce documents on:-

- **How To Appeal**
- **Disability discrimination in schools - How to Claim**

If you wish to appeal to SEND and you need help or advice contact:
National Autistic Society Education Rights Service Support Line 0808 800 4102

A list of schools with special provision for children with an Autism Spectrum Disorder and accredited by the NAS is included later in this document under 'Specialist Schools'.

Bullying

If your son or daughter is being bullied, action must be taken. Talk to the school to find out more information about what is happening and discuss how best to tackle the difficulties.

Children with autism can be at more risk of being bullied. This is often because the different ways in which children with autism communicate and interact can become more apparent to their peer group, especially as they get older. Because children with autism find it hard to read facial expressions and body language, they can't tell when someone is being friendly or if they are trying to hurt them. They also find it hard to put themselves in someone else's shoes and therefore don't understand another child's intentions. Children with autism 'may appear to be naïve and trusting, unable to discriminate between friendly approaches and those approaches which are intended to 'wind them up'. Some children with autism will try to fit into their peer group by doing things other children suggest – when bullies suggest things, it can often be something that can hurt the child with autism or get them into trouble with school staff.

Playground behaviour

A child with autism is an easy target in the playground as they often prefer to play alone in the playground. As a result, other children find it easy to 'pick' on them as they do not have a support structure around them. Other children may also pick on children with autism if they see them doing 'odd' things such as hand flapping or making inappropriate comments.

Being a bully

Children with autism can also become a bully themselves. Some children will become aggressive when a game is not being played the way they want and will try to take control of the situation. They may also become frustrated at being 'left out' in the playground and try to 'make' children become friends with them.

How to tell if your child is being bullied

The difficulty for you, as a parent, is that it is not always easy to tell if your child is being bullied. Because of problems with understanding others' intentions, children with autism may not always realise they are being bullied (Attwood, 2005). Communication difficulties can also make it difficult for them to tell you or school staff about an incident. As a result, you may need to look for other clues as to whether or not your child is being bullied.

The effects of bullying on your child

The long-term effects of bullying can be serious for a child. According to research findings, bullied children can end up with long-lasting insecurities, behavioural issues and low self-esteem, as well as poor concentration. They may refuse to take part in social situations because they are afraid of being bullied

What you can do

Talk to your child: with autism will find it difficult to talk to you face-to-face. Some may find it easier to write about the incidents or draw a picture about what happened.

Talk to the school: Once you have spoken to your child, make an appointment to talk to your child's class teacher. All schools are now legally required to have an anti-bullying policy (for more information, see Rights and responsibilities). Ask for a copy of your child's school anti-bullying policy to see what the school has put in place to deal with bullying.

Circle of Friends is a practical strategy used in some schools that can be an assistance to prevent or reduce bullying. Contact the school SENCO to ask about this. Or contact the National Autistic Society helpline 0808 800 4104.

Further Information

Organisations and helplines

Anti-Bullying Campaign – Helpline Tel: 0207 378 1446. The Anti-Bullying campaign can provide a list of local bullying counsellors.

ACE (Advisory Centre for Education) have produced a booklet *Bullying- a guide for parents*. They also run a Helpline Tel: 0808 800 5793. website: www.ace-ed.org.uk.

Kidscape is an organisation which has a Helpline for parents with a child who is involved with bullying.

Open weekdays 10am – 4pm Tel: Helpline 0845 1205204 Office 0207 730 3300.

Website: www.kidscape.org.uk

Bullying On Line is an internet based support group on bullying. Their internet site is www.bullying.co.uk. Email : help@bullying.co.uk

The National Autistic Society Helpline Telephone - 0808 800 4104.

Publications

Book “Words can REALLY hurt me”

This is an excellent guide to bullying problems. Educating other pupils about Asperger syndrome can be a great help if done in the right way and if the child has the right support from adults around him or her. It can be used as one strand of an anti-bullying strategy.

Brochure “B is for Bullied”

This brochure is part of the National Autistic Society's ‘Make School Make Sense’ campaign. It covers and discusses the following areas:-

- Why children with Aspergers can be vulnerable to bullying
- How does bullying affect children with Aspergers
- Effects of bullying on the family
- School Bullying Policies
- Preventing Bullying

It includes a number of quotations from children and their families on bullying and how it affects their enjoyment of school.

It makes a number of recommendations on bullying for National Government, Local Government and Schools.

Information Sheets

“Asperger syndrome in your classroom” This covers many essential issues that occur in school and is written for other pupils to read. It mentions the TV character Martin in Grange Hill who has “Asperger syndrome. It also gives details of websites for young people with Asperger syndrome to chat to others with the same condition. (See section on websites for people with Asperger syndrome).

Information Sheet “Bullying A Guide for parents” This covers what parents and carers can do about bullying – whether it is bullying in the school playground or cyberbullying – from talking to your child’s school about the bullying and trying a range of approaches to help you help your child. It also provides information on how to take your complaint further.

Information Sheet “A guide for Young People with an Autism Spectrum Disorder” This information sheet explains what bullying is, and what you can do if you are being bullied and how to get support.

B is for Bullied’ and the information sheets are available from the National Autistic Society Helpline. Call 0808 800 4104

Books and Booklets

‘Bullying and how to deal with it: A guide for pupils with Autism spectrum disorders’ by P. Thorpe. National Autistic Society

“What does it mean to have autism” by Louise Spilsbury, Heinemann press, 2001 is an excellent book for other young people to read so they understand Asperger syndrome better (older primary, and early secondary students).

Bullying and Autism Spectrum Disorders by Alice Stobart. A guide for school staff.

To help teachers understand more about how it feels to have autism and thus be in a better position to assist students, suggest they read **“Martian in the Playground”** by Clare Sainsbury, Lucky Duck press, 2000.

Break times and lunchtimes

The school playground is one of the places where children with autism can be most vulnerable. Unlike other children who find the playground the most relaxing time of the day, children with autism often find unstructured periods of time difficult as they are not sure what to do or what is expected of them. As a result, they may hide away in unsupervised areas of the playground or carry out an activity on their own.

It may be useful for your child’s school to bring some structure to break times/lunchtimes. For example, the school could provide lunchtime clubs or let your child go to the library or to use a computer during breaks. You could also ask the school to set up structured playground activities for your child and a couple of their peers. This way your child gets to socialise, but also knows what is expected of him.

Further Information

NAS Brochure Understanding Difficulties at Break Time and Lunchtime by Patricia Thorpe

Homework

There are several different reasons why children with an Asperger Syndrome might have problems with homework.

Possible reasons for difficulties

- If homework does not meet your child's level of need, he/she may find it too difficult and may become frustrated and not want to work at home
- Your child may have difficulty understanding why they have to do work for school when they're at home
- If your child has problems with writing and is not supervised when writing down homework, it may be unclear what work needs to be done when they get home
- After being at school all day your child may be tired and find it difficult to concentrate on other work
- There may be too many distractions at home for your child to concentrate on homework
- Your child may have problems organising themselves to do homework and may spend too long or too little time on it.

Making sure homework is suitable for your child

If your child is having difficulties with homework, it is important that you talk with your child's class teacher. If the teacher doesn't have much experience of autism it could also help to give school staff some information about autism spectrum disorders.

Further Information

NAS Information Sheet: Supporting Children with an Autism Spectrum Disorder with Homework

Information for Teachers

The National Autistic Society produce a number of information sheets and brochures to help classroom and Special Education Needs teachers more fully understand Asperger Syndrome.

Brochures

- Autism spectrum Disorders – A Guide For Schools
- Working with an Asperger pupil in secondary schools
- Exam Advice for young people with Autism and Asperger Syndrome
- Autism Spectrum Disorders in Young Children – A Guide for Early Years Practitioners

Information sheets

- A Schools Guide To Asperger Syndrome
- Asperger Syndrome In Your Classroom
- Lesson Plan for explaining Asperger Syndrome
- Autism Worksheet for Primary Schools

Parent Partnership Service

For each Local Education Authority there is a Parent Partnership Service (PPS) which is a service offering information, advice and support for parents and carers of children and young people with Special Educational Needs and to help parents understand their rights in relation to their child's education. PPS can help with disputes at school, and difficulties relating to special educational needs and the Statementing process.

The National Parent Partnership Network (NPPN) supports all local parent partnership services across England. It works under the aegis of the Council for Disabled Children and is funded by the Department of Education and Skills.

For more independent advice IPSEA and ACE both offer comprehensive advice and support about special educational needs and the law.

IPSEA – Tel: 0800 0184016 (Advice line)

ACE – Tel: 0808 800 5793 (Advice Line) www.ace-ed.org.uk

Be aware that if someone with Asperger syndrome does not have a SEN but is on the Code of Practice (Action/Action Plus), they may be the subject of an assessment under the Learning and Skills Act 2000 section 140.

Parent Partnership Service –: Local contacts are in the table below. Mention that your son or daughter has Asperger Syndrome.

AUTHORITY	CONTACT	ADDRESS	TELEPHONE
Bolton	Gill Bullock	Bolton Parent Partnership Service Lowndes Street Bolton BL1 4QB	01204 848722
Bury		Bury Parent Partnership Service Red Centre Morley Street Bury BL9 9JQ	0161 763 5001
Manchester	Maureen Howell	Manchester Parent Partnership Service Westwood Street Moss Side Manchester M14 4PH	0161 209 8356 or 0161 245 7300
Oldham		Oldham Parent Partnership Service 5 Barn Street Oldham OL1 1LP	0161 287 8555
Rochdale	Ann McBride Barbara Savage	Rochdale Parent Partnership Family Action 25 Lingmell Close Middleton M24 4HS	0161 653 4461
Salford	Maureen Fowler	Salford Parent Partnership Minerva House Pendlebury Road Swinton M27 4EQ	0161 778 0349
Stockport		Parent Partnership Stockport 12 School Lane Heaton Chapel Stockport SK4 5DG	0161 431 3024
Tameside		Tameside Parent Partnership Service Tameside Council Office Room 2.103 Wellington Road Ashton Under Lyne OL6 6DL	0161 342 3383

Trafford	Geraldine English Nicola Montes Amanda Window	Trafford Parent Partnership Service Cherry Manor Centre Cherry Lane Sale M33 4GY	0161 912 3150
Wigan	Sheila Robinson	Wigan Parent Partnership Service Progress House Westwood Park Drive Wigan WN3 4HH	01942 4861310

What if your child has difficulties with taking exams?

If the person has a Statement of Special Educational Need (SEN) the extra exam support should be written into the Statement.

If someone is at school and does not have a SEN and is likely to require extra support in exams talk to the Special Educational Needs Co-ordinator (SENCO) at the school to discuss whether arrangements can be made for extra time, or other provision.

If someone is likely to need exam concessions at GCSE start organizing the support when they are taking exams at an earlier age (SATs exams).

Some of the possible concessions required may include:

The examination room (for example young person may need to be invigilated separately, to avoid distractions and allow him or her to move about, if necessary)

Extra time (may be required for some young people)

Presentation of exam papers (occasionally the person may require scotopic sensitivity-friendly coloured paper)

Word processing instead of handwriting may be necessary if someone has fine motor difficulties.

Oral tests will require the examiner to be made aware of Asperger syndrome before the exam.

In Further Education getting exam concessions is often less complicated if the person has a Statement of Special Educational Need (SEN).

If someone does not have SEN but will encounter difficulties unless they have exam concessions, talk to the Learning Support co-ordinator at the college. It may be that a letter from the person's GP, or psychologist explaining the need for extra time will suffice.

Further Information

NAS Booklet Exam advice for Young people with autism and Asperger Syndrome: guidelines for teachers, parents and pupils.

Moving From Primary to Secondary School

The transition from primary to secondary school is a major change in a child's life. It could involve travelling to a new area as well as many other changes, such as:

- a much larger number of pupils
- being the youngest at the new school
- more teachers for different subjects
- a new building
- new timetables
- new and different routines, e.g. dinnertime arrangements.

Good preparation can help alleviate transfer difficulties. It is usual for the children to visit the secondary school once or twice before September to help smooth the transition and to help eliminate any concerns. Also, meeting the new teachers and learning support assistants can help lessen the stress.

If possible, a visit to the primary school by the special educational needs coordinator (SENCO) or a secondary school learning support assistant can be very beneficial, as staff at the primary school can give a good picture of possible anxieties.

Here are some guidelines covering the main areas of secondary school life.

- Travelling to school by bus
- The geography of the school
- Following a timetable
- Using lockers.
- School diaries
- Responsibilities for equipment and property
- Procedures for break and lunchtimes

Social and communication problems

Children with Asperger Syndrome often have major problems with socialising and making friends. A 'buddy' system or circle of friends can help.

It is important for the school to actively set up a dialogue with parents, who know their child better than anyone. An awareness of difficulties can help teaching staff to understand autism. Hopefully with a little understanding, the transition to secondary school will be a positive experience.

Further Information

NAS Brochures

Moving from Primary to Secondary Education by Patricia Thorpe
Understanding difficulties during break and lunchtime at secondary school: guidelines for pupils with autistic spectrum disorders by Patricia Thorpe

Specialist Schools

National Autistic Society Directory of Services website www.autismdirectory.org.uk contains an up to date national lists of specialist schools for children with Asperger Syndrome.

Sometimes local authorities cannot meet the specialist needs of someone with Asperger syndrome. There are few places nationally for those people who have high support needs. This is not a definitive list and as with all placements you must make your own assessment of the quality of provision.

NATSPEC is a national directory of specialist colleges. Check their website for details www.natspec.org.uk

Residential and Specialist Day Schools

Residential care is the term used to describe homes and units that offer 24 hour care and support. Some people with Asperger syndrome require this, although most don't.

If someone requires residential care they may wish to approach the Social Services team for assistance. There are many providers of residential care for people who have learning disabilities.

In order to get a residential placement Social Services would have to agree to fund the cost. Sometimes Health contribute to the cost if there are health needs.

If the child is likely to require residential care then have a good look around at the possible placements available.

Establishments accredited by the National Autistic Society Autism Service Accreditation programme in the North West currently include:

David Lewis School

The David Lewis School is a small, very specialist school catering for pupils aged 7-19, whose neurological impairment is their primary difficulty. Planned and residential respite services are just for their own pupils or children known to them.

Pauline Greenall

Headteacher

Mill Lane

Warford

Alderley Edge

Cheshire SK9 7UD

Telephone number: 01565 640066

Email: pauline.greenall@davidlewis.org.uk (launches email software)

Web link for contact: www.davidlewis.org.uk

Manchester Progressive School

Manchester Progressive School offers a full and balanced curriculum. The concentration of the teaching programme is on developing relevant skills and applying them to situations throughout the pupil's day. Our curriculum is planned to promote pupil's learning via a wide range of experiences and activities including personal, social and health education opportunities, and the development of leisure, independence and mobility skills. **Residential and Day Pupils.**

Diane Jones
Head Teacher
1524 Ashton Old Road
Manchester M11 1HN
Telephone number: 0161 371 5004
Email: di@europeanwellcare.com (launches email software)
Web link for contact: www.europeanwellcare.com

Royal School Manchester

Caters for students from 2-19 years with a Sensory Department which delivers education for students with a multi sensory impairment and /or autism.

Hilary Ward
Principal & Chief Executive
Royal School Manchester
Stanley Road
Cheadle Hulme
Cheshire
SK8 6RQ
Telephone number: 0161 610 0144 (School/College Secretary)
Email: hilary.ward@seashelltrust.org.uk (launches email software)
Web link for contact: www.seashelltrust.org.uk/contact/

Chetham's School of Music

Chetham's is the largest specialist music school in the United Kingdom (UK). It is an international specialist music school with a large boarding component. It is part of the government's music and ballet scheme. It has learning support provision for children with Asperger's Syndrome, but no special ASD courses.

Mrs. C J Hickman
Head
Long Millgate
Manchester M3 1SB
Telephone number: 0161 834 9644

Bright Futures School

Specialises in provision for children (5-19) with a diagnosis of autism or Asperger Syndrome and a statement of special educational need. They may well have good language skills but will have experienced difficulties in coping with the demands of other education settings. Parents will be seeking a school that provides a quiet environment, lots of personal 1:1 support and a different approach to learning.

Fees are paid to the school proprietor (Bright Futures Autism Limited) by the Local Authority. We are not able to consider private funding.

158 Huddersfield Road
Diggle
Oldham OL3 5PJ
Telephone Number : 01457 829 449
E-Mail: info@brightfuturesautism.com **website** www.brightfutureschool.co.uk

Remember that each potential placement must be visited to see whether it is suitable for the particular individual and that there are often long waiting lists for specialist placements.

Contact the National Autistic Society Accreditation Services for up-to-date details of 'accredited' places for people with Asperger syndrome locally. Tel: 0117 974 8429, or look at the National Autistic Society Directory of Services website www.autismdirectory.org.uk

Local Day Schools

Each local authority has special schools or a base within mainstream schools catering for children with Asperger Syndrome whose needs cannot be met within a standard mainstream school environment.

Note that attendance at some special schools requires the pupil to have a statement. Note that special schools vary considerably: some are just for pupils with an ASD while others are for pupils with moderate or severe learning difficulties, pupils with physical difficulties, or a mixture of the two.

Schools in each local authority area in Greater Manchester.

Note Schools in bold type will take pupils from outside the local authority area.

<p>Bolton</p> <p>Rumworth School (Ages 11-19) Tel: 01204 333600 Birtenshaw Hall School (Ages 5-19) Tel: 01204 306043 Ladybridge High School (Ages 11-16) Tel: 01204 333355</p>	<p>Bury</p> <p>Elms Bank Specialist Arts College (Ages 11-19) Tel: 0161 766 1597 Mersey Drive Community School (ages 4-11) Tel 0161 766 6298 Millwood Primary Special School (Ages 5-11) Tel: 0161 764 6957</p>
<p>Manchester</p> <p>Grange School Rusholme (ages 4-19) Tel: 0161 248 4841 Manchester Progressive School (Ages 4-19) Tel: 0161 371 5004</p>	<p>Oldham</p> <p>Counthill School (ages 11-16) Tel: 0161 624 6366 Kingfisher Community Special School (ages 3-11) Tel: 0161 925 3053</p>
<p>Rochdale</p>	<p>Salford</p> <p>Oakwood High School (Ages 11-16) Tel: 0161 786 1920 Inscape House (Ages 5-19) Tel: 0161 975 2340</p>
<p>Stockport</p> <p>Inscape School, Cheadle (Ages 4-16) Tel: 0161 283 4750 Valley School (ages 3-11) Tel: 0161 439 7343</p>	<p>Tameside</p> <p>CLASS (Communication Language and Autistic Spectrum Support) (ages 2-16) Tel: 0161 320 5232 Hawthorns Community School (ages 4-11) Tel: 0161 336 3389</p>
<p>Trafford</p> <p>Pictor School (Ages 2-11) Tel: 0161 912 3082 Brentwood School (Ages 11-19) Tel: 0161 928 8109 St. John Vianney School Tel: 0161 881 7843</p>	<p>Wigan</p> <p>Landgate School, Bryn Tel: 01942 776688</p>

SOCIAL SERVICES

Getting help for your child

Caring for a child with Asperger Syndrome can be hard work. It can be hard work for parents who may have to provide far more help and support for their child with Asperger Syndrome than they would for another child their age. It's not always easy for siblings either. They may feel they have to take on caring responsibilities while still very young, or they may feel neglected because their brother or sister takes up so much of their parents' time.

In addition to these difficulties the typical breaks that most parents may get because their children go to visit friends or are able to do things by themselves are often not an option. Families already under pressure have to spend more time supporting each other, not less. In these circumstances it isn't surprising that families often find they need to ask for help.

What services do I need?

Being clear about what your needs are makes it much easier to identify which services you require. Sometimes it becomes clear that you need a combination of services, such as respite care to give you a break, and behaviour management advice to help you cope better.

The following list shows just some of the sources of support families can use. Not all families have access to all these different types of help.

As well as help from family and support groups, and financial benefits such as Disability Living Allowance (DLA), parents may also require services from the local authority

Getting help from social services

The services that Social Services Departments are able to offer include:

- advice on benefits and funding special equipment or recreational activities
- occupational, social and recreational activities
- home help
- respite care
- assistance with travel
- assistance with holidays and out of school provision
- aids, equipment and grants for housing repairs and adaptations.

In most cases they can advise on a range of other services and provide you with appropriate contacts for further help.

The first step is to write to your local Social Services explaining that you have a child with an autism spectrum disorder and asking for an assessment using the model letter below.

Children with disabilities have rights to an assessment under the *Children Act 1989*. The local authority then has a duty to provide any services necessary to meet their needs. In theory this means that the local authority could fund virtually anything if it is necessary for the child's development. In practice disabled children and their families tend to be offered residential and home based respite care but very little else.

Lastly, the *Carers (Recognition and Services) Act 1995* and the *Carers and Disabled Children Act 2000* require local authorities to assess the needs of carers and where necessary to provide services to meet those needs. If you as a parent request an assessment for your child you should also request a carer's assessment.

Sample letter to write to Social Services for support

(Team address)

(Date of letter)

Dear Team Manager

Re: (Child's name) (date of birth) (address)

I would be most grateful if a social worker could contact me at the earliest opportunity in relation to the support needs of my son, (name), who has an autism spectrum disorder/ Asperger syndrome.

Can you arrange for my (son) to be entered on your Register of Disabled Children?

Can you arrange an assessment of my (son's) needs for support, under the Children Act 1989, and my own needs as carer under the Carers and Disabled Children Act 2000?

Some of the needs my (son) have included:

NOTE TO PARENTS: You may wish to include some of the following examples in your letter and add some of your own. The important principle is to be as clear and accurate about what the person actually needs.

1. the need to reduce his social isolation, help him leave the house/ bedroom
2. the need to be able to travel independently and use public transport safely
3. the need to improve his ability to relate to others (may include social skills); make friends
4. the need to live independently of his parent/ carers (housing options and planning)
5. the need to have someone to talk to outside the family (for example befriender schemes, clubs)
6. need for counselling – emotional difficulties; counselling relating to bullying
7. need to learn how to avoid attracting negative attention in public, grooming, wearing appropriate clothes, self presentation
8. the need to recognise dangerous social situations; “stranger danger”
9. the need to develop appropriate relationships/ sexual behaviour
10. the need to discuss Asperger syndrome and how it affects him or her
11. the need to be able to explain Asperger syndrome to others (acquaintances, school pupils, college students)
12. the need to develop practical life skills – dressing, cooking, laundry, cleaning
13. the need to develop financial independence/ ability to manage own money
14. the need to control his anger towards others
15. the need to control his anger towards himself
16. the need to understand personal safety outside the home, how to recognise and avoid ‘risk’ situations, reporting risk
17. the need to understand personal care, washing self, showering, getting enough sleep, how to relax
18. need to manage any additional physical difficulties (for example epilepsy, ADHD);
19. need to be encouraged to use prescribed medication
20. need for assistance with mental health and associated difficulties (for example, depression, obsessions, panic attacks, agoraphobia, anxiety)
21. the need for me as a parent include opportunity to occasionally have a break from full time caring for my son/daughter – I am interested in finding out information about respite and similar services – such as out of school clubs, playgroups, sitting services, local sport clubs etc
22. the need for my other child/ren to occasionally have some time with his/her parents without our son/daughter being present – I am interested in any services that your department has to meet the needs of siblings of disabled children.

My overall needs as a parent and carer are to have my own living space and for my son/daughter to grow up able to live independently of me in the future. I need to know that s/he will be safe and

looked after when I am no longer able to provide the support I do at present. I also need support at the present time with enabling my child to develop appropriately.

Can you provide practical and emotional support services to meet the needs identified during the assessments?

Can you provide advice on what help I can access from other relevant agencies, details of voluntary groups and information on Benefits?

I look forward to hearing from you as soon as practicable.

Yours sincerely

(parent/s signature)

(Name of parents)

Assessment Process – What actually happens

Government guidance on assessing children in need (*Frameworks for Assessment of Children in Need, 2000*) states that within one working day of a referral coming in, it is expected that Social Services should decide what response is required. If the decision is to take no action you should be notified promptly and given reasons for this.

It is important to know why you are asking for an Assessment of Need. Before writing or calling Social Services for support think carefully about the exact needs of the child.

Every local authority has eligibility criteria to determine whether an individual will receive services from the local authority and may use a priority system. The eligibility criteria are likely to be on your local authority's website or you can request a copy directly from them.

Initial Assessment

If the decision to do something is made, a social worker should contact you to carry out an initial assessment within seven working days. An initial assessment will help the department identify whether or not your child is in need, what services may be needed and whether the case is urgent or not. They will need to see and speak to your child at this stage as well.

The best results are usually achieved when families work co-operatively with the Social Services and give them all the information they need to make a reasonable assessment.

Core Assessment

After this they may decide to carry out a core assessment. A core assessment will be much more thorough and will require social services to fully evaluate the level of your child's needs and the help you as parents are able to offer as well as the services your child might need. They may liaise with other professionals with whom you have contact to find out more about your child.

If parents wish for support during the assessment, ask a friend along to take notes, or an advocate, perhaps from the local NAS Branch or a local autism support group or society (see later list).

The core assessment should be completed within 35 days. At the end of this time they should inform you of what services, if any, they are going to provide, and you should be given the opportunity to respond to this.

Parents can ask for a copy of the assessment when it is complete, and if anyone feels it is inaccurate, they should let the Social Services Care Manager know their dissatisfaction.

You should also be informed that you are entitled to use the local authority's complaints procedure if you're unhappy with the way the assessment has been conducted or the decisions made.

Families should not be pressured into accepting an assessment that does not represent their situation accurately.

What happens after Assessment?

Once the assessment has been completed the social worker should draw up a 'children in need care plan'. This outlines the needs that have come to light through the assessment process and the services that will be offered to your child as a consequence. They will not list services that need to be obtained from other statutory bodies such as the health authority or local education authority although they may make reference to the fact that you will be approaching these departments for further help.

Charging for services

Your local authority will almost certainly make a charge for the services offered to your child and to you. These charges will be means tested so your income and savings may be taken into account. They should only assess your income once they have decided which services to offer, so your ability to pay should not influence their decisions about what your child needs.

If you feel the charges are unreasonable or that it's not possible for you to pay them you should find out first how the charges were worked out. You should then seek specialist advice from one of the Helplines listed below. You may also be interested in the direct payments scheme listed below.

Involving the child with Asperger syndrome

Depending on ability and motivation, the child should be a part of whatever request is made for an assessment. It is good if they can express their needs themselves, although it is common for parents to need to 'interpret' at least some of the needs. Indeed it is usually parents who request a community care assessment on their son or daughter's behalf.

Either way, once a request for an assessment has been made, families should not be left waiting for months, before the assessment begins. As there is no exact timescale in law, ask to see local procedure on how long it should take for an assessment, if this is an issue.

Things to remember!

- Do ask for help if the child with Asperger Syndrome requires help - either now, or over the next few years.
- Do think carefully about what support he or she requires.
- Do put your request in writing to Social Services
- Do work co-operatively with the local authority and be prepared to be persistent

Who to write to in Social Services for support

<p>Bury Children's Advice and Assessment Team Tel: 0161 253 5454 Craig House 5 Bank Street Bury BL9 0BA sschildrenquiries@bury.gov.uk</p>	<p>Bolton Disabled Children's Services Crescent House Lever Street Bolton BL3 6NN. Tel: 01204 337100</p>
<p>Manchester Manchester Contact Centre for Social Care Services Specialist Resource Team Manchester Contact Service, Carisbrooke Resource Centre, Wenlock Way, West Gorton, Manchester M12 5LF Tel: 0161 255 8250</p>	<p>Oldham Children with Disabilities Team Woodfield, Manchester Road Oldham OL8 4ET. Tel: 0161 627 1749</p>
<p>Rochdale Team for Children & Young People with Disabilities, Whitworth Road Depot, Haynes Street Rochdale OL12 0EX Tel: 01706 925900</p>	<p>Salford Salford Childhood Disability Social Work Team Salford Families Project 222 Eccles Old Road Salford M6 8AL Tel: 0161 707 0222 salford-families.project@barnados.org.uk</p>
<p>Stockport Customer Enquiry and Referral Management Team, Mount Tabor Mottram Street, Stockport, SK1 3PA. Tel: 0845 644 4313</p>	<p>Tameside Children with Disabilities Team, Jubilee Gardens, Gardenfold Way, Droylsden, M43 7XA. Tel: 0161 371 2076. Or (if no social worker) Children's Customer Services Tameside Social Care and Health 56 Warrington Street, Ashton Under Lyne OL6 7JX</p>
<p>Trafford Children's Multi Agency Referral and Assessment Team (MARAT) Stretford Public Hall Chester Road Stretford M32 0LG Tel: 0161 912 5125</p>	<p>Wigan Wigan MBC Social Services Department Civic Centre Millgate Wigan WN1 1AZ or telephone the Duty Team on 01942 828300</p>

If you feel unhappy with the local authority response

If the local authority refuses to assess your child, or you feel that your child's assessment wasn't adequate or you're not happy with their care plan, then you have a right to complain.

Where the local authority has refused to assess your child, a formal letter should be written to the local Children's Social Services Director noting your concerns and mentioning their legal requirement to assess a disabled child. A sample letter is shown below.

Letter Challenging local authority's refusal to assess a disabled child

YOUR NAME
YOUR ADDRESS
DATE

Dear [NAME],

I am writing to you because I have been told that my son / daughter will not be assessed for services from the council. I was told this by *[insert name and job title of the person]* in a letter / telephone call / meeting on *[date]*. *[If you have asked for an assessment and there has been no response, set out instead when you asked and in what way – phone call, letter, email etc].*

My child *[name]* is *[age]* and has the following disabilities and special needs *[write a short summary here of your child's needs, including any diagnoses they may have]*.

As you can see my child *[is a 'disabled' child / may be a 'disabled' child]*. I understand that under section 17 of the Children Act 1989 there is a very wide definition of 'disabled' and there is a duty to assess every child who is or may be disabled. As such the council has a duty to assess my child.

I also understand that under the Framework for the Assessment of Children in Need and the Working Together to Safeguard Children guidance, an **Initial Assessment** must be carried out within **10 working days** of the referral, and a **Core Assessment** must be carried out within **35 working days** of the date of the referral or the date the Initial Assessment was completed, if the council decides to do an Initial Assessment first.

Please therefore confirm as soon as possible that the council will comply with its duties and carry out either an Initial Assessment or a Core Assessment in the time required by the guidance.

[If you want a particular service, ask here for this to be considered in the assessment – for example 'The main reason why I want my child to be assessed is because he does not get enough social opportunities and I want him to have the benefit of a regular short break. I also need a break from caring for him so I can recharge my batteries. Please confirm that the assessment will specifically consider our need for a short break']

I have written this letter using a guide which has been published by the Every Disabled Child Matters campaign. The guide was based on legal advice. I hope you will confirm that the council will act on its duty to assess my child, but if you do not I will have to consider taking the matter further.

I look forward to receiving your reply at the earliest possible date. Please respond no later than three working days from the date above so the assessment can be completed in the time required.

Yours sincerely...

Complaints Procedure

All local authorities have a complaints procedure. If you need to complain you should ask your social worker or someone in the Children's Social Services to send you a copy of this. All complaints procedures are slightly different, but they all have informal and formal stages. At the informal stage you need to let the authority know what's wrong. You can either speak to someone like your social worker or write to the authority. If you get a copy of your local authority's complaints procedure it will say who you should speak to at this stage. This is known as a Stage 1 complaint.

At the formal stage you will need to write to someone in a position of responsibility (usually the Director of Social Services- see list above) who will then arrange for your complaint to be investigated. This is known as a Stage 2 complaint. It's very important when you write to the social services, that you ask for the complaint to be registered as a Stage 2 complaint. The authority will then have to investigate the matter within **four** weeks.

If the problem isn't resolved after this, you can ask for the complaint to be referred to a review panel which can re-examine the decision the local authority made when they investigated your complaint. You'll be invited to attend this review and you can take an advocate or friend along to support you if you want. This is known as Stage 3 or the review stage of the complaints procedure.

You can skip the informal stage if you feel your complaint is serious and needs to be investigated urgently. In particular, if you feel you or your child need help urgently and that this isn't being offered, it may be a good idea to complain formally as soon as you can. If you're concerned about making a complaint you can contact one of the organisations listed at the end of this information sheet for advice. A letter you can copy when making a Stage 2 complaint is provided in Appendix 2 at the end of this information sheet.

The fact that both social services departments and health authorities are expected to fund services causes problems for some people. They may be 'stuck in the middle' while the two departments decide who should fund what. If you're in this position, making a complaint may help to speed up this process. You can also complain to the Health Authority using their complaints procedure. If you need help with a complaint to the Health Authority then your local Patient Advocacy Liaison Service (PALS) will be able to help.

If you want to take things further

If you've been through your local authority's complaints procedure and you're still not happy with the way things have been handled you may be able to complain to the Local Government Ombudsman. The Ombudsman can only deal with cases where 'maladministration' has occurred. For example, if you had to wait a very long time for your SSD to carry out an assessment this could constitute maladministration. The Ombudsman can't deal with your complaint if you're unhappy with the quality of the services you have received.

If you suspect that the local authority may have acted outside the law, you may also be able to apply for leave to go to Judicial Review. This is a legal process, which reviews the decisions made by public bodies to ensure that they are within the law. You must seek legal advice before taking this step. Advice on finding legal advice is given later in this document.

If you're happy with the local authority but have a problem with the service you're receiving

If you're receiving a service such as having a home help visit and you're unhappy with it you should complain to the person who manages that service as well as the local authority. If your child is attending a residential service such as a children's home then the organisation that runs the home will have a complaints procedure that you're entitled to see. If you feel your complaint isn't being listened to, then whoever is responsible for managing your care package from within the local authority should also be informed.

Further Information

- **NAS Information Sheet - Making A Complaint: Useful Tips**

Carers Needs and Rights

Parents and Carers of children with a disability such as Asperger Syndrome, may be entitled to financial and service support, and may be entitled to flexible working and parental leave.

Carers' needs should be taken into consideration automatically if your son or daughter has received a Children Act 1989 or NHS and Community Care Act 1990 assessment of need (see earlier pages). However it is worth remembering parents can request an assessment of need in their own right (Carers and Disabled Children Act 2000).

Being a parent of someone with Asperger syndrome usually involves a substantial amount of support. It is important for parents to get breaks from the caring role occasionally and also to plan for the future when they will not be able to offer the same level of support. Parents of young people with Asperger syndrome should be offered a short break from caring if this causes tiredness and stress.

Carer's Assessment

Parents who provide quite a lot of support for their son or daughter may ask for an assessment of their own needs under the Carers and Disabled Children Act 2000. (CDCA)

When the social worker visits to assess a parents needs as a carer he or she will probably ask questions such as those below. It is best if parents think about their answers to these questions before the assessment. It is easy for parents to forget how much 'extra' caring they do as a result of looking after someone with Asperger syndrome.

Parents can also request a carer's assessment in writing. (see below for template letter).

Carer's assessments can be carried out at the same time as the community care assessment of the child as described above.

The assessment looks at a carer's ability It should look into any difficulties the carer experiences, either with actual tasks or due to their own health concerns etc, and whether the carer has work, education or leisure commitments that they want to continue with.

Once the social worker has completed the carer's assessment, they will then decide what services need to be provided to (a) the individual and (b) the carer (under the Carers and Disabled Children's Act 2000), and include this in the care plan. It should include exactly how their carer's needs will be met by social services

A model letter to send to your social services department to request a carer's assessment

Dear Sir/Madam,

I am writing on behalf of [name of the child]. He/she is my [how they are related to you].

[Child you are caring for] needs assistance with [list all the things with which they need help, such as eating, sleeping, washing, getting dressed]. I am his/her carer and I would like to request a carer's assessment. I am having difficulties with [list the things you need help with, such as needing a break].

Please contact me to let me know when you will be able to carry out an assessment.

Yours sincerely,
[Your name]

What type of services can a carer get?

If a carer is found to be eligible for services, the types of services they can receive include:

- Respite (short break) so that the carer can take a break from their caring responsibilities. The individual may spend some time away from the home or the carer may spend time away, knowing that the person they care for is being looked after at home by care attendants provided by social services.
- Under the CDCA 2000, social services will provide vouchers to the carer that can be redeemed for respite and short breaks when the carer wants or needs a break. The vouchers will normally be accepted by a number of agencies that are suggested by the local authority.
- Carers can also receive direct payments to help pay for additional care services. If an eligible care need has been identified, these services could include:
 - trips (e.g. holidays or special events)
 - driving lessons
 - travel assistance (e.g. help with taxi fares)
 - training
 - laundry
 - gardening
 - help with housework.

Short breaks and Respite – Legal requirement

One of the most common requests from parents who have a disabled son or daughter is for a short break from their caring responsibilities.

Local authorities are now required by law to provide short breaks to assist parents and others with parental responsibility who provide care for disabled children, including those with Asperger Syndrome. The authorities have to produce a short breaks services statement and keep it under regular review.

What is a short break?

What we mean by short breaks is the provision or commissioning of services by the council which aim to support disabled children and their families over and above universal activities which are available to all families.

They form part of the range of services which support parents of disabled children to continue to provide care or to do so more effectively.

Why are short breaks provided?

Short breaks give disabled children and young people the chance to enjoy new experiences and make new friends with and away from their families

Short breaks support young people to spend time away from their parents , learn independence skills , gain confidence and take part in activities which challenge them

Short breaks enable parents to have a break from caring that they can use as they wish to take part in an educational or leisure activity, to meet the needs of the other children in the family, to catch up on household tasks or to have a rest.

Who can access short breaks?

Short breaks services are available for disabled children and young people aged from birth to 18. The description of disability used is from the Equality Act 2010 which brings together a number of existing laws, including Disability Discrimination Act 1995 into one place so that it is easier to use: " someone who has a physical or mental impairment that has a substantial and long term adverse effect on his or her ability to carry out normal day-to-day activities"

Parents are encouraged to register their child on their local authority disability data base; this will give them access to information about a range of short breaks available and enable them to use some services without the need for a formal assessment.

Some local authorities provide their 'short breaks' services under the 'Aiming High' service provision. Many produce regular newsletters outlining the details of their short break services. These generally take place during the holidays, after school or at the weekend.

SHORT BREAKS LOCAL AUTHORITY CONTACTS IN GREATER MANCHESTER

<p>Bolton</p> <p>Contact: Claire Rutherford Tel: 01204 337176 Email: shortbreaks@bolton.gov.uk</p>	<p>Bury</p> <p>Contact: Janice Cameron, (Project Lead) Tel: 0161 253 5957 Email: j.cameron@bury.gov.uk</p>
<p>Manchester</p> <p>Contact: Family Information Service Tel: 0800 083 7921 Email: fisinfo@manchester.gov.uk</p>	<p>Oldham</p> <p>Julie Hawkins Aiming High Project Manager Tel: 0161 770 3126 Email: Julie.hawkins@oldham.gov.uk</p>
<p>Rochdale</p> <p>Contact: Children with Disabilities Service Tel: 01706 925900 Email: cwd@rochdale.gov.uk</p>	<p>Salford</p> <p>Contact: Family Information Service Tel: 0161 909 6508 Email: FIS@salford.gov.uk</p>
<p>Stockport</p> <p>Contact: Services To People Tel: 0161 475 6700 Email: cyp@stockport.gov.uk</p>	<p>Tameside</p> <p>Contact: Bev Connolly Tel: 0161 371 2060 Email: bev.connolly@tameside.gov.uk</p>
<p>Trafford</p> <p>Contact: Amy Tinker and/or Kaye Hadfield Tel: 0161 912 5067 912 4023 Email: amy.tinker@trafford.gov.uk</p>	<p>Wigan</p> <p>Contact: Short Breaks Team Tel: 01942 404162 Email: shortbreaksteam@wigan.gov.uk</p>

Help for carers who work

Working and caring for a child with Aspergers can be difficult and stressful at times. Therefore whatever support an employer can give is always much appreciated. It's up to you if you want your employer to know that you are a carer but in some instances telling them can lead to more support being offered, such as access to a telephone, a car parking space near work, unpaid or paid leave and the option of working from home. Some companies also offer counselling services to their employees. It is worth speaking to your line manager or personnel manager to see what services are available to carers.

As a legal right, carers of children can now request flexible working hours from their employers to help them manage working and caring responsibilities.

Flexible working could be:

- working from home or teleworking
- job sharing
- flexible start and finishing times (flexi time)
- compressed hours (where you work your total number of agreed hours over a shorter period)
- part-time work.

In order to request flexible working, you have to meet the following criteria:

- be an employee who has worked for the same employer for at least 26 weeks
- be a parent of a child(ren) under six or a disabled child(ren) under 18 or

Although you have the right to request work flexibility, this does not mean your employer has to agree to it. However, they must seriously consider your application and can only refuse it if there are good reasons for doing so.

How can I request flexible working?

You can only make one application a year and this must be done in writing. You should explain what changes to your work pattern you would like, how it will affect your work and how it will affect your employer's business.

Your employer will follow a procedure when dealing with your request for flexible working, including a meeting with you. If your employer does refuse your request, they must give you reasons in writing and you will have a right to appeal within 14 days. You must make the appeal in writing and give reasons for appealing.

If your appeal is refused, you can get help from the Advisory, Conciliation and Arbitration Service (ACAS), or make a complaint to an employment tribunal. For more information on flexible working requests, visit www.direct.gov.uk

How much parental leave can I get for a parent of a disabled child?

If you have worked continuously for one year for the same employer, you will be entitled to parental leave. If your child is under five years of age you can take up to 13 weeks of unpaid leave for each child.

If your child has a disability, is under 18 years old (and is receiving Disability Living Allowance, or DLA) you can take up to 18 weeks of unpaid leave.

The purpose of parental leave is to look after your child and make arrangements for their care and welfare for when you eventually go back to work. You could use your unpaid parental leave for spending time with your child when they are young, accompanying them during stays in hospital, finding suitable schools or care provisions and settling them into new care arrangements etc.

Unpaid parental leave is an individual right and should be discussed and arranged with the cooperation and support of your employer.

Further Information

National Autistic Society Helpline Information Sheet 'Carer's Rights'

Carers UK

20 Great Dover Street, London, SE1 4LX
Tel: 020 7378 4999 Website: www.carersuk.org

Princess Royal Trust for Carers

Unit 14, Bourne Court, Southend Road, Woodford Green, Essex IG8 8HD
Tel: 0844 800 4361 Website: www.carers.org.uk

Kids Out

Tel: 01525 385 252 Website: www.kidsout.org.uk

National Autistic Society Community Care Service Call the NAS autism helpline on 0808 800 4104 to book a telephone appointment with the Community Care case worker, or email to communitycare@nas.org.uk

For information about local organisations offering support for carers please ring The National Autistic Society Family Services Project Tel: 0161 998 4667.

For general information and advice you can ring the Carers Line between 10am – 12.00pm and 2pm – 4 pm Wednesday and Thursday. **Carers Line** - Tel: 0808 808 7777 (Freephone)

There is also a government website for carers: www.carers.gov.uk

Local Carers Centres

These provide carers with specialist information, advice guidance and support.

<p>Bury Bury Carers Support Group 3 Savoy Court Cross Street Whitefield M45 7RA Tel: 0161 766 5168</p>	<p>Bolton Bolton Carers Support Thicketford Road Bolton BL2 2LW Tel: 01204 363056</p>
<p>Manchester Manchester Carers Forum London Scottish House 24 Mount Street Manchester M2 3NN Tel: 0161 819 2226 www.manchestercarersforum.org.uk</p> <p>There are sub groups in Central, North and South Manchester</p> <p>Princess Royal Trust- Manchester Carers Centre Vulcan Mill 12-18 Pollard Street Manchester M4 7AN Tel: 0161 272 7270 carersline@manchestercarers.org.uk</p>	<p>Oldham Oldham –The Princess Royal Trust 1 Phoenix Street Oldham OL1 1DB. Tel: 0161 770 1188</p> <hr/> <p>Rochdale The Carers Resource Centre 2nd Floor, Waterside House 7 Water Street Rochdale OL16 1TL Tel: 01706 925808 thecarersresource@rochdale.gov.uk Also Subgroups at Heywood and Middleton</p>
<p>Salford Salford - The Princess Royal Trust Salford Carers Centre 1 St Philips Place Salford M3 6FA</p>	<p>Stockport Stockport Signpost For Carers Torkington Close Torkington Road Hazel Grove Stockport SK7 4PY Tel: 0161 456 0096</p>
<p>Tameside Tameside Carers Centre 50 Warrington Street Ashton Under Lyne OL6 7SX Tel: 0161 342 3344</p>	<p>Trafford Trafford Carers Centre 13 Warwick Road Old Trafford Manchester M16 0QX Tel: 0161 848 2400</p>
<p>Wigan Leigh Carers Centre 27 Charles St Leigh WN7 1DB Tel: 01942 606086 (1pm-10.30pm.7 days) www.thecarerscentre.org.uk</p>	<p>Wigan Wigan Carers Centre 2-6 Jaxons Court Hallgate Wigan WN1 1LR Tel: 01942 826300 (9am-5pm.Weekdays) www.thecarerscentre.org.uk</p>

LOCAL PARENT SUPPORT GROUPS

Greater Manchester Groups

Autistic Society for the Greater Manchester Area (ASGMA)

1114 Chester Road
Stretford
Manchester
M32 0HL
Tel: 0161 866 8483
Email: information@asgma.org.uk www.asgma.org.uk

Provides a range of support services to parents and carers of children and adults with an Autistic Spectrum Disorder. This includes the provision of parents and carers support groups, a telephone support network, an E-mail and web based support network, an information and signposting service – including the provision of an extensive Parent Resource Pack, speaker meetings, awareness events and a regular newsletter.

The ASGMA Aspirations Project provides comprehensive direct support to people across Greater Manchester with Asperger Syndrome / Higher Functioning Autism aged 10+. Support includes 1-2-1 support, travel training, support to access education and training, Drop in sessions, specialist youth clubs and other personal and group support.

ASD Dads Support Group

No longer meets regularly, but contact Jonathan on 0161 439 7773 or jonathan@calmminds.com for further information

Local Groups

Bolton HANDFUL (Hyperactivity and Neuro-Developmental Family Unity Link)

Community Room
Farnworth Christian Spiritual Church
18 Darley Street
Farnworth
Bolton BL4 8AA
Tel: 01204 794979

Contact: Michelle Daubney

Email: handfulhelp@yahoo.co.uk

The organisers are all volunteers with first hand experience of Asperger Syndrome and other Autism and related conditions.

The group meets monthly and caters for children and young people to age 18.

Bury Autism Parents Society (BAPS)

Tel: 0161 761 0132

Contacts : Joanne and Tony Moran

www.baps-online.org.uk

At BAPS we have parents of children covering the entire spectrum, from severely autistic to Aspergers, Children to teenagers.

We can provide advice or just a friendly ear. Whatever the problems you may have, usually someone at BAPS will have had similar experiences, and will be able to offer valuable advice.

Newsletters keep members informed of events and activities.

Bury Autism/Asperger Syndrome Support Group

Bury Carers Centre
Victoria Buildings
9 Silver Street

Bury BL9 0EU
Meets Thursdays 1100-1300.
Contact: Chris Parkinson
Tel; 0161 763 4867 [email: busycarers@yahoo.co.uk](mailto:busycarers@yahoo.co.uk)

Bury 'The Red Centre'

Morley Street
Bury BL9 9JQ
Tel: 0161 763 3939
Contact: Karen Robinson

The Red Centre has been developed as a result of partnership working between Bury Metropolitan Borough Council, NCH, local charity Hurdles and West Pennine Housing Association.

The centre provides the following services:

Short breaks
Family support workers
Integrated play Schemes
Integrated youth project
Education advice, information and support
Information, advice and parental support
Parents' room
Play staff on site daily
Meeting room
Training courses
Family trips and social events
Project newsletter

Manchester – The Autumn Group

The TML Centre
1 Jocelyn Street
Monsall
Manchester M40 8PR
Contact; Sue Broaderst
[email: autumngroup@live.co.uk](mailto:autumngroup@live.co.uk)

Manchester – P.O.S.Y Parents of Special Youngsters

For parents of children with all disabilities
Contact: Leslye Vaughan
Tel: 0161 436 4043 or 07852 587079
Email; leslye.posy@yahoo.co.uk

Oldham Support Group for Carers In Autism (OSCA)

Woodfield Centre
Manchester Road
Oldham OL8 4ET
Tel: 0161 688 6156 or 07913 672175
Contact: Cathy Williams, or Maria Aspin [email: osca@bigfoot.com](mailto:osca@bigfoot.com)
www.fdk.org.uk/osca.html

OSCA is a local support group for parents and carers of children and adults with autism and related disorders. If you are a parent, care for, or are just interested in people with communication, social and behavioural difficulties then we can probably help. We meet on a monthly basis for mutual support, exchanging ideas and have occasional talks by invited speakers. We are also building up a resource library of information on autism and related pervasive developmental disorders such as Asperger syndrome, Rett's Syndrome and Semantic Pragmatic Disorder. OSCA meets on the second Tuesday of the month from 1.00 - 2.30 p.m at The Woodfield Centre, Manchester Road.

Oldham Asperger Support for Parents and Carers (ASPACE)

c/o Oldham Social Services
18 Greaves Street
Oldham OL1 1AD
Telephone: 01706 845060 (Val Foster- Chair)
01706 847455 (Pam Butler- Secretary)
Run a weekly Youth Club

Oldham Parents of Children with Aspergers and Autism Self Help Group (PAASH)

Support Group for parents of Children with Autism and Asperger Syndrome
Meets every other Thursday at Hollinwood Children Centre
Contact Julie Walker Tel 0161 633 8417
Website www.paashgroup.co.uk

Rochdale Parent Forum – Circles Support Group

Meet monthly at Hollins Sure Start Centre. Call 07901 854741 for further details.

Littleborough Autism, Aspergers Syndrome and ADHD Support Triangle (L.A.A.S.T.)

Telephone 07980 983872
Contact : Liesl Beckles email: lieslbe@yahoo.co.uk
The group no longer meets, but telephone support is still available from Liesl.

Salford Action For Autism (SAFA)

Eccles Gateway
18 Barton Lane
Eccles
Salford M30 0TU
Tel: 0161 909 6528
Contact; Carol Gray or Barbara Berry
Provide support for families and carers with children up to 18 who have an ASD.
Day and evening meetings

Living With Autism

Support Group for parents and carers of children on the Autistic Spectrum
Meetings are held at The Inscape Centre, Cheadle
Tel: 0161 283 4761
Contact: Sue Allison

AFASIC (Stockport)

Support for parents and carers of children with Communication Impairments
Contact: Ed Baines 0161 431 0326

Stockport ASD Partnership Project Support Group

Offering monthly sessions with invited speakers.
Tel: 0161 249 4474
Contact: Cheryl Salt cheryl.salt@stockport.gov.uk

Tameside Action & Support for Carers In Autism (TASCA)

Rosehill Children's Centre
Rosehill Road
Grange Road South
Ashton Under Lyne OL6 8YG
Tel: 0775 4873480
Contact: Neil Bayley or Valerie Bayley
www.tasca.org.uk email: tasca4u@ntlworld.com
TASCA is a support group for parents/carers of children with autism, autism spectrum disorder and Asperger syndrome, offering support, advice and information. TASCA holds regular monthly coffee mornings and meetings

Tameside Aspergers Syndrome Support Group

Contact: Julie Scrymgeour
Tel: 0161 604 3600

Trafford ADHD/ASD Family Support Group

1A Newton Court
Newton Road
Urmston
Contact 07947 798195 (Ruth) or 07969 459523 (Jess)
Email: sengroup@hotmail.com

Landgate Parent Support Group (Wigan)

The group is based at Landgate School in Bryn, Wigan and is open to parents of all children with an autism spectrum diagnosis in Wigan Borough, whichever school they attend. Members of the group meet regularly at Landgate School to discuss topical issues, support one another and share information.
Contact Caren on 01942 730134
Email: landgatesupport@aol.com

Embrace Wigan and Leigh

Platt Bridge Community Zone
81 Ribble Road
Platt Bridge
Wigan WN2 5EG
We actively promote and support disabled people to live the life they choose. We recognise that some people are socially isolated and do have difficulties accessing regular opportunities.
Contact: 01942 513053
www.embracewiganandleigh.org.uk

Paveways (Wigan)

Tel: 01942 519909
www.paveways.net

An information service providing disabled people and carers with help in claiming welfare benefits, getting access to services and equipment or any other disability related issue. Partially staffed by disabled people

PERSON CENTRED PLANNING

Person centred planning is a technique to produce an individualised 'plan' to ensure a person's current and future needs and preferences are fully documented and understood.

It can help a child with Asperger Syndrome by ensuring their needs are fully documented and shared with people they come into contact with. It will enable decisions to be made on the basis of the unique strengths and needs of the child, what it takes to keep him happy and safe. It will include for example what the child likes to do in leisure time, what food they like and dislike and anything they particularly enjoy (or dislike) doing. Contributions should be made by family members and others who know the child well.

The 'Person Centred Plan' needs to be kept up to date as the child's needs and preferences, likes and dislikes, change as they grow older.

"It's a living record of my son's daily choices."

"It's given me so much positive hope for the future."

"Once you get going on the plan you suddenly realise the benefits of what you are finding out."

"There are so many reviews, reports and everything else that they put together about your child. They do not talk about the person, their character, their gifts or anything like that. I had never been asked what I like about my child until I did Person Centred Planning."

"Person Centred Planning enables you to dream without denying the person's support needs and gives hope for a wonderful future."

"Inspired, enlightened and empowered"

"Person centred planning has given us hope and a vision for a better future for our son. We feel now we can have a say in how and what service support he receives. We no longer believe that only professionals know best for him. Also, his faith and cultural needs are recognised and responded to"

Further Information

Helen Sanderson Associates are locally based and a leading provider of training and consultancy for families, for people who want to develop their own Person Centred Plans. They also work with many local authority Person Centred Coordinators (PCP).

Helen Sanderson Associates
34 Broomfield Road
Heaton Moor
Stockport SK4 4ND
0161 442 8271 website; helensandersonassociates.co.uk/

Local authority and Parent Support Groups PCP Awareness Training

Some local authorities and parent support groups run Person Centred Planning events from time to time. Please contact your local person centred planning co-ordinator for any planned events.

BENEFITS AND WELFARE RIGHTS

Benefits and Welfare Rights Advice

Dealing with benefits claims and appeals can be complex and time consuming. It is very important to access benefits advice from advisors who have access to the latest updates on changes to entitlements and legislation because things alter constantly. **The National Autistic Society Autism Helpline service includes a Welfare Benefits Advisor. Call 0808 800 4104.**

Benefit entitlement and rates are always liable to change. For the most up to date information, look at the government website at www.direct.gov.uk

The following information on relevant benefits is up to date at the time of writing

Benefits You May Be Entitled To

You and your child may be eligible for the following benefits in addition to normal Child Benefit.

- Disability Living Allowance (DLA)
- Carer's Allowance

Details of these benefits and how to apply are described below.

In some circumstances benefits can be paid by an arrangement called Direct Payments, also outlined below.

Disability Living Allowance (DLA)

DLA is a tax-free benefit for children (and adults) who need help looking after themselves or who have difficulty walking because their disability. It is possible for some children with Asperger syndrome to qualify

DLA can be paid on top of earnings, benefits or tax credits and savings are not taken in to account. An award of DLA can lead to extra payments of Tax Credits, Income Support, Housing Benefit and Council Tax Benefit.

In terms of eligibility your child must need a lot more help or supervision than other children of the same age. The DLA is split in to two parts - **mobility and care**, where each has different rates of funding (low-high).

You are able to claim for **mobility needs** if your child:

- is unable, or virtually unable, to walk (from age three)
- is assessed to be both 100% disabled because of loss of eyesight and not less than 80% disabled because of deafness (from age three)
- is severely mentally impaired with severe behavioural problems and qualifies for the highest rate of care component (from age three)
- needs guidance or supervision when walking out of doors (from age five)

You can claim for **care needs** before your child is aged three months, but benefit will normally only be paid for children three months or older, except in special circumstances.

For further information or to request a claim form please contact the dedicated **Benefits Enquiry Line** on **0800 88 22 00**,

IMPORTANT: Do not complete the DLA forms until you have spoken to the National Autistic Society Autism Helpline 0808 800 4104

Disability Living Allowance – Care

To qualify for the DLA Care component, there are various tests:

You must be:

“so severely disabled physically or mentally that...you require [from another person]”
Therefore, without a diagnosis it may prove more difficult to get DLA.

DURING THE DAY

No. 1 “frequent attention throughout the day in connection with your bodily functions”

Or

No. 2 “continual supervision throughout the day in order to avoid substantial danger to yourself or others”

AT NIGHT

No. 3 “prolonged or repeated attention in connection with your bodily functions”

Or

No. 4 “in order to avoid substantial danger to yourself or others you require another person to be awake for a prolonged period, or at frequent intervals for the purpose of watching over you”

PART TIME DAY CARE

No. 5 “ you require in connection with your bodily functions attention from another person for a significant portion of the day (whether during a single period or a number of periods)”

If a person passes at least one of the day tests and at least one of the night tests they will receive the High rate of DLA Care component.

If a person passes at least one of either day or night tests, they will qualify for the Middle rate of the DLA Care component.

If a person passes at least one of the part time day care tests they will qualify for the Lower rate of DLA Care component.

Common ‘definitions’ of some of the terms:

“attention” = active help from another person to do things which you cannot do for yourself.

“bodily functions” = anything to do with the physical body and how it works.

“significant portion of the day” = about one hour, in total, of help is required each day.

“frequent” = means several times – not once or twice, throughout the day.

People with Asperger Syndrome may have a whole range of difficulties that will impact on the amount of extra support they require. The following is by no means an exhaustive list. Some are not relevant to children. These are just a few examples:

- loses things in public places – needs reminders
- forgets to lock up property – needs reminders

- needs help with personal care due to physical difficulties, for example, attention deficit disorder, epilepsy, deafness, bowel problems
- dressing appropriate to the weather, putting clothes on in the wrong order
- must have clothes laid out for him each morning
- needs prompts to get dressed
- has difficulties putting clothes on in right order
- not knowing when clothes are too dirty to wear only wears certain fabrics
- obsessional behaviour that requires support
- finds difficulty with cleaning himself
- unable to use public transport
- talks to strangers, cannot recognise risk
- fails to read important signs, for example, parking restrictions, or timetables
- puts self in danger because of not topping up oil, tyre pressure, petrol level, etc.
- stares at people in public places
- needs physical or verbal prompts to complete morning routine
- diurnal sleep patterns (sleeps all day, up all night)
- high degree of stress and anxiety in the morning, or all day - needs reassurance
- requires a phone call to awaken
- requires prompts to go to bed
- diet problems – eating too much or too little
- forgetting to drink enough
- not checking sell by dates
- not answering the door, leaving the front door open
- being conned out of money, due to lower social understanding
- losing money, for example due to anxiety
- not able to cope with or understand financial affairs
- social phobias, exposure anxiety, agoraphobia (unable to leave house)
- irrational fears, for example of weather, dogs or certain days of the week
- behaviour difficulties causing damage to property
- violent to self or others
- clumsiness leading to various problems – for example, needs help with co-ordination exercises
- self-injurious behaviour – requires supervision
- not knowing how close to stand to someone else (proxemic difficulties)
- staring at other people (eye contact difficulties)
- difficulties around hygiene which require prompts to prevent the person becoming socially isolated, and giving offence
- requires help with a special diet – for example gluten free
- needs prompts to try new food types, for example only eats dry food or certain brands
- needs prompts to eat in unfamiliar surroundings
- poor self care, leading to social or health problems
- unreliability to take medication – requires monitoring and prompts
- poor grooming and self presentation, for example not brushing teeth
- hyper-sensitivity to brushing teeth – needs encouragement
- will only wear certain clothes so if dirty will not go out
- eating stale or mouldy food
- not reporting illness
- unable to administer medications, needs reminders to take medicine
- forgetting to eat
- not understanding about healthy diet
- manual dexterity problems (e.g. shirt buttons, shaving, belt loops)

There are hundreds of other examples of the need for assistance in “bodily functions”. Not all these examples may be admissible but it is worth putting down all the practical difficulties so you give as clear a picture as possible of your son or daughter’s needs.

A good way to recall all the support provided for the person is to keep a two or three week diary with what support he gets what time of day/ night and how long he was assisted for.

Disability Living Allowance – Mobility

Some people with Asperger syndrome should qualify to receive the mobility part of DLA.

To receive the lower rate of DLA Mobility, the person must be:

'so severely disabled physically or mentally that, disregarding any ability you may have to use routes which are familiar to you on you own, you cannot take advantage of the faculty out of doors without guidance or supervision from another person most of the time'

In other words the lower rate of mobility component is for people with Asperger syndrome who are not safe to go to new places and cope, for whatever reason. This could be due to a lack of spatial awareness/co-ordination or due to high anxiety/ panicky feelings.

It may be your son or daughter has difficulties related to:

- walking
- physical disability
- sensory abnormalities such as acute hearing, over stimulated by noise, people, bright sunlight that make going out difficult
- difficult or challenging behaviour, for example will touch people with certain coloured hair or hit out if someone brushes past them accidentally
- only able to follow certain routes/ rituals that must be followed
- walks very slowly and cannot speed up
- regular tantrums due to hyper-sensitivity
- becomes panicky and refuses to move if confronted by objects of phobias, such as dogs, or thundery weather
- ignores instruction even when near busy roads/in dangerous situations
- deliberately disobeys any person who is supporting him or her outdoors, making it difficult to go out if there is just one adult
- easily distracted by what is going on around them
- uncomfortable if certain rigid routines are not followed
- cannot use public transport – fear of other people and sensory issues
- suffers from agoraphobia – fear of open spaces
- has no sense of danger of traffic
- unable to judge speeds and crossing times accurately, so not always safe crossing the road
- understands danger in theory but are easily distracted should something else come along e.g. they are normally fine on roads but will run across a busy street to avoid someone or to look in a particular shop window

How vulnerable do you think your son/daughter is when out of their home?

- Can his or her knowledge of stranger danger be easily overridden, for example if they are told a lie?
- Does he or she have an 'odd' walking style, for example, does not move arms, or walks very briskly, so marking them out as 'vulnerable'.
- Does their appearance make them look different in a way that makes them a potential target for attack?
- Does he or she get into dangerous situations in public because they have extreme views, stand too close to people, interrupt conversations, chat up other people's girlfriends, 'stare' too long at other people?
- Does he or she understand that certain rules can be broken, for example, once they have learnt to wait for the green man to indicate it is safe to cross the road, can they then learn that sometimes ambulances or fire engines go through red lights? Or that 'stranger danger' does not apply to asking to 'strangers' for directions if lost.

- Would your son/daughter report any dangerous situation – for example, escalating threats or verbal abuse from neighbours? Would they only let you know if you asked the right questions?

Only a very few people with Asperger syndrome are likely to qualify for the higher rate of the mobility component of DLA. A person must have:
 ‘...either severe physical disability or severely mentally impaired with extremely disruptive and dangerous behavioural problems’

If you think your son or daughter may qualify for the High rate of Mobility contact the NAS Autism Helpline 0808 800 4104.

Further Information

Whatever rate you apply for, phone for a copy of **National Autistic Society Information Sheets**

- **Claiming DLA**
- **Keeping a DLA Diary**
- **DLA tips for parents and carers**
- **Disability Living Allowance: Higher rate mobility for children with an autism spectrum disorder**

These are available from the NAS Autism Helpline 0808 800 4104.

To help your case, it is strongly advised that you speak to the NAS Helpline before completing the forms, or get good advice from someone who understands both Asperger Syndrome and the DLA benefits.

Remember, what is written in the claim is about what the person *should* be getting, regardless of whether that help is actually available at present. For example, a person may actually require someone with him when he is out at night to avoid dangerous situations and to help him integrate socially. He does not receive this support but that does not matter – he *should* receive this level of support – so put details about the necessary support in the claim.

Or, for example someone may require turning in the night, which no one is available to do at present. However turning is the care they require, so put this in the claim.

DLA Appeals

Decisions related to Disability Living Allowance (DLA) are made by a Department of Works and Pension’s (DWP) decision maker (not medical professionals) on behalf of the Secretary of State. A statement of reasons for a decision made relating to DLA can be requested within a month and must be provided to the person making the claim within 14 days. Decisions made by the DWP can be challenged.

You may wish to appeal because you have been refused DLA or have been offered the care and/or mobility component at a lower rate than you had hoped for. You can ask for a revision of the decision. If you are not satisfied after the review you can appeal.

If you request a review of any DLA award the revised decision may be worse than the original one. For example if you appeal against an award of DLA care component at the middle rate, the revised assessment may put you on the lower rate. Appeals are handled by the Tribunals service.

It is strongly recommended that you seek advice from the NAS Helpline or your local Citizens Advice Bureaux (CAB) before deciding whether to appeal.

Further Information

National Autistic Society Information Sheets : Disability Living Allowance Appeals and Benefits; Challenging Benefit Decisions

Carer's Allowance

Carer's allowance is the main state benefit for carers, which is paid to someone aged 16 or over providing care to a disabled child (or adult.)

If your child gets Disability Living Allowance (DLA) care component at the middle or highest rate, and you are caring for them for 35 hours a week or more, you may be able to get Carer's Allowance. Other benefits may also affect your eligibility. You should make a claim for Carer's Allowance within three months of the date you get a decision on your child's DLA, so that you don't lose any benefit.

Note that most children with Asperger Syndrome will not qualify for the higher rates of DLA and therefore not for Carer's Allowance.

Further Information

National Autistic Society Information Sheets : Carer's Allowance

Further Advice on Benefits

Breakthrough is a Manchester based charity helping people with disabilities throughout the North West on a variety of subjects. They can offer an overview of benefits, and suggest contacts for specialist advice tailored to your current circumstances. Breakthrough produce an on line booklet gives details of advisor services in Greater Manchester. www.breakthrough-uk.com

Breakthrough UK Ltd
Business Employment Venture Centre
Aked Close
Ardwick
Manchester M12 4AN
Tel: 0161 273 5412

Citizens Advice Bureaux (CAB) provide free, confidential and independent advice from nearly 3,400 locations across the country. Advice is available face-to-face and by telephone. Most bureaux offer home visits and some provide email advice. To locate your nearest CAB, visit www.citizensadvice.org.uk, or contact us on **0161 273 5412** for the details of your local bureau.

Adviceguide is the online advice service from the Citizen's Advice Bureau. It provides practical, up to date information on benefits, housing, employment and debt, consumer and legal issues: www.adviceguide.org.uk

Community Legal Advice helpline gives free advice to people eligible for Legal Aid about benefits and tax credits, debt, education, employment and housing problems.
Tel: **0845 345 4 345**. Minicom: 0845 609 6677 between 9am and 6.30pm, Monday to Friday.
Website: www.clsdirect.org.uk

National Autistic Society Welfare Rights Service Call the NAS autism helpline on 0808 800 4104 to book a telephone appointment with the Welfare Rights Adviser, or email to welfarerights@nas.org.uk

Local Authority Welfare Rights Services.

Each local authority provides a welfare rights service for its residents and many provide a drop-in benefits advice service at venues within their area.

Contact details for each local authority are in the following table.

<p>Bolton Welfare Rights Adult & Community Services Le Mans Crescent Bolton BL1 1SA</p> <p>Advice Line Tel: 01204 380460 (Monday-Friday 10-12 noon)</p>	<p>Rochdale Advice Service P.O Box 39 Municipal Offices Smith Street Rochdale OL16 1LQ (Opening Times M-F 10-12 1.30-3.30)</p> <p>Advice Line 01706 764132</p>
<p>Bury</p> <p>Bury Independent Advice Centre 12 Tithebarn Street Bury Tel: 0161 797 4326</p>	<p>Salford</p> <p>Welfare Rights Service Freepost Manchester M27 1BX Welfare Rights Advice Line 0800 3457375 (Monday to Friday 10-12 noon)</p>
<p>Manchester</p> <p>Manchester Advice PO Box 536 Town Hall Extension Manchester M60 2AF Tel: 0161 234 5678 (10-4) man-advice@manchester.gov.uk</p>	<p>Stockport</p> <p>Welfare Rights Benefits Advice Line Tel: 0161 474 3091 Monday to Friday 9am-1pm Email welfare.rights@stockport.gov.uk</p>
<p>Oldham</p> <p>Welfare Rights Service Telephone 0161 770 6655 (Monday to Friday 9-12 noon)</p>	<p>Tameside</p> <p>Welfare Rights Service Tameside MBC Council Offices Wellington Road Ashton under Lyne OL6 6DL Advice Line 0800 0749985 (Monday, Wednesday, Thursday 9.30-12.30)</p>
<p>Trafford</p> <p>Trafford Welfare Rights Benefits Advice Line Tel: 0161 912 2735 (Monday to Thursday 9.30-12.30)</p>	<p>Wigan</p> <p>Wigan Independent Advice Centre Tel: 01942 324851 A Welfare Rights Advisor will answer your call and take some essential details. If necessary, you will be invited to attend an interview at one of our surgeries</p>

The NAS have factsheets covering:

- Disability Living Allowance. What Is It?
- Challenging benefits decisions
- Disability Living Allowance appeals
- DLA - guidance for adults with ASD completing the form
- Disability Living Allowance. How to claim.
- Keeping a DLA diary

Useful Resources and Websites

Disability Benefits Enquiry Line

Tel: 0800 882200

Disability Alliance

Tel: 0207 247 8763

Their website includes information on social security benefits and tax credits for disabled people:

www.disabilityalliance.org

Disability Law Service

Tel: 0207 791 9800 Mon-Fri 10am - 1pm and 2 - 5pm

Disability Living Allowance (DLA) Helpline

Tel: 08457 123456

Tax Credits Helpline

Tel: 0800 300 3900

Department for Work and Pensions A-Z gives information about welfare benefits:

www.dwp.gov.uk/lifeevent/benefits/atoz.asp

Benefits Adviser is an interactive tool from Directgov to help you find out what benefits you may be entitled to. Contact us if you require assistance to use this:

www.direct.gov.uk/en/Dio11/DoltOnline/DoltOnlineByCategory/DG_073267

Benefits and Work is an independent website containing lots of useful information & guides on applying for and keeping benefits. It is subscription based so you have to pay to access most parts of it. Clients of Breakthrough's Advocacy Centre can access the material through us:

www.benefitsandwork.co.uk

Advicenow is an independent, not-for-profit website providing accurate, up-to-date information on rights and legal issues. www.advicenow.org.uk/topics > **Benefits**

Benefits for Parents/ Carers

For more advice contact the **Disability Benefits Advice Line 0800 88 22 00** or visit **the Guide To Financial Support For Carers** on www.direct.gov.uk.

Ferret Information Systems website www.ferret.co.uk contains information on Benefits and links to other sites.

If you are in receipt of DLA, you may qualify for grants for energy-saving work. Contact the **Warm Front Scheme Helpline** – Tel: 0800 952 0600.

Direct Payments

Direct Payments should be offered to all people with disabilities and their carers who have been assessed and found eligible for support.

With Direct Payments, the parent carer of a child with Asperger's can receive money directly from Social Services to employ staff of their choosing to provide the support that is needed. This can result in greater flexibility and choice about who works with an individual and the type of support that can be offered.

As a parent you can use direct payments to buy a placement at a nursery offering specialist support, for short breaks, equipment, for personal care or to provide assistance for your child to attend an activity or after school club. It could also be used to employ a person to support and care for your child as a day or overnight carer.

Although a high level of control and creativity is possible through the Direct Payment Scheme some individuals and carers have found the responsibility of recruiting, paying and managing staff difficult. If this is the case your local authority should have a named worker who can help you with these practical details. Here are the contact details for the Direct Payments Assessment contacts in each Greater Manchester local authority:

<p>Bolton</p> <p>Children with Disabilities Social Work Team Crescent House Lever Street Bolton BL3 6NN Tel: 01204 337100</p>	<p>Rochdale</p> <p>Direct Payments Scheme Floor 2 Brook House Oldham Road Middleton M24 1HF Tel: 01706 922999 Email: directpayments@rochdale.gov.uk</p>
<p>Bury</p> <p>Direct Payments Team 1st Floor Craig House 5 Bank Street Bury B19 0BA Tel: 0161 253 7366 or 0161 253 7401 Email: directpayments@bury.gov.uk</p>	<p>Salford</p> <p>Direct Payments Team Salford CVS The Old Town Hall off Irwell Place Eccles M30 0EJ Tel: 0161 789 8670 Email: office@suggest.org.uk</p>
<p>Manchester</p> <p>Manchester Contact Centre for Children Pink Bank Lane Longsight Manchester, M12 5QN Tel: 0161 255 8250 Email: dpscheme@manchester.gov.uk</p>	<p>Stockport</p> <p>Direct Payments Development Manager Regal House Duke Street Stockport SK1 3DA Tel: 0845 644 4313</p>
<p>Oldham</p> <p>Direct Payments Worker Children With Disabilities Team Woodfield Manchester Road Oldham OL8 4ET Tel: 0161 627 1749</p>	<p>Tameside</p> <p>Tameside Direct Payments Stalybridge Resource Centre Waterloo Road Stalybridge SK15 2AU Tel: 0161 342 2900</p>
<p>Trafford</p> <p>Direct Payments Team Broome House 54-56 Seymour Grove Old Trafford Manchester M16 0LN Email: direct.payments@trafford.gov.uk Telephone: 0161 912 2701</p>	<p>Wigan</p> <p>Direct Payments Team Department Of Adult Services Town Hall Market Street Leigh WN7 1DY Tel: 01942 404507 Email: direct.payments@wigan.gov.uk</p>

Further Information

NAS Helpline Information Sheets

- **Direct Payments – A Brief Guide for Parents and Carers of children with ASD**

Travel and Transport

Concessionary Travel Pass

Children with Asperger Syndrome may qualify for a National Concessionary Travel Pass. These are issued in our area by Transport for Greater Manchester

Benefits of a Concessionary Travel Pass

- Pass holders can travel for free between 09.30 am and midnight Monday to Friday, and all day at weekends and bank holidays, on buses, trains and Metrolink trams in Greater Manchester.
- Before 09.30 the concessionary fares will apply in Greater Manchester for each bus journey travelled.
- For local train and Metrolink journeys before 9.30am Monday to Friday, you will travel for half the current standard fare. If you are using a Metrolink ticket machine, you should press 'child single' or 'child return' depending on whether you will be making a return journey before 9.30am.
- On trains and Metrolink trams, you will not need a ticket to travel after 9.30am, just show your pass.

Your pass is valid for free or low-rate travel only for journeys which begin and end within the Greater Manchester train boundary. See

http://www.gmppte.com/pdfmaps/train_tram_boundary.pdf

Note that you cannot buy a combined train and Metrolink tram cheap ticket.

Remember, you can only travel for free if you have the child's pass with you.

There are no extra concessions for carers or those accompanying the qualifying child.

Metroshuttle buses linking the main stations, shopping areas and businesses in Manchester city centre, and **are free for everybody at all times.**

You cannot use your pass on excursions or tours.

Also, the pass can be used on all local bus services throughout England, between 0930 am and 1100 pm Monday to Friday and all day at weekends and Bank Holidays.

How To Apply

To apply for a travel pass you need to get an application form, which are available from

- Transport for Greater Manchester Travelshops
- By post from 2 Piccadilly Place, Manchester M1 3BG
- By telephone. Call Traveline on 0870 200 2233

You will need to send two passport-sized photographs with the application form. Passes will be issued in the form of a 'Smartcard'

Does My Child Qualify?

Concessionary Travel Pass

You may be able to get a concessionary travel pass for your child. if your child has :

- What Transport for Greater Manchester describe as a 'significant impairment of social functioning. ' **This should include people on the Autism Spectrum, including those with Asperger Syndrome.**

Free Travel At All Times (Disabled Person's Freedom Bus Pass)

In some circumstances your child may qualify for free travel at all times, and not just after 09:30.

If he cannot use ordinary buses, you may be able to get travel vouchers. You can use these to pay for taxis and door-to-door services, like Ring and Ride and Local Link.

For more information about free travel and travel vouchers, please phone Transport for Greater Manchester customer services department on 0161 244 1050. An application will need to be made through your local authority who will issue a pass if they feel your child meets eligibility criteria. This is similar to the Blue badge scheme criteria described below.

The Autistic Society Greater Manchester Area's *Aspirations Project* works closely with Transport for Greater Manchester and may be able to support people known to the project to apply for and gain an appropriate travel pass. For more details contact:

Peter Halliwell
Aspirations Project
Autistic Society Greater Manchester Area
1114 Chester Road
Stretford
Manchester M32 0HL
Tel: 0161 866 8485 Email: aspirations@asgma.org.uk

Blue Badge Scheme

The Disabled Persons Parking Badge Scheme allows people who are disabled various concessions and privileges relating to parking. These include being able to park in disabled bays and on some single and double yellow lines, and fewer restrictions on parking time limits. Badge holders are also exempt from paying the London congestion charge.

The scheme is often referred to as the blue badge scheme as this is the colour of the badge that people display on their windscreens. It replaced the old 'orange badge' scheme. It is a national scheme which entitles you to roughly the same provision across the UK.

Who issues blue badges?

Though it is a national scheme, blue badges are actually issued by local authorities who also decide on entitlement to the badges. The table below shows who to contact in your area.

On request, they will send you a blue badge application form. The criteria for the award of blue badges are laid down in national law. However, **local authorities may vary in the way they interpret the eligibility criteria and because of these variations, it is possible that in some areas blue badges are more likely to be granted to children with autism than others.**

Who is eligible for a blue badge?

Blue badges can be applied for on behalf of children aged two upwards. Obviously, young children cannot drive themselves so if you're applying on behalf of your child, you'll need to demonstrate that they will be the main beneficiary of the blue badge.

Completing The Application Form

Our Autism Helpline has compiled the following tips for parents and carers of children with autism (including Asperger syndrome) who are considering applying for a blue badge. This is not a definitive guide to applying for a badge; if you are seeking more specialist advice you might find that a local advice centre. Make sure you complete the Children's section of the form.

If your child receives the higher rate mobility component of Disability Living Allowance (DLA) then entitlement to a blue badge should be automatic. However, higher rate mobility DLA can be hard to obtain for people with autism as it is primarily concerned with severe physical problems with walking. It is possible, though, to apply for a blue badge if your child receives the lower rate of the mobility component of DLA, or even no DLA mobility award at all.

If your child does not receive the higher rate of the mobility component of DLA then the other qualifying criteria for blue badges can be looked at. Entitlement through these is more subjective and is open to further assessment by your local authority. Some of these criteria relate to a child needing access to a car to carry bulky medical equipment or in case they need urgent medical treatment. However, the criterion that is most often relevant to children with autism is that:

“They are unable to walk or have very considerable difficulty in walking because of a permanent and substantial disability.”

Although many children with autism may not have a physical disability as such, it can still be possible to apply for a blue badge using this criterion. When looking at a person's eligibility, local authorities use similar guidance to that which the Department for Work and Pensions uses when considering entitlement to the higher rate mobility component of DLA. That is whether **one** of the following conditions is satisfied:

- a child cannot take a single step
- a child is 'virtually unable to walk'. This takes into account the distance, speed, length of time and manner in which a child makes progress on foot
- the exertion to walk would 'constitute a danger to life or would be likely to lead to a deterioration in their health'. Bear in mind this relates to physical problems only such as serious heart and lung conditions.

Local authorities often interpret all of these criteria as being related to a **physical** disability. Though more relevant to Social Security Benefit entitlement, it may be worth mentioning that the view held by many professionals is that autism also has a physical cause because it is a disorder of brain development.

You might also mention, with reference to the 'virtually unable to walk' criterion, any 'refusal episodes' your child has had when walking, and point out that the behaviour of children with autism can often be unpredictable.

For example, children with autism may be able to handle an activity – such as walking to the shops – one day and not be able to do it the next because of factors such as anxiety, fear or stress: they may be scared of dogs and have passed one on the street, or they might become distressed by a particular noise and be unable to continue their journey.

If it can be demonstrated that these incidents happen on a frequent basis and are a direct result of their disability then you could argue they satisfy the criterion. You can also state how having a blue badge

could help you and your child to reduce the likelihood of these incidents happening, as you can stay in a familiar and 'safe' environment (your car) for longer.

Other factors

It is important to remember that autism is a complex and subtle condition and the impact that it has on a child's life can be hard to predict. You may find that you need to help your local authority to understand how disabling your child's condition is. You can do this by being as clear as possible in your blue badge application about the difficulties that you and your child encounter.

You may find some of the following points in your application help back up your case.

- Children with autism have difficulties with social interaction and may not always recognise what socially 'acceptable' or safe behaviour is. As a result, they may do things which are dangerous, such as sit down in the middle of a busy road. Having a blue badge may help to reduce these kinds of risks.
- Your child's road safety skills may not be comparable to other children of his/her age. Would they, for example, walk into busy roads or not use zebra crossings? Can you give a specific example of an occasion where your child's behaviour has put either his/her, or other pedestrians' and road users', safety at risk?
- If your child feels anxious, they may try to cope with this by doing things like running away. This is a fairly common behaviour for people with autism but can of course be dangerous, doubly so because difficulties with social communication mean that people with autism can be vulnerable when separated from those who know and care for them. Situations which children with autism find stressful can often be those which families are least able to avoid, such as busy supermarkets and crowded streets. Parking close to your destination may help to reduce the time you spend in some of these situations.
- Do you make a particular journey, for example to school or to the supermarket, where you would benefit from having a blue badge? How do you make this journey now – do two adults need to be with your child so that one can wait with them while the other person finds somewhere to park? If so, how does this impact on your family's routine and how would a Blue Badge help?
- Do you use parking meters or park illegally because you have to travel by car and need to park close to your destination? Have you ever received parking tickets because of this?
- Can your child use public transport if you accompany them? As this is difficult for many children with autism, because of the anxiety and distress that noisy, unfamiliar environments can cause, you could mention this in your application and highlight the importance of being able to use your car when taking your child out and about.
- Does your child become anxious or distressed if you visit an unfamiliar area? If so, explain how a blue badge would help by allowing you to park close to your destination, reducing the time you have to spend walking when your child may become upset.
- Does your child miss out on any social/leisure activities they would normally enjoy because you can't park nearby?

Medical assessments

Your local authority may seek a medical opinion on your child's entitlement to a blue badge. This could include, for example, an assessment by a community physiotherapist or occupational therapist. An assessment by your GP is generally seen as unsatisfactory as they may not have as detailed an understanding of the blue badge scheme as other health professionals.

If, however, your child's GP or another health professional can provide you with a supporting letter to back up your argument, it may be well worth having this.

Appeals

There is no centralised appeal scheme if a blue badge is refused (except if a badge is issued but then withdrawn for misuse).

However, local authorities have a process that they follow if you dispute their decision. Often, a senior manager in the team which issues the badges will consider your appeal and gather further information from you and/or relevant health professionals to decide if the decision can be overturned.

Further Information

National Autistic Society Information Sheets :

- Blue Badge Scheme : A Guide for Parents and carers
- Blue Badge Scheme : Example of a parental supporting letter

The Government publishes two free leaflets which explain more about the blue badge scheme:

- *Can I get a blue badge? (T/INF/1213)*
- *Blue badges: rights and responsibilities (T/INF/1214)*

You can order copies using the address or telephone number below and quoting the reference numbers:

The Publications Department
PO Box 236
Wetherby L23 7NB
Tel: 0870 1226 236

If you are issued with a blue badge, you may find the following website useful. It is an online map produced by The Office for Disability Issues and shows the location of disabled parking bays across the UK: www.direct.gov.uk/bluebadgemap

The following website also has a lot of information on the blue badge scheme: www.mobilise.info/

Local Authority Blue Badge Contacts

Bolton Access Bolton One Stop Shop Town Hall Victoria Square Bolton BL1 1RU Tel: 01204 337244	Rochdale Blue Badge Applications PO Box 615 Rochdale OL16 9TF Tel: 01706 922806
Bury Disablement Services Team Seedfield Resource Centre Parkinson Street Bury BL9 6NY Tel: 0161 253 6868	Salford Blue Badge Office Community, Health and Social Care Crompton House 100 Chorley Road Swinton M27 6BP 0161 793 2259
Manchester Manchester Equipment and Adaptations Partnership Blue Badge Scheme 4 th Floor, Victoria Mill Lower Vickers Street Miles Platting Manchester M40 7LH Tel: 0161 277 5919	Stockport Adults & Communities Directorate Blue Badge Dept Memorial Park Marple Stockport SK6 6BB Tel: 0161 474 3422 (2-4 pm)

<p>Oldham Blue Badge Scheme Unit J Prince of Wales Ind. Unit Vulcan St Oldham OL1 4ER Tel: 0161 770 3806</p>	<p>Tameside Blue Badge Section Tameside Adult Services Stalybridge Resource Centre Waterloo Road Stalybridge SK15 2AU Tel: 0161 342 2400</p>
<p>Trafford Access Trafford Ground Floor Waterside House Sale Waterside Sale M33 7ZF Email: access.trafford@trafford.gov.uk Telephone: 0161 912 2000</p>	<p>Wigan Department Of Adult Services Wigan Council Civic Centre Millgate Wigan WN1 1AZ Tel: 01942 827819 Email: ssdhq@wigan.gov.uk</p>

Blue Badge Application: Example of a Parental Supporting Letter

A parent produced this letter to accompany his application for a Blue Badge. It is included in the hope it will give parents some ideas of what they could include as supplementary evidence for their individual children, however it may be not all of the information applies to all children, it really should just serve as an example of what could be written.

Dear Sir/Madam

Application for Disabled Persons Car Badge - PART D: Supplementary information

I offer the following information regarding my child in relation to his application for the above badge. My child is currently in receipt of DLA Mobility (insert rate) component and (insert rate) care component. (see copy of DLA order book). I enclose a leaflet from the National Autistic Society which explains my child's condition.

Part D (1) what is your disability and how does this affect walking?

My child has an autistic spectrum disorder. This mental impairment is permanent and has resulted in severe behavioural difficulties (i.e. a substantial disability) on a day-to-day basis. Although my child does not have a physical impairment, his/her behaviour means that he/she has very considerable difficulty in walking. He requires constant adult supervision.

Specifically, my child needs a Disabled Persons Car Badge because:

- He/she will only walk very short distances from our family vehicle, and always needs prompting, help and close monitoring from an adult during these times. If he/she is required to walk any distance greater than 10 or 15 metres in unfamiliar surroundings, he/she often displays challenging behaviour such as screaming, biting and shouting. At times he/she is temporarily unable to move, lacking the social motivation to do so, for example by sitting in the middle of the pavement or standing in the middle of a road when crossing it. At other times he/she will attempt to run away from a perceived stressful environment.
- The vehicle he/she uses needs to be parked as close to amenities as physically possible, and entitlement to a Blue Badge would enable him/her to do this. It would also substantially ease the pressure on his/her parents and siblings when using facilities and amenities as a family.

- My child requires constant supervision, direction, prompting and guidance when visiting anywhere except very familiar surroundings. If he/she becomes anxious due to being in unfamiliar –and therefore stressful - surroundings he/she will often run away, so being close to the facility being visited is paramount to reduce the likelihood of this happening.
- He/she is at risk in unfamiliar public areas due to his/her lack of awareness of danger because of his/her immersion in routines and his/her “own world”. Parking very near to public facilities would reduce this risk.
- My child has no conception of danger from road traffic, and parking nearer facilities is essential in reducing the need for crossing roads, negotiating supermarket car parks etc.

Please do not hesitate to contact me if you need to discuss this application or need further clarification.

Yours sincerely

RADAR Disabled Toilet Key Scheme

RADAR, the disability network charity, runs the National Key Scheme (NKS) which offers independent access to disabled people to around 7,000 locked public toilets around the country. RADAR request all providers of accessible toilets to keep their toilets unlocked if at all possible. The NKS is suggested for use only if the provider concerned has to keep the toilets locked to stop vandalism and misuse.

RADAR makes no profit in supplying keys but needs to make a small charge to cover the costs of supply. If you would like a key contact RADAR.

RADAR
12 City Forum
250 City Road
London EC1V 8AF

Tel: 020 7250 3222 **E-mail:** radar@radar.org.uk

Families and Siblings

Having a person with autism (including Asperger syndrome) in your family has an impact on everyone, not just parents.

Siblings

Younger people who have a sibling with autism might experience teasing from other children, a lack of privacy, and disruption of their home life and a feeling of resentment that the whole focus of the family is always on the person with autism.

Older siblings may worry about whether they are going to have to look after their brother or sister after their parents have died.

However, being a sibling of a person with an autism spectrum disorder is not necessarily all bad. Research has suggested that, although it can be a stressful experience at times, it does not in the long run necessarily have a negative effect on the person. Many have reported that learning to see the world through the eyes of their autistic sibling has been an enriching experience and taught them to become more tolerant of people's differences.

If you have other children you may want to talk to them separately about your child's condition. You will need to adapt how you explain what autism is depending on the sibling's age.

How to offer support to a brother or sister

- Explain very clearly to brothers and sisters what an Asperger Syndrome is and how it may affect their sibling, using information appropriate to the sibling's age.
- Try to explain the impairments of the condition and how this affects their brother or sister's behaviour.
- Encourage siblings to ask questions about Aspergers.
- Take siblings along to support group meetings to give them the opportunity to meet other children with an ASD and their families.
- Encourage siblings to talk to their friends about their brother or sister's ASD.
- Encourage siblings to take information leaflets into school and maybe a lesson about ASD can be arranged to educate the class about the condition (NAS have a lesson plan Information Sheet available)
- Siblings can often feel left out as all attention seems to be on the child with an ASD. Try to include the sibling in any discussions about their brother or sister. For example, discussing and evaluating behaviour programmes, daily routines and general rules that need to be followed
- Invite siblings along to any meetings, ensuring that the sibling feels able to decline and not feel obligated.
- Make time for the sibling on his or her own
- Explain very clearly to siblings that although their brother or sister needs to be given boundaries and rules first as they don't always have usual levels of understanding and may not recognise consequences to their behaviour.
- Ensure that the sibling knows how to react when difficult behaviour is displayed and praise the sibling for being understanding when the child with an ASD displays difficult behaviour - they may wish to go away from the situation. Make sure that the sibling is comfortable doing this and doesn't feel like they are being pushed away.
- Ensure that the child with an ASD as well as the sibling is given tasks and household chores so that sibling does not always feel they have to do everything.

Sometimes a sibling may be bullied or teased about their brother or sister.

If bullying is taking place in school, make sure that the sibling's teachers are aware. Talk to teaching staff about raising awareness about ASD within school.

If the bullying or teasing is taking place outside of school ensure that the parents of the children who are involved in the bullying are made aware of the situation. Invite the children and their parents into the family home to raise awareness of the condition if you feel this is appropriate.

Further Information

National Autistic Society Information Sheets :

- **Information for Parents/carers about how to support siblings of people with an ASD**
- **Lesson Plan for Explaining Asperger Syndrome**

There are several good books on help for siblings:

Everybody Is Different by Fiona Bleach . (NAS). This is designed to answers questions from younger brothers and sisters and contains suggestions for making family life more comfortable for everyone concerned.

My Family is Different by Carolyn Brock. (NAS) Workbook for siblings of a child with ASD. Includes pictures to colour, puzzles and games.

Able autistic children – children with Asperger syndrome: a booklet for brothers and sisters by J Davis. The Early Years Diagnostic Centre. Designed for siblings of children with able autism or Asperger syndrome from the age of seven, this booklet focuses on Asperger syndrome and the sibling experience.

Can I tell you about Asperger syndrome?: A guide for family and friends by J Welton published by JKP. Adam is a 9 year old boy with Aspergers syndrome. Here he explains his talents and the difficulties as if talking to school friends and family. Jane Telford's cheerful pictures bring Adams words to life.

I'm a teenager get me out of here! by Carolyn Brock Published by NAS. A survival guide for teenage siblings of young people with autism. Cartoon illustrations and a wealth of information and experience combine to make this title a fantastic read for teenage brothers and sisters of people with an autism spectrum disorder (ASD).

Help! 2 Programme run by the NAS and includes an event on siblings. Information on forthcoming seminars can be found on the NAS website: www.autism.org.uk/help

SIBS are an organisation which runs workshops and conferences on sibling issues throughout the UK. They also produce fact sheets on sibling issues for siblings, parents and professionals and maintain a website on sibling issues. There is also an information line for siblings, parents and professionals.

Tel: 01535 645453 Email: info@sibs.org.uk

Family Coaching

Bill Goodyear offers a family coaching service using phone and Internet specifically for families with a family member with Aspergers. More details on his website www.billgoodyear.org

Siblings' Clubs

Bolton Bridges Family Support Service

Run a siblings group for 2 hours for a 7 weeks
Contact: Family Support Team tel: 01204 337121

Bury Young Carers

Bury Council Young Carers Service run a siblings support project for brothers and sisters of a disabled child. It covers all disabilities including autism spectrum.

Contact: Margaret Brewster,
4 Durham House
Castlecroft Court
Castlecroft Road
Bury BL9 0LN

Telephone: 0161 253 6902 **Email:** buryyoungcarers@bury.gov.uk

Bury Communications Difficulties Team

Run a Siblings course each Spring term for 5 weeks at the Phoenix Centre in Prestwich.
Tel: 0161 253 6420

Oldham Young Carers

Contact; Geraldine O'Keefe Tel: 0161 627 1749
Woodfield Centre
Netherfield Close
Off Manchester Road
Oldham OL8 4ET

Rochdale Siblings Group

Contact Sam Freeman tel; 07977 689490

Stockport Young Carers Project

Offers sibling support. Referrals accepted from young person, parent or professional.
Contact; Katie Frankland Tel: 0161 456 2006

Stockport ASD Partnership Project

The project provides support for families with a child with ASD who has behavioural support needs and has been accepted through the referral process. Part of the multi agency support involves active involvement of siblings.

Children and Young People's Disability Partnership
ASD Partnership Project,
C/O 8th Floor Regent House,
Heaton Lane,
Stockport SK4 1BS

Contact; Cheryl Salt Tel. No. 0161 249 4474

Trafford Thursday Night Club Project

Accessible to all family members of young people with an ASD. Application form from
Contact: Dawn Beesley tel; 07824534387

Embrace Wigan And Leigh Siblings Group

Embrace run three siblings groups (8 to 11, 12 to 15, and 16 to 18) for youngsters with a sibling with a disability. It covers all disabilities including autism spectrum. The groups meet Thursday evenings.

Contact Tel No : 01942 513053

Grandparents

Grandparents are very important in most children's lives with many undertaking caring responsibilities spending some time looking after their grandchildren.

If your grandchild has a condition like Asperger Syndrome, you may be the first person to notice they do not have a typical development pattern. This may especially apply if it is your son or daughter's first baby as they will not have the same experience of child development as you do. A child with an ASD can have erratic development, with some areas being advanced and others being behind that which would be expected. Such as a delay in language development, yet have fine motor skills as expected or advanced computer skills.

Knowing if, when and how to broach the subject with your own child can be tricky. It is important to come across as caring and supportive rather than as interfering and judgmental about their parenting skills. It may be that they are already worrying about their child's development but are hoping that all problems will go away.

If you have tried to gently broach the subject with your son or child and they do not want to listen, it may be that you will just need to wait. Be supportive but perhaps not mention the subject again, so when they do have to face it in the future they are able to turn to you for advice and support.

Perhaps, if your grandchild is young, you could mention a difference in speech development rather than autism as a beginning to broaching the subject with your son or daughter.

Looking after a child with ASD can, at times, be challenging. Doing everyday things like going out shopping or meeting friends with your grandchild, can prove to be difficult, an ASD is an 'invisible' disorder, the public can often unfairly pass remark on the child being naughty or the failings of parenting skills. Grandparents can also provide extra support to siblings of the child with Asperger syndrome either by spending special time with them when the parents are with the child with Asperger Syndrome, or vice versa.

Parents often say they feel devastated when they realise their child has an ASD and grieve for the child they thought they had. Parents can often feel depressed and do not know which way to turn. Grandparents can offer useful support by becoming their advocate, learning about Asperger Syndrome and ensuring parents get educational and benefit support for your grand child to which they are entitled.

Further Information

National Autistic Society Information Sheets :

- **Grandparents**

LEISURE ACTIVITIES

Play

Play is a diverse and complex behaviour that is viewed as central to the normal development of children. It implies some kind of fun, a way of entertaining oneself.

Play allows children to learn and practice new skills in safe and supportive environments. Social play, from the earliest exchanges between caregiver and baby to the complex interaction between primary school children, for example, by playing doctors and nurses, teaches about social relationships and how to engage in them, as well as about the cultural norms of the society in which the child is growing up.

Some children with autism do not give any indication that they want to play with other children, preferring to play by themselves; other children would like to but they can have great difficulty in indicating this wish. Indeed, in many cases it is a nursery teacher who first notes that a child may be on the autism spectrum.

However, it is suggested that the acquisition of play skills has much to offer the child on the autism spectrum and parents may have an important role in helping their child with Asperger Syndrome to develop play skills.

Further Information

National Autistic Society Information Sheet : Play

Popular Play Activities

Trampolining

Trampolining is very popular with children on the Autism spectrum, and it provides positive benefits. The fun and sense of well-being is augmented by sensory awareness of one's body positions and how the body responds to movement through space. Jumping and balancing on a trampoline can help physically and sensory integrate the body's different systems. Getting brothers and sisters involved provides a huge social benefit, too. Many clubs and groups offer trampoline activities.

LEGO®

LEGO® Therapy was developed after observing that children with autism were naturally attracted to LEGO® when presented with a room full of toys. Using LEGO® in a therapeutic and structured way was fun and seemed to naturally reinforce appropriate social behaviour. Studies show LEGO® is beneficial for the child with autism in developing group interaction and communication with peers, increasing self-initiated social contact and the duration of social interaction in other group settings such as in the playground and school cafeteria, and improved social competence in general.

For details on local groups and clubs offering organised play activities see section below.

Friendships and Social Skills

How can he be so clever but not know when to stop talking?

How can he be so selfish when he is playing? He's the first to tell others off if they are.

Is she really rude or does she just not understand?

You may have asked yourself these questions while watching your child try to interact with other children. Many parents are puzzled and frustrated by this imbalance in skill level in their children with an autism spectrum disorder (ASD), wondering what it is that makes them lack basic social skills, particularly if they have extraordinary abilities in other areas.

Social Skills - Three areas of difficulty

It's been recognised that social skills are a particular area of difficulty for children with Asperger Syndrome.

These life skills are a key part of the 'triad of impairments' children with Autism Spectrum Disorders have difficulty with.

Here's an outline of these three areas of difficulty:

- social interaction (difficulty with social relationships, for example appearing aloof and indifferent to other people)
- social communication (difficulty with verbal and non-verbal communication, for example not fully understanding the meaning of common gestures, facial expressions or tone of voice)
- social imagination (understanding others' points of view, difficulty in the development of interpersonal play and imagination, for example having a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively).

Most people with Asperger syndrome, despite the difficulties with socialising, do enjoy meeting new people and making friends if they have a degree of control over how, where and when this happens.

It's not that children with an ASD will never be able to learn these social skills, but more that they are going to need specific teaching in this area. Most children learn social skills by watching their peers, experimenting in imitation and refining their skills as they go. Children with an ASD can find this difficult and seem to miss many opportunities to use these skills. Social skills and social situations need to be broken down, explained, and practised so that children with an ASD can absorb them at a level that makes sense to them.

Many children with an ASD can be genuinely bewildered and overwhelmed in social situations. The following gives some practical ideas about ways you can help your child to develop their skills in this area so they can explore the social world with more confidence.

What do we mean by 'social skills'?

We all use a variety of social skills every time we interact with other people. Children who play on their own don't need to use social skills, which is why many children with an ASD retreat to solitary play – it's uncomplicated, they don't make mistakes and they can't get into trouble.

By 'social skills' we generally mean any of the following:

- **conversational skills:** greetings; joining a conversation; verbal turn-taking; listening skills; talking 'on topic'; awareness of personal space; ending a conversation
- **play skills:** observational skills; joining play; turn-taking; sharing; compromising; conflict resolution; coping with 'NO'; coping with losing; reciprocal play; ending play
- **understanding emotions:** reading facial expressions; reading body language; voice quality – intonation, pitch, speed; awareness of own body language; having an large emotional vocabulary (e.g. not just happy or sad); anger management and self-control
- **dealing with conflict:** as above – anger management and self-control; theory of mind (see section on p7); communication skills such as the ability to ask for help; ability to walk away from a stressful situation; being assertive but not aggressive; dealing with bullying
- **friendship skills:** many of the above but also grasping ideas such as what a friend is; being able to choose appropriate friends; recognising true friends from false friends; being able to share a friend; dealing with peer pressure.

These skills begin to develop in children who do not have an ASD, such as Asperger Syndrome, early in life and continue to do so over a number of years, generally without a lot of direct instruction. Children explore the environment around them, using trial and error to work out problems. They observe other children, try to imitate them and attempt to join in. If they make a mistake, they learn from it and continue playing. Skills become more refined as they grow and they begin to absorb social trends. However, children with an ASD do not seem to naturally absorb social skills in the same way their peers do. This is why you need to try to digest social situations for them and then explain it in a way that will make sense to them.

Teaching Social Skills To Your Child

Finding the time to teach your child social skills will depend on your family's circumstances. Some parents may choose to have spontaneous teaching moments when time allows. Others may like to have it scheduled into the weekly routine, e.g. every Saturday morning. Or others may adopt a combination of the two, aiding generalisation.

Important things to remember when choosing teaching opportunities:

- Don't teach during high times of stress.
- If you're going to have a planned, time-tabled activity, prepare your child for when it's going to take place and for what is going to happen during the session.
- Pick the day/time carefully.
- Make the first sessions really fun and short.
- Make the first sessions one-to-one if you can
- Try to create an environment of success.

Practical ideas for developing different social skills at home

- Recognising facial expressions
- Recognising body language

- Emotions
- Entering games/situations
- Conversational skills / turn-taking
- Making mistakes/coping with losing/conflict resolution

Social Stories™

What are Social Stories?

Social Stories were developed by Carol Gray in 1991 to assist individuals with autism spectrum disorders (ASD) to develop greater social understanding. A Social Story is a short description of a particular situation, event or activity, which includes specific information about what to expect in that situation and why. They can provide an individual with some idea of how others might respond in a particular situation and therefore provide a framework for appropriate behaviour. Social Stories also enable others to see things from the perspective of the individual with ASD and why the person may appear to respond or behave in a particular way.

Social Stories have a huge range of applications including:

- To develop self-care skills (e.g. how to clean teeth, wash hands or get dressed), social skills (e.g. sharing, asking for help, saying thank you, interrupting), and academic abilities.
- To assist an individual to cope with changes to routine and unexpected or distressing events (e.g. absence of teacher, moving house, thunderstorms).
- To provide positive feedback to an individual regarding an area of strength or achievement in order to develop self esteem.
- As a behavioural strategy (e.g. what to do when angry, how to cope with obsessions).

What is a Comic Strip Conversation?

Comic Strip Conversations are another technique developed by Carol Gray (1994) to assist individuals with ASD to develop greater social understanding. Comic Strip Conversations provide visual representations of the different levels of communication that take place in a conversation, using symbols, stick figure drawings and colour. By seeing the different elements of a conversation visually presented, some of the abstract aspects of social communication (e.g. recognising the feelings and intentions of others) are made more concrete and are therefore easier to understand. Comic Strip Conversations can also provide insight into the individual with ASD's perception of a particular situation.

Further Information

National Autistic Society Information Sheets :

- **Social Skills for Young Children with an autism spectrum disorder**
- **Social Stories™ and Comic Strip Conversations**

Books

There are several good books on making friends and also some good resources on learning to develop social skills:

Asperger's ... What does it mean to me? A workbook explaining self awareness and life lessons to the child or youth with high functioning autism or Aspergers by Catherine Faherty (Future Horizons)

Friends learn about Tobin by Diane Murrell. Helps children make friends with a classmate with ASD (Future Horizons)

The Cat-Kit: cognitive affective training by Annette Moller Nielsen, Kirsten Callesen, Tony Attwood (www.cat-kit.com/en)

The kit was developed to facilitate conversations about thoughts and feelings in children with social communication difficulties. It aims to help children gain better insight into social relationships, friendships and understanding others. Lots of visual aids and charts are included in this kit.

The Incredible 5-point scale: assisting children with ASDs in understanding social interactions and controlling their emotions by Kari Dunn Buron and Mitzi Curtis

Draw on your emotions: creative ways to explore, express and understand important feelings by Margot Sunderland and Philip Engleheart, published by Speechmark

Social Integration Skills Training by David Moat, Asperger Initiatives Ltd Hastings 01424 439691

Talkabout by Alex Kelly, Speechmark publishers, Bicester, Oxfordshire is aimed children or adults and is good because it relies on a lot of visual worksheets. 01869 244 644.

Socially Speaking by Alison Schroeder, LDA publishers. Aimed at Primary school children who have Asperger syndrome

Developing Social Interaction and Understanding by Fiona Knott and Aline-Wendy Dunlop .A resource for working with children and young people with Autism.

Play With Me by Isabel Telmo It gives classmates a better understanding of children with autism.

Autism – social skills approach for children and adolescents by Maureen Aarons and Tessa Gittens, Speechmark publishers, Bicester, Oxfordshire

Social Skills Training – for children and adolescents with Asperger syndrome and social communications problems by Jed E Baker, Autism Asperger Publishing Company 2003

Mind Reading: the interactive guide to emotions is an interactive study resource using CD-ROMs to understand emotions in faces and voices, by Simon Baron-Cohen produced by Cambridge University. Profits from sales go towards autism research. For use on PC or MAC. Published by Jessica Kingsley Publishers, 2002

The Gray Center for Social Learning and Understanding has a range of very useful information regarding Social Stories which is available at the following link www.thegraycenter.org

Many people like to meet others with the same diagnosis, but without a direct emphasis on 'learning social skills'. These are aimed at providing a relaxing, enjoyable atmosphere for people to meet each other. In the Greater Manchester area Autistic Society Greater Manchester Area *Aspirations Project* organises a range of social activities for people with Asperger syndrome.

ASPIRATIONS

1114 Chester Road
Stretford
Manchester M32 0HL
Tel: 0161 866 8485
Contact: Pete Halliwell
Email: aspirations@asgma.org.uk

Clubs, groups and social interests for children with Asperger syndrome

The Autistic Society Greater Manchester Area *Aspirations Project* is a comprehensive support service for people aged 10+ who have Asperger syndrome or higher functioning autism. Support the project offers includes:

- Support to the parents and carers of individuals with Asperger Syndrome / Higher Functioning Autism through the ASGMA Information and Family Support Project.
- 1-2-1 support to individuals with Asperger Syndrome.
- Advice, information and direct support for people with Asperger Syndrome. Support can be offered around issues such as education, training and employment.
- Travel Training and independence support.
- Outreach support – offering 1-2-1 and small group support in the local community.
- Social and leisure activities across Greater Manchester, often in small groups. This includes things like pub nights, bowling, laser quest, rambling, cinema, football, concerts, sporting events and museum visits.
- School and college holiday activities programme, including trips to places such as Alton Towers, National Film Museum etc
- Short break group holidays
- Local specialist youth club provision
- Classes, workshops and learning opportunities

The project also maintains and runs a Resource Centre geared around the needs of people with Asperger Syndrome / Higher Functioning Autism which contains:

- An arts and crafts room with various art and craft materials
- Pool Room and table football games room
- Computer suite with broadband Internet access
- Computer Games Room with X Box, Playstations etc
- Library with a good selection of specialist and non specialist books
- Social lounge with a large selection of board games etc
- Music Room with keyboards, guitars, drums etc.
- Training room
- Counselling room

Activities at the Resource Centre include:

- Youth Clubs geared around the needs of people with Asperger Syndrome
- Drop in services
- Counselling
- Classes including Art groups, Creative Writing, Drama, Music, Life Skills, Independence Skills, Social Skills etc
- Reference Library and Information Resources

Admittance onto the ASGMA Aspirations Project is by Professional Referral and people admitted onto the project receive a quarterly newsletter highlighting what they may be able to take part in.

For further details on the ASGMA Aspirations Project and details on how to make a referral contact:

Peter Halliwell

Aspirations Project

Autistic Society Greater Manchester Area

1114 Chester Road

Stretford

Manchester M32 0HL

Tel: 0161 866 8485 Email: aspirations@asgma.org.uk

Local ASD Social And Activity Groups

Bolton Kidz2gether

A registered charity who support young people up to 16 with social and /or communications difficulties to inclusive social settings. Activities include trampolining and other sports.

Horwich Resource Centre
Beaumont Road
Horwich BL6 7BG
Tel: 07919 864784 (Jacqueline) 07919 871014 (Steph)

Bury Youth Club

Youth Club for 13+ meeting every 2nd and 4th Wednesday during school terms. Facilities include pool, board games, a computer suite , playstations and a Wii. There is also a large screen TV, arts and crafts activities, a quiet room and a snack bar. Applications should be made through Bury Communications Difficulties Team.
Tel: 0161 253 7316/6416
Contact; Karen Ross Email: k.ross@bury.gov.uk

Oldham AYC Youth Club

Youth club for 10 to 16 year olds living in Oldham who have autism or Asperger syndrome. The club runs on Monday nights, 6-9 pm.
The Honeywell Centre
Hadfield Street
Oldham OL8 3BP
Tel: 0161 770 8777
Contact: Mark Hatton Email: Mark.Hatton@oldham.gov.uk

TASCA 10 Up Zone

A sub group of TASCA parent support group in Tameside. A youth group with activities directed by its members.
Contact; Valerie Bayley
Tel: 0775 4873480
Email: tasca4U@ntlworld.com website www.tasca.org.uk

TASCA Bizzy Bouncers

TASCA hold a monthly coffee evening for members' children and their siblings to have exclusive use of the bizzy bouncers play centre at Berkeley Business Park, Turner Street, Ashton Under Lyne
Contact; Valerie Bayley
Tel: 0775 4873480
Email: tasca4U@ntlworld.com website www.tasca.org.uk

Trafford Thursday Club

Open to 9-16 year olds on the Autism spectrum and their siblings and friends.
Meets Thursdays 7-8.30 in term time only.
Activities include football, music making, computers, art, trips.
Parents are welcome to drop in.
Tel: 0161 962 7716
Contact: Kath Anderson

Sportism – Trafford

Sportism is a voluntary group which is open to children in Trafford aged between 0-16 years who have high functioning Autism/Aspergers Syndrome. It is a family group where siblings are actively encouraged to come and play too.

The group organises soft play activities on Sunday mornings . These are held at different locations in Trafford. Contact Justine for more details and to discuss your child's needs in more detail.

To find out more contact Justine Bailey 0161 748 2994

Day/Time: Sunday 09:45:00 - 10:45:00

The Engine Shed Train Club

The Engine Shed is a free monthly train club aimed at children on the autistic spectrum who love trains, and their families. At the club there will be:

- Large Hornby layouts, kindly supplied by local model railway enthusiasts, for children to enjoy.
- Train sets of all kinds, for all ages and abilities to play with (including wooden Thomas sets, plastic Tomy, Hornby and lots more).
- Train books, craft activities and puzzles and other hands on trains activities.
- Free refreshments for everyone.
- The chance for parents to relax and chat while the children play!

Held on the last Saturday of every month. For further information please contact Liz

Syed on:

Tel: 01565 872 010

Email: liz_syed@yahoo.com

Web: www.engineshedcheshire.com

Address:

Independent Options

67 Chester Road

Hazel Grove

Stockport SK7 5PE (next to Hazel Grove railway station)

Other Clubs and Groups

Scout Movement Clubs - Cubs, Brownies, Beavers and Rainbows

Many children with Asperger Syndrome enjoy the structured play of scout groups. It is useful to tell the leader of your child's aspergers to ensure he or she is fully included in the activities that interest them.

Cycling Clubs

People with Asperger Syndrome often find it quite hard to access suitable recreational and exercise facilities. Cycling is a great solution as it is fun both independently and with family and friends joining in.

Wheels for All centres are co-ordinated by groups led by care workers, physiotherapists or enthusiastic parents/family members. The focus groups will then operate a regular base of cycle activities run special sessions for people with disabilities, including provision of adapted cycles.

Local centres are at Wigan, Salford, Bolton Arena and Bolton Leverhulme Park, and in Manchester at Boggart Hole Clough Park, Debdale Park, Wythenshawe Park.

Enquiries regarding Wheels For All centres and training courses to Hermine Briffa, Wheels for All Development Officer. If you would like to know more about Wheels for All, please contact Ian Tierney at Cycling Projects. Phone: 01925 234213 Email: ian.tierney@cyclng.org.uk

Wythenshawe Wheelers Wythenshawe Athletics Track Wednesday 10-12, Saturday 1p.m- 3p.m
Contact Sue Blaylock 07753 428937 or Nicky Boothroyd 0161 232 3116
Special sessions for people with disabilities, including provision of adapted cycles.

Further Information

National Autistic Society Information Sheets :

- **Autism: A guide for activity leaders and sports instructors**
- **Autism Worksheet – For Brownies, Cubs and Other Clubs**

Therapies

There are a number of practitioners who work with individuals with Asperger syndrome to help to encourage and develop their talents and interests.

- **Music Therapy**

Special Virtuosi, a music group designed to provide music provision to people with special needs, including Asperger Syndrome.

Students with or without previous musical experience can join our workshop sessions or receive one-to-one musical tuition from one of our experienced tutors.

Workshops are held at the Zion Arts Centre, Manchester, every Monday evening (for ages 15 and under) and Tuesday evening (ages 16 and above).

Students attending these sessions can expect to participate with a number of other students and tutors and play as part of a group.

Contact : Noriko Tsuzaki

Special Virtuosi

c/o Royal Northern College of Music

124 Oxford Road

Manchester M13 9RD

Website: www.specialvirtuosi.org.uk

Michael Gilbourne offers music workshops and one to one tuition using drums and keyboards.
Telephone : 01663 749870 Website mdrumtalk.co.uk

Rhythmweave is Rochdale based and offers workshops and individual tuition to disabled people including those with Aspergers using drum therapy. Contact 01706 521731 Website rhythmweave.co.uk

- **Yoga**

Yoga and Relaxation Classes by arrangement.

Fully insured and CRB checked

Contact : Kay Locke on 0161 718 7149 email: Kay.locke@ntlworld.com

Yoga tutor offers tailor made sessions for families, and will hold group sessions if sufficient demand

Independent Options

67 Chester Road

Hazel Grove

Stockport SK7 5PE

Contact: Rifath Khan tel; 0161 456 6502

- **Sensory Facilities**

Disabled Living have a sensory room at their facility in Cheetham, Manchester. The 'sensurround room' can be used for therapy, sensual stimulation, skill learning or simply an enjoyable and rewarding experience. It can be booked for a small fee for up to 8 people.

Contact: Disabled Living
Redbank House
4 St Chad's Street
Cheetham
Manchester M8 8QA
Telephone 0161 214 5959
Website : www.disabledliving.co.uk/sensurround.shtml

My Sensability is a multi-sensory venue in Bury town centre. Sessions are available on a one to one basis or for families, groups and parties. For bookings call 0161 637 0069.
website www.mysensability.co.uk

Boomerang multisensory Play Centre is a special facility for disabled children. Individual or group sessions. Booking essential.

Unit 2
Woodhill Street
Bury BL8 1AT
Telephone 0161 764 4842 www.boomerangcentre.co.uk

- **Riding Therapy**

Children with special needs and disabilities are welcome to benefit from donkey riding therapy at the Elisabeth Svendsen Trust riding centre in Debdale Park, Manchester.

Many families come along to family days and have a great time. These are usually held once a month.

For more information, dates and times please contact:

Tel: 0161 301 4051

Email: estmanchester@btconnect.com

Web: elisabethsvendsentrust.org.uk

Address:

Green Fold
Elisabeth Svendsen Trust
Abbey Hey
Manchester M18 8RJ

Relaxation

Find out what helps the person to relax and feel more comfortable. This may take time. Hobbies, interests can be important ways for the person to relax, but there may be other methods. Getting into the countryside, going for a walk, having someone spend some time listening and helping the person look at some of the good things that have been achieved by, or happened to, him or her – keeping a diary/photo album of positive events.

Hobbies And Special Interest Activities

Many of the 'special interests' that children with Asperger Syndrome develop can be positively channelled into a hobby interest which can improve the child's wider understanding and social skills. This may depend on the individual's particular areas of interest and level of ability.

Trains (often starting with Thomas the Tank Engine) , computers, dinosaurs or cartoon characters can be common special interests for children with autism spectrum disorders and as these interests are shared by many other children can be used as a way of helping develop social skills and joining clubs.

However many children with Asperger Syndrome prefer to spend their leisure time on their own. When the special interest is in a more unusual subject areas such as car registration numbers, bus or train timetables, pylons, postal codes, traffic lights, numbers, shapes or particular body parts such as feet or elbows then sharing interests becomes more difficult.

Some people will remain interested in one area for their entire lives; others develop interests in new areas after particular time periods.

Obsessions

Obsessions generally differ from other interests in their intensity (i.e. how much an individual will learn about a particular area and how strongly they feel about it) and their frequency and duration (i.e. how long a person will spend on their area of interest). Obsessions can be very intrusive in the child's life and limit their involvement in other activities and can distract from school work..

Further Information

National Autistic Society Information Sheet :

- **Obsessions, Repetitive Behaviours and Routines**

Befriending and Buddying

Befrienders (or Buddies) are people who voluntarily help children with Asperger Syndrome by becoming their 'friend'.

Typically, a befriender spends a few hours a week with a person with Asperger syndrome or their families. Most groups who offer a befriending service match volunteers with people and their families who have something in common.

A befriender might:

- be an extra pair of hands on a shopping trip
- take a youngster out to help with their special interest
- go along with a youngster to a sporting activity or a film
- meet up with an youngster for lunch
- spend time listening and talking to a member of the family
- offer the family a short break by spending time with a youngster in the home.

Many organisations and local authorities offer a befriending service, including the NAS.

Bury Befriending

Sylvia Boucher
Bury Befriending Scheme
Communication Difficulties, Seedfield Centre
Parkinson Street
Bury BL9 6NY
Telephone: 0161 253 7613
Email: s.boucher@bury.gov.uk (launches email software)

Rochdale Buddying Project

The Buddying Project is funded by Rochdale Council and run by the National Autistic Society. It is available for young people up to 18. The buddies then do all sorts of activities together, like going to the cinema, for a meal, or to a local youth group or sports session. The project also aims to give a short break to parent/carers and siblings as well as providing social and leisure opportunities for the young person with an ASD. Volunteer buddies 16 and over are welcome.

Contact: Emma Storrie (NAS) Tel: 07796 6184454 emma.storrie@nas.org.uk

Jubilee Garden Disabled Children's Centre

Tameside MBC
Children with Disabilities Team
Gardenfold Way
Droylsden M43 7XU
Telephone 0161 371 2060

Trafford Buddying Project

The Buddying Project is funded by Trafford Children and Young Peoples Service and run by the National Autistic Society. It is available for young people between 11 and 19. The buddies then do all sorts of activities together, like going to the cinema, for a meal, or to a local youth group or sports session. The project also aims to give a short break to parent/carers and siblings as well as providing social and leisure opportunities for the young person with an ASD. Volunteer buddies 16-21 are welcome.

Contact: Meredith Walsh (NAS) Tel: 07920 727444

Going Out

Trips out to places such as shops and to see people such as doctors and dentists can be very stressful for a child with Asperger's Syndrome and members of their family.

Their behaviour on a trip out can be affected by unexpected events and in particular by sensory difficulties and invasion of their space.

The National Autistic Society have produced a number of Information Sheets to try to help parents and carers reduce the stress their child may suffer in these situations.

These consider, in particular, trying to reduce the sensory impact on the child by planning ahead to minimise the unexpected.

For example:-

- visit busy places such as supermarkets at quiet times
- talk to professionals (dentists, hairdressers) ahead of a visit , so they are aware of any difficulties and can do their best to put the child at ease and avoid unnecessary touching
- organise a 'dummy' visit so the child can see what happens and it comes as less of a surprise to them when its their turn
- keep a diary of specific things that upset the child so they can be avoided or managed
- use visual aids (story board) to help the child understand what will happen
- if appropriate, reward the child if things go well

Further Information

The National Autistic Society produce a number of Information Sheets to help with potentially difficult trips out :

- Going To The Hairdressers
- Going To The Shops
- Doctor's: preparing for a visit
- Dentist : preparing for a visit
- Going To A Place Of Worship

Holidays

Planning a holiday is exciting and sometimes stressful for the parent or career of a child with Asperger Syndrome, and may involve extra organising and preparation.

Once you have decided on your destination, it is advisable to tell your child about the trip. Individuals on the autism spectrum find change difficult, and this may lead to high anxiety and possible challenging behaviour. However, by preparing your child as much as possible, any fears will hopefully be kept to a minimum.

You could compile a booklet about the holiday, including pictures from the holiday brochure. It may be useful to create a timetable of what you will be doing on each day, and if your child likes routines, include the times that you will have breakfast, lunch, and dinner.

Travel Plans

In any holiday plan or discussions, include details of the travel arrangements, including the duration of journeys and the necessity of queuing at airports, ferries or being held up on long car journeys.

Airport

The routines and queuing at Airports may present a particular problem for your child.

Manchester Airport have produced an excellent free guide and picture book called '**Airport Awareness**' aimed at helping children on the Autism Spectrum and their parents and carers with their journey through the airport and on boarding the plane.

Further Information

The National Autistic Society produce Information Sheets to help with holiday planning :

- Holidays: preparation and practicalities
- Holidays: Autism friendly venues (aimed at children on the more severe end of the spectrum)

Airport Awareness booklet produced by Manchester Airport. For your free copy contact:

Manchester Airport
Manchester M90 1QX
Tel : 0161 489 2700
Website www.manchesterairport.co.uk (downloadable)

Christmas

Christmas is an exciting and enjoyable time, but for the families of a child with Asperger Syndrome it can sometimes be stressful. They may become confused or distressed by all the new activity within the household and this in turn can be upsetting for the rest of the family.

Preparing for Christmas

Christmas, and the run up to Christmas inevitably involves a change in routine for you and your family. As the festive season approaches, it will be important to prepare your child for the changes that will occur, including preparing them for the time spent away from school or other normal activities.

A good way to do this is to highlight the holiday period beforehand on the household calendar, or your child's calendar if they have one. You may only want to highlight Christmas Day itself, or, in the case of a child, you might want to indicate when the school term ends and starts again. This will prepare them for the fact that they will be staying at home during this period. Give this period of time a name on the calendar, such as 'Christmas Time'.

Activities such as the arrival of the Christmas tree and its decoration, and visits to the house by friends and relatives who do not regularly call may cause the child some stress.

Further Information

The National Autistic Society produce an Information Sheet to help children on the autism spectrum help enjoy Christmas and gives suggestions for presents :

- Christmas And Autism Spectrum Disorders

Cinema Tickets - Free Tickets For Carers

This is a scheme run by the Cinema Exhibitors Association (CEA), and allows the cardholder one free ticket for each visit for the person accompanying them.

To be eligible for the card, a person must be receiving either Disability Living Allowance (DLA) or Attendance Allowance or hold a disabled person's railcard. The cinema card is valid for 3 years.

Application forms for the card are available from cinemas that support the scheme or download a copy from the CEA website.

Send a copy of the completed application form, together with a document confirming eligibility, one passport sized photo and £5.25 (to cover processing costs) to the card network address on the form. And your card will be sent in about 3 weeks.

Nearly all cinemas accept the card.

For more details visit the CEA website www.ceacard.co.uk or call 0845 1231295

Autism Friendly Film Screenings

Dimensions charity, in partnership with ODEON cinemas, have introduced a regular program of Autism friendly film screenings.

The screenings take place approximately monthly at various cinemas across the UK including the **Trafford Centre Odeon**, and will show films suitable for young people on the autism spectrum.

The screenings will have the following autism friendly features

- The lights will be on low
- The volume will be turned down
- There will be no trailers at the beginning of the film
- You'll be able to take your own food and drinks
- You'll be able to move around the cinema if you

Cinema tickets can be purchased as normal from the cinema box office or online. Support workers / carers can attend for free with a CEA card as described above.

Magazines and websites

Contact the National Autistic Society website www.autism.org.uk and look up the links page for a lengthy list of Asperger syndrome related chat rooms and other sites.

For Parents and Carers

Magazine

Aukids is a quarterly positive parenting magazine aimed at families with young children on the autism spectrum. It is written and produced locally in Stockport. It is downloadable from the Aukids website www.aukids.co.uk

Chat channels

- www.autismtalk.net

Online community site for people with an interest in autism. Site features include chat, bulletin board and other ways to contact site members such as on-site private messaging. Membership is free.

- WrongPlanet.com

This online community site for individuals with Asperger syndrome includes a forum where members can communicate with each other and a chatroom for real-time communication.

www.inlv.demon.nl/ list of support groups and chat rooms.

Email discussion lists, forums and blogs and help sites

Website names for the following sites are long and change frequently. It is suggested that names of sites listed below are entered in Google or another search engine to quickly find the site.

- [Autism Awareness](#)

A meeting place website is a meeting place for all people who care about autism – who want to raise awareness, share information and ideas

- [Autinet Forum](#)

An electronic list discussing all aspects of autism and developmental disorders, but especially high-functioning autism (HFA) and Asperger syndrome.

- [Autism Hub](#)

Autism Hub attempts to collect the best autism-related blogging together in one place. It includes blogs by a range of contributors, including people with autism, all of whom share a respect for the condition of being autistic.

- [The Autism List](#)

A lively discussion list with over 1,000 subscribers, including parents, professionals, students, people with autism spectrum disorders and others.

- [Autism Networks](#)

Autism Networks is a charitable body run by a group of like minded parents, carers, professionals and persons with autism. One of their aims is to network with anyone connected with autism.

- [Autism Resources](#)

Listing of discussions online.

- **Autism-UK Electronic Mailing List**

A UK-based list which is not affiliated to any one autism group but provides a forum for wide-ranging discussion on many issues related to autism spectrum disorders.

- **Delphi Forums**

Hosts a number of forums for people who on the autistic spectrum.

- **Talk Autism**

Talk Autism is an online forum where people with an ASD, family members and professionals can talk, seek advice and exchange tips on any aspect of autism and related issues.

- **www.thegraycenter.org/index.cfm** A US based discussion site

- **www.tonyattwood.com.au** The site of Tony Attwood, author and world expert on Asperger Syndrome.

For Younger Children

Websites

www.thomasandfriends.com Thomas The Tank Engine games and activities

www.thetransporters.com

DVDs

Transporters: Helps children on the autism spectrum understand emotions

By Young People with Asperger syndrome

www.aspergernauts.co.uk

www.assupportgrouponline.co.uk ASSGO is the website of Emma Thomson.

Asperger United is a magazine written by and for older children and young adults with Asperger syndrome. It is currently free to people with Asperger syndrome. Contact John Joyce for details 0207 833 2299.

National Autistic Society Information Sheet : Books and DVDs for Children and Young People. Contains a list of suitable books and DVDs and is updated regularly.

Storybooks and Children's Novels about autism

Under 9s

Understanding Sam by Clarabelle Van Niekerk (2006).

Buster and the Amazing Daisy by Nancy Ogaz (2002).

Ages 9-13

Blue Bottle Mystery Of Mice and Aliens Haze all by Kathy Hoopmann, Jessica Kingsley publishers.

Truth or Dare by Celia Rees (2000), Macmillan.

Wishing on the Midnight Star by Nancy Ogaz (2004), Jessica Kingsley Publications.

Dead Puzzling by Sue Birch (2009)

Asperger Syndrome, the Swan and the Burglar by Brenda Boyd (2007)

The London Eye Mystery by Siobhan Dowd (2008)

Dannie's Dilemma by Carol Haldane and Karen Jones

Adam's Alternative Sports Day (2004) by Jude Welton

The Curious Incident of the Dog in the Night-Time by Mark Haddon (2003) David Fickling Books

Hangman by Julia Jarman

Al Capone Does My Shirts Al Capone Shines My Shoes both by Gennifer Choldenko

For Parents

One by Nigel Pickard (2005)

LEGAL MATTERS

Sound legal advice is a must for anyone entering into a legal contract for a child with Asperger Syndrome such as setting up a trust fund.

As well as using a solicitor with knowledge of the area of law concerned it is prudent to use someone who is sensitive to and has experience in dealing with learning disabled individuals and their families. Such a person is likely to be better informed about specific issues relating to disability.

Finding appropriate advice services can be difficult and word of mouth is often the best recommendation. However, there are a number of sources of information available in each of the different areas of legal activity.

Criminal Justice System

The age for Criminal responsibility is 10, and is very unlikely that children with Autistic Spectrum Disorders will come into contact with the criminal justice system as offenders, although they may possibly as victims or witnesses.

Whilst the law makes no special provision for people with autistic disorders, if the victim of a crime is 'vulnerable', this may be considered an aggravating factor and lead to a higher sentence if a conviction results.

It is very important that those working in the criminal justice system, from police officers on the beat, through to desk sergeants, defence solicitors, magistrates and judges, are aware if a child they are talking to has an autistic condition and may behave or react in unpredictable ways. Work is underway to ensure these groups have a basic understanding of autism.

Tuckers in Manchester have legal representatives who specialise in criminal cases with a medical background. Contact 0161 233 4321 email : www.tuckerssolicitors.com

Hilary Dinham has extensive experience of working with people who have Asperger syndrome in court and other legal contexts. She can be contacted on 01895 258 664 or email at hjdinham@lineone.net

Wills And Trusts

There are a number of key issues to bear in mind when considering wills, trusts and other financial arrangements for people with conditions such as Asperger Syndrome.

Whilst every family situation is different and good legal advice should always be sought, there are a number of common goals in planning for the financial future of vulnerable people. Namely:-

- Preserving Benefits
- Balancing the interests of the person with those of their siblings
- Ensuring Grandparents and others do not make unsuitable arrangements
- Planning for what is to happen after you have gone.

If suitable plans are not made, money can possibly be wasted in the future on loss of benefits, housing costs and inheritance tax. If no will is made, the rules of intestacy (no will) apply, which may not distribute money left as you would want.

Some guiding principles for parents:

- Parents should make a will!

- Consider including in the will setting up a discretionary trust for the person with Asperger Syndrome, rather than leave money directly to them. This can limit the impact of taxes and loss of benefits. Money can then be paid from the trust to meet their living expenses.
- Savings for the person with AS may be better kept in the parent's names, again to avoid loss of benefits. However, this may depend on the parents' financial circumstances.

Wills should be kept up to date. Families' circumstances change, as does the law, so qualified legal advice is always advisable.

DWF Solicitors in Liverpool, Warrington and Manchester have a legal team specialising in wills and trust planning. Contact 0161 603 5000

Irwin Mitchell Solicitors in Manchester have legal representatives specialising in wills and trust planning email: www.irwinmitchell.com

Housing Options Nigel King is a specialist with knowledge of how to leave property to people with Asperger syndrome. 01993 705 012.

Mencap Trust Company Limited is a company that can assist with the set up management of discretionary trusts and wills for people with disabilities. Tel 0207 696 6925.
Email: willsandtrusts@mencap.org.uk

Disability Discrimination

The Disability Discrimination Acts of 1995 and 2005 clearly aim to end the discrimination that many disabled people, including those with autism, may face in their day to day lives. A carer or parent can also be discriminated against if the discrimination is due to their 'association' with somebody with a disability.

If you feel that you or children you care for with autism conditions have been discriminated against on the grounds of disability in relation to:-

- Employment
- Supply of Goods and Services
- Housing
- Education (over 16s).

then you may qualify for free legal advice.

Under the Disability Discrimination Act, as a disabled person you can be discriminated against if:

- For a reason relating to their disability, a person is treated less favourably than somebody who does not have that disability
- If the employer, service provider, manager of premises (e.g. landlord) or education provider fails to take reasonable steps to ensure that a person is not placed at a substantial disadvantage compared to other people who do not have that disability.
- In employment somebody can also be 'directly' discriminated against if treated less favourably because of a particular disability. A person is also protected against harassment on the grounds of disability or against victimisation if treated less favourably on the grounds of bringing a complaint of disability on behalf of yourself or another employee.

The Rochdale Law Centre (ROBB Project) has been granted funds by the new Equalities and Human Rights Commission (which now incorporates the Disability Rights Commission) to help people who feel they have been discriminated against in this way. It covers **the Boroughs of Rochdale, Oldham, Bury and Bolton (hence ROBB!)**.

Tameside Equality and Diversity Centre (EDC) provide a similar service for people who live in **Manchester, Stockport and Tameside** and **Trafford Law Centre** for those who live in **Trafford, Salford and Wigan**.

These services in support of the Disability Discrimination Acts, provide advice, case work and representation at Employment Tribunals and County Court level. As these services are centrally funded, advice and casework is **free of charge** regardless of income and in particular, regardless of eligibility for Legal Services Commission funding.

Who To Contact

If you feel you need to talk to somebody about a disability discrimination matter please contact the appropriate specialist law centre which covers your locality.

For people living in Rochdale, Oldham, Bury and Bolton.

Rochdale Law Centre
ROBB Project
15 Drake Street
Rochdale
OL16 1RE
Telephone Advice Line 01706 657766

For people living in Manchester, Stockport and Tameside

Tameside Equality and Diversity Centre of Excellence
22 Warrington Street
Ashton Under Lyne
OL6 6AS
Telephone: 0161 343 3399

For people living in Salford, Trafford and Wigan

Trafford Law Centre
4th Floor John Derby House
88-92 Talbot Road
Old Trafford
Manchester M16 0GS
Telephone: 0161 872 3669
When calling ask for Kalim Dean or Daxa Shah

Pannone in Manchester have a department specialising in Disability Rights. Contact 0800 0384 384 email: www.pannone.com

Levenes. London based solicitors specialising in Education and Disability law. Contact 0800 118899

Equality and Human Rights Commission Helpline 0845 604 6610 for legal advice about access to services, and employment and disability.

Disability Law Service Tel: 0207 791 9800 for assistance with legal matters relating to disability. Mon-Fri 10am - 1pm and 2 - 4.30pm or email advice@dls.org.uk

Other Legal Contacts

Lawyers for People with a Learning Disability (Anthony Quinn & Co). Anthony Quinn's company can be contacted on 0207 242 3332.

Anthony Collins Solicitors based in Birmingham specialise in helping people with social care issues. Contact 0121 200 3242

Law Society Tel: 0207 242 1222 have lists of solicitors who do legal aid work in your area. www.lawsociety.org.uk

Coram Children's Legal Centre advice line 0808 802 0008. Advice on all aspects of legislation relating to under 18s.

IPSEA Tribunal Helpline 0845 602 9579 (Daytime hours: Mon, Tues, Weds 10-1 and Thurs 10-4. Evening hours: Wednesday 7-9)

Special Education Needs And Disability (SEND) Tribunal website (www.sendist.gov.uk) provides information for parents whose children have special educational needs can appeal to the First Tier Tribunal (Special Educational Needs & Disability) against decisions made by local education authorities (LEAs) in England about their children's education. This covers children under 16 or in a school 6th form run by the LEA. See earlier section covering SEND.

Further Information

Book: A Parent's Guide To Disability Discrimination by Geraldine Hill. It can be downloaded free of charge from www.inclusivechoice.com.

Who to contact

Name of professional service	What service they offer	At what age should they be involved?	Contact numbers	What to ask for	Other information
Clinical Psychology	Psychological assessment and support.	Any age	Generally best to go through the GP	Help with counselling, therapy, support with behaviour difficulties, explaining the diagnosis etc	
Children's Social Services	Help with social support e.g. – help to develop independent living skills, social skills	From age 14 Social Services should be aware of the person, if not before.	If the person is under 18 years contact: Write to them - see sample letter. If the person is 18 or older and does not already have a social worker then write to them – see sample letter	If the person is under 18 ask for an assessment of Need under section 17 of the Children Act 1989.	It is important to know why you are asking for an assessment of need. Before writing or calling Social Services for support think carefully about the exact needs the person with Asperger syndrome has – see sample letter
Occupational therapy	Assessment and support in helping people to be functionally able in independent living, sensory integration, social skills	Any age	Ask the Social Services team for your son or daughter or your GP.	Ask how occupational therapy can help your son or daughter – services vary area to area	

Useful local telephone numbers

The NAS Family Services Development Project supports the development of local services for families, carers and people with autism/AS of all ages in Greater Manchester. The project also provides information and signposting to parent carers, people with ASDs and professionals throughout Greater Manchester.

Tel: 0161 998 4667

The Autistic Society Greater Manchester Area Aspirations Project - a comprehensive support service for people aged 10+ who have Asperger Syndrome or higher functioning autism..

Tel: 0161 866 8485

Prospects - Specialist employment consultancy service for people with Asperger Syndrome.

Tel: 0161 998 0577

ADD/ADHD and Related Syndromes Family Support Centre

Tel: 0161 790 1455 / 1422

Contact Carol Weston

Gaddum Centre - Answers questions about social and health care needs, people's rights under Community Care, Disability and Children's legislation

Tel: 0161 839 0421

Special Educational Needs Family Support Centre

Tel: 0161 755 3482

Useful national organisation telephone numbers

AFASIC (Association For All Speech Impaired Children) Helpline 08453 55 55 77/ 0207 490 9410. speech and language difficulties

ADHD Support Group Tel: 01380 726 710

ADDISS (ADHD information service) Tel: 0208 952 2800

British Dyslexia Association Tel : 0118 966 8271

British Epilepsy Association Tel: 01345 089599

British Stammering Association Helpline 0845 603 2001

Carers UK Tel: 0808 80877777 www.carersuk.org

Citizens Advice Bureau Tel : 0870 126 4626

Contact a Family Helpline Tel: 0808 808 3555 www.cafamily.org.uk.

Disability Law Service Tel: 0207 791 9800 for assistance with legal matters relating to disability. Mon-Fri 10.30 am - 1pm and 2 - 4.30pm

Disabled Living Tel: 0161 214 5959

Dyslexia Action

Wilmslow Centre is the nearest main branch Tel: 01625 530158.

There is also a smaller branches in Altrincham, Bolton, Didsbury and Oldham

National Tel: 01784 222 300

Dyslexia Foundation Tel: 01462 455016

Epilepsy Action Helpline Tel: 0808 800 50 50

Equality and Human Rights Commission (DRC) Helpline Tel: 0845 604 6610 for legal advice about access to services, and employment and disability. www.equalityhumanrights.com

Human Rights Unit Helpdesk Tel: 020 7210 1437 www.dca.gov.uk/peoplesrights.htm

Hyperactive Children's Support Group Tel: 01243 552019 www.hacsg.org.uk

I CAN Parent Forums of free information sharing events for all parents of children with communication disabilities Tel : 0845 225 4071

MIND (National Association for Mental Health) information line 0845 766 0163

National Autistic Society Professionals, Parents and People with Asperger syndrome
Helpline Tel: 0808 800 4104 for information on any aspect of Asperger syndrome exclusively for families affected by the condition.

National Autistic Society Parent to Parent Helpline Tel: 0808 800 4106

www.p2ponline.org.uk

a freephone line to enable parents to talk with another parent about their situation.

National Health Service Patients Charter Information Line Tel: 0800 66 55 44

NHS Direct Tel: 0845 4647

National Learning Disability Helpline Tel: 0808 808 1111

National Society for Epilepsy Helpline Tel: 01494 601 400 www.epilepsynse.org.uk

Outreach Advice Assistance Support and Information on Special Needs (OAASIS) Helpline
Tel: 01590 622880. Information on courses, publications and literature.

Pathological Demand Avoidance Contact Group Tel: 0208 715 6179 (after 8.30pm)

Royal Mencap Society Learning Disability Helpline Tel: 0808 808 11 11

Telephone numbers for education information and advice

National Autistic Society Education Advice Line Tel: 0808 800 4102

National Autistic Society Tribunal Support Scheme Tel: 0800 358 8668

SEN Legal Advice for Children, Cadney House Tel: 01284 723 952.

Advisory Centre for Education (ACE) Advice line Tel: 0207 354 8321

Contact a Family Education Advice Line Tel: 0808 808 3555 email: helpline@cafamily.org.uk

Parents Autism Campaign for Education – Tel: 0207 226 5525.

Independent Parental Special Education Advice (IPSEA) Tel : 0800 0184 016/ 01799 582030

SEN Code of Practice DfES publications Tel: 0845 60 222 60

Parents For Inclusion Tel: 0800 652 3145

Network 81 A national network of parents working towards properly resourced inclusive education for children with special educational needs Tel : 0870 770 3306

Transition Information Network An alliance of organisations and individuals who came together with the aim of improving the experience of disabled young people's transition to adulthood.
Tel : 0202 7843 6006 www.transitioninfonetwork.org.uk

Selected Booklist

The Complete Guide To Asperger's Syndrome – Tony Attwood (2006) Jessica Kingsley

Asperger Syndrome ; An Overview - Gillberg and Ehlers (2006) NAS

Freeks, Geeks and Asperger Syndrome – Luke Jackson (2002) Jessica Kingsley

Finding Out About Asperger Syndrome, high functioning autism and PDD – Gunilla Gerland (2000) Jessica Kingsley

Asperger syndrome: a practical guide for teachers,
Cumine, V. Leach L. & Stevenson, G. (1998) David Fulton publishers

Preparing for adulthood, Howlin, P. (1997) Autism - Routledge

Asperger syndrome and difficult moments, Smith Myles, B. & Southwick, J. (1999)
Autism Asperger Publishing Co. USA

What is Asperger syndrome and how will it affect me?
National Autistic Society Autism Helpline Tel: 0808 800 4104

All of these books are available from the National Autistic Society publications catalogue.

To place an order for books telephone 0845 458 9911

The NAS website (www.autism.org.uk) and the 'Shop With The NAS at Amazon site' (www.autism.org.uk/shop/amazon-store) contains useful lists of recommended titles including one for adolescents with autism and Asperger Syndrome, which are regularly updated.

Library

There is a collection of books on Asperger Syndrome and other autism spectrum subjects available for loan in the **Manchester Parent Carer Network Library** in Central Manchester. The collection includes those formerly kept at the NAS Manchester Office in Northenden.

Address:

**Manchester Carers Forum
London Scottish House
24 Mount Street
Manchester M2 3NN
Tel: 0161 819 2226**

Asperger syndrome organisations

The following list is of individuals and organisations that aim to support people with Asperger syndrome. It is not an exhaustive list, nor is it necessarily a list of recommendation.

ASD Therapy ASD Training Training and Advice Therapy for Autism spectrum disorders. Contact David Moat Tel: 07734 420997

ASPEN-UK Asperger Syndrome Professionals Network ASPEN UK is a group of professionals involved in developing services for children and adults with Asperger syndrome. ASPEN UK meets twice annually. Contact via NAS Helpline Tel: 0808 800 4104

Autism Independent UK (was SFTAH) (mostly education and training providers)
Tel: 01536 523 274. www.autismuk.com

Autism Initiatives (family support, residential and day care, outreach). Work in various parts of the UK, but not currently Greater Manchester
Tel: 0151 330 9500

Care Training Ltd. Training organisation with specialist (John Mortlock) in autistic conditions Tel: 01285 760242 www.care-training.co.uk

European Services for People with Autism (ESPA). Range of Further Education provision. Tel: 0191 516 5080

Hesley Group Education facilities for people with special needs
Tel: 01302 386900

OAASIS (Office for Advice, Assistance, Support and Information on Special Needs) 09068 633 201. The information service of the Hesley Group, offering information on a variety of special needs.

National Autistic Society Directory of Services website www.autismdirectory.org.uk contains an up to date national lists of support organisations and details of local organisations outside Greater Manchester.

John Davies
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