



Greater Manchester
Autism Consortium



The National
Autistic Society

The National Autistic Society
Family Services Development Project

AS INFORM

Greater Manchester



An information resource for **Teenagers and Adults**
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 teenagers and adults 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 community care, Further Education or Higher Education, employment, diagnosis, counselling, benefits and social support/ leisure.

Updates

This document is the Greater Manchester version of AS INFORM launched in 2004, and is regularly updated. This version was last updated on the date shown on the front sheet. 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**Family Services Development Project on 0161 998 4667** if you have new information which you think we should add, or out-of-date information we should remove.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 (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 teenagers and adults 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 before a young person leaves school and sources of support for adults in many areas.

There is some information about continued education, employment and getting social and housing services support.

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 someone 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

Getting a diagnosis of Asperger syndrome can be a really positive thing. A lot of people say their diagnosis has helped them to understand why they have difficulties with some things and why they are especially good at some things.

Having a diagnosis also means you can get easier access to support and benefits. However, the process of getting a diagnosis can be difficult for adults. This guide aims to help: the first step is to talk to your GP and ask for a referral.

Step 1: speak to your GP

To get a diagnosis you should first visit your GP and ask for a referral to a psychiatrist or clinical psychologist, preferably one with experience of diagnosing autism. Choose to see whichever practice doctor the person relates best to.

Make sure your diagnosis is the only thing you are seeing your GP about. If you try and mention it during a consultation about another subject, your GP may not address it fully.

Your GP needs a reason to refer you for diagnosis, so you may need to explain why you think you could have autism, and how a diagnosis would benefit you. If you think you might want a bit of help with this, ask someone you know to come with you.

You might say that you have been reading about autism, or that you've been in touch with The National Autistic Society (NAS). You think that you experience some of the difficulties that people with autism can face, and you would like to seek a formal diagnosis to be sure.

Below, we summarise the main difficulties that people with autism experience - you can discuss some of these with your GP (see 'Step 2: presenting your case').

Not all GPs will have an in-depth knowledge of autism, so it's important to explain things as clearly as you can. We have written a helpful guide for GPs which you can download from www.autism.org.uk/gpaspergerguide. Our website also has useful information about diagnosis for professionals: www.autism.org.uk/diagnosisguide

If you are seeing a different health professional for other reasons (for example, a psychologist if you have depression) you might prefer to ask them for a referral instead.

Step 2: presenting your case

Autism conditions are characterised by three main areas of difficulty and if you have autism, you'll be affected in some way in each of these areas. However, everyone with autism is different and no one person will have all of the traits listed below. Try to give your GP one good example from each of the three main areas of difficulty.

The three main areas of difficulty

Social communication

People with autism sometimes find it difficult to express themselves emotionally and socially. To give some examples, you may:

- have difficulty understanding other people's gestures, facial expressions or tone of voice
- be unsure about when to start or end a conversation, or how to choose topics to talk about
- talk or read very fluently but not fully understand the meaning of some of the more complex words and phrases you use

- be very literal yourself and sometimes struggle with jokes, metaphors, sarcasm or common turns of phrase, such as 'She nearly bit my head off'.

Social interaction

Plenty of people with autism want to be sociable and make friends, but often say they're unsure how to go about this. Socialising can be difficult and may cause considerable anxiety. To give some examples, you may:

- find it hard to make and maintain friendships
- find other people unpredictable or confusing
- not always understand the unwritten 'social rules' that other people just seem to know. How close do you stand to another person? How do you know what's an appropriate topic of conversation?
- be unsure how to behave in different social situations, and worry about getting things wrong.

Social imagination

People with autism have difficulty with social imagination. To give some examples, you may: find it hard to understand or interpret other people's thoughts, feelings or actions - and therefore to understand their intentions or to predict what they're going to do next
not always be comfortable with the idea of change, and prefer to stick to a routine
enjoy carrying out particular activities, or learning about certain topics, which as well as being enjoyable you may find really beneficial. Perhaps they help you to relax, or to deal with anxiety.

It's important to add that many people with autism are imaginative (for example, they are accomplished writers, artists and musicians). If you're quite creative, this shouldn't automatically be taken as a sign that you do not have autism.

Related characteristics and conditions

As well as the three main areas of difficulty, you may find you have some of the following characteristics or conditions, which are quite common in people with autism. You should tell your GP about these, too.

Sensory difficulties

Sensory difficulties can affect all seven senses: sight, sound, smell, touch, taste, balance ('vestibular') and body awareness ('proprioception').

You might find that you are either over-sensitive or under-sensitive to different stimuli. For example, you might be averse to bright lights, loud noises, some smells, particular food textures or the feeling of certain materials. Any of these could cause anxiety, possibly even pain.

You may also find it harder to use your balance and body awareness systems, which let us know how we're moving and where our bodies are in space. So you might find it harder to navigate rooms avoiding obstructions, or go up and down stairs. You might also find that repetitive activities such as rocking, hand-flapping and spinning (which many people with autism do) help your balance and posture.

Love of routines

In an effort to make the world less confusing, you may have rules and rituals (ways of doing things) that you insist upon. You might also have a strong preference for routine, and find it difficult to cope with change if you haven't been able to prepare for it in advance. For example, an unexpected delay to your journey to or from work might make you feel anxious or upset.

Special interests

People with autism may develop an intense interest in a particular subject or activity. Interests can change over time or be lifelong. Practically everyone has interests or hobbies but you may find that your interests are very strong, and that possibly you aren't especially interested in learning or talking about other things.

Mental health difficulties

Some of the more common mental health difficulties that people with autism can experience are anxiety and depression. A related issue is self-injurious behaviour, such as hitting or cutting yourself. Mental health difficulties can be addressed, and often more successfully if professionals know that a person also has autism, so it's important to discuss this with your GP.

Other conditions

Some people with Asperger syndrome also have difficulties such as [dyslexia](#) or conditions such as epilepsy. You may not have any of these conditions but if you do, it's helpful to describe them to support your case.

Step 3: getting a referral

If your GP agrees to refer you, we recommend that you tell them about local services that have experience of diagnosing autism.

As an adult seeking a diagnosis, we think it's really important that you are referred to the right person, or service, first time round. You are more likely to be accurately assessed, and will avoid having to go back to your GP to ask for a second referral. Be aware, though, that it can sometimes be hard to find a service or professional with experience of diagnosing autism in adults.

You can search for diagnostic services in your area online at www.autism.org.uk/directory (print details out and take them with you), or by calling our [Autism Helpline](#), who can search for you. Tel: 0808 800 4104 (open Monday-Friday, 10am-4pm), calls are free from landlines and most mobiles. Some of our local area have adult diagnosis services (see below). Once you have been referred, there is no more involvement from your GP.

You are most likely to be referred to a local diagnostic service - that is, within the area that your local primary care trust (PCT) covers. Most adults see a psychiatrist or a clinical psychologist, although this does vary. Waiting times also vary.

You can be referred to a service outside your local PCT area but as this costs more, your PCT might question why you need to go there, or whether you really need a diagnosis. Private diagnosis is always an option, if you can pay for one, but you may occasionally find that local service providers (for example, social services) will not accept private diagnoses. They will insist upon you having an NHS diagnosis, too.

What if my GP does not refer me?

If your GP decides not to refer you for a diagnosis, ask for the reason why. If you don't feel comfortable discussing their decision then and there, you can ask for a second appointment to talk it through.

Occasionally GP's may decide not to refer on for diagnosis because he or she cannot see the benefit of diagnosing someone in adulthood. However, there are good reasons for diagnosis as described below.

If you wish to complain about any aspect of referral or diagnosis, there is a complaints procedure that you can follow. See [Local authority and NHS complaints procedure](#) on our website, or call our [Autism Helpline](#) on 0808 800 4104 to ask for a printed copy.

Diagnosis: what to expect

It is difficult to give a precise explanation of what might happen when you go for a diagnosis of Asperger syndrome because, with adults, the procedure varies depending on where you live and who you have been referred to.

Below, we answer some of the more common questions people ask us about diagnosis. This may give you some idea of what to expect, but we emphasise again that procedures vary and people's experiences of diagnosis can be very different.

Who does the diagnosis?

Most commonly with adults, a psychiatrist or a clinical psychologist will carry out the diagnosis. We'll refer to them as the diagnostician.

Where will I go to be diagnosed?

You will usually be sent somewhere in your local area to be diagnosed (that is, the area that your local primary care trust covers). You will go to a place where the diagnostician works, for example a clinic or an assessment centre.

How will I be diagnosed?

Different diagnosticians use different methods to make a diagnosis of autism. There are several 'diagnostic tools' available, and diagnosticians aren't obliged to use a specific tool.

One of the more common diagnostic tools is called DISCO.

DISCO is a series of questions about your developmental history from when you were a young child. Because it asks about your childhood, parents need to be involved to answer some of the questions. If parents can't be involved, then siblings may be able to take part instead.

The GP may agree to write a referral letter so the person can be assessed for possible diagnosis. If the GP does agree to write then ask that:

- (a) the letter is addressed to a local psychologist or psychiatrist who understands about Asperger syndrome and
- (b) the letter requests the psychologist or psychiatrist "to assess for a possible diagnosis of Asperger syndrome".

What will I need to do during the diagnosis?

You will answer some questions about yourself and your developmental history, for example language, play and cognition (how we gain knowledge). Sometimes parents may need to be involved too, to tell the diagnostician what you were like as a young child.

A diagnosis is not a medical examination: you don't need to be examined physically and shouldn't be asked for any samples, such as blood.

Can I take someone with me when I go to be diagnosed?

There is no reason why you should not take someone with you when you go for a diagnosis. However, you are the person the diagnostician needs to speak to (and your parents, if they are using the DISCO tool). If you take someone else with you, such as a partner, they will not play an active part in proceedings.

Will I get a diagnosis on the day?

Practice varies but generally, you will not be given a diagnosis on the day. Instead, the diagnostician will write up a report that they send to you in the post. You might have to wait a while before the report arrives.

Sometimes, the diagnostician will call you and tell whether or not you have autism. Then they will send you the report.

Diagnostic reports can be difficult to read and understand in places. They may use language that diagnosticians are familiar with but that you might not be.

You can call the diagnostician to talk through any parts of the reports that you aren't clear about.

What happens if I don't agree with the diagnosis?

Sometimes people are told they do not have autism, and sometimes they may be given a diagnosis that they don't agree with.

You can seek a second opinion, which means you either:

- go back to your GP, explain that you aren't happy with your diagnosis and ask if your GP will refer you elsewhere
- pay for a private diagnosis.

If you pay for a private diagnosis, be aware that some local authorities - who provide services to people with autism - may not accept the results of private diagnoses. They will insist upon an NHS diagnosis as well.

If you go for a second diagnosis, remember that it may reach the same conclusion as your first diagnosis.

What if I want to complain about the service I have received?

There is a complaints procedure you can follow. See NHS Complaints Procedure later in this document.

What happens after I've been diagnosed?

If you are diagnosed with autism, you may have a lot of questions.

You might be wondering how you can find out more about your condition, meet other people with autism, or access services and support. The *After diagnosis* section of our website can tell you more about all these things.

You can also call the NAS Autism Helpline for information and advice. Tel: 0808 800 4104, open 10am-4pm, Monday-Friday. Calls are free from landlines and most mobiles.

Some diagnosticians offer follow-up services after diagnosis and might be able to answer your questions and point you towards support services. However, not all diagnosticians do this.

Support does not automatically follow diagnosis, but having a formal diagnosis does mean that you are more likely to be able to access services and claim any benefits you are entitled to.

Not everyone feels they need further support - for some people, simply getting a diagnosis seems to be enough.

Under the NHS Patients Charter the person is entitled to seek a second opinion regarding his or her care. This might include asking to see another professional for diagnosis. Telephone free on NHS Information line 0800 665544 for advice.

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 the individual to make sense of their history, often marked by experience of disadvantage and other's misunderstanding.

Diagnosis enables the individual to make necessary adjustments for their future living.

Diagnosis can help others - families, friends, partners, and carers to better understand and cope with the individual's needs, and behaviour.

Diagnosis can help the individual locate local support and social skills groups, and get more appropriate support from employers, social and housing services, benefit agencies, colleges 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** on Tel: 0161 998 4667.

What if the person does not wish to be diagnosed?

If someone is under 16yrs then it is usually easier for parents to take a child along to see a GP. However, it is best if the conversation with the doctor/psychologist/psychiatrist is positive. There are ways of explaining Asperger syndrome to accentuate the positive things about having a diagnosis. (See Selected booklist section).

Each person will be different but the person should not be left feeling confused and the diagnosis should be properly explained.

If someone is 16yrs or older and does not wish to be diagnosed then they cannot be 'forced'! As far as possible people should have control over the process of diagnosis.

Talk should be about "differences" not about what things are "wrong" with someone. Some parents find they can talk quite easily about the possibility of diagnosis when the person has got to the point when he or she really accepts the need for help. Then conversation more naturally lends itself to talking about what is difficult at the present time.

Alternative routes to diagnosis

If someone is at Further Education College undiagnosed the Learning Support Section may pay for an educational psychologist assessment which may assist in the diagnosis.

If someone has a Disability Employment Adviser (DEA) he or she may arrange for the person to see an Occupational Psychologist (employed by the Regional Disability Employment Services) who may be able to offer advice about diagnosis, or know who to refer on to.

Local Adult Diagnosis Services

Trafford

For adults registered with a GP in Trafford, referrals can be made by letter from the GP to:-

TES
Manor House
5 Queens Road
Urmston
Manchester M41 9HE
Tel: 0161 748 8642

Referrals should include a clinical history and information from the patient and the GP's observations.

Wigan

For Wigan borough residents, a diagnostic service is available through the local NHS trust. Referrals should be from a person's GP or a consultant psychiatrist, and needs approval from the 5 boroughs partnership trust.

Referrals should be to

Principal Clinical Psychologist
Hazelmere Unit
Leigh Infirmary
The Avenue
Leigh
WN7 1HS
Tel: 01942 264635 Contacts Dr.Kate Leonard (maternity leave) or Dr. S Field

Following diagnosis people will be signposted to other appropriate agencies for further support. It is in plan to establish a social group.

Other Areas

Request funding for an assessment from your local PCT using the following sample letter.

Sample Letter to request funding for a diagnosis for a person over 18

To
Chief Exec of the PCT

From (Your address)
Date

Dear Chief Exec

Re- (Insert Your name or the name of your family member, their DOB and address)

I am writing to request funding for an assessment for diagnosis of an Autism Spectrum Disorder. I feel that I (*or my family member*) may be on the autism spectrum.

Following the passing of the Autism Act 2009, the publication of the Adult Autism Strategy and subsequent statutory guidance, each area has to develop a trusted diagnostic pathway and appoint a lead professional to develop a diagnostic and assessment service for adults with autism.

As no such pathway exists in my area and I would like to request funding so that I can be referred to the nearest available service and that you inform the diagnostic lead that such a pathway should be developed as soon as possible.

Please note that a diagnosis of an Autism Spectrum Disorder can open doors to appropriate services to help me (*or my family member*) access education support, employment support and welfare benefits as well as have a psychological benefit to explain why I (*or they*) may have had difficulties in the past..

To find out more about the adult autism strategy and statutory guidance and to make sure you are meeting your obligations under the Autism Act 2009, please visit <http://www.autism.org.uk/autismstrategy>.

I look forward to hearing from you,

Yours Sincerely,

(Your name)

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 (will see adults also occasionally),
London Tel: 0207 919 2535

Dr Meera Roy, Birmingham-based but sees adults from across the UK Tel: 0121 255 8000

Vicky Bliss
The Missing Link
Clarks Cottage
Union Lane
Pilling
Preston PR3 6SS
Tel: 07971 569042
Email: vicky@missinglinksupportservices.co.uk

Hildegard Schakel offers a diagnostic service for adults (16+) with suspected Asperger syndrome
Consultant Clinical Psychologist
PO Box 243
Manchester M21 9US
Telephone number: 07847 352412
Email: admin@schakel.co.uk

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

Sheffield Asperger Syndrome Service

This is a national tertiary service provided by Professor Digby Tantam and Dr Sobhi Girgis that can accept referrals for ages 12+ from anywhere in England, Wales and Scotland. Referrals must be made by a social worker, Community Psychiatric Nurse, Team manager or GP. The referral must be accompanied by a letter of authorisation from your local PCT stating that they are willing to pay the cost of the assessment. (currently –Sept 2011) £1273 with a further £489 for a post-diagnostic follow up appointment.

Contact:
Carol Salkeld, Service Administrator
Sheffield Care Trust,
St George's Community Health Centre
Winter Street
Sheffield S3 7ND
Telephone number: 0114 271 6964
Email: carol.salkeld@sct.nhs.uk (launches email software)

Dr Tantam also takes private referrals from GPs to his consultancy. Details below.

Pat Watterson (For Professor Digby Tantam)
Administrator
Dilemma Consultancy
27 Brocco Bank
Sheffield S11 8RQ
Telephone number: 0114 266 0543
Email: administrator@dilemmas.org (launches email software)

Liverpool Asperger Team

Olive Mount Mansion
Old Mill Lane
Wavertree
Liverpool L15 8LW
Tel: 0151 737 4805

The team is able to diagnose and prepare a care plan for people outside of the Merseyside area. This is an NHS service and self referrals can be made but they need written confirmation from your PCT as regards funding for the assessment (Cost £2000).

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.

Further Information

National Autistic Society website: Diagnosis: the process for adults

www.autism.org.uk/about-autism/all-about-diagnosis/diagnosis-the-process-for-adults

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

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.

Sensory Difficulties

People 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 you are particularly sensitive to noise you should take 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)**

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.

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 people 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.

Preparing A Person with Asperger Syndrome for Change

A person 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 college 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 the person 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 person is going to a new school or college, 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'

Experiencing Anxiety

Anxiety is common in people with Asperger Syndrome. It can happen for a range of reasons and people can vary in their ability to cope with it. Anxiety can affect both the mind and the body, and produce a range of symptoms. The psychological and physical symptoms of anxiety are closely linked and so can lead to a vicious cycle that can be difficult to break. The psychological symptoms of anxiety are:

- easily losing patience
- difficulty concentrating
- thinking constantly about the worst outcome
- difficulty sleeping
- depression
- becoming preoccupied with or obsessive about one subject.

Its physical symptoms include:

- excessive thirst
- stomach upsets
- loose bowel movements
- frequent urinating (going to the loo)
- periods of intensely pounding heart
- periods of having gas
- muscle aches
- headaches
- dizziness
- pins and needles
- tremors.

If you do experience any of these symptoms, it is important to also get medical advice to rule out other medical conditions.

Strategies for managing anxiety

Once someone understands anxiety and has identified the things and situations that make them anxious, they can then take steps to cope with the anxiety. If you are looking after someone with an ASD, try and be aware of what makes them anxious and how best to help them manage certain behaviours.

Further Information

NAS Information Sheet - Anxiety in adults with an autism spectrum disorder

Book; Exploring Feelings – Cognitive Behaviour therapy to manage ANXIETY by Dr Tony Attwood

Anorexia Nervosa

A number of studies suggest possible connections between anorexia nervosa and autism spectrum disorders. When someone on the autistic spectrum has developed anorexia the complexity of the issues increases and makes helping the person more difficult.

Further Information

NAS Information Sheet Anorexia Nervosa and the link with autistic spectrum disorders

Sex Education and Personal Hygiene

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.

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

MENTAL HEALTH

It is not unusual for people 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, employment and relationships sometimes makes people 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 Mental Health Assessment service.

People (over 18) can also self refer to their local Mental Health Assessment service, or can be referred through local social services.

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

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.

Mental Health support in Greater Manchester is provided by specialist Mental Health Trusts within the National Health Service (NHS) in conjunction with local authority health and social care departments.. These trusts are separate from those that provide other health and medical services, but often share the same facilities and hospitals.

The Mental Health trusts that cover mental health support in Greater Manchester are organised as follows:-

- **Manchester Mental Health and Social Care Trust** (covers Adults in City of Manchester)
- **Pennine Care NHS Trust** (covers Bury, Oldham, Rochdale, Stockport and Tameside – also High Peak)
- **Greater Manchester West Mental Health NHS Foundation Trust** (covers Adults in Bolton, Salford and Trafford)
- **5 Boroughs Partnership NHS Trust** (covers Wigan – also St Helens, Warrington, Knowlsley and Halton)
- **Central Manchester and Manchester Children's NHS Trust** (covers children in Manchester and Salford)

Children and Adolescents Mental Health Services (CAMHS)

Within this trust structure, **CAMHS (Children and Adolescents Mental Health Services)** teams look after the Mental Health for those under 18.

How do I get a CAMHS appointment for my child?

If you are worried about your child, you should speak to your GP. GPs can offer general advice and support for a range of problems, and will be able to make a referral to CAMHS if this is needed. A number of other professionals can also make a referral, including a school nurse, health visitor and social worker.

Can parents and carers attend a CAMHS appointment?

CAMHS practitioners will ask the youngster who they would like to accompany them, and they may see the practitioner on their own, if this is what they'd prefer to do.

It is important that they communicate with the practitioner directly, if possible. But, Because people with autism can find communication and 'self reporting' difficult, input from

parents and carers and others regularly involved in their life, like teachers and learning support assistants, can be valuable. They can describe the person's usual behaviour and the changes they have noticed to help practitioners get to the bottom of the problem and identify the help needed. If you are worried about any aspect of your CAMHS visit and want more information, you can contact YoungMinds who have a specialist parent helpline: **0808 802 5544**

Who has to give consent for treatment?

Practitioners should involve the young person as much as possible in decisions about their care. Before treatment, the practitioner must establish whether the person has sufficient understanding and maturity ('capacity') to give their consent to treatment.

The law governing the treatment of children and young people differs depending on whether they are under 16 or 16 and over:

Under 16s

Under 16s can consent to treatment if, in the practitioner's opinion, they have the capacity to allow them to understand what is being proposed. Unless it's an emergency, the practitioner will obtain the consent of someone with parental responsibility if they feel the child is not competent (that is, does not have capacity).

If competent children under 16 insist that they don't want their family to be involved, then their right to confidentiality must be respected, unless this would put them at risk of significant harm.

16 and 17 Year Olds

The law considers all young people of 16 and over to have capacity to consent to treatment unless there is evidence to contradict this. Although practitioners should encourage young people in this group to involve their families in decisions about their care, if the young person wants things to be kept confidential, the practitioner should respect this unless this could lead to significant harm.

If a young person refuses treatment which is in their best interests to receive, a person with parental responsibility or the Court can override the young person's wishes.

Further Information

Patient UK: www.patient.co.uk and on the **Children's Legal Centre website:** www.childrenslegalcentre.com

YoungMinds has a special website for young people: www.youngminds.org.uk/youngpeople

The Royal College of Psychiatrists has produced a book (CAMHS inside out: a young person's guide to child and adolescent mental health services) and leaflet (CAMHS in brief: a young person's quick guide to child and adolescent health services). You can download these for free from their website: www.rcpsych.ac.uk

Mental Health contacts for people aged 18 and over

<p>Bolton Bolton Community Mental Health Team Park House Laurel Street Bolton BL1 4RB Tel: 01204 337550</p> <p>Horwich Community Mental Health Team (West) Paragon Business Park Chorley New Road Horwich Bolton BL6 6HG Tel: 01204 477200</p>	<p>Rochdale Sudden Health Centre Silk Street Rochdale OL11 3EU Tel:01706 702037</p> <p>Heywood Fox Street Centre Heywood OL10 1HE Tel 01706 927354</p>
<p>Bury (North) Community Mental Health Team Inwood House 5 Castlecroft Road Bury BL9 0LN Tel: 0161 253 7828</p> <p>Bury (South) 1A Lord Street Radcliffe Manchester M26 3AF Tel: 0161 253 7100</p>	<p>Salford Salford Community Mental Health Team 224 Eccles Old Road Salford M6 6AL Tel: 0161 789 5234</p>
<p>Manchester Manchester Mental Health & Social Care Trust Chorlton House 70 Manchester Road Chorlton M21 9UN Tel: 0161 882 1000</p>	<p>Stockport Mental Health Liaison Team c/o Hillside Stepping Hill Hospital Poplar Grove Stockport SK2 7JE Tel: 0161 419 5246 Contact: Annette Holt</p>
<p>Oldham Mental Health Services Initial Assessment & Intervention Services The Beeches 5 Waterloo Street Oldham OL1 1SP Tel: 0161 909 8088</p>	<p>Tameside Adult Community Mental Health Service RIAS (Referral, Information & Advice Service) Haughton House 67 Stamford Street East Ashton Under Lyne OL6 6QQ Tel 0161 339 2627</p>
<p>Trafford Trafford Early Assessment Team 54-56 Seymour Grove Old Trafford Manchester M16 0LN Telephone: 0161 912 4834</p>	<p>Wigan Mental Health Access Service Leigh Infirmary The Avenue Leigh WN7 1HS Tel: 01942 264536</p>

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 (under 16) Salford District Child Psychiatry Service Pendleton Gateway Centre 1 Broadwalk Pendleton Salford M6 5FX Tel: 0161 211 7260</p> <p>Salford (16-17) Salford Opportunities Centre 2 Paddington Close Churchill Way Salford M6 5PL Tel: 0161 603 6805</p>
<p>Manchester (South) (under 16) Carol Kendrick Unit Stratus House Wythenshawe Hospital Southmoor Road Manchester M23 9LT Tel 0161 902 3400</p> <p>Manchester (Central) (under 16) The Winnicott Centre Hathersage Road Manchester M13 0JE Tel 0161 248 9494</p> <p>Manchester (North) (under 16) Child Clinical Psychology Department The Bridge Madison Place Newton Heath Manchester Tel : 0161 203 3250</p> <p>Manchester (16-17) Emerge Millennium Powerhouse 140 Raby Street Moss Side Manchester M14 4SL Tel 0161 226 7457</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>
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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>

What If you are refused a diagnosis or mental health support

If you feel you have an autism spectrum disorder (ASD) and:

- you have been refused a referral to a diagnostician by your GP
- you have been refused a referral to a diagnostician of your choice
- a diagnostician has refused to assess you
- you have been refused access to a mental health assessment or services

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 Sheets

'Complaints Procedure for people unable to obtain an assessment with a consultant of their choice'

'Complaints about the NHS- children's procedure'

Counselling

Many people with Asperger syndrome develop emotional difficulties. These can be due to living in a world that generally does not understand 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 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, but some of it can be easily adapted for adults.

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 are 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.org.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:

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:

Respect For All are a Counselling Service for people on the autism spectrum, including Asperger's Syndrome, and also their parents/carers.

Provide help with a wide range of issues including: bereavement and loss, abuse - mental, physical, sexual - past and present, domestic violence, low self-esteem, depression, dealing with anger, relationship issues, caring/being a carer (both learning-disabled carers and others), diagnosis of and living with Asperger's, life transitions, sexuality, ill health and disability, drugs and alcohol, impact of crime, and other issues.

Our Services are for people who reside in the ten Greater Manchester Boroughs

Respect for All does receive limited funding, so we are able to offer eight free sessions. However, donations are very much appreciated

Counsellors negotiate the venue to suit the Client e.g. home visits, day-centres, schools etc.

Both day and evening appointments are available

We work with both children and adults.

Our ten qualified Counsellors have experience either personally or professionally of learning disabilities, autism, Asperger's Syndrome

- Susan Jennings
- Gill Linden
- Marcus Parkinson

- Alix Otten
- Fay Proctor
- Andy Flint.
- Tracy Holden
- Wayne McConnell
- Pat Ashworth

All Respect For All Counsellors are professionally qualified and abide by the BACP code of ethics. All counsellors maintain professional indemnity insurance cover and have been CRB checked.

Referral procedure

Self referral. Appointment required or referral through other agencies (any agency dealing with learning disabilities, carers' forums, support workers etc.)

Jan Maguire

Tel No: 07968 504317

Email; counselling@torviews.fsnet.co.uk

Practice location: Haslingden, Rossendale

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.

Dr. Vicky Bliss

Brief Therapy Support Services

Clarks Cottage

Union Lane

Pilling

Preston PR3 6SS

Tel: 0797 1569042

Email; vicky@btss.org.uk

Service offered:

Counselling for adults with ASD and siblings and parents.

Experience with ASD

Twenty years experience of working with people with ASD and Learning Disabilities.

Referral procedure

NHS in South Ribble and Chorley only. Private referrals within a 40 mile radius with negotiation.

Open referral procedure.

Dr Hildegard Schakel

Chartered Consultant Clinical Psychologist

PO Box 243

Manchester M21 9US

Telephone number: 07847 352412

Website www.schakel.plus.com **Email:** admin@shackel.co.uk

Service offered

Counselling service for adults (16+) with Asperger syndrome

Accredited Cognitive Behavioural Therapist

Psychological Consultation on Asperger Syndrome including advice to family, friends and professionals.

Psychotherapy for people with Asperger Syndrome

Private referrals for clients in the Greater Manchester region.

Disability Database

Local councils are required in accordance with the Children's Act to keep records of the number of children and young people up to 18 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 Rutherford	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 Jaas	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

General Tips if there is a problem at school or college

Here are some tips to note where there are school or college problems for you or 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 or college disability officer
- 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*
- Ask to see local authority's or college's guidance/policy relating to special educational needs.
- Keep records of discussions and meetings and a diary of events.
- Keep a diary about your or 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 you or 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 also.
- 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 Information Sheet - Making A Complaint: Useful Tips**

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-coordinator - 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.

'Asperger syndrome and Difficult Moments' by Brenda Smith Myles and Jack Southwick is a good book for managing difficult behaviour at school. It is in the NAS publications catalogue.

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.

If someone has a Statement of Special Educational Need (SSEN), then even if the person is not attending school, they should still have Transition reviews.

Issues with decisions of Schools and Local Education Authorities – Exclusions and Appeals

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.'

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

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.

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.

The Social Inclusion: Pupil support guidance also 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.

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**

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 or college.

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 Daytime hours: 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 Tribunal Support Scheme 0800 358 8668

Further Information

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

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.

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

The National Autistic Society produce a number of publications on bullying

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 Asperger's 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.

Information Sheet “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 cyber bullying – 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 other Bullying references

‘**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).

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.

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.

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

Information sheets

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

What if your child has difficulties with taking exams?

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

If someone is at school and does not have a SSEN and is likely to require extra support in exams talk to the Special Educational Needs Co-coordinator (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 (SSEN).

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

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

Transition - Planning for students who are leaving school and moving on to College or Employment

Not everyone with Asperger Syndrome will require lots of support when they finish full time school education. Some people go straight to jobs or college and settle fairly well.

However most people do benefit from outside support and advice as they start to think about their options after leaving school. This support and advice process is called 'Transition'.

The key person to discuss options with is the Connexions Personal Adviser. There is one for each secondary school. Ask the head teacher for details. Planning for students who are leaving school and have a Statement of Special Educational Needs

If the young person has a Statement of Special Educational Needs (SSEN), the production of a transition plan is a legal requirement.

The law says that Social Services and Education should communicate, share information and jointly plan for when the young person leaves school. This planning should start at Year 9 (14 years of age.) (Disabled Persons' Act 1986 section 5 and 6).

Each student with a SSEN has an Annual review of their Statement. From Year 9 onwards this Annual Review is renamed the Transition Review.

The Transition Review is like an Annual Review but includes discussion of the student's needs for the future – not just their educational needs but their social needs also.

The Transition Review is held each year from age 14 onwards, at school and should include a representative from Social Services and Connexions. Connexions should appoint a personal advisor who should attend this review.

The Review will include discussion about what support the young person will require in the future from agencies such as Social Services, housing, health, employment and Connexions.

Do try to ensure Social Services attend these Review meetings, and any other important professionals involved with the person. The Headteacher who arranges the Transition Review must invite the parent, the person with Asperger syndrome, the local education authority, Connexions, Social Services and sometimes Health.

So each year from Year 9 onwards the person should have a plan put together and updated for their future.

Some areas that should be addressed during a Transition Review meeting for young people with Asperger syndrome

The Transition Review should draw up a plan of how the person with Asperger syndrome will be prepared for adult life. The following list contains just some of the typical areas that may require planning for. Please note not all will be relevant for all people, though each may need to be considered:

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)
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, clubs)

6. the need for counselling – emotional difficulties
7. the need to learn how to look after himself, personal care and grooming
8. the need to recognise dangerous social situations
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, college students, employers);
12. the need to develop practical life skills – 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
17. the need to understand personal care, getting enough sleep, how to relax
18. the need to manage any additional physical difficulties (for example epilepsy, ADHD)
19. the need to be encouraged to use prescribed medication
20. the need for assistance with mental health and associated difficulties (for example, depression, obsessions, panic attacks, agoraphobia, social 'exposure' anxiety, paranoia)

IMPORTANT: the Transition Plan should aim to give precise details of how any needs identified will be met. The Transition Plan is not just a description of someone's difficulties; it is a list of actions to be carried out in order to address those difficulties.

For example, rather than writing "John needs to become more sociable with his peers", the Transition Plan might be written:

1. John will be put on the waiting list for a Befriender
ACTION: Social Worker.
2. John will be encouraged to visit his friend once a week after school, and to join an After School Club of his choice.
ACTION: Class tutor/parents.
3. Staff will arrange for John to meet with other young people with similar needs once a week to look at relevant issues, such as Transition, relationships, social skills, etc. ACTION: SENCO.
4. John and LSA to discuss the possibility of setting up a Circle of Friends and continue to use social stories to produce book on 'communication'.
ACTION: John and LSA.

Transition Planning for students who are leaving school and do not have a Statement of Special Educational Needs

If the young person does not have a Statement of Special Educational Needs (SEN) but is likely to require social support into adulthood in order to achieve independence, it is important to request support from Social and Housing Services.

The law says that if someone is disabled ("has a mental disorder of any kind") then he or she is a 'child in need' and may therefore be entitled to services under Section 17 of the Children Act 1989.

It is likely the local authority will need to carry out a Social Services assessment to determine whether the young person is entitled to a service. This will ask similar questions to those in the transition review list above.

Many families find that by *writing* to their local Social Services it is easier to be clear about what they are asking for.

Following is a draft copy of a letter you could base your letter to Social Services on.

Transition – Further Information

More information is available on the government website www.direct.gov.uk under ‘School and The Transition Plan’

Details of the Connexions service can be found later in this document.

For more information if your son or daughter is having difficulties at school:

- National Autistic Society Education Advice Line 0808 800 4102
- National Autistic Society Tribunal Support Scheme 0800 358 8668

For each Local Education Authority there is a Parent Partnership Service (PPS) which is a service to help parents understand their rights in relation to their child’s education. 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.

This assessment may take place for students who are in their last year of schooling and are on the Code of Practice. Connexions will have more information on this.

Things to remember!

- Do ask for help if the young person 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 and Housing Services.
- Do work co-operatively with the local authority and be prepared to be persistent.

The website www.after16.org.uk contains information on choices and challenges for young disabled people planning to leave school.

Progress is a magazine aimed at helping young people through all aspects of transition planning. More details at www.progressmagazine.co.uk

My Future Choices is the magazine of the Transition Information Network aimed at young people with disabilities and which is part of the Council for Disabled Children. It is available on line at www.myfuturechoices.org.uk. For more on the work of the Transition Information Network, their website is www.transitioninfonetwork.org.uk

What are the options available to the young person after leaving school?

The two most popular options are to leave school and find a job, or continue with studies either at Further or Higher Education. However, it may be the person is not ready or able to do either education or employment and so other options are also available.

Even if someone has a job or is at college that does not mean they do not require support from someone outside the family. If someone (18 or older) does require support for example help to live independently or to avoid becoming socially isolated the person should write or phone Social Services to ask for an assessment for community care services.

What if the person has finished school and is now at home not wishing to continue education or able to work?

Why do people “get stuck”?

Many young people with Asperger syndrome get “stuck” either before 16 or after. They may have dropped out of school, or finished school but feel unable to cope with the usual demands of adult life.

Many people with Asperger syndrome get feelings of being overwhelmed by the time they reach early adulthood. The difficulties faced at school with the other students, the stress of exams, the lack of structure once school finishes, the increasing responsibility of being an adult are just a few of the pressures people are under.

Some people “retreat” to the safety of their family surroundings and prefer to not go out of the house. This is an understandable reaction but it is important to maintain social contacts outside the family if at all possible.

If someone is anxious about leaving the house and doing new activities try to ensure you have covered all the basic principles, using the National Autistic Society approach called SPELL - Structure, Positive, Empathy, Low Arousal and Links.

Structure - Structure the week so the person knows what is going to happen on each day. Make sure he or she has trusted people around him or her. Try to ensure consistency, stability and familiar routines.

Positive - Be positive about Asperger syndrome and about the future. If someone is struggling then plan small steps towards the goal and be there to support them. Find out what the person can cope with and build from that. Some people may require a guiding hand (although they may not be able to thank you in advance for your support!).

Empathy - Try to understand what it is like to have Asperger syndrome. Whenever it is easier - try to adjust the environment to suit the person, rather than try to change the person. The most useful person to someone with Asperger syndrome is support from someone who understands Asperger syndrome.

Low Arousal - Be aware that social contact can be quite exhausting for many people. Do not overburden people with too many choices. However, it is best if the person is not left to do nothing. Some basic daily ‘duties’ around the home may be useful.

Links - Try to develop and maintain links with the local community, for example, local shops, cinema, pub, walks, groups and places of interest.

Use interests

Use what interests the person has to encourage activity outside the home. If possible maintain at least some daily routine to avoid the person 'opting out' altogether. Once someone gets in a cycle of inactivity it can be quite difficult to encourage him or her out of it again.

Join local groups

Is there a local group the person can join in order to develop social confidence and increase self-esteem? It is quite likely that the person will need someone to go along with them, at least to begin with.

Meet other people with Asperger syndrome

Find a safe social event that the person feels most comfortable with and make plans to attend. The Autistic Society Greater Manchester Area (ASGMA) *Aspirations Project* is an excellent Greater Manchester-wide service that runs a number of social groups and leisure activities for people with Asperger syndrome aged 10+.

Contact: ASGMA Aspirations Project – Tel: 0161 866 8485
aspirations@asgma.org.uk www.asgma.org.uk

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.

Counselling

Sometimes counselling can help and there are a number of private counsellors in the area who may be able to assist (see section on Counselling). These counsellors have all had at least some awareness training in Asperger syndrome although few are specialist counsellors in the syndrome. If you use a counsellor through your local GP surgery, make sure they have information on Asperger syndrome. Be aware that open-ended counselling may be less effective than a more structured practical approach. Contact the National Autistic Society Autism Helpline for advice before receiving counselling 0808 800 4104.

Prepare professionals

If the person is stuck at home and professionals visit ensure they understand at least the basics of Asperger syndrome. Tell the professional which approach to use in order for the person to feel most at ease and comfortable. It may take several visits before the person is confident enough to talk out loud or disclose more personal information. Remind the professional to put information in writing and be clear about what their job role is and is not. Anything merely implied will probably not be understood.

Exercise and good diet

Exercise and a balanced diet may help improve mood and general activity. Going for a walk may be enough to begin with.

Depression

Depression is probably the most common mental health difficulty for adults with Asperger syndrome. If the person appears to be depressed, consult with the GP about the best options. Generally the newer SSRI anti-depressants work more effectively, but be aware people with

Asperger syndrome may react atypically (for example experiencing increased stress on anxiolytics) to some medication.

Many people use St John's Wort for mild depression. This is available from chemists but it is best to consult with the GP before using this preparation, especially as it can affect the effectiveness of other medicines.

Mental health services for young people with Asperger syndrome

For young people who have Asperger syndrome and additional disturbed behaviour or thought, it is important to draw support from the local Child and Adolescent Mental Health Service. Ask the person's social worker about this.

If the person does not have a social worker then make an appointment to see your GP. You will not get a referral to Child and Adolescent Mental Health Services (CAMHS) direct, you must see your GP first.

Parents who wish to discuss what services the different teams offer before going to see the GP, can contact the Child and Adolescent Mental Health Services.

For details about your local CAMHS service please contact the NAS Family Services Development Project Tel: 0161 998 4667.

In some circumstances it may be necessary for the young person to receive assessment or treatment for their mental health difficulties.

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.

NAS Autism Helpline –Tel: 0808 800 4104

Family Services Development Project –Tel: 0161 998 4667

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.

Careers advice, support and guidance

Connexions

Connexions is an advice, guidance, support and careers service. They offer advice on vocational and life choices. This can include assistance going to college, university, finding work or further training etc. Connexions generally provide advice and support to the 13-19-age range, but people with disabilities may receive support up until 25yrs.

Connexions is planned to work in conjunction with local social services and other agencies as part of the Government's 'Working Together' initiative.

Each young person who is disabled should receive advice, guidance and careers from a Personal Adviser, from Year 9 onwards. There will be a Personal Adviser for each local school, including specialist adviser for 'special schools'/ units.

If the person has a Statement of Special Educational Needs (SEN) a Connexions Personal Adviser will be at the young person's Transition review, each year from age 14yrs onwards. Section 140 of the Learning and Skills Act will also apply (see below).

If someone with Asperger syndrome does not have a SEN he or she will receive support from the Connexions Personal Adviser and may be eligible for a section 140 assessment of need under the Learning and Skills Act 2000.

Section 140 of this Act talks about Assessment of disabled students in their final year of schooling. Learning Disability is defined in section 13 as a person who has:

"Significantly greater difficulty in learning than the majority of persons of his age"

OR

"has a disability which either prevents or hinders him from making use of facilities of a kind generally provided by institutions providing post 16 education or training."

So "disabled" is likely to include students on the new SEN Code of Practice (2001), and not just those with an actual Statement of SEN, but this needs to be clarified, by Connexions.

The Section 140 assessment says that during the disabled person's last year of compulsory schooling, (or if in Further Education up to 25 years of age) the person should have a "written report of his educational and training needs, and the provision required to meet them."

If you have a young person with Asperger Syndrome and wish to ensure he has an assessment of his education and training needs before he leaves school or college, ask your local Connexions representative about Section 140 assessment. It may or may not be relevant to your particular circumstances, but it is best to ask! Ask to speak to Personal Adviser for Learning Difficulties/ Disability.

Careers Helpline for Young People (was Connexions Direct) Tel:0800 100900 (from mobiles use callback facility) www2.cxdirect.com/home

LOCAL CONNEXIONS OFFICES	TELEPHONE CONTACT
Bolton	0800 052 5559
Bury	0161 253 7733
Manchester	0845 6713219
Oldham	0161 621 9300
Rochdale	01706 579515 or 0800 195 8528
Middleton	0161 643 3125
Heywood	01706 622770
Salford	0161 743 0163
Stockport	0161 475 7700
Tameside	0161 330 1528
Trafford	0161 911 8600
Wigan	0800 953 0109
Leigh	01942 404471

Strive

Strive is a programme run by YMCA Training to help youngsters who need supported transition into employment. It works in partnership with KIDS and EMPLOY to help young people aged 16-19.

It provides a safe and supportive environment for participants to develop personal, vocational and work related skills for employment. Participants take part in learning programmes within the YMCA Training locations, as well as having the opportunity for work placements with support local employers.

For more information about STRIVE locally contact:

Salford

Dawn Brannigan YMCA Training Manager
Tel: 0161 737 6699 email: d.brannigan@ymcatraining.org.uk

Manchester

Tel: 0161 228 1198

Oldham

Tel: 0161 620 2366

Wythenshawe

Tel: 0161 945 3415

Education At 16 and Over

College And University Courses

Important factors to consider before deciding on a College or University course

A common option for people with Asperger syndrome is continued education.

This will mean taking a course at a local further education or sixth form college, going away to residential college. After 18, with suitable qualifications there is the option of University or Higher Education.

Because Asperger syndrome affects people of varying intellectual ability there are many different options available.

Some people with Asperger syndrome benefit from pre-vocational courses. These are courses that are less academic and more aimed at helping the young person develop life skills. Most Further Education colleges and some academies have these type of courses on offer. One difficulty for some people with Asperger syndrome is that although they may need to learn life skills they do not wish to be on a course aimed at people who have learning difficulties.

Other people follow mainstream courses (GCSEs, A levels, diplomas, NVQs) and benefit from having a Learning Support Assistant, whereas a few require no additional support.

A Learning Support Assistant can support the person at college with study skills, communication, time management, presentation skills and revision.

The Learning Support Assistant does not have to go into lessons; he or she may just provide additional hours after formal lessons to go over the information, on a one-to-one basis with the person with Asperger syndrome.

Contact the Learning Support Section at the colleges *before* any visit to discuss the support on offer. This is especially important for students who may be nervous of any new environment. For example, to begin with it may be a good idea for the person to visit when the college is quiet (for example, during the holidays, then on a quiet term day), and build up their experience of the college gradually.

It is important to think carefully about which course to study.

If the person is using the course as a route to getting a job (for example doing a plumbing course) then spend some time with the Connexions Personal Adviser looking closely at where the person's potential for work lies.

For example, if someone finds it extremely difficult to deal with members of the public, do not go for a librarianship course, even if the person likes books and quiet rooms!

Before deciding on any particular placement make sure you have read through these questions. Not all of the following will apply to every person but they will provide a useful overview.

Questions to consider before starting any college or university course

What does the institution know about autism spectrum disorders and Asperger syndrome specifically?

If no prior knowledge, are they open to learning? Would they benefit from training if offered to staff?

Has the institution had prior experience of students with Asperger syndrome?

Did previous students succeed? What were the difficulties and how did the college overcome them? How did previous students cope socially?

What educational support was provided for previous students?

If you decide to visit, does the college listen to the student when s/he explains his learning needs?

Does the institution understand the need to listen to parents and other professionals about the person's learning and social needs?

How complex is the campus - can the person cope with getting around?

Is the whole course compatible with the person's abilities? Get the entire course outline in detail if possible. Check each module of the course. Does it cover areas of study that may prove impossible for the person to understand or pass an exam in? (For example a student who was excellent at engineering, but dropped out of the course because he couldn't cope with the module involving applied maths).

How is the course assessed? For example, essay writing may be very difficult for someone with Asperger syndrome; some people cannot cope with exams but would be OK if the course is mostly continuous assessment.

Does the course involve group work? If this will prove very difficult for the person, are there ways of being assessed that can be used to avoid too much group work?

How large are the tutor groups? If the groups are very large, will this be an environment the student can cope with?

If the person is quite inflexible can the college adapt to this? For example, having the same place for the person to sit at in the classroom?

Do the rooms change regularly? If so will this prove too much for the student?

What if the student 'calls out' during lectures? How will this be dealt with, to prevent the student being shunned by peers?

Does the college provide good, clear information on getting around the college? Are clear maps provided? Where are the toilets, restaurant, counsellors' room?

Is there an induction? Ideally, is there an induction handbook, in an easy to carry form, which allows the student to know clearly where everything is, and who to turn to when under stress, or in other difficulty?

Is there interest in ensuring the student feels relaxed and ready for this new environment?

Is there a good orientation offered? Is it possible for the student to visit before term, a few times to meet their new tutor/s and get accustomed to getting around college? Preferably, both in term time, to meet tutors and see how they cope with the numbers of students and during holiday time to

locate where all the facilities are on campus. Induction/orientation could be held over several days in the summer for Asperger syndrome students.

What support will be given on exit from college? For example to find work, link up with other professionals, careers advice?

Questions to ask about social support during college/ university

What facilities are there for pastoral support? Counsellors? Do they understand Asperger syndrome, any previous experience?

Is there any provision for students to learn the specific skills they find difficult? For example social skills type groups during lunchtimes, or twilight courses?

Is there a Asperger syndrome support group, or other disability group locally, or on campus?

Are there clubs which the person can link into, and share their interest? For example, computer games club, walking group, outdoor pursuits, games workshop club, film society, Christian Union, chess group, voluntary action group?

What leisure activities are there for relaxation, swimming, sauna, tai chi, etc.

What sport facilities are there – running track, badminton, football, canoeing, climbing wall, etc.

Is there a 'safe haven', or quiet room on campus which the student can use? Ideally the room should be designated for students who have communication difficulties and find college stressful. The room could have computer facilities to work at, and some comfortable chairs to relax in. It should be a 'common room' with individual lockers, which students with Asperger syndrome have some peace and quiet in.

Will there be a need for personal care support? Has an assessment been made of the students personal needs? Has s/he any difficulties with budgeting, self care, hygiene, grooming, social presentation, which will require active support? Who will do this? Who will pay for this? If this is an issue contact Social Services (see *Who to contact* section).

Does the college have a peer support system in place through the Student Union? Is there someone who can befriend the student, and include them in social events? Do these peer supporters have any training in Asperger syndrome? Ask the Students Welfare office at the University.

Some people benefit from informing a number of other students about their difficulties. It is best to use the term Asperger syndrome, if possible, because "communication difficulties" may be construed as a bit vague by others.

However it is better to use some term than none. If the person does wish to tell others, but does not like the term Asperger syndrome, perhaps using the term 'communication difficulties', may be of use. The most important thing is to explain behaviour and difficulties in such a way that others can understand, and know how to respond to.

The benefits of informing others includes better peer relationships, as other students know how to approach, and make 'allowances' for the person. One student at Weston College developed an information sheet that she could give out to fellow students in her tutor group about how to cope with her difficulties.

Is there the option of a learning support co-coordinator giving a talk to the other students about Asperger syndrome, so they understand their fellow students better? This should be done in conjunction with the person who has Asperger syndrome, who may however not wish to attend the meeting, but should have note of what was said.

Questions to ask about Education support during college/ university

Who will make an assessment of learning style, so that extra time or other assistance is made?

How will student cope with exams? Can s/he use an individual room to take exams?

How often are tutorials, and are they individual?

Are there places students can go for quiet study?

Does the college have learning support assistants who understand Asperger syndrome?

Is there a named 'stand-in' if the learning support is off sick/ on holiday etc.?

Is the learning support flexible, so the person can access them at different times of the day, according to need? Regular meetings are often useful as well, just to check all is well.

Will the student require assistance with deadlines, and organising work folders etc.?

Do tutors understand Asperger syndrome, and differentiate their work to suit the learning style? Will they provide notes for people with Asperger syndrome?

Does the student have a clear idea about where s/he will be, at any point during the day?

Does s/he require a discrete timetable to carry around with rooms/ tutors information and contact numbers, map of the campus.

Would the student benefit from a notebook and pen to carry around so s/he can make notes, and memory jogs as they occur?

Is it clear to the student what the expectations are during teaching periods, for example, turn taking, not answering all the questions, not contradicting the tutor, coping with lecturers turning up a few minutes late etc. This is an important area to assess, some students with Asperger syndrome can unintentionally alienate themselves from tutors and peers by their behaviour and insistence on doing things the 'right way'. Finding out if the student is 'pedantic' about anything, and informing the college beforehand will be of help. Strategies to deal with inflexible behaviour may need to be planned beforehand.

Does the student understand the learning expectations for the course? S/he may well require someone to take an active role in checking work has been done, even sometimes when the student says s/he is coping OK.

Who will take responsibility to ensure the student does not fall behind?

Can lectures be taped for the student? Or can another student take notes to photocopy?

Is there another student who can be trained to support the learning style of someone with Asperger syndrome in the college, by sitting near them, and reiterating what the lecturer says, and give tips on how best to do the work?

Is there scope for students to timetable personal project time so they can devote some of their energies to interests outside the course content?

If appropriate, will there be opportunity to learn job and other skills addressing such areas as interviewing technique, communication skills, time management, managing anxiety, how to ask for assistance, self-advocacy, assertiveness, disability and self awareness, presentation of self, and Asperger syndrome awareness, appropriate behaviour in the workplace, how to job search

effectively, preparing an application, CV writing, etc. (National Autistic Society Prospects Work Preparation Programme, for example).

For details of local Further Education Colleges please refer to the contact table for your area at the back of this document.

Further reading

For Lecturers and Tutors: Supporting Students with Asperger Syndrome In Higher Education (booklet) Rachel Pike National Autistic Society

For Students: Preparing For University (Information Sheet) National Autistic Society

Local Sixth Form and Further Education Colleges

Most of Greater Manchester has sixth form colleges which are state owned, but independent of the local authority. The City of Manchester still has some 11-18 schools which offer a sixth form education. Some of these are run by the local authority, but others are independent academies. All 16-18 schools and colleges have their own applications and enrolment procedures. Many offer vocational and skills training courses as well as traditional academic qualifications. It is a good idea to look at their websites and talk to their admissions staff to assess which one best suits your requirements.

Explain Asperger syndrome and ask what support is available to students to help them learn and socialise.

Most colleges have a Learning Support Section that may be able to arrange a helper to go into lessons or else give extra tuition time outside the class, or allow extra exam time.

Sixth Form Colleges and Schools with Sixth Forms.

Note that some colleges have more than one campus, and that some have a religious background.

Bolton	Salford
Bolton College Tel: 01204 482000. Website: www.boltoncollege.ac.uk	Salford City College 0161 631 5000
Bolton Sixth Form College Tel: 0800 0521460. College centres in Town Centre and Farnworth. Website: www.bolton-sfc.ac.uk	Now covers all colleges in Salford. Centres in Eccles, Pendleton, Walkden, Salford City Centre and Merchants Quay. Website: www.pendcoll.ac.uk
Westhoughton High School Tel: 01942 814122 Website: www.westhoughtonhigh.bolton.sch.uk	

<p>Bury</p> <p>Bury College Woodbury Centre, Market Street, Bury BL9 0BG Tel: 0161 280 8280 (freephone) Website; www.burycollege.ac.uk</p> <p>Holy Cross College Manchester Road Bury BL9 9BB Tel: 0161 762 4500 Website: www.holycross.ac.uk</p>	<p>Stockport</p> <p>Stockport College Town Centre Campus Wellington Road South Stockport SK1 3UQ Tel: 0300 300 0090 Website www.stockport.ac.uk</p> <p>Cheadle & Marple 6th Form College Cheadle Road Cheadle Hulme SK8 5HA. Tel: 0161 486 4600 and Hibbert Lane Marple Stockport SK6 5HA Tel:: 0161 484 4600 Website: www.camsfc.ac.uk</p> <p>Aquinas College Nangreave Road Stockport SK2 6TH Tel 0161 483 3237 Website: www.aquinas.ac.uk</p> <p>Stockport Academy Heathbank Road Cheadle Heath Stockport SK3 0UP Telephone: 0161 286 0330</p>
<p>Manchester</p> <p>Manchester College Tel: 0800 068 8585 Numerous locations across City Website: themanchestercollege.ac.uk</p> <p>Manchester Academy Moss Lane East Manchester M14 4PX Tel: 0161 232 1639 Website: www.manchester-academy.org.uk</p> <p>Loreto Sixth Form College Chichester Road South Manchester M15 5PB Tel: 0161 226 5156 Website; www.loreto.ac.uk</p> <p>Xaverian College Lower Park Road Manchester M14 5RB Tel: 0161 224 1781 Website: www.xaverian.ac.uk</p> <p>Parrs Wood Sixth Form Wilmslow Road East Didsbury Manchester M20 5PG Tel: 0161 434 5378 Website: www.parrswood.manchester.sch.uk/sixthform</p>	<p>Tameside</p> <p>Ashton Sixth Form College Darnton Road Ashton-under-Lyne OL6 9RL Tel: 0161 330 2330 Website: www.asfc.ac.uk</p> <p>Tameside College Beaufort Road Ashton-Under-Lyne OL6 6NX Tel: 0161 908 6600 Website: www.tameside.ac.uk</p> <p>Hyde Clarendon Sixth Form College Clarendon Road Hyde SK14 2JZ Tel; 0161 908 6800 Website: www.hydeclarendon.ac.uk</p>

Co-operative Academy Of Manchester

Plant Hill Road
Higher Blackley
Manchester M9 0WQ
Tel: 0161 795 3005
[Website: www.co-operativeacademy.org.uk](http://www.co-operativeacademy.org.uk)

East Manchester Academy

60 Grey Mare Lane
Manchester M11 3DS
Tel: 0161 230 8039
[Website: www.theeastmanchesteracademy.org.uk](http://www.theeastmanchesteracademy.org.uk)

The Manchester Health Academy

Moor Road
Wythenshawe
Manchester M23 9BP
Tel: 0161 998 3992
[Website: www.manchesterhealthacademy.org.uk](http://www.manchesterhealthacademy.org.uk)

Manchester Enterprise Academy

Simonsway
Wythenshawe
Manchester M22 9RH
Tel: 0161 499 2726
[Website: www.manchesterenterpriseacademy.org.uk](http://www.manchesterenterpriseacademy.org.uk)

Whalley Range 11-18 High School (Girls)

Wilbraham Road
Manchester M16 8GW
Tel: 0161 861 9727
[Website: www.whalleyrange.manchester.sch.uk](http://www.whalleyrange.manchester.sch.uk)

William Hulme's Grammar School Academy

Springsbridge Road
Manchester M16 8PR
Tel: 0161 226 2054
[Website: www.whgs-academy.org.uk](http://www.whgs-academy.org.uk)

King David High School

Eaton Road
Crumpsall
Manchester M8 5DY
Tel: 0161 740 7248
[Website: www.kdhs.org.uk](http://www.kdhs.org.uk)

<p>Oldham Oldham College Rochdale Road, Oldham OL9 6AA. Tel: 0161 785 4000 Website: www.oldham.ac.uk</p> <p>Oldham 6th Form College Union Street West Oldham OL8 1XU. Tel: 0161 287 8000 Website; www.osfc.ac.uk</p>	<p>Trafford Trafford College Manchester Road West Timperley Altrincham Cheshire WA14 5PQ Tel: 0161 952 4600 Also courses at Talbot Road Centre Talbot Road Stretford Manchester M32 OXH. Technology Centre, Moss Road Stretford Manchester Manchester Music Base 77 Newton Street, Manchester Website; www.trafford.ac.uk</p> <p>Loreto Grammar School For Girls Dunham Road Altrincham Cheshire WA14 4AH Tel: 0161 9283703 Website: loretogrammar.co.uk</p> <p>Ashton On Mersey School Cecil Avenue Sale M33 5BP Tel: 0161 973 1179 Website; www.aomschool.com</p>
<p>Rochdale Hopwood Hall College Rochdale Campus, St Mary's Gate Rochdale. OL12 6RY Tel: 01706 345346 Middleton Campus Rochdale Rd Middleton M24 6XH Tel: 0161 643 7560 Website: www.hopwood.ac.uk</p> <p>Rochdale 6th Form College College Road Rochdale OL12 6HY Tel: 01706 769800 Website: rochdalesfc.ac.uk</p>	<p>Wigan Wigan & Leigh College PO Box 53 Parsons Walk Wigan WN1 1RS Tel: 01942 761600</p> <p>Winstanley College Winstanley Road, Billinge Wigan WN5 7XF. Tel: 01695 633244</p> <p>St John Rigby College Gathurst Road Orrell Wigan WN5 0LJ Tel: 01942 214797</p>

Specialist day and residential colleges for people with Asperger syndrome

Sometimes a local sector Further Education College 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 college 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

National Autistic Society Directory of Services website www.autismdirectory.org.uk contains an up to date national lists of specialist colleges.

AALPS College (North)

Winterton Road
Roxby
Scunthorpe
North Lincolnshire
DN15 0BJ
Tel: 01724 733777
Email: office@roxbyhouse.co.uk (launches email software)
Autism/Asperger syndrome
Age range: 16+yrs

Arden College

40 Derby Road
Southport
Merseyside PR9 0TZ;
Tel: 01704 534 433
Email: arden.college@craegmoor.co.uk
Autism/Asperger syndrome
Age range: 15-25yrs

Bridge College

Curzon Road
Offerton
Stockport
SK2 5DG
Tel: 0161 487 4293
Website: www.togethertrust.org.uk
Email: enquiries@togethertrust.org.uk
Autism/Asperger syndrome
Age range: 16-25yrs

Bright Futures School

158 Huddersfield Road
Diggle
Oldham OL3 5PJ
Telephone Number : 01457 829 449
E-Mail: info@brightfuturesautism.com **website** www.brightfutureschool.co.uk
Autism/Asperger Syndrome with statement of special educational need
Age range 5-19

Chetham's School of Music

Head of Compensatory Education
Long Millgate
Manchester M3 1SB
Tel: 0161 834 9644

Chetham's is the largest specialist music school in the UK for children with exceptional musical talent. Students are educated in class for all academic subjects. There is some 1:1 provision at a level appropriate to each student's needs.

Age Range 8-18yrs

David Lewis College

Mill Lane
Warford
Nr Alderley Edge
Cheshire SK9 7UD;
Tel: 01565 640 160
Email: gillyg@davidlewis.org.uk
Website: www.davidlewis.org.uk
Epilepsy, Autism/Asperger syndrome
Age range: 16-25yrs

Derwen College

Oswestry
Shropshire
SY11 3JA
Tel: 01691 661 234
Email: Ruth.Thomas@derwen.ac.uk
Website: www.derwen.ac.uk
Autism/Asperger syndrome
Age range: 16-25yrs

Dilston College of Further Education

Dilston Hall
Corbridge
Northumberland NE45 5RJ
Tel: 01434 632692
Email: john.jameson@dilstonecollege.ac.uk
Website: www.mencap.org.uk
Autism/ Asperger Syndrome
Age Range 16-25

Dovestones, Tameside College

Tameside College
Beaufort Road
Ashton-under-Lyne
OL6 6NX
Tel: 0161 908 6570
Email: catherine.lavelle@tameside.ac.uk (launches email software)

Freeman College

Sterling Works
88 Arundel Street
Sheffield S1 2NG
Tel: 0114 252 5940
Email: info@rmet.org.uk
Autism/Asperger syndrome
Age range: 16-25yrs

Henshaws College

Bogs Lane
Harrogate
N Yorkshire HG1 4ED
Tel: 01423 886451
Email: college@hsbp.co.uk
Website: www.henshaws.org.uk
Visual Impairment with Autism/Asperger Syndrome
Age : 16+

Hereward College

Bramston Crescent
Tile Hill Lane
Coventry
CV4 9SW;
Tel: 024 7646 1231
Email: enquiries@hereward.ac.uk
Website: www.hereward.ac.uk
Autism/Asperger syndrome
Age range: 16+

Langdon College

9 Leicester Avenue
Salford
M7 4HA
Tel: 0161 740 5900
Email: admin@langdoncollege.ac.uk
Website: www.langdon.info
Aimed at students from Jewish communities, but all are welcome
Autism, Asperger Syndrome
Age Range 16-25

Lindeth College of Further Education

The Oaks
Lindeth
Bowness on Windermere
Cumbria
LA23 3NH;
Tel: 01539 446 265
E-mail: lindeth.college@craegmoor.co.uk (launches email software)
Autism/Asperger syndrome
Age range: 16-25yrs

Linkage College (Two sites in Lincolnshire - Grimsby and Spilsby)

All applications to
The Vine House
Transition Team (Applications)
Weelsby Campus
Weelsby Road
Grimsby
Lincolnshire
DN32 9RU
Tel: 01472 372400
Email: college@linkage.org.uk (launches email software)
Autism/Asperger syndrome
Age range: 16-25yrs

Loppington House Further Education Unit And Adult Centre

Loppington
Nr Wem
Shrewsbury
Shropshire SY4 5NF
Tel: 01939 233926
Email: loppingtonhouse@shealthcare.co.uk
Website; www.loppingtonhouse.co.uk
Autism/Asperger Syndrome
Age 16+

Lords House Farm

Lords House
Brougham
Penrith
Cumbria CA10 2AB
Tel: 01768 866766
Email: mary.walker@lordshousefarm.co.uk
Website : lordshousefarm.co.uk
Autism/Asperger Syndrome
Age range 16+

Regent College

77 Shelton New Road
Shelton
Stoke On Trent ST4 7AA
Tel : 01782 263326
Website: www.regentcollege.org.uk
Autism/Asperger Syndrome
Age Range 16-25

Runshaw College

Langdale Road
Leyland
Lancs PR25 4QZ
Tel : 01772 622677
Website: www.runshaw.ac.uk
Autism/Asperger Syndrome
Age Range 16+

Sheffield College Autism Support Service

Sheffield College offers support for students with Asperger Syndrome across its college sites. Staff within the Autism Service are always pleased to offer advice and guidance, either to those who have Autistic Spectrum Disorder or to those who support them.

- Sheffield City College 0114 260 2087 Anne Briggs - Lecturer
- Hillsborough College 0114 260 2253 Amanda Towers - Lecturer
- Norton College 0114 260 2305 Anne Briggs - Lecturer

Website : www.sheffcol.ac.uk
Asperger syndrome, Autism, Autistic spectrum
Age Range 18-99yrs

Shrewsbury College of Art and Technology

London Road
Shrewsbury
Shropshire SY2 6PR
Tel: 01743 342342
Website : www.shrewsbury.ac.uk
Asperger syndrome, Autism, Autistic spectrum, High functioning autism
Age 16-25

Tasker House College (ESPA)

1 The Elms
Ashbrooke
Sunderland
SR2 7BZ;
Tel: 0191 565 9800
Website: <http://www.espa.org.uk>
Asperger syndrome
Age range: 16-25yrs

Thornbeck College (North East Autistic Society)

Carley Hill Estate
Sunderland
SR5 1SG
Tel: 0191 548 8206
Email: enquiries@ne-as.org.uk
Autism/Asperger syndrome
Age range: 18yrs-life

Whitegates Further Education Centre (NoRSACA)

The Dukeries Centre
Park Street
Worksop
Nottinghamshire
S80 1HH
Tel: 01909 509400
Email: feu@fnorsaca.freeseve.co.uk
Autism/Asperger syndrome
Age range: 16-25yrs

Higher Education (University)

Higher Education is an opportunity for some people. Where the person applies will be dictated by a number of factors such as where is the best place to study the subject?, how far from 'home' is it?, which university will accept the A level grades achieved? etc.

If someone is considering Higher Education they should not feel it is essential to live away from home if they are very apprehensive about living away on a campus.

Some people may prefer to avoid the social difficulties of campus living and opt for an Open University degree or other course. For further information contact:

Open University
351 Altrincham Road
Sharston
Manchester
M22 4UN
Tel: 0161 998 7272
Email north-west@open.ac.uk

Disabled Students Allowances

If the person is thinking of moving away from the parental home to study then approach your LEA, and ask whether the person is eligible for a Disabled Students Allowance.

Disabled Students Allowances (DSAs) provide extra financial help if you have a disability (including Autism Spectrum Disorders). They are available on top of the standard student finance package and don't have to be repaid.

They are grants to help meet the extra course costs students can face as a direct result of a disability and are aimed at helping disabled people to study on an equal basis with other students.

Eligible full-time, part-time and postgraduate students can apply for Disabled Students' Allowances.

The amount you get doesn't depend on your household income. DSAs are paid on top of the standard student finance package, and don't have to be paid back.

What they can be used for

Disabled Students' Allowances can help pay for:

- specialist equipment you need for studying - for example, computer software
- a non-medical helper, such as a note-taker or reader
- extra travel costs you have to pay because of your disability
- other costs - for example, tapes

These allowances may be made available if there are extra needs arising from the disability. However, they are for extra educational help rather than social assistance. If someone requires social support talk to the Students Welfare Dept, and you may need to approach Social Services for help to pay for costs.

Eligibility

You can apply if you are doing:

- a full-time course that lasts at least one year (including a distance-learning course)
- a part-time course that lasts at least one year and doesn't take more than twice as long to complete as an equivalent full-time course (including a distance-learning course)

Checking that you're eligible for student finance

To apply, both you and your course must meet certain conditions. It's worth checking these before you make your application and you will have to show evidence of your disability, for example, a letter from an appropriate medical professional or evidence in the form of a 'diagnostic assessment' from a psychologist or suitably qualified specialist teacher. If you have had a diagnostic assessment in the past, it may need to be updated. You may also be referred for assessment to the local assessment centre of the NNAC (National Network of Assessment Centres) who will produce a report on your eligibility. The NNAC website is www.nnac.org

You may have to pay for any tests to establish your eligibility for Disabled Students' Allowances. If you need a test but cannot afford to pay for it, you may be able to get financial help through your university or college's Access to Learning Fund.

How much you can get? This is based on your individual needs, but there are maximum amounts.

How to apply There are two different ways of applying for DSA. Which one you use will depend on whether you are either:

- doing a full-time higher education course
- studying part-time or doing a postgraduate course

Most universities and colleges have a disability adviser. They can help with your application and give you advice about other sources of funding.

Full-time higher education students

- From 2009, if you're a new student you should apply for Disabled Students' Allowances by completing form DSA1 and returning it to Student Finance England.

Student Finance England
PO Box 210
Darlington
DL1 9HJ

Telephone 0845 300 50 90

- If you started in 2008/2009 or earlier, you'll usually need to send your form to your Local Authority Student Finance department (see table below)

If you tick the relevant box on your main student finance application, you'll be sent a copy of the DSA1 form automatically - or you can download one.

Postgraduates and part-time higher education students

If you're studying part time or doing a postgraduate course, you need to take the DSA1 form to your college or university, ask them to sign it and then send it to the address on the form.

Open University students

Apply directly to the Open University's Disabled Students' Allowances (DSA) office.

If your application is turned down

If you disagree with the decision, you can ask Student Finance England or your local authority - whichever one assessed your application - to review your case. If the decision is reviewed and you still feel it is wrong, ask how you can appeal against it.

Further Information on Disabled Students Allowance

For further information go to the Government website www.direct.gov.uk and search for 'disabled students allowances' and 'student finance England'.

The booklet **Bridging The Gap** – a guide to Disabled Students Allowance can be downloaded from the website or by calling 0800 731 9133 and asking for a copy.

Local Authority Student Finance departments

<p>Bolton Student Support Bolton MBC PO Box 53 Paderborn House Civic Centre Bolton BL1 1JW Tel: 01204 332136</p>	<p>Salford Student Support Team Salford City Council MInerva House Pendlebury Road Swinton Manchester M27 4EQ Tel: 0161 778 0207 or 0209 Email: student.support@salford.gov.uk</p>
<p>Bury Student Awards Office Education Department Bury MBC Atheneum House Market Street Bury BL9 0SW Tel: 0161 253 5676</p>	<p>Stockport Student Finance Team Business Services Directorate Town Hall Stockport SK1 3XE Tel: 0845 644 4303 email: student.finance@stockport.gov.uk</p>
<p>Manchester Student Support Section PO Box 191 Overseas House Quay Street Manchester M60 3ST Tel: 0161 234 7078 (surnames A-K) Tel: 0161 234 7079 (surnames L-Z) Email; fund4study@manchester.gov.uk</p>	<p>Tameside Student Awards Section Tameside MBC Education and Cultural Services Wellington Road Ashton Under Lyne OL6 6DL Tel: 0161 342 2203 Email: student.awards@tameside.gov.uk</p>
<p>Oldham Oldham Student Support PO Box 40 Civic Centre West Street Oldham OL1 1XJ Tel ; 0161 770 3352 email: studentsupport@oldham.gov.uk</p>	<p>Trafford Student Support Trafford MBC Waterside House Waterside Sale M33 7ZF Tel: 0161 912 1888</p>
<p>Rochdale Student Finance Section Revenues and Benefits Service PO Box 490 Rochdale OL16 9AJ Tel: 01706 925115 Email: studentsupport@rochdale.gov.uk</p>	<p>Wigan Student Loans Team Wigan MBC Progress House Westwood Park Drive Wigan WN3 4HH Tel: 01942 486268 (surnames A-E) Tel: 01942 486077 (surnames F-P) Tel: 01942 486078 (surnames Q-Z)</p>

For those people who wish to study locally there are several good universities to consider:

University of Manchester

Lower Ground Floor
John Owens Building
Oxford Road
Manchester
M13 9PL
Tel: 0161 275 7512/8518
Website: disability.ac.uk/disability
Email: dso@manchester.ac.uk
Contact: Elaine Shillcock, Head of Disability Services
Bryan Coleman, Deputy Head of Disability Services

University of Manchester now includes UMIST.
Norman Darwen of Prospects is available for advice on Fridays only contact via Website

Manchester Metropolitan University

Learning Support Team
1st Floor All Saints Building
Oxford Road
Manchester
M15 6BH
Tel: 0161 247 3491
Email: l.support@mmu.ac.uk
Contact: Emma Flynn, Learning Support Co-Coordinator:

University of Salford

Equality and Diversity Office
Ground Floor
Humphrey Booth House
Salford M5 4WT
Tel: 0161 295 9000
Email: equalities-academic@salford.ac.uk

University of Bolton

Deane Road
Bolton BL3 5AB
Tel : 01204 903086
Email: kj2@bolton.ac.uk
Contact: Katie Jennings, Senior Disability Adviser

Stockport College

Additional Learning Support Services
Town Hall Campus
Wellington Road South
Stockport SK1 3UQ
Tel : 0161 958 3425
Email: accessibility@stockport.ac.uk

In the Greater Manchester area you can contact:

Access Summit: Joint University Disability Resource Centre

St Peter's House
Oxford Road, Manchester
M13 9GH
Tel: 0161 275 0990
Website: access-summit.org.uk

'Our aim is to provide information for people interested in disability support in higher education.'

Access Summit is here to assist:

- Students and prospective students with disabilities or specific learning difficulties (including dyslexia) studying in higher education.
- Staff working in, or those advising people entering, higher education.

'We work particularly closely with staff and students in the universities of Manchester and Salford, therefore some of the advice and guidance provided relates specifically to those institutions and their arrangements.'

DISABILITY ALLIANCE has taken over some of the services for disabled students previously undertaken by SKILL which is no longer operating. The following services are available.

- Updated FAQs and information booklets for disabled students
- Young people's website
- Helpline service - freephone helpline 0800 328 5050 or email skill4disabledstudents@disabilityalliance.org
- Policy and campaigns work - Disability Alliance has a strong track record in evidence-based campaigning with disabled people to break the link between poverty and disability. Disability Alliance will continue Skill's work to include disabled students in policy development and trying to influence government policy on education and training. For more information contact alewis@disabilityalliance.org.

AUTUNIV-L is a useful link site on the National Autistic Society website www.nas.org.uk for people with Asperger syndrome in continued education.

PROSPECTS (National Autistic Society) has set up a new service offering training to colleges and universities staff to help them understand the needs of people with Asperger syndrome. Contact Judith Kerem for further details.

Office Number 0207 704 7450

Work mobile 07795667749

E-mail judith.kerem@nas.org.uk"

PROSPECTS in the Manchester area may also be able to offer individual student support. Contacting the disability officer of the college concerned.

Books

Managing Asperger Syndrome at College and University by Juliet Jamieson and Clare Jamieson, David Fulton Publishers, 2004.

Aquamarine Blue 5: Personal Stories of College Students with Autism edited by Dawn Prince-Hughes, published by Ohio University Press

New e-booklet of advice for students with Asperger's

The University of Melbourne and the Australian Catholic University have produced a very useful e-booklet called "Towards Success In Tertiary Study with Asperger syndrome and other autism spectrum disorders", which can be downloaded for free from

<http://www.services.unimelb.edu.au/edp/policy/publications.html>.

SOCIAL SERVICES

The services that Social Services Departments are able to offer depends on the person's age and their eligibility for support.

All Social Services support in local authorities in Greater Manchester is separated into Children's Services, for those under 18, and Adult Services for those over 18.

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, or a young person in your care, has an autism spectrum disorder and ask for an assessment use the model letters below.

Sample letter to write to Social Services for support for under 18s

(Team address)
(Date of letter)

Dear Team Manager

Re: (Childs 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 (sons) 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.

Best wishes

Yours sincerely

(parent/s signature)

(Name of parents)

Who to write to in Social Services for support for under 18s

<p>If the person lives in Bury and is under 18yrs write to: Children's Advice and Assessment Team Tel: 0161 253 5454 Craig House 5 Bank Street Bury BL9 0BA sschildrenquiries@bury.gov.uk</p>	<p>If the person lives in Bolton and is under 18yrs write to: Disabled Children's Services Crescent House Lever Street Bolton BL3 6NN. Tel: 01204 337100</p>
<p>If the person lives in Manchester and is under 18yrs write to: Manchester Specialist Resource Centre Manchester Contact Service, Carisbrooke Resource Centre, Wenlock Way, West Gorton, Manchester M12 5LF Tel: 0161 255 8250</p>	<p>If the person lives in Oldham and is under 18yrs write to: Children with Disabilities Team Woodfield, Manchester Road Oldham OL8 4ET. Tel: 0161 627 1749</p>
<p>If the person lives in Rochdale and is under 18yrs write to: Team for Children & Young People with Disabilities, Whitworth Road Depot, Haynes Street Rochdale OL12 0EX Tel: 01706 925900</p>	<p>If the person lives in Salford and is under 18yrs write to: 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>If the person lives in Stockport and is under 18yrs write to: Customer Enquiry and Referral Management Team, Mount Tabor Mottram Street, Stockport, SK1 3PA. Tel: 0845 644 4313</p>	<p>If the person lives in Tameside and is under 18 write to: 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>If the person lives in Trafford and is under 18yrs write to: Children with Disabilities Team 4th Floor, Waterside House Waterside Sale M33 7ZF First referral to Multi Agency Referral and Assessment Team (MARAT) Stretford Public Hall Chester Road Stretford M32 0LG Tel: 0161 912 5125</p>	<p>If the person lives in Wigan and is under 18yrs write to: Children with Complex Needs Team Claire House Lower Ince Health Centre Phoenix Way Ince Wigan WN3 4NW First referral to 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 (under 18s)

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...

Social Services support for adults (18 years and over) who already have a social worker

Many people aged 18 and over will require some support from other people throughout their lives. Much of this support comes from family members, but there may also be a need for outside professional assistance.

This type of support from outside the family is called community care.

Community care includes getting help with housing, social problems, independent living and health. It can sometimes include help with employment.

To find out if a person with Asperger syndrome can get community care support, he or she will need to have their needs assessed.

The assessment is called a Community Care assessment of need (section 47 of the NHS and Community Care Act 1990).

Getting a Community Care assessment if the person or family already has a social worker

If you already have contact with a professional in Social Services or health phone him or her.

Discuss with him or her how to arrange for an assessment of need for community care services (under the NHS and Community Care Act 1990 section 47).

If the person or family is in any doubt contact:

The National Autistic Society Family Services Development Project, Tel: 0161 998 4667

Or

The National Autistic Society Helpline 0808 800 4104.

Social Services support for adults (18 years and over) who do not have a social worker

If the person has not had a social worker in the last year or so, then it is often best to write a letter to the local adult care Social Services team. The letter will be a request for community care.

IMPORTANT: Although it is usually more effective to put the request for help in writing, if the person or family need support immediately then do telephone Social Services for assistance.

An example of a letter to write is on the next page but one, but first find out who to address your request for support to.

<p>If the person lives in Bolton and is 18yrs contact: 01204 337970 and ask for the Adult Advice and Assessment Duty Officer or write to Adult Services Department Le Mans Crescent Bolton BL1 1SA www.bolton.gov.uk</p>	<p>If the person lives in Bury and is 18yrs or contact: Advice And Assessment Referral Officer 7 Whittaker Street Radcliffe M26 9TD Tel: 0161 253 7190 ssadultenquiries@bury.gov.uk</p>
<p>If the person lives in Manchester and is 18yrs or over write to: Manchester Contact Service Second Floor Pinkbank Lane P.O Box 204 Manchester M12 5WL Tel: 0161 234 5001 Email: mcsreply@manchester.gov.uk</p>	<p>If the person lives in Oldham and is 18yrs or over write to: Vulnerable Adults Service Oldham Social Services Department 18 Greaves Street Oldham OL1 1AD. Tel: 0161 620 1359.</p>
<p>If the person lives in Rochdale and is 18yrs or over write to: Rochdale Adult Care Services Second Floor Brook House, Oldham Road Middleton M24 1AY Tel: 0844 2640867</p>	<p>If the person lives in Salford and is 18yrs or over write to: Joint Learning Difficulties Service White Moss House Bracken Avenue off Sharp Street Walkden M28 3SS. Tel: 0161 607 6988</p>
<p>If the person lives in Stockport and is 18yrs or over write to: Stockport Community Learning Disability Team 4th Floor Regal House 1 Duke Street Stockport SK1 3AB Tel: 0161 218 1220</p>	<p>If the person lives in Tameside and is 18yrs or over write to: Reception and Initial Assessment Team Tameside Social Care and Health Stalybridge Resource Centre Waterloo Road Stalybridge SK15 2AU. Tel: 0161 342 2400.</p>
<p>If the person lives in Trafford and is 18yrs or over write to: Initial Assessment Team 1st Floor Trafford Metropolitan Borough Council Waterside House Sale Waterside Sale M33 7ZF Tel: 0161 912 5199 iat@tafford.gov.uk</p>	<p>If the person lives in Wigan and is 18yrs or over write to: Dept Of Adult Services Central Duty Team Hyndelle Lodge King Street Hindley Wigan Tel: 01942 828777</p>

Sample letter to write to Social Services for support for adults (18 years and over)

(Team address)

(Date of letter)

Dear Team manager

Re: (persons 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 registered as a disabled person, under Chronically Sick and Disabled Persons Act 1970?

Can you arrange an assessment of my sons needs for support, under the NHS and Community Care Act 1990, and my own needs as carer under the Carers and Disabled Children Act 2000?

Some of the needs my son has include

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)
4. the need to live independently of his/her parent/carers (housing options and planning)
5. the need to have someone to talk to outside the family (for example befriender, clubs)
6. the need for counselling - emotional difficulties/ mental health difficulties
7. the need to learn how to present himself, wear appropriate clothes, grooming, how to avoid attracting negative attention in public
8. the need to develop safe appropriate relationships/ sexual behaviour and health
9. the need to discuss Asperger syndrome and how it affects him or her
10. the need to be able to explain Asperger syndrome to others (acquaintances, college students, employers)
11. the need to develop financial skills (for example, budgeting, paying bills, assessing values, dealing with door salesmen, saving money)
12. the need to develop morning routines (for example, early morning call, waking and getting up, washing, choosing appropriate clothes, grooming, personal hygiene, self presentation)
13. the need to develop organisation and reminder systems (for example, weekly timetables, note keeping, maps, using a mobile phone, useful telephone numbers book, keeping appointments, using a calendar).
14. the need to develop meal preparation skills (for example, shopping, recipes, cooking safely)
15. the need to understand food hygiene (for example, cleaning the fridge, checking sell-by-dates, cooking at the right temperature).
16. the need to understand dietary requirements (for example, understanding of a balanced diet, remembering to eat and drink enough and to exercise).
17. the need to avoid loss of personal possessions (for example, crime prevention awareness, not leaving possessions unattended, not lending items to strangers).
18. the need to develop home safety skills (for example, locking up at night, not leaving the gas on, shutting windows, when to ask for assistance).
19. the need to learn basic domestic skills and maintenance (for example, cooking, dealing with uninvited guests, changing a plug, ironing, washing up, adjusting to seasonal changes, unblocking a sink, heating, doing the laundry, putting rubbish out, when to ask for assistance).
20. the need to develop financial independence/ ability to manage own money
21. the need to control his anger towards others
22. the need to control his anger towards himself
23. the need to develop community skills to avoid social isolation and increase personal safety outside the home (for example, using pubs, cafes, clubs, taxis, using public transport letting someone know whereabouts, using libraries, information about driving lessons, basic manners, how to recognise and

- avoid dangerous social or other risk situations, how to explain Asperger syndrome/ASD to others, how to say 'no', awareness of own behaviour, reporting incidents, dealing with neighbours, useful conversation topics with acquaintances, personal disclosure, not 'staring', who to ask for help)
24. the need to have support with finding work or other occupation, in order to structure his/her week
 25. the need to understand about getting enough sleep, how to relax, and carry out personal care (for example, (for example, reporting illness, medication, hygiene, sexual health, getting enough sleep, how to relax).
 26. the need to manage any additional physical difficulties (for example tics, epilepsy, ADHD)
 27. the need to be encouraged to understand and use prescribed medication appropriately
 28. the need for assistance with mental health and associated difficulties (for example, depression, obsessions, panic attacks, agoraphobia, social 'exposure' anxiety, paranoia)
 29. the need for me as a parent 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 social groups, leisure opportunities, local sport clubs etc
 30. 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 needs as a parent and carer are to have my own living space and for my son to grow up able to live independently of me. I need to know that he will be safe and looked after when I am no longer able to provide the support I do at present. I also require support now with enabling my child to develop appropriately and meeting our family's needs.

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

Can you advise me 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. If there is likely to be a waiting period before assessment, please acknowledge this letter and give me an indication how long I may expect to wait.

Best wishes

Yours sincerely

(Parent/ Carer signature)

(Parent/ Carer name)

What actually happens during the assessment of need for community care services?

If a family has requested an assessment of need they should hear from the local Social Services team who will usually appoint a Care Manager to assess the situation. The Social Services should ask both the Carer and the person with Asperger Syndrome about their needs.

The Care Manager (often a social worker) should consult with all relevant people to get the 'full picture'.

If the person with Asperger syndrome requires an advocate, Social Services may have details of people who can provide this.

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 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.

Parents and people with Asperger syndrome 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.

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

Parents and people with Asperger syndrome are usually entitled to a Written Assessment :

"All assessments are likely to be recorded on some kind of proforma... A copy of the assessment of needs should normally be shared with the potential user, any representative of that user and all the people who have agreed to provide a service."
(SSI - SWSG 1991 p 56).

Local authorities have to impose 'eligibility criteria' to ensure resources are equitably divided between those in greatest need. It may be that the local authority does not consider a particular situation to be a priority so may not be able to offer a service.

Parents and people with Asperger syndrome should bear in mind that with limited resources it will sometimes feel as if the onus is on them to 'demonstrate' the need.

If the person with Asperger syndrome is judged to require a community care service (for example support to attend a social group, help with finances and budgeting, support to move to more independent living) the family should receive a written Care Plan.

"Except where no intervention is deemed necessary, this record (assessment) will normally be combined with a written Care Plan setting out how the needs are to be addressed..."
(SSI - SWSG 1991 p 56).

If a family feels unfairly treated they should get in contact with the Social Services Care Manager, and if still unsatisfied, speak to the team manager, stating the case clearly.

Valuing People and Fair Access to Care Services

Valuing People is the key document for social care in relation to adults with learning disabilities. *Valuing People* initially explicitly excluded people with an ASD but with 'average or above-average intelligence'. However, the supplementary guidance to *Valuing People* changed this, and again gave the right for people with Asperger syndrome or higher-functioning autism to access learning disability services. It stated that these people may require an assessment of their social functioning and communication skills in order to establish their level of need.

Fair Access to Care Services (FACS) is the recent guidance from the Department of Health on eligibility criteria for social care services – in other words, who should be able to get support. This document says that all people with autism spectrum disorders should be able to get support if they really need it.

If you are experiencing difficulties accessing Social Services support it can help to write to your local Social Services department quoting this guidance. On the next page are draft letters that adults can fill in and send to their Social Services department. They can easily be adapted to come from a carer. It may help you explain why you or the person you care for need services. It might be a good idea to reiterate the person's support needs (see the previous draft letter for ideas about the kind of information to include).

If you are still not satisfied then you have the right to complain, and each local authority has a Complaints Procedure to follow. There is also the route of involving the local MP, or ombudsman. The Ombudsman will be available through the local authority's Town Hall, or Civic Centre.

Fair Access To Care Services – Guidance On Eligibility Criteria for Adult Social Care

Setting the eligibility criteria

In general, councils may provide community care services to individual adults with needs arising from physical, sensory, learning or cognitive disabilities and impairments, or from mental health difficulties. In this regard, councils' responsibilities to provide such services are principally set out in the:

- National Assistance Act 1948.
- Health Services and Public Health Act 1968.
- Chronically Sick and Disabled Persons Act 1970.
- National Health Service Act 1977.
- Mental Health Act 1983.
- Disabled Persons (Services, Consultation and Representation) Act 1986.

Councils should use the following eligibility framework to specify their eligibility criteria. In other words, they should use the framework to describe those circumstances that make individuals, with the disabilities, impairments and difficulties eligible for help.

The eligibility framework is based on the impact of needs on factors that are key to maintaining an individual's independence over time. The framework makes no reference to age, gender, ethnic group, religion, disabilities, impairments or similar difficulties, personal relationships, location, living and caring arrangements, and similar factors. In themselves, these factors do not threaten independence; however, they may need to be taken into account as needs are assessed and services considered.

The eligibility framework is graded into four bands, which describe the seriousness of the risk to independence or other consequences if needs are not addressed. The four bands are as follows:

Critical – when

- life is, or will be, threatened; and/or significant health problems have developed or will develop; and/or
- there is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or
- serious abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out vital personal care or domestic routines; and/or
- vital involvement in work, education or learning cannot or will not be sustained; and/or
- vital social support systems and relationships cannot or will not be sustained; and/or
- vital family and other social roles and responsibilities cannot or will not be undertaken.

Substantial – when

- there is, or will be, only partial choice and control over the immediate environment; and/or
- abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or
- involvement in many aspects of work, education or learning cannot or will not be sustained; and/or
- the majority of social support systems and relationships cannot or will not be sustained; and/or
- the majority of family and other social roles and responsibilities cannot or will not be undertaken.

Moderate – when

- there is, or will be, an inability to carry out several personal care or domestic routines; and/or
- involvement in several aspects of work, education or learning cannot or will not be sustained; and/or
- several social support systems and relationships cannot or will not be sustained; and/or
- several family and other social roles and responsibilities cannot or will not be undertaken.

Low – when

- there is, or will be, an inability to carry out one or two personal care or domestic routines; and/or
- involvement in one or two aspects of work, education or learning cannot or will not be sustained; and/or
- one or two social support systems and relationships cannot or will not be sustained; and/or
- one or two family and other social roles and responsibilities cannot or will not be undertaken.

**Further detail on the Department of Health website at
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653**

Sample letter if your Local Authority has refused to assess your needs (Over 18)

(Your Details Here)

(Details of your Director of Social Services, or the Assistant Director with responsibility for Learning Disability Services here)

Dear...(Name of the Director / Assistant Director)

I am writing to appeal against the refusal by your department to assess my needs. (Provide personal details, including any diagnosis, here).

I would like to point out that under the NHS and Community Care Act 1990, section 47, I am legally entitled to an assessment of needs. Also, the supplementary guidance to Valuing People stated that all people with autism spectrum disorders, such as myself, are entitled to access learning disability services and may require an assessment of their social functioning and communication skills in order to establish their level of need. ¹

The recent Fair Access to Care Services guidelines instruct local authorities to base eligibility for services on an individual's presenting needs, rather than their diagnosis. ² The practice guidance states explicitly that:

Some councils... (declare) that they do not help particular groups of individuals, such as those with higher functioning autism/Asperger Syndrome, and make no attempt to assess needs as they should do. This is unacceptable.³

I need support in the following areas (e.g. support with independent living skills, support to find a home, access to an independent advocate – explain why each of these are needed).

This means that my 'presenting needs' are high and represent a real barrier to my ability to live independently. I hope you will accept that I am entitled to an assessment of need and that your department will contact me shortly to arrange a date and time.

Yours sincerely,

(Your name here)

¹ Department of Health. (2001) *Valuing people: a new strategy for learning disability for the 21st century: implementation*. London: Department of Health. Health Circular 2001/016; Local Authority Circular (2001) 23.
² Department of Health (2002) *Fair access to care services: guidance on eligibility criteria for adult social care*. London: Department of Health. Local Authority Circular (2002) 13.
³ Department of Health (2003) *Fair access to care services: practice guidance*. London: Department of Health, p14.

A letter to use if your Local Authority has refused to provide services

(Your Details Here)

(Details of your Director of Social Services, or the Assistant Director with responsibility for learning disability services here)

Dear...(Name of the Director / Assistant Director)

I am writing to appeal against the refusal by your department to provide the services that I need. (Provide personal details, including any diagnosis, here).

I would like to point out that under the NHS and Community Care Act 1990, section 47, your authority has a duty to assess my needs and provide services based on that assessment. (Give details of any assessment, and if you think an assessment was not right explain this.)

Also, the supplementary guidance to Valuing People stated that all people with autism spectrum disorders, such as myself, are entitled to access Learning Disability Services and may require an assessment of their social functioning and communication skills in order to establish their level of need. ⁴

The recent Fair Access to Care Services guidelines instruct local authorities to base eligibility for services on an individual's presenting needs, rather than their diagnosis. ⁵ The practice guidance states explicitly that:

Some councils... (declare) that they do not help particular groups of individuals, such as those with higher functioning autism/Asperger Syndrome, and make no attempt to assess needs as they should do. This is unacceptable. ⁶

I need support in the following areas (e.g. support with independent living skills, support to find a home, access to an independent advocate – explain why each of these are needed). This means that my 'presenting needs' are high and represent a real barrier to my ability to live independently. I hope you will accept that I am entitled to the services that I have described above and that your department will contact me to confirm that I will be able to access these services.

Yours sincerely,

(Your name here)

⁴ Department of Health. (2001) *Valuing people: a new strategy for learning disability for the 21st century: implementation*. London: Department of Health. Health Circular 2001/016; Local Authority Circular (2001) 23.

⁵ Department of Health (2002) *Fair access to care services: guidance on eligibility criteria for adult social care*. London: Department of Health. Local Authority Circular (2002) 13.

⁶ Department of Health (2003) *Fair access to care services: practice guidance*. London: Department of Health, p14.

What if my son or daughter refuses to be assessed?

This is often a difficult area for families, because their son or daughter may not wish to be “assessed” despite having needs, so any letter may need to alert the Local Authority Social Services of the difficulty for the young person, and suggest ways to engage with him or her.

Just because the person does not wish to be assessed, this does not stop the Local Authority carrying out an assessment.

The person’s refusal to speak to anyone, may slow the process of assessment, but it should not prevent it.

If there is refusal to meet with a social worker or similar person, the Local Authority should look instead to other sources of information – from discussions with parents, other agencies that do get to see the person. It may also mean that the local authority should think about ways to engage with the person which do not involve coming round to the house with a note book and pen, asking lots of questions!

The Carers and Disabled Children Act 2000 says that parents (and other significant carers) are entitled to an independent assessment of *their* needs, whether or not their son or daughter wishes for an assessment. So this is a useful Act to use if it proves very difficult to get the son or daughter to see a social worker. (See section on Carers Needs for more information).

Involving the person with Asperger syndrome

Depending on ability and motivation, the person should be a part of whatever request is made for an assessment. It is best if the request comes directly from them, 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. (Hopefully this will change in the future as more people with Asperger syndrome are diagnosed earlier and are given opportunity to articulate their own needs).

Perhaps the young person does not wish to meet the social worker at home – so parents may wish to suggest another place to meet elsewhere, or maybe ask them to write about what support they would like, and give the social worker the letter.

Crucially if it is not possible to talk frankly in front of the person, parents may request a separate meeting or some other way to get the information required to the social worker. This will be particularly important if the person and parent have very different views about the future!

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 person requires help - either now, or over the next few years.
- Do think carefully about what support he or she requires.
- If possible do put your request in writing to Social and Housing Services.
- Remember to mention the Fair Access to Care Services guidance.
- Do work co-operatively with the local authority and be prepared to be persistent.

Complaints Procedure

All local authorities have a complaints procedure. If you need to complain you should ask your social worker or someone in 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.

CARERS NEEDS

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.

Often parents find difficult behaviours emerge during the teenage years and they may wish for some help with this. Parents of young people with Asperger syndrome should be offered a short break from caring if this causes tiredness and stress.

Parents of people with Asperger syndrome remain as carers of their grown up children long after most adults have moved away from the parental home. This is usually because getting appropriate supported housing is not very easy. It is also because sometimes discussing 'moving out' can cause anxiety for the person with Asperger syndrome.

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.

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.

What support do you provide for your son or daughter? (reminders to do things, make sure he or she makes appointments, cook meals, helping him with letters and paying bills, money advice and management, helping him or her to relax or calm down, doing their laundry, teaching to use domestic appliances – ironing, washing machine, vacuum machine, collecting allowances, shopping, checking his or her presentation before leaving the house, giving advice and information about events and other people, social skills information, helping with transport to places, being his or her companion on outings in lieu of same age friends, explaining other people's behaviour to him or her, offering emotional counselling support, having to explain his or her behaviour to others to avoid misunderstandings etc.)

- Are you able to get enough sleep?
- Is your health affected by being a carer?
- Are you able to have time to yourself?
- How does being a carer affect your relationships with friends outside the home?
- How does being a carer affect the time you have for any other children in the family?
- Does being a carer affect your ability to work? or have you had to give your job up?
- Is the person you care for getting enough support?

It is possible for a social worker to decide that the Carer requires a service in his or her own right, even though the young person refuses a service.

For example the parent may require a break from caring for, in which case a Befriender service for the young person may be appropriate.

It may be that the parent would benefit from some practical help with household tasks, in which case a 'home help' type service could be used.

If parents wish to have an evening out as a break or take out siblings for the day but the person with Asperger syndrome refuses to leave the house, a sitting service might be useful.

It sometimes requires considerable tact and skill from the social worker, to introduce such a service, but that should not stop parents asking for help, if appropriate.

Carers can also ask the social worker about Direct Payments – whereby the parent receives money direct to pay for their own care/support. This may be better for the person with Asperger syndrome who can have more choice about who supports them, for example a family friend.

Also be aware that if someone cares for someone who gets the Disability Living Allowance at mid-rate care and earns less than about £95 per week (as at March 2009) they will probably be entitled to Carers Allowance. Ring 0800 882200 (Benefit Enquiry Line) for more details.

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

NAS Help! Programme

The aim of the NAS Help! Programme is to provide parents and full time carers with information advice and support. It helps develop an understanding of autism spectrum disorders and positive management strategies, as well as knowledge of rights, benefits, and local support services.

Most events are aimed at school age children with a recent diagnosis, but occasional programmes aimed at 16+ age group are held. For further information contact the NAS Help! Team telephone 0742 5624592.

Carers And Parents Information and Support Groups in Greater Manchester

Greater Manchester Groups

NAS Manchester Autism Resource Centre

Victoria & Biscuits Parents Support Group
Victoria Road
Northenden
Manchester M22 4JN
Tel 0161 945 6830

A group for parents and carers of children and adults with autism. Meets monthly between 7 and 9pm. Some meetings include guest speakers.

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

Parent's 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 Carers Forum

London Scottish House

24 Mount Street

Manchester M2 3NN

Tel: 0161 819 2226

www.manchestercarersforum.org.uk

The Manchester Carers Forum was formed in 1993 in order to provide a major voice for carers in Manchester. Speakers from Health and Social Services are invited to the meetings so that carers can receive information about services and question the decision-makers direct. Carers are also

asked for their views about new services that are being developed or about the quality of existing services.

There are sub groups in Central, North and South Manchester

The Manchester Carers Forum holds regular lunchtime meetings at the Manchester Carers Centre, at address above. Carers and former Carers meet to share experiences and to offer support to each other. Travel expenses and sitter costs are available to Carers from Manchester so that as many as possible can attend.

Manchester - The Princess Royal Trust

Manchester Carers Centre
Vulcan Mill
12-18 Pollard Street
Manchester M4 7AN Tel : 0161 272 7270
carersline@manchestercarers.org.uk

Provides support and information for parents and families of children with learning disabilities. Also advice and information, play scheme, advocacy, parenting courses, adult leisure, pamper days and much more. Run by parents for parents. There is a drop in facility, training classes and support groups. Staff can also make home visits to parents

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
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

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: lieselbe@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

Salford - Princess Royal Trust

Salford Carers Centre
1 St Philips Place
Salford M3 6FA

Stockport Signpost For Carers

Torkington Close
Torkington Road
Hazel Grove
Stockport SK7 4PY
Tel: 0161 456 0096
Provide information on facilities for carers including Carer's grants.

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 Carers for Adults on the Autistic Spectrum

The Newbridge Centre
Cromer Street
Stockport SK1 2NY
Contact: Rayonette Jude 0161 439 0627
Email: StockportCAAS@gmail.com
Provide monthly evening meetings for carers of adults on autism spectrum

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

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.

Contact Justine Bailey 0161 748 2994

Day/Time: Sunday 09:45:00 - 10:45:00

Trafford Carers Centre

13 Warwick Road

Old Trafford

Manchester M16 0QX

Carers' Helpline Tel No: 0161 848 2400 Mon,Wed,Fri 9.30am - 4pm Tues,Thurs 9.30-8 pm

Contact: Carers' Support Team

The Carers' Centre aims to provide information and emotional support for adults in Trafford who are caring for relatives or friends. A range of services includes advice and information for Carers', a regular newsletter, information and relaxation days, quarterly Carers' Council meetings and weekly coffee mornings.

Trafford ADHD/ASD Family Support Group

1A Newton Court

Newton Road

Urmston

Contact 07947 798195 (Ruth) or 07969 459523 (Jess)

Email: sengroup@hotmail.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

Wigan And Leigh Carers Centre

3 Frederick Street

Hindley

Wigan WN2 3BD

Tel: 01942 705959 (9.30am-16.30pm.Mon-Fri)

The role of the Carers Centre is to actively support carers of all ages through the provision of information, training and support. In addition it offers an activity programme tailored to the needs of carers, including:

- Benefit advice
- Carers information pack;
- Access to leisure activities, complementary therapies and short breaks;
- Access to health checks;
- Training;
- Assisting carers back into education and employment.

Employment

It is important to think very carefully about whether work is the best option for someone with Asperger syndrome and if so what sort of work the person would be most suited to.

For example, although many people wish to obtain full-time permanent jobs, this should not be assumed. Some people quite like short-term contracts or agency work.

Other people spend a lot of time doing temping, but really wish they could find a more permanent position.

Some people find that part-time work best suits their situation. Others wish to build up to paid employment by doing some voluntary work.

It may be that the person is not quite ready for work and so more training or a college course would be beneficial.

Also it is worth bearing in mind what someone enjoys is not necessarily what will get them a job.

For example, someone may be very interested and knowledgeable about local history but if the only job available is a museum guide and the person finds it hard to tailor his conversation to the needs and interest of the listener then it may be advisable to try another tack for finding work.

A key person to contact regarding finding work or training is the **Disability Employment Advisor (DEA)**. These are specialist employment advisors based within Job Centre Plus.

People with Asperger syndrome may wish to access support from a Disability Employment Adviser (DEA) who specialise in disability work related issues. They often have contacts with disability aware employers.

The person with Asperger syndrome will need to inform the DEA that they have the disability, to get the best help possible.

DEAs can be contacted by telephoning the local Jobcentre and asking for an appointment.

For contact details of your local DEA's please refer to the contact table for your area at the back of this document.

It is advisable to read through this section on employment before making any decisions about finding work. It will help the person focus on the important issues.

Is the person ready for paid work now?

Although with the right approach many people with Asperger syndrome make excellent employees, it also has to be acknowledged that work is not for everyone with the condition.

Some individuals will not be able to work for a variety of reasons, and it is more important that the person's mental health and physical well-being are looked after than trying to fit someone into an inappropriate job.

If someone has not been looking for work previously but is starting to now then seeking advice from GP may be useful, if there are doubts about someone's capacity for work.

If someone has already been looking for a job, but doubts are raised about whether work is appropriate, and if you have involvement with a Disability Employment Adviser (DEA) from the Job Centre, then it may be that an Occupational Health Assessment would be advisable. This would be an option if there is concern about how work will affect someone's physical or mental health.

Employment Support Allowance (ESA)

Whilst people are considering what work is suitable for them, if any, or they are unable to work should consider applying for **Employment Support Allowance (ESA)** (which is replacing Incapacity Benefit).

ESA will offer personalised support and financial help, so that each claimant can do appropriate work, if able to. It also gives access to a specially trained personal adviser and a wide range of further services including employment, training and condition management support, to help manage and cope with illness or disability at work. The aim is to look at what people 'can do' rather than what they 'can't do'.

ESA involves a new medical assessment called the Work Capability Assessment. This assesses what the person can do, rather than what they cannot, and identifies the health-related support that might be needed. Most people claiming ESA will be expected to take steps to prepare for work, including attending work focused interviews with their personal adviser.

Under ESA, if an illness or disability that severely affects one's ability to work, they will get increased financial support and will not be expected to prepare for a return to work.

Jobcentre Plus publishes an information leaflet called 'Employment and Support Allowance - help if you are ill or disabled'. Also, you can download the leaflet from the Jobcentre Plus website.

It includes information on eligibility, rates and how to claim.

Other Employment Programmes

Those seeking employment may be eligible for the Work Programme initiative. This has replaced a number of previous schemes. Contact your local Job Centre. You can find their Telephone numbers on the contact tables at the back of this document.

It may be that the individual could work if they could catch public transport, so this may require some preliminary work before considering the next step.

It may be there needs to be some preparation work on getting to places on time. It may be necessary to develop a support structure around the person so they get up on time, and arrive for work.

Getting someone into a routine may be a first step before job-readiness. It may be necessary first to get the person into a morning routine before thinking about work. The person may need a new alarm clock, (or two alarm clocks!), the support of parent/friend to call, instructions to get ready may need to be written up on the wall of the bedroom and a waterproof list/flowchart for the bathroom.

For some people an afternoon placement is better to begin with, perhaps using a Work Preparation Provider (ask the DEA).

DEAs can help by arranging short work trials.

Connexions and **YMCA Training** for young people can assist by organising further local training. Training may be through a local college or firm leading to a number of different qualifications. Training providers are funded by the Learning and Skills Council. See Section on Careers Advice.

DEAs can also sometimes arrange residential courses for people who require more skills before looking for work.

You can get further information about residential training from:

Residential Training Unit,
Government Office For The North East,
Citygate,

Gallowgate,
Newcastle upon Tyne, NE1 4WH
Telephone: 0191 202 3579
www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/index.htm
Email: rtu@gone.gsi.gov.uk

Are there any personal care difficulties which need preparation? For example, grooming, selecting suitable clothes for work, combing hair, hygiene, taking a packed lunch. How long does it take the person to complete all these things? Is the person able to get himself or herself ready for work in time?

Another possibility is that the person requires some preliminary work on self-awareness. It is often important for individuals to understand a bit about Asperger syndrome and how it affects them because they may need to make their employer aware of their needs.

Practicing how to describe Asperger syndrome to an employer in positive and straightforward terms may be a useful technique for those who decide to disclose their condition during, before or after an interview.

If someone is not ready for paid work, but may be ready in the medium term, then voluntary work may be of use to develop skills, and maintain an occupational routine.

There is a balance to be achieved between stress and boredom. Will doing a paid job cause too much stress, and result in the person becoming unwell? Sometimes a voluntary job is the best option for someone, as it provides a daily routine but does not cause too much stress, and is more likely to allow for occasional 'days off'.

How will looking for paid work affect any benefits?

This is another important consideration. It is a complex area and everyone's benefit entitlement is different and needs to be checked out before starting work to ensure people will be better off in work, although this will normally be the case. Having a job is usually a source of self-esteem for an individual, but the monetary implications should at least be considered.

It could be that someone's well-being is sustained by their receipt of state Benefits, and a full-time job would have negligible effect on their self-esteem, and might jeopardise their lifestyle.

Part-time work is sometimes a way to give someone sufficient structure, whilst avoiding loss of important Benefit money.

For example, "Therapeutic Earnings" means someone can earn up to £60.50 (approximately), without benefits such as Incapacity Benefit, ESA, SDA, DLA being affected, if

the work is for less than 16 hours a week, and:

- if it helps to, "improve or prevent or delay deterioration in the disease or bodily or mental disablement which causes your incapacity for work".
- However, if someone is on Income Support, this will affect Therapeutic Earnings. Therapeutic Earnings may also affect Council Tax Benefit and Housing Benefit.

For more advice about this or any other benefit contact the **Disability Benefits Helpline**
Tel: 0800 882200, or the DEA, or your local Citizens Advice Bureau who have welfare benefits officers. .

If the person is ready for paid work, then complete a “Skills Profile”, i.e. a listing of the qualifications, talents, strengths, skills and weaknesses s/he has got.

This process should involve the DEA information gathering from as many useful sources as practicable, as well as the self report of the individual with Asperger syndrome, for example:

- people who know the individual well, including parents
- possibly an Occupational Psychologist
- staff from school/ Further Education/ Higher Education
- Connexions/Careers staff

It is important, as early as practicable, to be thinking about what qualifications and skills the individual has which may be of use in the work place.

It is also important to be precise and honest about someone's strengths, as well as weaknesses.

Sometimes what a person enjoys should remain a hobby, not a vocation, for example someone with Asperger syndrome may enjoy child-care but in fact not be quite intuitive or responsible enough, to be a child care worker.

However, there will be times when someone's interest can be used in a work capacity. For example someone who loves taking electrical objects apart may find work in a small repairs shop.

Always select a type of work that is going to match your particular strengths and skills.

The most common jobs people with AS are placed in are:

Clerical/admin

Data entry

IT support

Jobs involving statistics

Cheque clearance

Computer programming

Warehouse work

Customer service

But each person needs to be considered individually.

Courtesy Russell Harding, Prospects, 1999

It is important to spend time finding out how the person sees their own skills, weaknesses and their ambitions. Carefully exploring their self-perceptions will highlight what is achievable and what is unrealistic.

Try to draw up a list of which sorts of jobs will suit the person's strengths and weaknesses. Often clerical jobs work well for people with Asperger syndrome, but also computers and engineering type jobs, some routine manual jobs etc. However, as more people with Asperger syndrome are diagnosed it is becoming clear they are employed in a wide range of settings.

This process of building up a skills profile should not be rushed, because the most important thing is to find work that suits the person's skills.

The DEA may refer people to an Occupational Psychologist for an assessment. This will give the

individual a better picture of where to look for work.

Once the skills profile is complete, start planning the next step – further training, employment or other path

Having found out what are the person's skills, strengths and talents, as well as weaknesses, it should then be possible to begin deciding on what sort of job is best to apply for.

Jobs that tend to work best:

--*Tasks involving numbers/statistics/facts*

--*Jobs that involve attention to detail*

--*Try to think about jobs where your work will be guided by systems, procedures and processes*

--*Look for work that is quite routine, well structured and fairly predictable*

--*Avoid jobs that require advanced people or interaction skills.*

Courtesy Russell Harding, Prospects, 1999

Sometimes this process of looking carefully at skills will have shown that the person has previously been searching in the wrong places for work.

This can make the person feel a bit unsure about trying a new tack, so it is important to develop their confidence.

If someone is a bit unsure about trying a new job then a work placement should be considered and viewed as a learning experience.

The person may need to visit the work or training placement before actually starting, to reduce the stress of making a change of environment. This can provide opportunity to ask questions and allay fears.

Sometimes until you see the person in the new context it is hard to imagine whether they will cope or not. It is better to 'go slow' and just visit with a planned outcome of 'visiting places where people do training'. This allows assessment to take place without setting anyone up to fail.

A few preliminary visits may enable a smooth transition to the training or work placement. If work placement is the next step, then a thorough pre-placement report needs to address exactly what skills the individual has, and what areas require work.

The placement should build on the vocational strengths of someone with Asperger syndrome. Bear in mind everyone is different but generally a job that has most of the following may be beneficial:

- entails attention to detail
- is fairly predictable, or repetitive,
- allows the person to work alone quite a bit,
- uses any ability in memory for facts,
- involves processes which can be explained and easily followed,
- does not involve lots of individual problem-solving and initiative (the exception may be for some very technically able people with Asperger syndrome)
- is not highly pressured 'deadline' environment,
- does not involve lots of complicated social contact, or supervising others

These should all be considered before placing a person with Asperger syndrome to give them a better chance of success.

There will be often need to be the same level of support in a placement as will be required if the person starts work in a permanent job.

It is essential that the training or work placement has sufficient understanding of Asperger syndrome. Do the staff, as well as the manager, understand Asperger syndrome and make necessary adjustments? What training has the company received and how up to date is this?

The technical aspects of the job should be detailed but also the social and communication skills to be developed should be part of any review during the placement. Setting small, and achievable targets as relevant to the individual's needs may be useful, for example:

present a small piece of work to a group of work colleagues
demonstrate ability on 3 occasions a day to ask colleagues for assistance
use bus to go home after work twice a week

An End of Placement Report should be detailed and give an indication of where the person's job future lies.

Another option, once the "skills profile" has been completed, is to consider whether further qualifications are an option to pursue. This may be necessary if someone has the skills but not the 'paper' qualification, or is under confident about an area of work.

How many hours are manageable?

It will be important to consider what hours are realistic and sustainable in the long term for people with Asperger syndrome. For example, there may need to be a job with a later start time for some people.

Because many people with Asperger syndrome find prolonged contact with people, combined with the self-organisation of a job, quite exhausting. Therefore, sometimes less than full-time work may be worth considering. Indeed the vast majority of people with a disability work less than full-time.

For people coming back to work, part-time work may be the best re-introduction, or for those who become stressed relatively easily. Issues of transport will also need to be considered, bus routes, train timetables.

What type of support is necessary in the workplace?

Many people with Asperger syndrome will require some adjustments made to the job, in order to make it sustainable in the long term.

This could include the use of an employment support worker through the Employment Service. This is currently via a scheme called Access To Work. Ask a DEA about this, and other ways to gain support in the job. There are various schemes currently – such as WORKSTEP, Job introduction scheme and New Deal for Disabled People.

One of the most important success factors in any placement is a person who is close at hand, and who understands Asperger syndrome.

Another success factor is staff who are patient and supportive.

It may be best from the outset to inform the employer, and as many staff as necessary, about Asperger syndrome and how it affects the individual. The individual may wish to inform colleagues him or herself, or ask a third party such as the DEA to explain their needs. This is a matter of personal choice but Prospects have found that honesty and openness with employers is the most successful policy.

For some jobs it may be more appropriate if the person who provides this support comes from outside the placement. Ideally the person would work with both the placement and the person with

Asperger syndrome. They would facilitate three-way meetings between the Placement Supervisor and the person to 'iron out' any difficulties on a regular basis. Ask the DEA about this before going for interview.

The person with Asperger syndrome needs to have access to the nominated support person. They need to know who they can seek advice from when the nominated person is not available.

The job should be specific and clear from the outset. Instructions from staff should be unambiguous. The person may benefit from a written detailed timetable of events during the day. If there are different supervisors for different aspects of the job write this down.

Feedback from the workplace should be honest about the standard of work and explicit advice about how to improve should be given.

Feedback on work performance and behaviour should be immediate, but given sensitively, and unobtrusively. The person should not be 'told off' or corrected in front of other employees.

The person should also know about the unwritten rules of the workplace and, if necessary, information about how to behave including use of humour, what to wear, what greetings are acceptable, topics of conversation, not to castigate colleagues who are late for work, where to sit for lunch, are they expected to eat in the canteen, or at their desks, how tidy should their desk be kept?

The individual should be included in social events but with awareness that he/she may decline some of these as they may be too stressful.

The workplace may need to provide a lot of written materials as well as verbal instruction. "Task Sheets" can be drawn up with the employer and the person with Asperger syndrome. These will detail all tasks undertaken in the job/placement. The sheet has step-by-step instructions on how to do each task.

It will be necessary to carry out an assessment of what the job entails and go through this with the person. For example does the job entail using a mobile phone, working in groups, orientating around a large building. All these are easy for most people but can be very stressful for people with Asperger syndrome.

If there are bits of any jobs that cause major difficulty for an individual and there is a fairly easy way around it the employer should pursue this. This is called making a "reasonable adjustment", and is the law (Disability Discrimination Act 1995).

Where someone has work from several sources and prioritising is necessary, the person can be helped to draw up a "work request" form. This can be used with colleagues so they make it clear what work they require, who asked for it, and give deadline times etc.

The exact on-going training needs of the person should be detailed, and an honest monitoring and reviewing system established. It is best if the placement progress is evaluated regularly, so any difficulties, for example in social behaviour, are quickly picked up and remedied.

Strategies for success - summary

1. Do not make assumptions – unless the person is told he/she may not know what to do especially with new tasks
2. Be precise and direct – this does not mean rude, but it does mean be exact in what the person is told to do. The employer may need to check the person has actually understood an instruction.
3. Be careful to use language that won't be misinterpreted – people with Asperger syndrome can sometimes confuse joking for serious intent
4. Show respect – the person needs to be treated as an adult, not spoken down to. Although people with Asperger syndrome have a particular way of learning they have average or higher intelligence

5. Use visual methods to communicate tasks/ information – write down instructions, use flowcharts/organisation charts etc to make understanding easier
6. Have clear expectations of work– employers need to make reasonable adjustments but also they should expect good quality work. Employers must be clear about what they need done, and by when and what the person should do if they need help etc.
7. Have clear expectations of social behaviour – people with Asperger syndrome may not be the most socially skilled but they should have any social conventions in the workplace fully explained as necessary e.g. appropriate length of time for breaks.
8. Regular meetings with line manager will keep misunderstandings to a minimum and iron out any potential difficulties

Further Information

National Autistic Society Booklet 'The Undiscovered Workforce- Looking For A Job'

Supported Employment

Many Asperger's Syndrome students leaving education can often feel rather 'insular' within their learning environment, thus becoming largely oblivious to the outside world. This can make the transition to the world of work difficult.

However, recent government initiatives may be of help in reducing the anxiety a person with Asperger's Syndrome may face during such a transition.

Work Choice

The Work Choice programme has replaced the Workstep programme, Work Preparation programmes and the Job Introduction Scheme as part of the government's Welfare to Work initiative. Contracts have been awarded by the Department of Work and pensions (DWP) for organisations to provide the required services. Work Choice aims to provide support and guidance for applicants with any disability who are aged 16 – 65 years in finding and holding down a job.

For a person with Asperger's Syndrome, support can be provided to help with:-

- Developing social skills required to both obtain employment and communicate effectively as an employee
- A route to personal development and independence
- A careful matching of your skills with an employer's needs
- Practical and on going support for you and your employer

This support can take many forms depending on the needs of individuals, and development may take place with informal sessions of socialising in different environments on a casual basis with a support worker.

As far as hands-on employment is concerned, Work Choice will assist in:-

- job searching
- submitting application forms
- attending interviews
- negotiating with Employers
- help with sorting out welfare benefits and tax credits
- on going support as you start work and learn the job
- workplace support to boost your skills and ensure you feel part of the team

Additionally, when in employment, support can be provided to an employee in their workplace. For those with little employment experience, Work Choice can provide training for both clients and employers.

If you are interested in Work Choice, you can have an informal chat with the contacts for your local authority listed in the table below, or contact the Disability Employment Advisor (DEA) from Jobcentre Plus – these are based in local Jobcentres. For more information on the programme or visit <http://www.direct.gov.uk/en/Employment/Jobseekers/>

Hopefully, Work Choice can help a lot of people with Asperger's Syndrome avoid the anxiety experienced by others who have had to make such a difficult transition without much help.

The DEA should refer you to the Shaw Trust or to Remploy who provide the first level of Work Choice support service in Greater Manchester.

The Shaw Trust may forward your need to a local support provider in conjunction with the local authority. This may be an organisation in the voluntary sector or not for profit agencies who specialise in supported employment.

Contact details for Shaw Trust and Remploy are as follows:-

Remploy

42-44 Fountain Street
 Manchester M2 2AX
 Tel 0300 456 8028
 Email: Manchester.branch@remploy.co.uk

Shaw Trust –

<p>Bolton and Bury</p> <p>Shaw Trust 4th Floor Suite 4B Acresfield House Crompton Place Shopping Centre Exchange Street Bolton BL1 1DF Tel: 01204 537960</p>	<p>Manchester Stockport and Tameside</p> <p>Shaw Trust 414 Broadstone House Broadstone Road Stockport SK5 7DL Tel: 0161 953 4457</p>
<p>Oldham</p> <p>Shaw Trust 1st Floor Aksa House 2 Media Square Phoenix Street Oldham OL1 1AN Tel: 0161 925 3890</p>	<p>Rochdale</p> <p>Tel: 017894 799303</p>

The contacts for the Greater Manchester authorities are in the following table.

<p>Bolton</p> <p>Bolton STEPS Victoria Hall Knowsley Street Bolton BL1 1AS Tel: 01204 397976 Contact: Ruth Haigh www.boltonsteps.org.uk</p>	<p>Bury</p> <p>Bury EST 24 Ribchester Drive Bury BL9 9JT Tel: 0161 761 4662 www.buryest.org.uk email: enquiries@buryest.org.uk</p>
<p>Manchester</p> <p>Jobsteps Manchester Piccadilly House 49 Piccadilly Manchester M1 2AP Tel: 0161 212 1720 Contact: Sean Lewer, Programme Manager Email; jobstepsinfo@autismplus.co.uk www.autismplus.org</p>	<p>Manchester</p> <p>Breakthrough UK Manchester Employment Support Team B.E.V.C. Aked Close Ardwick Manchester M12 4AN Tel: 0161 273 5412 E-mail: empman@breakthrough-uk.co.uk</p>

<p>Manchester</p> <p>Pure Innovations Ltd Sanderling Building Bird Hall Lane Cheadle Heath Stockport SK3 0RF Tel: 0161 474 5900 www.pureinnovations.co.uk</p>	<p>Oldham</p> <p>Remploy 19-25 Union Street Oldham OL1 1HA Tel: 0300 456 8046</p> <p>The Wellbeing Service Rock Street Resource Centre Rock Street Oldham OL1 3HJ Tel: 0161 770 8500 email: socs.tie@oldham.gov.uk</p>
<p>Rochdale</p> <p>Rochdale Employment Development Service (REDS) Unit F6 The Gatehouse Ground Floor Fieldhouse Road Rochdale OL12 0AA Tel: 01706 922799</p> <p>Remploy 1st Floor Octagon House 25-27 Yorkshire Street Rochdale OL16 5DD Tel: 0300 456 8063</p>	<p>Stockport</p> <p>Pure Innovations Ltd Sanderling Building Bird Hall Lane Cheadle Heath Stockport SK3 0RF Tel: 0161 474 5900 www.pureinnovations.co.uk</p> <p>Jobsteps Floor 1 Victoria House Wellington Street Stockport SK1 3AD Tel: 0161 429 7755 www.jobsteps.org</p>
<p>Salford</p> <p>Skills And Work Supported Employment Service Cromwell Road Salford M6 6SB Tel: 0161 909 6503 Email: ses@salford.gov.uk</p>	<p>Tameside</p> <p>Routes To Work Frederick House Dunkirk Lane Hyde SK14 4QD Tel: 0161 342 5200 www.tameside.gov.uk/routestowork</p>
<p>Trafford</p> <p>United Response Consultants 1st floor Statham House Talbot Road Old Trafford Manchester M32 0FP Tel: 0161 873 7479 Email: trafford.employment@unitedresponse.org.uk Contact; Sarah Farmer</p>	<p>Wigan</p> <p>Wigan Supported Employment Department Of Adult Services Ince Green Lane Ince Wigan WN3 4QX Tel: 01942 828439 Email: supempt@wigan.gov.uk</p>

Whether or not to tell an employer about having Asperger syndrome

PROS:

It gives you a better chance of getting the correct support and understanding, from an employer.

It gives you a better chance of getting the correct support and understanding, from a Disability Employment Adviser (DEA). Enquire at your local Jobcentre and ask for an appointment to see one. DEAs are specialist Employment Advisers who can access special help for people with disabilities to get into work.

It allows the individual a better chance of being placed in an appropriate job.

It gives you recourse to the law (Disability Discrimination Act 1995, s. 6(6)). If someone has told an employer he or she has Asperger syndrome it means the employer must make "reasonable adjustment" during recruitment, interviewing, training, promotion and dismissal. If an employer with over 15 employees treats a disabled person less favourably than anyone else, for a reason connected to their disability, unless there is a good reason they are breaking the law.

It can relieve the sense of 'covering up' and stress of people 'not knowing'. This in turn may reduce stress, and improve social communication.

CONS:

Some employers may be put off by the disclosure of diagnosis, due to lack of understanding and find a way to avoid interviewing or appointing the individual.

It is hard for many people with Asperger syndrome to tell others about the syndrome because they meet blank faces, and are often given unhelpful responses. People report that they do not wish to be "singled" out, or be seen as 'different'.

Employment – Important telephone numbers and contacts

British Association For Supported Employment (BASE)

The British Association for Supported Employment is the national trade association representing agencies involved in securing employment for people with disabilities. Their website contains an up to date list of supported employment agencies in the area.

www.afse.org.uk

Remploy Limited

Stonecourt
Siskin Drive
Coventry
CV3 4FJ
Tel: 0800 1387656

Remploy is an employment support service available to those in receipt of ESA, Incapacity or a related benefit. If you ring the national number provided above they will put you in touch with your local service.

If someone is 13-19yrs and wishing to try out work-based training contact their local Connexions office for details.

There are a number of bigger employers who are members of the **Employers Forum On Disability (EFD)** 0207 403 3020. This means that they work together to ensure their workforces have a good representation of employees - disabled and non-disabled. The EFD has an up-to-date list of employers the person with Asperger syndrome may wish to approach for work.

An up to date alphabetical list of the Forum members can be found on the website www.employers-forum.co.uk

Other Sources of Information & Advice

The Disability Discrimination Act 1995 gives people with Asperger syndrome more rights under the law than previously. To find out more contact the **Disability Rights Commission Helpline** Tel: 08457 622 633.

Another useful number is the **Association for Supported Employment (AfSE)** 0772 935 6264. www.afse.org.uk Maybe especially useful for people who have struggled to find work and would like some advice about getting supported type of employment.

The National Autistic Society produce an Information sheet 'Help with Getting and Keeping A Job'

The DWP publish a leaflet called 'Make It Work – A Guide to Specialist Services for Disabled People' (DS2JP)

SKILL (the National Bureau for Students with Disabilities) provides information on jobs, training, disability issues, advice and guidance to students and employers. Their information service is open Monday to Thursday 1.30pm - 4.30pm. Tel: 0800 328 5050 Textphone: 0800 068 2422 Email: info@skill.org.uk

Skill produce free online information leaflets including:

- Help for disabled jobseekers from Jobcentre Plus;
- Training, Careers and Work for Disabled People;
- Looking for work: disclosing disability;
- Disability Discrimination Act 1995;
- Making a complaint;
- Get that Job - an internet publication for disabled jobseekers

Useful priced publications available from Skill's online bookshop include (all priced at £2.50). The complete set of the series is also available for £21.00. Reference copies of these publications are available in the Careers Resource Centre:

- Into Architecture - for those considering a career in architecture and related areas. Includes profiles written by people with disabilities;
- Into Art - discusses access for students with disabilities to art courses, and contains profiles of disabled students and artists;
- Into Law - This is for those who are considering a career in Law. It contains a section on useful contacts and profiles written by disabled people;
- Into Science and Engineering - This publication discusses access for students with disabilities to science and engineering courses, and contains profiles of disabled people who have studied science and engineering;
- Into Volunteering - A guide for disabled people interested in volunteering. It contains profiles of disabled volunteers;

PROSPECTS. Prospects is the National Autistic Society employment and training service for people with an autism spectrum disorder (ASD) who wish to work. Its aim is that people with an ASD should have the same training and employment opportunities as non-disabled people. It also work with employers to help with the recruitment, training and retention of staff with an ASD. It also offers employment advice and guidance including:

Work Choice
Access To Work (support for people in work)
Student Support
General Employment Related Queries (n.b not benefit advice)

Tel: 020 7704 7450 [email: prospects@nas.org.uk](mailto:prospects@nas.org.uk)

www.auties.org is a site for all people on the Autistic Spectrum who are ready to dare reach out to occupation and employment, open the doors to the community and market their abilities directly to the public and for those interested in supporting these pioneers.

Some notes on Asperger syndrome for employers

Asperger syndrome is a condition that affects approximately 1 in 300 people.

Asperger syndrome describes people who have autism but have average or higher intelligence. It causes difficulties in relating intuitively to other people.

It is defined by the “triad of impairments”.

The triad refers to difficulties in the areas of social interaction, social communication and social imagination.

- Social communication can include difficulty with knowing what to say to other people, with understanding what they are saying, and with non-verbal communication.
- Social interaction can include difficulty knowing what to do when with other people, and understanding social ‘rules’.
- Social imagination can include finding it hard to imagine how others think and feel, and not understanding the consequences of one’s actions.

The National Autistic Society has found that people with Asperger syndrome can make excellent employees in many workforces. The most important requirements are an understanding of the condition, and some forward planning.

Positive attributes in the workplace

Every person with Asperger syndrome is different, but these are some of the more common attributes employees display:

- Conscientiousness
- Punctuality
- Get on with the task, less social chit-chat
- Honesty
- Directness

- Reliability on routine tasks
- Interesting hobbies
- Areas of expertise
- Less concern with 'office politics'!
- More tolerant of 'unexciting', predictable work

Hints for employers

Some of these comments are aimed more towards line managers, others are general hints for all staff colleagues.

Again, remember every person is different, some of these guidelines will be of more use than others depending on the individual. The best advice is get to know the individual a bit, then see if any of these tips apply.

Anything merely implied will probably not be understood by the person with Asperger syndrome. Be clear in your language.

1. Gradual introduction to the work situation, with support
2. Clear specific job tasks that are made clear in written form to the employee. State exactly what you want the person to do.
3. Written diagrammatic or pictorial instructions of job tasks. Checklists and timetables for work.
4. A structured work pattern that enables the employee as far as possible to complete one task before moving on to the next.
5. Immediate clear and open feedback about the standard of work done.
6. Put instructions in writing, as appropriate.
7. Clear line management and an informed supervisor or mentor, who can be available to give rapid advice.
8. Don't assume the person will know what you want them to do, check understanding.
9. Don't shout instructions across the room. Speak to the person and ensure you have their attention first.
10. Initial close supervision, to check the person understands the task.
11. Be aware that asking for help may be difficult for the person, you may need to 'teach' them to do this.
12. Explicit rules of behaviour and advice about unwritten rules of the workplace. It is important that people are told if they do or say something which is inappropriate in the workplace.
13. Don't promise something which you cannot deliver, or change agreed plans without fully explaining the reasons for the change.
14. Guidelines for colleagues about how they can meet the individual needs in the workplace.
15. Contingency plans for dealing with unbearable stress e.g. a place to go for refuge, and contact with someone who will give support.

16. It will take some time to understand the person. Asperger syndrome is quite a complex condition.
17. The person with Asperger syndrome may not seem very socially skilled, this is their condition, or disability. It is not their attempt to be difficult, rude or appear superior! The person will not have the innate ability to develop working relationships, they have to work hard to establish these.
18. The person may require a bit of time on their own as social contact may be quite exhausting. Respect this need, it is not about being anti-social, it is just a need for many people with Asperger syndrome.
19. Include the person in breaks, and lunchtimes. This may seem to contradict the previous advice. It is about balance. Offer to include the person, but also be aware they may need to have time apart. The person may find 'social' time quite difficult to use without feeling a bit stressed. This is precisely because this time involves your social skills.
20. Do not patronise, or talk down to the person.
21. Try not to 'overload' the person by giving too much information at once.
22. Give clear feedback, be honest, but constructive and positive
23. People can really benefit if colleagues are able to be open about any 'social slip ups' they may have made. This should be done discreetly in a clear and calm manner (preferably at the time or soon after the event) saying what was inappropriate, and what they could do instead. It may be better for one or two colleagues to give feedback and provide social information. For example, the person may choose a couple of people they get on better with, to give them advice. Discuss with line manager in a tactful way first.
24. Consistency is vital. Avoid different people giving different advice.
25. Be aware that people with Asperger syndrome may be more sensitive to certain environments. For example, smoky rooms, open windows, central heating, noises from outside, and so reasonable adjustment should be made for difficulties of this sort.
26. Do not rely on humour to establish a rapport. People with Asperger syndrome do have humour but this may be different to yours! Once you know the person how much and what type of humour the person enjoys will be apparent.
27. Don't assume if someone is doing something socially uncommon that they are being rude, offensive, or odd...more likely they are not aware of their behaviour.
28. Point out socially inappropriate behaviour, in a sensitive, and clear way if that is your role, if it isn't then tactfully discuss with the person's line manager.
29. Be aware of AS....Asperger syndrome....AS....Anxiety and Stress
30. Uncertainty, and lack of clarity can cause enormous anxiety for many people with Asperger Syndrome
31. If someone with Asperger syndrome is struggling in the workplace get assistance from the National Autistic Society, don't wait until things start to go seriously wrong.

Key message

- **People with Asperger syndrome do want to do a good job.**

Further Information

Advice Lines

- National Autistic Society Information Centre for professionals advice 0207 903 3599
- National Autistic Society Prospects employment consultancy 020 7704 7450

Booklet

There is a booklet for employers produced by The National Autistic Society (Prospects) – **The undiscovered Workforce - Looking for staff?** . It gives an excellent overview for employers of the skills and benefits to their workforce of employing someone with Asperger syndrome

Books

- **Employing people with Asperger syndrome: a practical guide**

Author: Martha Fausset, based on the experience of the Prospects Employment Team. Published by National Autistic Society

A helpful and practical book that covers recruitment, selection, getting started, successful management, support and further information. Aimed at employers, this book will also be helpful to people with Asperger syndrome, their families and those who work with them. Based on the experience and knowledge of people who really know about employing people with Asperger syndrome: the NAS Prospects Employment Consultancy Team. Contact the team on Tel: 0207 704 7450.

- **Asperger's On the Job**

Author : R.Simone. (Future Horizons)

Must have advice for people with Asperger's or High Functioning Autism and their employers.

The author has interviewed over 50 people with Asperger Syndrome to describe their experiences with work and employment.

Housing

Residential Care

If someone with Asperger syndrome requires support 24 hours a day then one common option to pursue is residential care (see next section). However, this is not the only option and people with high support needs can be supported in small group homes – that is two or three individuals who all require continuous support/supervision – with a support team or in a supported living situation.

Supported Living

Most people with Asperger syndrome do not require 24 hour support, they can usually manage with a fairly low level of targeted support which is built around each individual's needs.

If the person has a social worker talk to him or her about what options are available.

If someone does not have a social worker a good first step is to get the person on the Housing Needs Register, (and also speaking to the Supporting People Officer for your area). This involves filling out a form. Phone the telephone number for the person's area and ask for the necessary forms.

Explain about Asperger syndrome and tell the Housing Needs Officer if the person will require any support if he or she lives alone. Be clear in your forms where the person can and cannot live and why. Also contact the person's social worker or care manager to ask them to support the housing application and enquire whether they are able to support or fast track the individual's request for housing. This is very important if the person needs support to enable them to live alone. The individual's support needs should be assessed by Social Services prior to the housing being allocated or acquired.

If the person will be able to live alone or with others either with support or without, there are various ways in which housing can be accessed, including buying a property either outright or through shared ownership schemes (these include specialist schemes for people on benefits. (Contact the Housing Corporation Head Office in London to find out who operates the Shared Ownership Scheme for People with Learning Disabilities), renting a property from a private, local authority or housing association landlords or through a voluntary sector organisation list of "preferred housing providers" for your area. In the Greater Manchester area the following Housing Associations have a particular interest in meeting the needs of those with disabilities:

Great Places Housing Group (includes Manchester Methodist Housing Association (MMHA) and Salford First.

Great Places have a number of housing sites in the Greater Manchester area.

Southern Gate
729 Princess Road
Manchester
M20 2LT
Tel: 0161 447 5000
Website: www.greatplaces.org.uk/Supported-Housing.asp

Irwell Valley Housing Association

Paragon House
48 Seymour Grove
Manchester M16 0LN
Tel: 0161 610 1000
Email: supported@irwellvalleyha.co.uk

Johnnie Johnson Housing

North West Office
90 Chester Road
Poynton
Cheshire
SK12 1HG
Tel: 0845 604 1027
Email: general.enquiries@jjhousing.co.uk

West Pennine Housing Association Limited

Regenda House
Enterprise Business Park
Northgate Close
Horwich
Bolton BL6 6PQ
Telephone: 0844 7360066

Creative Support Ltd

5th Floor
Dale House
35 Dale Street
Manchester
M1 2HF
Telephone: 0161 236 0829
email :enquiries@creativesupport.co.uk

Sanctuary Carr Gomm

Paragon House
48 Seymour Grove
Old Trafford
Manchester M16 0LN
Tel: 0161 877 8847

Progress Housing Group

Sumner House
21 King Street
Leyland
PR25 2LW
Tel: 01772 450600
www.progressgroup.org.uk

Association for Supported Living

c/o Advance Housing & Support Ltd
2 Witan Way
Witney
Oxon
OX28 6FH
Tel: 01993 772885
Email: info@advanceuk.org

Housing Options provide advice and Guidance and a number of factsheets on housing for people with disabilities.

Housing Options
Stanelaw House
Sutton Lane
Witney
Oxfordshire
OX29 5RY
Tele: 0845 4561497 E-mail: enquiries@housingoptions.org.uk

You can get a complete local list by phoning your Housing Department and asking for a list of “**preferred housing providers**” for your area.

National Autistic Society Directory of Services website www.autismdirectory.org.uk
 Contains a national list of housing associations who assist with housing needs of people with Asperger syndrome

Contact the **Supporting People** Officer for your area. Supporting People is a way of paying for support needs. This may be of use to some people with Asperger syndrome.

<p>Bolton Supporting People Team Bolton Council Le Mans Crescent Bolton BL1 1SA Tel: 01204 335313 Contact: Susan Chinn www.bolton.gov.uk/supportingpeople</p>	<p>Rochdale Supporting People Team Strategic Housing Service PO Box 423 Municipal Offices Smith Street Rochdale OL16 1WB Tel: 01706 926718</p>
<p>Bury Supporting People Team 1st Floor, Craig House Bank Street Bury BL9 6BU Tel: 0161 253 6265 Email: supporting.people@bury.gov.uk</p>	<p>Salford Supporting People Team Salford City Council Civic Centre Swinton Salford, M27 5BY Tel: 0161 922 8755 Email: supporting.people@salford.gov.uk</p>
<p>Manchester Supporting People Team PO Box 356 Town Hall Extension Manchester M60 2AF Tel: 0161 234 3605 www.supportingpeople@manchester.gov.uk</p>	<p>Stockport Supporting People Team 6th Floor Regal House Duke Street Stockport SK1 3DA Tel: 0161 474 4317 Email: supporting.people@stockport.gov.uk</p>
<p>Oldham Supporting People Team Meadowbank Tweedale Way Oldham OI9 8EH Tel: 0161 770 8115 Contact: Pauline Rutherford</p>	<p>Tameside Supporting People Tameside MBC Wellington Road Ashton-under-Lyne OL6 6DL Tel: 0161 342 3267</p>
<p>Trafford Supporting People Team PO Box 14 Trafford Town Hall Talbot Road Stretford M32 OYZ Tel: 0161 912 4070 Email: supporting.people@trafford.gov.uk</p>	<p>Wigan Supporting People Team Civic Centre Millgate Wigan WN1 1AZ Tel : 01942 827181 Email: supportingpeople@wigan.gov.uk</p>

Supporting People – Government Program

The Supporting People programme offers vulnerable people the opportunity to improve their quality of life by providing a stable environment which enables greater independence. It will deliver high quality and strategically planned housing-related services which are cost effective and reliable, and complement existing care services. The planning and development of services will be needs led. Supporting People is a working partnership of local government. More details on the Supporting People website. www.communities.gov.uk/housing

Shared Ownership Schemes

It may be possible for some people with Asperger Syndrome to make use of one of the specialist Shared Ownership schemes for people with learning disabilities and/or mental health problems.

Shared ownership involves part buying a property with a housing provider – such as a Housing Association. The good thing about this option is that the person buying the property only pays the 'interest' on the value of the loan/ mortgage. They also pay rent for the part of the property owned by the Housing Association. These costs may be eligible to be paid by Housing Benefit if it can be proved that the new property "meets the individual's needs more effectively" and the person meets the eligibility criteria.

The individual's equity in the property grows as the house goes up in value and if they want to move they are able to do so.

Residential Care

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 person 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:

Wirral Autistic Society

2 Grisedale Road
Old Hall Estate
Bromborough
Wirral CH62 3QA
Tel: 0151-334-7510
e-mail: admin@wirral.autistic.org

Autism Initiatives and Adult Residential Services

7 Chesterfield Road
Great Crosby
Liverpool , L23 9XL.
Tel: 0151 330 9500

Cygnetside Stockport

1 Brownsville Road
Heaton Moor
Stockport SK4 4PE
Tel: 0161 443 4060

Pendleton Care Ltd

384/386 Lower Broughton Road

Salford M7 2HH

Telephone number: 0161 792 6046

Contact: John T Russell email: pendletoncare@tiscali.co.uk

The National Autistic Society Adult Services

Manchester Service

Anglo House

Chapel Road

Northenden, Manchester, M22 4JN

Tel: 0161 945 0040

Email: Manchester@nas.org.uk

Contact: Steve Owen, Area Manager

The National Autistic Society (NAS) Adult Service in Manchester provides a range of support services to people who are 16yrs or over who have been diagnosed as having an Autism spectrum disorder (i.e. Autism or Asperger Syndrome).

The following services are currently available-

- A residential service
- A day resource
- A home support service.

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

Respite/ short breaks

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

If someone requires short breaks away from their parental or other home, this may be arranged by the Social Services depending on the person's level of need.

If Social Services cannot provide a short break, they may still be able to provide some money to access social clubs or days out or access to a befriender scheme etc. Contact the NAS Family Services Project or Aspirations (a social and leisure group for those with Asperger syndrome) to find out what is available in your area.

NAS Family Services Development Project – Tel: 0161 998 4667
Aspirations – 0161 866 8485

Benefits and Welfare Rights Advice

Some people with Asperger syndrome may be entitled to Benefits from the Department of Work and Pensions.

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

It is important to get the best advice when applying for benefits. See section below on 'Getting Benefits Advice'.

A Summary of Relevant Benefits

The following information on relevant benefits is up to date at the time of writing.

Jobseeker's allowance

If someone is out of work, but actively seeking employment, he or she may apply for Jobseeker's Allowance (JSA).

Employment Support Allowance (ESA) and Incapacity Benefit

If someone is unable to work and their GP has agreed, the person may apply for Employment Support Allowance (ESA) which is replacing Incapacity Benefit and Income Support on incapacity grounds as an alternative to Jobseekers Allowance. This is a long term benefit for people who are may not be able to work for many months if not years.

ESA will offer personalised support and financial help, so that each claimant can do appropriate work, if able to. It also gives access to a specially trained personal adviser and a wide range of further services including employment, training and condition management support, to help manage and cope with illness or disability at work. The aim is to look at what people 'can do' rather than what they 'can't do'.

ESA involves a new medical assessment called the Work Capability Assessment. This assesses what the person can do, rather than what they cannot, and identifies the health-related support that might be needed. Most people claiming ESA will be expected to take steps to prepare for work, including attending work focused interviews with their personal adviser.

Under ESA, if an illness or disability that severely affects one's ability to work, they will get increased financial support and will not be expected to prepare for a return to work. **See NAS Information Sheet: Employment and Support Allowance and Work Capability Assessment for more details.**

Jobcentre Plus publishes an information leaflet called 'Employment and Support Allowance - help if you are ill or disabled'. Also, you can download the leaflet from the Jobcentre Plus website.

It includes information on eligibility, rates and how to claim.

Income Support

If someone is out of work or unable to work and has income below a certain level set by the government, they may be currently entitled to Income Support. This is a means tested benefit and can include additional amounts of money called 'premiums', you may be entitled to if you receive DLA. Telephone 0800 88 22 00 for details.

Carers Allowance

Is paid to carers (aged 16 and over) who spend at least 35 hours a week looking after the person with Asperger syndrome. If the carer also works their earnings must not exceed a government set

figure. The person with Asperger syndrome must be receiving the Care component of Disability Living Allowance at the middle or high rate.

Statutory Sick Pay (SSP)

If someone is out of work due to short-term illness (less than 28 weeks) he or she may be entitled to Statutory Sick Pay (SSP). If the person cannot go back to work after 28 weeks he or she may then be entitled to ESA.

Disability Living Allowance (DLA)

It is possible for some people with Asperger syndrome to qualify for Disability Living Allowance (DLA). To get a claim pack for DLA (DLA1) phone 0800 882200 (Benefit Enquiry Line).

IMPORTANT: Do not complete the DLA forms until you have spoken to the National Autistic Society Autism Helpline 0808 800 4104

The legal context for Disability Living Allowance (DLA) is the Social Security Contributions and Benefits Act 1992.

There are 2 components to DLA. The Care component and the Mobility component. The Care component relates to the care and support that someone needs with daily living. More details below.

Working Tax Credits

Those who are in low paid employment working more than 16 hours a week are entitled to claim working tax credits. For people who are also entitled to DLA, the working tax credit is topped up further with an extra disability related element. **For further information, and a claims pack call the Tax Credits helpline on 0800 300 3900.**

Getting 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.**

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

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 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) Advice Line 01706 923513</p>
<p>Bury Bury Independent Advice Centre 12 Tithebarn Street Bury BL9 0JR Tel: 0161 797 4326</p>	<p>Salford Welfare Rights Service 100 Chorley Road Swinton Salford M27 6PB Welfare Rights Advice Line 0800 3457375 (Monday to Friday 10-12 noon)</p>
<p>Manchester Manchester Advice PO Box 536 Town Hall Extension Manchester M60 2AF Tel: 0161 234 5678 (Monday to Friday 10-4) man-advice@manchester.gov.uk</p>	<p>Stockport Welfare Rights Benefits Advice Line Tel: 0161 474 3093 Monday to Friday 9am-1pm Email welfare.rights@stockport.gov.uk</p>
<p>Oldham Welfare Rights Service Telephone 0161 770 6655 (Monday to Friday 9-12 noon)</p>	<p>Tameside 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>
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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)”

Or

No.6 “you cannot prepare a cooked main meal for yourself if you have the ingredients” [this test is only for people of 16+ years].

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.

The cooking test is to check whether a person over 16 can cook a main meal for themselves. If they cannot cook a main meal the person should be entitled to the lower rate of the Care component of DLA.

The test is whether your son or daughter can prepare a proper meal (not a snack, frozen or convenience food in a microwave). Those who decide on whether you pass the test have in mind a fairly traditional concept of a main meal which involves cutting up vegetables, using hot pans and boiling water, and using a traditional cooker.

Even if it is possible for someone to physically cook a main meal the concept of "reasonableness" is relevant to this. In other words if you could cook a meal but it would be unreasonable for you to do so then you may pass the test. Examples might be, if cooking a meal takes you hours to complete, or leaves you very tired, or would be a safety risk.

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. 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)
- not able to cook a hot meal for self – for example, unable to use a cooker - set the right temperature (health risk if cooking meat), plan a meal – buy ingredients, tell if food is cooked properly, unable to sequence a meal with correct cooking times, so the food is ready at right times, dexterity difficulties of hot pans, or using knives (gets easily distracted, prone to accident), lack of concentration makes cooking test unfeasible

- 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 cleaning the fridge to make it hygienic
- leaving the freezer door open, oven on
- does not clean house
- not opening post for important bills, or letters from benefits agency!
- not clean sheets and bedding, this can be a health risk, for example, causing skin conditions
- not changing light bulbs, for example, causing staircase landing to be unlit and therefore unsafe
- not noticing or reporting gas leaks
- having only cold water, forgetting to put the heating on;
- not reporting illness
- incorrectly fixing plugs
- 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)
- cannot do laundry

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.

Whatever rate you apply for phone for a copy of **The National Autistic Society Factsheet – Claiming DLA** and also ask about **Keeping a DLA Diary**, Autism Helpline 0808 800 4104.

This may be of help when writing the claim form. Do get good advice from someone who understands both Asperger Syndrome and the DLA benefit before sending off the claim.

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.

The NAS have factsheets covering:

- Disability Living Allowance. What Is It?
- Benefits: Challenging benefits decisions
- Benefits Appeals
- Disability Living Allowance appeals
- DLA - guidance for adults with ASD completing the form
- Disability Living Allowance. How to claim.
- Keeping a DLA diary
- Employment and Support Allowance and Work Capability Assessment

For further information about Benefits

Disability Benefits Enquiry Line

Tel: 0800 882200

Disability Alliance

Their website includes information on social security benefits and tax credits for disabled people:

Tel: 0207 247 8763 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

Useful Resources and Websites

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/Diol1/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

If the person with Asperger syndrome is receiving Disability Living Allowance (DLA) at the Middle or Higher Care rate and they have support from a parent or carer for more than 35 hours a week they may qualify for **Carer's Allowance**.

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 to be in need of support. With Direct Payments either an adult with Asperger Syndrome or the parent carer of a person 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.

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 Managers in each Greater Manchester local authority:

<p>Bolton Jubilee Centre Darley Street Halliwell Bolton BL1 3DX Tel: 01204 337075 Contact: Anne Webster, Direct Payments Manager</p>	<p>Rochdale Direct Payments Scheme Aked Close Ardwick Manchester M12 4AN Tel: 01706 758327 (Tuesdays-Fridays) or 0161 273 1823 (Mondays) Email: mail@direct-payment-manchester.org.uk Contact: Vincent Beaman</p>
<p>Bury C/o Independent Living (Direct Payments) Scheme Carisbrooke Resource Centre Wenlock Way West Gorton Manchester M12 5LF Tel: 0161 253 7366 or 0161 253 6576 Email: dpscheme@globalnet.co.uk</p>	<p>Salford 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 Independent Living (Direct Payments) Scheme Carisbrooke Resource Centre Wenlock Way, West Gorton Manchester, M12 5LF Tel: 0161 273 1823 Email: dpscheme@manchester.gov.uk</p>	<p>Stockport Direct Payments Development Manager Regal House Duke Street Stockport SK1 3DA Tel: 0161 477 3700</p>
<p>Oldham Self Directed Support Team Highbarn Resource Centre 2nd Floor Highbarn Street ROYTON OL2 6DW Tel: 0161 770 1173</p>	<p>Tameside Direct Payments Support Centre Loxley House 85 Birch Lane Dukinfield SK16 5AU Tel: 0161 368 5832</p>

<p>Trafford</p> <p>Direct Payments Team Broome House 54-56 Seymour Grove Old Trafford Manchester M16 0LN</p> <p>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</p> <p>Tel: 01942 404510 Email: direct.payments@wigan.gov.uk</p>
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Helping People Manage Direct Payments

Embrace Wigan and Leigh offer an advocacy service called Compass. This is planned to help people to make best use of their Direct Payments with a quality checking and support planning service. Telephone No. 01942 513053

Further Information

NAS Helpline Information Sheets

- **Direct Payments – A Brief Guide for Adults and Young people who have an ASD**
- **Self Directed Support**
- **Self Directed Support - Myths Busted**

Managing Money

This provides a basic overview of how to manage your finances. It is aimed at people with Asperger Syndrome and may also be useful for their friends and family.

What do we mean by 'Managing Money'?

By managing money, we mean keeping your money safe, making sure you have at least enough to pay for your needs, and staying in control of any payments you have to make. This information sheet explains a few ways of doing this, including using a bank account, budgeting, paying bills, saving, borrowing money and taking out insurance. These are the basic activities that most people in the UK carry out to keep in control of their finances.

The National Autistic Society (NAS) in conjunction with the Consumer Financial Education Body (CFEB) have produced a guide 'Managing Money' to help people on the autism spectrum with looking after their money. More details on how to obtain a free copy are below.

Why manage your money?

For many people, managing money is not very interesting. But it is important. Here's why:

- It helps you avoid stressful situations, such as getting into debt, or running out of money so you can't pay for things.
- It helps keep your money safe – for example, in a bank account.
- It helps you get the most out of your money – for example, by making sure you do not pay more than you need to for services, by shopping around.
- It can help you do things more simply – for example, setting up automatic payments of bills rather than having to remember to pay them each time.
- It enables you to plan ahead – for example, booking a holiday several months in advance, when you know you will have sufficient money to pay for it.
- It can be satisfying to feel in control of this part of your life, and perhaps to watch your savings grow. Saving even small amounts of money as regularly as you can will help give you the security of knowing that you have some you can use if an emergency arises.

Budgeting

A budget is a plan detailing how you spend, based on how much money you have coming in and how much you need to pay out.

The first step in managing your money is to work out your budget and keep to it. This means looking at your income (the money you are receiving) and your outgoings (the money you are spending), and making sure you have more coming in than going out. This will tell you whether you have enough to pay for everything. If you add up what you spend and discover that your outgoings are higher than your income, you need to find ways to reduce what you are spending.

Budgeting will help you:

- keep track of money going out
- avoid spending money that you don't have
- deal with debt by planning repayments in a way that you can manage
- work out how much (if any) money you can save
- decide whether you can afford to buy something that you'd like.

Using a bank account

A bank is a safe place for you to keep your money until you want to spend it.

If your financial affairs are very simple, you could choose to receive payments and pay bills exclusively in cash. There are some advantages of doing this – for example, you can see easily how much you have available to spend. But most people do keep their money in a bank (or building society, or a post office account), for the following reasons:

- Keeping money in a bank is safer than carrying large amounts of cash or keeping it at your home, as it could become lost or stolen.
- Some companies, such as internet shops, will not accept cash.
- If you keep money in the bank you might earn interest, so the amount you have will grow.
- By using a bank account you can make and receive payments conveniently and sometimes more cheaply than with cash. For example, many companies charge less if customers pay their bills by direct debit (see p10).
- If you have a cashpoint card, then depending on the facility that your account offers you can access your money easily from many cash machines around the UK and (with some cards) around the world..
- If you need to spend more money than you have at present, a bank might give you an overdraft – a temporary loan (please see our Information sheet *Borrowing money and managing debt*).
- Having a bank account can help you to develop a credit record – information about your past financial activity. If in the future you want to borrow money from a bank, credit card company or mortgage lender, they will need to look at your credit history to see if you are reliable.

Paying bills

If you receive regular bills from a particular supplier of services (for example, the telephone company which provides your mobile phone service, or from your provider of gas and electricity), think about the most convenient way for you to pay:

- **If you prefer receiving bills** (usually four times a year), you can go to the post office and pay in cash, or with a cheque, or you might prefer to pay by phone or online.
- **If you prefer making monthly payments** you can set up a standing order or direct debit through your bank. This will enable you to pay a smaller amount each month rather than a lump sum four times a year. Standing orders are for a fixed amount, so that you will know how much you should expect to pay, while with direct debit the amount may change each month (see page 10). You may, however, receive statements showing what you have paid on a quarterly basis.

Whichever way you choose to pay, it is important that you budget for your bills so that you do not have a surprise when you open your bill to find that you owe a lot of money but have nothing in the bank. When you set up a standing order or direct debit, consider arranging for it to come out of your account a few days after your regular income normally arrives in your account, so you know you will have enough money to pay.

If you cannot pay a bill, the worst thing you can do is to stay quiet about it. As soon as you realise there is a problem, phone the company and explain your situation. They may be able to help reduce your payments. If you want advice before you talk to the company, contact one of the debt advice helplines in the useful contacts list.

Saving

Saving means putting money aside over time so that it builds up to an amount that you can use as you choose. There are typically three main reasons you might want to do this:

- **To pay over time for something specific** – for example, to help you pay for something expensive, such as home improvements, going away to college, or retirement.
- **To build up a fund for treats** – If you put aside money each week or month, you will have a sum of money that you can use occasionally to buy something such as new clothes or a night out.

- **To protect yourself in the future** – This will help make sure that you will have enough money to pay for essentials if things go wrong – for example, if you are unable to work, or if you need emergency repairs for household equipment.

Tip: Before you start saving for particular circumstances – for example, if you were unable to work due to sickness – check to see whether you would be covered by insurance or state benefits (contact the Benefits Enquiry Line – please see the useful contacts list).

You might want to save by putting money aside as and when you can. If you decide to start saving regularly, try to decide on a regular amount and stick to it. Doing the budgeting activity will help you decide how much you can afford. Choose a bank account that will give you high levels of interest. This means that as well as your savings, you will earn a little extra from the bank.

Borrowing and debt

If you don't have any savings and feel that you may need to pay for something expensive, you may be thinking about borrowing some money. Before you make a decision to borrow, ask yourself the questions below, because you will also need to commit yourself to repaying this money.

Do you need to borrow at all?

Borrowing money can lead to serious problems with debt if your income drops or you lose your job etc ... So before you borrow, see if there are other options. For example:

- Could you wait, and save up some money first? This is often the best option.
- Do you really want or need the item in question?
- Could you sell something that you don't need?
- Are you receiving all the benefits and tax credits you are entitled to?
- If you are receiving benefits, are you eligible for a loan or grant from the Social Fund? (Contact the NAS Welfare Rights Service to make an appointment for advice about benefits by phoning the Autism Helpline on 0808 800 4104. Alternatively, contact the Benefits Enquiry Line (see the useful contacts list).

Some ways of borrowing are cheaper than others, so if you do need to borrow money make sure you do your research. Find out the APR – the annual percentage rate – which will tell you how much interest (extra money) you will be charged for the loan (the amount you borrow) – and make sure you can afford the repayments. Please use the budgeting information on pp 4-7 to help you work this out. Find out about any other charges and what will happen if you miss a repayment or want to repay the money early. Generally it is better to pay back a loan as soon as possible to avoid paying too much interest. However, make sure that you avoid being charged for early repayment.

Insurance

Insurance is a way of protecting you against unforeseen circumstances – for example:

- a driving accident
- a flood in your home
- your television breaking
- being burgled
- needing expensive dental treatment
- losing your suitcase on holiday.

How does insurance work?

An insurance company will agree to cover your costs against a particular set of circumstances – for example, home insurance covers you against a range of damage that might happen to your home. You buy this by paying what is called an insurance premium in one annual payment or in monthly instalments. If something goes wrong (for example, your home is flooded), the insurance company

will then pay out as long as the circumstances meet all its conditions. However, insurance can be very expensive, and it has many exclusions and conditions. For example, if you were flooded because you forgot to turn off a tap, then the insurance might be invalid, and the insurance company would not have to pay you anything. Always check all the exclusions and conditions listed before taking out any insurance to make sure that there is nothing in your circumstances which might make it invalid.

Some types of insurance are compulsory. For example, it is illegal to drive a car without being insured. If you buy a house or flat, mortgage lenders normally insist that your property is protected by buildings insurance. However, most forms of insurance are optional. You need to decide what level of risk you are prepared to take, and whether the payments you would make on an insurance policy are likely to be worthwhile. Instead of taking out insurance, you might decide that you can use your savings, rely on benefits or borrow money instead.

Tip: Before you agree to take out any insurance policy, take time to think about it, and consider discussing it with someone you can trust. Never agree to anything if you feel rushed or under pressure. Think about whether you really need or want it.

Money and your rights

Managing your money is a complicated area in which many – though not all – people with Asperger Syndrome feel they need some extra support. Under the *Disability Discrimination Act 1995*, banks and other finance companies must not discriminate against anyone on the grounds of disability or treat disabled people less favourably than anyone else because of their disability. They must also make ‘reasonable adjustments’ for disabled people. This means that they have a duty to change any practice, policy or procedure that makes it difficult for people to use their services – for example, by providing bills or statements in more accessible formats, or by agreeing to meet the person face to face rather than writing letters to them.

Some people with an ASD have problems using online facilities and PIN numbers. In this case, the bank is required to offer an alternative way of paying. Others have problems signing their name consistently. In this case, there are a range of alternative options, such as writing some other form of mark, providing ID or nominating someone else to sign instead.

If you have any problem using financial services, talk to your bank. If you are still not satisfied, contact the Equality and Human Rights Commission helpline.

Managing someone else’s finances

If someone does not have the mental capacity to make decisions about their finances, or if they would prefer someone else to make these decisions, they will need someone else to manage their financial affairs and make transactions on their behalf – for example, writing cheques or withdrawing money from their savings account. The person acting on someone else’s behalf could be:

- an attorney appointed under an Enduring Power of Attorney or Lasting Power of Attorney
- a deputy appointed by the Court of Protection
- someone acting under a court order
- an appointee of the Department of Work and Pensions.

To find out more see **NAS information sheet *Lasting powers of attorney*, available from the Autism Helpline on 0808 800 4104.**

In some cases banks have refused to allow anyone other than the account holder to use their PIN or access internet banking on the person’s behalf. However, the Equality and Human Rights Commission has helped overturn these decisions. If you need help in arguing your case, contact them (see contacts list under legal matters).

Useful contacts

Consumer Credit Counselling Service

Tel: 0800 138 1111

Website: www.cccs.co.uk

Provides free confidential service to help achieve realistic solutions to debt problems, avoid bankruptcy and learn to handle money.

Consumer Direct

Tel: 08454 040506 (English)

Email: Via the website (see below)

Website: www.consumerdirect.gov.uk

Provides consumers with clear, practical, impartial advice to help sort out any problems and disagreements they may be having with suppliers of goods or services.

Credit Action

Tel: 0800 138 1111

Email: office@creditation.org.uk

Website: www.creditaction.org.uk

National money education charity providing information about debt and saving.

Financial Ombudsman Service

Tel: 0845 080 1800

Email: complaint.info@financial-ombudsman.org.uk

Website: www.financialombudsman.org.uk

Independent organisation that deals with disputes between consumers and businesses providing financial services.

Independent Financial Advisers Promotion Ltd

Tel: 0800 085 3250

Email: contact@ifpa.org.uk

Website: www.unbiased.co.uk

The industry body responsible for promoting independent financial advice in the UK. Provides details of independent financial advisers in your local area.

Mailing Preference Service (MPS)

Tel: 0845 703 4599

Email: mps@dma.org.uk

Website: www.mpsonline.org.uk

A central service where you can announce your wish not to receive unsolicited mail

National Debtline

Tel: 0808 808 4000

Email via the website (see below)

Website: www.nationaldebtline.co.uk

Free confidential advice and support for people with debt problems.

Telephone Preference Service

Tel: 0845 070 0707

Email: tps@dma.org.uk

Website: www.tpsonline.org.uk

A central opt-out register where you can register your wish not to receive unsolicited sales and marketing telephone calls.

Further Information

Managing Money Guide

The National Autistic Society (NAS) in conjunction with the Consumer Financial Education Body (CFEB) have produced a guide 'Managing Money' to help people on the autism spectrum with looking after their money.

Managing Money is available both as a book and as an on line reference and interactive learning website. It covers everything to do with money from opening bank accounts to benefits, savings and tax, to paying bills and getting value for money when shopping.

To get a free copy go to <http://www.autism.org.uk/pubs>. Scroll down to 'Workbooks, Course Materials and Software' and click, and then click on: 'Managing Money'. It will ask to register your mailing details.

The on line version website is www.managingmoney.org.uk. The site is interactive and has a learning facility which you can take at your own pace. It includes a virtual cash machine, video clips, quizzes and downloads to help you to manage your money.

To find our more see NAS Information Sheet Managing Money, available from the Autism Helpline on 0808 800 4104.

Relationships and Social Skills

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.

There is wide variation in how people with Asperger syndrome decide to pursue relationships. For example, some people find intimate relationships too complex and prefer to have friendships, whilst others have sexual relationships and some marry.

Given the complications to social understanding that Asperger syndrome brings it is vital that people are given proper education and support to enjoy and make sense of their adult relationships.

There are several good books on relationships – see section on **Partners**, and also some good resources on learning to develop social skills:

Socialeyes - Exploring the social world with people on the autism spectrum

Socialeyes is a new and innovative approach to facilitating social skills and social understanding with people on the autism spectrum. This learning resource has been developed with people with autism and Asperger syndrome, alongside leading professionals in the field.(DVD and CD-ROM)

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, was originally aimed at Primary school children but may well be good to adapt for use with some adults who have Asperger syndrome

Autism – social skills approach for children and adolescents by Maureen Aarons and Tessa Gittens, Speechmark publishers, Bicester, Oxfordshire, may also be useful for some.

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. It costs about £66.25

If someone wishes to develop their social skills, it is likely to be best to join a group that is led by someone who has experience and understanding of working with people who have Asperger syndrome. Sometimes there are course at local colleges on social confidence or social skills but do check these will be relevant for the person with Asperger syndrome.

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

Travel

Concessionary Travel Permit

People with Asperger Syndrome may qualify for a National Concessionary Travel Pass issued 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 train journeys which begin and end within the Greater Manchester train boundary. See http://www.tfgm.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 or at the low fare if you have your permit with you.**

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 permit 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'

Qualification Criteria

Concessionary Travel Pass

You may be able to get **free** travel between 9.30am and midnight Monday to Friday, and all day at weekends and bank holidays, if you:

- Have what Transport for Greater Manchester describe as a 'significant impairment of social functioning. ' **This include people on the Autism Spectrum, including those with Asperger Syndrome.**
- Have been or would be refused a driving licence for medical reasons.

Free Travel At All Times

In some circumstances you may qualify for free travel at all times, and not just after 09:30.

If you 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.

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

Travel Training

ASGMA (Autistic Society Greater Manchester Area) have developed a travel training guide to help and encourage people with Asperger Syndrome who wish to use public transport to get around.

The guide includes a training guide to help those who work with people with Asperger Syndrome to help them with planning to travel independently.

Copies are available from

ASGMA
1114 Chester Road
Stretford
Manchester M32 0HL
Telephone 0161 866 8483

Partners

We now know that there is a genetic element to autism in some families and it is recognised that many people with Asperger syndrome have relationships and children.

There are some sources of support for people who are in relationships with someone who has Asperger syndrome.

Books

Maxine Aston's books:

The Other Half of Asperger syndrome, National Autistic Society,

Aspergers in Love, Jessica Kingsley Publishers (JKP)

The Asperger Couple's Workbook (JKP)

provide excellent practical coverage of relationships affected by Asperger syndrome.

An Asperger Marriage (JKP) Chris and Gisela Slater-Walker is another book on this subject giving a personal account.

Alone Together: Making an Asperger Marriage Work by Katrin Bentley (JKP)

The Asperger Love Guide by Genevieve Edmonds and Dean Worton is a practical guide for adults with ASD to seeking, establishing and maintaining successful relationships. Paul Chapman Publishing.

Asperger syndrome and Long Term Relationships Ashley Stanford (JKP)

Living and Loving with Asperger syndrome (JKP) by Patrick, Estelle and Jared McCabe – this book gives family perspectives on Asperger syndrome, including issues of parenting (including how a teenager can deal with having a father with Asperger syndrome)

Love, Sex and Long Term Relationships; What People with Asperger Syndrome Really Want by Sarah Hendrickx (JKP)

Asperger Syndrome – A Love Story by Sarah Hendrickx and Keith Newton

Asperger Meets Girl: Happy Endings for Asperger Boys by Jonathan Griffiths

Loving Mr. Spock titles by Barbara Jacobs

Autistics' Guide to Dating: A Book by Autistics, for Autistics and Those Who Love Them or Who Are in Love with Them by Emilia Murry Ramey, Jody John Ramey

Asperger Counselling for Couples by Barrie Thompson

Websites

www.jkp.com - Jessica Kingsley publishers 020 7833 2307

www.onelist.com/subscribe/aut-partners is a mailing list for partners of people with Asperger syndrome.

www.onelist.com/subscribe/AutisticSpectrum-couples is a mailing list for couples where both have autistic conditions

www.faaas.org/information.html is another site for families affected by members with Asperger syndrome.

Families and Siblings

Having a person with an autism spectrum disorder in the family can have an impact on all its members, not just the parents.

Siblings

Problems for younger people who have a sibling with autism can include teasing from other children, lack of privacy, disruption of home life and a feeling of resentment that the whole focus of the family is always on the autistic member.

Older siblings may worry as to 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.

Siblings Clubs

Oldham Young Carers (Sibling Support)

Contact; Geraldine O'Keefe Tel: 0161 627 1749
Woodfield Centre
Netherfield Close
Off Manchester Road
Oldham OL8 4ET

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.

81 Ribble Road
Platt Bridge
Wigan WN2 5EG
Contact Tel No : 01942 513053

Further Information

Everybody Is Different by Fiona Bleach . Published by NAS. This is designed to answers questions from younger brothers and sisters and contains suggestions for making family life more comfortable for everyone concerned.

Why does Chris do that? by Tony Attwood. Published by NAS.

Aimed at adult siblings, Tony Attwood offers a better understanding to siblings of the unique difficulties associated with autism and Asperger syndrome. This is a really practical book, full of useful advice.

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).

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

Clubs, groups and social interests for people 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

YASP (Young Adult Advice & Support Project) is part of the Manchester MIND (formerly HARP project) in Manchester aimed at helping young people (15-25) experiencing stress.:

832 Stockport Road
Levenshulme
Manchester M19 3AW
Telephone: 0161 221 3054

Email: info.yasp@harp-project.org website: www.harp-project.org

- **Cafe and Computer Access:**

YASP run a drop in café (address above – on 192 bus route). Just turn up if you at a loose end, want to make friends, learn new skills or just have a coffee and a healthy meal. Computer use is available for free. Food is available at very reasonable prices

- **Advice**

YASP offers an advice service to help you sort out any difficulties with housing, benefits and debts.

- **Counselling**

If you think talking to someone might help you, you can refer yourself to the YASP counsellor. You can arrange a session just to see whether you think counselling might help. If you think it might, further sessions can then be arranged. .

- **Get Involved**

YASP works in partnership with service users to promote skills, improve service delivery and to guide future development. There is a service user group, Raising Our Voice, which meets monthly with the HARP Service User Involvement Coordinator. On top of that there are opportunities for people to volunteer in the kitchen to increase their skills and confidence.

Zac's Bar (Farnworth)

Zac's is an alcohol-free youth bar based in a former pub in Farnworth town centre. As well as providing a facility for local teenagers, we provide after-school clubs and arrange special activities for children of all ages in our community, including those with special needs

Checkers Club Nights

Checkers is a disco for adults with learning disabilities, physical disabilities and mental health, their friends and families. It is held every month at the Cresta Court Hotel, Altrincham. It aims to provide a nightclub atmosphere where people of all abilities can enjoy themselves in a safe environment and free from discrimination. Contact Raquel on 07504124176 or e-mail checkersdisco@yahoo.co.uk if you require any further information or wish to book tickets.

Local ASD Social 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: Lisa Stapleton

Email: Lisa.Stapleton@oldham.gov.uk

Oldham 16+ Service for People with Autism and Aspergers

The 16+ service is designed for young people and adults who are on the Autism spectrum, with or without a formal diagnosis.

It gives the opportunity to take part in structured activities and meet other people. It includes use of an internet café, a computer room, a quiet room and an arts and crafts room.

Chadderton Court

Middleton Road

Chadderton

Oldham OL9 9LB

Tel: 0161 770 8777

Contact: Lisa Stapleton

Email: Lisa.Stapleton@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

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

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

Autism and Asperger Union -Wigan

Social Group for Adults with Autism or Asperger Syndrome in Wigan and other nearby areas.
Contact David O'Keefe Tel: 07972 390189
Email: autismunion@yahoo.co.uk

ASPECS

An informal group for lesbian, gay, bisexual and transgender (LGBT) people with autism or Asperger syndrome. The group plans to have a get-together once a month at a venue in Manchester Gay Village, but it could expand into other activities. As well as LGBT people who have autism spectrum disorders, members of the gay community who have friends/relatives with autism, or who are involved in the care/support of people with autism, will also be welcome to attend.
Contact: 07896 474243 (text messages preferred)
Email; dan@alacroart.com

RADAR Disabled Toilet Key Scheme

RADAR, the disability network charity, run 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

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.

Therapies and Special Interest Activities

There are a number of practitioners who work with individuals with Asperger syndrome to help to encourage and develop their talents and interests.

- **Occupational Therapy**

Local authorities. All local authorities offer some assessment and support in helping people to be functionally able in independent living, sensory integration and social skills. Contact your local Social Services team or go through your GP.

AS Insight Occupational Therapy Services. A small, local independent occupational therapy service based in Rochdale is able to assist young adults (16 - 30 years old) who have a diagnosis of Asperger syndrome in the area.

It carries out holistic client-centred assessments on clients to determine their occupational needs, set goals in partnership with clients to address their occupational needs and then provide client-centred occupation-focused graded intervention programmes both in clients' homes and in the community to address their individual needs. E.g. preparing a healthy meal on a budget, addressed through a graded series of occupation-focused (activity-based) interventions and regular reviews. Reports can be produced and home visits made. Sessions can be supervisor if required.

Contact: Ryan Cowan, State Registered Occupational Therapist
Tel: 01706 340563 Email: info@asinsightot.co.uk

- **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

- **Aromatherapy Massage and Bowen Technique**

Marie Hurst is a complementary therapist who has worked with a number of clients with Autism spectrum disorders. Marie works mainly from home in Blackrod.

Contact; 01942 833898. email bodyharmonyuk@yahoo.co.uk

- **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 mult-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

- **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 coordinated 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@cyclring.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

- **Skiing Lessons**

The Chill Factor runs an adaptive Ski School delivering lessons 7 days a week provided by Disability Snowsport UK. The lessons are adapted for individuals with any disability, including Asperger Syndrome. The lessons can be one to one or in a group and are taught by a fully qualified instructor.

Fees cover slope fees, skis and boots, adaptive equipment and instructor time. Provide your own warm waterproof clothing.

For further information contact
Chill Factor
Trafford Quays Leisure Centre
Trafford Way

Manchester M41 7JA
Telephone 0161 749 2222
Website : www.chillfactore.com

- **Riding Therapy**

People with Asperger Syndrome are welcome to benefit from donkey riding therapy at the Elisabeth Svendsen Trust riding centre in Debdale Park, Manchester. Family days 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

Magazines of interest to people with Asperger syndrome

Asperger United is a magazine written by and for people with Asperger syndrome. It is currently free to people with Asperger syndrome. Contact John Joyce for details 0207 833 2299.

Progress is a magazine aimed at helping young people through all aspects of transition planning. More details at www.progressmagazine.co.uk

Thinking Different is a magazine written locally by and for people with Asperger Syndrome. It is published by Aspirations and is available on line at www.thinking-different.com

Websites of interest to people with Asperger syndrome

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. Including:

Social Network sites

- **www.aspiesforfreedom.com**
Campaign for the rights of people with AS
- **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
- **www.inlv.demon.nl/irc.asperger**
This IRC chat channel is only open to individuals on the autistic spectrum. A safe place to communicate and meet others.
- **WrongPlanet.net**
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.
- **Second Life**

Second Life (SL) is an advanced social networking site that is very different to other forms of social networking, such as Facebook or MySpace.

In Second Life you enter a web-based 3D virtual world in which users can become 'residents' and interact with each other using virtual animated versions of themselves (known as 'avatars').

Second Life is only available to over-18s, but a junior version called Teen Second Life has now been launched for people aged between 13-18.

Second Life has received a great deal of coverage in the media, particularly surrounding its appeal for people with Asperger syndrome. For people who experience difficulties with social communication, or who are non-verbal, Second Life provides an opportunity to express yourself and engage with other people socially in a way that could be very challenging in the real world. As such, it may provide opportunities for learning and developing social skills, and is being used by some therapists for that purpose.

Online penpal registries

- **[The Square Circle](http://www.squarecircles.net) www.squarecircles.net**

An email pen-pal list for people with Asperger syndrome and similar autism spectrum disorders

Email discussion lists, forums and blogs

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.

- **[Aspies Dugout](#)**
A place for adults with an autism spectrum disorder to talk.

- **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 (www.autism-hub.co.uk)**

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.

- **Independent Living on the Autistic Spectrum**

A series of support lists/forums for individuals 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.

- **University Students With Autism and Asperger syndrome Mailing List (AUTUNIV-L)**

Email list for students in higher education (full-time or part-time) with autism or Asperger syndrome.

- **www.thegraycenter.org/index.cfm** A US based discussion site

Sites by young people with Asperger syndrome

www.aspie.com is the website of Liane Holliday Willey containing a number of articles on Asperger syndrome.

www.aspergernauts.co.uk

www.aspievillage.org.uk

www.assupportgrouponline.co.uk ASSGO is the website of Emma Thomson.

uk.dir.groups.yahoo.com/group/AspiesUniteUK This group is for AS/Autism sufferers aged 18 and over whom live in the UK. Group offers support chat and social events. Please come and join this friendly group

Befriending and Buddying

Befrienders (or Buddies) are people who voluntarily help those 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 or adult out to help with their special interest
- go along with a teenager to a youth club or aerobics class
- meet up with an adult for lunch or to go and see a film
- 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)
(Supports Befriending for Youngsters up to 18)

Rochdale Befriending Scheme

The Befriending Scheme 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 Scheme

The Buddying Scheme 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

E-Befriending

The National Autistic Society offer an 'e-befriending' service.

If you or a member of your family has Asperger Syndrome, and regularly uses a computer, an e-befriender can provide regular online support and social contact.

NAS e-befrienders exchange emails with you or another member of your family, chatting about things that interest or concern you and offering a friendly, supportive link with the wider community.

The NAS take the time to match you with an e-befriender you have something in common with.

Apply for an e-befriender

Applying for an e-befriender is easy. Email e-befriending@nas.org.uk and the NAS will send you an application form by post or email.

Please include your full name and address if you want to receive the application form by post. We can guide you through your application over the phone if you need us to.

The NAS e-befriending service is web-based, so you will need to be able to use the internet to make contact with your e-befriender. You can live anywhere in the UK as all correspondence is online.

Once you have completed an application form, the NAS will send you a link to the e-befriending site where you can register your details, choosing your own username and password.

Novels about autism for young people

Blue Bottle Mystery (2000), Of Mice And Aliens (2001) and Haze (2003)

all by Kathy Hoopmann , Jessica Kingsley Publications.

Truth or Dare by Celia Rees (2000), Macmillan.

Wishing on the Midnight Star by Nancy Ogaz (2004), Jessica Kingsley Publications.

The Curious Incident of the Dog in the Night-Time by Mark Haddon. (2003) David Fickling Books

Al Capone Does My Shirts and **Al Capone Shines My Shoes** by Gennifer Choldenko

Eye Contact by Cammie McGovern

Legal Matters

Sound legal advice is a must for anyone entering into a legal contract such as house purchase or, setting up a trust fund or any other type of agreement for a person with Asperger syndrome, or if the person comes into contact with the criminal law.

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

People with Autistic Spectrum Disorders do sometimes come into contact with the criminal justice system, both as victims and witnesses and unfortunately in some cases as offenders.

Their difficulty with communication can on occasion lead to the police and others misconstruing their behaviour as being obstructive. People with autism are often unaware of the effect their behaviour will have on others and on the consequences of their actions because they do not instinctively link cause and effect. Occasionally, some can display extreme behaviour in certain circumstances resulting from their high anxiety levels, and this requires appropriate support and understanding.

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 somebody 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.

However, it is very important that if your loved one does get involved with criminal matters, those you are dealing with are aware he or she has an autistic condition. Carrying and showing an 'Autism Alert' or 'This Young Person has Autism/Asperger Syndrome' card may help (see details below). In particular, ensure solicitors are fully aware and can brief magistrates and judges at the start of any court hearing that the witness or defendant before them has an autistic condition.

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

Scott-Moncrieff Harbour and Sinclair Lucy Scott-Moncrieff 0207 485 5588 may be able to assist with people who are detained under the Mental Health Act 1983 or in prison. Email: scomo@scomo.com

A father and criminal justice professional in USA, **Dennis Debbaudt** has put together advice relating to preventing situations occurring involving the Police. www.policeandautism.cjb.net

The Mental Capacity Act 2005

This Act Of Parliament which came into force in 2007, establishes a single and comprehensive legal framework for decision making for people over 16 who may not be able to make their own decisions about things affecting their life. It covers personal welfare issues, property and general affairs of the individual.

The underlying principle of the Act is that individuals must be allowed to make their own decisions on matters affecting their lives, where possible.

When required and appropriate, help should be given to assist individuals make decisions, and where they cannot make their own decision through lack of mental capacity, others who make decisions on their behalf have a legal duty to do so in the person's '**best interest**'.

The measure of whether an individual has mental capacity to make decisions is 'decision specific' and may depend on the magnitude and complexity of what they are trying to do. For example, a person may be able to give instructions on a college course, but not be able to manage their financial affairs. The Act includes suggested proformas of items to consider when making particular decisions.

The Court of Protection, a division of the High Court, will have the legal powers relating to the Act, and where necessary appoint official 'deputies' to help people make decisions.

Irwin Mitchell Solicitors in Manchester have legal representatives specialising in the Mental Capacity Act 2005 email: www.irwinmitchell.com

Further Information: A Guide To The Mental Capacity Act 2005 J. Lumb Published by NAS. Downloadable from NAS website. www.autism.org.uk

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

Slater Heelis Collier Littler provide a wide range of legal help, including advice on wills, probates and trusts. Karen Chadderton is a volunteer with the NAS tribunal support scheme and her awareness of autism can assist clients seeking advice in other areas.

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.

If you feel that you or people 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.
- A carer or parent can also be discriminated against for the above situations if the discrimination is due to their 'association' with somebody with a disability.

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. Email: info@equalityhumanrights.com
Website: www.equalityhumanrights.com

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

Further Information

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

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.

National Youth Advocacy Service (NYAS) NYAS is a UK charity and socio-legal services. They offer information, advice, advocacy and legal representation to children and young people up to the age of 25yrs through a network of advocates throughout England & Wales. NYAS is also a community Legal Service. Freephone Tel: 0800 616101
Email: help@nyas.net

The Office of Public Guardian

Tel: 0845 330 2900

Email: customerservices@publicguardian.gsi.gov.uk

Website: www.publicguardian.gov.uk/

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.

Over 16s at Sixth Form and Other colleges are covered by Disability Discrimination Act outlined above.

Greater Manchester Police E Card

The GM Police E Card is an information card providing essential details of the cardholder in case they need help or need to assist emergency services. It is credit card sized and comes with a self seal laminating pouch.

The E Card should be completed to clearly show key information on the cardholder including;

- The cardholder's name and space for an optional photo
- Details of Next of Kin or a contact person and a contact number for them
- Any relevant medical Information
- Useful Information, such as what special help or consideration they may need

The E Card is a general card and is not specially designed for people with autism or asperger syndrome. It should be carried somewhere where it will be quickly seen.

For more information, or to obtain a card contact 0161 856 2206 or email diversity@gmp.police.uk

The National Autistic Society Information Card

The National Autistic Society have produced a card for people with Asperger Syndrome to carry with them in a wallet or purse.

The card is to show to people in authority who may not appreciate that the individual has a problem with communication skills. It requests such people help the person by being understanding and showing tolerance.

Copies are available from the NAS helpline 0808 800 4104.

Advocacy

The aim of advocacy is to speak and act on behalf of a person, including those with Asperger Syndrome, who sometimes cannot fully plead their cause themselves. The aim is to ensure the person's voice is fully heard and to secure the rights and services the person believes they are entitled to. The issue could be to do with:

- Money or benefits
- Relationships with family/carers
- Changes to or lack of support
- Making complaints about services
- Making a choice in where to live

Advocacy is often also used for education provision and in employment situations (e.g. help with job interviews). Advocacy assistance in these areas is listed in the relevant part of this document.

Advocacy can also be of great assistance to people with Asperger Syndrome in areas including social and health care.

In some cases advocacy can be funded by agencies and local authorities for individuals who need an advocacy service. Alternatively, or if funding is not available, advocacy services can be purchased by the person or their carers and families.

The following people and organisations offer advocacy services. Note that although they are listed by authority, they are not necessarily restricted to those who live in those authority areas.

<p>Bolton</p> <p>MHIST (Mental Health Independent Support Team) Deajon House 30 Chorley New Road Bolton BL1 4AP Tel: 01204 527200 Take people with ASD who also have a mental health problem e.g. anxiety, depression</p>	<p>Bury</p> <p>RED CENTRE Morley Street Bury BL9 9JQ Tel: 0161 797 0082 Contact: Karen Robinson</p>
<p>Manchester</p> <p>There are a number of advocacy organisations in the City Of Manchester. See table below</p>	<p>Oldham</p> <p>OPAL 6/7 Ascroft Court Peter Street Oldham OL1 1HP Tel: 0161 633 5544 Contact: Christine Gibbons Website: www.opal-advocacy.org.uk Email: admin@opal-advocacy.org.uk OLDHAM SOCIAL & HEALTH CARE ADVICE LINE Tel: 0161 839 0421 (1-4p.m) Run by Gaddum Centre – see under Manchester</p>
<p>Rochdale</p> <p>ROCHDALE CITIZEN ADVOCACY Spotland Community Centre 92/96 Spotland Road Rochdale OL12 6PJ Tel: 01706 659921 Contact: rochdale.ca@zen.co.uk</p> <p>LINKS (formerly HEYWOOD & MIDDLETON ADVOCACY) 73A Dale Street Milnrow Rochdale OL16 3NJ Tel: 01706 647300 Contact: Liz Halpern</p>	<p>Salford</p> <p>MIND IN SALFORD The Angel 1 St Philips Place Salford M3 6FA Tel: 0161 839 3030</p> <p>SALFORD CHILDREN'S RIGHTS SERVICE 73 Sycamore Court Paddington Close Salford M6 5FR Contacts; Heather McMurdo, Bev Costello Tel: 0161 743 0744 Email; childrensrights@spurgeons.north.com</p> <p>SALFORD BEING HEARD Old Town hall Church Street Eccles Salford M30 0ET Tel: 0161 789 7878</p>

<p>Stockport</p> <p>STOCKPORT TOTAL ADVOCACY TRUST LTD 23 High Street Stockport SK1 1EG Tel: 0161 480 8979 Email: stockportadvocacy@tiscali.co.uk Website: www.stockportadvocacy.org.uk Contact: Mary Edwards or Mandy Gyaamie who works with young people.</p> <p>STOCKPORT MIND Dove House 65 Union Street Stockport SK1 3NP Tel: 0161 480 7393 Contacts; Kim Lingard, Jayne Shaw, Suzanne Sephton</p> <p>STOCKPORT FLAG Graylaw House 39 Chestergate Stockport SK1 1LZ Tel: 0161 474 1042 Email: info@stockportflag.org.uk Advice on health and social care services</p>	<p>Trafford</p> <p>TRAFFORD ADVOCACY Future Visions 1st Floor Statham House Talbot Road Old Trafford Manchester M32 0FP Tel: 0754 2296120 Email: futurevisions@ymail.com Advocacy organisation for individuals with learning disabilities.</p> <p>TRAFFORD CVS ADVOCACY Cadman House Wharf Road Sale M33 2AF Tel: 0161 976 2448 Email; enquiries@traffordcv.org.uk</p> <p>TRAFFORD MENTAL HEALTH ADVOCACY SERVICE Park House 73 Northenden Road Sale M33 2DG Tel: 0161 969 8686 Email: tmhas@vcatrafford.org</p> <p>TRAFFORD CARER'S CENTRE Advocacy for Carers 226 Seymour Grove Stretford M16 ODU Tel: 0161 861 0101 Provides advocacy for CARERS ONLY of people with mental health problems, learning disabilities.</p>
<p>Tameside</p> <p>TAMESIDE SPEAK Festival Hall Peel Street Denton M34 3JX Tel: 0161 320 8111 Contact: Imelda Watson and Jenny Lamidey</p> <p>PEOPLE FIRST TAMESIDE Suite 10, 3rd Floor St Michael's Court St Michael's Square Stamford Street Ashton-under-Lyne OL6 6XN Tel: 0161 308 3699</p>	<p>Wigan</p> <p>ADD A VOICE 53 Church Street Leigh WN7 1AY Tel: 01942 601563</p> <p>EMBRACE WIGAN AND LEIGH Platt Bridge Youth Zone 81 Ribble Road Platt Bridge Wigan WN2 5EG Tel: 01942 513053</p> <p>WIGAN AND LEIGH PEOPLE FIRST St Catherine's Vicarage Catherine Terrace Wigan WN1 3JW Tel: 01942 867888</p>

<p>Manchester</p> <p>MANCHESTER MENCAP</p> <p>Crossacres Resource Centre 1 Peel Hall Road Manchester M22 5DG Tel: 0161 437 9465 Contact: Kath McDermott</p> <p>MENCAP have now set up a Citizen Advocacy Service for people with learning difficulties</p>	<p>GADDUM CENTRE</p> <p>Gaddum House 6 Great Jackson Street Manchester M15 48X Tel: 0161 839 6069 Contact: Ashley Wood</p> <p>Very helpful staff. Are prepared to help individuals with letters to agencies i.e. SSD requesting assessment of care etc.</p> <p>Provides Community Care information and advice and if there is funding available can provide advocacy.</p>
<p>MANCHESTER CARERS' CENTRE</p> <p>Manchester Carers Centre London Scottish House 24 Mount Street Manchester M2 3NN Tel: 0161 819 2226 www.manchestercarersforum.org.uk</p> <p>Contact: Miriam McLeod-Iredale, Carers Support Information worker Only able to help a Carer with letter-writing to services/agencies.</p>	<p>MIND IN MANCHESTER</p> <p>Unit 25 The Progress Centre Charlton Place Ardwick Green Manchester M12 6HS Tel : 0161 272 8204 Website: mind-in-manchester.org.uk</p>
<p>SHELTER</p> <p>20 Swan Buildings Swan Street Manchester M4 5JW Tel: 834 4809</p> <p>Provides Advocacy re housing issues only.</p>	<p>TALBOT HOUSE SUPPORT CENTRE</p> <p>Monsall Street Harpurhey Manchester M40 8QF Tel: 203 4095 Contact: Bernie Wood Email: info@talbothouse.info Provides advocacy for parents of children and adults.</p>

NATIONAL YOUTH ADVOCACY SERVICE

The NYAS is a UK charity providing information on rights and socio-legal services. They offer information, advice, advocacy and legal representation to children and young people up to the age of 25yrs through a network of advocates throughout England & Wales. NYAS is also a community Legal Service.

Freephone Tel: 0800 616101
Website www.nyas.net Email: help@nyas.net

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

Parent Partnership Service – offers information, advice and support for parents and carers of children and young people with Special Educational Needs. Local contacts are in the table below. Mention that your son or daughter has Asperger Syndrome.

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.

Contact a Family North West Financial Advice For Families with children with disabilities
North West Helpline Tel: 0161 743 0700 www.cafamily.org.uk/northwest

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 Centre Westwood Street Moss Side Manchester M14 4 PH	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 486131

Useful national organisation telephone Numbers and websites

AFASIC (Association For All Speech Impaired Children) Helpline 08453 55 55 77/ 0207 490 9410. speech and language difficulties www.afasic.org.uk

ADHD Support Group Tel: 01380 726 710 www.adders.org.uk

ADDISS (ADHD information service) Tel: 0208 952 2800 www.addiss.co.uk

British Dyslexia Association Tel : 0845 2519002 www.bdadyslexia.org.uk

British Stammering Association Helpline 0845 603 2001 www.stammering.org.uk

Careers Helpline for Young People Tel:0800 100900 (from mobiles use callback facility)
www2.cxdirect.com/home

Carers UK Tel: 0808 80877777 www.carersuk.org

Citizens Advice Bureau Tel : 0870 126 4626 www.adviceguide.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 www.dls.org.uk

Disabled Living Tel: 0161 214 5959 www.disabledliving.co.uk

Dyslexia Action www.dyslexiaaction.org.uk
Wilmslow Centre is the nearest main branch Tel: 01625 530158.
There are also a smaller branches in Altrincham, Bolton, Didsbury and Worsley

Epilepsy Action Helpline Tel: 0808 800 50 50 www.epilepsy.org.uk

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 Tel: 020 3334 3734 www.justice.gov.uk

Hyperactive Children's Support Group Tel: 01243 539966 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 www.ican.org.uk

Mencap Learning Disability Helpline Tel: 0808 808 11 11 www.mencap.org.uk

MIND (National Association for Mental Health) information line 0845 766 0163 www.mind.org.uk

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 www.autism.org.uk

National Autistic Society Parent to Parent Helpline Tel: 0808 800 4106
a freephone line to enable parents to talk with another parent about their situation
www.p2ponline.org.uk

NHS Direct Tel: 0845 4647 www.nhsdirect.nhs.uk

National Society for Epilepsy Helpline Tel: 01494 601 400 www.epilepsysociety.org.uk

Outreach Advice Assistance Support and Information on Special Needs (OAASIS) Helpline
Tel: 0800 1973907 Information on courses, publications and literature www.oaasis.co.uk

Pathological Demand Avoidance Contact Group Tel: 0114 2589670 www.pdacontact.org.uk

Voice UK National Charity supporting vulnerable people who have experienced crime and abuse
www.voiceuk.org.uk

YMCA Training. Supported Transition into Employment Tel 01295 252082
email: info@ymcatraining.org.uk

Telephone numbers for education information and advice

National Autistic Society Education Rights Advice Line Tel: 0808 800 4102
www.autism.org.uk/advocacy

National Autistic Society Tribunal Support Scheme Tel: 0800 358 8668

Careers Helpline for Young People Tel:0800 100900 (from mobiles use callback facility)
www2.cxdirect.com/home

SKILL Information on Further Education and Higher Education www.skill.org.uk

SEN Legal Advice for Children, Cadney House Tel: 01284 723 952. www.senlegal.co.uk

Advisory Centre for Education (ACE) Advice line Tel: 0207 354 8321 www.ace-uk.org.uk

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 Panel for Special Education Advice (IPSEA) www.ipsea.org.uk
Tel : 0800 0184 016 (Helpline) 0845 602 9579 (Tribunal Helpline)

SEN Code of Practice DfES publications Tel: 0845 60 222 60

Parents For Inclusion Tel: 0800 652 3145 www.parentsforinclusion.org.uk

Network 81 A national network of parents working towards properly resourced inclusive education for children with special educational needs Tel : 0845 0774055 www.network81.org.uk

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 (not a helpline) www.transitioninfonet.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

Asperger syndrome: a practical guide for teachers,
Cumine, V. Leach L. & Stevenson, G. (1998) David Fulton publishers

Preparing for adulthood, Howlin, P. (2004) Autism - Routledge

Asperger syndrome and difficult moments, Smith Myles, B. & Southwick, J. (2005)
Autism Asperger Publishing Co. USA

What is Asperger syndrome and how will it affect me?
National Autistic Society Autism Helpline Tel: 0808 800 4104

How To Be Yourself In A World That's Different Yuko Yoshido (2006) Jessica Kingsley

A Self Determined Future With Asperger Syndrome by Vicky Bliss and Genevieve Edmonds
(2007) Jessica Kingsley

Can I Tell You About Asperger Syndrome – A Guide For Family And Friends Jude Welton
(2003) Jessica Kingsley

Asperger's and Girls by Tony Attwood, Teresa Bolick, Catherine Faherty, Lisa Iland, Temple Grandin, Jennifer McIlwee Myers, Ruth Snyder, Sheila Wagner, Mary Wrobel

Aspects of Asperger's: Success in the Teens and Twenties (Lucky Duck Books)
By Maude Brown, Alex Miller

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 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

Education Services for People with Autism (ESPA). Range of Further Education provision. Tel: 0191 516 5080 www.espa.org.uk

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.

Original Version
Andrew Powell
National Autistic Society © all rights reserved 2003
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Updated Greater Manchester Version
John Davies
National Autistic Society © all rights reserved 2007, 2008, 2009, 2010, 2011
Reg. Charity No. 269425