



# *A.S. INFORM*

An information resource for parents of teenagers and  
adults with Asperger syndrome

Based upon a document of the same name produced by Andrew  
Powell (Avon) in conjunction with the National Autistic Society.

# An information resource for parents of teenagers and adults with Asperger syndrome in Bury Metro

## 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.

## Acknowledgments

This document is based upon *A.S. INFORM – 2003*, a document produced by Andrew Powell with the support of the National Autistic Society and families, professionals and members of the Avon and Somerset Asperger Pub Group who offered their advice and information for the resource.

It has been modified and adapted to meet the needs of young people, their families, and other professionals working with people who have autistic spectrum disorders in Bury Metropolitan Authority.

## Updates

It is hoped that we will be able to update this booklet regularly and each copy will be marked with the date it was produced.

Please contact the Autism Services Development Team if you have new information which you think we should add, or out of date information we should remove.

Contacts: K. Sherrington Tel. 0161 253 6430 ([K.sherrington@bury.gov.uk](mailto:K.sherrington@bury.gov.uk))

## **Important numbers 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:

Communication Difficulties Team 0161 253 6430

Bury Autism Parents Support Group 0161 280 6791

National Autistic Society **Greater Manchester** 0161 998 4667 (mari.saeki@nas.org.uk)

National Autistic Society - **Parents and people with Asperger syndrome** helpline  
0870 600 8585

National Autistic Society - **Professionals** information centre 0207 9033 599

National Autistic Society - **Education Advice Line** (Advocacy service) 0207  
9033500

PARIS (Public Autism Resource and Information Service) available through

[www.nas.org.uk](http://www.nas.org.uk) or [www.info.autism.org.uk](http://www.info.autism.org.uk)

**Bury Metro Social Services** produce a booklet **Carers Guide** which contains useful contact details for a wide range of services. Copies available from The Carers Centre, 146 Hornby Street, Bury, BL9 5BB Tel. 0161 253 6903

## **Asperger syndrome is an autistic 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 references to people with Asperger syndrome in this resource use the male pronoun. This is for economy of style.

Although most people with Asperger syndrome are male, we do not know the exact male to female ratio, so it is important to remember many people with Asperger syndrome are female.

# **CONTENTS**

**How to use this resource**

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

**What if your child refuses to go to school?**

**Bullying**

**What if your child has difficulties with taking exams?**

**Planning for students who are leaving school and have a Statement of Special Educational Needs**

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

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

**Who to write to in social services for support for under 18s**

**Sample letter to write to social services for support for under 18s**

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

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

**Sample letter to write to social services for support for adults (18 years and over)**

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

**Carers Needs**

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

**Connexions - Advice, support, guidance and careers**  
**Important factors to consider before deciding on a**  
**College or University course**  
**Contact details for Further Education Colleges**  
**Specialist day and residential colleges for people with**  
**Asperger syndrome**  
**Higher education (University)**  
**Employment**  
**Housing**  
**Residential care**

**Daytime occupation**  
**Diagnosis**  
**Relationships and social skills**  
**Counselling**  
**Benefits**  
**Partners**  
**Clubs, groups and social interests for people with Asperger**  
**syndrome**  
**Magazines and websites for people with Asperger syndrome -**

**Parents and Carers support groups**  
**Legal issues, wills and trusts**  
**Who to contact**  
**Useful local telephone numbers**  
**Useful national organisation telephone numbers**  
**Telephone numbers for education information and advice**  
**Selected Booklist**  
**Asperger syndrome organisations**  
**National list of social groups for adults with Asperger**  
**syndrome**

## **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.

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 in-depth 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 for support.

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

## **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.

The key person to discuss options with is the Connexions Personal Adviser. There is one for each secondary school. Ask the headteacher for details.

## **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 school teacher, or school Special Educational Needs Coordinator (SENCO). Try to find out if there have been any changes at school to upset the person or if the school work 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.

Ask the school to contact the service for Pupils with Communication Difficulties (0161 253 6430)

For independent advice contact Parent Partnership: Tel. 0161 763 5001

The National Autistic Society also runs an **Education Advice Line** 0800 358 8667.

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.

Help and support for schools is available from the Communication Difficulties Team, an advisory service for pupils who have social and communication difficulties. Tel. 0161 253 6430/6416

**'Asperger syndrome and Difficult Moments'** by Brenda Smith Myles and Jack Southwick is a good book for help in managing difficult behaviour at school. It is in the NAS publications catalogue. Bury schools can get it from the SEN Resource library at Seedfield.

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 (SEN) then, even if the person is not attending school, they should still have Transition reviews.

## **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 0207 378 1446.

**ACE (Advisory Centre for Education)** have produced a booklet *Bullying- a guide for parents*. They also run a helpline: 0207 354 8321.

**Kidscape** is an organisation which has a helpline for parents with a child who is involved with bullying. Open weekdays 10am – 4pm telephone number 0207 730 3300.

The National Autistic Society book **“Words can REALLY hurt me”** is a guide to bullying problems. Telephone National Autistic Society helpline 0870 600 8585.

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.

The National Autistic Society has produced a factsheet **“Asperger syndrome in your classroom”** which can be sent from the National Autistic Society helpline 0870 600 8585. This covers many essential issues that occur in school and is written for other pupils to read. 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).

The Communication Difficulties Team are also available to both support the school and talk to other pupils where appropriate and offer support and strategies to the young person with Asperger’s syndrome.

**“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 0870 600 8585. 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.

These books are available to schools in the Learning Support SEN resource library at the Seedfield Centre.

Some young people with Asperger’s syndrome find it helpful to meet other young people with Asperger’s of a similar age. Contact The Communication Difficulties Team (0161 253 6430/6416), The Befriending Service (0161 253 6418) or The Red Centre (0161 797 0082) to find out if there are suitable social opportunities available in your area.

Aspirations is a group that runs various social opportunities for young people with Asperger’s syndrome. It is based at 1114 Chester Road, Stretford, but runs outings and other events at other venues to suit the needs of the young people. Contact 0161 866 8485 for further information or [www.aspirations.info](http://www.aspirations.info)

## **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 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.
- It is possible to alter the colour of the background on a computer or word-processing screen if it is helpful to the student.
- 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 SENCO at school or Learning Support Co-ordinator if it is a college. It may be that a letter from the person's GP, or psychologist explaining the need for extra time will suffice.

Most schools will have a member of staff who is responsible for examination arrangements, (examinations officer).

The regulations change annually but schools and parents may access the relevant new documents on the DFeS website. ([www.dfes.gov.uk](http://www.dfes.gov.uk))

## **Planning for students who are leaving school and have a Statement of Special Educational Needs**

Pupils with Asperger syndrome will require varying amounts of support when they finish full time school education.

**If the young person has a Statement of Special Educational Needs (SSEN)** 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 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 age 14 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.

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, a representative from Health services.

Each year, from the age of 14 onwards, the person should have a plan put together and updated for their future.

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

First contact your school's SENCO or other professionals involved in your child's education (Eg advisory teacher, educational psychologist)

SEN Team 0161 253 5652

Parent Partnership 0161 763 5001

BAPS – 0161 280 6791 [www.baps\\_online.co.uk](http://www.baps_online.co.uk)

National Autistic Society **Education Advice Line** 0800 358 8667 National

Autistic Society **Tribunal Support Scheme** 0800 358 8668

[www.nas.org.uk](http://www.nas.org.uk)

## **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.

## **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.

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

On the next page is a draft copy of a letter you could base your letter to Social services on.

## **Who to write to in social services for support for under 18s**

If the person lives in **Bury** and is under 18 write to:

Childrens and Families Team

Advice and Assessment

Craig House

Bank Street

Bury BL9 0BA

Tel. 0161 253 5454

## 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 would contact me at the earliest opportunity in relation to the support needs of my son, (name), who has an autistic spectrum disorder/ Asperger syndrome.

Would you arrange for my (son) to be entered on your register of disabled children?

Would 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) 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) 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. the need for counselling – emotional difficulties; counselling relating to bullying;
7. the 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. 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, 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.

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

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

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

Yours sincerely

(parent/s signature)

(Name of parents)

Be aware that if someone with Asperger syndrome does not have a SSEN but is on the Code of Practice (Action/ Action Plus), they may be 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.

## **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 helpline 0870 600 8585.

## **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 phone social services for assistance.

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

## **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 autistic spectrum disorder/Asperger syndrome.

Would you arrange for my son to be registered as a disabled person, under Chronically Sick and Disabled Persons Act 1970?

Would 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 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 present himself, wear appropriate clothes, grooming, how to avoid attracting negative attention in public;
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 recognize and avoid 'risk' situations;
17. the need to understand about getting enough sleep, how to relax, and carry out personal care;
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)

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 social groups, leisure opportunities, 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 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.

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

I would appreciate advice on what help I can access from other relevant agencies, details of voluntary groups and information on Benefits.

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

Yours sincerely

(Parent/ Carer signature)

(Parent/ Carer name)

Who to write to for support from Social Services (over 18 without a social worker)

If you live in **North Bury**: (Bury, Church, Elton, Manchester Road, Moorside, Ramsbottom, Redvales, Tottington)

Referral's Officer

Advice and assessment Officer

Craig House

Bank Street

Bury

BL9 0BA

Tel. 0161 253 5451

If you live in **South Bury**: (Prestwich, Radcliffe, Unsworth, Whitefield)

Advice and Assessment Service

Whittaker Street

Radcliffe

Bury

Tel. 0161 253 7190

If you need to contact a social worker out of normal working hours (5.00pm – 8.45am and weekends and bank holidays) there is a special number for the emergency Duty Team – Tel 0161 253 6606

## **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 Support Group.

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.

If the family is not satisfied then they have the right to complain, and each local authority has a Complaints Procedure to follow. The social worker should have a copy of this, or one should be available at any social services office. You are also able to complain via the Bury MBC website ( [www.bury.gov.uk](http://www.bury.gov.uk) ). 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.

## **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 autistic 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.

# A letter to use if your Local Authority has refused to assess your needs

(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 autistic 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.<sup>1</sup>

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. <sup>2</sup> 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.<sup>3</sup>

I need support in the following areas (eg 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)

---

<sup>1</sup> 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.  
<sup>2</sup> 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.  
<sup>3</sup> 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 autistic 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. <sup>4</sup>

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. <sup>5</sup> 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. <sup>6</sup>

I need support in the following areas (eg 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)

---

<sup>4</sup> 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.

<sup>5</sup> 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.

<sup>6</sup> *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 below – 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.
- Do work co-operatively with the local authority and be prepared to be persistent.

### **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 children's 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 (may not be appropriate in all cases!).

Also be aware that if someone cares for someone who gets the Disability Living Allowance at mid-rate care and earns less than about £72 per week they will probably be entitled to **Carers Allowance**. Ring 0800 882200 for more details.

There is also a government website for carers: [www.carers.gov.uk](http://www.carers.gov.uk)

For support and information in Bury:

**Bury Crossroads for Carers**

146 Hornby Street

Bury

BI9 5BB

Tel. 0161 763 4163

Fax 0161 761 6707

[www.burycrossroads.org.uk](http://www.burycrossroads.org.uk)

This is a voluntary organization that provides respite care attendants who come into the home and take over from the carer for a few hours each week. The care attendants are trained and are willing to assist the carer, either by taking the young person out, or remaining in the home, enabling the carer to get some rest, go out shopping or go out in the evening etc. This service is free, although any donation is greatly appreciated.

**Carer's Partnership**

146 Hornby Street

Bury

B19 5BB

Tel. 0161 253 6903

They provide a range of opportunities and activities in response to carers needs. For example, lifting techniques, First Aid, Health issues, Stress management, Assertiveness and Continence.

Direct Payments Officer

C/o Independent Living (Direct payments) Scheme

Carisbrooke Resource Centre

Wenlock Way

West Gorton

Manchester

M12 5LF

Tel. 0161 273 6805

Email: [dpscheme@globalnet.co.uk](mailto:dpscheme@globalnet.co.uk)

**NAS Adult Services:**

Manchester Service

Anglo House

Chapel Road

Northendon

Manchester

M22 4JN

Tel. 0161 945 0040

Fax 0161 945 3038

Email: [Manchester@nas.org.uk](mailto:Manchester@nas.org.uk)

The NAS adult service in Manchester provides a range of services to support people who are 16 or over who have been diagnosed as having an Autistic Spectrum Disorder.

The following services are currently available-

- a. A residential Service
- b. A day resource.
- c. A home support service.

For advice on any aspect of being a 'Carer' for your son or daughter contact the **CarersLine on 0808 808 7777**. Weekdays but not between 12 and 2pm.  
also the government website:

[www.carers.gov.uk](http://www.carers.gov.uk)

## **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.

### **Go out with a Befriender**

Some people with Asperger syndrome would venture out of the house, but do not have a friend they can call on.

### **Meet other people with Asperger syndrome**

Find a safe social event that the person feels most comfortable with and make plans to attend. If the person wishes to meet other people with the same diagnosis there are a few opportunities in the area:

Aspirations: this is a group of young people with Aspergers syndrome who meet at 1114 Chester Road, Stretford. They meet other places as well.

Tel. 0161 866 8485 for further information. Or [www.aspirations.info](http://www.aspirations.info)

Bury Autism Parent Support (BAPS) may know of opportunities for socialization. 0161 280 6791 [www.baps\\_online.co.uk](http://www.baps_online.co.uk)

Communication Difficulties Team (Tel: 0161 253 6430/6416)

The Mosses Community Centre have a daily 'drop in' centre for young people with some learning disabilities. This runs every weekday from 9.30am until 12.30pm. Although this is not exclusively for young people with Asperger's syndrome, it will suit a lot of youngster's with this diagnosis.

There is also a social evening on Thursdays from 7.30pm until 9.30pm.(over 18s) and Friday evenings from 6.00pm until 7.30pm(under 18s)

Contact Margaret Barker: Tel. 0161 797 2463 for further information.

The Mosses Centre  
Cecil Street Bury  
BL9 0SB

### **Relaxation**

Find out what helps the person to relax and feel more comfortable. 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 counselors 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. The National Autistic Society have a helpline for advice about receiving counselling. (Tel. 0870 600 8585.)

## **ADVOCACY**

### **Bury People First**

This is a group of self-advocates who are involved in all the decision making bodies of the Bury Learning Disabilities Partnership Board. They also provide advocacy, support and training for people with a learning disability. They also provide advice to professional bodies.

Contact: William Kemp-Heaton

St Peter's Road

Bury

Tel.0161 764 9840

### **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.

It is also good practice for the professional to only offer what is definitely going to be made available and to give clear guidance on the timescales.

### **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.

Inclusive Fitness (Tel: 0161 253 6388) Sessions are held at Castle Leisure Centre. Staff there are made aware of the persons needs and offer extra support accordingly. Yvonne Hall is the Disability Co-ordinator.

### **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 thoughts, 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 team offers before going to see the GP, can contact the Child and Adolescent Mental Health Services:

Child and Family Services

Fairfield Hospital

Rochdale Old Road

Bury

Tel: 0161 778 3526

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

Bury (North) has a Mental Health Team based at Inwood House. Te: 0161 253 7828

Bury (South) has a Mental Health Team based at Lord Street, Radcliffe. Tel: 0161 778 2150

### **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 the National Autistic Society.

## **Connexions - Advice, support, guidance and careers**

Connexions is the information, advice, guidance, and support service for Bury. 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 25.

Each young person who is disabled should receive information, advice, guidance and support 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 (SSEN) a**

Connexions Personal Adviser will be at the young person's Transition review, each year from age 14 onwards. Section 140 of the Learning and Skills Act will also apply (see below).

**If someone with Asperger syndrome does not have a SSEN** 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."*

The definition agreed across Greater Manchester Connexions includes those with statements of need, those at school action plus on the Code of Practice and those with 'developing conditions'.

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." It applies only to students who are considering courses funded by the Learning and Skills Council. (eg. Further Education or Training courses.)

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.

**Connexions** offices:

13-15 Broad Street

Bury

BL9 0DA      Tel. 0161 763 5884

## **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 college, going away to residential college or University.

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 which are less academic and more aimed at helping the young person develop life skills. Most Further Education colleges have this type of course 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 Guidance Centre at Bury College or the Learning Support Section at Holy Cross College to discuss the young person's needs.

Get the prospectus for each College as this has valuable information and telephone numbers.

Both Colleges have Open days when you can look around the building and meet staff, other students and representatives from Connexions.

**APPLICATIONS NEED TO BE IN COLLEGE BY THE SPECIFIED CLOSING DATE.** Applications later than this date may result in not getting the course of choice, or a place at all.

Put as much information on the application form as possible. Say what the young person's difficulties are likely to be, as well as his/her strengths. A psychologist report from school is also helpful. This should be available if you ask the special needs co-ordinator at school.

Apply for a place if you think it may be appropriate, even if you may change your mind later. It is better to turn down a place, than not have one available.

It is also possible sometimes to change the course you have asked for, if it turns out to be inappropriate at a later stage.

Representatives of both Colleges visit all high schools in the area throughout the academic year and parents may attend these visits. If your child attends a school out of the area you will need to make sure you still get the information by telephoning the colleges and asking them to send a prospectus.

Both colleges have web sites that have information about the courses. You can email them for information.

Bury College : [www.burycollege.ac.uk](http://www.burycollege.ac.uk)

Holy Cross: [www.holycross.ac.uk](http://www.holycross.ac.uk)

Students are interviewed individually prior to being offered a place at either College. If you feel your child needs support at this interview, please inform the college in advance and they will try and make appropriate arrangements.

Students are invited to attend for a 'taster' day before the end of year, if they have been offered a place.

Individual arrangements are also possible to help the young person get used to the building and staff if you discuss this with the college first. 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 quietrooms!

Before deciding on any particular placement make sure you have read through the following questions. Not all of them 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 Autistic Spectrum Disorders and Asperger syndrome specifically?

If no prior knowledge, are they open to learning? Would they benefit from training if offered to staff? (This may be available from the Communication Difficulties Team 0161 253 6430)

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

Did the previous student succeed? What were the difficulties and how did the college overcome them?

What educational support was provided for previous students?

How did previous students cope socially?

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.

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-ordinator 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 as 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).

## **Contact details for local Further Education Colleges**

Bury College : [www.burycollege.ac.uk](http://www.burycollege.ac.uk)

Holy Cross: [www.holycross.ac.uk](http://www.holycross.ac.uk)

## **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.

**COPE** is a compendium of post 16 education and training in residential establishments for young people with special needs. Wiltshire Lifetime Careers, Trowbridge. 01225 716 023.

**NATSPEC** is a national directory of specialist colleges. Check their website for details [www.natspec.org.uk](http://www.natspec.org.uk)

**Catherine College** is based at Trowbridge College is an Asperger syndrome Further Education facility. Contact Andy Chiffers 01373 463 172.

**.Interact College in Bristol** – this is due to open in September 2004! Get in touch with James Graham for details.0208 896 1911

**Wing Centre**, Hesley Group, Hampshire (16-19 year olds) 01590 677 986  
**ASPIN House**, [ACCREDITED BY THE NAS] Hampshire Autistic Society (, 16-19 provision,including lifeskills) 02380 900 905.

**Westfield Tech College, Dorset** - 01305 833518, Alison Crawford.  
**ESPA** have 3 colleges in the North East. Christine Smith is the Principal. They have a good reputation.

**South Hill College**, Ashbrooke, Sunderland 0191 567 3523.

**Nautical College**, Glasgow, Peggy Nicholson - 0141 565 2806

**Linkage College**, Grimsby – 01472 241 044

Arden College  
40 Derby Road  
Southport  
Merseyside  
PR9 0TZ;  
Tel: 01704 534 433  
Autism/Asperger syndrome  
Age range: 15-25yrs

Ashleigh College (ESPA)  
3 Elmfield Park  
Gosforth  
Newcastle upon Tyne  
NE3 4UX  
Tel: 0191 213 0833  
Fax: 0191 213 2614  
High-functioning autism/Asperger syndrome  
Age range: 16-25yrs

Bridge College  
Curzon Road  
Offerton  
Stockport  
Cheshire  
SK2 5DG  
Tel: 0161 487 4293  
Fax: 0161 487 4294  
Email: [admin.bridgce@virginnet.co.uk](mailto:admin.bridgce@virginnet.co.uk)  
Autism/Asperger syndrome  
Age range: 16-25yrs

David Lewis College  
Mill Lane  
Warfard  
Nr Alderley Edge  
Cheshire  
SK9 7UD;  
Tel: 01565 640 160  
Fax: 01691 640 260  
Email: [wayneb@davidlewis.org.uk](mailto:wayneb@davidlewis.org.uk)  
Website: [www.davidlewis.org.uk](http://www.davidlewis.org.uk)  
Autism/Asperger syndrome  
Age range: 16-25yrs

Derwen College  
Oswestry  
Shropshire  
SY11 3JA;  
Tel: 01691 661 2345  
Fax: 01691 670 714  
Email: [derwen@enterprise.net](mailto:derwen@enterprise.net)  
Website: [www.derwen.org.uk](http://www.derwen.org.uk)  
Autism/Asperger syndrome  
Age range: 16-25yrs

Fairfield Opportunity Farm  
Dilton Marsh  
Westbury  
Wiltshire  
BA13 4DL  
Tel: 01373 823 028  
Fax: 01373 859 032  
Autism/Asperger syndrome  
Age range: 16-25yrs

Hereward College  
Bramston Crescent  
Tile Hill Lane  
Coventry  
CV4 9SW;  
Tel: 024 7646 1231  
Fax: 024 7669 4305  
Email: [enquiries@hereward.ac.uk](mailto:enquiries@hereward.ac.uk)  
Website: [www.hereward.ac.uk](http://www.hereward.ac.uk)  
Autism/Asperger syndrome  
Age range: 16-25

Interact Centre  
Hanwell Community Centre  
Westcott Crescent  
Hanwell  
London  
W7 1PD;  
Tel: 020 8575 0046; fax: 020 8575 0046  
Email: [info@interactcentre.com](mailto:info@interactcentre.com)  
Website: [www.interactcentre.com](http://www.interactcentre.com)  
High-functioning autism/Asperger syndrome  
Age group: 17-25yrs

LEAP (NAS)  
Acton Centre  
The Woodlands Building  
Mill Hill Road  
Acton  
London  
W3 8RR;  
Tel: 020 8992 6611  
Fax: 020 8992 6644  
Email: [Leap@nas.org.uk](mailto:Leap@nas.org.uk)  
Autism/Asperger syndrome  
Age range: 18yrs-life

Lindeth College of Further Education  
The Oaks  
Lindeth  
Bowness on Windermere  
Cumbria  
LA23 3NH;  
Tel: 01539 446 265  
Fax: 01539 488 840  
E-mail: Lindeth.College@nbol.co.uk  
Autism/Asperger syndrome  
Age range: 16-25yrs

Ruskin Mill Further Education College  
Mill Bottom  
Old Bristol Road  
Nailsworth  
Gloucestershire  
GL6 0LA;  
Tel: 01453 837 521  
Fax: 01453 835029  
High-functioning autism /Asperger syndrome  
Age range: 16-25yrs

Tasker House College (ESPA)  
1 The Elms  
Ashbrooke  
Sunderland  
SR2 7BZ;  
Tel: 0191 565 9800  
Fax: 0191 565 9271  
Asperger syndrome  
Age range: 16-25yrs

Thornbeck College (Tyne & Wear Autistic Society)  
14 Thornhill Park  
Sunderland  
SR2 7LA  
Tel: 0191 510 2038  
Fax: 0191 510 8242  
Email: thornbeckcollege@aol.com  
Autism/Asperger syndrome  
Age range: 18yrs-life

Toynton Hall Campus – Linkage  
Toynton All Saints  
Spilsby  
Lincolnshire  
DN32 9RU  
Tel: 01790 752 499  
Fax: 01790 754 058  
Email: [college@linkage.org.uk](mailto:college@linkage.org.uk)  
Autism, Asperger syndrome  
Age range: 16-25yrs

Weelsby Hall Campus - Linkage  
Weelsby Road  
Grimsby  
North East Lincolnshire  
DN32 9RU  
Tel: 01472 347800  
Fax: 01472 242375  
Email: [college@linkage.org.uk](mailto:college@linkage.org.uk)  
Autism, Asperger syndrome  
Age range: 16-25yrs

Whitegates Further Education Centre (NoRSACA)  
The Dukeries Centre  
Park Street  
Worksop  
Nottinghamshire  
S80 1HH  
Tel: 01909 509400  
Fax: 01909 475162  
Autism/Asperger syndrome  
Age range: 17-30yrs

## 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 and which university will accept the A level grades achieved?

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. Contact Open University, 4 Portwall Lane, Bristol on 0117 925 6523 for details.

If the person is thinking of moving away from the parental home to study then approach your LEA, for ask whether the person is eligible for a Disabled Students Allowance. This will involve phoning your LEA department and asking for the Student Support section (or similar name). Explain to this section of the education department that the young person is going to university, and needs to have an assessment of his/her needs ("Study Aids and Strategy Assessment Report").

The LEA pays for this assessment (if they agree it is necessary) so they need to be sure the young person is actually going to university. Also the person needs to prove he or she has a disability. So they may ask for proof, such as (a) a letter from the university confirming a place, and (b) a letter from a psychologist/psychiatrist or similar saying the person has Asperger syndrome, or autistic spectrum disorder, and it is a disability.

The assessment takes place at an **Access Centre** (eg Southampton 023 8059 5000, or Plymouth 01752 232 278), by a trained assessor.

The assessment will produce a report that details the young persons needs. The young person may be able to access:

- Non-medical helpers allowance
- General disabled students allowance
- Special equipment allowance

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.

For more information about applying to get a Disabled Students Allowance phone 0800 731 9133 and ask for a copy of "**Bridging The Gap**" – a guide to **Disabled Students Allowance**. Or the National Federation of Access Centres 01752 232 278/ 01752 232 696. [www.nfac.org.uk](http://www.nfac.org.uk)

**SKILL** is an organization which offers advice and support for students with disabilities in Further or Higher Education. Phone 0800 328 5050 (Monday to Friday 1.30-4.30pm)

For people with Asperger syndrome in continued education try [www.skill.org.uk](http://www.skill.org.uk) then go through web pages information, then linkspage, then into specific disability organisations, and there is a link to a website [www.users.dircon.co.uk/~cns/index.html](http://www.users.dircon.co.uk/~cns/index.html) for people with Asperger syndrome in continued education.

**AUTUNIV-L** is a useful link site on the National Autistic Society website [www.nas.org.uk](http://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 Penny Deakin or Justin Penny for further details. 0207704 7450.

[www.cando.lancs.ac.uk](http://www.cando.lancs.ac.uk) contains careers advice for students with a disability.

## 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 on. but if the only job available is 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 Adviser (DEA). (Julie Connor Job Centre Plus, Bury, Prestwich and Radcliffe – John Beech Job Centre Plus Radcliffe and Prestwich)**

People with Asperger syndrome may wish to access support from a Disability Employment Adviser (DEA). These are employment officers who specialise in disability work related issues. They have contacts with disability aware employers and Bury Employment Support and Training (B.EST).

The DEA may refer a young person to B.EST, or the young person may self-refer to B.EST. B.EST may work in liaison with the DEA in finding suitable work placements for young persons.

B.EST provides help with real jobs that would otherwise be done by non-disabled workers, with the same wages, conditions and opportunities for advancement. The service is open to people who have a learning disability (including Asperger's syndrome) or long term mental health illness who receive disability benefit or a service from Health or Social Services.

B.EST – 24 Ribchester Road, Bury BL9 9JT Tel. 0161 253 6588

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 phoning the local Jobcentre and asking for an appointment.

These are the contact numbers for Disability Employment Advisers (DEAs) in the area:

Radcliffe – 0161 253 3302

Prestwich 0161 912 8870

Bury 0161 253 8060

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. However, B.EST aim to assess each individual to help the young person to find appropriate employment that will help overcome these difficulties.

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.

For people who are unable to work, Incapacity Benefit may be a possibility, or Income Support (if the person does not have enough National Insurance contributions).

For people who are on Incapacity Benefit (and some other disability benefits) but wish to work, they may be eligible for New Deal for Disabled People. This is a government initiative designed to improve the job prospects of long term unemployed people. For further information – Tel. 0800 3899374 (General enquiries) or 01204 365995.

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 such as BEST and Rathbones (ask the DEA).

Rathbones. Tel. 0161 797 5310

Parents may also contact ACCESS to Work – Tel. 01204 516480. This office may be able to help with such things as travel support (taxis to and from work), specific materials and seating required in order to continue in a job.

DEAs can help by arranging short work trials.

Connexions 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 Connexions.

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'. The person can gain some skills and experience of life at work, they can experience whether they would like to go out to work, they experience mixing and talking to people and are in a position to get a reference from someone they have worked for. Bury CVS is a voluntary service where clients could be forwarded to other areas of voluntary work or may be able to complete some voluntary work there.

### **How will looking for paid work affect any benefits?**

This may need to be another consideration. 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 jeopardize their lifestyle.

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

For example, "Permitted Work" means someone can earn up to £72.00 (approximately), without benefits such as Incapacity Benefit, 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".

This may be subject to regular review.

However if someone is on Income Support, this will affect Permitted Work.

Permitted Work and may also affect Council Tax Benefit and Housing Benefit. For more advice about this or any other benefit contact the Disability Benefits Helpline 0800 882200, or the DEA.

**If the person is ready for paid work, then complete a "skills profile", ie a listing of the qualifications, talents, strengths, skills and weaknesses s/he has got.**

This process should involve 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
- the DEA
- B.EST
- 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.'  
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.

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.

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

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

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 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 fulltime 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**, but it may change next year. Ask a DEA about this, and other ways to gain support in the job.

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

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 ( An employment support service run by the National Autistic Society) 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 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.

## **Whether or not to tell an employer about having Asperger syndrome**

### **Pros :**

1. It gives you a better chance of getting the correct support and understanding, from an employer.
2. 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.
3. It allows the individual a better chance of being placed in an appropriate job.
4. 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.
5. 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:**

1. 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.
2. 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’.

## **Some notes on Asperger syndrome for employers**

(These notes can be photocopied to pass on to any potential employer)

Asperger syndrome is a condition that affects approximately 1 in 300 people. Asperger syndrome describes people who have autism but 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.

(i) Social communication can include difficulty with knowing what to say to other people, with understanding what they are saying, and with non-verbal communication.

(ii) Social interaction can include difficulty knowing what to do when with other people, and understanding social ‘rules’.

(iii) 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 eg a place to go for refuge, and contact with someone who will give support.

52

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.

53

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.

### **Things to remember**

\_\_ People with Asperger syndrome want to do a good job.

\_\_ Do use this information sheet!

\_\_ National Autistic Society Information Centre for professionals advice 0207 903 3599

\_\_ National Autistic Society Prospects employment consultancy 020 7704 7450

There is a leaflet for employers produced by The National Autistic Society (Prospects) – **Looking for staff?** that gives an excellent overview for employers of the skills and benefits to their workforce of employing someone with Asperger syndrome. 0207 9033 595.

## **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, he or she may 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.

Supporting People Team Unit

Bury Business Centre

Kay Street

Bury BL9 6B                      Tel. 0161 253 6265

[www.supporting.people@bury.gov.uk](http://www.supporting.people@bury.gov.uk)

Explain 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.

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

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.

One option for some people is 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. Both costs are paid by Housing Benefit if it can be proved that the new property "meets the individual's needs more effectively". 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.

There is a supported Housing Project for people with a disability being built by the Irwell Valley Housing Association. It is presently called The Boxing Club, due to being sited on land where a boxing club previously stood, but may be renamed. The scheme will be open to anyone living in Bury who has a disability, needs housing related support and is able to develop their skills and move on to independent living within two years. Contact Irwell Valley Housing association. (Tel. 01204 454916) for further details.

**BUILD:** Bury Independent Living Development is a supported living scheme for adults with learning disabilities who live within Bury. It was started by a group of parents who wished to see their sons and daughters settled in homes of their own with the support **they** needed. It aims to offer

- person centred plans for individuals
- services based on individual needs be it 24 hour support or only a few hours per week.
- Support to live lives in ordinary settings, or support to continue in the family home.
- Activities that use community resources.
- Regular reviews so that supports reflect changing needs.

- Trained staff who value the individuals they support in a skilled and sensitive way.
- Sufficient paid and unpaid support.

Contact: Project Manager Unit  
 17 Bury Business Centre  
 Kay Street  
 Bury  
 BL9 GBU

Tel. 0161 763 6471

Email; BuryILD@aol.com

## 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. Contact the National Autistic Society helpline and National Autistic Society Autism Accreditation service for up to date information.

### 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.

Canbeck Close provides residential short-term care for people who have additional physical and behaviour needs. (these are usually more severe)

Bolton and Bury Adult placement may arrange short term residential support in family homes. Tel: 01204 337515/337 516

Woodbury is a hostel in Wesley Street, Tottington, that offers short term residential support and has an emergency bed service. Tel: 01204 88 7424/7910

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.

Social services under the Carers and Disabled Children Act 2000 can also give direct payments to parents so that they can choose ways to enjoy some leisure time – as a way to relax and de-stress.

Contact Community Care is a small, friendly local organization whose members enjoy going to the pub for a drink, having a meal together, a night at the disco and even holidays.

Start Buildings  
 275 Bury New Road  
 Whitefield M45 8QP

Tel: 0161 796 1580

## **Day time occupation (other than education or work)**

There are three Day Centres for people with learning disabilities in Bury. Many people with Asperger syndrome do not go to the day Centres because attendance requires a social worker referral and most people with Asperger syndrome do not have a learning disability. However for some people these settings do work.

The learning Disability Day Services has a range of day services including:

Whittle Pike Day Centre, Ramsbottom. A day centre that offers a variety of activities according to individual need.

Wheatfields day Centre, Whitefield. This has places for 20 individuals with complex needs and 40 places for individuals with moderate needs.

William Kemp Heaton day Centre, St Peter's Road, Bury. This has 22 places for individuals with complex needs and 38 places for individuals with moderate needs.

The outreach service is a dispersed day service based in community situations throughout the borough.

Contact the disability assessment Team Tel. 0161 253 6136

The Mosses Community Centre have a daily 'drop in' centre for young people with some learning disabilities. This runs every weekday from 9.30am until 12.30pm. Although this is not exclusively for young people with Asperger's syndrome, it will suit a lot of youngsters with this diagnosis. There is also a social evening on Thursdays from 7.30pm until 9.30pm.(over 18s) and Friday evenings from 6.00pm until 7.30pm(under 18s)  
Contact Margaret Barker: Tel. 0161 797 2463 for further information.

The Mosses Centre  
Cecil Street Bury  
BL9 0SB

The Longfield Companions is a social evening on the second Wednesday in each month held at The Longfield Suite at Prestwich.

## **Diagnosis**

It is possible to diagnose someone with Asperger syndrome before they start school, however the average age of diagnosis is around about 11 years of age, because many GPs do not know a great deal about Asperger syndrome and nor do all psychologists/ psychiatrists. Indeed many young people and adults remain undiagnosed and face some difficulties getting an assessment.

The usual route for diagnosis is to see the GP who will then refer on to a psychologist or psychiatrist, so the first step, if the person wishes to be assessed to see whether they have Asperger syndrome, is to make an appointment to see the GP.

Choose to see whichever practice doctor the person relates best to.

Before you go to see the doctor make sure you have thought about why the person

may have Asperger syndrome. Maybe consider writing some notes. It may be that a parent could put in writing why they think their son or daughter has Asperger syndrome.

The National Autistic Society has produced a **GP guide to adults with Asperger syndrome** that is aimed at helping GPs understand the more subtle outward signs of Asperger syndrome in adults, not diagnosed as children. This guide has been sent to over 34000 GPs nationally but don't assume your GP will have the guide to hand. Get a copy from The National Autistic Society 0117 974 8400 Development team. Don't 'tag' on discussing Asperger syndrome at the end of a doctor's appointment, when other physical health difficulties are being discussed. Go to the GP to discuss Asperger syndrome as a separate subject.

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

Explain about the person's condition and the reasons why you believe it may be Asperger syndrome and that you would like to be referred to a specialist for assessment.

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".

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. Phone free on NHS Information line 0800 665544 for advice.

If the GP decides not to refer on, you may wish to discuss with the **National Autistic Society helpline** 0870 600 8585.

Occasionally GPs 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:

#### **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.

## **What if the person does not wish to be diagnosed?**

If someone is under 16 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.

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

If someone is 16 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.

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

There is a free diagnostic service based in Cambridge called CLASS 01223 333936/746001. This requires a letter from the person's GP to ask for an assessment, but does not cost the GP any money.

There is also a free diagnostic service based in London at the Behavioural/Genetics clinic 0208 776 4256.

Dyscovery Centre, Cardiff 02920 628222. NHS and private referrals.

Professor Bill Fraser 02920 564 457. Adult diagnosis by arrangement. (Also does some court work, if people have come into contact with the criminal justice system).

Dr Chris Williams is clinical psychologist at Royal Devon and Exeter Hospital, Heavitree in Exeter. He is very experienced, and may see people out of area, if a GP sends a referral. 01392 403172

Dr Lorna Wing and Dr Judith Gould

Centre for Social and Communication Disorders,

Elliot House, Kent

0208 466 0098

Professor Pat Howlin

St Georges Hospital, London

0208 725 5604

Michael Rutter Centre for children and young people (will see adults also occasionally), London

0207 919 2535

Dr Meera Roy, Birmingham, based but sees adults from across the UK

0121 255 8000

## 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:

**Social Integration Skills Training** by David Moat, Asperger Initiatives Ltd, Hastings 01424 439 691

**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.

**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.

Mind Reading is an interactive study resource using CD-ROM to understand emotions in faces and voices, produced by Cambridge University. It costs about £50 – 0845 130 6142

[www.human-emotions.com](http://www.human-emotions.com)

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.

Aspirations: this is a group of young people with Aspergers syndrome who meet at 1114 Chester Road, Stretford. They meet other places as well.

Tel. 0161 866 8485 for further information. Or [www.aspirations.info](http://www.aspirations.info)

Bury Autism Parent Support (BAPS) may know of opportunities for socialization. 0161 280 6791 [www.baps\\_online.co.uk](http://www.baps_online.co.uk)

The Mosses Community Centre have a daily 'drop in' centre for young people with some learning disabilities. This runs every weekday from 9.30am until 12.30pm. Although this is not exclusively for young people with Asperger's syndrome, it will suit a lot of youngster's with this diagnosis.

There is also a social evening on Thursdays from 7.30pm until 9.30pm.(over 18s) and Friday evenings from 6.00pm until 7.30pm(under 18s)

Contact Margaret Barker: Tel. 0161 797 2463 for further information.

The Mosses Centre, Cecil Street, Bury, BL9 0SB

# Counselling

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

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

There is little information at present on how best to provide counselling to 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 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 postdiagnostic 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.

There are a few 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 are happy to visit the person with Asperger syndrome at their home, but usually sessions take place at the counsellor's home.

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 – 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 0870 600 8585.

**SPOD** Sexual and Personal Relationships of people with a disability, has a counselling line 0207 607 8851, for people with a relationship difficulty.

The British Association of Counselling (BAC) 01788 550899 for a list of accredited counsellors working in each region.

UK Council for psychotherapy (UKCP) 0207 436 3002 for a list of psychotherapists in each region.

British Association for Behavioural and Cognitive Psychotherapies (BABCP) 01245 875 277.

# Benefits

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

## **Job seekers allowance**

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

## **Incapacity Benefit**

If someone is unable to work and their GP has agreed, the person may apply for Incapacity Benefit. This is a long term Benefit for people who are unlikely to work for many months if not years.

## **Income Support**

If someone is out of work or unable to work and has not paid enough National Insurance contributions he or she may be entitled to Income Support, rather than Incapacity Benefit. There are several 'premiums' you will be entitled to if you receive DLA. 0800 88 22 00 for details.

## **Invalid Care Allowance (ICA) /Carers Allowance**

Is paid to parents or other carers (aged 16 and over) who spend at least 35 hours a week looking after the person with Asperger syndrome. The person with Asperger syndrome must be receiving the Care component of Disability Living Allowance at middle or high rate. You can earn approximately £77 net before you start to lose this benefit. The benefit is about £43.

## **Sickness Benefit**

If someone is out of work due to short term illness (less than 28 weeks) he or she may be entitled to Sickness Benefit. If the person cannot go back to work after 28 weeks he or she may then be entitled to Incapacity Benefit.

## **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 helpline!

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 part and the Mobility part. The Care component relates to the care and support that someone needs with daily living.

## **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 coordination 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 (eg 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 your 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 – requires supervision
  - 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 disobey 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
- does your son or daughter need to have someone with him or her when they are outdoors in places they do not know well?
- does he or she suffer from agoraphobia – fear of open spaces?

why does your son or daughter require someone with them outdoors?

does your child have a sense of danger?

unable to judge speeds and crossing times accurately, so not always safe crossing the road

do they need assistance even if a situation or a journey is familiar?

do they understand danger but are still easily distracted should something else come along e.g. they are normally fine on roads but will run across a busy street to get 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 helpline 0870 600 8585.

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**, helpline 0870 600 8585.

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.

For information about Benefits:

Disability Benefits Enquiry Line

0800 882200

For more information on DLA contact 0161 831 2048/2038

Disability Living Allowance helpline 08457 123456

National Autistic Society Information Centre for professionals 0207 903 3599  
National Autistic Society HELPLINE for parents and carers 0870 600 8585. We have a new fact sheet on DLA. So do phone for a copy!

**IMPORTANT:** Do not complete the DLA forms until you have spoken to the National Autistic Society helpline!

### **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 Invalid Care Allowance (ICA).

For more advice contact the Disability Benefits Advice Line 0800 88 22 00

[www.ferret.co.uk](http://www.ferret.co.uk) website contains information on Benefits and links to other sites.

## **Partners**

We now know that there is genetic element to autism in some families and it is recognised that some 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.

Maxine Aston's books **The Other Half of Asperger syndrome**, National Autistic Society, and **Aspergers in Love**, Jessica Kingsley Publishers (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.

There is also **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)

[www.jkp.com](http://www.jkp.com) - Jessica Kingsley publishers 020 7833 2307

[www.onelist.com/subscribe/aut-partners](http://www.onelist.com/subscribe/aut-partners) is a mailing list for partners of people with Asperger syndrome.

[www.faaas.org/information.html](http://www.faaas.org/information.html) is another site for families affected by members with Asperger syndrome.

## **Clubs, groups and social interests for people with Asperger syndrome**

## **Magazines and websites of interest to people with Asperger syndrome**

The Avon and Somerset Asperger Pub Group: [www.asapg.org.uk](http://www.asapg.org.uk)

Contact the National Autistic Society website [www.nas.org.uk](http://www.nas.org.uk) and look up the links page for a lengthy list of Asperger syndrome related chat rooms and other sites.

Including:

[www.inlv.demon.nl/](http://www.inlv.demon.nl/) list of support groups and chat rooms.

[www.aspie.co.uk](http://www.aspie.co.uk)

[www.aytistics.org](http://www.aytistics.org)

[www.aspergers.com](http://www.aspergers.com)

[www.isnt.autistics.org/](http://www.isnt.autistics.org/)

[www.egroups.com/group/asperger/info.html](http://www.egroups.com/group/asperger/info.html)

By young people with Asperger syndrome [www.rusalka.demon.co.uk](http://www.rusalka.demon.co.uk) or

[www.ccis.org.uk/users/Gareth/](http://www.ccis.org.uk/users/Gareth/)

[www.gareth25.supanet.com](http://www.gareth25.supanet.com)

For young people [www.faculty.washington.edu/chudler/aut.html](http://www.faculty.washington.edu/chudler/aut.html)

Email lists abound. Here are just a few:

[AspergersUK-owner@onelist.com](mailto:AspergersUK-owner@onelist.com)

[aut-older-owner@onelist.com](mailto:aut-older-owner@onelist.com)

**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 020 7903 3541.

**Morning News** is an American publication which Ros Lord imports for sale in the UK. Details from National Autistic Society helpline.

Novels about autism for young people: **Blue Bottle Mystery** by Kathy Hoopmann (2001), Jessica Kingsley publishers.

**What is Asperger syndrome and how will it affect me?** £1.50 National Autistic Society

## Parent and carer support groups

### Legal issues, wills, trusts

Provenio Financial Planning Ltd. Dave Robinson specialises in financial planning for parents of people with learning difficulties. 01275 857711.

Alison Reed at Bennetts solicitors will be able to give advice to parents about setting up trusts, or special funds for the person with Asperger syndrome. She can be contacted on 01934 862 786.

Nigel King of the Housing and Support Partnership has knowledge of how to leave property to people with Asperger syndrome. 01993 705 012.

Occasionally people with Asperger syndrome become involved in court cases. 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](mailto:hjdinham@lineone.net)

Anthony Quinn is chair of solicitors for people with a learning disability. His company can be contacted on 0207 242 3332.

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. [scomo@scomo.com](mailto: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.autismandpolice.cjb.net](http://www.autismandpolice.cjb.net) or try

[www.homepages.infoseek.com/~ddpi/ddpi.html](http://www.homepages.infoseek.com/~ddpi/ddpi.html)

Law Society 0207 242 1222 have lists of solicitors who do legal aid work in your area. [www.lawsociety.org.uk](http://www.lawsociety.org.uk)

Children's Legal Centre advice line 01206 873 820. Advice on all aspects of legislation relating to under 18s.

Disability Rights Commission Helpline 08457 622 633 for legal advice about access to services, and employment and disability.

Disability Law Service 0207 791 9800 for assistance with legal matters relating to

disability.

Mon-Fri 10am - 1pm and 2 - 4.30pm

Chambers and Hind solicitors, Derbyshire 0115 932 4134 claim to offer "comprehensive legal advice to disabled people, their carers and children, in respect of community care needs and related matters". Contact Philip Pepper, who has experience of challenging local authorities assessments of needs etc.

## **Useful national organisation telephone numbers**

**AFASIC** helpline 08453 55 55 77/ 0207 236 3632 speech and language difficulties

**ADHD** support group 01380 726 710

**ADDISS** (ADHD information service) 0208 906 9068

**British Epilepsy Association** helpline 01345 089599

**British Stammering Association** helpline 0845 603 2001

**Carers National Association** 0207 490 8818

**Connexions** What Now? Helpline 0800 51 11 11

**Contact a Family** helpline 0808 808 3555

**Disability Rights Commission Helpline** 08457 622 633 for legal advice about access to services, and employment and disability.

**Disability Law Service** 0207 791 9800 for assistance with legal matters relating to disability.

Mon-Fri 10am - 1pm and 2 - 4.30pm

**Dyslexia Institute** South West 01225 420 554.

National number 01784 463935.

**Dyslexia Foundation** 01462 454 986

**Family Fund** book After age 16 – what next? 01904 621115. Free to people with disabilities and their carers.

**Human Rights Unit** 020 7273 2166 [www.homeoffice.gov.uk/hract](http://www.homeoffice.gov.uk/hract)

**Irlen South West** 01460 65555

**Mencap** 0207 454 0 454

**MIND** (National Association for Mental Health) information line 0208 522 1725

**National Autistic Society Professionals information centre** 0207 9033 599

**National Autistic Society Parents and people with Asperger syndrome helpline** 0870 600 8585 for information on any aspect of Asperger syndrome exclusively for families affected by the condition.

**National Autistic Society Parent to Parent helpline** 0800 9 520 520

[www.p2ponline.org.uk](http://www.p2ponline.org.uk)

a freephone line to enable parents to talk with another parent about their situation.  
92

**National Health Service** information line 0800 66 55 44

**National Learning Disability** helpline 0808 808 1111

**National Society for Epilepsy** helpline 01494 601 300.

**Outreach Advice Assistance Support and Information on Special Needs (OAASIS)** helpline - 0891 633201. Information on courses, publications and literature.

**Pathological Demand Avoidance** Contact Group 0208 715 6179 (after 8.30pm)

**People First** 0207 713 6400. People with learning difficulties self advocacy organisation.

## Telephone numbers for education information and advice

National Autistic Society **Education Advice Line** 0800 358 8667

National Autistic Society **Tribunal Support Scheme** 0800 358 8668

**Connexions** Learning Information helpline 0800 923 0323.

**SKILL** Information on Further Education and Higher Education  
[www.skill.org.uk](http://www.skill.org.uk)

**CANDO** (Careers Advisory Network on Disability Opportunities)  
Lancaster University Careers Service 01524 594 370  
[www.cando.lancs.ac.uk](http://www.cando.lancs.ac.uk)

**Rathbone** offer advice on special educational needs 0800 917 6790.  
(Asian Education line 0800 085 4528)

**SEN Legal Advice for children, Cadney House.** 01284 723 952.

**Advisory Centre for Education (ACE)** Advice line 0207 354 8321.

**Parents Autism Campaign for Education** – 0207 226 5525.

Transitions Factsheet information **Contact a Family** 209-211 City Rd London EC1V 1JN - 0207 608 8700.

**Independent Panel for Special Education Advice (IPSEA)** 0800 0184 016/ 01394 382814

National Autistic Society **new SSEN Code of Practice factsheet** from National Autistic Society 0800 358 8667.

Copy of the **new SEN Code of Practice** DfES publications 0845 60 222 60.

## Selected Booklist

All of these books are available from the National Autistic Society publications catalogue – 0870 600 8585 for your copy.

For orders call: 01268 522 872

Barnardos Despatch Services

Paycocke Rd

Basildon, Essex

SS14 3DR

Attwood, T. (1998) Asperger syndrome – a guide for parents and professionals, Jessica Kingsley

Cumine, V. Leach L. & Stevenson, G. (1998) Asperger syndrome: a practical guide for teachers, David Fulton publishers

Howlin, P. (1997) Autism - Preparing for adulthood, Routledge

Smith Myles, B. & Southwick, J. (1999) Asperger syndrome and difficult moments, Autism Asperger Publishing Co. USA

What is Asperger syndrome and how will it affect me? National Autistic Society Autism helpline.

## 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.

Action ASD, Lancashire, tel. 01282 412021 [www.actionasd.org.uk](http://www.actionasd.org.uk)

Baps 0161 280 6791 [wwwbaps\\_online.co.uk](http://wwwbaps_online.co.uk)

Bolton Autism Action Group Tel.01204 371768 [www.boltoncommunity.co.uk/baag](http://www.boltoncommunity.co.uk/baag)

Greater Manchester Consortium [www.autismgm.org.uk](http://www.autismgm.org.uk)  
Asperger Syndrome Professionals Network (ASPEN) NAS, Nottingham. 0115 911 3360  
Aspergers Advisory Line, David Moat 01206 525 980  
Asperger Back-up Campaign (raising awareness of the needs of 'partners', information) contact NAS for details.  
Asperger United (a magazine by and for people with Asperger syndrome) 0207 903 3500  
Autism Services Accreditation Programme (NAS) 0117 974 8429  
Autistic Society for the Greater Manchester Area (ASGMA). (Aspirations -social activity groups, 16-25) 0161 793 1323  
Autism Care (UK) Ltd. (working towards NAS accreditation) Lincs, residential and supported housing and independent living skills 01526 322 444  
Autism Independent UK (mostly education and training providers) 01536 523 274.  
Autism Initiatives (family support, residential and day care, outreach) 0151 3309 500  
Autism Tasc Services. (working towards NAS accreditation, supported independent housing and residential care) Staffs, 01782 658156  
Autism West Midlands (working towards NAS accreditation) (housing and independent living) 0121 471 1913  
Ashlar House, Leeds Christian Home for adults with autism (residential care, not AS specific, outreach and training) 0113 226 2700  
Asperger Initiatives Ltd. (Training, books, advice, support) 01424 439 691  
Asperger Norfolk (social groups and a range of services) 01603 620 500  
BBi (London based long term lifestyle support) 0208 677 6550.  
Breakthrough (Asperger syndrome drop in and information resource for families and professionals in North Somerset) 01275 878 034.  
Bromley Autistic Trust (Social groups and a range of services) 01689 857 886.  
Brookdale Healthcare, Elm House (housing) 01707 858585  
Burnham Service (NAS) Residential care and supported housing 01278 792 962 95  
Cambridge Lifespan Asperger syndrome Service (CLASS) a national diagnostic service for adults. 01223 746 109  
Centre for Social and Communication Disorders, Elliot House, Bromley, Kent. (diagnosis assessment and training) 0208 466 0098.  
County Durham Autistic Support Group (advice and information) 01388 819 880.  
Craegmoor Healthcare (care homes) 01905 791 971  
Disabilities Trust, Berkshire (Dee Constable, Dyson's Wood House) 0118 972 4553  
European Services for People with Autism (ESPA). Range of Further Education provision. 0191 567 3523.  
Farleigh Sixth Form College, Frome, Somerset (schools and further education provision) 01373 475470.  
Hampshire Autistic Society (ASPIN House, 16-19 provision, including lifeskills) 02380 900 905.  
Hesley Group (schools, information). Southern office 01590 624484.  
Hill Park Housing Association, Bexleyheath (Frank House for adults with Asperger syndrome) 0208 319 5783.  
Glasgow Nautical College, Transitions programme, a life-skills programme for people not yet ready for a vocational college course. 0141 565 2806.  
Gloucester Group Homes (residential, day and outreach service for adults) 01453 835 023.  
Hayes Unit (NAS) for adults requiring a secure setting 01454 632 311

help! is the NAS Post-diagnostic programme of information advice and support for parents. Jan Snook (UK HELP Programme Manager) 0117 974 8400.  
Hoffman de Visme Foundation, London (outreach and counselling) 0208 342 7310  
Hyndburn Service (NAS) tiered housing support for people with Asperger syndrome and social services involvement. 01254 888 535  
Independent Community Living, Caerphilly (residential and day services) 029 2088 1994.  
Interact College, further education provision for people who require some life skill training before going into a vocational college placement. 0208 575 0046. Soon to open in Bristol (September 2004)  
John Mortlock Ltd. (training provider) 01424 439 691.  
Kennard, Mr and Mrs (long term residential care for able adults with autism and Asperger syndrome – 3 services in Hastings) 01424 200854  
Kent Autistic Trust. Family support officer (information, advice) 01634 405 168.  
Kingsweston specialist autism provision, Bristol (school) 0117 903 0394  
Leicestershire Autistic Society (Monday Club, social and independent living skills group, 18+) 01455 448144 (evenings).  
NAS Hyndburn service. 01254 888 535 (Asperger syndrome supported housing etc.)  
NAS New Ground service to develop work based skills, including horticulture, carpentry, office skills. 01633 866 339.  
NAS Thirsk Supported Living Scheme (supported tenancy) 01845 574 386  
NAS Training and Consultancy Services 0115 911 3363.  
NAS Volunteering and Befriending Manager. 0115 911 3360.  
NAS West London, Southall, London 020 8813 8222  
Nottingham Regional Society for Autistic Children and Adults (NoRSACA) 0115 987 3655 (Social activities group and befriending).  
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.  
Oxford Autistic Society 01865 750160.  
'Partners'. NAS London. 0207 903 3500. For partners of adults with Asperger syndrome to gain information, advice and support  
Ruskin Mill Education Centre (further education) 01453 837500/ 837521. College that caters for students with Asperger syndrome.  
St Georges Hospital Medical Centre, London. (diagnosis and assessment) 0208 672 1255.  
SACAR, Bradford (social awareness training, for local service users) 01274 424621.  
S.A.F.E. (Supporting Asperger Families in Essex) 01206 240 931.  
Sheffield Counselling Service for people with Asperger syndrome. 0114 230 2550  
Southlands school, Lymington (school and post 16 provision) 01590 675 350.  
Speakeasy - Hampshire Autistic Society (advocacy service) 01256 332 795  
Spectrum (various services Cornwall and Devon area) 01872 279 198.  
Spectrum Support Services 01424 44 7318  
Stop Gap - Herts Careers Service (lifeskills training for young people with Asperger syndrome) 01707 281411  
Sussex Autistic Community Trust (residential care, community support, social skills, buddy service for people in continued education) 01580 88 1715  
Sussex Autistic Society 01273 841 254.  
Thornbeck college (Tyne and Wear Autistic Society) 0191 510 2038  
Threshold Housing and Support, SW London, 0208 87 55 555  
TRACS, Wales (residential, day and outreach services) 01792 459 571.

United Response, Huddersfield (group homes) 01484 531 965  
Wargrave House School (5-19 provision, autistic spectrum disorder, some Asperger syndrome) 01925 224 899.  
Wessex Autistic Society (community outreach, supported housing) 01202 483360  
Wirral Asperger syndrome Parents Support (WASPS) 0151 653 8877  
Wirral Autistic Society, 0151 334 7510 (wide range of services).  
Yates, Pam (independent consultant in Asperger syndrome and autism) 0208 832 9213