The Autistic Spectrum Handbook

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Developed as part of the Surrey Autism Project 2004 - 2007

Good Practice
Local Support
Information
Services

A booklet for adults with Autistic Spectrum Disorders, their friends, families and staff.

Funded by The Learning Disability Partnership Board in Surrey.
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The content of this handbook was developed by:

• Tom Moore - Autism Project Manager, Surrey County Council
• Howard Childs - Behaviour Specialist, Surrey and Borders Partnership NHS Trust
• Mike Leat - The Clear Communication People Ltd
  with support from the Surrey County Autism Group

It was designed by The Clear Communication People Ltd
email: mike@communicationpeople.co.uk

It was made with photosymbols. Go to www.photosymbols.com
We have designed this booklet for people with Autistic Spectrum Disorders (ASD), friends, relatives, and staff.

Different people will find different parts of this booklet most useful. Some people with an ASD and a learning disability may need help to read and understand the information.

It may help to read through the booklet together with someone.

We have used lots of boxes to separate chunks of text as people have told us this makes information easier to read.

Much of the information in the good practice section aims to give staff and families information about how to support people with ASD.

The last section, Help in Surrey and the UK, is full of addresses and phone numbers of useful organisations. These may be useful to you now or in future. It is a good idea to keep the booklet safe in case you need these contacts in the future.
An Autistic Spectrum Disorder (ASD) is a lifelong developmental disability that affects the way people communicate and relate to other people.

People with ASD have difficulties with everyday social life. They may find it hard to develop friendships, and have difficulties understanding other people’s feelings.

People with ASD may also have a learning disability. Everyone with ASD shares a difficulty in making sense of the world.

The term ‘Autistic Spectrum Disorder (ASD)’ is used these days to describe people who have autism or Asperger Syndrome. This is because people on the Autistic Spectrum can be so different from each other that we can think about ASD as a rainbow. Asperger Syndrome is a term that describes people usually at the higher functioning, or more able, end of the autistic spectrum.

Below are short profiles of three people who are on different parts of the autistic spectrum.

**Jonathan**
- Above average intelligence
- Likes computers
- Follows his local football team, goes to all the games
- Has a small group of friends who share his interests
- Dislikes parties and socialising
- Can suffer from anxiety
- Finds it hard to understand other people’s feelings

**Andrew**
- Very likable person
- Has a learning disability and ASD
- Takes words literally
- Makes mistakes socially. Can get teased and taken advantage of
- Lives at home with parents and gets a lot of support
- Likes a set routine, gets anxious if things change
- Can be over friendly with people

**Samantha**
- Doesn’t use speech, but signs a little
- Seems happy on her own but will join in when supported
- Loves going out in the car and walking on a windy day
- Needs 24hr support
- Loves making shapes by twiddling string - is better than anyone at this.
- Can get scared in busy places and also gets angry if pestered a lot
People with ASD usually have 3 main difficulties

Social Interaction
This is about making & keeping friendships.
Some people may seem unfriendly and others may want to be friendly but find it difficult.
People may not see the point of socialising.

Flexibility
It can be hard to make choices and cope with unexpected changes.
They may have a small range of activities, sometimes copied and often repetitive.
People find it hard to imagine what other people are thinking.

Communication
People may find it hard to understand the meaning of gestures, tone of voice or body language.
People often take words literally which can cause confusion.
Some people find it hard to communicate with speech.

These 3 areas are used to diagnose whether people have an ASD or not. The good practice section of this booklet has lots of useful information and practical advice on how best to support people with Autistic Spectrum Disorders.

Other difficulties people may have include:

- Anxiety and worry - people on the autistic spectrum often find the world a confusing place where the rules are not consistent. This can often lead to high levels of anxiety.

- Sensory difficulties - people may be more sensitive to noise, light, smells, touch and tastes.

People with ASD have many strengths too:

- Having an excellent memory
- Being a loyal friend
- Being honest and valuing the truth
- Having a unique sense of humour
- Paying attention to detail
- Not afraid to be an individual
There are 3 main areas of good practice in this section.

**Communication**
- Communicating with speech
- Signing
- Visual Supports
- Communication Passports
- Intensive Interaction

**Anxiety and Social Situations**
- Anxiety Management
- Autism Alert Card
- Explaining Social Situations in Writing
- Social Skills Training

**Support and Environment**
- Autism Friendly Environment
- Person Centred Planning
- Routines, Rules and Interests
- Autism Champions
- Police and The Criminal Justice System
I) Communicating with Speech

It is good to keep your language as literal as possible.

Instead of saying
‘We are popping round John’s’ and ‘I’ve got a bone to pick with you’

Say
‘We are going to John’s house’ and ‘I want to talk to you about something you did.’

People with ASD are less likely to take clues from the emphasis on a word, the tone of your voice and your body language.

Be clear about your message
Often the important part of the message is not in the words used but how we say them.

Some people with a learning disability and an ASD may only take in 2 or 3 key words per sentence.

For many people it is important to keep sentences short, simple and clear
This gives people time to take in what you are saying.

Some kinds of language are harder to understand than others

Imagine what you might say to someone who has just played a trick on you

Easiest to understand

Literal - you just played a trick on me. That wasn’t nice.

Simile - you are like a sly old fox

Metaphor - you’re a sly old fox

Irony - you’re obviously a nice honest straightforward guy

People often learn similes and metaphors. Ironic and sarcastic phrases are the hardest for people to work out. These should always be avoided.

“What did you say? What do you mean?” is an illustrated guide to learning common metaphors.
Freaks, Geeks, and Asperger Syndrome is written by a teenager with ASD and has a good section on language

These books are available from the National Autistic Society. See page 22 for their contact details
COMMUNICATION IDEAS

2) SIGNING

Some people with a learning disability and ASD use Makaton signs to communicate. Go to www.makaton.org for more information. Many people who have a hearing impairment use British Sign Language to communicate. Go to www.british-sign.co.uk for more information.

3) VISUAL SUPPORTS

Visual supports are more permanent than speaking and signing.

A visual support could be:
- an object - for example car keys
- a photo, picture or symbol
- written words, flowcharts and lists.

A visual support can help people to:
- make and communicate choices
- understand routines, timetables and calendars
- get ideas for what activity to do from a range of pictures
- make menu choices and understand shopping lists
- understand important information like safety signs
- take in complex information by reading it at their pace.

Commonly used visual support systems

- PECS is a system used to help people with ASD develop language and communication - find out more at www.pecs.org.uk
- TEACCH is commonly used in schools supporting children with autism. It is used in some adult services. It uses visual schedules to help give children structure & create a learning environment - find out more at www.teacch.com

FURTHER READING

Making Visual Supports shows a range of ways of using pictures and photos to support people with ASD. It’s available from the National Autistic Society. See page 22 for their contact details.

Using Words, Photos and Symbols is a free booklet that cover many aspects of communication including visual supports. Download it from www.communicationpeople.co.uk
4) Communication Passports

Communication Passports are a practical way of supporting people who cannot easily speak for themselves.

They show the unique personality of the person in a fun and informative way. A communication passport is not used instead of a communication tool.

The section on communication is important. It will explain how the person communicates, and how to use their communication tools with them.

A communication passport should be easily available for everyone who supports the person to read. It can make sure the person gets consistent support.

The Call Centre in Scotland have written an excellent book called ‘Personal Communication Passports Guidelines For Good Practice’.

The book is available to buy from their website.
Go to - http://callcentre.education.ed.ac.uk/

5) Intensive Interaction

Intensive Interaction teaches the pre-speech basics of communication to people who have severe learning difficulties and / or autism.

A person may be very ‘difficult to reach’, living a socially isolated life, perhaps having a range of self-stimulatory behaviours and not showing motivation to be with other people.

Intensive Interaction helps people develop use and understanding of eye contact and facial expressions, taking turns in exchanges of behaviour, and gets a relationship going. It’s a shared, fun, social experience.

To find out more go to the Intensive Interaction website: www.intensiveinteraction.co.uk
To find out more about Intensive Interaction in Surrey, including training courses, visit the ‘Us In A Bus’ website: www.usinabus.org.uk
1) ANXIETY MANAGEMENT

Developing a plan to help someone cope with anxiety can be very useful.
A plan can have information for the person themselves and for families and staff.

For the person

A list of calming activities that may involve:
- exercise
- eating
- repetitive activities
- relaxation techniques
- space away from others
- fun things.

The calming activities can be listed on a prompt card which outlines good choices
to make when anxious or angry. Doing is generally more relaxing than talking!

A list of where and how to get help when needed:
- who can be contacted
- how to contact them, and when they are likely to be available.

For families and staff

It can be useful to make and keep lists:
- of common worries and solutions
- of signs that the person may be getting anxious, worried, or upset
- of activities that have helped the person calm down in the past.

A person with severe anxiety may need support from mental health professionals.
Your GP can refer you. See page 16 for more information

2) AUTISM ALERT CARD

A person may find themselves struggling to cope in a challenging social situation. An Autism Alert card can be shown to others to explain that the person may need support. The card has space for an emergency contact number to be added. They sell for £2.50 from www.nas.org.uk (2007 price)
3) EXPLAINING SOCIAL SITUATIONS IN WRITING

People with ASD can often find certain social situations very confusing and stressful. People may make social mistakes. Examples can include going to see the doctor, what to do if a train is late, and what to do at lunch time at work.

Writing about social situations

It’s important to explain what is likely to happen, the social rules of the situation and the choices the person has in that situation. For example:

‘Sometimes my train will arrive later than 8.40am. There could be many reasons for this including leaves on the line or a signal failure. It is not the driver’s fault if his train is late.

I can look at the boards to see if there is a message saying what time they think my train will arrive. If there is no message I can ask a member of staff who is wearing a railway uniform if they know what time the 8.40am train from Caterham is due to arrive.

If I am worried about being late for work I can use my mobile to phone my boss John on 01372 383016 and tell him my train is late. John knows that trains are sometimes late and will not be angry.

For many people it’s a good idea to use pictures as well as words to explain the social situation. The person may read their story many times as it is reassuring. Even if the person can’t read the story themselves their supporters can go through it with them. This results in consistent support from supporters.

This idea has been developed by Carol Gray into a technique called ‘Social Stories’. Visit her website: www.thegraycenter.org

Revealing the hidden social code: Social Stories™ for people with autistic spectrum disorders is available from www.nas.org.uk

4) SOCIAL SKILLS TRAINING

People with ASD often need specific help to understand and learn to use social skills. This may include teaching of things like:

- how to greet people
- using the telephone
- interview techniques and many other situations

Go to www.assists.org.uk/aspire.html to find out more about the Aspire social skills group in Surrey
1) Autism Friendly Environment

People with ASD are likely to cope much better if the environment:
- is uncluttered, with minimal distractions
- is visually clear - e.g. blank walls
- has a quiet place to get away to
- takes into account the person’s sensory needs
- has large spaces - some people need a lot of space when they are anxious.

This leaflet - Creating An Autism Friendly Environment is available from The National Autistic Society
www.nas.org.uk
(2007 price = £1)

2) Person Centred Planning

Person Centred Planning is about planning support and services around the needs of the individual rather than slotting the person into the services that already exist. Person centred planning is not just about the end result, it’s about involving the person fully in planning for their life. People with ASD may need support to get involved and make choices.

A Person Centred Approach:
- the person chooses who is involved
- the person chooses where and when meetings take place
- the focus is on what the person can do, their strengths and gifts as well as their needs.
- listening to the person’s dreams and aspirations for their life - even if they can’t all happen now
- is more accessible - often plans are designed using pictures and photos.

Also see page 16 for information about Health Action Plans.

In recent years new laws like Direct Payments, which give you money to buy and manage your own services and support, have helped people plan their own support. Individualised Budgets develop this idea further and will begin in the next few years.

Here are two good books on Person Centred Planning:
- A Little Book about Person Centred Planning
- People Plans and Possibilities
Both are available via Inclusion Distribution. Phone: 01625 269 243.
3) ROUTINES, RULES AND INTERESTS

Routines and structure can give security and reduce anxiety. It’s good to help people develop routines and unhelpful to change routines without good reason. It’s good to help people with ASD to fill and organise their time (especially naturally unstructured times such as evenings or lunch breaks).

People with ASD often understand the world best through rules. They need to understand and agree with the rules. It’s good to explain society’s rules, & help people develop personal rules that work for them.

People with ASD often develop strong interests. As well as being a source of enjoyment they can often be a great way for people to learn, develop relationships, fill their leisure time and gain employment.

4) AUTISM CHAMPIONS

There is a network of Autism Champions in organisations across Surrey, who learn about the autistic spectrum, and then train their teams.

The champions work in services like day services, housing associations and health trusts. The network was recognised as a national good practice example in the Department of Health’s document Better Services for People with an Autistic Spectrum Disorder. Find out more at www.aboutus.org.uk/autismchampions.htm

5) POLICE AND THE CRIMINAL JUSTICE SYSTEM

If someone with an ASD comes into contact with police either as a victim, witness or as an alleged perpetrator it is useful to inform the police of the diagnosis. There are Police officers who are trained in supporting vulnerable adults.

You may be able to get support from an appropriate adult if being interviewed about an alleged crime. If a case comes to court then lawyers may be able to call on experts in Autistic Spectrum Disorders.

The National Autistic Society produces information for criminal justice professionals. See page 22 for their contact details.
There are many ways you can get support and information in Surrey and the UK.

**Health**  
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**Social Care**  
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**Housing**  
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**Benefits**  
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**Adult Education**  
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**Safeguarding Adults**  
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**Advocacy**  - page 21

**National and Local Groups**  - Page 22

**Getting a diagnosis of ASD**  - Page 23
Primary care services are health services you can use directly like your GP (family doctor), dentist and pharmacist (chemist). It should be easy to use these services.

**To register with a doctor or a dentist in Surrey.**

Phone: 0208 335 1400

**NHS Choices** is the new service that gives you information about staying healthy & health conditions and finds the services you need like chemists and hospitals. **Website:** www.nhs.uk

**Phone NHS Direct** if you are feeling unwell and need advice.

Phone: 0845 4647

**Phone for an ambulance** if someone is seriously injured or seriously ill

Phone: 999

### SPECIALIST HEALTH SERVICES

**Your GP can help you to get support from specialist health services in your community.** These services include:

- Community Learning Disability Services
- Community Mental Health Services

**Community Learning Disability Teams**

Community Learning Disability Teams aim to meet the specialist health needs of people who have a learning disability. They may support the person by providing training, education and specific therapies. The aim is to help people with learning disabilities stay healthy and well. They can help write a health action plan for a person.

**A Health Action Plan** is a plan about what a person can do to be healthy, and says what services and support they need to have a healthy life. Usually the person keeps a copy of the Health Action Plan.

**Community Mental Health Services**

Can support people who are suffering from conditions like severe depression, anxiety, and schizophrenia. They also have an out of hours crisis response team.
Surrey County Council organise social care services in Surrey. They provide some services and buy other services from other organisations. Surrey County Council have eligibility criteria. These are rules that say who does and doesn’t qualify for services.

To see if you qualify for support you can contact Surrey County Council and ask for a community care assessment. People with autistic spectrum disorders (ASD) are most likely to qualify for support if they have a learning disability, or are thought to be at risk from harm if they don’t get support.

Fair Access to Care Services (FACS) are Government guidelines that say services should be provided for people who would be at risk if their needs were not met. They have 4 levels of risk - low, moderate, substantial and critical.

Support can include short breaks for families, day services, work projects and support at home. This support can be provided for you, or you can choose a direct payment where you have the money to organise your own support.

The EmployAbility Service helps people to find jobs and supports them in work. Phone: 01483 519690 for more information

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The Surrey County Council Contact Centre is open from 8am to 6pm

**Phone number:** 08456 009 009

**Email:** contact.centre@surreycc.gov.uk

**Website:** www.surreycc.gov.uk

The local learning disability teams can be contacted directly:

- **North East Surrey** 020 8541 9694 or 01372 202141
- **North West Surrey** 01276 800280
- **South East Surrey** 01737 737242 or 01737 733970
- **South West Surrey** 01483 517460

Surrey County Council services are not always free of charge. They have a charging policy which means many people are asked to pay towards services like day services, home care and short breaks.
Each local council in Surrey has its own housing department. They all have a housing register (housing waiting list). You can ask to join your local council’s housing register.

Some councils still have their own housing that they rent, but many these days work with housing associations who rent the housing. The council’s housing department is still responsible for deciding who is most in need of housing.

**Elmbridge Borough Council**  
Phone: 01372 474597  
E-mail: housingoptions@elmbridge.gov.uk

**Epsom & Ewell Borough Council**  
Phone: 01372 732436  
E-mail: housing@epsom-ewell.gov.uk

**Guildford Borough Council**  
Phone: 01483 444244  
E-mail: housingadvice@guildford.gov.uk

**Mole Valley District Council**  
Phone: 01306 879210  
E-mail: housing@molevalley.gov.uk

**Reigate & Banstead Borough Council**  
Phone: 01737 276000  
E-mail: housing.advice@reigate-banstead.gov.uk

**Runnymede Borough Council**  
Phone: 01932 425832  
E-mail: housing@runnymede.gov.uk

**Spelthorne Borough Council**  
Phone: 01784 446380  
E-mail: housing.needs@spelthorne.gov.uk

**Surrey Heath Borough Council**  
Phone: 01276 707127  
E-mail: housing@surreyheath.gov.uk

**Tandridge District Council**  
Phone: 01883 732825 / 732826  
E-mail: housingneeds@tandridge.gov.uk

**Waverley Borough Council**  
Phone: 01483 523452  
E-mail: housingoptions@waverley.gov.uk

**Woking Borough Council**  
Phone: 01483 743833  
E-mail: housingneeds.enquiries@woking.gov.uk
Benefits

Disability Living Allowance (DLA)

DLA can be paid whether you are in or out of work. DLA is not taxed or means-tested or based on national insurance contributions. DLA can be paid in addition to any other benefits you are getting and may also qualify you for extra money if you get a means tested benefit such as Income Support, Housing Benefit or Council Tax Benefit.

DLA is for people who need a lot of support and care to look after themselves and/or who find it difficult to get around. It has two parts:

- Care Component paid at three rates
- Mobility Component paid at two rates.

How much you get depends on the level of your disability.

Claim by ringing the Benefit Enquiry Line on 0800 88 22 00

If you provide at least 35 hours of care a week for someone getting the middle or highest rate care component of DLA, then you may be able to claim Carer’s Allowance.

You can get a copy of a Benefits for Carers Guide by phoning the Surrey County Council Contact Centre 08456 009 009, or download it from www.carersnet.org.uk

Incapacity Benefit

This is a weekly benefit for people who are incapable of work. Most people will have to have paid enough national insurance contributions to qualify, except for young people under 20 (or 25 in some cases). In October 2008, Incapacity Benefit will be replaced by a new benefit called Employment and Support Allowance.

Income Support

This is a means tested benefit to cover people’s daily living needs if they have little or no income. It can be paid in full or as a ‘top-up’ to other benefits. Extra amounts are paid if you have a disability. Income Support can also act as a ‘passport’ to other help such as full housing or council tax benefit and free NHS benefits like hospital travel expenses and prescriptions.

To claim Income Support and /or Incapacity Benefit phone the Jobcentre call line on 0800 55 66 88 or contact your local Jobcentre.

Further Advice and Support

If you have a social worker or care manager then you can get further benefits advice and support by either ringing the Surrey County Council Contact Centre or one of the learning disability teams – see page 17.

If you don’t have a social worker or care manager then you should contact your local Citizen’s Advice Bureau – see your telephone directory for contact details.
ADULT LEARNING

Surrey County Council has a wide range of adult learning courses taking place in over 100 venues across Surrey. Courses include computers, yoga, arts, photography, languages, sports and cooking. There is a 50% discount for people on benefits.

There will be a brochure advertising your local courses at your library. You can find out more online.
Visit www.surreycc.gov.uk go to learning then adult learning
You can search for courses in your area on this website.

THE LEARNING AND SKILLS COUNCIL

The Learning and Skills Council can give you information on support, planning and funding for students in further and higher education, and advice on eligibility for grants or funding.

Address: Surrey Learning and Skills Council, 48-54 Goldsworth Road, Woking, Surrey GU21 6LE
Phone: 01483 803201 Fax: 01483 803330
E-mail: surreyinfo@lsc.gov.uk Website: www.lsc.gov.uk/regions/SouthEast/

CONNEXIONS SURREY

Connexions Surrey offers information, advice, guidance, personal development opportunities and practical support to young people aged 13 to 25 who have special needs and live in Surrey.

Address: Connexions Surrey, 2nd Floor Connexions House, 83 East Street, Epsom, Surrey KT17 1DN
Phone: 080 800 13219 Text: 07766 413219
E-mail: info@connexionssurrey.co.uk Website: www.connexionssurrey.co.uk

You can talk to a Connexions Personal Adviser who can give you the support and guidance that will help you make your own positive choices about your future.
The Safeguarding Adults Team is part of the Surrey Safeguarding Adults Board. Their aim is to safeguard vulnerable adults against abuse and to raise awareness throughout the community to help prevent further abuse taking place.

A vulnerable adult is someone aged 18+, who may be at risk because of a mental, physical or learning disability as well as age or illness and cannot always take care of themselves, or protect themselves against harm or exploitation.

Abuse can be discriminatory, financial, neglect, physical, psychological, sexual, verbal and can happen anywhere and to anyone.

If you suspect someone is at risk ...please say something!

Contact us via our Contact Centre on 08456 009 009 or in an emergency dial 999. Safeguarding adults is everybody’s business. Your action could prevent abuse!

Advocacy Services

Advocacy Partners
Covers East Surrey
Phone: 020 8330 6644
E-mail info@advocacypartners.org
Website: www.advocacypartners.org

Just Advocacy
Covers West Surrey
Phone: 01483 527759
E-mail staff@justadvocacy.org.uk
Website: www.justadvocacy.org.uk

Advocacy is about:

- having your say – it is sometimes called speaking up for yourself
- having someone who is on your side when you want to say something
- having someone listen to what you want and make sure people listen to you
- having someone to speak out on your behalf at meetings or to professionals
- helping you to change your services
- helping you know your rights and making sure that they are respected
- helping you find information so that you can make choices and sort out problems
- having support to make difficult decisions
- helping you make a complaint if you are not happy about something.
The National Autistic Society (NAS)
The NAS champions the rights and interests of all people with autism and aims to provide individuals with autism and their families with help, support and services that they can access, trust and rely upon and which can make a positive difference to their lives.

The NAS website includes information about autism and Asperger Syndrome, the NAS and its services and activities.

**Autism Helpline:** 0845 070 4004  
**Website:** [www.nas.org.uk](http://www.nas.org.uk)

Mencap
Mencap works with people with a learning disability and their families and carers.

**Learning disability helpline:** 0808 808 1111. Can give you information on things like housing, jobs, benefits and local services.

**Website:** [www.mencap.org.uk](http://www.mencap.org.uk)

The NAS runs an information and support group called ASSIST, and a social skills group called ASPIRE.
These are both for people with Asperger Syndrome.

They also run a group called Focus Leisure for people with ASD and learning disabilities. For any of these groups **Phone:** 07747 460621  
**Email:** bettina.stott@nas.org.uk

There is a monthly social group for people with Asperger Syndrome based in Banstead, and one based in Oxted.
For more details **Email:** asocialgroup@hotmail.co.uk for the Banstead group, and Elaine.Holloway@surreycc.gov.uk for the Oxted group.

**NAS Surrey Branch** - volunteer-run support group for families of children and adults with ASDs. Contact: Sara Truman

**Phone:** 01483 822630  
**Email:** nas@mugsy.org  
**Website:** [www.mugsy.org](http://www.mugsy.org)
Getting a Diagnosis

How is diagnosis done?

Autistic Spectrum Disorders (ASD) can only be diagnosed through people’s behaviour.

A qualified health professional will use interviews and / or observations to determine whether somebody has an ASD.

How to get a diagnosis

Diagnosis is usually done by the health service. The first stage is to explain to your G.P. the difficulties you experience. It can be helpful to take somebody who you trust, and knows you well, to the appointment.

The National Autistic Society (see page 22 for details) provides information sheets with useful information to tell your G.P. As early childhood development is important in diagnosis, it is helpful also for the health professional who assesses you to speak to someone who knew you very well as a young child.

Benefits of a diagnosis

It can be difficult to get a diagnosis as an adult. A diagnosis does not necessarily lead to services being provided.

There are benefits to receiving diagnosis:

- It can help you understand yourself better.
- There are more and more useful strategies and guides available.
- It can help other people around you understand you better.
- If you are in receipt of professional help (e.g. mental health services), then your needs can be catered for more appropriately.

If you feel you, or someone you support in Surrey, has Asperger Syndrome you can make an appointment to speak to someone at Assist in Godalming. They offer information and support. See page 22 for their contact details.

The Autism Research Centre at Cambridge University also produces research including various tests. Visit their website at www.autismresearchcentre.com
Due to costs only a limited number of these booklets have been printed. If you want to see or print another copy it is available as a pdf download from The Learning Disability Partnership Board in Surrey website.

Go to www.surreypb.org.uk

In the information section look under ‘other information’ and look in the autism section.