Healthcare Improvement Scotland

SIGN

Autism spectrum disorders

A booklet for young people

Evidence

Acknowledgement

We would like to thank all the young people who took part in the focus groups to provide us with their ideas and illustrations for this booklet.

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What is this booklet about?

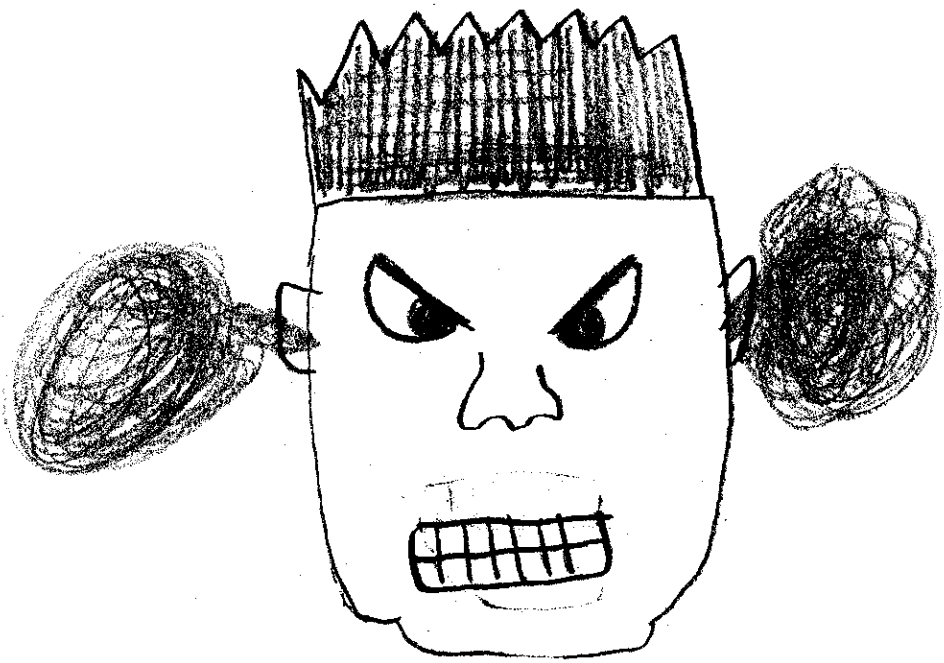
This booklet is for young people who may have autism spectrum disorder (ASD). The booklet explains:

- what ASD is;
- how it is diagnosed; and
- what can help.

There are details of other places where you can get more information at the end of the booklet on page 18.

This booklet is for young people but you may like to read it with a parent or another adult who can help if there are parts that you don't understand.

Thoughts from young people with ASD



When we decided to produce this booklet for young people with ASD, we thought we would ask some young people with ASD about their experiences.

We wanted to hear:

- what it was like for young people before and after they knew they had ASD;
- how young people were told they had ASD;
- what they had found helpful; and
- what information people needed about ASD.

We asked young people how they felt before they knew they had ASD. These are just examples and your experience may be different.

- ★ "I was angry and upset before I was diagnosed."
- ★ "I felt confused and angry."
- ★ "I was excluded from school."
- ★ "I was just like everybody else."
- ★ "Bad tempered."
- ★ "I was picked on."

We asked the young people how they felt when they were told they had ASD. You may be familiar with some of these statements. Again, these are just examples and your experience may be different.

- ★ "I was confused, I didn't know what it meant."
- ★ "I thought they had got it wrong."
- ★ "I was very angry."
- ★ "I wasn't bothered."
- ★ "I felt better once I knew what was wrong."
- ★ "I understand more."
- ★ "I think people put in more effort to understand me now."
- ★ "It's better socially."
- ★ "Things have been ok for me."
- ★ "This boy didn't speak to me."
- ★ "I've got plenty of friends actually."
- ★ "I felt relieved because I knew what was wrong, that I wasn't a freak."
- ★ "People are more understanding."

Young people felt it was important to:

- be told you have ASD;
- be told you are not a 'freak'; and
- tell a teacher if you are being bullied.

The young people we spoke to also felt that it is important that the people who work with you and your family understand that you may:

- need some space;
- get confused;
- lose your patience;
- find it hard to concentrate; and
- need a quiet place to go.

The young people we talked to had read a number of different books to help them understand ASD. In case you might like to read them too, we have listed these books on pages 18 and 19. You might like to talk to someone who has ASD. Tell the people who work with you or your parents or carers that you would like to do this and they can help to arrange this.

What are autism spectrum disorders (ASD)?

Autism spectrum disorders (ASD) is the name for a group of similar conditions including autism, atypical autism and Asperger's syndrome. We use the name ASD in this booklet to cover all of these.

If a young person has ASD, they usually have three areas of difficulty during their development. These are:

- ★ social difficulties (see the table on page 7);
- ★ difficulties with language and communication; and
- ★ difficulties with their behaviour and using their imagination.

In Scotland there are about 8000 young people who have ASD. Studies show about one in 100 young people have ASD. ASD is more common in boys than girls. Sometimes children can show early signs of ASD and can be diagnosed during their childhood. Other children may be diagnosed during their teenage years. Some possible signs of ASD are listed in the tables opposite.

We know that ASD can be linked to some medical conditions. But, for many young people, the cause of ASD is not known.

Signs of possible ASD in school-aged children
Communication difficulties
You may: • have had unusual language development when you were younger (in other words, used language that was different from children who were the same age as you); • sound unusual when you speak (for example, your voice may be too loud or soft, or too fast or slow, or not go up and down like voices usually do); • have unusual speech (for example, you may say things over and over again); or • use unusual words for your age.
Social difficulties
You may: • find it difficult playing easily with other children; • do things that others find difficult to understand (for example, you may criticise teachers or not do as you are told); or • not like people coming into your personal space or being hurried.
Difficulties with interest, activities and behaviour
You may: • struggle to join in with games in which you need to understand what other young people might be thinking (for example, a game of football), or find it difficult to share imaginary stories or ideas with other young people; • have difficulties with large open areas (for example, you may prefer to stay round the edge of the playground); or • find it difficult to cope with changes or new situations (for example, school trips or teachers being away).

Other factors

You may:

- have unusual skills (for example, you may have a very good memory, or be gifted at maths or music); or
- not like the sound, taste, smell or touch of certain things.

Signs of possible ASD in teenagers

General

You may:

- have difficulties in social situations such as school breaks or work breaks, although you don't have any problems with the lessons or work;
- not be 'streetwise' (in other words, not have the skills and knowledge needed to deal with modern life); or
- not be as independent as other people the same age as you.

Language, social skills and communication

You may:

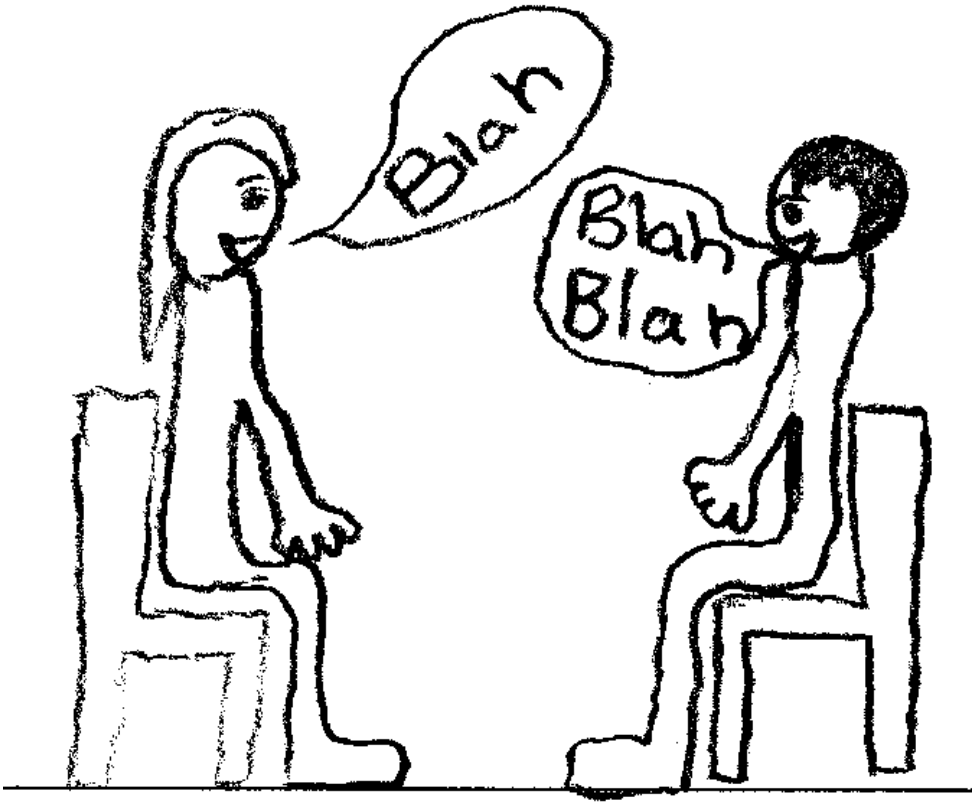
- have problems with communication, even if you know a lot of words and use grammar in the normal way (for example, you may be quiet, you may talk at other people rather than having a two-way conversation, or you may provide too much information on things you are especially interested in);
- not be able to change the way you communicate in different social situations (for example, you may sound more adult than other people your age or be overfamiliar with adults); or
- not understand when someone is being sarcastic.

Social difficulties

You may:

- find it easier to make friends with adults or younger children and less easy with young people of your own age;
- not share the same attitudes or interests as other people your age; or
- find it uncomfortable to have someone get physically close to you and may not know how close you should get to someone else.

Thinking and behaviour
You may: • prefer very particular interests or hobbies, or may enjoy collecting, numbering or listing things; • have a strong liking for familiar routines and may repeat things you have done; or • find it difficult using your imagination (for example, in writing or planning ahead).
This information may seem complicated but it is important that you are aware of these signs. You can ask any of the people working with you to help you understand the information in these tables.



Assessment and diagnosis

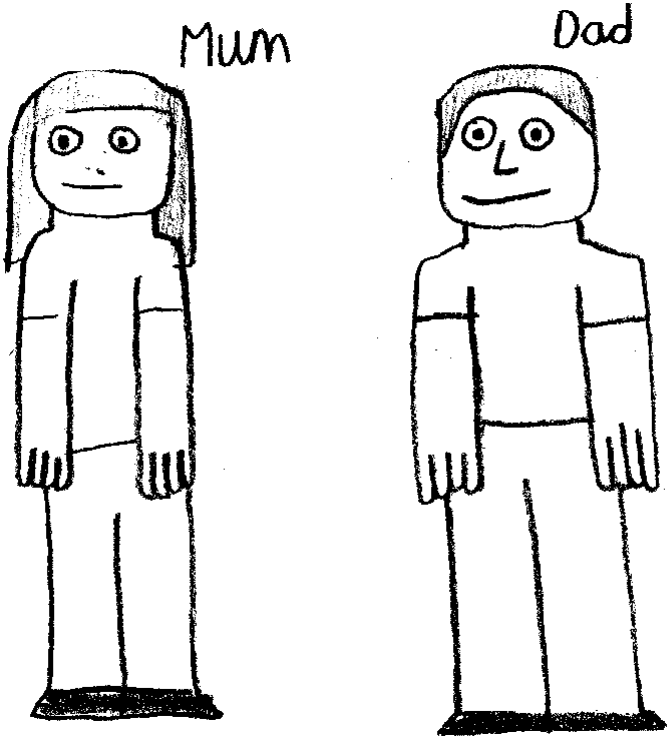
How do people find out if I have ASD?

You might have noticed things yourself - for example, you may not get on easily with other people who are the same age as you. You may also find it difficult to fit in at school.

Your parents, carers, friends or family members may have concerns about you. Sometimes you may be aware of other problems - for example, if you have speech or language difficulties, or you feel depressed.

A number of other people might also have concerns about you. These people could include:

- doctors;
- nurses;
- therapists;
- teachers and other school staff;
- social workers; and
- outreach workers (youth or community workers).



If these people think that you need help and may have ASD, they should talk to you and your parents or carers about the advantages and disadvantages of assessing you further. The assessments will be done by a team of specialists. Having an assessment for ASD is not a test.

Specialist teams can include different kinds of professionals, for example:

- ★ nurses;
- ★ paediatricians;
- ★ psychiatrists;
- ★ psychologists;
- ★ speech and language therapists; and
- ★ occupational therapists.

We have explained what these people do on pages 22 and 23.

The assessment can help to get a better overall picture of what you are good at or find difficult.

An assessment should involve:

- ★ asking you and your family about any difficulties and strengths you have;
- ★ seeing how you are in the clinic; and
- ★ collecting information about how you get on day-to-day (for example, in school).

It can take some time to decide if you have ASD and the team may have to see you and your family several times.

The team will try to understand your strengths and difficulties in communication, learning and how you manage day-to-day. This may involve doing other assessments – for example, someone might look at how you learn things or an occupational therapist might talk to you about how you cope with day-to-day activities.

What will happen after my assessment?

The team will talk with you about the results of your assessment as soon as they can. They will want to meet with you and your family, and also write something down to share with you. They will usually want to try to agree this with you, and they will give you a copy of this.

Sometimes it may be difficult to agree about everything as ASD can make it difficult to see things from other people's point of view. You may not agree that you have ASD. If this happens, the team will try to agree with you how your difficulties could be explained, or find a name for them which would feel comfortable for you.

Can my assessment find out anything else about me?

Children and young people with ASD can have other medical problems which need to be assessed and treated separately. You may have noticed some problems yourself - for example, you may feel very anxious or unhappy. Other problems that you may have include:

- ★ anxiety;
- ★ depression;
- ★ attention deficit and hyperactivity disorder (ADHD);
- ★ epilepsy;
- ★ eating problems; and
- ★ difficulty sleeping.

You should be given help with these problems too, but this will not be part of your assessment for ASD.

Will my condition change?

All young people with ASD change as they grow up. It is not possible to predict exactly what will happen to you.

What can help?

There are many things that can be done to help you with ASD, although there is no medical treatment to cure it. You, your family and the team looking after you may want to try a number of ways to help you develop skills and interests, or to adapt things so that you can manage better.

When you are diagnosed with ASD, the team should talk with you and your family about the different things you could try. ASD affects young people in different ways. What works for you might not work for someone else. Your team will talk with you and your family to find the best way for you. Everybody working with you should try to help you lead a life that satisfies you.

Having ASD can make life difficult for you and you may need extra help with day-to-day activities. Your parents or the people looking after you should get advice from your team about how to make changes to help you live from day-to-day. For example, your school could allow you to find a place in the classroom which is in less sunlight (if you are sensitive to this).

Your teacher could start to use a timetable each day so you know exactly what is happening at certain times. Using lists or calendars may also help you.

Can a special diet help?

Your doctor will not advise you to eat a special diet or take nutritional supplements such as vitamins.

All young people benefit from a healthy balanced diet.

Are there any medicines that can help?

Medication (drug treatment) has not been shown to help the main problems of ASD. You should not take medication on its own to help with your ASD – it should be part of your overall care.

Medication can be useful for some of the symptoms or difficulties you may have (for example, ADHD or very aggressive behaviour).

Before considering medication, health-care staff should find out about your surroundings (at school and home) and your daily routines (for example, your sleep, meals and activities). Changing some of these may help. The health-care staff will also talk with you and your parents or the people looking after you about the risks and benefits of taking medication. Medication can be used along with other kinds of treatment, and sometimes they may work together to be more effective.

Coping with aggression, tantrums or self-harming

If you behave very aggressively, have tantrums or sometimes hurt yourself (for example, banging your head), a treatment called risperidone may help you in the short term. If you are taking this medicine, health-care staff should check your weight regularly, because sometimes risperidone can cause you to put on weight.

Coping with ASD and ADHD

If you have ASD and ADHD, you may benefit from taking methylphenidate. This can improve your attention and ability to concentrate, and reduce how overactive you are. You will be able to take a test dose of methylphenidate to check if you get any side effects. Any side effects of methylphenidate should be carefully monitored. They can include:

- reduced appetite;
- feeling irritable;
- having problems sleeping; and
- emotional outbursts.

Coping with sleep problems

If you have problems sleeping, health-care staff may consider giving you a drug called melatonin. Melatonin is used to treat children and young people (including some with ASD) who have sleep problems.

Before you start taking melatonin, you should be asked to keep a diary of your sleep pattern (in other words, what time you go to sleep and what time you wake up). Once you start the medicine, you should keep going with your sleep diary and continue with your usual bedtime and waking-up routine if you have one. The sleep diary can help to show if the medicine is useful for you.

Help with other medical problems

If you have other medical problems, these should be treated the same way as they would for someone who doesn't have ASD.

Services

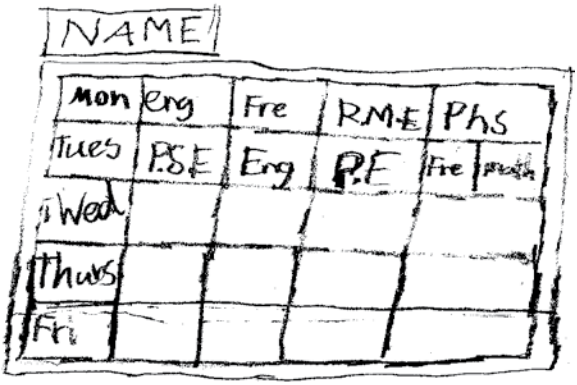
It is important that everyone who is working with you understands you as much as possible. They should have the knowledge and skills to be able to deal with ASD. For example, teachers should be able to include you in their classroom. The following people who work with you should know about ASD.

- Teachers
- Doctors
- Social workers
- Careers advisors
- Youth workers
- Anyone else who works with you

What should happen as I get older?

The things you need to help you cope with your ASD will change as you get older, so the services you get should also change. This may present you with new challenges and opportunities. To make it easier, there should be a plan about what will happen.

We understand that you will want this plan to be as clear as possible. You, your family and the people who work with you should be involved in making the plan. Social-work departments should also help you.



Information and support

It is important that you get different types of information to help you understand your condition. This information may include:

- ★ explanations from your team;
- ★ a booklet explaining what ASD is;
- ★ copies of letters sent to your team about you; and
- ★ copies of any reports about you.

You can read the information in your own time to help you understand.

You should be able to ask as many questions as you want and make sure the team explain things to you in a way that you understand. Your team should offer as much support as you need.

Where can I find out more?

We have listed some useful sources of information which may help you learn and understand about ASD.

Personal accounts written by children and young people who have ASD

You can buy any of the following books from bookshops. You may also be able to borrow them from your local library.

Asperger Syndrome, the universe and everything
Kenneth Hall, Jessica Kingsley Publishers (2001)

Martian in the playground
by Claire Sainsbury, Lucky Duck Publishing (2000)

Freaks, geeks and Asperger Syndrome. A user guide to adolescence
Luke Jackson, Jessica Kingsley Publishers (2002)

Standing down falling up: Asperger's Syndrome from the inside out
Nita Jackson, Lucky Duck Publishing (2002)

Survival strategies for people on the Autism Spectrum
Marc Fleisher, Jessica Kingsley Publishers (2005)

Fiction and adventure stories where the main character of the story has ASD

Blue bottle mystery: an Asperger Adventure
Kathy Hoopman, Jessica Kingsley Publishers (2001)

Haze
Kathy Hoopman, Jessica Kingsley Publishers (2003)

The curious incident of the dog in the night-time
Mark Haddon, David Fickling Books (2003)

Born on a blue day
Daniel Tammet, Hodder and Stoughton (2007)

Other helpful books

Different like me: my book of autism heroes
Jennifer Elder, Jessica Kingsley Publishers (2006)

How to be yourself in a world that's different
Yuko Yoshida, Jessica Kingsley Publishers (2007)

Succeeding in college with Asperger syndrome. A student guide
John Harpur, Maria Lawlor and Michael Fitzgerald, Jessica Kingsley Publishers (2004)

Leaflets

You can download the following booklets free from www.sign.ac.uk/patients/network.html or phone 0131 623 4720 to ask for a paper copy.

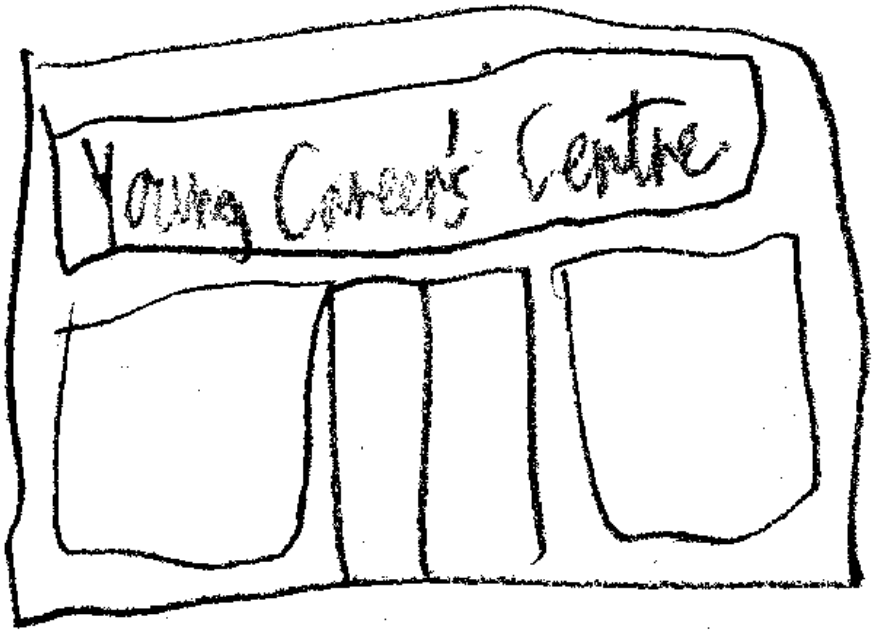
For patients: epilepsy in children and young people
Scottish Intercollegiate Guidelines Network (2007)

For parents: autism spectrum disorders
Scottish Intercollegiate Guidelines Network (2007)

DVD

You can buy the following DVD or you may be able to borrow it from your local library.

Autism and me
Rory Hoy, Jessica Kingsley Publishers (2007)



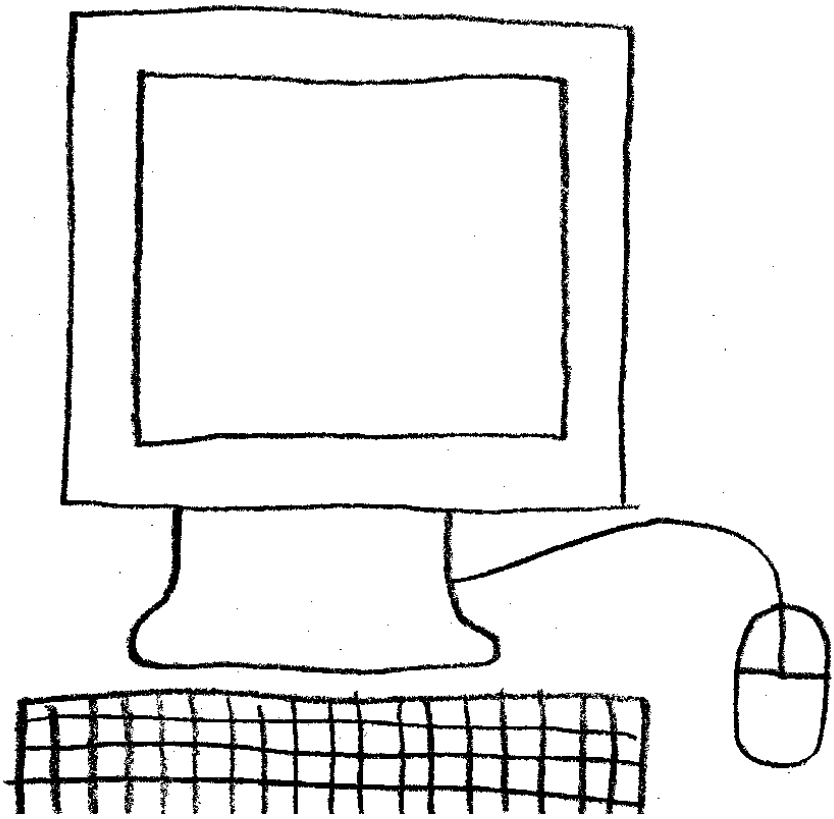
Websites

www.myworldofwork.co.uk
Jobs and career advice to people of all ages.

www.do2learn.com
Excellent practical educational activities, games and organisation charts such as calendars.

www.skill.org.uk
An information and advice service for young people and adults with any kind of disability in post-16 education, training and employment.

www.wrongplanet.net
An online resource and community for people with Asperger's syndrome.



List of useful terms

Attention deficit hyperactivity disorder (ADHD) – a condition in which a child or young person has consistently high and inappropriate levels of activity, acts impulsively and is unable to pay attention for long periods of time.

Autism spectrum disorders (ASD) – a range of conditions including autism, atypical autism and Asperger's syndrome.

Asperger's syndrome – a form of autism where a person has all three main areas of difficulty (see page 6) but does not have learning difficulties or delayed speech.

Atypical autism – a form of autism where a person does not have all three main areas of difficulty (see page 6). The condition may not be noticed until the person is at least three years old.

Autism – a lifelong developmental disability affecting behaviour and social and communication skills.

Melatonin – a drug used to treat sleep problems in children and young people, including some with ASD.

Methylphenidate – a drug used to help reduce problems with attention, concentration and overactivity.

Occupational therapist – a professional who is trained to help people manage and adapt their daily activities.

Paediatrician – a medical doctor who specialises in treating children and young people.

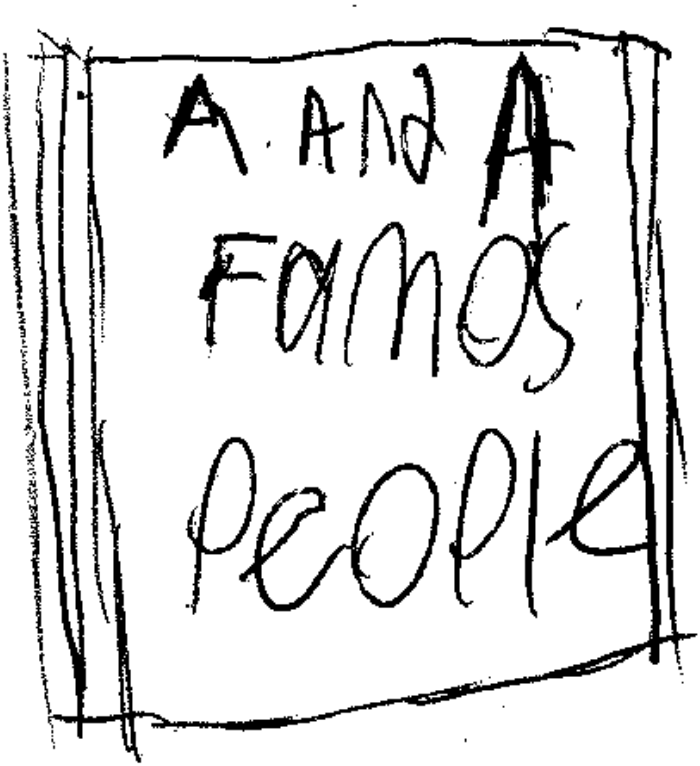
Psychologist – a professional who specialises in the study of the human mind and behaviour.

Psychiatrist – a medical doctor who specialises in diagnosing and treating problems people have with thinking, emotion and behaviour.

Risperidone – a drug used to help people with ASD to control their aggression, tantrums or self-harm, and to treat other conditions.

Social worker – a professional who works with children, young people and families to support them with their day-to-day living.

Speech and language therapist – a professional who works with children and young people who have problems with communication.



What is SIGN?

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice to doctors, nurses, surgeons, physiotherapists, dentists, occupational therapists and patients about the best treatments that are available. We write these guidelines by working with doctors, nurses and other NHS staff and with patients, carers and members of the public. The guidelines are based on the most up-to-date evidence.

Other formats

If you would like a copy of this booklet in another language or format (such as large print), please phone Karen Graham, Patient Involvement Officer, on 0131 623 4740, or e-mail her at **karen.graham2@nhs.net**.

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The Healthcare Environment Inspectorate, the Scottish Health Council, the Scottish Health Technologies Group, the Scottish Intercollegiate Guidelines Network (SIGN) and the Scottish Medicines Consortium are key components of our organisation.

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