

Autism spectrum disorders

Booklet for parents and carers



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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ISBN 978 1 905813 27 8

First published 2008

SIGN consents to the photocopying of this booklet for the purpose of implementation in NHSScotland

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What is this booklet about?

This booklet is for parents and carers of children and young people who:

- may have autism spectrum disorder (ASD); or
- have already been diagnosed with ASD.

We have written another booklet especially for young people, and there are details about this on page 34. Both booklets are based on a national guideline on children and young people with ASD.

The booklet explains:

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

There are details of support organisations and other places where you can get more information at the end of the booklet on pages 31-41.

We have also explained the terms we use in this booklet on page 42.

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;
- difficulties with language and communication; and
- difficulties with their behaviour and using their imagination.

Some signs of possible ASD are listed in the tables on pages 5-9. Children may show early signs of ASD during their childhood, or only later in their teenage years.

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

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.

Initial concerns

How will I find out if my child might have autism spectrum disorder (ASD)?

As a parent or carer, you may be able to see for yourself that your child has a problem with their development. Sometimes your child's difficulties in communicating with other children may only become clear once your child starts nursery or school. Concerns which other people such as nursery staff or teachers have are also important. It is important that health professionals respond if you are concerned. You should expect them to discuss these concerns with you.

The signs of ASD show themselves in different ways at different ages. We have set out this information in the tables on pages 5-9. This information may seem complicated but it is important that you know about these signs.

You can ask any member of your child's health-care team or other professional to help you understand the information in these tables. Not all children and young people with ASD will show all of these signs. Also, it is important to remember that if your child has some of these signs, they may have other conditions instead of ASD.

Signs of possible ASD in pre-school children

Your child may:

- not speak as well as would be expected for a child of their age, or may not speak at all;
- not appear to notice other people around them;
- not respond to other people's facial expressions or feelings;
- have little or no imagination or not pretend when playing;
- not be interested in other children or play with them;
- not take turns when playing;
- not share enjoyment or happiness;
- have problems with non-verbal communication (for example, eye contact, facial expressions);
- not point at objects to get someone else to look at them;
- have problems looking to see where another person is looking (known as 'gaze monitoring');
- not start activities or play;
- use unusual repetitive hand and finger movements; or
- react, or not react at all, to particular sounds or sights.

Signs of possible ASD in school-aged children

Communication problems

Your child may:

- have had unusual language development when they were younger (used language which is different to that used by other children their age);
- sound unusual when they speak;
- repeat words or phrases which they have heard rather than responding to them;
- refer to themselves as 'you', 'she' or 'he' after the age of three;
- use unusual words for their age; or
- use only limited language or talk freely only about things they are interested in.

Social difficulties

Your child may:

- not be interested in playing with other children;
- try inappropriately to join in with other children's play (for example, your child may seem aggressive);
- behave in a way which other people find difficult to understand (for example, they may criticise teachers or not do as they are told);
- be easily overwhelmed by being around other people;
- not relate normally to adults (for example, they may be too intense or not have any relationship at all); or
- not like people coming into their personal space or being hurried.

Signs of possible ASD in school-aged children

Difficulties with interest, activities and behaviours

Your child may:

- struggle to take part in pretend play with other children or play in which they need to co-operate and take turns;
- have difficulties in large open spaces (for example, they may stay round the edge of the playground); or
- find it difficult to cope with changes or situations that aren't routine, even ones that other children enjoy (for example, school trips or teachers being away).

Other factors

Your child may have:

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

Signs of possible ASD in teenagers

General

Your child may:

- show differences between their ability at school and their intelligence in social situations (for example, they may have difficulties with school breaks or work breaks, but not with the lessons or work);
- not be 'streetwise' (in other words, have the skills and knowledge needed to deal with modern life); or
- not be as independent as people the same age as them.

Language, social skills and communication

Your child may:

- have problems with communication, even if they know a lot of words and use grammar in the normal way – for example, they may be quiet, talk at other people rather than have a two-way conversation, or may provide too much information on things they are especially interested in;
- not be able to change the way they communicate in different social situations (for example, they may sound more adult than other people their age, or be overfamiliar with adults);
- not understand sarcasm (when someone is making fun of them); or
- make eye contact, gestures and facial expressions at unusual times.

Signs of possible ASD in teenagers

Social difficulties

Your child may:

- find it easier to make friends with adults or younger children, and struggle more with their own age group;
- not share the same attitudes or interests as other people of the same age; or
- find it hard having someone get physically close to them or may not know how close they should get to someone else.

Thinking and behaviour

Your child may:

- prefer very particular interests or hobbies, or may enjoy collecting, numbering or listing things;
- have a strong liking for familiar routines, or may have repetitive behaviour; or
- show difficulty in using their imagination (for example, in writing or planning ahead).

Assessment and diagnosis

What should happen if my child has possible signs of ASD?

If health professionals have concerns that your child may have ASD, they should refer your child to a team of specialists (see below) for an assessment. If a health professional is considering referring your child for an assessment, they should discuss this with you and organise support for you and your child while you wait to go and see the specialists. The tables on pages 27-30 tell you what information and support you should receive.

What happens at a specialist assessment?

A specialist assessment will usually be carried out by different professionals from health services (known as a multi-disciplinary team), or even a 'multi-agency team' including professionals from outside the health service (for example, from education and social work).

The assessment should involve:

- finding out about any problems your child is having, how they have developed, and about the family situation (known as 'history-taking');
- seeing how your child behaves, plays or does tasks while at the clinic (known as 'direct observation'); and
- getting information about how your child behaves in other situations outside the clinic.

History-taking will include:

- asking about any problems your child is having now;
- looking into your child's development from when they were born to the present time;
- asking if members of your family have had any speech and language difficulties, mental-health disorders, learning disabilities or epilepsy; and
- asking about any changes in the family (such as divorce or a family member dying) which may be affecting your child's behaviour.

When asking about your child's history, the specialists may sometimes use a special approach (for example, the ADI-R, 3di or DISCO). These are interviews that help specialists to be consistent when asking about important issues connected with ASD. The specialists involved in your child's assessment can tell you about these kinds of parent and carer interviews.

It is also important for the specialists to observe your child. They will either observe your child playing or doing tasks, or interview them in the clinic. Sometimes the specialist team will use a specific instrument – for example, the Autism Diagnostic Observational Schedule (ADOS) or the Childhood Autism Rating Scale (CARS). Again, these help the specialists to make consistent observations about children.

The specialist team will also want to gather information about how your child gets on in their day-to-day life. They will do this by contacting other people who can provide relevant information (for example, your child's teacher or social worker).

Sometimes the specialist team will ask for specific reports (for example, from your child's school or from an educational psychologist). This may mean carrying out other assessments. For example, an educational psychologist can observe your child at school. They can identify any particular strengths or difficulties your child has with their performance in the class, or how they act in social situations in the more unstructured parts of the school day (for example, playtime).

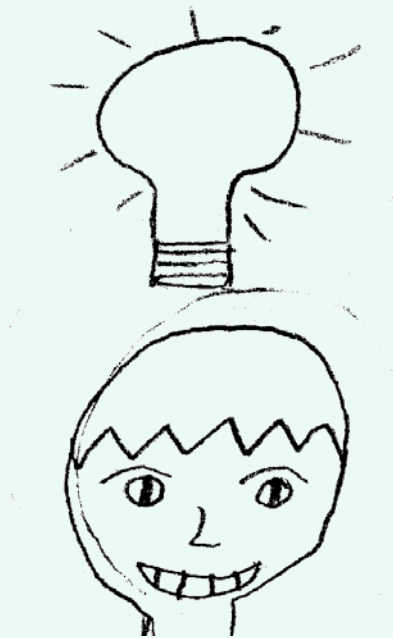
The specialists may also consider assessing your child's mental-health needs if this is appropriate.

The assessment process will let the specialist team decide whether your child has ASD.

Understanding your child's profile

Children and young people with ASD have different strengths and weaknesses and all have communication problems. These can range from speaking very little to having subtle problems in communication (for example, not being able to understand sarcasm). When your child is being assessed for ASD, their speech, language and communication skills should also be assessed. This will involve observing your child both in the clinic and at nursery or school. This will help the health-care staff decide what type of approach should be taken to help your child.

Also, children and young people with ASD may have a range of skills or problems with:



- intelligence;
- everyday tasks; and
- psychological skills.

Health-care professionals should also consider assessing these to help them decide on the best possible ways to help your child.

If the health-care professionals involved with your child's care think it would help, they may ask an occupational therapist or physiotherapist to assess your child.

The specialists should discuss the findings of their assessment with you, and your child, when appropriate.

They should explain these to you and answer any questions you may have.

Will the doctor be able to find out what causes my child's ASD?

There are many different known causes of ASD, but for many children and young people a cause is not found. Your doctor may suggest some investigations to try and find the cause of your child's ASD.

In some families who have a child with autism, there is a higher risk that any brothers and sisters will also have the condition. There is interest in other possible causes of ASD, but at the moment there is not enough research evidence to justify investigating these factors in clinical practice.

Does having an ASD make my child more vulnerable to other problems?

Some other problems are more common in children with ASD, including:

- mental-health problems (particularly anxiety and depression);
- attention deficit and hyperactivity disorder (ADHD);
- unusual behaviour when separated from or reunited with people who provide care (known as 'insecure attachments');
- sleep problems; and
- difficulties with movement (for example, clumsiness and tics).

Children and young people with ASD may also be more likely to have:

- epilepsy;
- sight problems; and
- hearing problems.

Your child's health-care professionals should regularly check your child for signs of these conditions. If they suspect that your child may be affected, they should make sure that these problems are accurately identified and managed.

It is also important to remember that your child may have the same medical problems or emotional difficulties as other children or young people without ASD, and they should receive appropriate medical care for these.

Could my child's condition change?

All children with ASD change as they grow up. In some cases, your child's ASD may get worse or improve (with or without being treated or managed). There is some evidence that the outlook may be better in children with ASD who do not have a learning disability.

Some children in their early years lose skills in communication and how they behave around other people. This does not necessarily mean that they will behave differently in later childhood to children who are not affected in this way.

What can help?

When your child is diagnosed with ASD, you should expect to be able to discuss different interventions (approaches) and treatments for ASD with your doctor and other professionals. It is also important to remember that your child has a right to benefit from their education and wider life experiences. The professionals should start interventions with your child as soon as they identify concerns. Everybody working with your child needs to promote and develop your child's skills. They will also need to consider adapting the environment to help with your child's difficulties.

This guideline is looking at health-service interventions but educational support is also very important. The support given to your child and wider family through other agencies such as social services and the voluntary sector is important too.

We use the term 'interventions' to acknowledge that, at the time of writing, ASD cannot be cured. Although there is no treatment to cure ASD, there is good evidence to show that there are benefits to the many interventions that can be included in your child's care.

Education, skills and training for parents

Some programmes take the form of a type of education for you as the child's parent or carer. These programmes (known as 'parent mediated intervention programmes') can teach you skills to help your child's development and communication, and should be considered as an option if your child is affected by ASD.



Help with early communication skills

Your child should be offered support for early communication skills. This support might include visual approaches such as pictures, and interventions to help your child communicate in social situations. Behavioural interventions can be considered to help a wide range of behaviour in children and young people with ASD (for example, sleep problems).

However, you and the health-care professionals working with your child need to understand that some behaviour only takes place because your child is using it to make up for their lack of skills, such as a problem communicating.

There is no evidence that behavioural programmes will result in a child having normal communication skills in the future.

Some interventions, such as auditory integration training and facilitated communication (see the list of terms), have no proven benefits and should not be used with your child.

Other treatments such as occupational therapy may help by adapting your child's environments and helping them with day-to-day activities and routines.

ASD affects children in different ways and it is important to remember that what works for other children might not work for your child. Professionals will talk with you and your child to decide on the best treatment based on your child's individual needs.

Are special diets helpful?

There continues to be very active research into the role of some interventions, such as diet and nutritional supplements for children and young people with ASD. The research has not shown that there are definite benefits in these interventions, and so your doctor cannot prescribe nutritional supplements to treat ASD symptoms. If your child has gastrointestinal (tummy) symptoms (for example, constipation and diarrhoea), they should be treated the same way as they would be for a child who does not have ASD.

Some children with ASD are very choosy about food and your doctor may need to refer them to a dietitian for advice about whether or not your child is getting enough of the right kinds of nourishment when they only eat a limited diet.

Are there any medicines that can help?

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

Medication can be useful for some of the symptoms or difficulties your child may have (for example, ADHD or very aggressive behaviour). Medication can help in the short term but there is currently no information to show that it helps in the long term.

Your child may also have epilepsy or other medical problems and may need medication for those. This guideline does not cover this but you can read more about how epilepsy is treated in our patient guideline on epilepsy in children and young people – see page 34 for details.

Before considering medication, health-care professionals should assess your child's surroundings (at school and home) and daily routines (for example, their sleep, meals and activities). Changing some of these may help your child. The health-care professionals should also talk to you and your child 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.

Your child should only be given medication by health-care staff who have been trained and can get help or advice if they need it. If your child is trying any medication, there should be a plan about how long to try it and how you will decide if it helps.

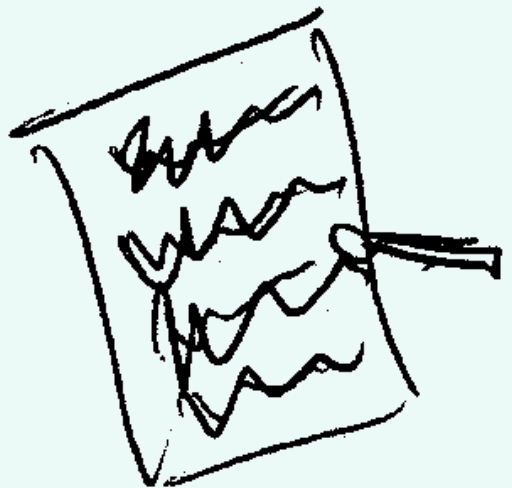
Coping with aggression, tantrums or self-harming

If your child behaves very aggressively, has tantrums or harms themselves (for example, by banging their head), a treatment called risperidone may help treat this in the short term. If your child is taking this medicine, health-care professionals should monitor your child's weight as risperidone can sometimes cause children and young people to put on weight.

Coping with sleep problems

If your child still has problems sleeping despite receiving treatment, health-care staff may consider prescribing melatonin. Melatonin is used to treat sleep problems in children and young people, including children and young people with ASD.

Before giving your child melatonin, you should be asked to keep a diary of your child's sleep pattern (in other words, what time they go to sleep and what time they wake up). Once your child starts to take this medicine, the sleep diary can show you if the medicine has helped. When your child starts to take melatonin, you should continue to keep a sleep diary and they should continue with any bedtime and waking-up routine.



Coping with ASD and ADHD

Children and young people with ASD and ADHD may benefit from a treatment called methylphenidate. It may help improve your child's attention and concentration, and reduce how overactive they are. Your child will be able to try a test dose to check if they have any side effects. Side effects of methylphenidate should be carefully monitored. They can include:

- reduced appetite;
- feeling irritable;
- sleep problems; and
- emotional outbursts.

Side effects from methylphenidate do not seem to be worse in children with ASD than in children who do not have ASD.

Secretin

Secretin does not help ASD.

Other medicines

Depending on your child's individual difficulties and other medical problems, your doctor may consider using other medicines.

Services

Will people involved in my child's care be trained in ASD?

It is important that everyone who is working with your child has the knowledge and skills to be able to deal with ASD. For example, teachers should be able to include a child with ASD in their classroom. Local authorities and NHS boards should make sure that staff are suitably trained to work with children who have ASD.

Will I receive information and training?

It is important that you and your child receive clear and accurate written and verbal information about ASD. You should be given a report of the results of the assessments your child has had and the final diagnosis. If you do not understand or need things explained, do not be afraid to ask.

Caring for a child with ASD can be stressful for you and your family. To help you cope with this, you should be offered education and the chance to develop skills to help your child. Having a good network of social support can also help you to cope. Health-care professionals will ask you about this and will consider helping you get some extra support if you need it. You may find it useful to be put in touch with voluntary groups who can offer you advice and give you the chance to meet other people who are going through a similar experience. We have listed some of these organisations on pages 31-32.

What happens when my child moves from one service to another?

What your child needs will change as they get older. There will be times when your child has to move between services (for example, from childhood services to adult services). This may present you and your child with new challenges and opportunities. To make these changes as easy as possible, you and the services you use should plan ahead to make sure new support is in place when your child moves. You should also be able to contact social workers during the move between services.

In Scotland, your child will be allowed to make decisions about their own health care once they are judged able to do this. If they are not able to make their own decisions, you have responsibility for them until they are 16 and so can make this decision for them. However, this responsibility ends when your child reaches 16.

If you feel that you should still be involved in decisions about your child's treatment after that, you can do so by getting permission under the Adults with Incapacity (Scotland) Act 2000. You can find out more on this law from www.scotland.gov.uk.

Information and support

What information will my family get?

Living with ASD can be confusing and frustrating. Many young people with ASD feel better once they know that ASD affects them in particular ways. Children and young people who have ASD may experience bullying at school from other children who may not understand the condition. It is important for young people with ASD to know that they are not 'mad' or 'stupid'. It can help if you talk to your child about their ASD and encourage them to learn about it. For example, you could encourage your child to read the separate booklet we have written for young people, or other books about ASD. You can find a list of books which may help your child on pages 33-38.

When you care for your child, it can help if you understand the condition yourself. Health-care staff should encourage you and your child to learn about ASD and find out about the interventions used to help children with ASD. It is important to understand that your child may:

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

As well as discussing your child's ASD with you, professionals should also give you and your family good-quality information. You can take this home and use it in your own time to help you understand your child's condition. You should also be encouraged to ask questions at any time when discussing your child's ASD.

The tables on pages 27-30 explain the information and support you and your child should expect to receive at the different assessment and intervention stages.

Checklist for what services & information you should receive

Before your child is assessed

The initial professional concerned (for example, a health visitor, teacher or GP) should:

- explain to you and your child that their behaviour shows a number of 'clinical clues' that may suggest your child has ASD or a difficulty communicating with or being around other people;
- talk to you (and your child, if appropriate) about the advantages and disadvantages of your child being assessed and check that they have your permission to organise this; and
- ask you about any other information which might show that your child has other conditions (for example, ADHD, depression) or allow the professional to make a different diagnosis (for example, a specific language difficulty).

The specialists you are referred to should:

- make sure you and your child receive information about what will happen now (the information should include the likely timescale of any pre-assessment and assessment stages, and who will be involved);
- consider giving you copies of any correspondence they have sent to and received from professional colleagues about the assessments;
- tell you that you are welcome to bring someone else with you if you want to; and
- explain that, if any part of the assessment is to be recorded on video, the team will get written permission from you and your child (if appropriate) to keep the recording.

Checklist for what services & information you should receive

At the assessment

The specialists should:

- check you and your child understand the reasons for your child being assessed, and how far you agree with the concerns of the professional who referred you;
- explain the assessment and agree with you and your child how these will be organised and which colleagues will be involved; and
- repeat their explanations and change their arrangements if necessary.

At any feedback appointments

The specialists should:

- allow enough time for them to explain the findings and discuss them with you (they should consider that you and your child may be upset, and meet your needs separately);
- find out what your child and your family understand about the diagnosis, and add information as appropriate - for example, if your child has been diagnosed with ASD, a member of the team should explain the three areas of difficulty (see page 3).
- based on their current knowledge, offer basic information about:
 - the cause of your child's ASD;
 - what interventions should be used;
 - how ASD will affect your child in the future;
 - any investigations the specialists will carry out; and
 - the next steps to take for a multi-agency team to provide appropriate support;

Checklist for what services & information you should receive

- provide information about what written feedback will be made available, and check with you and your child (as appropriate) how it should be made available to relevant colleagues;
- if any part of the assessment has been recorded on video, get written permission from you and your child (if appropriate) to keep the recording;
- if your child is considered unable to have the outcome of the assessment explained to them at the feedback appointment, discuss with you how and when to do this; and
- in cases where a definite diagnosis cannot be made, discuss with you how and when to best review or repeat the assessment, or the options for another specialist assessment to take place.

Interventions (after ASD has been diagnosed)

Multi-agency and multi-disciplinary teams should:

- involve relevant colleagues from other organisations (education, social work, voluntary sector, careers advisors, and so on);
- work with you to tailor the interventions to meet your and your child's needs;
- provide more information if necessary (for example, about the three areas of difficulty or any other medical problems);
- consider putting specific interventions in place, including for any other medical problems which may have been diagnosed;
- discuss possible educational approaches with you and your child (as appropriate), including extra support for learning;
- have arrangements in place for consulting and sharing information with education services;

Checklist for what services & information you should receive

- discuss respite care (giving you a break from caring), social work, and how brothers, sisters and the wider family can provide support;
- provide information about :
 - any benefits you or your child may be entitled to;
 - voluntary or community support;
 - available opportunities for being trained to deal with ASD; and
 - other sources of information; and
- organise for your family to have a named contact for ongoing help.

Where can I find out more?

National organisations working with ASD

The Scottish Society for Autism

Hilton House

Alloa Business Park

Whins Road

Alloa

FK10 3SA

Phone: 01259 720 044

E-mail: autism@autism-in-scotland.org.uk

Website: www.autism-in-scotland.org.uk

Provides information, advice and support to families of children and young people with ASD.

National Autistic Society – Scotland

Central Chambers

109 Hope Street

Glasgow

G2 6LL

Phone: 0141 221 8090

E-mail: autismhelpline@nas.org.uk

Website: www.autism.org.uk

Provides information, advice and support to families of children and young people with ASD.

NHS Education for Scotland (NES)

NES has an information booklet for parents and carers whose children have been recently diagnosed with ASD. You can ask for a copy of this booklet from the Scottish Autism Network by phoning 0141 950 3072 or by e-mailing scottishautismnetwork@strath.ac.uk.

NES, with the University of Birmingham, has also developed a learning resource about ASD for primary-care professionals, including GPs. This includes a website (www.nes.scot.nhs.uk/asd), where leaflets can be downloaded.

Contact a Family – Scotland

Craigmillar Social Enterprise and Arts Centre
11/9 Harewood Road

Edinburgh

EH16 4NT

Phone: 0131 659 2930

E-mail: scotland.office@cafamily.org.uk

Website: www.cafamily.org.uk/scotland/index.html

Contact a Family is a charity which provides support, information and advice to families of children and young people with a disability or health condition.

Useful publications

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

A mind apart: understanding children with autism and Asperger's syndrome

P Szatmari, Guilford Press (2004)

Explaining the enigma

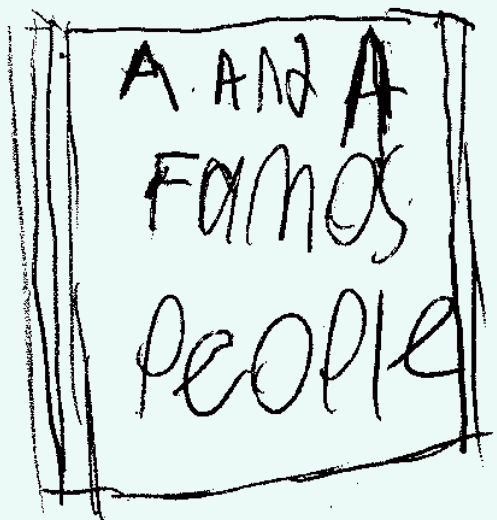
U Frith, Blackwell Publishing (2003)

People with autism behaving badly: helping people with ASD move on from behavioural and emotional challenges

J Clements, Jessica Kingsley Publishers (2005)

Sensory perceptual issues in autism and Asperger's syndrome

O Bogdashina, Jessica Kingsley Publishers (2003)



Leaflets

Autistic spectrum disorders: good practice guidance
Department of Education and Skills, DfES Publications

Free to download from
www.teachernet.gov.uk/wholeschool/sen/asds

Improving Scottish Education: education for pupils with
Autism Spectrum Disorders
HM Inspectorate for Education (2006)

Free to download from www.hmie.gov.uk/documents/publication/epasd.pdf. You can also ask for a free paper copy by phoning 01506 600 200.

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

Free to download from www.sign.ac.uk/pdf/pat81.pdf.
You can also ask for a free paper copy by phoning
0131 718 5090.

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

Free to download from www.sign.ac.uk/pdf/pat98.pdf
You can also ask for a free paper copy by phoning
0131 718 5090.

For parents of younger children

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

Autism: how to help your young child
Leicestershire County Council and Fosse Health Trust
(1998)

Autism in the early years: a practical guide
V Cumine, J Leach and G Stevenson
David Fulton Publishers (2000)

Sleep better! A guide to improving sleep for children with special needs
VM Durand, Jessica Kingsley Publishers (1998)

Toilet training for individuals with autism and related disorders: a comprehensive guide for parents and teachers
M Wheeler, Jessica Kingsley Publishers (1999)

Can't eat, won't eat; dietary difficulties and autistic spectrum disorders
B Legge, Jessica Kingsley Publishers (2001)

For teenagers

For young people: Autism Spectrum Disorders
Scottish Intercollegiate Guidelines Network (SIGN) (2007)

Free to download from www.sign.ac.uk/pdf/pat98.pdf.
You can also ask for a free paper copy by phoning
0131 718 5090.

Books for brothers and sisters of children with ASD

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

Everybody is different. A book for young people who have brothers and sisters with autism

F Bleach, The National Autistic Society (2001)

Can I tell you about Asperger syndrome?

J Welton, Jessica Kingsley Publishers (2003)

Personal accounts (autism)

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

George and Sam

C Moore, Penguin Publishers (2004)

Through the eyes of aliens. A book about autistic people

JL O'Neil, Jessica Kingsley Publishers (1999)

Emergence labeled autistic

T Grandin, Warner Books, Arena Press (1986)

For parents of older children and teenagers

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

Understanding and working with the spectrum of autism
W Lawson, Jessica Kingsley Publishers (2001)

The complete guide to Asperger's Syndrome
T Atwood, Jessica Kingsley Publishers (2006)

Asperger syndrome. A practical guide for teachers
V Cumine, J Leach and G Stevenson
David Fulton Publishers (1998)

Asperger syndrome and adolescence. Helping preteens
and teens get ready for the real world
T Bolick, Fair Winds Press (2004)

A parent's guide to Asperger syndrome and high
functioning autism
Ozonoff, Dawson and McPartland, Guilford Press (2002)

Autism and Asperger Syndrome: preparing for adulthood
(2nd edition)
Patricia Howlin, Routledge (2004)

Transitions

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

Transition toolkit. A framework for managing change
and successful transition planning for children and young
people with ASD

K Broderick and T Mason-Williams
BILD publications (2005)

Succeeding in college with Asperger syndrome. A student
guide

J Harpur, M Lawlor and M Fitzgerald
Jessica Kingsley Publishers (2004)

Personal accounts (Asperger's syndrome)

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

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

Pretending to be normal
L Holliday-Willey, Jessica Kingsley Publishers (1999)

Eating an artichoke
E Fling, Jessica Kingsley Publishing (2000)

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

Leaflets for professionals which you may find useful

Supporting your patient: what GPS and primary care practitioners need to know
NHS Scotland (2006)

Free to download from www.nes.scot.nhs.uk/asd/documents/Flyer1270606.pdf. You can also ask for a free hard copy by phoning 0131 220 8050.

Supporting the family: what GPS and primary care practitioners need to know
NHS Scotland (2006)

Free to download from www.nes.scot.nhs.uk/asd/documents/Flyer2270606.pdf. You can also ask for a free hard copy by phoning 0131 220 8050.

Has my next patient got an autism spectrum disorder?
NHS Scotland (2006)

Free to download from www.nes.scot.nhs.uk/asd/documents/Flyer3270606.pdf. You can also ask for a free hard copy by phoning 0131 220 8050.

Autism Spectrum Disorders and additional conditions: what GPS and primary care practitioners need to know
NHS Scotland (2006)

Free to download from www.nes.scot.nhs.uk/asd/documents/Flyer4270606.pdf. You can also ask for a free hard copy by phoning 0131 220 8050.

Websites

British Dietetic Association

www.bda.uk.com

Provides a range of fact sheets about diet, including diet and autism spectrum disorders.

Careers Scotland

www.careers-scotland.org.uk

Provides services, information and support for people of all ages.

Do to learn

www.dotolearn.com

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

Enquire

www.enquire.org.uk

Offers a flexible outreach and training service aimed at parents, carers and people who are involved in educating children and young people who need extra support for learning.

National Autistic Society (NAS)

www.autism.org.uk

The NAS website is detailed and easy to use. Includes information on parent training and support programmes, EarlyBird and Help!

Asperger and ASD UK On-line Forum

www.asd-forum.org.uk

A well supported, well organised internet support group with e-mail discussions and bulletin boards for sharing information.

Department for Work and Pensions

www.dwp.gov.uk/lifeevent/discare

Information on benefits and Disability Living Allowance.

Skill Scotland

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.

Sleep Scotland

www.sleepscotland.org

A charity providing support to families of children and young people with extra support needs and severe sleep problems.



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.

Auditory integration training – an approach to help hearing disorders, such as hearing loss or distorted hearing.

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 3) 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 3). 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.

Behavioural disorders – behaviour patterns that do not fit in with normal development.

Clinician – someone who is trained and working as a health-care professional (for example, a doctor)

Facilitated communication – a method of communication in which a child’s hand is supported by someone else to type out messages on a keyboard with letters, words or pictures.

General practitioner (GP) – a doctor who provides general medical treatment.

Insecure attachment – a pattern of behaviour, shown during a specific test used for children aged between 12 and 21 months, which involves a child being separated from, and then reunited with, a person who provides care (also known as the ‘Strange situation’ test). An ‘insecure attachment’ is when the child shows either less distress when separated and avoids the person when they are reunited, or more distress when separated and is difficult to comfort when reunited with the person.

Intensive behavioural programmes – techniques which are based on behaviour theory, and can be used to increase behaviour which is wanted, or to reduce behaviour which is unwanted. Behaviour theory looks at what people actually do (their behaviour) and identifies types of things to increase or reduce it.

Intervention – an approach which will help your child but will not cure them.

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.

Non-verbal – communication through the use of facial expressions, gestures and body movements.

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

Paediatrician – a doctor who specialises in treating children.

Physiotherapist – a health-care professional who helps with physical problems.

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

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

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

Secretin – a gastrointestinal hormone.

Social worker – a professional who works with children and families to help with them cope with day-to-day living.

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

Tics – a sudden and uncontrolled small movement or noise.

Diagnostic tools

3di (developmental, dimensional and diagnostic interview) – a history-taking instrument used by clinicians.

ADI-R (autism diagnostic interview - revised) – a history-taking instrument used by clinicians.

CARS (childhood autism rating scale) – a scale used by clinicians when observing your child to help them make a diagnosis.

DISCO – a history-taking instrument used by clinicians.

Space for your notes

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.



This booklet is based on a clinical guideline issued to all NHS staff.

The Scottish Intercollegiate Guidelines Network (SIGN), developed this 2007 guideline. It is based on the most up-to-date published evidence.

You can download the full clinical guideline from our website at www.sign.ac.uk/pdf/sign98.pdf

A short version is also available at www.sign.ac.uk/pdf/qrg98.pdf

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