

Autism



**A booklet for parents, carers and families
of children and young people with autism**



We would like to thank all the parents and carers who
contributed to this booklet.

Cover image: Photograph posed by models.

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This booklet can be photocopied for use by organisations and
individuals in Scotland.

Contents

Who is this booklet for?	1
What is this booklet about?	2
What is autism?	3
Worried your child may have autism?	6
How do professionals find out if your child has autism?	14
Understanding your child's profile	21
What would help?	28
What services are available?	39
Information and support	42
Where can you find out more?	45
How are SIGN guidelines produced?	58

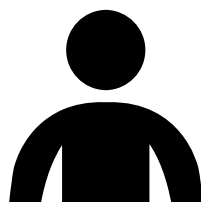
Who is this booklet for?

This booklet is for parents, carers and families of children and young people up to the age of 18 who:



have already been
diagnosed with autism

or



may be going
through diagnosis.

We have written another booklet especially for young people, and there are details about this on page 48. Both booklets are based on a national guideline on assessment, diagnosis and interventions for autism spectrum disorders. The full guideline is available on our website www.sign.ac.uk/pdf/SIGN145.pdf.

What is this booklet about?

This booklet explains the recommendations in a clinical guideline, produced by the Scottish Intercollegiate Guidelines Network (SIGN), about:

- getting assessed and diagnosed for autism, and
- the approaches that can help.

It gives you information about the care your child is likely to get.

There are details of support organisations and other places where you can get more information on pages 45 to 55.

The clinical guideline is based on what we know from current research. It also gives advice based on the opinion of healthcare professionals who are trained on how best to care for your child.

If you would like to see the clinical guideline, please visit

www.sign.ac.uk

There are four different types of recommendations in this booklet.



Strong

recommendation

based on good-quality
research evidence.



Recommendation

based on
research evidence.



Recommendation

based on clinical
experience.



Not enough

research evidence
to tell us if something
is of benefit.

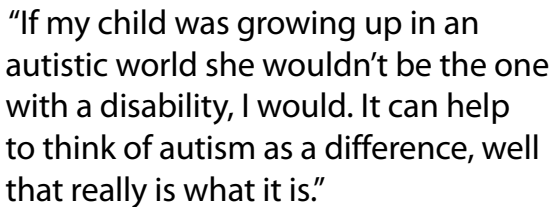
On page 58 you can find more about us at SIGN and how we produce guidelines.

What is autism?

Healthcare professionals and researchers use the term autism spectrum disorders (ASD) to describe and diagnose a group of similar conditions. Over the years, different words have been used to describe ASD, including autism, atypical autism and Asperger's syndrome.

For diagnosis and research, it's helpful to include all these conditions in one term, namely autistic spectrum disorder (ASD).

Autism spectrum disorder is now the most common diagnosis.



"If my child was growing up in an autistic world she wouldn't be the one with a disability, I would. It can help to think of autism as a difference, well that really is what it is."

Parent of child with autism

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

Asperger's syndrome is a form of autism where a person has all the main areas of difficulty but does not have learning difficulties or delayed speech.

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

ASD may occur alongside any level of thinking or learning ability. Signs of ASD range from subtle problems of understanding and impaired social function to severe disabilities.

STUDIES SHOW ABOUT
**ONE
IN 100**
YOUNG PEOPLE HAVE ASD
ASD IS RECOGNISED
MORE OFTEN IN BOYS
THAN GIRLS.

Some people prefer the term autism spectrum condition (ASC) rather than using the word 'disorder'.

We use the term **autism** in this booklet to cover all of these because parents and carers have told us this is the term they prefer to use. We are aware that people have different preferences.

If a young person has autism, they usually have difficulties with the following:

- Social communication and interaction.
- Restrictive repetitive behaviour.
- The use of imagination and play.
- Sensory sensitivities.

Some individuals with autism also have difficulties with language development and a learning disability (or both). They may have unusual responses to sensory input or aspects of their environment.

Children may show early signs of autism during their childhood, or only later in their teenage years. Some signs of possible autism are listed on pages 6 to 12.

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

Worried your child may have autism?

As a parent or carer, you may be able to see for yourself that your child has difficulties with their development. Sometimes your child's difficulties in communicating with other children may only become clear once your child starts nursery or school.

"I knew he was different when he was about 2 years old, he didn't play like other kids." **Parent of child with autism**

Concerns that other people such as nursery staff or teachers have are also important.

What should I do if I am concerned?

You should speak to your GP or Health Visitor (if your child is younger) about your concerns. It would be helpful to take along a list of behaviours you have noticed. Health professionals should respond if you are concerned and discuss your concerns with you.

"Autistic behaviours such as **stimming** and needing lots of down time are usual and almost always important as it helps an autistic self regulate."

Parent of child with autism

Stimming is short for self-stimulatory behaviours. Stimming might be rocking, head banging, repeatedly feeling textures or squealing.

What are the signs of possible autism in pre-school children?

Your child may:

- experience delay in developing speech or not speak at all
- seem not to notice other people around them and be difficult to engage with, even to the extent of avoiding interaction
- respond unusually to other people's facial expressions or feelings or not respond at all
- play with little or no imagination or pretence
- not be interested in other children or play with them
- not take turns when playing
- have reduced sharing of 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 difficulty looking to see where another person is looking (known as 'gaze monitoring')
- rarely or never start activities or play
- use unusual repetitive hand and finger movements
- react, or not react at all, to particular sounds or sights.

Not all children with autism will show all the signs we have listed.

What are the signs of possible autism in school-age children?

Your child may have difficulty communicating with people

Your child may:

- have had unusual language development when they were younger
- use different language to that of other children their age
- sound unusual when they speak
- repeat words or phrases 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
- use only limited language or talk freely only about things they are interested in, or
- have difficulty using or noticing non-spoken communication signals.

Not all children with autism will show all the signs we have listed.

"My son didn't speak then when he did he sounded different." Parent of child with autism

Your child may behave differently in social situations

Your child may:

- not be interested in playing with other children
- try to join in inappropriately with other children's play (for example, your child may seem aggressive)
- behave in a way that other people find difficult to understand (for example, they may criticise teachers or not do as they are told)
- have difficulty understanding other people's feelings and perspectives
- 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.

Your child may have difficulties with interests, 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
- find large open spaces difficult (for example, they may stay at 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).

Your child may think and act differently to other children.

Your child may have:

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

Your child may also show some of the signs on page 7. Not all children with autism will show all the signs we have listed.

"Autism isn't something to be ashamed of."
Parent of child with autism

What are the signs of possible autism in young people?

Your child may:

- show differences between their ability at school and how they cope in social situations (for example, they may have difficulties with school breaks or work breaks, but manage 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 them.

Your child may have difficulty communicating with people

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), or
- not understand sarcasm – for example, when someone is making fun of something; or make eye contact, gestures and facial expressions at unusual times.

Your child may behave differently in social situations

Your child may:

- make friends easier with adults or younger children than with their own age group
- not share the same attitudes or interests as others in their own age group, or
- dislike someone getting physically close to them or not know how close they should get to someone else.

Your child may think and act differently to other children

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).

Not all young people with autism will show all the signs we have listed.

Your child may also show some of the signs on pages 8 to 10.

You can ask any member of your child's healthcare team or other professional to help you understand the information we have given on signs of autism.

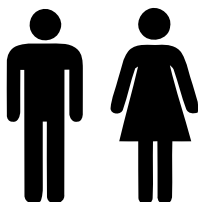
It is important to remember that if your child has some of these signs, they may have another condition instead of autism.

Girls may try harder to fit in with friendship groups by hiding their difficulties. They might do this by copying interesting behaviours of other girls in their class or by having more socially acceptable focused interests.



Recommendation based on research evidence

Health professionals should consider that girls and young women with autism may come to them with different signs to boys and young men.



How do professionals find out if your child has autism?

What should happen if your child has possible signs of autism?



Recommendation based on research evidence

If you and the professionals have concerns that your child may have autism, they may help you to fill out a particular type of questionnaire. This is to help gather information about your child, which will help decide if your child should be referred for an autism assessment.



Recommendation based on clinical experience

If you and the professionals think your child has autism, your child should be referred to a team of specialists for an autism assessment. This should be discussed with you. Support can be arranged for you and your child while you wait to see the specialists.



Recommendation based on research evidence

Children under three years who have regression (loss or significant deterioration) in language or social skills should be referred for an autism assessment.



Information

Before your child has an autism assessment, professionals making the referral should do the following.

- ☐ Explain to you that your child's experiences and behaviour suggest they may have autism
- ☐ Discuss the advantages of further assessment
- ☐ Check your understanding of the reasons for referral
- ☐ Explain to you how long you should expect to wait until your child goes for assessment
- ☐ Give you a copy of your child's referral letter to read in your own time
- ☐ Offer you and your family support

What happens at a specialist assessment?



Recommendation based on clinical experience

Because signs of autism vary, a specialist assessment should be carried out by various professionals from health and social care (known as a multidisciplinary team).

During the assessment, professionals will want to get to know your child and hear about their experiences.



Recommendation based on clinical experience

The assessment should involve:

- finding out about how your child has developed, the family situation and any problems your child is having (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:

- 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, autism spectrum disorders, mental health disorders, learning disabilities or epilepsy
- asking about any changes in the family (such as divorce or a family member dying), which may be affecting your child's behaviour, and
- asking about any problems your child is having now.



Recommendation based on research evidence

When asking about your child's history, the specialists may sometimes use a particular type of history-taking tool – for example, the Autism Diagnostic Interview, Revised (ADI-R); Developmental, Dimensional and Diagnostic Interview (3di); or Diagnostic Interview for Social and Communication Disorders (DISCO). These are interviews that help specialists to be consistent when asking about important issues connected with autism.



The specialists involved in your child's assessment can tell you about these kinds of parent and carer interviews. The organisations listed on pages 45 to 47 can also give you information on these interviews.

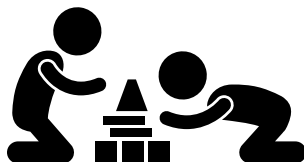
Space for your notes



Strong recommendation based on good-quality research evidence

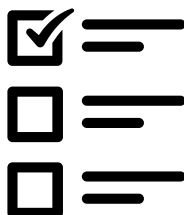
It is also important for the specialists to watch your child. They will either watch your child playing or doing tasks, or ask them specific questions. Sometimes the specialist team will use specific tools – for example, the Autism Diagnostic Observational Schedule (**ADOS**). These help the specialists to make consistent observations about children and young people.

ADOS is used to assess communication, social interaction, and play (or imaginative use of materials) for people suspected of having autism.



Recommendation based on clinical experience

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 with your permission, by contacting other people who can provide relevant information (for example your child's teacher or social worker).





Recommendation based on clinical experience

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

"I found the best thing for me to remember when going through assessment and diagnosis, and Dr X confirmed it for me, was that he was still my wee boy and was the same as he was the day before the diagnosis and would still be my wee boy after diagnosis." **Parent of child with autism**



Recommendation based on clinical experience

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 during lessons in the class, or how they act in social situations in the more unstructured parts of the school day (for example, playtime).

Educational psychologists help children and young people who have difficulties that hinder their learning and participation in school and other activities. These problems can include a range of emotional and social problems or learning difficulties.

What information should I receive at the assessment?



Recommendation based on clinical experience

To make sure you know what is happening, you should routinely receive written information. This may include copies of letters sent to the various professionals who have been asked to assess your child.



The specialists should do the following.

- ☐ Check that you and your child understand the reasons for your child's assessment.
- ☐ Explain the assessment and agree with you and your child how this will be organised and which professionals will be involved; and repeat their explanations and change their arrangements if necessary.

Understanding your child's profile

"It was a mistake to keep comparing my child to others and to focus on just the gaps and not strengths. Autism is a developmental difference and so of course there will be differences at any point in time."

Parent, one of whose children has autism

Children and young people with autism may have different strengths and problems, and all have communication difficulties. These can range from no speech to subtle difficulties such as not being able to understand sarcasm.



Strong recommendation based on good-quality research evidence

When your child is being assessed for autism, their speech, language and communication skills should also be assessed.

Assessment of speech, language, social interactions, facial expressions, body language and communication will involve observing your child in the clinic and observing or gathering information about how they behave in nursery or school. Finding out about your child's communication profile will help you and the healthcare professionals decide if anything more needs to be done to support your child's communication. It also helps the specialist team in its assessment.



Recommendation based on research evidence

Children and young people with autism may have a range of skills or difficulties with:

- thinking and learning
- everyday tasks such as self-care and keeping safe
- emotional and mental wellbeing.

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



Recommendation based on clinical experience

If you and the healthcare 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.

Occupational therapists are professionals who are trained to help people manage their daily activities

Physiotherapists are healthcare professionals who help with physical problems



Recommendation based on clinical experience

Children and young people with autism may process sensory information differently, such as sounds, sights and smells. Sensory difficulties should be taken into account when assessing your child's needs.

"A lot of the time she can't stand the noise in the gym hall. She needs to go to a quiet place for a while."

Carer of child with autism

Autism can be associated with other underlying conditions. If healthcare professionals think this may be so for your child, they will investigate further.



Recommendation based on research evidence

Healthcare professionals should consider whether your child should be offered a:

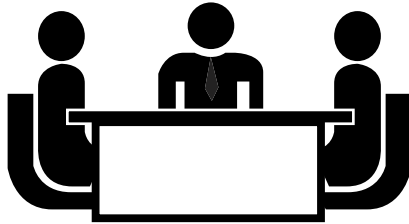
- physical examination
- hearing examination
- genetic testing, or
- investigations to rule out specific causes of autism.

What happens after the assessment?



Recommendation based on clinical experience

The team will talk with you about the results of your child's assessment as soon as they can. They should also send you a written report summarising what the assessment found and the team's decision about your child's diagnosis.



"For many people a blanket diagnosis of autism is not that useful – just what exactly does that mean?"

Parent of child with autism

"Some families and parents struggle to come to terms with diagnosis – they can need help with acceptance and also what this means for the future."

Parent of child with autism



Specialist autism assessment teams should do the following.

- ☐ Work with other agencies, in line with the 'getting it right for every child (GIRFEC)' approach stated in the Children and Young People (Scotland) Act 2014.
- ☐ Involve their colleagues from other agencies (education, social work, voluntary sector, careers advisors, and so on).
- ☐ Consider with you what interventions might meet your and your child's needs and refer your child on for such services as needed.
- ☐ Provide any necessary information about your child's particular place on the autism spectrum and about any other issues identified during assessment.
- ☐ Consider putting specific interventions in place, including for any other medical problems that may have been diagnosed.
- ☐ Discuss possible educational approaches with you and your child (as appropriate), including extra support for learning.
- ☐ Ensure that education professionals responsible for your child are fully informed about the assessment findings.
- ☐ Discuss any other issues that may be relevant to your situation, for example, the possibility of respite care (to give you a break from caring), social work support and how you can get support from your family.
- ☐ Provide information about:
 - any benefits you or your child may be entitled to
 - voluntary or community support
 - available opportunities for training to support autism.
- ☐ Identify other possible helpful information sources. Arrange for your family to have a named contact for ongoing help.

Does having autism make my child more vulnerable to other problems?

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

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

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

- epilepsy
- problems with eyesight
- hearing problems, and
- intellectual disability.



Strong recommendation based on good-quality research evidence

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



Recommendation based on clinical experience

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 autism. They should receive appropriate medical care for these.

In some families who have a child with autism, there is a higher risk that any brothers and sisters will also have the condition.

You can use this space to write down any questions you may like to ask.

What would help?

When your child is diagnosed with autism, your doctor and other professionals involved should discuss any possible interventions (approaches) that might help. It is also important to remember that your child has a right to benefit from their education and wider life experiences. Professionals involved should start interventions with your child as soon as they identify concerns (early intervention). Everybody working with your child needs to promote and develop your child's skills. To support your child, they will also need to consider adapting the surroundings that your child regularly encounters.

There is good evidence to show there are benefits to the many interventions that can be included in your child's care.

"Early intervention is really important – a meltdown at 3 years is quite different to a meltdown in a later age group." **Parent of child with autism**

"After diagnosis, everywhere I looked (literature, the internet, even the diagnostic criteria) focused on 'deficits', things that needed to be 'fixed'. Instead I sought to understand how she experiences the world, her anxiety. I was then able to support my daughter and see her strengths shine through."

Parent of child with autism

Education, skills and training for parents



Recommendation based on clinical experience

Education programmes for you as the child's parent or carer known as 'parent mediated intervention programmes' can teach you skills to help your child's development and communication. These should be considered as an option for your child.



"Knowing how to deal with normal everyday occurrences such as hair cutting and over sensory stimulation and the distress and consequent meltdowns is important."

Parent of child with autism



Recommendation based on research evidence

Interventions to support communication, for example the Picture Exchange Communication System (PECS) or visual supports should be considered for your child.

Help with early communication skills



Recommendation based on research evidence

If your child needs help with communicating and coping at school, professionals will consider their individual needs and suggest an intervention that is best suited to them.



Recommendation based on clinical experience

Adapting your child's communicative, social and physical environment may be helpful; for example, teachers could use a timetable each day so your child knows exactly what is happening at certain times. Using lists or calendars may also help your child.



"When people gave me advice about different ways to help my child I wished I had asked more to understand why they were important and how they would help (for example, visual timetables). I think then I would have been able to use them more successfully at the beginning."

Parent, one of whose children has autism

Behavioural interventions



Recommendation based on research evidence

Behavioural interventions can be considered to help a wide range of behaviour in children and young people with autism (for example, sleep problems, relationships with siblings, meal times and visits to the dentist).



Recommendation based on research evidence

Children with autism should have access to support from staff trained in applied behaviour analysis-based technologies (for example the Picture Exchange Communication System, discrete trial training, task analysis, prompting, fading, shaping) to build their skills, communication, coping in school situations and adapting to new or different things. You can find out more about these from the healthcare professionals working with your child.

You and the healthcare 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, for instance in communicating, or it may be related to their overall level of development.



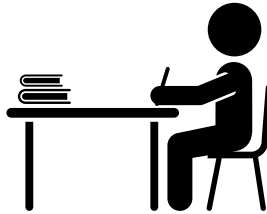
Recommendation based on research evidence

If your child experiences anxiety (feeling scared and worrying), a psychological therapy called cognitive behavioural therapy (CBT) can be used to help with this. CBT involves working with a healthcare professional to identify and deal with patterns of thinking that cause distress.



Recommendation based on clinical experience

Occupational therapy may help by adapting your child's environments and helping them with day-to-day activities and routines.



Autism 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 approaches based on your child's individual needs.

Are special diets helpful?



Not enough research evidence to tell us if something is of benefit

The research into interventions such as a special diet and nutritional supplements for children and young people with autism has not shown definite benefits. There is no need for your child to eat a special diet or take nutritional supplements such as vitamins.



If your child has difficulty eating a healthy diet, your doctor may ask a dietician for advice.



Recommendation based on clinical experience

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 autism.

Can any medicines help?

Medication (drug treatment) has not been shown to change autism itself, but it can help with problems that emerge because of autism, for example, ADHD symptoms or behaviours that challenge, such as aggression. Medication can help in the short term, but there is no information to show that it helps in the long term. Your doctor should carefully monitor the duration of any treatment. They will look at the balance between benefits and possible unhelpful side effects.



Before considering medication, healthcare 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 healthcare 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.



Recommendation based on clinical experience

Your child should only be given medication by healthcare staff who have been appropriately trained and who can get further help or advice if they need it. If your child is trying any medication, there must be a plan about how long they will try it for and how you and your doctor will decide if it has helped.

Coping with sleep problems



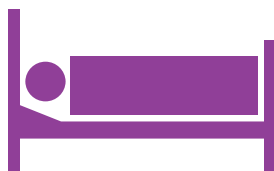
Recommendation based on clinical experience

Behavioural therapy should be considered for children and young people with autism who experience sleep problems.



Recommendation based on research evidence

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





Recommendation based on clinical experience

Before giving your child melatonin, you may 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.



Recommendation based on clinical experience

Children with autism who have sleep difficulties may also show signs of possible 'sleep apnoea' or the less severe 'sleep disordered breathing' (snoring, choking or periodic stopping of breathing during sleep). As well as causing sleep difficulties, these are possible causes of daytime behavioural difficulties (because of lack of sleep and tiredness). Your child should be referred to sleep medicine services for assessment, if these problems are suspected.

Coping with behaviours that challenge



Recommendation based on research evidence

Healthcare professionals should consider prescribing **antipsychotic medication** to reduce **behaviours that challenge**, but only for the short term (eight weeks). You should be informed of potential side effects (such as tremor, drooling, sedation and weight gain) before your child starts treatment.



Recommendation based on research evidence

Your child should be reviewed after three or four weeks of taking **antipsychotic medication**. If there is no benefit after six weeks, treatment should be stopped.

Behaviours that challenge

include withdrawal, isolation, aggression, self injury, and disruptive and destructive behaviours. These behaviours can be related to agitation and distress, for example because of sensory overload or a change in routine.

Antipsychotic medication is

used to help calm your child if they are agitated. It can also be used to treat severe anxiety in the short term.

Coping with difficulties concentrating and hyperactivity



Recommendation based on research evidence

Children and young people with autism and **ADHD** may benefit from a treatment called methylphenidate. It may help your child's ability to concentrate and reduce any impulsive behaviour or overactivity.

ADHD

is a condition where a person has consistently high and inappropriate levels of activity, acts impulsively and is unable to pay attention for long periods of time.



Recommendation based on clinical experience

If your child tries methylphenidate, they will be given a test dose to check if they experience any unhelpful side effects. These can include:

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

Any side effects that might emerge if treatment continues should be carefully monitored.

What services are available?

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



Strong recommendation based on good-quality research evidence

It is important that everyone who is working with your child has the knowledge and skills to support autism. For example, teachers should be able to include a child with autism in their classroom.

Local authorities and NHS boards should make sure staff are suitably trained to work with children who have autism.



Will I receive information and training?



Strong recommendation based on good-quality research evidence

It is important that you and your child receive clear and accurate written and verbal information about autism. A report detailing the findings and outcome of the autism assessment should be sent to you and (with your agreement) those multiagency professionals involved in supporting your child. If you do not understand any aspect of this report, or need things explained further, don't be afraid to ask.



Recommendation based on clinical experience

Caring for a child with autism can be stressful for you and your family. To help you cope, 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. Healthcare professionals will ask you about this and will consider helping you to 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 45 to 47.

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.

"I would say that going to support groups and meeting other families worked for us and we didn't feel so isolated."
Parent of child with autism

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

“Change can be highly distressing and needs to be communicated and planned for.” **Parent of child with autism**



Recommendation based on clinical experience

Moving from one service to another can be made easier by:

- you and the services planning ahead to make sure support is in place when your child moves
- increasing the contact you have with social workers during the move between services, and
- professionals making you aware of relevant legislation under the Adults with Incapacity Act (Scotland) and the Children and Young People Act (Scotland) 2000.

In Scotland, your child will be allowed to make decisions about their own healthcare when 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 you should still be involved in decisions about your child's care 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 autism can be confusing and frustrating. Many young people with autism feel better once they know that autism affects them in particular ways. Children and young people who have autism may experience bullying from other children at school who may not understand the condition. It is important for young people with autism to know they are not 'mad' or 'stupid'.



Recommendation based on clinical experience

To help you and your child cope with the difficulties of living with autism, healthcare staff should encourage you both to learn about autism and about the interventions and support available.

You could encourage your child to read the separate booklet we have written for young people, or other books about autism. You can find a list of books that may help your child on pages 48 to 52.



"An autistic person is always autistic, but through maturity, opportunities to learn how to self regulate and the right support my son is achieving more than I thought he would."

Parent, one of whose children has autism

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 autism 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 autism.

"I would recommend that new parents find out about autism and autistic experiences, speak to other parents who are further down the line, and seek to truly understand your child. Get together with other parents and their newly diagnosed children, or speak with autistic adults who are real autism experts."

Parent, one of whose children has autism

You can use this space to write down any questions you may like to ask.



Information you should be given when attending any feedback appointments

The specialists should do the following.

- ☐ Allow enough time 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 autism, a member of the team should explain the main areas of difficulty (see page 5).
- ☐ Based on their current knowledge, offer information about:
 - what interventions could be tried
 - how autism might affect your child in the future
 - any further investigations the specialists might need to carry out, and
 - the next steps that a multiagency team should take to provide appropriate support.
- ☐ Provide information about what written feedback they will give you, and check with you and your child (as appropriate) how it should be made available to relevant professionals.
- ☐ 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 they think your child should not have the outcome of the assessment explained to them at the feedback appointment, discuss with you how and when it should be done.
- ☐ If 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.

Where can you find out more?

If you haven't found what you need in this booklet, here are some further sources of information. Some will be more relevant to you than others. The organisations we have listed may be able to answer any questions and provide support. You can ask your healthcare professional for details of local support groups who can help.

National organisations working with autism

NHS inform

The national health information service for Scotland.

Phone: **0800 22 44 88**

Website: www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/autistic-spectrum-disorder-asd

Autism Initiatives

A parent-led charity offering support to people with autism and their families.

Phone: **0131 551 7260**

Website: www.autisminitiatives.org

E-mail: hos@aiscotland.org.uk

Autism Network Scotland

Autism Network Scotland connects and communicates with those interested in the field of autism. It signposts autism professionals and practitioners, people with autism, their families and carers toward examples of good practice, resources and useful information.

Phone: **0141 444 8146**

Email: autism.network@strath.ac.uk

Website: www.autismnetworkscotland.org.uk/

National Autistic Society Scotland

The National Autistic Society Scotland works across Scotland to provide quality, personalised support and advice services for people with autism and their families and carers. Its website hosts a range of information on autism.

Phone: Autism Helpline **0808 800 4104** (10am–4pm, Mon-Fri)

Email: nas@nas.org.uk

Website: www.autism.org.uk

Research Autism

Research Autism provides information on high-quality, independent research into new and existing health, education, social and other interventions.

Phone: **020 3490 3091**

Email: info@researchautism.net

Website: www.researchautism.net

Scottish Autism

Scottish Autism provides a team of autism advisors trained and experienced in working with people on the autism spectrum and who can offer personalised help and support.

Phone: **01259 222 022**

Email: autism@scottishautism.org

Website: www.scottishautism.org

Carers Trust Scotland

Carers Trust is connected to a unique network of local carers centres across Scotland. These centres provide support by giving information and advice, providing access to breaks from caring, and helping carers to maintain their own health and wellbeing.

Phone: **0300 123 2008**

Email: Scotland@carers.org

Website: www.carers.org

Contact a Family – Scotland

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

Phone: **0131 659 2930**

Email: scotland.office@cafamily.org.uk

Website: www.cafamily.org.uk/scotland

Useful publications

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)

For young people

Autism: a booklet for young people

Scottish Intercollegiate Guidelines Network (2016)

Free to download from www.sign.ac.uk/pdf/pat145.pdf You can also ask for a free paper copy by phoning 0131 623 4720.

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)

Books for brothers and sisters of children with autism

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's syndrome?

J Welton

Jessica Kingsley Publishers (2003)

Siblings: The Autism Spectrum Through Our Eyes

J Johnson, A Van Rensselaer

Jessica Kingsley Publishing (2010)

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)

The Reason I Jump: one boy's voice from the silence of autism

D Mitchell

Sceptre (2014)

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)

I'm not Naughty I'm Autistic. Jodi's Journey

J Shaw

Jessica Kingsley Publisher (2002)

Pretending to be Normal

L Holliday-Willey

Jessica Kingsley Publishers (2014)

Eating an Artichoke

E Fling

Jessica Kingsley Publishers (2002)

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)

Freaks, Geeks and Asperger Syndrome: A user guide to adolescence

L Jackson

Jessica Kingsley Publishers (2002)

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

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)

Websites

We do not accept responsibility for the content of the websites listed.

Autism Toolbox

Website: www.autismtoolbox.co.uk

The Autism Toolbox website is provided by the Scottish Government in partnership with the national charity Scottish Autism with support from Autism Network Scotland.

It is a resource to support the inclusion of children and young people with ASD in mainstream education services in Scotland.

Asperger and ASD UK On-line Forum

Website: www.asd-forum.org.uk

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

British Dietetic Association

Website: www.bda.uk.com

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

Department for Work and Pensions

Website: www.dwp.gov.uk/lifeevent/discare

Provides information on benefits and Disability Living Allowance.

Enquire

Website: 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.

My World of Work

Website: www.myworldofwork.co.uk

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

National Autistic Society (NAS)

Website: www.autism.org.uk

The NAS website includes information on parent training and support programmes, EarlyBird and Help!

Research Autism

Website: www.researchautism.net

Dedicated to the promotion of high-quality research into autism treatments and other approaches.

Scottish Transitions Forum

Website: www.scottishtransitions.org.uk

The Scottish Transitions Forum aims to improve the experience of people with additional support needs, as they go through life transitions, particularly the transition of young people from school or college to adult life.

Skill Scotland

Website: www.skillsotland.co.uk

An information and advice service for young people over 16 and adults with any kind of disability in education, training and employment.

Sleep Scotland

Website: www.sleepscotland.org

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

Talk about Autism

Website: www.talkaboutautism.org.uk

Part of the Ambitious about Autism website and is a safe and friendly online community to share experiences, get support and discuss autism.

You can use this space to write down any questions you may like to ask.

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How are SIGN guidelines produced?

Our guidelines are based on the most up-to-date scientific evidence. We read research papers to find evidence for the best way to diagnose, treat and care for patients. If we cannot find this out from the research evidence, we ask healthcare professionals to use their clinical experience and judgment to suggest treatments.



1

Identify questions



2

Search for evidence



3

Look at the evidence



4

Make judgements
and recommendations



5

Publish



6

Let everybody know
about our guidelines

You can read more about us by visiting www.sign.ac.uk
or you can phone **0131 623 4720** and ask for a copy of our booklet
'SIGN guidelines: information for patients, carers and the public.'

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice for healthcare professionals, patients and carers about the best treatments that are available.

We write these guidelines by working with healthcare professionals, other NHS staff, patients, carers and members of the public.

If you would like a copy of this booklet in another language or format such as in large print, please phone **0131 623 4720**.

www.sign.ac.uk



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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.

