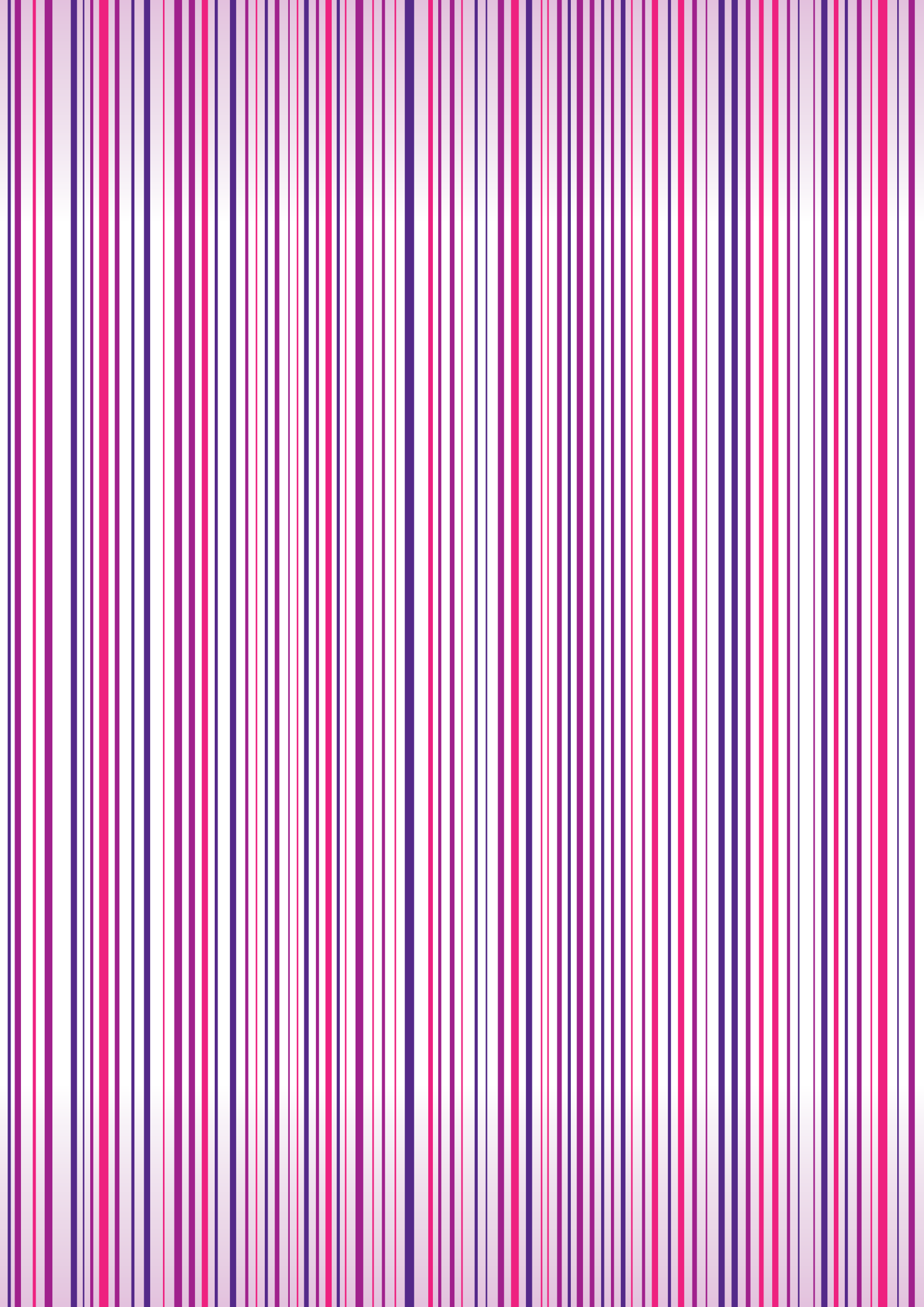


Information

for parents and carers with a child or young person recently diagnosed with **Autism**

Get Set  Autism

ENABLING FAMILIES



Foreword

The booklet is based on an information pack that was developed by Autism Argyll in 2001. We recognise the time around diagnosis can be difficult and emotional for parents, and the type and quality of information they receive can be variable.

Professionals in Argyll and Bute who are involved in diagnosing children with autism can give this booklet to parents. It is not meant to be comprehensive about autism, but it does give parents good-quality, unbiased information that will help immediately after diagnosis.

In 2015 Scottish Autism and Autism Argyll worked in partnership and successfully achieved five year funding from the Big Lottery Fund to deliver the Get Set 4 Autism project across Argyll and Bute.

Get Set 4 Autism offers all parents of recently diagnosed children in Argyll and Bute support from an Autism Advisor and access to the award winning online parent and carer support programme, Right Click.

We feel sure this project will be helpful and informative for you at this time.

25 September 2018

Scottish
autism



Delivered by Scottish Autism in partnership with Autism Argyll, funded by The Big Lottery.

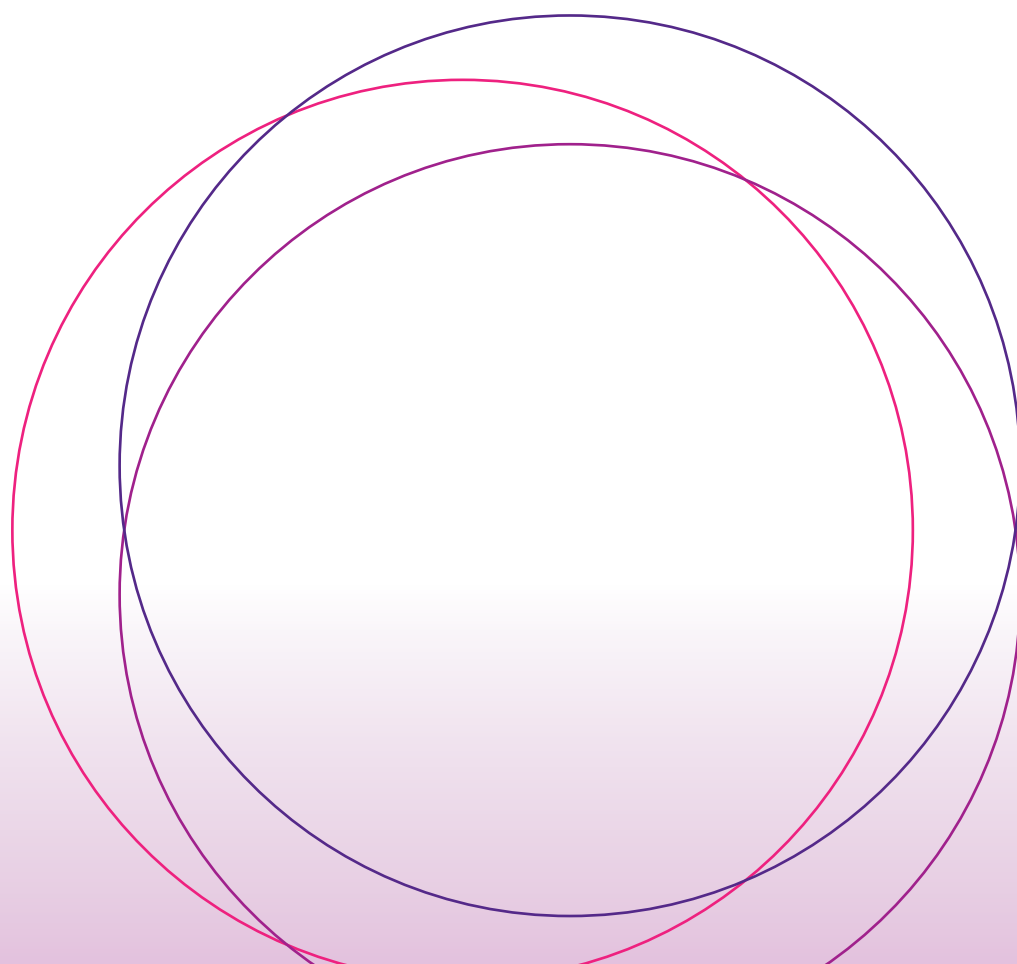
About the author

Alison Leask wrote this booklet intending it for parents and carers at the time their child or young person is diagnosed with autism.

Alison had worked for over 25 years as a health professional before her eldest son was diagnosed with autism. She then realised that better knowledge and understanding of the condition was important for all concerned.

In 2006 she gained her Master's in autism from the University of Strathclyde.

Alison was chair and co-founder of Autism Argyll: a parent, carer and professional information and support group that formed in August 2000 and ended in November 2018. She is currently Vice Chair of Scottish Autism and has been involved in many local and national autism initiatives.



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Introduction

If you have just been told that your child or young adult has been diagnosed with autism this booklet will tell you the main things you need to know.

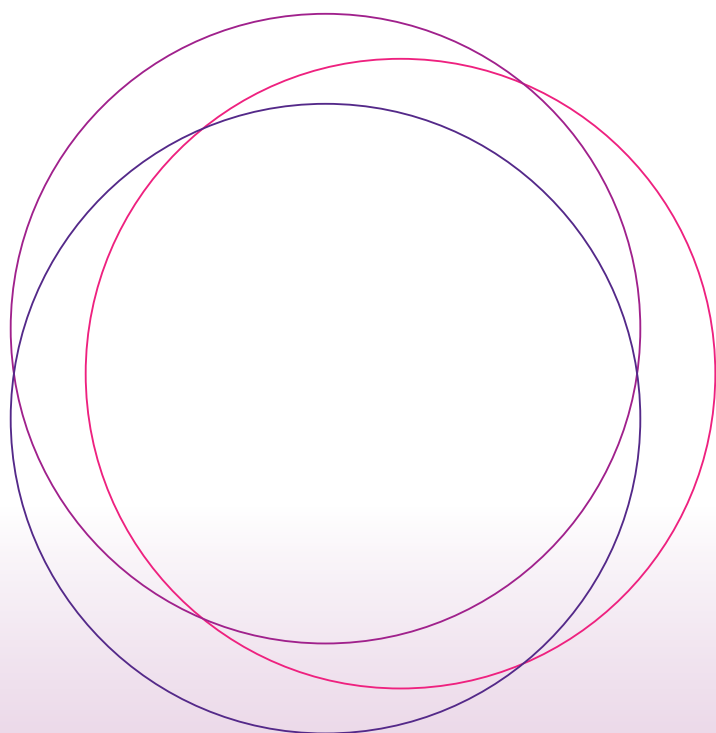
Although the diagnosis may leave you with mixed feelings, it will allow you and your family to better understand and help your child with their genuine difficulties.

This booklet is a first step and gives you the kind of information on autism that will be most helpful at this time. It is not meant to cover everything in depth but will explain where to find further good-quality, useful and unbiased information.

The next step for you and your family will be the Get Set 4 Autism project. You can read about the Get Set 4 Autism project in more detail on Page 30 of this booklet.

Your Autism Advisor will arrange a meeting soon after your child receives their diagnosis and help you to understand all about autism. They will also explain what the Right Click programme is and how you can sign up and take part.

You and your family will now be learning about how to deal with the issues you face every day.



Diagnosis

Medical or mental health professionals generally make the diagnosis of autism, but this depends on where you live as services develop to meet local needs. For pre-school and school-age children, multi-professional teams should make the diagnosis. The team may include various combinations of a paediatrician, psychiatrist, psychologist, speech and language therapist, and occupational therapist.

People with autism react in different ways in different places. For example, how they behave in school may differ from how they behave in a one-to-one session or at home. The diagnosis will be based on assessments made in different settings by some of the team. You will also have been asked for information about your child's development and any areas of concern that you have. It may have taken several months to gather and assess all this information.

The assessments give a complete picture of your child's strengths as well as their areas of difficulty. As well as enabling the health professionals to make a diagnosis, assessments are used as a basis for discussion on how best to support and help your child. As parents or carers you will be closely involved in these decisions. You are an expert on your child. Your input is central.

There are no medical tests to diagnose autism. However, medical tests may be needed to find out about other difficulties your child may have. The diagnosis is based on detailed observation of their communication skills, social understanding, behaviour and development, along with the information you give.

The team will use one of two sets of criteria in making their diagnosis: the World Health Organisation International Classification of Diseases-10 (ICD-10) (revised edition due in 2018) or the American Diagnostic and Statistical Manual 5th Edition (DSM-V). Both are internationally recognised.

Diagnosis

This will be a time of emotional upheaval and distress, even if you were expecting and felt prepared for the diagnosis. It may have been a long and difficult process.

Knowing why your child behaves or reacts in the way they do helps you to learn ways of dealing with their quirky behaviours and particular difficulties. It allows you as a family to move from asking 'why?' to 'what can we do to help?'

Autism is a widely recognised and accepted developmental condition. The diagnosis is not given lightly. Nor is it used to label children as naughty or parenting as poor.

A diagnosis informs everyone involved with your family, giving reasons for the way your child behaves and also allowing services and help to be developed in a specific and autism friendly way.

For older children and adolescents there may be mixed feelings and different opinions about receiving a diagnosis. The diagnosis helps to understand patterns of behaviour, likely progress in the future and what will help. However diagnosis is really a private matter for young people and their families. They may wish to think about the advantages and disadvantages of mentioning or not mentioning the diagnosis when seeking help or talking to others.

You will find yourself learning a lot about autism and will soon be using phrases and discussing topics that previously would have been unfamiliar. This is an important and necessary period of learning for the whole family as you will always be the advocate for your child. However it can feel like a roller-coaster and you do need to draw breath and find some time to relax, unwind and just be a family.

Family issues

No matter how well prepared you were for a possible diagnosis of autism, when it becomes a reality you may feel upset and distressed. This is perfectly natural. Parents/carers sometimes say that coming to terms with the diagnosis is like bereavement. You are mourning the loss of the child you thought you had and coming to terms with the child you actually have.

But remember that your child is still the same child. The only difference is that you now have a name for their quirky, idiosyncratic ways.

In the period after diagnosis, parents/carers often concentrate on finding information and learning as much as they can to help the child. This is understandable as all you want to do is the very best for your child. Having to grasp what this diagnosis means for your family, as well as meeting various professionals and learning 'their language', can be very daunting.

Families react in all sorts of ways and take varying lengths of time to come to terms with the diagnosis, and it's essential to help and support each other through this period. Sometimes talking to others is helpful; sometimes parents/carers may just wish to retreat to their own family home and shut out the world for a while. All these responses are normal.

Grandparents, close family and friends can often help and support you at this time, particularly if you have other children who need life to go on as before. However, depending on their age, your other children will probably be aware that something has happened and do need some explanation.

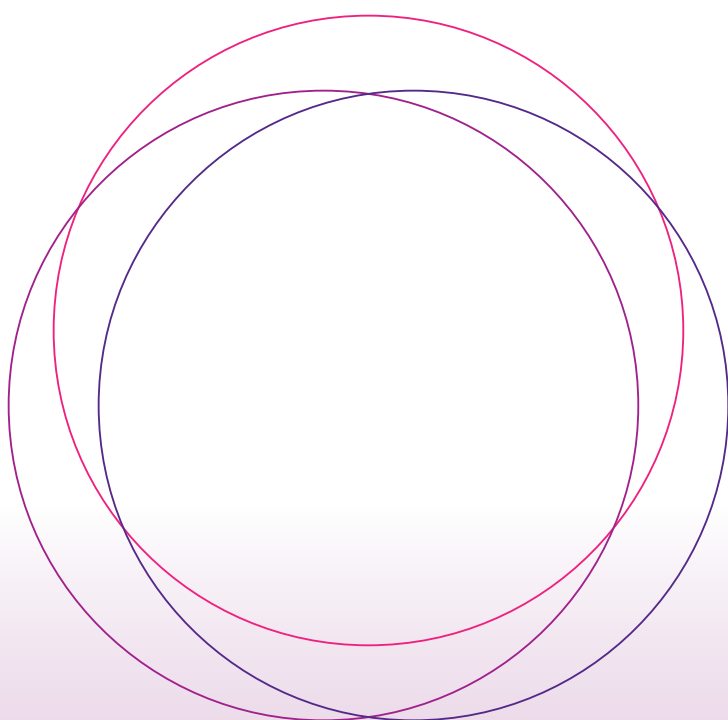
Family issues

There are a number of helpful books written for brothers and sisters that will explain autism in terms they can understand. You'll find a short list in the information and resources section of this booklet.

Many parents/carers have said that meeting other parents/carers who have gone through a similar experience can be very helpful. As well as giving emotional and practical support, they will be able to tell you about local activities (for the easiest way to find your nearest parent/carer support group, you can contact Scottish Autism).

With the growth of the internet, numerous online support groups can be found. However, as with all resources and information online, the quality varies from excellent to poor. An online community that can be recommended is 'Talk about Autism' www.ambitiousaboutautism.org.uk/talk-about-autism where you will be able to read about family experiences of living with autism.

Online support and information can be really helpful for various reasons, including ease of access, speed of finding information and keeping in contact. Families living in remote and rural areas may get particular benefit from Internet access.



What does autism mean?

Autism is an umbrella term. It covers a group of complex developmental disabilities and autistic children are affected in a variety of ways and to different degrees, and this is why it is sometimes referred to as a spectrum. They all share a set of core characteristics that affect an individual's ability to:

- understand and interpret social behaviour; this, in turn, affects their ability to interact with people
- understand and use both verbal and nonverbal communication
- be flexible in their thinking and in their behaviour

The term autism includes a number of sub-groups such as:

- autism (sometimes called Kanner's or classical autism)
- Asperger syndrome
- high functioning autism
- atypical autism
- pervasive developmental disorder (PDD)
- pervasive developmental disorder not otherwise specified (PDDNOS).

Scottish Autism has a short interactive animated online resource that has been developed in partnership with a person with Asperger syndrome which helps to visually explain the autism spectrum. This resource can be found at www.understandautism.org

What does autism mean?

Autism can be diagnosed in people with all levels of ability from those with significant learning disabilities to those with a high IQ.

Autistic individuals often perceive light, noise, smell, taste and touch in a way that is either: hyper (more intense responses than expected), or hypo (less intense responses than expected).

Autism is more common in boys than girls, though it is likely to be under-diagnosed in girls. The causes of autism are poorly understood with no clear, single underlying cause. Research increasingly points to genetic (inherited) factors.

Parents or carers do not cause autism to appear nor is it caused by a lack of affection or the way a child is brought up.

Autism can occur alone or with other conditions, such as attention deficit hyperactivity disorder, dyspraxia, dyslexia, sensory impairments, epilepsy, and learning disability.

Autism also occurs more often in people with genetic syndromes such as downs syndrome, fragile X and tuberous sclerosis.

Autistic children commonly have high levels of anxiety because of difficulty in making sense of the world around them. This is compounded by their difficulties in communicating how they are feeling and their anxiety may be displayed through such behaviours as tantrums, distress or trying to withdraw from particular situations.

Looking at the core characteristics in more detail

Like everyone, an autistic person is an individual first and foremost with his or her own personality, so these are general observations.

To be diagnosed with autism, the child must have difficulties in all three key areas set out below, but some difficulties may be more obvious than others.

Difficulties with social understanding

This is one of the areas that parents/carers and family are particularly aware of, with your child having difficulty in starting and maintaining conversations, and recognising or understanding other people's points of view. Eye contact may be limited or appear abnormal; for example, the child may stare or be reluctant to make eye contact.

Some individuals may be aloof and actively avoid social contact. Others may seek contact but in ways that seem odd or inappropriate.

Autistic children find it hard to play and make friends because they don't understand the social rules of life that most of us learn without conscious effort.

Sometimes autistic individuals are thought to be lazy, difficult or just naughty by people who don't know they have genuine difficulty understanding what is expected of them. This can make parents/carers feel inadequate and doubt their ability to deal with their own children.

Your child has a particular set of difficulties that need kindness, help and understanding from all those involved in their life.

Case Study

Jack (age 4) has a diagnosis of autism. Because he does not speak, his behaviour communicates his feelings.

He attends nursery five mornings each week.

Jack seems content to be in the room with the other children but rarely plays with them.

One of his favourite activities is water play, and he will also stand alongside and watch another child play with the water.

He likes toy cars too and spends time organising them in a particular way. But Jack becomes upset and distressed if one of the other children approaches him or tries to join in his game by moving cars.

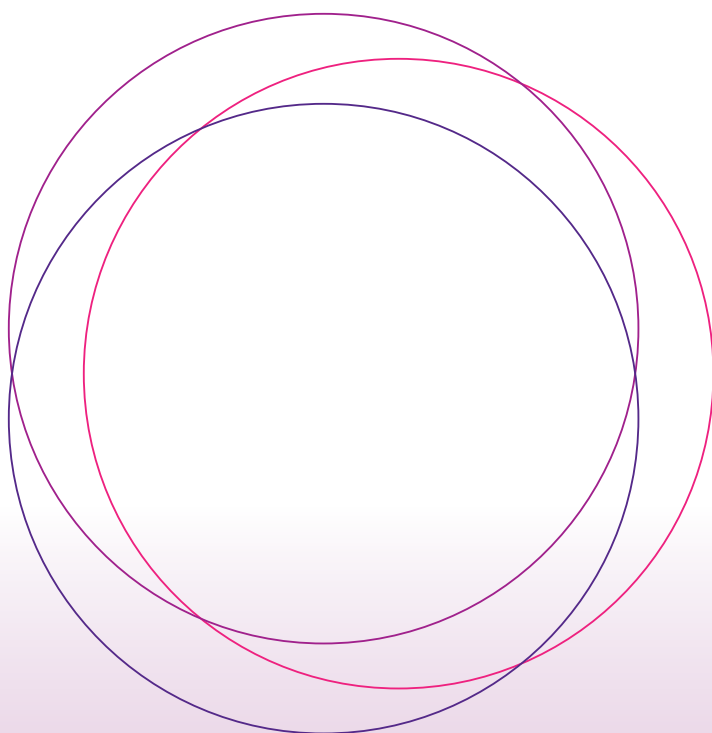
The nursery staff support Jack by showing him different ways of playing with the cars and encouraging him to play alongside other children. When he is comfortable with that, the next step would be to introduce turn-taking play.

Difficulties with communication

Communication can be broadly divided into verbal (speech and words) and non-verbal (body language, facial expressions). Autistic individuals will have impairments in all these aspects of their communication, although it may show up in different ways in different individuals. Many autistic young children are late in developing speech, or may repeat or echo what is said to them and this is known as echolalia. Some autistic children may never develop functional speech. However, there are many different ways of encouraging meaningful communication, such as using pictures, photos, gestures, sign language or written words. The choice will depend on the child's preference and ability.

Those with Asperger syndrome are often fluent speakers but they may sound over-formal and very precise. Their speech will lack intonation and they interpret comments in a very literal way. Rather than having a conversation with you they may talk at you regardless of the level of interest you show.

Their good verbal ability can mask genuine difficulties in understanding what others are communicating and even in making themselves understood as they would wish.



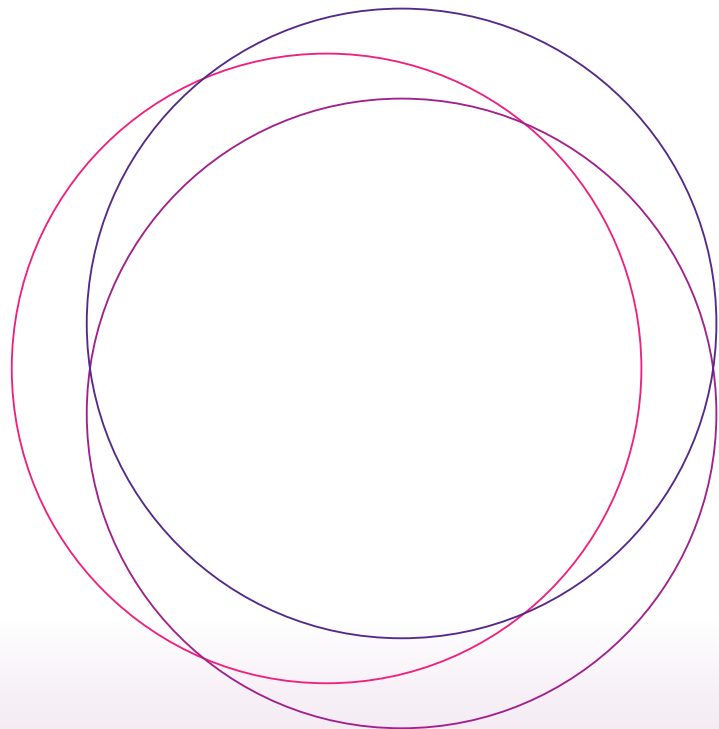
Case Study

Sundar is a young man with Asperger syndrome. His special interest is gaming and he will talk at length and in great detail to anyone who expresses even a passing interest in his favourite game.

Sundar cannot 'read' the signs of lagging attention of his classmate Simon and will continue talking regardless.

A simple tactic could be:

'Sundar, you can speak about your favourite game for five minutes and then we are going to talk about Simon's favourite game'.



Difficulties with thinking and behaving flexibly

Autistic children are limited in their ability to develop pretend play and often will not play with toys in a conventional way. They may be more interested in the texture or smell of objects or be fascinated by one particular aspect of a toy, like the wheels.

They may imitate scenes from a favourite film, DVD or TV programme – they may be word perfect but unable to include other children in their game. They prefer to play alone or alongside other children rather than with them.

Many autistic individuals develop a 'special interest' or hobby that may be on an unusual topic, e.g. road-signs, types of safes, cash registers. Their attention to detail is excellent and they derive great pleasure from these interests. A special interest can be used as a route to meaningful interaction with the child. These interests can sometimes become all-consuming and interfere with the family's daily life if not controlled and limited in a kindly way. Their reliance on set, predictable learned routines to help make sense of the world means that any unexpected change may result in confusion, extreme reactions and difficult behaviour.

As parents, carers and adults we have to learn how to be more predictable and to prepare the autistic individual for change. Certain challenges can be particularly demanding for the families of some children, including problems with sleeping, diet, toilet training and developing personal care skills. You will find a list of useful contacts and recommended books in the resources section.

Case Study

David (age 9) loves cash registers. He spends many happy hours poring over a catalogue with pictures of his favourite designs, memorising all sorts of detailed information.

Shopping trips became very difficult for the family as David only wanted to visit the shop that used his favourite type of cash register. He also found it very distressing to leave the shop.

A simple strategy was introduced:

David was promised that he would be taken to his favourite shop and allowed to spend a specific period of time there after the family shopping was completed.

This was supported visually with a picture of the supermarket, then a picture of the favourite shop and cash register, then a picture of home. The pictures were placed in order on a card that David could take with him.

This gave David the knowledge that his activity would actually happen and it allowed the family to have a more pleasurable outing.

What can you as a family do to help?

Although it is the child or young person who is diagnosed with autism, the family has to live with it every day. This is why it is most important to involve the whole family in learning and understanding about the condition, with everyone working together and supporting each other. Grandparents and close family members or friends can be very supportive and are often willing to help in practical ways, particularly if they understand some of the issues.

Everyone involved with the child or young person can learn some simple activities that will make a significant and immediate difference:

Use plain simple language – use key words or short simple phrases and support the words with a visual clue.

Give the individual time to think about the request or question and then time to form their answer without interruption (this could take as long as 10 - 20 seconds).

Be clear, concise and calm. Say what you mean and mean what you say. This is not always easy but it can prevent issues from escalating out of control.

Start using visual supports to help with everyday communication and understanding. (Pictures and photographs are useful for all ages; calendars and lists can be very helpful to more able young people).

Approaches and Interventions

There is no known cure for autism however with the right support people can progress. Key to this is an appropriate education. It is important that any support is personalised and takes account of the way autism impacts on thinking, information and sensory processing.

All autistic children benefit from a clear structure and regular routines in their daily life and this is central to any management plan. There is a lot of debate about different approaches, with parents, carers and professionals often holding strong views about particular interventions they feel have worked for them.

Approaches aim to promote your child's development and are either focused on helping them to learn skills or changing their environment to support their learning. No one approach is recognised as better than another, so you often need to try out various methods to see what works best for the child and the family.

Many parents say they would like help and advice with everyday issues such as sleep, diet, and toilet training. As you work your way through the Right Click programme you will learn a great deal about which approaches could be helpful to your child and family.

The online resource Research Autism www.researchautism.net is a useful place to find good quality information on approaches and interventions.

Education issues

Education is always uppermost in the minds of parents/carers and this is especially true when your child has additional needs. The type of education provided depends on local authority policy and where you live. Most autistic children attend a mainstream school or possibly a specialist unit attached to a mainstream school. Some children will attend a special school for children with learning disabilities.

Whichever type of school your child attends, it is important that everyone involved with them has a basic knowledge, understanding and awareness of the implications of autism and how best to deal with it.

Education is a complex and important area for a family with an autistic child, and there are many sources of information to explore. The Autism Toolbox is an excellent online resource developed for all schools in Scotland. There is a section in the Toolbox called 'Partnership with Families' that will be helpful to you as a parent. The Autism Toolbox can be found at www.autismtoolbox.co.uk

You could consider taking a trusted friend, relative or person who is knowledgeable about autism to important meetings to support you and give you confidence. This person is called an advocate. You may find it useful to make a list of questions you would like to ask at the meeting.

It is crucial the links between the family, the school, and all professionals involved with the family are strong. Communication, collaboration and respect are important for the child's progress and success.

Financial help

Having a family member with autism can be expensive so it's a good idea to be aware of the financial options that may be available. It is helpful to make a copy of any completed application forms before sending them. This allows you to refer back to exactly what was written if there is a query.

There are a number of ongoing changes to disability benefits and therefore it would be best to contact the Department of Work and Pensions for current information at www.gov.uk/browse/benefits/disability

Argyll and Bute Council offer information and advice on all aspects of Welfare Benefits. For further information and contact details for the Welfare Rights officer in your area go to www.argyll-bute.gov.uk/social-care-and-health/welfare-rights

Disability Living Allowance (DLA)

The main benefit for disabled children up to the age of 16 years is Disability Living Allowance (DLA). You may be able to claim DLA if the person needs more help than others of the same age. There are two components to DLA: a care component (payable at one of three rates from birth) and a mobility component (payable at two rates – the lower rate is payable from the age of five and the higher rate from the age of three).

Filling out detailed forms can be daunting, and the DLA application form requires you to focus on all the difficulties (and none of the achievements) that your child or young person has with daily living. Through your local support group you may find parents or carers who have successfully claimed DLA for a child with autism and may be able to answer your questions and give advice on filling out the form. The National Autistic Society website has very useful hints and tips on how to complete the form at www.autism.org.uk/about/benefits-care/benefits/children/parents-carers-tips.aspx

You can also get further information about DLA for children at www.gov.uk

Financial help

Carer's Allowance

This is a benefit paid to informal carers who look after someone with substantial caring needs. You can claim Carer's Allowance if the person you care for receives the higher or middle rate care component of DLA or Attendance Allowance and you spend at least 35 hours a week caring for the person. You can get further information about Carer's Allowance at www.direct.gov.uk

Self-Directed Support

Self-Directed Support (SDS) is a term that describes the way in which individuals and families can have informed choice about the way support is provided to them. SDS will be offered to individuals following an assessment and responsibility for assessment remains with the Local Authority. Further information on SDS can be found at www.selfdirectedsupportscotland.org.uk/ or from your local Social Work Department.

The Blue Badge Scheme

If you receive the higher rate mobility component of DLA, you automatically qualify for the Disabled Persons Parking Badge, or Blue Badge. Your local authority runs this scheme and further information can be found at www.argyll-bute.gov.uk/

The Family Fund Trust

The Trust provides grants and information relating to the care of severely disabled children. You can get more information on the Family Fund at www.familyfund.org.uk

Managing Money

The National Autistic Society has produced a resource which gives a basic overview of how to manage your finances. It is written for people with autism but may also be useful for their friends and family. You can find this information at www.autism.org.uk/managingmoney

Short Breaks

Living with a child with autism can be stressful and exhausting for the whole family, particularly if your child struggles with sleeping. Short breaks or some form of respite can be organised through your local Social Work Department. These can include a wide variety of schemes, ranging from play schemes or one-to-one activities to residential short breaks. As well as offering the child new experiences in their own community, the family benefit from having some free time to relax and recharge their batteries.

Contact your local social worker or Social Work Department to find out what is available in your area. Meantime, here are some useful tips to help keep things in perspective and make life feel a little easier:

You are not alone. Many parents/carers and families are going through similar experiences. Local support organisations or online forums are useful for sharing ideas.

You are not to blame.

Teaching basic communication and social skills and learning to deal with challenging behaviour in a positive way will improve family life for everyone.

Your child will continue to learn and develop, although the rate of development will be slower than average.

Keep a notebook and list contact details of any professionals and services involved with your family. The list can include sources of information or help that you have found particularly useful.

Some families find that a digital camera is valuable for producing visual supports in a quick and flexible way.

If everyone involved with your family works together, more will be achieved more easily.

Final comments

This booklet contains a great deal of information. It may have given you some answers; made you think of many more questions, and suggested various avenues to explore.

At the centre of all of this is your child or young person, and as the people closest to them your role as parents or carers is vital. You are the carers, managers, advocates, interpreters and teachers for this person in this complex and ever-changing world.

Parents/carers need to do all they can to help their children, and this help should start as soon as possible. Parents, carers and professionals must focus together on helping these vulnerable young people make sense of the world.

By providing support and giving them the tools to help them function more easily and less stressfully, we can hope that many grow up to live independent, fulfilling lives.

That is what we all aspire to.

Information and Resources

Scottish Autism Hilton House
Alloa Business Park Whins Road
Alloa FK10 3SA
Tel: 01259 720044
E-mail: autism@scottishautism.org
Website: www.scottishautism.org

National Autistic Society
– Scotland Central Chambers
109 Hope Street Glasgow
G2 6LL
Tel: 0141 221 8090
E-mail: Scotland@nas.org.uk
Website: www.autism.org.uk

Argyll and Bute Council Kilmory
Lochgilphead PA31 8RT
Tel: 01546 605517
Website: www.argyll-bute.gov.uk

North Argyll Carers Centre Albany Street
Oban PA34 4AL
Tel: 01631 564 422
Website:
www.carers.org/partner/north-argyll-carers-centre

Helensburgh & Lomond Carers SCIO
17e East King Street
Helensburgh G84 7QQ
Tel: 01436 673 444
Website:
www.carers.org/partner/helensburgh-lomond-carers-scio

Contact a Family Scotland
Craigmillar Social Enterprise and Arts Centre 11/9
Harewood Road
Edinburgh EH16 4NT
Tel: 0131 659 2930
E-mail: scotland@cafamily.org
Website: www.cafamily.org.uk/scotland

Sleep Scotland
8 Hope Park Square Edinburgh
EH8 9NW
Tel: 0131 651 1392
E-mail: sleepscotland@btinternet.com
Website: www.sleepscotland.org

Jessica Kingsley Publishers produce an extensive collection of books on autism and related conditions.

Jessica Kingsley Publishers 116 Pentonville Road
London
N1 9JB
Tel: 020 7833 2307
Website: www.jkp.com

Recommended reading

There is a wealth of information available on autism, including books, videos and of course the internet. At times parents/carers can feel overwhelmed by it all and at a loss where to start, so this list will give a starting point for good-quality information.

The Autistic Spectrum: A Guide for Parents and Professionals
L Wing. Constable (1996)

A Mind Apart: Understanding Children with Autism and Asperger Syndrome
P Szatmari. Guilford Press (2004)

Explaining the Enigma
U Frith. Blackwell Publishing (2003)

Books for parents/carers of younger children

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

Sleep Better! A Guide to Improving Sleep for Children with Special Needs. V M 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)

Sensory Perceptual Issues in Autism and Asperger Syndrome. O Bogdashina. Jessica Kingsley Publishers (2003)

Books for siblings, friends and family

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)

Siblings. The Autism Spectrum Through Our Eyes
J Johnson A Van Rensselaer. Jessica Kingsley Publishing (2010)

Books for autistic adolescents

Finding out about Asperger syndrome, high-functioning autism and PDD.
G Gerland. Jessica Kingsley Publishers (1997)

Freaks, Geeks and Asperger Syndrome.
L Jackson. Jessica Kingsley Publishers (2002)

What is Asperger syndrome and how will it affect me?
National Autistic Society (2001)

Personal accounts (for families with an autistic child)

George and Sam. C Moore. Penguin Publishers (2004)

Through the Eyes of Aliens: A Book about Autistic People. J L 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)

Recommended reading

Personal accounts (for families with a child diagnosed with Asperger syndrome or high functioning autism)

Martian in the Playground.

C Sainsbury. Lucky Duck Publishing (2000)

Pretending to be Normal.

L Holliday Willey. Jessica Kingsley Publishers (2014)

Eating an Artichoke.

E Fling. Jessica Kingsley Publishers (2002)

Recommendations for parents/carers of older children/adolescents

Understanding and Working with the Spectrum of Autism. W Lawson. Jessica Kingsley Publishers (2001)

Asperger's Syndrome: A Guide for Parents and Professionals.

T Attwood. Jessica Kingsley Publishers (1997)

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.

S Ozonoff G Dawson J Mc Partland. Guilford Press (2002)

Recommendations for Teachers

Many of the books already recommended will be of interest to teachers. The books listed below are specifically for educational settings.

Autism in the Early Years: A Practical Guide.

V Cumine J Leach & G Stevenson. David Fulton Publishers (2000)

Asperger syndrome: a practical guide for Teachers.

V Cumine V Dunlop G Stevenson. Routledge. (2010)

A Best practice Guide to Assessment and Intervention for Autism and Asperger Syndrome in Schools.

L Wilkinson. Jessica Kingsley Publishing (2010)

Educating Pupils with Autistic Spectrum Disorders. A Practical Guide.

M Hanbury. Chapman Publishing (2005)

"Your going to love this kid!" teaching students with Autism in the inclusive classroom. P Kluth. Paul H Brookes. Maryland. (2010)

The Autism Toolbox. Autism Resource for Scottish Schools. A W Dunlop C Tait A Leask L Glashan A Robinson H Marwick. Scottish Government, Edinburgh. (2009)

The Autism Toolbox Online Resource
www.autismtoolbox.co.uk

Internet Resources

A word of caution: while the internet provides limitless information, assessing its quality can be very difficult.

Always be wary of any website offering a cure for autism.

Always be wary of any website looking for money in relation to autism.

Always be wary of any website offering or suggesting drug treatments for autism.

A website called 'Apraxia-Kids'

www.apraxia-kids.org/apraxia_kids_library/because-its-your-child-evaluating-information-on-the-internet/ published a short paper called 'Because it's Your Child!' by Sharon Gretz on how to assess the quality of information on a website. Although not about autism in particular, the general issues mentioned are relevant to all individuals looking for health information via the Internet.

Recommended websites.

Scottish Autism is the largest provider of autism specific services in Scotland and a leading authority and advocate for good autism practice.

www.scottishautism.org

The National Autistic Society is a UK Charity for people with autism and their families.

www.autism.org.uk

Healthtalk.org is a website with information on a range of conditions, including autism, from seeing and hearing people's real life experiences.

www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/topics

Research Autism is dedicated to the promotion of high quality research into autism treatments and other approaches.

www.researchautism.net

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

www.ambitiousaboutautism.org.uk/talk-about-autism

Get Set Autism

ENABLING FAMILIES

GET SET 4 AUTISM

In partnership with Autism Argyll and funded by The Big Lottery, Scottish Autism's five year Get Set 4 Autism project aims to provide post diagnostic support to parents and carers of children and young people aged 5-18 years old across Argyll and Bute diagnosed as being autistic.

Get Set 4 Autism combines Right Click, a comprehensive online support programme with enabling support from our Autism Advisors.

OUR AIMS

- Ensure that, following the diagnosis of their child, parents and carers have access to enabling support and reliable information.
- Provide a proactive and positive start for families at the time of diagnosis.
- Support families who have ongoing needs as a result of recent diagnosis.
- Improve the quality of family life by ensuring parents and carers have the confidence to support their child to manage the impact of autism on their development.
- Increase the empathy and understanding of professionals involved in the care, support and education of children and families.

HOW TO ACCESS

There are two main ways that families can access the Get Set 4 Autism programme:

- Parents and carers can refer themselves to the project.
- We can also accept referrals on behalf of families from professionals who are involved with them e.g. Paediatricians, Social Workers or Teachers.

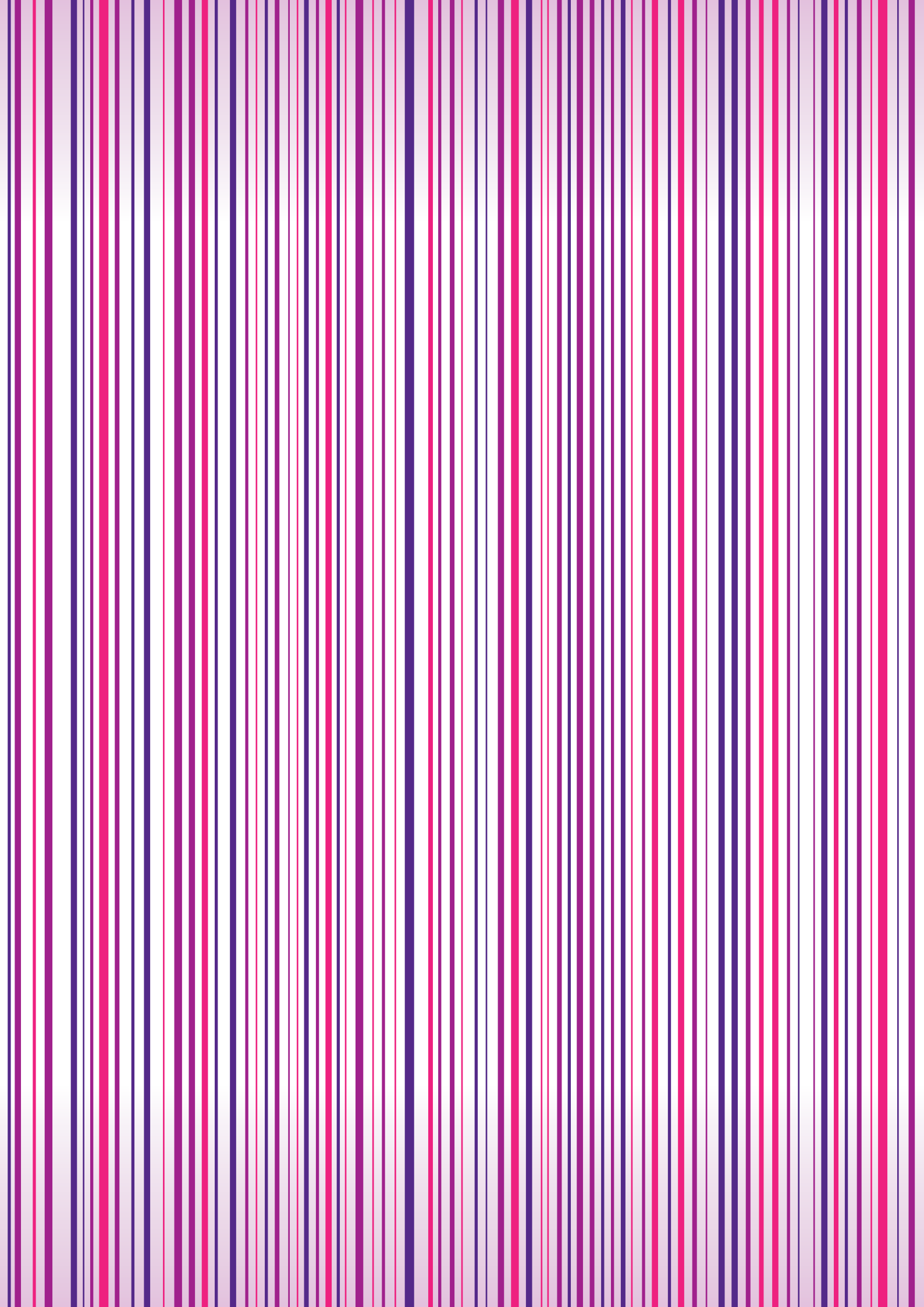
CONTACT US

To make a referral, please contact us on:

Email: getset@scottishautism.org

Tel: 07738755326 or 07713 475174

For further information visit: www.scottishautism.org



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