

A really simple guide

to wills and trusts for
people living with autism



Accept difference.
Not indifference.

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About this guide



Parents, carers and family members of people with autism often ask us for advice on providing for their loved ones in the future, and this booklet is a starting point.

It's designed to guide you through the options available, some things to consider and some of the related terminology that might be new to you. Please remember that it's important to take professional advice before making any long-term financial and legal decisions. This booklet should prepare you for meeting with a legal adviser.

About The National Autistic Society (NAS)

We are the leading UK charity for people with autism (including Asperger syndrome) and their families.

We were founded in 1962, by a group of parents who were passionate about ensuring a better future for their children. Today we have 20,000 members and over 100 branches, and we provide information, support and pioneering services for 100,000 people living with autism each year. We continue to campaign for a better world for people with autism.

Terminology

You'll see that some of the terms we use are [highlighted in blue](#). You can find an explanation of each of those terms in our glossary on page 32.

Peace of mind

Taking care of your family's future

Many people find themselves asking what will happen to their family member with autism when they're no longer around to care for them. You might have considered the same question – how to make sure your loved ones are provided for and looked after in the future. You know about their needs and you want to make sure those needs continue to be met after you are gone.

Making a will gives you the opportunity to have a say in the future of your loved ones and make sure they're provided for. It's a really important step to take – it will make sure your money goes where you want it to and that your loved ones get the best care and provision possible.

Providing for someone with autism

Care and provision for a person with autism can be complex, especially when benefits are involved. A trust makes it possible for you to leave money to someone with autism without affecting their entitlements to state support and to choose the people you would like to look after that money.

If you have a family member receiving community care services or means-tested benefits and you want to make sure that support continues, it's important to think about setting up a trust as part of your will.

We're here to give as much guidance and support in that process as we can.



Preparing a will can help to ensure financial security for your child

Gavin and Mhairi's story

When Gavin, six, was diagnosed with autism, his mum Mhairi struggled to come to terms with it. "I couldn't focus on anything work-related. I ended up on long-term sick leave, receiving medication. It put an incredible strain on family life, but fortunately, the NAS was always at the end of the phone."

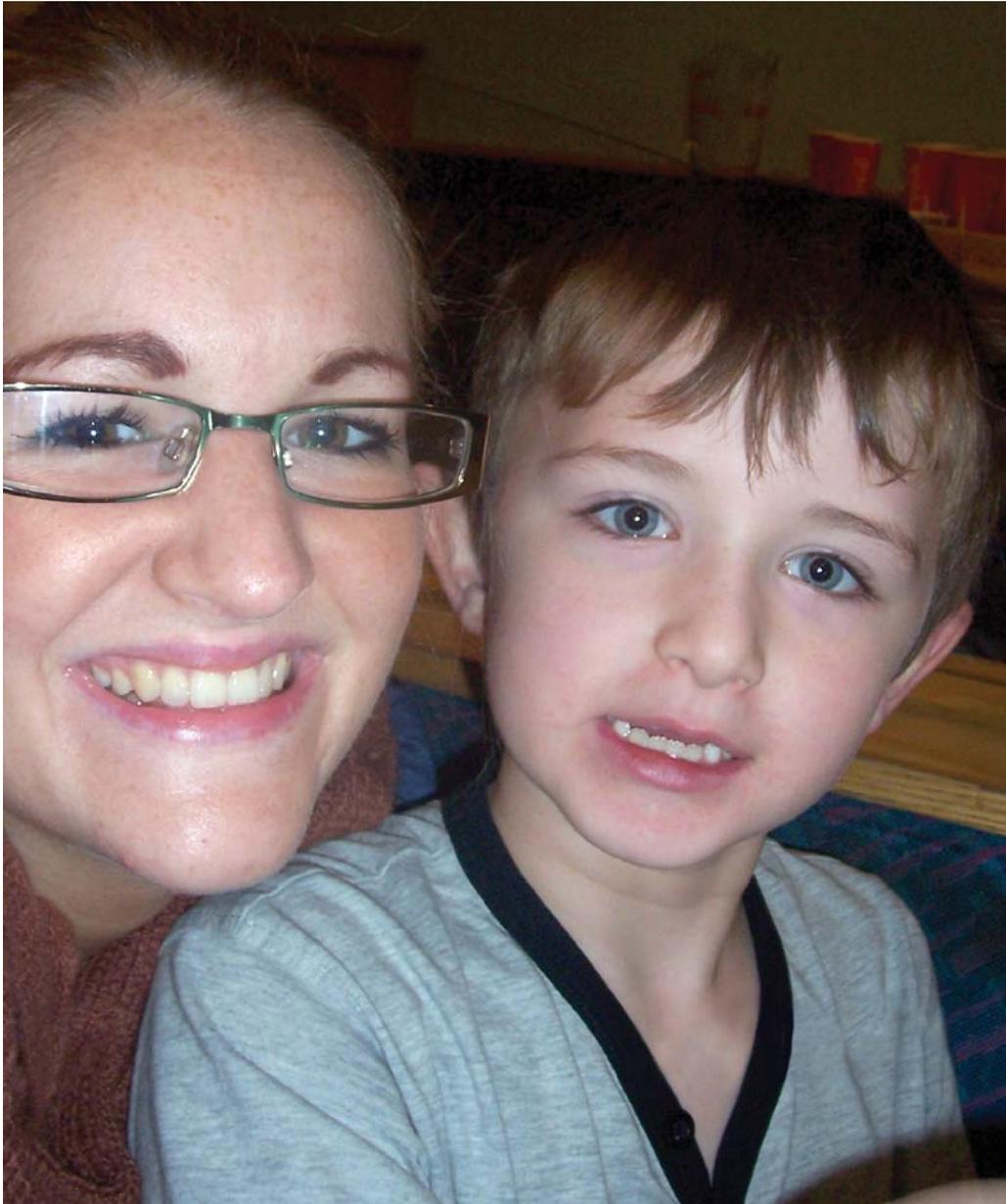
Mhairi's relationship with her daughter Emily was suffering, as they never got to spend time together without Gavin. Our Helpline told her about our befriending service, and Gavin was matched with a befriender called Rachel.

Gavin treasures the time he spends with Rachel, and now Mhairi can spend more time with Emily, doing the simple things Emily was missing out on before. For Mhairi, the help her family has received from the NAS has been priceless:

"No matter how much money you have got, you couldn't pay enough. I could never thank Rachel enough for what she has done." As for Gavin, when asked the best thing about Rachel coming to visit, he said: "She's just like mummy, only she's Rachel."

A gift in your will costs nothing during your lifetime, but it makes a huge difference in the future.

Thanks to the generous gifts people have made in the past, The National Autistic Society can help families like Mhairi and Gavin's.



Gavin and Rachel, his NAS befrienders

Making a will

You might think that making a will is expensive, but it doesn't have to be. And it's well worth the time and effort it takes. Here we help you to approach it in manageable stages.

Finding a legal adviser

Before you make any decisions about your will, it is important to speak to a legal adviser like a qualified solicitor or a professional will writer. You can easily find one online through search engines or using sites like www.yell.com – just search for solicitors or will writers in your area.

It's a good idea to check that they are experienced in advising about providing for someone with a disability, and to check costs before you set up a meeting.

Preparing for a meeting

Before you meet your legal adviser, it helps to list all the information you will need, for example:

- names and addresses of the people you would like to leave money to
- names of the people you want to carry out the wishes you express in your will ([executors](#))
- the money and other things of major value that you own ([assets](#)) and any debts ([liabilities](#))
- names of the people you would like to manage any trusts you plan to set up ([trustees](#))
- any gift that you would like to leave to charity, after you've provided for your loved ones.

We've provided a list of questions to guide you in the 'Helping you get started' section on page 26 of this booklet.



A resident at one of our adult residential services

Making a will

Once you know how much you are likely to leave in a will, and who you want to benefit, it's easier for your legal adviser to advise you correctly. They may help you consider things like how to reduce any Inheritance Tax, what kind of trust you could set up, and how to avoid affecting state support. You can find out more about the government figures for the level of capital allowed before state support is affected at www.directgov.uk in the section 'Money, tax and benefits'.

Choosing a guardian

If you have a child with autism, you can include guidance on how you would like them to be looked after in your will. For example, you can name a person that you would like to act as your child's **guardian**.

If your will includes provision for someone who is under 18 (or under 16, in Scotland), it's important for you to choose a guardian, or guardians, who will be responsible for that child's general upbringing.

Understanding types of gifts in a will

Gifts in a will are also sometimes called **legacies** or **bequests**.

There are three different types of gift that you can make.

Pecuniary gift – This is a set amount of money, or an item, that you choose to give. It is possible that this gift will decrease in value over time, so get advice from your legal adviser on how to make sure the value stays as you initially intend it.



Residuary gift – This is a proportion of everything you own, after all expenses, taxes and other outstanding debts have been paid. The remaining balance (which may increase in value as the value of what you own increases) can be divided between as few or as many people or organisations as you choose.

Reversionary gift – This is a gift such as a house, money invested in a trust, or stocks and shares, which you would like someone else to use during their lifetime. After that, the gift passes to a different person or organisation.

Keeping your will up-to-date

It's really important to keep your will up-to-date. If there is any change to your circumstances, or the circumstances of the people benefiting from your will, you need to consider whether your will is still appropriate. For example, if you marry or divorce, all or part of your will becomes invalid and the document may not work as you had planned. So it's a good idea to check your will every few years and change it if you need to.

Making changes

You can make a simple change, for example the name of the person who deals with your affairs after your death (**executor**), in a document called a **codicil**. But because nothing must be attached to your will, there is a risk that a codicil could become separated and lost and it may be safer to ask your legal adviser to make a new will. If the changes are only small, they may charge a reduced fee.

Lisa and James' story

Lisa has set up a trust to provide for her son James, who has autism, in case anything should happen to her.

"As a mother, it frightens you to think someone else could be looking after your child's money, but my solicitor explained that you can choose other people, who you trust, to help them make sure certain financial choices are the right ones."

"The one thing I felt after I included the trust in my will was a sense of relief. As a parent of a child with autism, you find so much is out of your control. It's nice to be actively doing something to help my son. I think every parent's fear for their child is what will happen in their future; especially their future without you. Once I'd made a will and included the trust, I felt less stressed."

Lisa is a member of The National Autistic Society and, when she re-made her will, she kindly left a gift to us. "I felt it was important to support such a vital service to people with autism and their families. The NAS has helped me and provided information which has helped my son, and I'm sure they will continue to do so as he grows up."

A gift in your will costs nothing during your lifetime, but it makes a huge difference in the future.

Thanks to the gifts that generous people like Lisa have made in their will, The National Autistic Society can help more families living with autism.



Lisa has written a trust into her will

Trusts: the options available

It's worth bearing in mind that there is a cost involved in setting up a trust, as well as annual administrative costs. But those costs should be minimal when balanced against the needs of the person with autism.

One of the simplest options you have is to leave your assets to a responsible person of your choice, in the hope that they will look after your loved one with autism. However it's worth bearing in mind the risks involved in this, for example what happens if that responsible person dies, becomes bankrupt, or for some other reason fails to look after your child as he or she promised.

Here's a summary of the different types of trusts to consider:

1) Life interest trust

One option is to set up a life interest trust (called a [liferent](#) in Scotland). This gives the person with autism the right to benefit from income generated by the trust fund during their lifetime. It means you can provide an income for your loved one with autism throughout their life, and after that, the trust fund passes to whoever you choose, for example siblings or grandchildren. If the person with autism has no other relatives and has been supported by a charity during their life, you may decide you want the fund to pass to that charity, to help more people with autism.

One thing to bear in mind with this type of trust is that it will be taken into account in the calculation of means-tested benefits. So it is unlikely to be appropriate if the person with autism will need any level of state support. Another issue is that the income from the trust will belong to the person with autism, so this option is only suitable if that person can manage their own finances.



A pupil at one of our schools

Trusts: the options available

2) Discretionary trust

A discretionary trust is the most flexible type of trust. It gives the **trustees** full powers to decide if and when the **beneficiaries** should receive either capital or income from the trust fund. This means that the money in the trust fund does not belong to any of the people who may benefit from it, and so it does not cause any loss of state support. The amount given to the person with autism can also be controlled so that it is within the limits for means testing, allowing maximum income benefits.

This is a helpful option if the person with autism is likely to be in residential care for life, dependent on substantial state support or unable to manage their own finances. You need to bear in mind that there are taxes that apply to trusts, and the administration of trusts, so it's a good idea to discuss this with your legal adviser before making your decision.

You can extend the provision made through a discretionary trust by setting up a personal fund to pay for the needs that will not be met by state support, such as holidays or computer equipment. Trustees can be given a power to advance capital, so that rather than paying the funds to the person with autism, they pay the funds directly to the supplier, for example the travel agent. These payments would not be taken into account in calculating entitlement to state support.

If you do include a discretionary trust in your will, it is very important to keep your will up-to-date, taking into account any changes to state support.



3) Disability trust

This is a type of discretionary trust that can be set up for a person who is disabled (according to the definition outlined by the government). As well as the benefits already mentioned under discretionary trusts, the benefit of a disability trust is that it is not taxed in the same way as other trusts. Whereas other trusts are affected by **periodic taxes** which happen every 10 years or so, taxing a trust for 6% of the total amount at that time, those charges don't apply to a disability trust.

However, with a disability trust, at least 50% of the funds must go to a disabled person. For example, if a disability trust is set up for three children, one of whom has a disability, and the children were to be given £100 out of the trust, then two of the children would receive £100 but the disabled child would have to get £200.

4) Private charitable trust

This type of trust can be useful if a person with autism is likely to be cared for in a residential service managed by a charity. It has the advantages of freedom from tax and protection from any loss of state support.

A potential drawback of this type of trust is that it can't be used purely for the benefit of your child. If you set up a private charitable trust by way of another trust (e.g. Charities Aid Foundation), you could name your child as a potential beneficiary, but there would be no binding obligation for the charity, as that would compromise both the charitable status of the gift and the state support of the beneficiary.

Trusts: the options available

Choosing trustees

If you are considering setting up a trust, you will need to consider who you would like to be the **trustees**. It is important to weigh up the balance between those people who are best able to understand the needs of the person with autism and those people who will also be able to cope with the administration of the trust (which can involve tax and investment implications). A family member, together with professionals such as a legal adviser or accountant, may be a sensible mix. Professionals will charge a fee. It is a good idea to compare rates and check their terms and conditions before you make any decisions.

The trustees you choose must be able to co-operate with each other, as their decisions must be unanimous. As a trust may continue to exist for up to 80 years, it is important that the terms include the possibility for new trustees to be appointed and others to retire. It is recommended to have between two and four trustees.

It is important to remember that you cannot control the trustees' decisions. For the trust to be of real benefit to the person with autism, the trustees should be given flexible powers. This will enable them to deal with any change in the circumstances of the person with autism. The best you can do is to have the terms of the trust written extremely carefully, whether in your will or a **trust deed**. If you want a discretionary trust to be set up, you can leave a **letter of wishes**. This is a document that gives your trustees guidance on how you would like the trust to be run.

Telling other relatives

If you do create a trust, it's really important to tell other relatives. Telling your family members in good time will enable them to draft their own wills to benefit the person with autism appropriately – guarding against the potential loss of state support by leaving any assets intended for a person with autism to the trust.



A child from one of our family support services

Ilse and Helen's story

Back in the 1960s, Ilse Burnell was deeply frustrated by a lack of understanding faced by her daughter, Helen, in school. Helen has autism, and the education system didn't know how to deal with her. Thankfully, Helen was able to attend Sybil Elgar School in Ealing – the very first school established by the NAS.

"I started doing my own research and that's when I found out about a brilliant lady named Sybil Elgar who set up a school for children with autism.

In the beginning there was no money or staff; just her and a group of determined parents who wanted their children to be accepted by society. Helen, my daughter, was one of ten children who attended this school. The school followed a similar curriculum to the national system and taught the children – initially deemed unable to be educated – to talk, read, write and socialise with others.

The NAS opened a door to my family when we didn't know where to go. I'm so grateful for the work that they do. I have decided to leave a legacy to the NAS, as I know it will help towards continuing their good work."

Make sure help is always at hand for children and adults with autism and their families. Leaving a gift to The National Autistic Society will help more families like Ilse and Helen's in future.



Ilse, Helen and Felix (Helen's dad). Ilse has left a gift to the NAS in her will

Give families a better future

Will you help us create a world where people with autism are respected and understood? Where families like Mhairi and Gavin's, Lisa and James', and Ilse and Helen's, get the support they need to live healthier, happier lives in the years to come?

Because we are a charity, we rely on your support to provide our services, information and advice, training and campaigns. You can help future generations of families living with autism, by considering leaving a gift to The National Autistic Society in your will. It doesn't have to be a lot, just whatever you can afford to give. We really appreciate any amount, and any type of gift you can offer, because it all helps us to create a better future for families living with autism.

Reaching out to all those affected by autism

There are over half a million people in the UK with autism – that's around 1 in 100. If you include their families, autism touches the lives of over two million people every day. No other charity has our breadth and depth of autism expertise, combined with our reach and potential to help so many families living with autism.

All people living with autism should be able to lead the life they choose

We envisage a world where everyone living with autism:

- › gets the support, education and training they need
- › lives with dignity and as independently as possible
- › feels part of their community and wider society
- › is understood by all professionals who support them
- › is respected for who they are by a knowledgeable public.

Give a lifetime of support

A gift to The National Autistic Society in your will can support people with autism throughout their lives. It could give children with autism the education they deserve through our specialist schools. It could help more families in crisis through keeping our helplines open. It could give adults with autism dignity and independence by funding our employment service. It could change the world for everyone with autism through funding our national campaigning and lobbying.

In the years to come, you can be a part of our work to support children and adults with autism and their families in so many ways.

Remember the NAS with a gift in your will, and improve the future for families living with autism

£1,000 could pay for a family like Mhairi and Gavin's to receive much-needed support from a befriender like Rachel, for a whole year.

£10,000 could fund a political campaign to support families like Ilse and Helen's, raising awareness and improving access to support and employment (like our Autism Act campaign, which made legal history).

£50,000 could help to fund our Autism Helpline, helping thousands of families like Lisa and James' with the advice and support they so desperately need.

Your questions answered



Phil Kenny, a professional will writer from Just Wills Ridgeway, answers some of the most frequently asked questions about wills and trusts.

Is making a will or changing a will expensive?

It's a common perception that making a will is expensive, when in fact it doesn't have to be. If your situation is complex, or you want to set up a trust, you will find that the costs are higher. But that initial cost should be worthwhile when you consider the benefits to you and your family in the future.

What is the difference between a will and a trust and do I need both?

A will is a legal document that gives instructions about what should happen to your money and possessions after you die. It needs to be signed, dated and witnessed by two people. A trust is a legal arrangement that allows a person or organisation to look after someone else's money when they can't themselves. If you want to provide for someone with autism in future, it's a good idea to have both.

How should I go about setting up a trust?

Once you've read the information on page 14 of this booklet, it's a good idea to get advice from a legal adviser, who will be able to advise you on the options and which one might work best for you.



How can I limit the amount of Inheritance Tax paid?

Once you have listed everything you own and owe, set up a meeting with a legal adviser to get advice on this.

Is it worth leaving money to the NAS if it's not that much?

Yes, absolutely. Any gift you choose to give to The National Autistic Society will always be gratefully received and will enable them to help more families like those you can read about in this booklet.

Can the NAS be my executor?

Unfortunately the NAS cannot act as executor to your will. Most people generally appoint a friend, a family member or a professional. If you do appoint a professional, your estate will need to pay their fees. A beneficiary can also act as executor.

Can a gift to charity help me pay less tax?

Any gift you leave to charity is currently exempt from tax and can help in reducing the tax your estate pays. HMRC or your legal adviser can advise you on the current thresholds for Inheritance Tax, which tend to change each year in April.

Can I give a donation to the NAS 'in memory' of a friend or loved one?

Yes. It is a really good way to remember and pay tribute to someone close to you. By making a donation in their memory, you are making sure that their memory lives on through the vital work that the NAS does for people with autism. For more information on this type of gift, please visit: www.autism.org.uk/donateinmemory

Helping you get started

We've provided these checklists to help you to be as prepared as possible for your meeting with a legal adviser.

After each question is a space for you to make notes in. There is further room for notes on pages 29 - 31.

Questions about your will

- What are your assets, and their estimated value? What are your liabilities? (Use our checklist on page 28 as a guide).

- Who do you want to leave gifts to in your will (i.e. who would you like to name as beneficiaries)?

- What are the full addresses (including postcodes) of those beneficiaries?

- Who do you want to be the executors of your will?

- Who do you want to be trustees, if you plan to set up a trust?

- 
-
- > Who do you want to name as a guardian for your child?

- > Do you have any particular wishes for your funeral?

Things to take to the meeting

- > Details of your bank and building society accounts.

- > Any shares and pension details.

- > Address details of any property/land you own or have any share in.

- > Names and addresses of the people you would like to be beneficiaries of your will.

- > Details of any previous will you have made.

Assets and liabilities checklist

Assets

Property £

Savings £

Investments £

Insurance £

Pension £

Belongings £

(for example car,
jewellery or other
items of value).

**TOTAL
ASSETS** £

Liabilities

Mortgage £

Loans £

Credit Cards £

Any other debts £

**TOTAL
LIABILITIES** £

BALANCE £

Glossary

Assets – Money and any other valuable things that you own, like your home, car, jewellery and investments.

Beneficiary – A person who benefits from provisions made in your will.

Bequest – Like a legacy, this is another name for a sum of money left in your will to a particular person or organisation.

Codicil – An extra document to your will, which can be read together with your will.

Dependant – A person who depends on you for financial support, because they are a child or they have particular needs.

Estate – The sum of the money, property and other assets that you are leaving in your will.

Executor – A person responsible for carrying out the requests you make in your will.

Guardian – A person given responsibility for taking care of a child, or an adult in need of support.

Inheritance Tax – A tax that is charged on the value of everything you own after your death. Not everyone pays Inheritance Tax on death. If the value of what you own is more than the limit set by the government (which varies from time to time), the tax is payable by your executors. For more information visit www.hmrc.gov.uk/inheritancetax

Legacy – Like a bequest, this is another name for a sum of money left in your will to a particular person or organisation.



Letter of wishes – An informal letter to your executors, signed and dated by you, where you can give more detail on the instructions in your will. It should be kept with your will.

Liabilities – Anything you owe, like mortgages, loans and any other debts you may have.

Liferent – (In Scotland) A legal right to receive the benefits of a property or other asset, during a lifetime.

Life tenant – Another name for a person who benefits from provisions made in your will.

Periodic taxes – All trusts are subject to taxes every so often. Make sure you find out the details of these from a legal adviser before you set up a trust.

Testator – A legal term for the person making a will.

Trust – A legal arrangement that allows a person or organisation to look after someone else's money.

Trust deed – A written legal document stating the terms of the trust and the trustees.

Trustee – A person responsible for managing a trust.

Will – A legal document that gives instructions about what should happen to your money and possessions after you die. It needs to be signed, dated and witnessed by two people.

Useful contacts

The National Autistic Society

393 City Road, London EC1V 1NG

Switchboard: 020 7833 2299

Autism Helpline: 0808 800 4104

Legacy Fundraising Manager: 020 7903 3559

Email: legacies@autism.org.uk

Website: www.autism.org.uk/legacies

The Law Society

Provides information on solicitors and can answer general legal enquiries.

Tel: 0870 606 2500

Email: info.services@lawsociety.org.uk

Website: www.lawsociety.org.uk

The Law Society of Scotland

Tel: 0131 226 7411

Email: lawscot@lawscot.org.uk

Website: www.lawscot.org.uk

The Law Society of Northern Ireland

Tel: 028 9023 1614

Email: info@lawsoc-ni.org

Website: www.lawsoc-ni.org

ENABLE trustee service

Its trustee service can help anyone in Scotland to set up a trust for a person with a learning disability.

Tel: 0141 226 4541

Email: trustee@enable.org.uk

Website: www.enable.org.uk



Office of the Public Guardian

Provides financial protection services for clients who are not able to manage their own financial affairs because of incapacity. It covers England and Wales only.

Tel: 0300 456 0300

Email: customerservices@publicguardian.gsi.gov.uk

Website: www.direct.gov.uk/mentalcapacity

The Society of Trust and Estate Practitioners

Tel: 020 7340 0500

Email: step@step.org

Website: www.step.org (find your local branch)

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The National Autistic Society
393 City Road,
London
EC1V 1NG

Switchboard: +44 (0)20 7833 2299
Autism Helpline: 0808 800 4104
Minicom: 0845 070 4003
Fax: 020 7833 9666
Email: nas@nas.org.uk
Website: www.autism.org.uk



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