

National Autistic Society Annual General Meeting (AGM) 2024

Members' Questions and Answers

Please note that questions have been edited for clarity and all personal details have been removed.

Questions answered during the AGM

Q: It has been proposed that the Articles be amended so as to require a certain number or proportion of trustees to be openly autistic.

We have corresponded with the person who submitted the question. A summary of the answer is:

The board requires a range of experience and expertise. When we do recruit we are generally looking for people who can fill any perceived gaps in the board's skills base at that time, for instance this may be social care experience, or financial management experience.

We also recognise that it's important that our trustees have firsthand knowledge and experience of autism, whether that's through an autistic family member, a professional role working with autistic people or because they themselves have an autism diagnosis. Our rules state at least 50% of our trustees must have such a connection. At this time, more than 50% of our trustees have a connection to autism.

In addition, we have developed and are implementing a number of initiatives we hope will enable us to recruit and create a more diverse organisation, including more autistic people. These initiatives have been driven by our organisational strategy, <u>Vision to Reality 2023-26</u> which outlines our focus and priorities for the next two years. One of the Foundations is "Making commitments to become a more ethnically diverse and inclusive workplace."

We have launched a programme called Pioneer, led by one of our autistic colleagues to specifically focus on this. Our Executive Board and Trustees have put their full weight behind this programme and we look forward to reporting back on its progress this time next year.

Q: Two points were raised by a member, which he requested be on the AGM agenda (i.e. not relegated to the Q&A session):

- 1. He wants each trustee to set out their personal objectives and areas of focus and to summarise their personal achievements in the year, and
- 2. He wants to know what the targets for the 'email your MP' campaign were, and whether these have been achieved.

We have corresponded with the person who submitted the question. A summary of the answer is:

1. Each of our trustees is listed on our website with a short biography.

Over the past few years, we have used professional recruitment agencies for trustees and as part of that process trustees send a covering letter which sets out why they want to take on the role. This specifies their objectives and skills in the role.

Following this, a panel of trustees interview them.

As you will be aware, members ratify the appointment of new trustees at our AGMs and ratification gives members the opportunity to consider their experience and the contribution they can make to tour charity so they have the opportunity to consider each trustee individually.

We recognise that it's important that our trustees have first hand knowledge and experience of autism, whether that's through an autistic family member, a professional role working with autistic people or because they themselves have an autism diagnosis. Our rules state at least 50% of trustees must have a connection. At this time, more than 50% of our trustees have a connection to autism.

2. Re the 'email your MP' campaign: We have corresponded with the person who submitted this question. A summary of our response is that there would be an update on our campaigning generally at the AGM – which you saw earlier in the presentation. "Email your MP" wasn't a campaign specifically, it was a single email subject.

Q: Member asks if we have plans to invite Kemi Badenoch to the meeting or to some other event to discuss her views on autism.

Our charity issued a public response to the views of Kemi Badenoch and some of the comments featured in the 'Conservatism in Crisis' pamphlet.

The comment is available to read in the News section of our website and on our X channel, and was also issued to media outlets.

You can read our full comment about this on our website at: www.autism.org.uk/what-we-do/news/the-national-autistic-society-has-responded-to-kem.

Our charity regularly runs Understanding Autism sessions for parliamentarians and we invite all MPs. We are running two sessions in November and will be running more in 2025.

Q: How many undiagnosed adults born before the 1990s has the NATIONAL AUTISTIC SOCIETY been involved in positively diagnosing in the past year?

Our National Diagnostic Centre at the Lorna Wing Centre was set up by Drs Lorna Wing and Judith Gould in 1991 and continues to provide an exceptionally high standard of care and support to those seeking an assessment for autism. The centre assesses both autistic adults and children.

We don't have the number of confirmed diagnoses for adults since it began, we will follow up and see if this information is available. It may be of interest to you to know that in 2026 we plan to expand our services and hope to increase the number of assessments that take place.

Q: Member asks...

- Why have the membership fees gone up?
- Will there be more chances for autistic adults to get involved with the National Autistic Society in 2025, i.e. by having their say on what works for autistic adults and what can be better, and will we get chances to speak up about our experiences of autism at a big event, because that usually reaches out to lots of people? Will we get chances to take part in campaigns and this time a chance to have our stories in next year's reports or on the website? Will there be any events autistic adults can go to?

Thank you, good questions!

1. Re the price increase:-

- We raised the price of membership by £2 this year, though this change came in in September, so members who have yet to pay their annual subscription have not felt this change yet.
- This was not a quick decision the driving force behind the change is rising costs, predominantly in producing and sending Your Autism magazine to our thousands of members.
- As well as this, we have been working hard on improving the membership package, for example, by introducing a new series of exclusive webinars for members. Some of you might have joined the first webinar in August, which featured insight from the designers of our RHS Chelsea Flower Show garden.
- With all this in mind, we need to make sure our costs are covered while we
 continue to provide all this, but we also don't want to alienate our
 members an audience that is very important to the charity.

2. Regarding the second question:-

We involve autistic people in all our campaigns. For instance, often we
have campaign focus groups or steering groups made up of autistic
people. We put callouts for people to join these each time so people can

- register their interest for them. We have ran focus groups just two weeks ago for a campaign we are launching in April that focuses on changing public understanding of autism.
- We also have a Young Ambassadors group who direct their own campaigns, such as one happening right now relating to the health care of autistic people.
- We have a magazine called Spectrum, by and for autistic people you can find information on our website about that (we'll share the link in our write-up of our answers on the AGM webpages published later). We're continually gathering the stories from autistic people for our Stories from the Spectrum also on our website.
- Finally, in relation to our events, we do endeavour to ensure we have autistic speakers at each see for instance the panel for our upcoming Professionals Conference.

Q: Why can't the minutes, updated articles of association, and annual report and accounts be shared before the meeting? Does the charity not wish to encourage informed debate at its AGMs?

This information is shared with everyone before the meeting – it is all on the website but I appreciate your feedback and will let the team know that we need to find ways to make this clearer in future.

Q: Would it be possible to send out reminders one month before membership direct debits are due, for those of us who pay by direct debit? I am an autistic adult and it came as a shock when you took my member DD without reminding me in advance. Can you give advance notice or a reminder please?

We are so sorry to hear that the recent payment of your membership subscription was a surprise to you.

We do send monthly reminders to all direct debit payers but I am sorry to hear this has not reached you. We will ask the team to review this.

Q: How do I refer myself for adult services at the National Autistic Society? I am the parent of an autistic young adult and our Local Authority are not meeting my social needs and most of my personal care needs are not met. How do I access National Autistic Society Adult Services, please?

Thank you for your question. Referrals to our services are made by the NHS or Local Authorities. I suggest you speak to either your GP or contacts in your local social services first.

We have an enquiry form for service referrals. I should note though that All referrals to our adult services should come from the budget holder or broker who will be funding the provision.

The form is on our website at:

www.autism.org.uk/what-we-do/adult-residential-services/enquiry

We will share this answer and link after the AGM.

Q: How many trustees and staff are autistic?

It is not mandatory for anyone to declare whether they are autistic or not and therefore we cannot give this information. We have recently taken steps to ask colleagues to voluntarily update their personal information and we will use this to improve our understanding of our workforce profile and how we improve our inclusive approach to employment and employee experience. I refer you to the earlier answer regarding how trustees are selected and how we look for a connection to autism. It is for trustees to decide if and how to share their personal connections and we would never mandate that anyone does this.

As we said in the earlier answer, we also recognise that it's important that our trustees have firsthand knowledge and experience of autism, whether that's through an autistic family member, a professional role working with autistic people or because they themselves have an autism diagnosis. Our rules state at least 50% of our trustees must have such a connection. At this time, more than 50% of our trustees have a connection to autism.

We are well aware of the challenges autistic people face in getting and keeping jobs and tackling this is a key part of our <u>Vision to Reality 2023-26</u> strategy.

We have developed and are implementing a number of initiatives we hope will enable us to recruit and create a more diverse organisation, including more autistic people. We have a programme called Pioneer which will achieve the goal in our organisational strategy to be a better employer of autistic people. The project will seek to obtain the Autism Inclusive Employer Award and is being delivered alongside and with the engagement of autistic colleagues.

All our staff receive training in autism as soon when they join the charity, and we are also Level 2 Disability Confident employers—which ensures we take steps to encourage and support people with disabilities, including autism to apply for our roles and to interview disabled applicants who meet the minimum essential criteria for the role. We also make reasonable adjustments for candidates who request them. Where practicable, we will include an autistic colleague on the interview panel.

Q: Belief 1 cites 5,000 calls & emails to ask for support. Would you expect more than 5,000 people to reach out to the National Autistic Society? Is there enough publicity?

Thank you for your question. We try to ensure as many people are able to find their answers directly via our website. We have millions of people who visit our

website each year to use this. We also have a very active online community where people reach out.

We are continuing to grow our online information and resources. You may have seen recently we did a big overhaul of all our information on diagnosis which we publicised heavily on our website, social media and via advertising. Next, we're doing the same for all our information and resources on employment.

In 2026, we also plan to add more advice topics, and also more online tools to help people find this advice more easily as well as routes for them to get more specific support where their questions aren't answered by our online information.

Q: Re the online community platform and Autism Services Directory. What is the target date for completion?

The online community platform upgraded happened in the last two weeks and we are continuing to work on it to sort out some initial glitches which is often the case with new technology. We plan to keep enhancing it. It is very well used and loved by those who use it. I encourage you to visit it.

The Autism Service Directory has also had a revamp of the technology which ensures those adding services now have more control of their listing and are asked to check their listing every year so we are confident they are up to date. We are very soon to publish the other side of the directory- the side you see as a user. That is due early December.

Once the year ahead we will be reaching out to more organisations to add themselves to the directory so it grows and continues to be incredibly useful.

Q: How is the sale of the City Road offices progressing?

The former head office site has been on the market for some two years but during that time the market for office space has been depressed. We have changed our agent and have applied for outline change of planning consent for the site to be developed for residential use and the property will be placed back on the market in the spring.

It should be noted that when it does sell the proceeds will be reinvested in projects such as the rebuild of Robert Ogden School.

Questions answered after the AGM

We did not have time to get through all the questions we received during the AGM; all remaining questions are detailed and answered below.

Q: You mentioned the autism bill for Scotland but I was told it was not going through parliament in Scotland by National Autistic Society Scotland, so how can we push for it to happen and how can an autistic adults be more involved and get the chance to meet with Scotlish MPs in parliament to say why autistic adults needs this autism bill?

The Scottish Government has confirmed that the Learning Disability, Autism and Neurodivergence Bill will not go through the Scottish Parliament until after the May 2026 Holyrood Election. During this time the Scottish Government will continue to work on getting the Bill right before moving forward.

The National Autistic Society is involved in this work and there may be possibilities for you also to be involved too. Indeed we were really pleased you were able to take part in the SNP Conference as a speaker and hopefully there will be other opportunities too. Our External Affairs Manager in Scotland, who you know will be in touch when there is an opportunity.

Q: Will there still be a chance to take part in fundraising if there's a problem with money will we still get a medal and certificate for autism challenges if money tighter?

Thank you so much for this question. There will always be the chance to take part in fundraising for the National Autistic Society! And we are so very grateful to our supporters for doing so. We really could not do the work we do without the kindness of our donors and fundraisers.

For many of our fundraising challenges, we are delighted to be able to offer medals and certificates to participants. We do this to reward the hard work of our fundraisers but also to incentivise fundraising.

We have no plans to stop offering this kind of incentive for a number of our fundraising events and challenges, though we will continue to plan all fundraising activity in light of <u>all</u> costs and other factors driving income and expenditure.

So – we do not expect to have to stop offering medals and certificates in the near future, but we will continue to budget for all fundraising expenditure to enable fundraisers to raise as much as possible, while keeping costs as low as we can.

Q: I have been diagnosed with Autism Spectrum Disorder. I do peer support at Birmingham Mind although I am a service user there. I did a bit of research and there is not a lot of support for people diagnosed with ASD in Birmingham and I was just wondering if there was anything I could do to set up some support groups in Birmingham in line with our visions and beliefs?

Thank you for your question; please contact our branches team as they may be able to advise you on this or put you in touch with others in your area.

You can have a look at our branches page online too as there may be one close to you already: www.autism.org.uk/what-we-do/branches.

Q: Stephen Ladyman mentioned a "new Mental Health Act". Do you mean the Mental Health Bill 2025 introduced in the House of Lords on 6 November 2024?

Yes, that is correct.

Q: Should we have received some documents ahead of the AGM? My "vote" email only had 2 things on it, and it stated that if I had not attended the 2023 AGM that I should abstain. Should there have been some papers shared ahead of the AGM?

This information is shared with everyone before the meeting – it is all on the website but I appreciate your feedback and will let the team know that we need to find ways to make this clearer in future.

Q: Which National Autistic Society services have been closed in 2023/2024?

This information is in our Annual report which you can find here: https://www.autism.org.uk/what-we-do/who-we-are/annual-reports.

Q: The National Autistic Society worked with 100,000 professionals but only 5,000 people with autism? Is this consistent?

The 5,000 referred to people who emailed or called us last year, and does not refer to the only autistic people who have engaged with us. Many thousands more use our services and are among the millions of people each year that visit our website, use our online community, are members, and attend our schools and our services.

Q: Is there a list of the 100+ organisations?

All these organisations will be included in our Autism Services Directory with the relevant accreditation logo when the new edition of the Directory launches https://www.autism.org.uk/autism-services-directory

Q: Are they publicising their support of employees with autism?

This is down to individual organisations to decide but is something we would encourage.

Q: Contact your MP had 25,000 responses. How many did you expect before you started? Any response from any MPs? How many are needed to achieve anything?

We use a variety of different tactics to influence government policy.

Sometimes we set up campaigner actions giving people the facility to email

their MP with a message. This is sent from the individual and so we do not receive any reply from the MP, as it is correspondence between the campaigner and their MP. Although it is out of our control, most MPs will prioritise responding to their constituents. Sometimes people share their responses with us.

However, this is only one tactic and what our Policy and Campaigns team work on is developing what asks we can put on MPs, for example, through:

- Writing letters to the relevant minister
- Speaking in debates
- Asking questions in Parliament
- Meeting with constituents
- Meeting with ministers
- Attending an event to learn more about an issue.

Our campaigning goals are achieved through a mix of all these things, alongside direct engagement with civil servants. We don't set numerical targets for our campaigner actions and it depends on the scale of the issue what response we get from our campaigners. However, if an action attracts a lot of campaigners, we will often reference large numbers, as it helps highlight the importance of an issue.

Q: Which ministers has Caroline Stevens met with?

As Chief Executive of the National Autistic Society, Caroline Stevens meets with a variety of senior and high-profile stakeholders, including ministers. Which ministers she meets with will depend on the issue. Key ministerial relationships for the National Autistic Society include the Minister for Social Care, who oversees the national autism strategy, and the Minister for Disabled People and Social Security.

Q: Is there a danger that the message is lost in amongst other topical issues such as Assisted Dying?

We are unsure as to what this question refers.

Q: Re autistic people being locked up. What actions have you and the National Autistic Society taken to publicise and ask for this scandal to end?

It is not quite clear if this question relates to autistic people in prison or in inpatient mental health hospitals. We will provide more information about both:-

Prisons

Over a number of years our Autism Accreditation Team developed standards and rolled out a programme of accreditation for prisons. This was important as we knew that autistic people in prison were often having worse experiences than their non-autistic peers, due to poor understanding and

support. We continue to offer this accreditation to prisons willing to do the work to achieve the status.

We are also commissioned by HM Prison and Probation Service to provide a neurodiversity probation advice service for neurodivergent people on probation. This service works with Probation Professionals to adapt their practice and also directly supports neurodivergent people.

<u>Inpatient mental health hospitals</u>

The latest monthly Assuring Transformation NHS Digital data shows that in October 2024:

- In total 2,050 autistic people and people with a learning disability are in inpatient mental health hospitals in England
- 1,410 (69%) of these people are autistic
- There are 215 under 18s in inpatient units that are autistic or have a learning disability. Of these, 95% are autistic.

We are very clear: this is a scandal and it has to end. It is widely recognised that for most autistic people, care in an inpatient unit is rarely helpful – in fact, it can be deeply damaging.

The average length of stay is around 4.9 years and we continue to hear alarming cases of overmedication, seclusion and unnecessary restraint. The overwhelming majority (92%) of autistic people and people with a learning disability who are detained in hospital are put there using the Mental Health Act 1983. We and hundreds of thousands of campaigners have been calling for changes to mental health law for years, so it respects autistic people's rights.

In June 2022, the former government published a draft bill to reform the Mental Health Act which could stop people being sectioned just because they're autistic and make it easier for autistic people in hospitals to leave. This was a big step forward, but delays in bringing the Bill to Parliament meant it was not passed into law.

However, after including the Bill in this year's King's Speech, the new Government has now introduced the Mental Health Bill to Parliament. The First Reading of the Bill was held last month in the House of Lords, and it will now go through the Parliamentary process where it can be scrutinized and strengthened.

We are working hard and meeting with parliamentarians from all parties and government officials to make sure this Bill is as strong as possible and comes with the funding that is needed to make sure autistic people can get mental health support in their community when they need it.

Q: What is the National Autistic Society actively doing (or planning to do) to minimise its energy consumption?

National Autistic Society initiatives outlined in our Annual report include:

LED lighting

Whenever feasible, contractors and staff are encouraged to replace outdated, inefficient lighting with LED alternatives as part of regular maintenance, especially when existing lamps reach the end of their lifespan.

Electric vehicle introductions

We have begun to electrify our fleet. While the impact has been minimal this year, we are committed to significantly expanding this initiative in the future.