## **COMMITTEE ON THE AUTISM ACT 2009: CALL FOR EVIDENCE**

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#### Introduction

The Autism Act 2009 Committee in the House of Lords is looking into how well the Autism Act 2009 and the Government's autism strategy are working.

As part of this, the Committee is holding a call for evidence asking for information and views from you. To allow as much time as possible for people to respond, the call for evidence is open for two months (a longer period than usual), until **2 June 2025.** 

You can use either the conventional or the easy read version of this document.

Please read the information in this document before sending in your response to the call for evidence.

We are very grateful to autistic people working with national autism charities who gave us feedback on this document to help us make it accessible.

If you have a question about something on this page, you can get in touch with us:

- via email: <u>HLAutismAct2009@parliament.uk</u>
- via post: Clerk to the Select Committee on the Autism Act 2009, Committee Office, House of Lords, London SWIA 0PW

Your question will be handled by the Committee staff team.

## Who should respond to the call for evidence?

The Committee wants to hear from a wide range of people and organisations with different experiences and perspectives.

We particularly welcome your views if any of the following apply to you:

- you are an autistic person (including if you have a diagnosis or if you consider yourself autistic)
- you have an autistic person in your family, or you care for/support an autistic person
- you work with autistic people in your job
- you work on research into how to support autistic people.

We would like to hear from a range of people with different characteristics (for example, across gender and gender identity, age, support needs, co-occurring conditions, caring responsibilities, socioeconomic and ethnic background, religion, location, and sexuality).

We want to make sure you can send us evidence in a way that works for you. You are welcome to:

- work with someone else (such as a friend, family member or carer) to prepare your evidence
- ask someone else to submit evidence on your behalf
- ask for help from an organisation that supports you to prepare your evidence
- submit a voice recording as evidence, which we will transcribe into a published written document.

You can contact us if you need help to send us your evidence, or if anything is unclear.

## Why do House of Lords committees hold calls for evidence?

Committees in the House of Lords hold inquiries about parts of Government policy. This is when they investigate what the Government is doing, ask how well it is working, and consider what the Government should do differently in the future

To help do this, committees often hold calls for evidence. This is when they ask anyone interested to share information and views about the topic they are investigating.

Committees use this evidence to write reports. Committee reports say what the committee has found out and make recommendations about what the Government should do.

You can find out more about House of Lords committees here: <a href="https://www.parliament.uk/business/lords/work-of-the-house-of-lords/lords-select-committees/">https://www.parliament.uk/business/lords/work-of-the-house-of-lords/lords-select-committees/</a>

# Why is the Autism Act 2009 Committee holding this call for evidence?

The Autism Act 2009 Committee was appointed on 30 January 2025 to consider the Autism Act 2009 and to make recommendations to the Government.

To help it do this, the Committee is holding this call for evidence to seek information and views from you. The Committee will also seek evidence in different ways, for example by hearing evidence from people at public meetings in Westminster and by going on visits.

The Committee will consider all the evidence that it receives. Evidence will also normally be published online.

The Committee plans to publish its report by 30 November 2025. The Committee's report will summarise and cite the evidence received and make recommendations to the Government.

The Government will publish a response to the Committee's report and recommendations. This should happen within two months of the report's publication.

You can follow the progress of the Committee's inquiry here: <a href="https://committees.parliament.uk/committee/770/autism-act-2009-committee/#:~:text=Lords%20Select%20Committee,2009%20and%20to%20make%20recommendations">https://committees.parliament.uk/committee/770/autism-act-2009-committee/#:~:text=Lords%20Select%20Committee,2009%20and%20to%20make%20recommendations</a>.

## What is the Committee investigating?

The Committee wants to understand how well the *Autism Act*, the autism strategy and the statutory guidance are working. This is so that we can make specific, practical recommendations about what the Government should do next.

- The <u>Autism Act 2009</u> is a law that says the Government must publish an autism strategy for England and statutory guidance about supporting autistic people.
- The Government's autism strategy is a plan for how to improve the lives of autistic people and their families. The current <u>autism strategy</u> is about the period from 2021

- to 2026. The strategy sets out the Government's plans to improve autistic people's lives across different areas, including public understanding, health, social care, education, employment and criminal justice.
- The <u>statutory guidance</u> says what the NHS and local authorities should do to make sure the autism strategy works.

You might want to read the <u>Autism Act 2009</u>, the <u>autism strategy</u> and/or the <u>statutory</u> guidance before sending us evidence. You don't have to do this.

In this call for evidence, we are mainly asking about support for autistic people in England. This is because the *Autism Act 2009* is about England. We will make our formal recommendations to the UK Government about what it should do in England. You can still tell us about support for autistic people in Scotland, Wales and Northern Ireland and in other countries in response to the questions in section D.

We know we may not be asking specific questions about every part of Government policy that is important to autistic people in England. This is because we want to focus on the *Autism Act 2009*, the autism strategy and the statutory guidance. We do not want to duplicate work that other Parliamentary committees are doing.

For example, we are not asking detailed questions about SEND provision for autistic children. This is because the House of Commons Education Committee is carrying out an inquiry into Solving the SEND Crisis. Instead, we want to understand how well the Government's autism strategy supports autistic children and young people to access education and how this could be improved in the future.

You might want to check if another Parliamentary committee is holding a call for evidence about an issue that is important to you. Committees consider areas of Government policy including:

- Health and social care
- Education
- Work and pensions

You can find a list of all Parliamentary committees here: Find a committee - Committees - UK Parliament

### Questions

The questions in this call for evidence ask for your views on the issues we are investigating. In your submission, we encourage you to focus on the issues that are most important to you. For example, you could:

- answer a small number of questions
- tell us about a small number of issues, using the questions as a rough guide.

#### You don't have to answer every question.

We encourage you to answer the questions in a way that reflects your specific knowledge and experience. For example, in response to a question about supporting autistic people in the community, you could tell us about a specific part of this (such as supported housing).

In your answers to the questions, you should tell us your views about:

- what the main problems are for autistic people and why
- what is going well
- what you think the Government should do differently in the future.

When you tell us your view about something, you should tell us what information you are basing that view on. We particularly encourage you to share information that is specific to you or your organisation. For example, this could come from:

- your own experiences
- your organisation's work
- research you have done.

If you are mainly basing your answers on your own experiences, you might want to focus on answering the questions in Section C.

You should try to make sure that your submission is no more than six pages long in total. If your submission is longer than six pages, you should include a one-page summary. This is because we may receive a lot of submissions from different people and we want to be able to consider each one carefully.

## Section A: Evidence about autistic people and what they need

In this section we are asking questions about what we know about autistic people in England and what they need from the Government.

You may want to answer the questions in this section if you know about this topic from research you have done.

#### Question I

- a) What evidence is there about the numbers of autistic people (diagnosed and undiagnosed) in England and their demographic characteristics (for example, age, gender or ethnic background)?
- b) How is the evidence on the numbers of autistic people (diagnosed and undiagnosed) in England and their demographic characteristics changing over time?

#### **Question 2**

- a) What evidence is there about what autistic people need from the Government and public services and the most important policy issues for autistic people and their families/carers?
- b) How is this changing over time?

- a) What new evidence does the Government need in order to make new policies and to plan services for autistic people?
- b) Who should collect this evidence?

# Section B: The Autism Act 2009, the Government's autism strategy and the statutory guidance

In this section we are asking questions about the Autism Act 2009, the Government's autism strategy and the statutory guidance.

You may want to answer the questions in this section if you know about this topic from your work, your own experience or research you have done.

#### **Question 4**

- a) In what ways have the *Autism Act 2009* and successive Government autism strategies been successful or unsuccessful in improving support for autistic people?
- b) What are the reasons for this?

#### **Question 5**

- a) How effective has the Government's approach been to:
  - setting policy aims in each autism strategy;
  - funding and implementing actions to achieve those aims; and
  - evaluating progress?
- b) Should the Government do this differently in future? If so, how?

#### **Question 6**

- a) How effective has statutory guidance to the Autism Act 2009 been in improving support for autistic people?
- b) To what extent are the NHS and local authorities achieving the duties set out in the statutory guidance?
- c) How could the statutory guidance be made more effective?

- a) What processes are there for holding national and local bodies (including the Government, the NHS and local authorities) to account for progress against the autism strategy and statutory guidance?
- b) How could those processes be made more effective?

## **Section C: The Government's priorities**

In this section we are asking questions about the priority areas in the Government's autism strategy for 2021 to 2026 and what the Government should prioritise in its next strategy.

You may want to answer the questions in this section if you know about any of these topics from your own experience, your work or research you have done.

### Overview

#### **Question 8**

In this question we are asking about what the Government should prioritise to improve autistic people's lives.

- a) The autism strategy for 2021 to 2026 says that the Government plans to take action to improve autistic people's lives across six priority areas:
  - improving understanding and acceptance of autism within society
  - improving autistic people's access to education, and supporting transitions into adulthood
  - supporting more autistic people into employment
  - tackling health and care inequalities for autistic people
  - building the right support in the community and supporting people in inpatient care
  - improving support within the criminal and youth justice systems.

Do you think that they are the right priority areas? Why or why not?

b) Is there anything else that the Government should prioritise to improve autistic people's lives?

## Public understanding and acceptance

In these questions we are asking about public understanding, acceptance and inclusion of autistic people. Your answers could focus on specific parts of this. For example, when we ask about community inclusion for autistic people, you could focus on access to businesses, public sector services, transport, culture or sport.

#### **Question 9**

- a) What are the main problems with public understanding and acceptance of autistic people?
- b) What is going well?
- c) How can public understanding and acceptance of autistic people be improved?

- a) What are the main problems with community inclusion for autistic people?
- b) What is going well?
- c) How can community inclusion for autistic people be improved?

#### Healthcare

In these questions we are asking about identification, diagnosis and support for autistic people. Your answers could focus on specific parts of this. For example, you could focus on accessing post-diagnostic support as an adult.

#### Question II

- a) What pathways are there for the identification and support of autistic people, including:
  - when they need it (including if they do not have a diagnosis);
  - through assessment, diagnosis and post-diagnostic support; and
  - throughout their lives?
- b) What are the strengths of those pathways?
- c) What are the main problems with those pathways?

#### Question 12

- a) How can the Government improve assessment, diagnosis and post-diagnostic support for autistic people?
- b) How can the Government improve the identification and support of autistic people when they need it (including if they do not have a diagnosis)?
- c) How can the Government improve support for autistic people throughout their lives?

#### **Question 13**

In this question we are asking about access to healthcare for autistic people. Your answer could focus on specific parts of this. For example, you could focus on going to see the GP, going to the dentist or accessing mental health services.

- a) What are the main problems for autistic people in accessing healthcare?
- b) What is going well?
- c) How can access to healthcare for autistic people be improved?

### Community support and inpatient care

In these questions we are asking about building community support for autistic people, reducing the use of inpatient care, and improving the quality of healthcare and community support. Your answers could focus on specific parts of this. For example, you could focus on accessing social care or supported housing.

#### **Ouestion 14**

- a) What are the main problems with access to community support for autistic people?
- b) What is going well?
- c) How can community support for autistic people be improved?
- d) How can the use of inpatient care be reduced?

#### Question 15

- a) What are the main problems with the quality of healthcare and community support for autistic people?
- b) What is going well?
- c) How can the quality of healthcare and community support for autistic people be improved?

#### Education and transitions to adulthood

In these questions we are asking about access to education and transitions to adulthood for autistic children and young people. Your answers could focus on specific parts of this. For example, you could focus on including autistic children in mainstream schools, going to a specialist school, home-schooling or moving to further education.

#### Question 16

- a) What are the main problems for autistic children and young people in accessing education?
- b) What is going well?
- c) How can access to education for autistic children and young people be improved?

- a) What are the main problems for autistic young people in transitions to adulthood (including the move from children's to adult services)?
- b) What is going well?
- c) How can transitions to adulthood for autistic children and young people be improved?

## **Employment**

In these questions we are asking about supporting more autistic people into employment. Your answers could focus on specific parts of this. For example, you could focus on accessing an internship or apprenticeship, accessing supported employment or accessing reasonable adjustments at work.

#### **Question 18**

- a) What are the main problems for autistic young people in the move from education to work?
- b) What is going well?
- c) How can the move from education to work for autistic children and young people be improved?

#### **Question 19**

- a) What are the main problems for autistic people in both finding and staying in work?
- b) What is going well?
- c) How can support for autistic people to find and stay in work be improved?

## Criminal and youth justice

In this question we are asking about supporting autistic people who come into contact with the criminal and youth justice systems. Your answer could focus on specific aspects of this. For example, you could focus on support for autistic people who are suspects, defendants, offenders, victims or witnesses.

- a) What are the main problems with support for autistic people who are in contact with the criminal and youth justice systems?
- b) What is going well?
- c) How can support for autistic people who are in contact with the criminal and youth justice systems be improved?

# Section D: Scotland, Wales and Northern Ireland, and around the world

In this section we are asking questions about support for autistic people in Scotland, Wales and Northern Ireland, and around the world. You may want to answer the questions in this section if you know about support for autistic people somewhere outside England. This could be from your own experience, your organisation's work or research you have done.

#### Question 21

- a) What could the UK Government learn from the devolved governments in Scotland, Wales and Northern Ireland on effective ways to support autistic people?
- b) How should the UK Government work with the devolved governments in supporting autistic people?

#### **Question 22**

What could the UK Government learn from other countries around the world on effective ways to support autistic people?

## Important information about sending us evidence

Please read this section before you send us a written evidence submission. This information is particularly important if you are sending a written evidence submission about your own experiences.

## How should I prepare my written evidence submission?

You should prepare your written evidence submission specifically for the Committee. We can't accept anything that has not been prepared specifically in response to this call for evidence, or that has been published elsewhere already. You are welcome to include references to information published elsewhere to support your answers.

#### You should:

- include your name and briefly say why you are responding
- say whether you're submitting evidence as an individual or on behalf of an organisation
- say which questions you are answering
- number the paragraphs in your submission and use section headings
- put the date on your submission.

You can find more advice on how to submit evidence here: <a href="https://publications.parliament.uk/pa/cm/written-evidence-guidance.htm">https://publications.parliament.uk/pa/cm/written-evidence-guidance.htm</a>

You can look at some examples of submissions to a previous committee inquiry here: <u>The transition from education to employment for young disabled people - Written evidence - Committees - UK Parliament</u>

## How should I send in my written evidence submission?

You can:

- send us your written submission online in Word document format using the form available at <a href="https://committees.parliament.uk/call-for-evidence/3625/">https://committees.parliament.uk/call-for-evidence/3625/</a>
- send your written submission or voice recording by email to <u>HLAutismAct2009@parliament.uk</u>.

Please contact us by email if you:

- find it difficult to send us your submission online
- want to send us your submission in a different format
- want to send us your submission after the deadline has passed
- need any other changes so that you can send us your submission.

# What will happen to my written evidence submission after I send it to you?

You will receive an acknowledgement that your submission has been received.

The Committee will decide whether to accept your submission as evidence. This is usually a formality, as long as your submission follows the guidance in this document. We will tell you when this happens.

Once the Committee accepts your submission as evidence, it will normally be published on the internet. This is so that everyone can see the information the Committee has considered in its inquiry and who wrote it.

## Published evidence cannot be changed or removed. That means that other people will be able to find and read what you send us.

If you have included your name or any personal information in your submission, that will normally be published too.

You should consider how much personal information you want or need to share. Your contact details will never be published.

We'll read your submission and we'll use it to help the Committee's inquiry. For example, the Committee might use your name and your submission in a report.

We'll keep your contact details and we might use them to get in touch with you about the Committee's work, for example to ask for further information.

## What should I not include in my written evidence submission?

This section provides advice on what not to include in your written evidence submission.

If you're not sure whether to include something in your submission or not, you can contact us for advice.

#### Requests for help

You can talk about your personal experiences in your submission, but we can't help you with individual problems or complaints.

If you would like political support or advice, you may wish to <u>contact your local Member of</u> Parliament.

If you have an urgent problem, you can find sources of help here: https://www.autism.org.uk/contact-us/urgent-help

#### Information about other people

Please do not include personal information about other people (including your friends and family) in your submission. If you do this, the Committee may decide not to publish your submission.

We won't publish submissions that contain statements that could be defamatory. This is when you say something untrue that could harm someone's reputation.

#### Legal cases

Please do not tell us about an ongoing legal case, or information about anything that is likely to be the subject of future legal proceedings, in your submission.

We can't publish submissions that mention ongoing legal cases.

#### Safeguarding concerns

If your submission raises any safeguarding concerns about you, or anybody else, then we have a responsibility to raise those concerns with the appropriate safeguarding authority.

If you are, or someone else is, at immediate risk or in danger, you should contact the police on 999.

### What if I want my evidence to be published without my name?

You can let us know if you want your submission to be anonymised. Please explain at the start of your submission why you are asking for this.

The Committee will decide whether or not to publish your submission on an anonymous basis. Anonymised evidence is published, but names and identifying details are removed.

We may anonymise or redact some of your submission if it is published, even where you have not requested this. We will contact you if we think this is needed.

We will never publish your name if you have asked us not to.

#### What if I want to send you evidence, but I don't want it to be published?

You can let us know if you want us to accept your submission on a confidential basis. Please explain at the start of your submission why you are asking for this.

Confidential evidence is available to the Committee but is not published or referred to in public. The Committee will decide whether to accept your submission on a confidential basis.

We may treat your submission confidentially, even where you have not requested this. We will contact you if we think this is needed.

We will never publish your submission if you have asked us not to.

## Who will be legally responsible for my submission?

Your submission will become the property of the Committee when it is accepted.

Once we have told you that your submission has been accepted, you may publicise or publish it yourself. When you do this, you must indicate that it was prepared for the Committee. You must not publish your submission before the Committee does.

Parliamentary privilege refers to the rights and powers that belong to Parliament and that enable it to fulfil its role. In particular, it gives legal protection for freedom of speech in Parliament, including for people who give evidence in writing or in person to committees. Once your submission is accepted, it will be protected by parliamentary privilege.

If you publish your submission separately, you will be legally responsible for its content.