HOUSE OF LORDS

Select Committee on the Autism Act 2009

Report of Session 2024–26

Time to deliver: The Autism Act 2009 and the new autism strategy

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Select Committee on the Autism Act 2009

The Select Committee on the Autism Act 2009 was appointed by the House of Lords on 30 January 2025 to consider the Autism Act 2009 and to make recommendations.

Membership

The Members of the Select Committee on the Autism Act 2009 were:

Baroness Rock (Chair)
Lord Addington
Baroness Browning
Lord Crisp
Lord Elliott of Mickle Fell
Baroness Goudie
Baroness Hodgson of Abinger
Lord Hope of Craighead
Baroness Pitkeathley
Baroness Ritchie of Downpatrick
Lord Scriven
Lord Wigley

Declaration of interests

See Appendix 1.

A full list of Members' interests can be found in the Register of Lords' Interests: https://www.parliament.uk/mps-lords-and-offices/standards-and-interests/register-of-lords-interests

Publications

All publications of the Committee are available at: https://committees.parliament.uk/committee/770/autism-act-2009-committee/publications/

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Committee staff

The staff who worked on this Committee were Stuart Stoner (Clerk), Lucy Valsamidis (Policy Analyst), Abdullah Ahmad (Committee Operations Officer), Clayton Gurney (Committee Operations Officer) and Aneela Mahmood (Press and Media Officer).

Contact details

All correspondence should be addressed to the Autism Act 2009 Committee, Committee Office, House of Lords, London SW1A 0PW. Telephone 0207 219 4621 Email HLAutismAct2009@parliament.uk

Social media

You can follow the Committee on Bluesky: @hlautismactcom.parliament.uk; LinkedIn: https://www.linkedin.com/showcase/autism-act-2009-committee/ and
X (formerly Twitter): @HLAutismActCom

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Evidence is published online at https://committees.parliament.uk/committee/770/autism-act-2009-committee/publications/ and available for inspection at the Parliamentary Archives (020 7219 3074).

Q in footnotes refers to a question in oral evidence.

SUMMARY

Our inquiry: examining the Autism Act 2009

The Autism Act 2009 is a law for and about autistic people in England. The Act requires the Government to produce an autism strategy, backed up by statutory guidance for the NHS and local authorities.

The House of Lords asked our Committee to look at how well the Autism Act has been working, how it could work better in the future, and what the current autism strategy has achieved. We have examined what the Government needs to do to develop an effective new strategy for launch in July 2026, when the current one ends. The Government has committed to use this report to help it develop the strategy.

We heard from dozens of autistic people and people who support them, and took written evidence from hundreds more. The views of thousands of others were shared with us by individuals and representative groups. We were constantly struck by the moving and powerful testimony of the people who shared their experiences with us.

Autistic people are as diverse as our country and represent an integral, valuable part of it. Yet autistic people are beset by persistent inequalities, holding them back from living fulfilling lives and our society back from an inclusive future.

Sixteen years of the Autism Act

In 2009, awareness of autism was low. When autistic people sought help, they often fell through the gaps between mental health and learning disability services. Autistic people were often invisible.

The Act, successive autism strategies and statutory guidance have helped change that. They have made national and local government recognise and respond to the needs of autistic people. They have also expanded access to autism assessment. However, they have not succeeded in breaking down the barriers that autistic people face.

When the Act was passed, about 1% of people were estimated to be autistic. Diagnosis rates are now much higher than this in younger people, but still much lower in older people. This change has been driven by evolution in the medical and social understanding of autism. But there are also signs that autistic people are struggling to cope and are seeking a diagnosis to access even basic help. Services for autistic people are unable to cope with the numbers seeking assessment and support.

Outcomes have not improved. A new approach is now urgently needed.

The new autism strategy

The Government autism strategy for 2021–26 set ambitions reflecting key priorities of autistic people and those who support them. However, after the first year, successive governments produced no plan to deliver or fund the strategy.

The Government must now take a different approach and launch a new strategy, identifying priority outcomes, producing a costed, deliverable plan to achieve them, and making clear who is responsible and accountable for delivery. Autistic

people and those who support them must be meaningfully involved in every stage of the development and delivery of the new strategy.

Autistic people often face cliff edges in access to support: it is at the times of transition in life when support is most needed that it is most likely to fall away. The new strategy must take a lifespan approach, enabling every autistic person to access the right kind and level of support when they need it.

Too many autistic people access no support until they reach a crisis point. This costs money and lives. To end the reactive, crisis-led approach, the Government must give public services incentives to invest in timely, preventative support. Support must be based on good practice and strong evidence. The Government should develop co-designed interventions to improve autistic people's lives and support trailblazing services to help build capability across mainstream services.

The new strategy must be reinforced by updated statutory guidance, making clear what the NHS and local authorities must do to implement the strategy. The Government must make clear how services will be delivered, how they will be held accountable, and what the consequences will be when they fail to meet autistic people's needs.

Public understanding, acceptance and accessibility

Awareness of autism has rapidly grown since 2009, but public understanding and acceptance have not kept pace. Most autistic people still do not feel accepted or understood. Public spaces and facilities are too often inaccessible. This drives loneliness and mental ill health and stops many autistic people from fully participating in society.

Public discourse about autism is often unhelpful and, at worst, based on alarming misconceptions. This has a damaging impact on autistic people and those who support them.

The Government must now step up and show its support for autistic people, running a public understanding campaign in partnership with autistic people and those who support them. The Government must monitor this campaign and evaluate its impact.

To make public spaces accessible to autistic people, the Government must commission and evaluate mandatory, co-produced training for public-facing staff and make clear how they should meet their duties towards autistic people under equality law.

Identification, assessment and support

Autism diagnosis can change lives, enabling autistic people and those around them to understand and respond to their needs. However, the autism assessment system can also become a bottleneck, giving overstretched services a means to ration access to support.

Successive governments have focused limited resources on increasing capacity to carry out autism assessments, rather than providing support before and after diagnosis. The autism assessment system is now under severe pressure. Thousands wait years for a diagnosis and receive little to no support even when it comes.

The Government wants to see more autistic people receive needs-led support without a diagnosis. However, many fear that this will become an excuse to withhold diagnosis and make it harder to access any support at all.

The Government urgently needs to invest in autism assessment. But this will not be enough on its own. A radical shift is needed. Working in close partnership with autistic people and those who support them, the Government must identify how to move towards a stepped, lifelong model of support.

Reducing health inequalities and building support in the community

Autistic people face unacceptable inequalities in health outcomes and life expectancy. The Government has acted to make healthcare services more accessible for autistic people, by rolling out the Oliver McGowan Mandatory Training and trialling health checks for autistic adults. To build on this progress, the Government must test and roll out evidence-based ways of meeting autistic people's healthcare needs and develop capability across the health and care workforce.

Autistic people still often fall into gaps between mental health and social care services. Many are turned away from mental health services just because they are autistic. Services must be given backing and incentives to provide low-level, integrated support to prevent care needs from developing and from escalating into a crisis. This support often costs little, but makes a big difference.

Too many autistic people are still being detained in mental health hospitals for no good reason. To put a stop to this at last, the Government must set out a roadmap for the development of strong community services. Autistic people also die early far too often. The Learning from Lives and Deaths Review process must be made mandatory and an independent process set up to make sure recommendations are implemented.

Access to education and transitions to adulthood

Autistic children and young people do not have equal access to education. Thousands are unhappy at school or out of school altogether, with many families turning to home education in desperation. The Government must build up capability for educating autistic children and young people across all types of educational provision, supporting high-performing specialist schools to act as centres of excellence.

Young autistic people typically face a gulf in access to support when they become adults. Just when they should be spreading their wings, vital support falls away. Services must be developed to help young autistic people through this crucial transition, bringing together education, employment, housing and mental health support.

Employment

Most autistic people are not in work, but many would like to be. Supporting more autistic people to find and stay in work is not only critical to enabling those who wish to work to fulfil their aspirations, but would also help unlock economic benefits for the country as a whole.

Supported internships and supported employment programmes have a track record of helping autistic people move into work. Expanding access to such

schemes is crucial. Employers also need better support and incentives to enable more autistic people to find, stay and thrive in work. The Government should promote voluntary accreditation schemes like Autistica's Neurodiversity Employers Index and strengthen the Disability Confident scheme so it rewards employers that really do offer good support.

Criminal justice

Autistic people are at higher risk of falling through the cracks in systems of support. This can put them at risk of becoming involved in the criminal justice system, as victims, witnesses, or offenders.

The evidence on autistic people in the criminal justice system, while limited, is concerning. Autistic people face barriers to having their needs understood and met when they come into contact with the police, in courts, in prisons and on probation. This may increase their risk of not being diverted out of the system.

There are numerous initiatives to improve support for autistic people in the criminal and youth justice systems, but they are piecemeal. The Government must now develop, test and roll out effective forms of support across the whole system.

Conclusion

The Government must now use our recommendations as a basis to develop the new autism strategy to take effect in July 2026. At the heart of the strategy must be ambitions to involve autistic people in all decisions that affect them, to enable every autistic person to receive the right support at the right time, and to help build a more inclusive and prosperous society. Achieving these ambitions will take time. The starting point is to set realistic goals, make a plan to deliver them, monitor progress, and work together to build change.

LIST OF CONCLUSIONS AND RECOMMENDATIONS

Chapter 1: Introduction

1. Within the current parliamentary rules for committee work, we have sought to ensure that autistic people and those who support them have been given many opportunities and a variety of means for meaningful involvement in the Committee's work. (Paragraph 60)

2. *We invite the House of Lords Procedure and Privileges Committee (which is responsible for recommending changes to House of Lords procedure) to consider ways in future to facilitate the meaningful involvement of a diverse range of people with lived experience in the work of committees such as ours, and the Liaison Committee (which is responsible for recommending the appointment of new committees) to provide committees with sufficient time and resources to do so.* (Paragraph 61)

3. Our report sets out a path to addressing the needs and aspirations of autistic people through the new autism strategy. Each of our recommendations requires urgent action as part of that strategy. The Minister for Care has made a commitment to bring forward the new autism strategy in 2026, to ensure there is no vacuum when the current strategy expires in July that year, and to put in place an implementation plan. *The Government must now meet that commitment in full.* (Paragraph 62)

4. The Minister for Care has also made a commitment to use this Committee's work to help shape the new autism strategy. We will judge the Government's response against that commitment. It is in that spirit that we make this report for debate. (Paragraph 63)

Chapter 2: The Autism Act, autism strategy and statutory guidance

5. The Autism Act 2009 was a critical step forward in the recognition of autistic people and their needs. (Paragraph 142)

6. The Autism Act, successive autism strategies and statutory guidance have been vital in driving national and local action to improve autistic people's lives. They have set lines of responsibility for meeting autistic people's needs and brought more autistic people and those who support them into decisions about the services they use. They have also helped drive change in the way that services are organised and run, most significantly through the expansion of access to autism assessment for adults. (Paragraph 143)

7. However, the Act and successive autism strategies have failed to tackle the key barriers that stand in the way of improving outcomes. Meanwhile, numbers of autistic people and families seeking assessment and support have risen rapidly. This is likely to be because of changes in the understanding of autism; because more autistic people are struggling to cope; and because thresholds for access to support from overstretched public services have risen. In the words of one witness, the state is fighting the state. (Paragraph 144)

8. *The Government must immediately begin development of the new cross-government, all-age autism strategy, so it takes effect when the current one expires in July 2026. The new strategy should be structured around the six key themes outlined in this report: improving understanding, acceptance and accessibility; identification, assessment and support; reducing health inequalities and building support in the community; access to education and transitions to adulthood; employment; and criminal justice.* (Paragraph 145)

9. *The new strategy should be based on principles that:*

- *the meaningful involvement of autistic people and those that support them will be critical to the strategy's success;*
- *ensuring autistic people can access the right support at the right time is vital to enabling them to live fulfilling lives;*
- *autistic people and their needs are diverse; every autistic person has different strengths and needs; and those needs may fluctuate over the lifespan, so support must be flexible, responsive and person-centred;*
- *autistic people often need most support just at the times of transition in life when support may be most likely to fall away; and,*
- *making society more inclusive for autistic people will help make it better for everyone.* (Paragraph 146)

10. *The Government must:*

- *meaningfully involve a diverse range of autistic people and people who support them in every stage of the development and delivery of the new strategy and of every policy under it;*
- *produce a deliverable and costed plan for the implementation of the strategy. This should make clear who will be responsible and who will be accountable for national, regional and local delivery of the strategy. A named Government minister must be accountable for the overall delivery of the strategy. Annual progress reports must be published;*
- *identify in the strategy a focused set of priority outcomes, actions that will help achieve them, and how progress against each priority will be measured; and,*
- *set out in the strategy a plan to improve cross-government data collection and reporting on outcomes.* (Paragraph 147)

11. *To be a success, the strategy will need to identify cross-cutting, systemic barriers to improving outcomes for autistic people and set out how the Government will overcome those barriers. In particular:*

- Responsibility and accountability for meeting autistic people's needs are fragmented, meaning services have little incentive to provide timely support. *The strategy must set out how the Government will give services the support and incentives they need to invest in early support and ensure they are held to account for failures to provide such support.*
- There are too often barriers to the meaningful involvement of autistic people in service design and delivery. *The strategy must set out a plan to strengthen the involvement of autistic people and those who support them in the development and delivery of services at every level.*
- There are some exemplary services supporting autistic people, but they are patchy and too many autistic people have no access to them. *The strategy must set out how the Government will support specialist services and professionals to advise and build capability across mainstream services.*
- Evidence on the best ways to meet autistic people's needs is still limited. *The Government must establish a research initiative to fund, develop and test*

co-designed interventions to improve priority outcomes for autistic people and enable effective interventions to be scaled up. (Paragraph 148)

12. *The Government must produce updated statutory guidance to the Autism Act to support the new autism strategy. This should:*

    - *identify a clear, focused set of duties for the NHS and local authorities, making clear what it is mandatory, and what it is recommended, they do to implement the autism strategy;*
    - *make clear the relationship between duties under the Autism Act and duties under other relevant legislation, including duties towards autistic children and young people;*
    - *confirm that each local authority should have a named joint commissioner or senior manager to lead the commissioning of care and support services for autistic people;*
    - *confirm that each local authority should set up a meaningful autism partnership arrangement;*
    - *set out what information local authorities and NHS bodies will need to provide to the Government to enable progress against the strategy to be measured, for example through a new self-assessment framework;*
    - *make clear how the Government will hold a local authority or NHS body to account if it does not follow the statutory guidance and does not have a good reason why not; and,*
    - *make clear how autistic people and those who support them can access independent recourse when services fail to meet their needs.* (Paragraph 149)

Chapter 3: Improving understanding, acceptance and accessibility

13. There has been a welcome increase in public awareness of autism since the Autism Act came into force. Younger people in particular are perceived to be embracing neurodiversity and demonstrating acceptance of autism. There are positive signs that these trends have created an environment where people are more willing to seek and be open about an autism diagnosis. (Paragraph 213)

14. However, understanding of autism and acceptance of autistic people continue to lag behind. The aim of the current autism strategy for there to be a significant improvement in public understanding and acceptance by 2026 is unlikely to be met. There remain fundamental misunderstandings and misconceptions about autism, and autistic people remain subject to stereotyping, stigma and discrimination. (Paragraph 214)

15. There is also a real fear among autistic people and those who support them that the misinformed public discourse about autism at the present time is increasing the stigma that autistic people face. In particular, rhetoric suggesting there is an overdiagnosis problem has had a damaging impact. The ambition that there comes a time when acceptance becomes embracement of autism remains far off. (Paragraph 215)

16. Against that backdrop, the failure by successive governments to meet the commitment in the current autism strategy to develop an autism public

awareness and understanding initiative is both striking and unacceptable. (Paragraph 216)

17. *The Government must as a matter of urgency implement a new initiative to improve understanding and acceptance of autism. This should be led at ministerial level and produced with autistic people and those who support them. This initiative should be designed to engage and inform both the public in general, and staff in public-facing roles in particular. It must reflect the diversity of experience of autistic people. It must also be evaluated robustly, including by autistic people.* (Paragraph 217)

18. *This initiative should be underpinned by regular polling, tracking changes to public attitudes to and understanding and acceptance of autism.* (Paragraph 218)

19. *As a key part of this, the Government must commission a national programme of accredited mandatory training in autism and neuroinclusion for public-facing staff in all public bodies and service providers. This training should also be developed with and led by autistic people and those who support them, and should be made available to private sector businesses and organisations.* (Paragraph 219)

20. Autistic people continue to face fundamental barriers to the accessibility of a wide range of public services and environments. This has a damaging impact not only on effective service provision, but also on the wellbeing of autistic people and those who support them. (Paragraph 220)

21. *Strengthened and updated statutory guidance needs to set out how the NHS, local authorities and all public bodies and service providers must meet their duties in equality law to ensure that public services and environments are fully accessible to and inclusive of autistic people. This must take account of the principles of universal design and the British Standards Institution guidance (PAS 6463) on designing buildings to be accessible to neurodivergent people. It must also involve meaningful consultation with autistic people and those who support them about accessibility needs.* (Paragraph 221)

Chapter 4: Identification, assessment and support

22. An effective autism assessment system is critical to improving lives. Diagnosis plays a vital role in enabling an autistic person and those that support them to understand and respond well to their needs. For many, diagnosis is life-changing. However, in practice the autism assessment system can also become a tool for public services to ration limited access to support, forcing some to pursue diagnosis to access even basic help. (Paragraph 287)

23. The current autism assessment system is not fit for purpose. Access to autism assessment has widened, but the number of people coming forward for assessment has risen much more rapidly than services have been expanded. Thousands of people wait years for a diagnosis and are left with little to no support even when it comes. (Paragraph 288)

24. Successive Government strategies have focused on using limited capacity to increase the number of assessments carried out, at the expense of supporting autistic people before and after diagnosis. This means vital opportunities to offer timely support are routinely missed. (Paragraph 289)

25. The Government is seeking to provide more needs-led support and reduce numbers of people seeking diagnosis. However, there is real fear among autistic people and those who support them that this could mean that the

intrinsic benefits of diagnosis are lost and in practice make it even harder to access any support at all. (Paragraph 290)

26. A new way forward is needed. To tackle unacceptable waiting times, the Government will need to continue to scale up autism assessment services. By itself, this will not be sustainable. To enable every autistic person to access the support they need in a timely way, the Government needs to build a stable, equitable model of identification, assessment and support that can be stepped up and down throughout life. (Paragraph 291)

27. *The Government must immediately:*

    - *invest in driving down autism assessment waiting times, while also building up capacity to provide high-quality support both before and after diagnosis; and,*
    - *set up a commissioning framework to develop, test and scale up stepped, evidence-based identification, assessment and support pathways for autistic children and adults.* (Paragraph 292)

28. *In close partnership with autistic people and those who support them, the Government must establish the evidence and build a consensus on:*

    - *the reasons why people seek autism assessment;*
    - *the kinds of support that should be offered on the basis of need with and without an autism diagnosis, in healthcare and beyond;*
    - *how to shift away from a binary model of autism assessment towards a model of stepped identification of strengths and needs at clinical and sub-clinical levels;*
    - *how to ensure autism assessment services are not siloed, so that there is a 'single front door' for the assessment of autism and of associated neurodevelopmental and mental health conditions;*
    - *how to move towards a model of lifelong, stepped support for people across all services;*
    - *how to enable specialist autism assessment services to help build capability across mainstream services; and,*
    - *how to set training and quality assurance standards for autism assessment.* (Paragraph 293)

29. *The Government should use its findings as the basis of a new commissioning framework, workforce plan and funding settlement for autism assessment.* (Paragraph 294)

Chapter 5: Reducing health inequalities and building support in the community

30. We welcome the Government's commitments to address unacceptable inequalities in health outcomes and life expectancy in the new autism strategy. NHS services are too often inaccessible for autistic people. Even when people do access NHS services, those services often lack the capability they need to offer the right support. (Paragraph 340)

31. Important progress has been made in improving autistic people's access to healthcare in recent years, in particular through the introduction of the Oliver McGowan Mandatory Training. Building on this progress is vital. (Paragraph 341)

32. *In the new autism strategy and statutory guidance, the Government should identify priority health outcomes for autistic people and actions to improve them. Local authorities and NHS bodies should be required to report on progress towards these outcomes.* (Paragraph 342)

33. *The Government must ensure that the requirement for all staff at registered health and care providers to undertake mandatory training on autism and learning disability is implemented in full.* (Paragraph 343)

34. *Subject to the forthcoming evaluation of the Oliver McGowan Mandatory Training, the Government must ensure that all health and care staff who may be required to provide a service to an autistic person or a person with a learning disability have completed Tier 2 of that training at a minimum.* (Paragraph 344)

35. *The Government should roll out health checks for autistic people across the NHS. The Government should immediately reinstate the target to increase uptake of health checks for people with a learning disability in NHS planning guidance. It should do the same for health checks for autistic people as they are rolled out.* (Paragraph 345)

36. *Using the priority health outcomes for autistic people as a basis, the Government must develop a plan to reduce health inequalities for autistic people. This must set out how the Government will:*

    - *build up capability to support autistic people in the health and care workforce, including enabling specialist services to advise and support mainstream services; and,*

    - *develop, test and scale up effective models for meeting the needs of autistic people across general and mental health services.* (Paragraph 346)

37. Too many autistic people are unable to access the support they need to live well in the community. Many still fall through gaps between mental health and social care services. Failures to provide early, timely support increase the risks of crisis. (Paragraph 387)

38. *The Government should develop a national framework for the integration of healthcare and community support for autistic people to prevent care needs from developing and escalating, underpinned by a plan to develop capability in the health and care workforce.* (Paragraph 388)

39. We welcome the Government's commitment to make it a priority in the new autism strategy to ensure autistic people can leave and stay out of mental health inpatient settings. (Paragraph 389)

40. *The Government must set a clear timeline and roadmap for strong community services to be put in place, so that provisions in the Mental Health Bill to prevent the unnecessary detention of autistic people and people with a learning disability can be commenced.* (Paragraph 390)

41. Autistic people are at unacceptable risk of harm in health and care settings and in informal care relationships. There is also concerning evidence to suggest

that some carers of autistic people, and autistic carers, are unfairly blamed or treated with suspicion when they try to access help. (Paragraph 391)

42. *In new statutory guidance to the Autism Act, the Government must make clear how it will ensure autistic people, their families and carers are able to raise and escalate concerns about risks of failures to keep people safe and how services will be held to account for such failures.* (Paragraph 392)

43. It is unacceptable that so many autistic people and people with a learning disability die prematurely. *The Government must make it mandatory for Integrated Care Boards to complete LeDeR reviews into the lives and deaths of autistic people and people with a learning disability. The Government must also set up an independent mechanism to oversee the implementation of recommendations made in LeDeR reviews.* (Paragraph 393)

Chapter 6: Access to education and transitions to adulthood

44. Autistic children and young people do not have equal access to education. Most autistic children and young people attend mainstream schools; many are unhappy there. Increasing numbers of families of autistic children are turning to home education not because they want to but because school is no longer an option for them. Rates of suspension and exclusion are also too high. A new generation of young autistic people is being set up to struggle. (Paragraph 441)

45. Mainstream schools need more support and stronger incentives to provide autistic children and young people with the support they need. We endorse the recommendation of the House of Commons Education Select Committee that an inclusive mainstream education system must be underpinned by principles that:

- "education settings and environments must be accessible, safe, and designed to meet a wide range of sensory and physical needs;
- "teachers and teaching assistants and other support staff should have the expertise, training, and confidence to support diverse learners, underpinned by regular access to embedded specialist professionals;
- "the curriculum must be flexible, relevant, and reflect the representation of young people with SEND; and the Government must ensure the curriculum itself and the assessment of it reflect and accommodate their needs;
- "accountability systems must examine and prioritise the progress and outcomes of all pupils, on a rounded set of indicators which include but are not limited to academic attainment, so that inclusion is embedded as an essential component of quality for all settings; and,
- "good inclusive practice must always ensure rigorous, systemic approaches to understanding the individual needs of every child and delivering personalised support." (Paragraph 442)

46. Improving outcomes for autistic children and young people must be a key measure of the success of any reform to the education system. *In the new autism strategy, the Government should set priority outcomes for better access to education for autistic children and young people and report regularly on progress towards those outcomes.* (Paragraph 443)

47. *To help achieve those outcomes, the Government should develop, test and scale up approaches to building capability to support autistic children and young people across all types of educational setting, including by enabling high-performing specialist schools to act as centres of excellence.* (Paragraph 444)

48. Young autistic people very often face a cliff edge in access to support in the transition to adulthood, just when they need that support most. *In the new autism strategy, the Government must set priority outcomes for better transitions to adulthood for young people and benchmarks by which progress will be measured. The Government must set clear lines of responsibility and ministerial accountability for progress.* (Paragraph 454)

49. *The Government must produce a commissioning framework for local authorities and NHS bodies to provide integrated, evidence-based services for young autistic people during the transition to adulthood, including support with education, mental health, housing and employment.* (Paragraph 455)

Chapter 7: Employment

50. The Government's Get Britain Working plan offers opportunities to enable more autistic people to move towards and into work, in particular through the expansion of access to supported employment. (Paragraph 495)

51. *In the new autism strategy, the Government should make a significant increase in the employment rate for autistic people a priority outcome and should report regularly on progress towards this goal. To achieve this, the Government should fund the expansion of evidence-based initiatives to support people to find and stay in work, including through supported internships and supported employment.* (Paragraph 496)

52. *In updated statutory guidance to the Autism Act, the Government should require that local authorities and NHS bodies work with the Department for Work and Pensions and employers to support autistic people to move into work and to collect evidence and data on progress against this goal.* (Paragraph 497)

53. Employers have a vital role to play in enabling autistic people to find, stay and thrive in work, but they need more support and stronger incentives to do so. (Paragraph 527)

54. *The Government should develop and publish standards on what employers should do in practice to enable autistic applicants and employees to access their legal rights to reasonable adjustments, drawing on evidence and experience from employers and employees.* (Paragraph 528)

55. *The Government should run a campaign to promote evidence-based voluntary peer-to-peer learning and accreditation schemes for employers, such as the Autistica Neurodiversity Employers Index.* (Paragraph 529)

56. *The Government should develop, test and scale up financial incentives for employers to support more autistic and disabled people to find and stay in work, for example through taking into account the percentage of an organisation's workforce that is disabled in the awarding of public contracts, or through the use of tax incentives and/or national insurance relief.* (Paragraph 530)

57. *The Government should reform the Disability Confident scheme so that certification at Levels 2 and 3 is based on objective criteria, including the percentage of the workforce that is disabled.* (Paragraph 531)

Chapter 8: Criminal justice

58. The current autism strategy aims for all parts of the criminal justice system to have made demonstrable progress by 2026 in ensuring that autistic people have equal access to care and support where needed. This aim is unlikely to be met. While there are many pockets of good practice, support across the system as a whole is patchy and inconsistent. The system is not joined up in its support for and understanding of autistic people, and there is no effective mechanism for best practice in a particular institution or part of the system to be applied across the system as a whole. (Paragraph 608)

59. We identify six specific problems:

- poor identification, screening and assessment pathways within the criminal justice system;
- poor and inconsistent collection and sharing of data on numbers of autistic people and the needs of individuals;
- a lack of understanding of autism and the specific difficulties that people may face in the criminal justice system;
- a lack of support and adjustments for autistic people across the system;
- continued cases of inappropriate treatment; and,
- inconsistent practice across the system as a whole. (Paragraph 609)

60. The July 2021 *Neurodiversity in the Criminal Justice System: a review of evidence* report made six core recommendations:

- A coordinated and cross-government national strategy.
- A common screening tool to help more accurately determine the prevalence of neurodivergence in the criminal justice system.
- Systematic collection and analysis of data to help more accurately determine the prevalence of neurodivergence in the criminal justice system.
- A programme of awareness-raising and specialist training for staff in the criminal justice system.
- Adjustments throughout the criminal justice system for those with neurodivergent conditions.
- A coordinated means for all criminal justice system agencies to work together and with other statutory and third sector organisations to understand and meet the needs of neurodivergent individuals in the community, preventing offending and supporting rehabilitation. (Paragraph 610)

61. *We endorse these recommendations. The Government must publish a full account of progress in each part of the criminal justice system towards meeting these objectives, and how it will seek to address them in the context of the next autism strategy.* (Paragraph 611)

62. *In particular, we call on the Government, working with all parts of the criminal justice system, the NHS and local authorities, to develop an evidence base on,*

test and roll out effective ways to identify and support autistic people. This should address support for victims, witnesses, suspects, defendants or those convicted of a crime. It should also focus on: preventing people entering the criminal justice system; screening, support and adjustments; tailored rehabilitation; and training for frontline staff. (Paragraph 612)

Time to deliver: The Autism Act 2009 and the new autism strategy

CHAPTER 1: INTRODUCTION

The Autism Act 2009

1. The Autism Act 2009 is a very short Act—only four pages long.[1] However, its importance far outweighs its size.

2. The Government autism strategy for 2021–26 states: "The introduction of the Autism Act 2009 was ground-breaking because it was the first disability-specific piece of legislation in England."[2] It was a Private Member's Bill that won Government support thanks to the unstinting efforts of its sponsor, the late Rt Hon Cheryl Gillan DBE MP. We pay tribute to her and her dedication to improving support for and acceptance of autistic people.

3. At its Second Reading in the House of Commons on 27 February 2009, Cheryl Gillan explained the purpose of the Bill:

> "The Bill is not intended to do everything that is required to help [autistic people], but it aims to address some of the structural disadvantages that they face and to vitalise local activity around autism. It clearly specifies the actions needed to stop [autistic] adults … being excluded from receiving the services that they need and to which they are entitled. Existing Department of Health guidance states that local authorities should already be working to assess the needs of [autistic] adults … in their area. However, the reality on the ground is that most local authorities are not even fulfilling their obligation to know how many [autistic] people … there are in the local area. Guidance has not had the required impact, and legislation is essential to ensure that [autistic] people … do not continue to be excluded."[3]

4. Tim Nicholls, Assistant Director of Policy, Research and Strategy, National Autistic Society (NAS), explained the need for the Act:

> "Before the Act came to Parliament … autistic adults too often were not getting the support that they needed, and they were often falling down what was often known as the gap between traditional services: people were not eligible for learning disability services or mental health services, but there were no services available that would meet their needs as autistic adults … People, quite simply, did not know that autistic adults existed. It was still very often seen as a young person's condition that people grew out of, therefore autistic adults were often utterly invisible in the system."[4]

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1 Autism Act 2009

2 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021. The Down Syndrome Act passed in 2022 is a subsequent example of disability-specific legislation.

3 HC Deb, 27 February 2009, col 490

4 Q 1 (Tim Nicholls)

5. The Act's key statutory provisions are to require the Government to introduce and review an adult autism strategy for England and statutory guidance for the NHS and local authorities. The first autism strategy for adults and the statutory guidance were both published in 2010.[5] The strategy and statutory guidance were updated in 2014 and 2015, respectively.[6] The current strategy (which included children and young people for the first time) was published in 2021, covering the period up to 2026. However, the statutory guidance has not been updated since 2015 and is now critically out of date.

What is autism?

6. A medical diagnosis of autism is based on specific diagnostic criteria (as detailed in Box 1).

Box 1: Clinical diagnostic criteria for autism

In the context of a clinical diagnosis, autism is described as 'Autism Spectrum Disorder' (ASD). National Institute for Health and Care Excellence (NICE) guidelines state that an autism diagnosis should be based on criteria listed in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) or the International Classification of Diseases 11th Revision (ICD-11).

According to the DSM-5, the features of 'Autism Spectrum Disorder' include:

- Criterion A: persistent deficits in reciprocal social communication and social interaction.
- Criterion B: restricted, repetitive patterns of behaviour, interests or activities.
- Criterion C: symptoms must be present in the early developmental period.
- Criterion D: symptoms cause clinically significant impairment in social, occupational, or other important areas of functioning.
- Criterion E: these disturbances are not better explained by intellectual disability or global developmental delay.

According to the ICD-11, the features of 'Autism Spectrum Disorder' include:

- Persistent deficits in initiating and sustaining social communication and reciprocal social interactions that are outside the range of typical functioning given the person's age and level of intellectual development.
- Persistent restricted, repetitive and inflexible patterns of behaviour, interests, or activities that are clearly atypical or excessive for the person's age and sociocultural context.
- The onset of the disorder occurs during the developmental period, typically in early childhood, although characteristics might not fully manifest until later in life due to increased social demands.
- Characteristics result in significant impairment in personal, family, social, educational, occupational or other important areas.

Source: American Psychiatric Association, The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR), 2022 and World Health Organization, International Classification of Diseases 11th Revision (ICD-11), 2022

5 Department of Health, *Fulfilling and rewarding lives: the strategy for adults with autism in England*, March 2010

6 Department of Health, *'Think Autism': an update to the government adult autism strategy*, 2 April 2014, and *Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy*, March 2015

7. The core characteristics of autism manifest differently in different people. Common social characteristics of autism include:

    - Differences in the way a person interacts and communicates with others, particularly with those who are not autistic (such as finding it hard to judge how much information is deemed appropriate to share in a conversation).

    - Differences in non-verbal communication (such as using and understanding eye contact, gesture, body language and facial expressions differently from non-autistic people).

    - Differences in the development and maintenance of relationships with others (which may include a lack of interest in others, or a significant reliance on a few close others, for example).

8. Common non-social characteristics of autism may include:

    - A preference for order, predictability and routine, with even small changes potentially leading to significant anxiety and/or distress. Distress is sometimes manifested in what are described as 'meltdowns' and 'shutdowns'—intense responses to overwhelming situations where the autistic individual temporarily loses control of their behaviour.[7]

    - Repeated movements or behaviours (such as hand flapping, spinning), which are often referred to as self-stimulatory behaviours or 'stimming'.

    - Focused and dedicated interests (such as a strong passion for a particular subject, which may be considered unusual in intensity or topic).

    - Differences in sensory processing, which may include being extremely sensitive to some aspects of the environment (such as sounds or lights), while not being sensitive to others (such as reduced responses to pain).

9. These characteristics can change and fluctuate over the course of an individual's life, and may be heavily shaped by the environment that they are in. The social and non-social characteristics of autism may not always be immediately obvious, particularly if an individual is 'masking'. Masking (or camouflaging) is a term used to describe how some autistic people (either consciously or unconsciously) alter their behaviour to appear outwardly more like their non-autistic peers. For example, masking may include suppressing stimming in public.

10. Since every autistic person is different, it is not possible to apply a 'one size fits all' approach to strategies for support for autistic people. Our witnesses consistently reminded us of a well-known mantra, widely attributed to Dr Stephen Shore, that "when you have met one autistic person, you have met one autistic person".

Evolving understanding of autism and use of terminology

11. The diagnostic criteria for autism are grounded in a medical model of disability, which focuses on an individual's 'deficits' or 'impairments' across both social and non-social domains. In legal terms, disability is the basis for protections for autistic people under the Equality Act 2010.[8]

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7 National Autistic Society (NAS), *Meltdowns*

8 Equality Act 2010. See Box 5.

12. While some people appreciate the framing of autism within a medical model (for instance in highlighting the significant challenges that autistic individuals may face, across a range of areas), others prefer to view autism through alternative lenses. The National Autistic Society states that "some autistic people prefer not to say that autism is a disability. Instead, they say autistic people are disabled by the barriers they face in society."[9] This aligns with the social model of disability. Disability Rights UK states that this model "was developed by Disabled people and describes people as being disabled by barriers in society, not by our impairment or difference. If modern life was set up in a way that was accessible for Disabled people, then we would not be excluded or restricted."[10]

13. The formal medical diagnostic description of autism is 'Autism Spectrum Disorder' (ASD). However, many autistic people and others see autism not as a disorder but as a difference, bringing strengths as well as challenges.[11] The 'neurological diversity' or 'neurodiversity' concept was developed by autistic activists in the mid-1990s.[12] Neurodiversity is the notion that different people's brains absorb, process and respond to information in different ways. Most people's brains operate in a broadly similar way, which is described as 'neurotypical'. However, a significant number of people are thought to be 'neurodivergent', whereby their brains operate in different (but not lesser) ways.[13]

14. The neurodiversity concept therefore frames autism as a different—but equally valid—way of experiencing and interacting with the world. Through such a lens, the core social criteria for autism are reframed as challenges that arise due to an interaction between the autistic individual and the non-autistic world they are navigating. As one example, proponents of the neurodiversity concept avoid the notion of autistic 'deficits in reciprocal social communication and social interaction' (as outlined in the diagnostic criteria) in favour of an appreciation that communication and interaction are two-way endeavours. Indeed, just as autistic people may struggle to understand the perspectives of non-autistic people, the reverse is also true (an observation referred to as the 'double empathy problem').[14]

15. Moving away from a medical model of disability also ensures that autism is framed as a 'different' rather than a 'deficient' way of being. For example, autistic people often reframe the notion of 'restricted, repetitive patterns of behaviours, interests or activities' (as outlined in the diagnostic criteria) as a preference for order or routine and/or focused or intense interests. This reframing acknowledges how such behaviours may serve a helpful, self-regulatory function for the individual, and/or may even be an area of strength.

16. It is also important to stress that autistic people have varying support needs. Some autistic people need constant care, while others need help with specific

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9 National Autistic Society (NAS), *What is autism*

10 Disability Rights UK, *Social Model of Disability: Language*

11 NHS England, *A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards*, 5 April 2023

12 Monique Botha et al, 'The neurodiversity concept was developed collectively: An overdue correction on the origins of neurodiversity theory', *Autism*, vol 28, Issue 6, (2024): https://doi.org/10.1177/13623613241237871

13 National Autistic Society (NAS), *What is autism*

14 Damian E M Milton, 'On the ontological status of autism: the 'double empathy problem', *Disability & Society*, vol 27, Issue 6, 2012: https://doi.org/10.1080/09687599.2012.710008

aspects of life or can manage with little support.[15] On an individual level, autistic people may require different levels of support in certain environments or at certain stages of their lives. Autism has long been described as a 'spectrum condition' because it affects people differently. However, there is increasingly a move away from considering autism as a linear spectrum.[16] One witness described autism instead as "like an audio mixing board, with a whole host of different sliders for different traits that often increase and decrease in different situations and environments."[17]

17. Some feel that the definition of autism is too broad to be useful, and draws focus and attention away from those with most significant needs. The National Autistic Society acknowledges this, but argues that autistic people with different support needs often face similar challenges.[18]

18. One significant factor in terms of the broad nature of autism is that Asperger's disorder/syndrome is no longer given as a diagnosis. Asperger's disorder/syndrome was a diagnosis given to some autistic people without a learning disability between around 1994 and 2013. A diagnosis of Autism Spectrum Disorder is now given regardless of whether a person has a learning disability or of their support needs.[19] However, people who received a diagnosis of Asperger's disorder/syndrome will normally retain their original diagnosis and may still use the term (or terms like 'Aspie') to describe themselves.[20]

19. The National Autistic Society states that, based on its research in the UK, 'identity-first' language (for example 'autistic person') as opposed to 'person-first' language (for example 'person with autism') is preferred by most autistic people because they see being autistic as integral to who they are, not as something they have. However, this is not universally true, and some people with a diagnosis prefer person-first language.[21] There are controversies around whether terms such as 'profound' or 'severe' autism are helpful or unhelpful descriptors. There are also some terms that were once widely used but are now being moved away from (for instance referring to autistic people as being 'high functioning' or 'low functioning') as they are considered overly simplistic and potentially stigmatising.

20. We respect people's preferences around the use of terminology, and acknowledge the strong (and sometimes opposing) views that autistic people and those who support them (including family members and professionals) have around these issues. It is not possible to reflect all these views in our report. We therefore use terminology (including identity-first language)

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15 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021

16 Patrick Dwyer, 'The Autism Constellation', *Autism Scholar*, October 2020

17 Written evidence from Cheryl Lewis (AAC0017)

18 National Autistic Society (NAS), *What is autism*

19 In the 1940s, Austrian physician Hans Asperger described autism in children without a co-occurring learning disability. See Nicole E Rosen, Catherine Lord and Fred R Volkmar, 'The Diagnosis of Autism: From Kanner to DSM-III to DSM-5 and Beyond', *Journal of Autism and Developmental Disorders*, vol 51, (2021), pp 4253–4270: https://doi.org/10.1007/s10803–021-04904-1; The Autism History Project, *Autism in the DSM*. After 2013, Asperger's disorder/syndrome was folded into the definition of autism on the basis that there was no clear distinction. Use of the term Asperger's disorder/syndrome has declined further since it was shown in 2018 that Hans Asperger had cooperated with the Nazi 'euthanasia' programme for the murder of disabled children. See Herwig Czech, 'Hans Asperger, National Socialism, and 'race hygiene' in Nazi-era Vienna', *Molecular Autism*, vol 9, article number 29, 2018: https://doi.org/10.1186/s13229–018-0208-6.

20 National Autistic Society (NAS), *Asperger syndrome (Asperger's)*

21 National Autistic Society (NAS), *How to talk and write about autism guide*, June 2025

that reflects the current legal framework and guidance from the NHS and principal autism charities,[22] other than when directly citing evidence that uses other terminology. We recognise that some will disagree with the terminology we use. We also acknowledge that our understanding of autism, and the terminology used to describe autism, will continue to evolve.

Misconceptions and controversies around autism

21. There are also many misconceptions or controversies in public discourse around autism. It is therefore important to stress these facts:

- Autism is not an illness. The NHS warns against use of various fake or harmful claimed cures or treatments.[23] Theories about vaccines causing autism have been shown to be unfounded.[24] The Medicines and Healthcare products Regulatory Agency has confirmed that taking paracetamol during pregnancy remains safe and there is no evidence it causes autism in children.[25]

- Autism is not a learning disability, although it should be noted that autistic people may also have a learning disability.

- Autism is not a mental health condition, although it should be noted that autistic people may also have one or more mental health conditions.

- Autistic people may also have other neurodevelopmental conditions or forms of neurodivergence, including attention deficit hyperactivity disorder (ADHD) and specific learning difficulties (such as dyslexia and dyspraxia).[26]

The work of this Committee

Background to the appointment of the Committee

22. House of Lords committees are appointed to examine issues in detail, including Government policy, proposed new laws and policy topics. They comprise a small number of members of the House of Lords from across political parties and groups represented in the House. Committees are independent of the Government, but make recommendations to the Government for action in their reports. The Government must respond to Committee reports within two months, after which the Committee's report is debated in the House of Lords. The role of committees is to scrutinise the Government and its policies. They do not have the power to examine or rule on individual cases and complaints.

23. The House of Lords appoints four special inquiry committees each year for a set period of time (usually from January to November of a calendar year) to examine a specific topic. These committees cease to exist upon

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22 *Ibid.*

23 NHS, *Treatments that are not recommended for autism*, and National Autistic Society (NAS), *So called cures*

24 National Autistic Society (NAS), *The causes of autism*

25 Autistica, *The Trump administration and autism: a joint statement from leading UK autism charities*, 22 September 2025; and Medicines and Healthcare products Regulatory Agency, *MHRA confirms taking paracetamol during pregnancy remains safe and there is no evidence it causes autism in children*, 22 September 2025

26 See NHS England, *Update on Learning Disability and Autism Programme*, September 2025, Parliamentary Office of Science and Technology, *Autism*, POSTnote 612, January 2020, and NHS, *Other conditions that affect autistic people*.

agreement of their report. At least one of the committees appointed each year is usually a post-legislative scrutiny committee (conducting an inquiry into the effectiveness of an existing Act of Parliament).

24. The Liaison Committee advises the House of Lords on the appointment of new special inquiry committees. On the basis of a proposal by Baroness Browning and Lord Touhig, the Liaison Committee recommended in its December 2024 report *New committee activity in 2025*[27] that a post-legislative scrutiny committee be appointed "to consider the Autism Act 2009". The Liaison Committee further recommended that the new Committee's inquiry could focus on the implementation of the Autism Act, the operation of the statutory guidance and the effectiveness of the autism strategy.[28]

25. The Liaison Committee's report and recommendations were agreed by the House of Lords on 18 December 2024,[29] and the new Committee on the Autism Act 2009 was appointed on 30 January 2025 with a remit to agree its report by 30 November. The new Committee met for the first time on 10 February 2025. We agreed this report on 10 November.

26. Whereas post-legislative scrutiny committees usually undertake detailed scrutiny of the provisions of an Act, given the brevity of the Autism Act we have taken a different approach. While we have examined evidence concerning the purpose and effectiveness of the Act (and whether it has met its original aims), we have focused in particular on the autism strategy and statutory guidance for which the Act provides.

27. The remit of the current strategy has informed our inquiry in two key ways. First, while the first two iterations of the strategy were focused on adults in line with the Act's provisions, the 2021–26 strategy was for the first time extended to children and young people "in recognition of the importance of ensuring that they are diagnosed and receive the right support as early as possible and across their lifetime."[30] Our inquiry likewise focused on the needs of autistic people of all ages: children, young people and adults.

28. Secondly, the current strategy is due to expire in July 2026. A key motivation in establishing the Committee, and a key driver of our work, has been to help shape the scope and implementation of the new strategy to come into force after July 2026. In his evidence to us, Stephen Kinnock MP, Minister of State for Care, Department of Health and Social Care (DHSC), stressed that the Government is "absolutely committed … to there being a strategy … to there not being a vacuum [when the current strategy expires] … and to there being an implementation plan." He added that "the strategy we will bring forward is being shaped as we speak", the Government will be

27 House of Lords Liaison Committee, *New committee activity for 2025* (3rd Report, Session 2024–26, HL Paper 56)

28 The Liaison Committee recommended that the Committee scrutinise: how far the Act has achieved its goals; how far the Act remains effective given the developments in the policy and legislative landscape since it received Royal Assent; the Government's approach to carrying out the duties set out in the Act and setting and measuring progress against goals in the autism strategy; how effective the statutory guidance has been in improving NHS and local authority support for autistic people and how consistently statutory duties are being met; and, how successful the Government has been in meeting the goals set out in successive autism strategies, on public understanding, education and transitions to adulthood, employment, health; social care and community support, and criminal justice.

29 HL Deb, 18 December 2024, cols 266–67

30 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021

"developing the strategy in 2026" and "the input from this Committee will help us shape that strategy."[31]

29. We have been mindful of the wider policy context, including a number of relevant developments and Government announcements during the course of the inquiry:

- Reform to the NHS. In July 2025, the Government published *Fit for the future: 10 Year Health Plan for England*.[32]
- Schools reform (including Special Educational Needs and Disabilities (SEND)). The Government is planning to publish a schools white paper in the new year.[33]
- Work and benefits policy and legislation, including the *Get Britain Working* white paper, the *Pathways to Work* green paper, and the Universal Credit Act 2025.[34]
- The Mental Health Bill,[35] and its provisions to limit the length of time that autistic people can be detained under the Mental Health Act,[36] if they do not have a co-occurring mental disorder that needs hospital treatment and have not committed a criminal offence.
- Ongoing Government-commissioned reviews, including: the independent commission for reforming adult social care chaired by Baroness Louise Casey;[37] the Neurodivergence Task and Finish Group commissioned by the Department for Education and chaired by Professor Karen Guldberg;[38] the *Keep Britain Working* review chaired by Sir Charlie Mayfield;[39] and the Expert Academic Panel on Neurodiversity and Employment chaired by Professor Amanda Kirby. Professor Guldberg, Sir Charlie and Professor Kirby each gave evidence to the Committee.[40]
- The independent statutory inquiry investigating the deaths of mental health inpatients in Essex between 2000 and 2023, led by Baroness Kate Lampard CBE (the Lampard Inquiry).[41]
- The current fiscal context in which the Government is operating.

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31 Q 170 (Stephen Kinnock MP)
32 Department of Health and Social Care, and Prime Minister's Office, 10 Downing Street, *10 Year Health Plan for England: fit for the future*, 3 July 2025, CP 1350
33 Correspondence, *Secretary of State for Education to Chair of the Education Select Committee*, 22 October 2025
34 See Universal Credit Act 2025, Department for Work and Pensions, *Press release:* Further details on welfare reforms published ahead of Second Reading, 30 June 2025, Department for Work and Pensions, HM Treasury and Department for Education, *Get Britain Working White Paper*, 2 September 2024, and Department for Work and Pensions, *Pathways to Work: Reforming Benefits and Support to Get Britain Working Green Paper*, updated 30 October 2025.
35 Mental Health Bill (Bill 272 (2024–26)
36 Mental Health Act 1983
37 Department of Health and Social Care, *Independent commission into adult social care: terms of reference*, 11 July 2025
38 HM Government, *Neurodivergence Task and Finish Group*
39 Department for Work and Pensions and Department for Business and Trade, *Keep Britain Working Review: Final report*, 5 November 2025
40 Department for Work and Pensions, *Press release: Employment prospects for neurodiverse people set to be boosted with launch of new expert panel*, 30 January 2025
41 The Lampard Inquiry

30. We have taken this wider context into account insofar as it relates to support for autistic people and the Government's autism strategy. However, these issues each have policy implications far beyond the Committee's remit. A number of parliamentary committee reports into these issues have recently been published.[42] We have sought to avoid duplicating such work as far as we can.

31. Although the Autism Act extends legally to England and Wales, in practice it and the UK Government's autism strategy apply to England only. Our scrutiny is therefore focused on autism policy in England. However, the Committee invited evidence on what the UK Government could learn from the Governments in Wales, Scotland and Northern Ireland in supporting autistic people. We are grateful to the Scottish Government, Welsh Government and Northern Ireland Executive for submitting evidence to the Committee. We have also received evidence on examples of international practice.[43]

Committee members and staff

32. The members of committees are chosen by the leaders and coordinators of political parties and the independent 'crossbench' members in the House of Lords. Members are obliged to declare financial and professional interests, and these are set out in Appendix 1. Committee members are not required to disclose personal matters such as a diagnosis of autism or another neurodivergent condition either for themselves or a family member. A decision whether to refer to such experience publicly is a decision for each member. However, we acknowledge the argument put to us that "if the work of the Committee can encourage influential autistic people such as autistic politicians to openly acknowledge being autistic, that would provide such valuable leadership and role modelling."[44]

33. In that context, we wish to disclose that the membership of the Committee reflects a range of relevant experience, and each of the 12 committee members expressed an interest in serving on the committee because of their personal or professional interest in the subject. A majority of members of the Committee have some form of personal and/or professional connection to the work of the Committee. Their experience includes:

- a personal diagnosis of a neurodivergent condition;
- close family members (including dependants) with a diagnosis of autism and/or other neurodivergent conditions;
- previous experience of senior leadership roles, including UK and devolved government departmental ministers, the judiciary, the NHS and local government; and,

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42 See House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492), House of Commons Health and Social Care Committee, *Adult Social Care Reform: the cost of inaction* (2nd Report, Session 2024–26, HC Paper 368), and House of Commons Work and Pensions Committee, *Get Britain Working: Pathways to work* (3rd Report, Session 2024–25, HC Paper 837).

43 Written evidence from Tom Arthur MSP, Minister for Social Care and Mental Wellbeing, Scottish Government (AAC0328), Sarah Murphy AS/MS, Minister for Mental Health and Wellbeing, Welsh Government (AAC0373), Mike Nesbitt MLA, Minister of Health, Northern Ireland Executive (AAC0375) and Autistica (AAC0105)

44 Q 51, footnote 9 (Dr Mary Doherty)

- current and former leadership roles in charities and campaign organisations representing and working with autistic people, people with a learning disability, dyslexic people and carers.

34. In common with most House of Lords committees, we had a small staff team of three full-time officials, supported by other officials who work with all committees. Committee staff are politically impartial parliamentary officials who support the Committee's work, and Committee members bear sole responsibility for this report.

The Committee's Specialist Adviser

35. The Committee also received expert professional support that informed its deliberations. Professor Laura Crane is Professor of Autism Studies within the School of Education at the University of Birmingham, where she is also Director of the Autism Centre for Education and Research (ACER), and Director of Research for the School of Education. Professor Crane acted as Specialist Adviser to the Committee. We are grateful to Professor Crane for her invaluable contribution to our work, and for her high-quality advice.

Involvement of autistic people and those who support them

36. One of the key messages conveyed by witnesses is the importance of the principle of "nothing about us without us". Traditionally, decisions about autistic people's lives have been made for rather than by them. Over the past decade or so, and largely driven by autistic advocacy, there has been a push towards giving autistic people more of a say in the decisions that affect them and their day-to-day lives. Importantly, this autistic involvement must not be tokenistic in nature and should, ideally, be at every stage of a process from start to end. The involvement of those who support autistic people is also crucial, such as when decisions directly affect supporters' day-to-day lives and practices, or where the autistic individual may not be able to participate fully in decision-making (for instance in the case of very young children).

37. In practice, meaningful involvement can take different forms in different contexts. For example, there are now widespread efforts to co-produce, co-design or co-deliver health and social care services. Such efforts can be defined as "relationship[s] where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities".[45]

38. We endorse and acknowledge the importance of the principle of meaningful involvement. Our recommendations stress the need for the Government to ensure the meaningful involvement of autistic people and those who support them as it develops and implements the new autism strategy. We thought carefully about meaningful autistic involvement in our own work. The unique nature of parliamentary proceedings in general, and parliamentary committee work in particular, placed us under some unavoidable constraints. Only members of the House of Lords are permitted to be members of House of Lords public policy committees, and there is no mechanism for non-parliamentarians to form part of a committee's membership.[46] Consequently, a committee's report can only be formally considered and agreed by its

45 Social Care Institute for Excellence (SCIE), *Co-production: what is it and how to do it*, July 2022

46 The only House of Lords bodies whose members include non-parliamentarians are the Management Board, House of Lords Commission and Conduct Committee, which all deal with internal (known as domestic) matters rather than scrutiny of public policy.

members. In addition, Special Inquiry Committees operate to a restricted 10-month timetable.

39. It is important to point out that parliamentary committees are not government bodies. They are not responsible for government policy development and implementation. Rather, their role is to make recommendations to the Government for action. While the Government must publish a response to committee reports, it is not obliged to adopt a committee's recommendations.

40. Parliamentary committee reports are evidence-based. This means that committees reach their conclusions and recommendations on the basis of oral evidence (where a witness answers questions from the Committee in a formal session) and written evidence (where an individual or organisation sends the committee a document with their views).[47]

41. Within the current constraints of committee work, we sought to ensure that autistic people and those who support them were given opportunities to share their views and experiences through a variety of means. We have received the views directly of several hundred autistic people and those who support them, including through oral evidence, written evidence, private engagement and Committee visits, while several thousand more have contributed to surveys and consultations undertaken by autism charities and submitted to the Committee as evidence. We set out more details of this below.

Oral and written evidence

42. We held our first public oral evidence session on 10 March 2025, and continued taking oral evidence until 7 July. In all, the Committee held 24 oral evidence sessions with 67 different witnesses, including many autistic people and those who support them from across the country and from different demographic groups, reflecting both on their personal experiences and their professional expertise. We did not make a distinction between autistic people giving evidence in a personal or professional capacity. Autistic people have valuable evidence to provide in relation both to their personal and professional experience, and the two are mutually reinforcing and not exclusive.

43. Several of our witnesses publicly declared that they are autistic. Making such a declaration is a personal choice, and it was not appropriate for us to insist that witnesses declare whether they are autistic. It is therefore not possible to provide a breakdown of the number of autistic and non-autistic witnesses. However, we stressed to the organisations we engaged with the importance of hearing directly from autistic people and those who support them, and invited them to consider carefully the diversity characteristics of those they nominated to represent them.

44. Senior representatives of four of the principal autism charities were invited to give evidence, both at the beginning and end of the Committee's oral evidence programme. This enabled them to provide advice on the Committee's inquiry at the outset and to respond to the evidence put to the Committee, including by Government Ministers.

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47 It should be noted that evidence submitted to a court of law is dealt with under strict formal rules aimed at proving facts in a legal proceeding and is presented under oath with potential significant consequences if found to be untrue. In contrast, evidence to parliamentary committees is designed to aid the Committee's investigation and subsequent policy recommendations.

45. The Committee published a Call for written evidence on World Autism Acceptance Day, 2 April.[48] We provided a number of ways to help people to submit evidence. These included:

- The publication of Easy Read and audio versions of the Call for evidence;
- Sharing the Call for evidence in draft with a network of autistic people (facilitated by autism charities) for review and comment before publication;
- A longer consultation period of two months, and providing deadline extensions to those who requested them;
- The possibility of submitting written evidence either by email or via an online portal;
- The possibility of submitting written evidence either with the submitter's name published, anonymously or in confidence; and,
- The possibility of submitting evidence in audio or handwritten form, subsequently transcribed for publication.

46. In response to this we received nearly 400 submissions (364 published and 22 submitted in confidence), which we understand to be a record high number of responses to a House of Lords Committee inquiry. Several hundred of these submissions were from autistic people and those who support them.

47. Notwithstanding the steps we took to help people to submit evidence, we acknowledge that some witnesses said that the lengthy and technical nature of the Call for evidence made it inaccessible for some who wished to give evidence. Others said that we did not go far enough in enabling autistic people with a learning disability and non-speaking autistic people to provide evidence. We are grateful to witnesses including Autism Action, Charli Clement, Lou Chandler, Georgia Holliday and Chelsea Webster who took proactive steps to share the Call for evidence and make it more accessible for the autistic community.[49]

48. In addition, numerous submissions assimilated and synthesised evidence from a very wide range of autistic people and those who support them. For example, Autism Action's written submission was based on a survey of over 5,000 people, including nearly 2,700 autistic people and over 3,200 parents of autistic people.[50] Autistica's submission draws on focus groups with autistic adults.[51] Several self-advocacy groups, support services and autism partnership boards drew on feedback from people with personal experience

48 See Appendix 3.

49 Written evidence from Autism Action (AAC0233) was based on a survey of over 5,000 people, including 2,688 autistic people, 3,247 parents and carers of autistic people (of whom 938 were autistic), 946 parents and carers of autistic people with a learning disability (of whom 275 are autistic), and 812 people who work in the field of autism. Written evidence from Charli Clement (AAC0122), Lou Chandler (AAC0119), Chelsea Webster (AAC0115) and Georgia Holliday (AAC0134) cited the views of over 200 autistic individuals and their carers. Their submissions stated: "Concerned that many autistic people might find the official call for evidence inaccessible, I have proactively gathered input from a wide range of autistic individuals, aiming to ensure the committee hears from as many diverse voices as possible, reflecting their true experiences and needs."

50 Written evidence from Autism Action (AAC0233)

51 Written evidence from Autistica (AAC0105)

in their submissions, including autistic people with a range of support needs.[52] Other submissions were based on engagement or research with hundreds of autistic people.[53]

49. Overall, the Committee received oral and written evidence from a wide range of individuals and organisations, including:

- autistic people and those who support them sharing their own personal experience and campaign work. A number of these were submitted anonymously or in confidence;
- several large and small autism and disability charities, representative organisations and campaign organisations;
- ministers from three Government departments;
- representatives of regulators and agencies including the Care Quality Commission, National Institute for Health and Care Excellence (NICE), HM Inspectorate of Probation and HM Inspectorate of Prisons;
- senior officials from local authorities and NHS England;
- chairs of previous or current Government-sponsored reviews;
- education providers and professionals;
- employers and organisations helping support autistic people in employment;
- police and criminal justice representatives;
- academics, medical professionals, professional representative organisations and research organisations; and,
- senior parliamentarians, including Dr Marie Tidball MP, Chair, All-Party Parliamentary Group (APPG) on Autism, and Professor Sheila the Baroness Hollins, former Chair, Oversight Panel review of Independent Care (Education) and Treatment Reviews.

Private meetings

50. We recognised that not all those wishing to share their views with the Committee would want to do so in public, and that it was important to provide other ways of engaging with the Committee. We therefore held a

52 See for example written evidence from Birmingham Autism and ADHD Partnership Board (AAC0195), Cloverleaf Advocacy (AAC0199), Live! Cheshire (AAC0087), Sunderland People First (AAC0093), Rotherham Parents Forum Limited (RPFL) (AAC0113), Speak Out Peterborough (AAC0284), Hesley Group (AAC0302), Mission Impossible Peer and Self-Advocacy Group (AAC0291), Brightstars Autistic Club (AAC0341) and Outside the Box (AAC0169).

53 For instance, written evidence from Dr Jan Lawler (AAC0295) on employment was based on research interviews with 69 participants: 52 autistic job applicants, eight employers and nine stakeholders. Written evidence from Dr Anne Cockayne (AAC0303) was based on academic work exploring career experiences of autistic people and consultation with employer representatives, including occupational psychologists experienced in coaching, diagnostics, screening and workplace assessments for neurodivergent people, managers of autistic people and recruiters. Sectors represented were the civil service, design and creative, assistive technology and manufacturing. Written evidence from Charli Clement (AAC0122) and others reflected the views of over 200 autistic people and their carers on employment.

series of private meetings (facilitated by a range of organisations) with dozens of people sharing their personal experience, including:

- Two meetings with the House of Commons Autistic Champions, a group of autistic adults working to review and provide feedback on Parliament's public engagement services from the perspective of autistic people. These meetings were held at the beginning and end of the Committee's evidence programme, and provided an opportunity to discuss key issues for autistic people and priorities for the Committee's inquiry and final report.[54]

- A meeting facilitated by NDTi with people with personal experience of trying to access health and care services as an autistic person, or for autistic children. This included experience of working with the NHS and other organisations to improve services for autistic services. Some participants had previous lived experience of mental health inpatient admission.[55]

- A meeting with NHS and local authority professionals, also facilitated by NDTi. All the participants in this meeting had experience of developing and co-producing NHS and/or local authority services for autistic people. Some of the participants were autistic.[56]

- A meeting with young autistic people and parents, facilitated by Ambitious about Autism. The parents in the group had autistic children between the ages of six and 14 with experience of both specialist and mainstream education. The young people in the group were currently attending mainstream college or university.[57]

51. Notes of these meetings are published as appendices to this report and on the Committee's website.

Committee visits

52. In May, the Committee visited St Thomas' Hospital in the London Borough of Lambeth. This visit was to learn about the partnership between Guy's and St Thomas' NHS Foundation Trust and CareTrade, a charity founded in 2009 to support autistic people into employment, including through The Autism Project (TAP), a full-time, two-year employability programme for young autistic people aged 18-25 with an Education, Health and Care Plan (EHC plan). The Committee met senior hospital trust and CareTrade representatives as well as current and previous participants in The Autism Project. A number of the participants in the meeting were autistic.[58]

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54 Appendix 4 and Committee on the Autism Act 2009, *Note of meeting with the House of Commons Autistic Champions*, 24 April 2025, an, Appendix 10 and Autism Act 2009 Committee, *Note of meeting with the House of Commons Autistic Champions*, 7 July 2025. These meetings were facilitated by the House of Commons Engagement and Participation team. See Annie Waddington, *The Autistic Champions programme*.

55 House of Lords Committee on the Autism Act 2009, *Note of meeting with experts by experience*, 1 May 2025

56 Appendix 5 and Autism Act 2009 Committee, *Note of meeting with NHS and local authority professionals*, 1 May 2025

57 Appendix 7 and Autism Act 2009 Committee, *Note of meeting with autistic young people and parents*, 12 May 2025

58 Appendix 8 and Autism Act 2009 Committee, *Note of Committee visit to St Thomas' Hospital, London Borough of Lambeth*, 19 May 2025

53. In June, the Committee visited Phoenix School in the London Borough of Tower Hamlets. Phoenix School is an all-aged special school for children and young people from 3 to 19. All pupils have a diagnosis of autism or have been assessed and are waiting for one. Pupils have a range of complex needs and are academically working below their equivalent year group. The Committee met the Executive Headteacher, staff, pupils and parents, and toured the school's primary and secondary campuses.[59]

54. Notes of these visits are also published as appendices to this report and on the Committee's website.

Other steps to enhance the accessibility of the Committee's work

55. We also provided a number of other means to enhance the accessibility of the Committee's work. These included:

- A 15-page illustrated accessibility guide for witnesses giving evidence to the Committee. This document was shared in draft with a network of autistic people (facilitated by autism charities) for review and comment. The final version of this document was sent to all witnesses. Easy Read and audio versions of this document were also produced and made available upon request.
- Briefing calls offered in advance to all witnesses and people meeting the Committee in private.
- Sharing questions with witnesses in advance, and giving them an opportunity to indicate whether or not they were willing to answer supplementary questions without prior notice.
- Offering witnesses and those meeting the Committee with the opportunity to be accompanied by a supporter.
- Offering witnesses and those meeting the Committee with the opportunity to be accompanied by parliamentary staff through security and/or via a quieter, accessible route.
- A nine-page illustrated accessibility guide for members of the public attending Committee meetings published on the Committee website.[60]
- Use of a meeting room offering a calmer sensory environment than those typically used by House of Lords committees.
- Availability of another meeting room as a quiet room for witnesses and visitors to the Committee.
- Offering all those meeting the Committee the option of participating in a meeting in-person or remotely.
- Offering all those meeting the Committee the option of meeting breaks if required.

56. These steps go far beyond what is typical for engagement with House of Lords Committees. A number of witnesses to the Committee offered positive

59 Appendix 9 and Autism Act 2009 Committee, *Note of Committee visit to Phoenix School, Bow, London Borough of Tower Hamlets*, 11 June 2025

60 Autism Act 2009 Committee, *A guide to attending meetings of the House of Lords Committee on the Autism Act 2009*, 24 April 2024

feedback on the steps taken to improve the accessibility of the Committee's work.[61] However, we acknowledge we did not get everything right. We hope that other committees can learn from our experiences and build on what we did in future.

57. We thank everyone who gave evidence to the Committee and met the Committee. We are particularly grateful to those who were willing to share sensitive or distressing accounts of their own experience, which have immeasurably aided our understanding.

This report

58. The report first examines the case for the new Government autism strategy, and then sets out the Committee's findings, reflecting the key areas of focus in the current autism strategy, as follows:

- Chapter 2: The Autism Act, autism strategy and statutory guidance;
- Chapter 3: Improving understanding, acceptance and accessibility;
- Chapter 4: Identification, assessment and support;
- Chapter 5: Reducing health inequalities and building support in the community;
- Chapter 6: Access to education and transitions to adulthood;
- Chapter 7: Employment; and,
- Chapter 8: Criminal justice.

59. Readers are advised that the report contains sensitive and distressing material throughout, and in particular in Chapter 5.

Conclusions and recommendations

60. **Within the current parliamentary rules for committee work, we have sought to ensure that autistic people and those who support them have been given many opportunities and a variety of means for meaningful involvement in the Committee's work.**

61. ***We invite the House of Lords Procedure and Privileges Committee (which is responsible for recommending changes to House of Lords procedure) to consider ways in future to facilitate the meaningful involvement of a diverse range of people with lived experience in the work of committees such as ours, and the Liaison Committee (which is responsible for recommending the appointment of new committees) to provide committees with sufficient time and resources to do so.***

62. **Our report sets out a path to addressing the needs and aspirations of autistic people through the new autism strategy. Each of our**

61 See for example Q 51, footnote 9 (Dr Mary Doherty). Dr Doherty said: "I would like to add how incredibly helpful it was to have all the information that the Committee provided in advance of the meeting, as that hugely reduced the anxiety associated with a new experience and a daunting one at that. I wanted to say thanks and highlight the contrast, the fact that we do not generally have such advance information in healthcare, which obviously increases the challenges for autistic people attempting to access healthcare."

recommendations requires urgent action as part of that strategy. The Minister for Care has made a commitment to bring forward the new autism strategy in 2026, to ensure there is no vacuum when the current strategy expires in July that year, and to put in place an implementation plan. *The Government must now meet that commitment in full*.

63. **The Minister for Care has also made a commitment to use this Committee's work to help shape the new autism strategy. We will judge the Government's response against that commitment. It is in that spirit that we make this report for debate.**

CHAPTER 2: THE AUTISM ACT, AUTISM STRATEGY AND STATUTORY GUIDANCE

Introduction

64. In this chapter, we examine how well the Autism Act and successive Government autism strategies have worked. We then consider what the Government needs to do to make the new autism strategy work better.

The effectiveness of the Autism Act and successive autism strategies

65. The Act requires that the Secretary of State "prepare and publish a document setting out a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults."[62] Tim Nicholls, Assistant Director of Policy, Research and Strategy, National Autistic Society, told us:

> "The Autism Act … is also dependent on the performance of a number of other statutory obligations such as the Care Act, the Equality Act and the Health and Care Act. We know that implementation of those other Acts is also a problem. That means that autistic people will often end up at the sharp end of those things. However, the key purpose and the key strength of the Autism Act is that it is the only place that ties all those regimes together for the benefit, and the purpose of improving the lives, of autistic people."[63]

66. Representatives of the major autism charities told us that the Autism Act has played a vital role in making the Government, the NHS and local authorities recognise and address the needs of autistic adults. Adam Micklethwaite, Director, Autism Alliance UK, told us the Act was "a challenge to the way that the system was operating to make it operate in a different way to meet autistic people's needs." He said: "There has been some progress in the middle tier of the system … with more specialist autism teams and greater coverage of diagnostic services."[64] On the other hand, witnesses acknowledged that many key outcomes for autistic people have not improved since the Act was passed. Tom Purser, CEO, Autism Action, told us it was extremely difficult to tell if the Act had succeeded in improving the provision of relevant services because of a failure "to set appropriate benchmarks; to put in place robust monitoring; and to measure progress."[65] The evolution of our understanding of the population of autistic people and their needs during this period may also make it more challenging to measure progress.[66]

67. Some autistic people and those who support them stressed the importance of the Act in galvanising recognition of autistic people and action to improve services. Others told us that they had not heard of the Act before we issued our Call for evidence; did not see how it had made any difference to their lives; or thought things had not improved or were getting worse.

62 Autism Act 2009
63 Q 1 (Tim Nicholls)
64 Q 1 (Adam Micklethwaite)
65 Q 37 (Tom Purser)
66 See paras 80–101.

Box 2: Comments from autistic people and those who support them about the Autism Act 2009 and autism strategies

"[The Autism Act] has highlighted the needs of autistic people and what local authorities should do to help autistic people. It has also brought together the police, the NHS, the local councils and experts by experience to ensure they all work together."[67]

"Hampshire has seen several initiatives developed to help raise acceptance and understanding of autism. It is unlikely these would have developed without the underpinning of the Autism Act 2009."[68]

"The Autism Act 2009 was a milestone, but it has not led to the kind of meaningful, lived change that autistic adults need. The challenges we face are structural, systemic, and worsening in the face of benefit reform and austerity."[69]

"The Autism Act 2009 was supposed to improve things, but from my experience, it hasn't made much difference in practical terms."[70]

"I had never heard of this strategy and, in the circles I move in, no one else had heard of it either, so it is really difficult to judge its effectiveness."[71]

The early days of the Act: the 2010 and 2014 strategies

68. We heard of some successes in the early days of the Act, under the first autism strategy in 2010 and the updated 2014 Think Autism strategy and associated statutory guidance.

69. Dr Conor Davidson, clinician and Autism Champion, Royal College of Psychiatrists, told us that the 2015 Think Autism statutory guidance had had the biggest impact of all the documents produced under the Act, because "it carried some legal weight behind it. It was very clearly written. It was quite prescriptive, which is actually no bad thing in this field. It literally said to NHS trusts: you must do this. It said to local authorities that they should do that; they must do this."[72]

70. Simon Froud, Representative, Association of Directors of Adult Social Services (ADASS), and Director of Adult Social Care and Statutory DASS, Telford & Wrekin Council, told us that, as a consequence of the Act and statutory guidance, "we have autism strategies across most, if not all, 150 local authorities."[73] Tim Nicholls told us that "there is now a senior responsible commissioner for autism in every local authority, which there was not before."[74] Dr Marie Tidball MP, Chair, All-Party Parliamentary Group (APPG) on Autism, said that the widespread establishment of local autism partnership boards "meant that autistic people had a voice within a local authority, and, most importantly, that they could give scrutiny to the implementation of the requirements in the Autism Act and the autism strategy." Though imperfect, she told us that these were at best "extremely effective".[75]

67 Written evidence from Valerie Fitch (AAC0080)
68 Written evidence from Hampshire Autism Voice (AAC0160)
69 Written evidence from Anonymous 12 (AAC0051)
70 Written evidence from Jade McCullum (AAC0004)
71 Q 86 (Anita Harrington)
72 Q 30 (Dr Conor Davidson)
73 Q 110 (Simon Froud)
74 Q 2 (Tim Nicholls)
75 Q 146 (Dr Marie Tidball MP)

71. One of the key achievements of the Act, strategy and statutory guidance has been in widening access to autism assessment for adults. Tim Nicholls told us: "The Act, the strategy and the first statutory guidance mandated that every area has to have a pathway to diagnosis for autistic adults." Almost every local authority area now has a pathway for adult autism diagnosis, up from only half in 2007.[76] Dr Marie Tidball MP told us that in some places implementation of the autism strategy and statutory guidance had enabled autistic adults without a learning disability to access some services that would previously have been closed to them, such as a referral for social care assessment.[77]

72. These early changes were delivered with little funding. Tim Nicholls told us:

> "When the Autism Act first went through and the first strategy came out, it did not come with implementation money. In 2014, when the 'Think Autism' strategy came out, it came with around £4 million of implementation money … Three-quarters of that was capital and therefore could not really go to the revenue spending that local areas really needed to improve their services."[78]

The 2021–26 autism strategy

73. The current Government autism strategy was published in July 2021 and covers the period from 2021 to 2026. The overarching goal of the strategy was "nothing less than making sure autistic people from all backgrounds, ethnicities, genders, sexualities and ages—in all parts of the country—get the support they need to live full and happy lives." The strategy set out government objectives in six priority areas across public understanding, health, social care, education, employment and criminal justice.[79]

74. The 2021 autism strategy said that the Department of Health and Social Care (DHSC) and Department for Education (DfE) would form a national executive group overseeing implementation, including autistic people and family members. This was to report biannually to the Minister for Children and Families and the Minister for Care. Commitments were assigned to different Government departments and public bodies and £73 million of funding was allocated for the first year of the strategy, mostly to NHS England.[80]

75. Witnesses agreed that the 2021 autism strategy focused on broadly the right issues. The six themes for the strategy had been identified through consultation with autistic people and their families and carers. Some local authority representatives told us autistic people and those who support them have independently identified very similar key themes in engagement on the development of local strategies.[81]

76. We also heard broad support for the inclusion of children and young people in the strategy. A few witnesses thought it did not make sense for the strategy

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76 Q 2 (Tim Nicholls)
77 Q 142 (Dr Marie Tidball MP)
78 Q 2 (Tim Nicholls)
79 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021
80 *Ibid*.
81 Written evidence from Dr Gavin Hutchison (AAC0050)

to cover children, when the Act and statutory guidance only cover adults.[82] Ambitious about Autism argued that the Act should be amended to include children.[83] On the other hand, we also heard that the strategy had helped some local authorities to take an all-age approach, complementing their legal duties to children and young people with SEND in the Children and Families Act 2014. Nigel Minns, Chair of Health, Care & Additional Needs Policy Committee, Association of Directors of Children's Services, and Executive Director for Children and Young People, Warwickshire County Council, told us that the Act "has meant great opportunities in terms of all-age join-up … My local area, Coventry and Warwickshire, using the ICB [Integrated Care Board] footprint, has a single all-age autism strategy and a single all-age partnership board."[84]

77. Hopes for the 2021 strategy came to little. No implementation plan or funding details were published after the first year of the strategy. The national executive group ceased to meet. Updated statutory guidance was drafted, but never published.[85] Witnesses told us the strategy had over-promised and under-delivered. Jolanta Lasota, CEO, Ambitious about Autism, and Chair, Autism Alliance UK, told us: "The autism strategy was a collection of aspirations without real outcome measures … so we have not seen real change over these years."[86] Dr James Cusack, CEO, Autistica, said: "The Government have a strategy but not a plan when it comes to autism. That is where we are: we have a set of themes and strategic priorities, but there is nothing of any substance underpinning them."[87]

78. This does not mean that successive governments have done nothing to improve support for autistic people since 2021. In fact, the Government described numerous initiatives across a wide range of departments and public bodies.[88] This is an important part of the legacy of the Autism Act. Tim Nicholls told us: "There has been a recognition that these things will need proper money to happen."[89] Yet we heard that too little is done to coordinate these initiatives across government and ensure they make a difference to autistic people's lives. Fazilet Hadi, Director of Policy, Disability Rights UK, told us:

> "We have seen some strides with specific NHS and education initiatives, but almost with a backdrop of the state fighting the state and it being very un-joined up … it is almost like things are given with one hand and taken away with the other."[90]

79. Some of the progress in strengthening local responsibility and accountability made under previous strategies has been eroded during this period. The National Autistic Society told us that many local autism partnership boards stopped meeting during the COVID-19 pandemic and have not started again since.[91] Asperger's Syndrome Self Advocacy (ASSA) West Sussex told

82 Written evidence from Ambitious about Autism (AAC0206). See also written evidence from Autistica (AAC0105).
83 Written evidence from Ambitious about Autism (AAC0206)
84 Q 150 (Nigel Minns)
85 Written evidence from Susan Kirkman (AAC0180)
86 Q 10 (Jolanta Lasota)
87 Q 10 (Dr James Cusack)
88 Written evidence from UK Government (AAC0231)
89 Q 2 (Tim Nicholls)
90 Q 2 (Fazilet Hadi)
91 Written evidence from National Autistic Society (NAS) (AAC0232)

us that the 2021 autism strategy had not restated the need for local autism partnership arrangements, meaning that they were no longer able to argue successfully for funding for theirs and it lapsed.[92]

The Autism Act in a changing world

80. Since the Act was passed, understanding of the population of autistic people in England and their needs has changed substantially. This evolution will continue in the years to come. Part of our task was therefore to understand what is changing and what it means for the role of the Autism Act today and for the future.

Change in the population of autistic people

81. The 2021 autism strategy cited an estimate that 700,000 people in the UK are autistic, or around 1% of the population.[93] Dr Ken Courtenay, Consultant Psychiatrist in Learning Disability, NHS England, told us that the accepted true prevalence of autism was about 1.1% to 1.2% of the population, based on research studies including previous iterations of the Adult Psychiatric Morbidity Survey (APMS) in 2007 and 2014.[94] True prevalence refers to the proportion of the population who would meet the criteria for a diagnosis if they were to be assessed, regardless of whether or not they have received a diagnosis. The latest iteration of the APMS was carried out in 2023/34; the results on estimated true prevalence of autism are expected to be published in late November 2025.[95]

82. In a long-term trend over recent decades, the prevalence of autism diagnosis in England has been rising rapidly, with one study showing a "787%, exponential increase in recorded incidence of autism diagnoses between 1998 and 2018".[96] The Government shared evidence that 1.33% of people in England have an autism diagnosis based on Health and Care of People with Learning Disabilities (HCPLD) data for 2023/24, which covers more than half of patients registered with a GP in England. This compares to 0.1% of people in 1998.[97]

92 Written evidence from Asperger's Syndrome Self Advocacy (ASSA) West Sussex (AAC0317). See also written evidence from National Autistic Society, Calderdale Branch (AAC0222).

93 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021

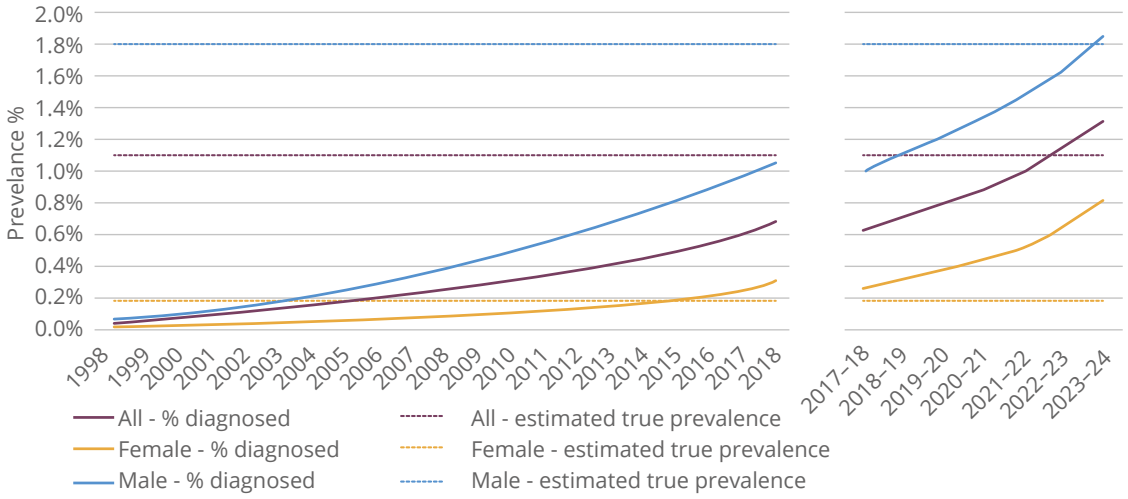
94 Q 160 (Dr Ken Courtenay)

95 NHS Digital, *Adult Psychiatric Morbidity Survey: Survey of Mental Health and Wellbeing, England, 2023/4*, 26 June 2025

96 Written evidence from Autistica (AAC0105) and Ginny Russell et al, 'Time trends in autism diagnosis over 20 years: a UK population-based cohort study', *Journal of Child Psychology and Psychiatry*, vol 63, Issue 6, (2021), p 674: https://doi.org/10.1111/jcpp.13505

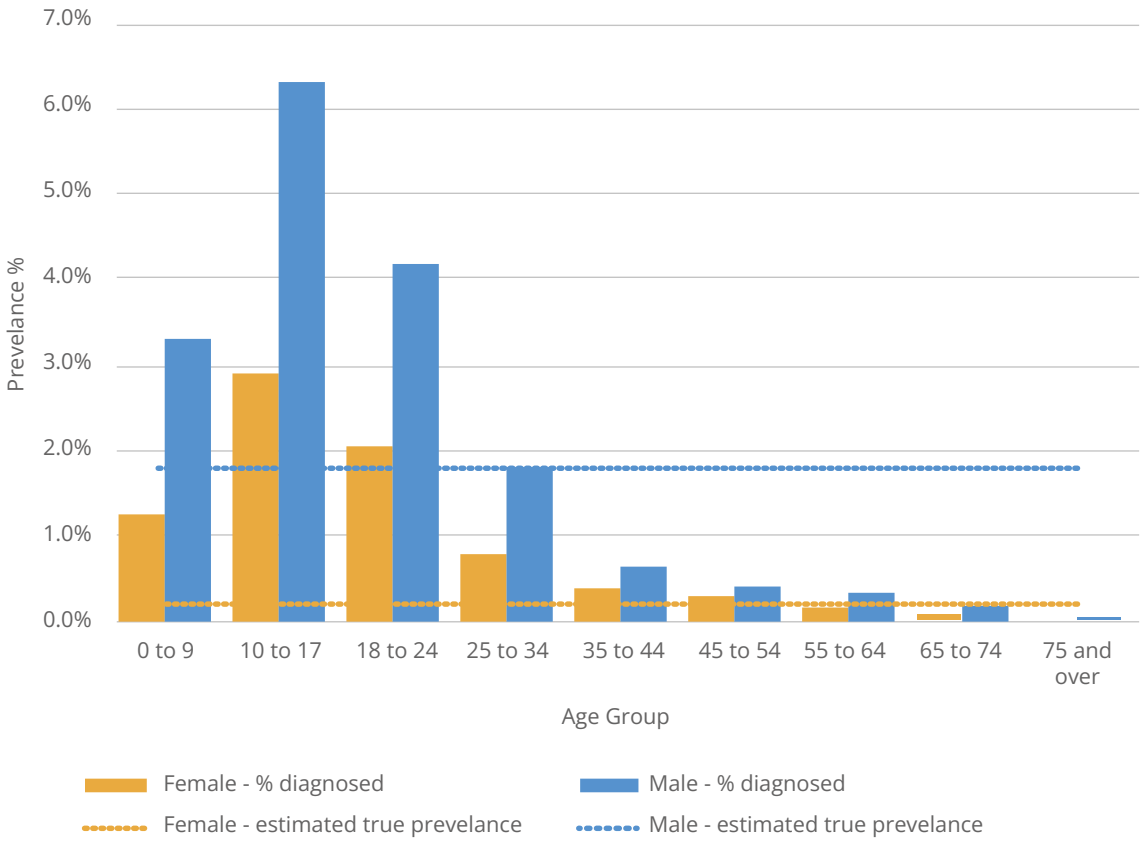
97 Written evidence from UK Government (AAC0231) and Autistica (AAC0105)

Figure 1: Recorded diagnosis of autism in England since 1998, compared to previous estimates of the true prevalence of autism



Source: Written evidence from UK Government (AAC0231). Based on Clinical Practice Research Datalink (CPRD) data until 2018 (Ginny Russell, Sal Stapley, Tamsin Newlove-Delgado, Andrew Salmon, Rhianna White, Fiona Warren, Anita Pearson, Tamsin Ford, 'Time trends in autism diagnosis over 20 years: a UK population-based cohort study', Journal of Child Psychology and Psychiatry, vol 63, Issue 6, (2021), pp 674–82: https://doi.org/10.1111/jcpp.13505) and Health and Care of People with Learning Disabilities (HCPLD) data records since then.

Figure 2: Variation in the recorded diagnosis of autism dependent on age and sex, compared to previous estimates of true prevalence of autism, 1 April 2023–31 March 2024[98]



Source: Written evidence from UK Government (AAC0231), using Health and Care of People with Learning Disabilities (HCPLD) data.

98 Written evidence from UK Government (AAC0231)

83. HCPLD data for 2023/24 shows that the rate of diagnosis was highest in young people aged 14 to 17 (4.63%), and lowest in those aged 75 and over (0.03%). Compared to previously estimated true prevalence, diagnosis rates are therefore now much higher in younger people, and much lower in older people. The Government cited a 2023 population-based cohort study estimating that less than 10% of autistic people aged over 50 have a diagnosis.[99]

84. HCPLD data shows a diagnosis rate for women and girls of 0.82%, less than half the rate for men and boys (1.84%).[100] In previous iterations of the APMS, estimates of true autism prevalence were much lower for women (at about 0.2% of the population) than for men (between 1.1% and 1.8%).[101] This means the gap between diagnosed prevalence and previously estimated true prevalence is much wider for girls and young women than it is for boys and young men. The National Autistic Society raised concerns about this:

> "To accept these prevalence studies as true, you would need to accept that females are significantly less likely to be autistic which is increasingly becoming clear is not the case. The latest NHS data on autism assessment waiting times has a just under 50% split between males and females waiting."[102]

85. Autistica said that potential factors behind lower diagnosis rates for women and girls include under-diagnosis, lack of recognition of traits common to women and girls in assessment tools, and the fact that many genetic conditions more readily affect males.[103] The Government told us that all assessment tools have limitations and that the assessment tools used in the APMS have been carefully evaluated. They also noted that it is a strength of the APMS that the same methodology is used in repeated studies, enabling prevalence estimates to be compared over time.[104]

86. The 2023/24 HCPLD data shows that people from a mixed ethnic group or multiple ethnic groups had the highest diagnosis rate, at 1.87%. People from Asian or Asian British ethnic groups had the lowest diagnosis rate, at 0.67%.[105]

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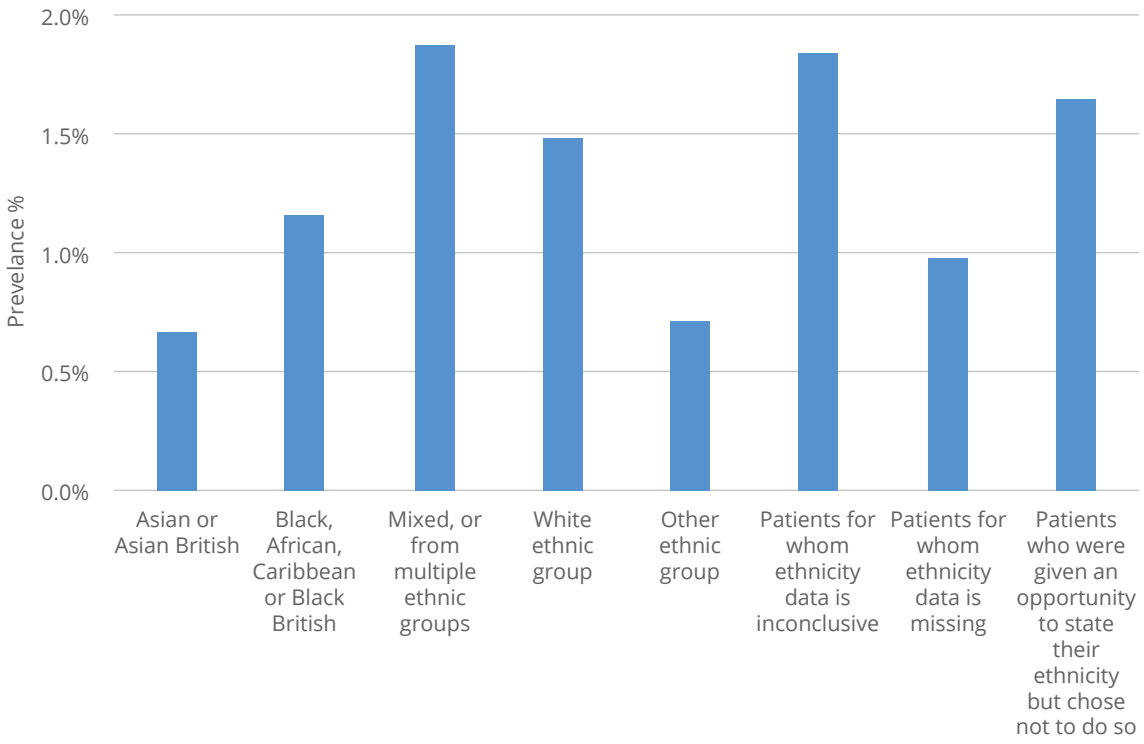
99 *Ibid.*
100 Written evidence from UK Government (AAC0231). See also written evidence from Nottinghamshire Integrated Care System Learning Disability and Autism Operational Delivery Group, Nottinghamshire Healthcare NHS Foundation Trust (AAC0339).
101 NHS Digital, Adult Psychiatric Morbidity Survey, *Chapter 6: Autism spectrum disorder*, 29 September 2016
102 Written evidence from National Autistic Society (NAS) (AAC0232)
103 Written evidence from Autistica (AAC0105)
104 Written evidence from UK Government (AAC0231)
105 *Ibid.*

Figure 3: Variation in the recorded diagnosis of autism dependent on ethnicity, 1 April 2023–31 March 2024



Source: Written evidence from UK Government (AAC0231), using Health and Care of People with Learning Disabilities (HCPLD) data.

87. People in the most deprived areas were more likely to have a diagnosis (1.66%) than people in the least deprived (1.34%). A 2023 population-based cohort study of primary care data in England showed that people in the most socio-economically deprived localities were almost twice as likely to be newly diagnosed than people in the least deprived localities.[106]

88. Services have not kept pace with these increases in the identified population of autistic people. The NHS Mental Health Services Dataset counts well over 200,000 people waiting for an autism assessment.[107] Dr Emma Bradley, Consultant Paediatrician, Sirona Care & Health, and Chair of the Royal College of Paediatricians specialist advisory committee for community child health, told us: "The autism strategy is not really reflective of the current demand … I do not think the Government could enforce at the moment or fund what they are saying autistic people should have the right to access."[108]

Change in diagnosis, need and access to services

89. We heard different views on how this increase should be interpreted and addressed. Stephen Kinnock MP, Minister of State for Care, Department of Health and Social Care (DHSC), told us that "the challenge is around not fully understanding why this is happening." He argued that "it is not always right to have that clinical, medicalised approach", suggesting that numbers of people seeking diagnosis would fall if more support were available without

106 *Ibid.*
107 NHS Digital, *Autism Waiting Time Statistics*. See further para 246ff.
108 Q 111 (Dr Emma Bradley)

a diagnosis.[109] Representatives of the largest autism charities objected to the Minister's framing. Adam Micklethwaite told us: "Saying that this is something we should try to dampen down, or indeed characterising it as a general problem of overdiagnosis, fails to recognise the intrinsic value of diagnosis … and it forgets, fundamentally, that this is a failure of society and services to adapt to a human difference that has always been there."[110]

90. Autism diagnosis rates are increasing across high-income countries. There is good evidence and widespread agreement that key drivers of this are changes in medical and social understanding. As Professor Catherine Lord, Dr Mayada Elsabbagh, Professor Gillian Baird and Dr Jeremy Veenstra-Vanderweele have noted, "in the past 50 years, [autism] has gone from a narrowly defined, rare disorder of childhood onset to a well-publicised, advocated, and researched lifelong condition, recognised as fairly common and very heterogeneous."[111] Increased public understanding of autism has made people more likely to identify autism in themselves or in others (Chapter 3) and access to diagnostic services has widened (Chapter 4). Medical and social understanding of autism in women and girls have evolved, narrowing the gender gap in identification.[112] Autism diagnosis rates are also increasing among people who have previously been given other diagnoses (including learning disability and some mental health conditions).[113] These changes are welcomed by the major autism charities.[114]

91. At the same time, however, life has become more difficult for many autistic people in the years since the Act was passed. Fazilet Hadi told us: "Since 2009, many disabled people would have felt that things had got a lot worse for them", pointing to the impact of cuts to disability benefits and public services, the COVID-19 pandemic, and the cost of living crisis.[115] One consequence of this may be that more autistic people are struggling to cope and seeking help, including through diagnostic assessment. Autistica said:

> "Diagnostic criteria for autism require … 'significant impairment in … important areas of functioning' … and this can change as the person's environment changes. An increase in diagnosis of autism may therefore indicate a world that is becoming more inaccessible, such that those who may have 'got by' previously are now struggling enough to warrant a clinical diagnosis."[116]

92. Government policy may also have some influence on diagnosis rates. Access to statutory support is typically meant to be based on need, but high thresholds for support mean that a diagnosis is very often in practice required. Sometimes, this may lead an autistic person or their family to seek a diagnosis where they would not have done otherwise.[117] When a person

109 Q 183 (Stephen Kinnock MP)
110 Q 193 (Adam Micklethwaite)
111 Prof Catherine Lord et al, 'Autism spectrum disorder', *The Lancet*, vol 392, Issue 10146, (2018), pp 508–520: https://doi.org/10.1016/S0140–6736(18)31129-2
112 Written evidence from Autistica (AAC0105), Ginny Russell et al, 'Autism spectrum disorder', *The Lancet*, vol 392, Issue 10146, (August 2018), pp 508–520: https://doi.org/10.1016/S0140–6736(18)31129-2
113 Q 24 (Prof Jonathan Green)
114 See written evidence from Autistica (AAC0105) and National Autistic Society (NAS) (AAC0232).
115 Q 2 (Fazilet Hadi)
116 Written evidence from Autistica (AAC0105). See also written evidence from Helen Haddon (AAC0254).
117 See Children's Commissioner, *Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions*, 15 October 2024.

faces long waits to access support, their needs can escalate and become more complex.[118] Autistica told us: "Legally, a diagnosis is not required to offer and implement an EHCP; however, in practice, schools and local authorities routinely insist on a formal diagnosis to manage demand, which in turn drives demand for clinical assessment."[119] We consider the purpose of the autism assessment system in Chapter 4.

Change in approaches to autism and neurodivergence in policy

93. The focus on meeting the needs of autistic adults was an important, and novel, feature of the Autism Act.[120] The 2021 strategy was broader in focus, including autistic people of all ages and recognising the importance of neurodiversity.[121] This reflects not only increasing recognition that autistic people exist but the increasing diversity of the identified population of autistic people.[122]

94. The demographics of the identified population of autistic people are changing. Tim Nicholls told us: "Everything suggests that the [autistic] population is going to get bigger, older and, probably, more female … in terms of the people who are identified … we are going to see a situation where the population of autistic people that we know about is more reflective of society as a whole."[123] In years to come, increasing numbers of identified autistic children and young people will reach adulthood; meanwhile, more identified autistic adults will age into older people's services.[124] We saw limited evidence that services are planning how they will respond to these future changes.

95. Many autistic people face intersecting forms of inequality: for example, autistic women and girls and autistic people from ethnic minorities face distinct forms of disadvantage.[125] A number of our witnesses called for the Government to take an intersectional approach to a future autism strategy.[126]

96. It is also clear that a large proportion, and perhaps the majority, of people who would meet criteria for an autism diagnosis have not been diagnosed.[127] There is little firm evidence about the needs of undiagnosed autistic people. However, Professor Martin Knapp, Professor of Health and Social Care Policy, London School of Economics and Political Science, told us emerging evidence suggests "quite substantial difficulties in these people's lives and actually quite substantial use of services."[128] Professor Amanda Kirby, Chair, Neurodiversity employment academic panel, told us: "It is important that support should not hinge on a diagnosis, otherwise we are going to

118 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)
119 Written evidence from Autistica (AAC0105)
120 Q 1 (Tim Nicholls)
121 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021
122 Written evidence from Autistica (AAC0105)
123 Q 201 (Tim Nicholls)
124 See for example written evidence from Essex County Council (AAC0191).
125 Written evidence from Autistica (AAC0105)
126 Written evidence from Autistica (AAC0105) and Lou Chandler (AAC0119)
127 Ginny Russell et al, 'Time trends in autism diagnosis over 20 years: a UK population-based cohort study', *Journal of Child Psychology and Psychiatry*, vol 63, Issue 6, 682 (2021) pp 674: https://doi.org/10.1111/jcpp.13505
128 Q 7 (Prof Martin Knapp)

leave behind a swathe of individuals who do not have a diagnosis but require support."[129]

97. Beyond autism, neurodevelopmental and mental health conditions are common. About 3–5% of people in England have ADHD.[130] Although estimates vary, about one in seven people has one or more forms of neurodivergence (including for example dyslexia and dyspraxia, as well as autism and ADHD).[131] About 1.3 million people in England have a learning disability, around a third of whom are autistic.[132] Around one million have a neurodegenerative condition.[133] Mental ill health is also common in the general population. APMS data suggests one in five people of working age has a common mental health condition.[134] About 500,000 people are registered with a severe mental illness.[135] It should also be noted that many non-autistic people have autistic traits at a sub-clinical level.[136] Sarah Wild, Headteacher, Limpsfield Grange School, told us that there was a risk of overlooking the bigger picture of neurodiversity by focusing on autism alone.[137]

98. In recognition of this, there have been efforts to develop law and policy about supporting autistic people as part of a broader approach to neurodiversity. The Scottish Government has consulted on proposals for a Learning Disabilities, Autism and Neurodivergence (LDAN) Bill. The aim of the Bill would be to ensure that the rights of people who are autistic, neurodivergent or have a learning disability are "better respected, protected and championed."[138]

99. In England, some local authorities and NHS bodies have structured autism services and partnership arrangements in a way that is not autism-specific. Fazeela Hafejee, Representative, Association of Directors of Adult Social Services (ADASS), and Assistant Director for Adults with Disabilities, Bradford Council, referred to the Healthy Minds Partnership Board, which covers mental health, learning disability and neurodiversity, as well as substance use.[139] Different configurations are used elsewhere.[140]

100. Some differences emerged among our witnesses on the issue of whether there should be autism-specific policy and services. Many told us that there are still large gaps in services for autistic adults without a learning disability; for some, this meant there should be services for autistic people that are separate from (for example) learning disability or other neurodevelopmental services.[141]

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129 Q 106 (Prof Amanda Kirby)
130 NHS England, *Report of the independent ADHD Taskforce: Part 1*, April 2025
131 Parliamentary Office of Science and Technology, *Support for neurodivergent children and young people*, POSTnote 733, October 2024
132 Mencap, *How Common Is Learning Disability In The UK?* and NHS Digital, *Health and Care of People with Learning Disabilities, Experimental Statistics 2023 to 2024*, December 2024
133 National Institute for Health and Care Excellence (NICE), *Working at the forefront of neurodegenerative disease research*, 30 March 2023
134 NHS Digital, *Adult Psychiatric Morbidity Survey: Survey of Mental Health and Wellbeing, England, 2023/4*, June 2025
135 NHS *Mental health: physical health checks for people with severe mental illness*
136 Q 199 (James Cusack)
137 Q 78 (Sarah Wild)
138 Written evidence from Tom Arthur MSP, Minister for Social Care and Mental Wellbeing, Scottish Government (AAC0328)
139 Q 151 (Fazeela Hafejee). See Bradford District and Craven Health and Care Partnership, *Healthy Minds strategy*.
140 See for example written evidence from Birmingham Autism and ADHD Partnership Board (AAC0195) and Cheshire West All Age Autism and Neurodivergence Partnership Board (AAC0354).
141 See for example written evidence from Kirklees Council, and Kirklees Health and Care Partnership (AAC0118), Anonymous 18 (AAC0067) and Su Seymour (AAC0371).

Others cautioned against this. Professor Sheila the Baroness Hollins, former Chair, Oversight Panel review of Independent Care (Education) and Treatment Reviews, told us: "The Autism Act is for all autistic people. Having a learning disability as well is what a co-researcher and expert by experience described as having … a double whammy."[142] Dr Anita Z Goldschmied, Learning Disability Nurse and Social Worker, and Senior Lecturer, Sheffield Hallam University, argued that strategies should not be "organised around pathological medical conditions but instead embrace the myriad aspirations and hopes we humans possess."[143] Sarah Wild suggested "a piece of legislation around neurodiversity and inclusion."[144]

101. The question of whether the Government should legislate for the needs of people with different forms of neurodivergence was beyond our remit. However, there was broad agreement that the Government will need to use a combination of autism-specific policy interventions with needs-based and universal interventions to make a difference to autistic people's lives. Dr James Cusack told us that different issues in autism policy could usefully be seen through different lenses:

> "The neurodiversity lens acknowledges that everyone thinks about and understands the world in a different way. Then there is a neurodevelopmental conditions or neurodivergence lens, which is about whether the issue is about neurodevelopmental conditions. Then there is the autism lens … The policy area dictates the lens through which we look at it. There is no right answer; it is simply a case of thinking about what the area is and the right lens to look through."[145]

Making the new autism strategy work

102. The current autism strategy expires in July 2026. As we have seen, Stephen Kinnock MP told us the Government will produce a new one: "I can say that we are absolutely committed to there not being a vacuum, to there being a strategy and to there being an implementation plan."[146] Mr Kinnock said that he saw the new strategy as part of the Government's aim to "build a more inclusive society … based on that fundamental principle: how do we harness the huge potential of this group of people who are autistic?"[147] Professor Martin Knapp told us that an effective autism strategy would not only meet autistic people's needs but would further the Government's missions to grow the economy, build an NHS fit for the future, and break down barriers to opportunity.[148]

103. The Minister identified three key challenges for the new strategy: addressing increased demand for autism assessment; moving more autistic people out of mental health inpatient settings; and improving health outcomes for autistic people. He also told us that he wanted DHSC to work with DfE and the Department for Work and Pensions (DWP) to develop a holistic, cross-government strategy.[149]

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142 Q 79 (Prof Sheila the Baroness Hollins)
143 Written evidence from Dr Anita Z Goldschmied (AAC0194)
144 Q 76 (Sarah Wild)
145 Q 14 (Dr James Cusack)
146 Q 170 (Stephen Kinnock MP)
147 Q 183 (Stephen Kinnock MP)
148 Q 8 (Prof Martin Knapp)
149 Q 179 (Stephen Kinnock MP)

104. The new autism strategy will need to avoid the pitfalls of previous strategies. Adam Micklethwaite told us: "Because the strategy did not in itself address the deep barriers in the system—stigma, access to diagnosis, accountability and funding—we have not seen the improvements in autistic people's outcomes that we would have wanted to see through the original policy intent."[150] Autism Action shared survey data showing strong support among autistic people and their families for propositions that the Government should always include autistic people in decisions about them; set achievable, measurable targets; ensure accountability is built in; ensure there is high-quality data; and ensure the Autism Act provides clear legal protection.[151]

105. We now consider in more detail what has limited the success of previous autism strategies and what would enable the new autism strategy to work better.

Meaningful involvement for autistic people

Box 3: Comments from autistic people and those who support them about the new autism strategy

"There must be no more decisions about us without us. Government consultations must actively include autistic people and their families, particularly those from underrepresented communities, to ensure that policies reflect lived experiences rather than outdated assumptions".[152]

"The Autism Act 2009 was a landmark, but its implementation has fallen short because autistic voices haven't been central to policy design. Autistic people still face barriers in education, employment, and beyond. To fulfil its vision, the Government must fund autistic-led solutions, ensuring 'nothing about us without us' shapes policy."[153]

"Autism and disability have been dominated by people acting with the best of intentions but, because they failed to include the actual voices of people on the ground, the worst of actions happened … We need effective co-production that perhaps goes beyond advisory groups."[154]

106. First, the Government must meaningfully involve autistic people and those who support them in the development of the new autism strategy. As a party to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the Government has committed to consulting disabled people closely when making policy and drafting legislation that concerns them. Too often, this is not the reality.[155] Meaningful involvement has a particular importance in the context of autism policy because non-autistic people often struggle to understand and respond well to autistic people's needs. Professor Ashok Roy OBE, Consultant Psychiatrist and Associate Medical Director, Coventry and Warwickshire Partnership NHS Trust, told us: "Most people do not understand what autism is like if we were not autistic when we were

150 Q 2 (Adam Micklethwaite)
151 Written evidence from Autism Action (AAC0233)
152 Q 22 (Marsha Martin)
153 Written evidence from Dr Lauren Powell and Jacob Lewis (AAC0058)
154 Q 21 (Leo Capella)
155 United Nations, *UN Convention on the Rights of Persons with Disabilities*, Article 4(3) & Article 7(3); Public Services Committee, *Think Work First: The transition from education to work for young disabled people* (1st Report, Session 2024–26, HL Paper 12)

young … So we need to take advice and support from all the people that know."[156]

107. Many of our witnesses told us that it is vital that autistic people have an equal role in designing and delivering policy and services and are fairly compensated for this work.[157] Stephen Kinnock MP supported the principle of co-production: "It will be doomed to fail if we try to develop policy in the ivory tower of Whitehall or Westminster. Whatever the precise mechanism, whether it is an oversight board or a reference group, we absolutely must ensure that we co-produce the strategy with those with lived experience."[158]

108. Successive governments have made some efforts to include autistic people in developing and delivering previous autism strategies. Those efforts have not been consistent. A programme board oversaw the implementation of the 2014 Think Autism Strategy, bringing together representatives of the Government with autistic people and family members.[159] The 2021 strategy replaced this with a national executive group. This quickly ended. One former member of the national executive group told us there had been no meetings of the executive since the General Election in 2024 and the meetings had been "very sporadic" before that.[160]

109. Many NHS bodies have also been making efforts to involve autistic people in making decisions about how services are run and delivered. Nigel Minns told us: "I have at times been critical in public about the NHS's commitment to co-production. I think that these are an exception. Many mental health trusts and community trusts, where autism arrangements often sit, understood the benefits of experts by experience early."[161] Autistic experts by experience working with the NHS told us that at best they were included in every aspect of a project and supported to share their experiences in a safe way. However, they also told us that experts by experience were sometimes used to rubber-stamp projects, asked to share traumatic experiences and then left without support or adequate compensation.[162] Local authority and NHS representatives told us that partnerships enabled them to design services that better met the needs of users, but that they often failed to capture the views and experiences of autistic people who were also marginalised in other ways or who had substantial communication differences.[163]

A holistic, cross-government strategy and plan

110. The Government needs to ensure departments are responsible, and ministers accountable, for delivery of the strategy. Having a plan to deliver the strategy will be key to this. Dr James Cusack told us: "Anyone who is running an organisation or who has been in a situation where they are responsible for something knows that you do not get very far with just a strategy and not a plan underpinning it."[164] Adam Micklethwaite said: "You could make

156 Q 65 (Prof Ashok Roy OBE)
157 Appendices 5 and 6, Autism Act 2009 Committee, *Note of meeting with NHS and local authority professionals* and *Note of meeting with experts by experience*, 1 May 2025
158 Q 179 (Stephen Kinnock MP)
159 UK Government, Adult Autism Programme Board, and Department of Health and Social Care, *Think Autism strategy: governance refresh 2018*, updated 25 July 2018
160 Written evidence from Susan Kirkman (AAC0180)
161 Q 150 (Nigel Minns)
162 Appendix 6 and Autism Act 2009 Committee, *Note of meeting with experts by experience*, 1 May 2025
163 Appendix 5 and Autism Act 2009 Committee, *Note of meeting with NHS and local authority professionals*, 1 May 2025
164 Q 10 (Dr James Cusack)

improvement in outcomes a condition of success: there would be a target or measure, and somebody would be directly accountable for making that happen."[165]

111. The strategy will need to be holistic and cross-government. Joining up responsibility and accountability in central government is not easy. Fazilet Hadi told us that this is a problem across disability policy: "As a disabled person, my life is quite joined up, is it not? Maybe I work, maybe I have benefits, maybe I use public transport and maybe I need social care. I want all those things to join up. If we look at how government works, it is very siloed". She suggested that the Government would need to prioritise what to focus on in the strategy.[166]

Local delivery and accountability

112. Local authorities and NHS bodies will hold important responsibility for delivering the autism strategy. Stephen Kinnock MP said: "One of the principles of our implementation plan will be devolution, but we have to agree key performance indicators and desired outcomes with those operating at the coalface."[167] The Local Government Association (LGA) told us it would help for the Government to set a "clear policy direction."[168]

113. Under current statutory guidance to the Autism Act, local authorities should allocate responsibility to a named joint local commissioner or senior manager to lead commissioning of care and support services for autistic adults. The Health and Care Act 2022 also requires that each ICB must now have an executive lead for learning disability and autism at board level, who is responsible for planning to meet the needs of autistic people.[169] Baroness Hollins told us: "They tend to also be the lead for about six other things. The possibility for them to be effective as champions for autistic people is difficult, but they are accountable and they need to be held accountable."[170] The 2021 autism strategy set a commitment to roll out a qualification for local authority and NHS commissioners who work with autistic people and people with a learning disability.[171]

114. To support implementation of the new strategy, the Government needs to update statutory guidance to local authorities and NHS bodies. The current statutory guidance is 10 years old; it does not reflect the current strategy or legislative context and makes recommendations to NHS bodies that no longer exist. New statutory guidance was drafted in the early years of the current strategy, then dropped.[172] The LGA told us: "A key comment we made on the draft guidance was that many of the recommendations were challenging because of lack of resources and pressures of demand. We also felt that the guidance needs to be wider than health and social care." It argued that new guidance should set and distinguish mandatory and discretionary legal responsibilities for councils.[173] Essex County Council told us it would

165 Q 6 (Adam Micklethwaite)
166 Q 6 (Fazilet Hadi)
167 Q 179 (Stephen Kinnock MP)
168 Written evidence from Local Government Association (LGA) (AAC0198)
169 NHS England, *Executive lead roles on integrated care boards*, 26 July 2024
170 Q 82 (Prof Sheila the Baroness Hollins)
171 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021
172 Written evidence from Autistica (AAC0105) and Peter Hopkins (AAC0374)
173 Written evidence from Local Government Association (LGA) (AAC0198)

help if the statutory guidance was "shorter [and] more accessible, as well as having clearer depiction of outcome and duties."[174]

115. Local authorities and the NHS need to be held accountable for implementation of the strategy and statutory guidance. Establishing autism partnership boards more widely and strengthening their roles will be key to this. Dr Marie Tidball MP told us that in the early days of the Act: "There were good examples, where service directors, including adult social services directors, would come along to speak and listen to autistic members, almost like mini select committees."[175] Some witnesses told us that local autism partnership boards remain an important source of accountability.[176] Some people who have served on autism partnership boards told us that they were not always effective because funding was not allocated to the implementation of the strategy and services could not effectively be held to account for progress.[177]

116. Until 2018, the Government held a national self-assessment exercise on implementation of the autism strategy and statutory guidance, asking local authorities to complete and return a survey. Tim Nicholls said that this was a helpful mechanism because the autism partnership board needed to check and, in some cases, sign off the return. About 95% of local authorities had typically submitted a return.[178] Local authority representatives Fazeela Hafejee and Nigel Minns in principle supported the reintroduction of the self-assessment framework.[179]

Prioritising accessibility and embracing neurodiversity

117. Stephen Kinnock MP said that the strategy would be "driven by an ethos of mainstreaming … We will seek to ensure that there is no silo for autistic people over here, while the rest of society are over there."[180] Adam Micklethwaite told us that this "could be a good thing, in the sense that their needs are genuinely met, or it could mean vanishing autistic people's experiences and outcomes into a generalised approach that does not have any difference at all."[181]

118. Several witnesses stressed the principle of universal design, sometimes known as neuroinclusion. Professor Rebecca Charlton, Professor of Psychology, Goldsmiths, University of London, said that "if we focus on making services universally accessible, that benefits autistic people, but it benefits lots of other people … as well."[182] Dr Ken Courtenay, Consultant Psychiatrist in Learning Disability, NHS England, said: "If we get it right for autistic people, we get it right for a lot of other people too."[183]

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174 Written evidence from Essex County Council (AAC0191)
175 Q 146 (Dr Marie Tidball MP)
176 Q 151 (Nigel Minns), written evidence from Rotherham Parents Forum Limited (RPFL) (AAC0113)
177 See written evidence from Jo Phillips (AAC0278), Christopher Barber (AAC0304), Hampshire Autism Partnership Board (AAC0352), Learning in Harmony Trust (LiHT) (AAC0218), Anonymous 34 (AAC0221) and Anonymous 50 (AAC0290).
178 Q 6 (Tim Nicholls)
179 Q 151 (Nigel Minns), Q 152 (Fazeela Hafejee)
180 Q 183 (Stephen Kinnock MP)
181 Q 194 (Adam Micklethwaite)
182 Q 66 (Prof Rebecca Charlton)
183 Q 169 (Dr Ken Courtenay). See also written evidence from Autism Alliance UK (AAC0143), Cheshire West All Age Autism and Neurodivergence Partnership Board (AAC0354), Prof Nicola Martin (AAC0309) and Q 69 (Prof Sue Fletcher-Watson).

119. Some witnesses suggested this could help reduce need for intensive, personalised support at a population level. Professor Mark Mon-Williams, Chair in Cognitive Psychology, University of Leeds, told us: "You can walk into some schools and they are autism-friendly schools; you could have the same individual in that school, and they would thrive … whereas for the same child in another school, the wheels come off."[184] However, Jolanta Lasota said: "To me, 'mainstreamed' means that all policy takes into account autistic people. It does not mean a dilution of the need for specialism for autistic people, which is why we have an Autism Act. We know that generic methods and approaches do not always work."[185]

Delivering the right support at the right time

120. Stephen Kinnock MP told us that the Government wanted to see autistic people able to access the right support at the right time.[186] Many witnesses expressed similar hopes.[187]

121. Autism is lifelong. Every autistic person has different support needs; needs can vary across the lifespan. Autistic people often need particular support through times of transition, including the teenage years and the transition to adulthood; becoming a parent; losing a parent or carer; going through the menopause; retirement; and age-related ill health. Yet in practice it is often just at the times autistic people need support most that it falls away.[188] Without timely support, an autistic person's needs can escalate and result in crisis. Baroness Hollins told us about her recent experience with her adult son, who is autistic and has a learning disability, when she was told: "If there is a crisis, don't worry, we can always admit him … We do not do prevention but if there is a crisis let us know."[189]

122. Such failures have a human cost; they also have an economic one. Professor Martin Knapp referred to 'bad costs', where money is: "used to respond to crises, which comes in too late to support people when things have got to be escalated and have become very complicated." He argued that there needs to be more spending on the 'good costs' of prevention and early intervention.[190]

123. Professor Knapp told us that the Government needs to give public services the incentives they need to invest in early intervention, enabling autistic people to thrive and crises to be averted:

> "Why should I spend my money, when the main pay-offs are going to be in somebody else's budget, many years into the future? You have this double barrier that people in public sector agencies often face. We need to think about a coordinated strategy from government to support local and other agencies to invest long, to invest in a coordinated way, and to be patient for those outcomes to arrive."[191]

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184 Q 34 (Prof Mark Mon-Williams)
185 Q 193 (Jolanta Lasota)
186 QQ 180 and 184 (Stephen Kinnock MP)
187 See for example Q 198 (Adam Micklethwaite).
188 Written evidence from Greater Manchester Specialist Support Team (AAC0299) and Q 89 (Alice Willans, Anita Harrington)
189 Q 80 (Prof Sheila the Baroness Hollins)
190 Q 10 (Prof Martin Knapp)
191 Q 12 (Prof Martin Knapp)

124. Local authorities and NHS bodies will need funding to deliver the new autism strategy, or guidance on how to reallocate existing funding.[192] To avoid reactive, crisis-led spending and promote early intervention, this funding needs to be pooled. James Bullion, Interim Chief Inspector of Adult Social Care and Integrated Care, Care Quality Commission, told us that integration "is such an unlocker of activity if it is dealt with properly … There is no mechanism for that integration mandated in the 153 councils and the 42 health systems."[193]

125. Another key barrier to delivering the right support at the right time is that services that specialise in supporting autistic people are isolated and at nothing like the scale needed to meet need. Dr Conor Davidson said that overstretched adult autism assessment services typically offer little in the way of pre- and post-diagnostic support: "A colleague of mine in the Royal College of Psychiatrists described it as a kind of Rolls-Royce assessment service, sitting in a desert with nothing before or after."[194] Professor Ashok Roy OBE told us: "We have not actually got a service model … In my clinical role, I see autistic people encountering islands of service: very crowded services with no bridge to the next island of service."[195]

126. Some initiatives are underway to build specialist capacity in supporting autistic people across mainstream public services. Staff at Phoenix School, a large special school in the London Borough of Tower Hamlets, told us how they had developed a specialist classroom model in local mainstream schools, enabling staff and autistic pupils at those schools to benefit from specialist expertise.[196] Dr Conor Davidson told us that there were localised efforts to bring autism assessment into general mental health services or primary care.[197] However, overstretched services often struggle to change the way they work without knock-on effects on the people they serve. Professor Bryony Beresford, Professor of Social Policy, University of York, asked: "When services are under such pressure, who has the headspace to redesign?"[198]

Improving data, strengthening the evidence base and scaling up effective interventions

127. Paula McGowan OBE, Founder, Oliver McGowan Mandatory Training on learning disability and autism, said that, to ensure proper accountability: "You have got to require local authorities and NHS bodies to publish annual data on autistic people's outcomes in health, housing and social care."[199]

128. The 2021 autism strategy recognised improving research and data as a key enabler of success. As part of the strategy, the Government committed to develop an autism research action plan and cross-government action plan to improve data collection and reporting.[200] A five-year NHS England

192 Written evidence from Essex County Council (AAC0191)
193 Q 84 (Prof Sheila the Baroness Hollins, James Bullion)
194 Q 31 (Dr Conor Davidson)
195 Q 61 (Prof Ashok Roy OBE)
196 Appendix 9 and Autism Act 2009 Committee, *Note of Committee visit to Phoenix School, Bow, London Borough of Tower Hamlets*, 11 June 2025
197 Q 31 (Dr Conor Davidson)
198 Q 25 (Prof Bryony Beresford)
199 Q 59 (Paula McGowan OBE). See also written evidence from Miguel Hayworth (AAC0066).
200 Department of Health and Social Care, and Department for Education, *Autism strategy implementation plan*, 22 July 2021

research strategy was published in 2022 and a national autism research team established in NHS England;[201] however, no cross-government plan on research or data was developed.[202] The Government told us that it monitors a wide range of sources of data and evidence to evaluate the effectiveness of policy, pointing to NHS datasets on autism assessment waiting times, autistic patients in GP records, and autistic people in mental health inpatient settings.[203]

129. One important task is to understand the underlying prevalence of autism and the demographic characteristics of autistic people. As we have seen, recorded prevalence of autism in younger age groups is now higher than previous estimates of true prevalence and there are wide disparities in rates of diagnosis across different demographic groups. This hinders service planning. Tim Nicholls told us: "At the moment, too many of the planning tools that are used at a local level use '1 in 100', which gives you no granularity about what those people look like or what their lives look like."[204] Although the 2023/24 APMS will produce an estimate of underlying autism prevalence, it has some limitations: for example, it provides limited evidence on differences in prevalence across demographic groups. Some of our witnesses called for the Government to run a new prevalence study.[205]

130. Improving and linking up administrative data can give the NHS and local authorities the information they need to develop more effective services. Professor Martin Knapp said that data on autistic people is fragmented: "The data we have tends generally to be silo by silo, sector by sector, system by system."[206] Professor Mark Mon-Williams told us how analysis of Born in Bradford longitudinal birth cohort study data and Connected Bradford administrative data showed early opportunities to support autistic children are being missed. [207]

131. There is also a need to strengthen the evidence base on the best ways to improve autistic people's lives. Autistica told us: "Research on meeting the support needs of autistic people, across the spectrum and across the lifespan, is still in its infancy. This means clinicians and other professionals are left guessing at what works—something that would not be acceptable in the general population." They called for the Government to fund a strategic national initiative for research into support for autistic people.[208] Many witnesses pointed to particular gaps in evidence on how to support autistic people across different demographic groups, including autistic women and girls, autistic people from ethnic minorities, autistic people with co-occurring conditions or different profiles of need, and autistic people at different stages of the life course.[209]

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201 NHS England, *Five-year NHS autism research strategy for England*, 28 March 2022, and NHS England, *National Autism team*

202 Written evidence from Autistica (AAC0105)

203 Written evidence from UK Government (AAC0231)

204 Q 201 (Tim Nicholls)

205 Q 198 (Jolanta Lasota, Tim Nicholls)

206 Q 7 (Prof Martin Knapp). See also written evidence from Hampshire Autism Voice (AAC0160).

207 Q 31 (Prof Mark Mon-Williams). See also Q 151 (Fazeela Hafejee).

208 Written evidence from Autistica (AAC0105). See also written evidence from Sarah Jackson (AAC0019).

209 See for example written evidence from Autistica (AAC0105) (women and girls), PDA Society (AAC0268) (people with a pathological demand avoidance profile), Brightstars Autistic Club (AAC0341) (ethnic minorities), SEDSConnective (AAC0201) (people with co-occurring conditions) and Shaji Rajamony (AAC0223) (older people).

132. Even where there is good evidence on interventions to support autistic people, those interventions are often not scaled up. Professor Knapp drew attention to emerging evidence on the cost-effectiveness of some service models that seek to meet autistic people's needs, but acknowledged that "they do not address all the big issues" that autistic people face.[210] Professor Jonathan Green, Professor of Child and Adolescent Psychiatry, University of Manchester, told us that the devolved commissioning model in the NHS can hinder the expansion of evidence-based interventions: "If you have someone in my position, who would like to advocate for a particular kind of model with evidence behind it, you have to speak to 70-plus commissioners in ICBs around the country." He advocated for a central model for commissioning and rolling out effective forms of support.[211]

Holding services to account for meeting autistic people's needs

133. Witnesses agreed that public services need to be held to account when they fail to meet the needs of autistic people. We heard that services systemically fail autistic people and those who support them and that there is little or no accountability when they do.[212] Dr Rachel Moseley, Principal Academic in Psychology, University of Bournemouth, told us about how families fought for more than a decade for the Lampard Inquiry into deaths of mental health patients in Essex:

> "It was eventually necessary for this to be a statutory inquiry because NHS staff engagement with former individual non-statutory inquiries was shockingly low. One article I found said that 11 members of staff out of 1,400 agreed to attend an evidence session."[213]

134. When services are not held accountable for meeting individual needs, autistic people and those who support them are left to fend for themselves. Parent and advocate Dr Virginia Bovell OBE told us:

> "Too often it is families who are resourced and tenacious enough to go through the courts … We have talked about the waste of resources—look at the amount of time, money and resources spent in judicial process. Because of the lack of accountability, it is up to individuals to follow through if they can bear it."[214]

135. Such struggle can itself become a significant cause of harm to autistic people and their families. Leo Capella, Training Consultant (Employment Specialist), National Autistic Society, said: "People in the autism scene … are locked in a constant fight for services and understanding"[215]

136. The Autism Act itself in theory offers one route to judicial accountability and redress. The Act provides that statutory guidance is to be treated as though it were guidance issued under section 7 of the Local Authority Social Services Act 1970.[216] The statutory guidance to the Act explains:

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210 Q 10 (Prof Martin Knapp). See Prof Martin Knapp et al, *The Economic Case for Prioritising Autism in Policy and Reform*, December 2024.
211 Q 29 (Prof Jonathan Green)
212 Q 82 (Prof Sheila the Baroness Hollins). See also written evidence from Autism Action (AAC0233).
213 Q 56 (Dr Rachel Moseley)
214 Q 58 (Dr Virginia Bovell OBE)
215 Supplementary written evidence from Leo Capella (AAC0188)
216 Local Government Act 2000, section 7

> "Local authorities and NHS bodies must not only take account of this guidance, but also follow the relevant sections or provide a good reason why they are not doing so (one example might be because they can prove they are providing an equivalent or better alternative). If they do not follow the guidance and cannot provide a good reason, they may be liable to judicial review or action by the Secretary of State."[217]

137. Tim Nicholls told us that this provision had some practical effect in enabling autistic people to advocate for their rights, though no judicial review has ever been brought:

> "We know that, up and down the country, there are people who write letters or make complaints who cite the Autism Act. They may even have to issue a letter before a claim … The reason that we have not seen a real test case in the courts is because, when that letter before the claim goes, it is so clear that that autistic person has a right to access a diagnosis service or a care assessment that the local authority or the statutory agency involved backs down."[218]

138. Successive Secretaries of State have never taken any action against a local authority or NHS body for failing to follow the statutory guidance. The Government told us that it was "technically possible" for the Secretary of State to instigate a judicial review, but that they would be much more likely to take action short of this, including "seeking full account from the body concerned of any alleged unjustified failure to follow the guidance and engaging in dialogue about future compliance."[219] We saw no evidence that the Government has any process for identifying bodies that are failing to follow statutory guidance to the Autism Act or holding them to account.

139. Autism Action cited survey data showing strong support for the idea that the Government should make the Autism Act enforceable, "making it clear to autistic people and carers what rights the Autism Act gives them, and how they can make a legal challenge if they are not getting the services, education, or care that they have a right to."[220] Some witnesses suggested that the Government could create a commissioner for autistic people in England, citing the new role of the independent Autism Reviewer in Northern Ireland and the proposed new commissioner or commission for learning disabilities, autism and neurodivergence in Scotland.[221]

140. Others cautioned that setting up a new oversight process or body might not help. Nigel Minns argued against "another inspection framework or process. Children's services in particular are probably the most highly regulated—some would argue overregulated—sector in the country."[222] Stephen Kinnock MP was open to the idea of creating an independent commissioner in principle; however, he also said: "The question when you create a new body is always whether you are potentially just adding an extra layer of

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217 Department of Health and Social Care, *Adult autism strategy: supporting its use*, 26 March 2015
218 Q 2 (Tim Nicholls)
219 Supplementary written evidence from UK Government (AAC0377)
220 Written evidence from Autism Action (AAC0233)
221 Q 6 (Adam Micklethwaite), Q 66 (John Phillipson). See also written evidence from Tom Arthur MSP, Minister for Social Care and Mental Wellbeing, Scottish Government (AAC0328), and Mike Nesbitt MLA, Minister of Health, Northern Ireland Executive (AAC0375).
222 Q 72 (Prof Sue Fletcher-Watson)

bureaucracy and decision-making that can potentially slow things down and blur the lines of accountability."[223]

141. Fazeela Hafejee said that, instead of creating a new oversight body, the Government could strengthen existing inspection processes so that they judge services on how well they meet autistic people's needs.[224] Paula McGowan OBE called for autistic experts by experience to be employed on decision-making boards and inspection teams, including at the Care Quality Commission.[225] James Bullion of the Care Quality Commission said that "the very existence of the Act itself is quite an important enabler" to allow it to examine whether the needs of autistic people are being met in inspections.[226]

Conclusions and recommendations

142. **The Autism Act 2009 was a critical step forward in the recognition of autistic people and their needs.**

143. **The Autism Act, successive autism strategies and statutory guidance have been vital in driving national and local action to improve autistic people's lives. They have set lines of responsibility for meeting autistic people's needs and brought more autistic people and those who support them into decisions about the services they use. They have also helped drive change in the way that services are organised and run, most significantly through the expansion of access to autism assessment for adults.**

144. **However, the Act and successive autism strategies have failed to tackle the key barriers that stand in the way of improving outcomes. Meanwhile, numbers of autistic people and families seeking assessment and support have risen rapidly. This is likely to be because of changes in the understanding of autism; because more autistic people are struggling to cope; and because thresholds for access to support from overstretched public services have risen. In the words of one witness, the state is fighting the state.**

145. ***The Government must immediately begin development of the new cross-government, all-age autism strategy, so it takes effect when the current one expires in July 2026. The new strategy should be structured around the six key themes outlined in this report: improving understanding, acceptance and accessibility; identification, assessment and support; reducing health inequalities and building support in the community; access to education and transitions to adulthood; employment; and criminal justice.***

146. ***The new strategy should be based on principles that:***

- ***the meaningful involvement of autistic people and those that support them will be critical to the strategy's success;***
- ***ensuring autistic people can access the right support at the right time is vital to enabling them to live fulfilling lives;***

223 Q 182 (Stephen Kinnock MP)
224 Q 151 (Fazeela Hafejee)
225 Q 59 (Paula McGowan OBE)
226 Q 79 (James Bullion)

- ***autistic people and their needs are diverse; every autistic person has different strengths and needs; and those needs may fluctuate over the lifespan, so support must be flexible, responsive and person-centred;***

- ***autistic people often need most support just at the times of transition in life when support may be most likely to fall away; and,***

- ***making society more inclusive for autistic people will help make it better for everyone.***

147. ***The Government must:***

- ***meaningfully involve a diverse range of autistic people and people who support them in every stage of the development and delivery of the new strategy and of every policy under it;***

- ***produce a deliverable and costed plan for the implementation of the strategy. This should make clear who will be responsible and who will be accountable for national, regional and local delivery of the strategy. A named Government minister must be accountable for the overall delivery of the strategy. Annual progress reports must be published;***

- ***identify in the strategy a focused set of priority outcomes, actions that will help achieve them, and how progress against each priority will be measured; and,***

- ***set out in the strategy a plan to improve cross-government data collection and reporting on outcomes.***

148. ***To be a success, the strategy will need to identify cross-cutting, systemic barriers to improving outcomes for autistic people and set out how the Government will overcome those barriers. In particular:***

- **Responsibility and accountability for meeting autistic people's needs are fragmented, meaning services have little incentive to provide timely support.** ***The strategy must set out how the Government will give services the support and incentives they need to invest in early support and ensure they are held to account for failures to provide such support.***

- **There are too often barriers to the meaningful involvement of autistic people in service design and delivery.** ***The strategy must set out a plan to strengthen the involvement of autistic people and those who support them in the development and delivery of services at every level.***

- **There are some exemplary services supporting autistic people, but they are patchy and too many autistic people have no access to them.** ***The strategy must set out how the Government will support specialist services and professionals to advise and build capability across mainstream services.***

- **Evidence on the best ways to meet autistic people's needs is still limited.** ***The Government must establish a research initiative***

to fund, develop and test co-designed interventions to improve priority outcomes for autistic people and enable effective interventions to be scaled up.

149. ***The Government must produce updated statutory guidance to the Autism Act to support the new autism strategy. This should:***

- ***identify a clear, focused set of duties for the NHS and local authorities, making clear what it is mandatory, and what it is recommended, they do to implement the autism strategy;***
- ***make clear the relationship between duties under the Autism Act and duties under other relevant legislation, including duties towards autistic children and young people;***
- ***confirm that each local authority should have a named joint commissioner or senior manager to lead the commissioning of care and support services for autistic people;***
- ***confirm that each local authority should set up a meaningful autism partnership arrangement;***
- ***set out what information local authorities and NHS bodies will need to provide to the Government to enable progress against the strategy to be measured, for example through a new self-assessment framework;***
- ***make clear how the Government will hold a local authority or NHS body to account if it does not follow the statutory guidance and does not have a good reason why not; and,***
- ***make clear how autistic people and those who support them can access independent recourse when services fail to meet their needs.***

CHAPTER 3: IMPROVING UNDERSTANDING, ACCEPTANCE AND ACCESSIBILITY

The 2021–26 autism strategy

150. The 2021–26 autism strategy stated:

> "By 2026, we want to demonstrate that we have significantly improved public understanding and acceptance of autism, and that autistic people feel more included in their communities and less lonely and/or isolated. We want the public to have a better understanding of autism and to have changed their behaviour towards autistic people and their families.
>
> "By the end of the strategy, we want many more organisations, businesses and public sector services to have become autism-inclusive, so that autistic people can engage in their communities, just like everyone else. … In five years' time, we want to show that autistic people feel more able to take part in their communities than they do today, including feeling more comfortable using public transport."[227]

151. The evidence we received indicates that, while awareness may have risen, there remain significant obstacles to better understanding and acceptance of autistic people. Furthermore, the evolution in the way that autism is perceived since the Autism Act came into force has given rise to a new set of issues that were not anticipated at the time.

Testimony of autistic people and those who support them

152. The Committee heard a range of perspectives and reflections on personal experiences from autistic people and those who support them. While they expressed diverging points of view at times, they all agreed that public understanding and acceptance urgently need to improve.

Box 4: Testimonies from autistic people and those who support them about understanding of autism and acceptance of autistic people

"The general population still holds a view that autistic people are either 'absolutely fine' or 'completely incapable' … this can leave me feeling like I'm in a canyon in the middle where people don't understand what it means to be autistic unless you're showing it very obviously every second of the day."[228]

"People are still shocked when I say I'm autistic because I'm verbal, I can make eye contact when masking, and I've held a job."[229]

"Before I knew I was autistic, I thought the way I experienced the world was just something to push through. I didn't realise I was already doing the hard work of adapting and shapeshifting to everyone else, constantly, to a world that never felt built for me."[230]

"Harmful phrases like 'everyone is a little autistic' or 'you don't look autistic' dismiss real needs and are deeply damaging."[231]

227 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 21 July 2021
228 Written evidence from Cheryl Lewis (AAC0017)
229 Written evidence from Daniel White (AAC0152)
230 Written evidence from Anonymous 60 (AAC0121)
231 Written evidence from Charli Clement (AAC0122)

> "I refused to accept my autism diagnosis because I said, 'I am not Rain Man. I am not Sheldon from the 'Big Bang Theory'. I do not fit the idea of what autism is'. However, when I was able to connect with neurodivergent women—neurodivergent people—from the LGBTQIA+ community and neurodivergent people of colour, I was able to see myself reflected."[232]
>
> "It causes some distress to us that an author or actor able to work in the mainstream can call themselves 'autistic' when our daughter, who cannot speak, write or engage in any sort of normal life, is bracketed with apparently the same condition."[233]

Greater awareness

153. There is undoubtedly greater awareness of autism than ever before. The Government cited a 2015 YouGov poll of 2,159 UK adults commissioned by the National Autistic Society which found that more than 99.5% of people had heard of autism.[234]

154. Dr James Cusack, CEO, Autistica, noted that:

> "We are seeing better public awareness and understanding … What we should see is a generation of autistic children who understand themselves and who are entering the adult world in a better position than the prior generation, so that they can understand themselves, advocate for themselves and, I hope, thrive in society. That would be extremely positive."[235]

155. Autistica's written submission noted that younger people in particular are more likely to talk about autism and neurodiversity.[236] Zaynab (ZeZe) Sohawon, Young Ambassador, National Autistic Society, and Founder, Emotion Dysregulation in Autism, said that "the youth community has good language and literacy around neurodiversity and is good at making reasonable adjustments and accommodations for those who are autistic."[237]

156. Greater awareness is commensurate with the increase in the identified population of autistic people that we previously outlined. However, the fact that services have not kept pace with increasing demand means that autistic people's expectations for the support that they need are not being met.[238]

Continued misunderstanding and lack of acceptance

157. Some witnesses thought that this increased awareness had led to an increase in acceptance and understanding. Dr Adrian James, Medical Director for Mental Health and Neurodiversity, NHS England, said that "people talk to family and friends, they speak to their GP and they come forward."[239]

158. However, many witnesses told us that there was a significant disconnect between awareness of autism on the one hand and understanding and acceptance of autistic people on the other. Stephen Kinnock MP, Minister of

232 Q 122 (Char Bailey)
233 Written evidence from Anonymous 48 (AAC0281)
234 Written evidence from UK Government (AAC0231)
235 QQ 199 and 201 (Dr James Cusack)
236 Written evidence from Autistica (AAC0105)
237 Q 16 (Zaynab (ZeZe) Sohawon)
238 See para 88.
239 Q 160 (Dr Adrian James)

State for Care, Department of Health and Social Care (DHSC), described the paradox of a massive increase in awareness that has not been accompanied by an increase in understanding, and the need to close the gap.[240]

159. The Government cited a 2022 YouGov poll commissioned by Autistica which "revealed a huge lack of understanding about autism across the UK. For example, nearly 30% of adults in Britain are unsure whether autism can be cured and over a third (35%) still believe it to be a learning disability."[241]

160. Witnesses identified several reasons for this.

Stigma and prejudice

161. Tim Nicholls, Assistant Director of Policy, Research and Strategy, National Autistic Society, said that while awareness of autism had increased, "stigma remans pervasive and a sinister force in our society."[242] Autism Alliance UK cited data from one small-scale study showing that 91% of autistic people feel that society does not or only sometimes accepts them. They stated that stigma and prejudice arise "from a lack of knowledge and understanding of autism" and "fundamental societal barriers in accepting difference, particularly when the way difference presents challenges basic assumptions and beliefs."[243]

162. One submission referred to a 2024 National Autistic Society survey showing that one in four autistic people receive a negative reaction when mentioning they are autistic to a member of the public; and that almost all autistic people and those supporting them reported negative assumptions being made by members of the public, describing autistic people as anti-social, rude, weird and strange.[244] The survey found that 93% of autistic people report that they have been described as, or have been assumed to be, "strange" more than once.[245]

Communication and support differences

163. Witnesses highlighted a lack of understanding of the broad nature of autism and the communication and support differences among autistic people. Autistica Insight Group focus group participants observed "widespread but shallow 'awareness'" often based on inaccurate stereotypes and media portrayals, creating rigid and unrealistic expectations of what autistic people are like, and dismissal of their diagnosis or needs if they do not fit people's preconceptions. Reported comments include "you don't look autistic", "we're all a bit autistic", and "you're well-spoken and seemingly intellectually capable, so you must have no support needs."[246]

164. One autistic adult noted that "high-masking individuals … often struggle to obtain recognition and support because they have learned to suppress their autistic traits in order to fit in to neurotypical society."[247] Sheffield Autism

240 Q 184 (Stephen Kinnock MP)
241 Written evidence from UK Government (AAC0231)
242 Q 193 (Dr Tim Nicholls)
243 Written evidence from Autism Alliance UK (AAC0143)
244 Written evidence from Sarah Francis-Soutar (AAC0174). See National Autistic Society, *Autism Awareness survey report*, 2024.
245 Written evidence from UK Government (AAC0231)
246 Written evidence from Autistica (AAC0105). See also written evidence from The Diversity Project (AAC0146) and Sarah Labovitch (AAC0247).
247 Written evidence from Connor Passey (AAC0003)

Research Lab (ShARL), University of Sheffield, said that "sensory issues and the risk of sensory overload of autistic people are generally overlooked and misunderstood." In particular, meltdowns and shutdowns are not well understood by the public.[248]

165. Laura Davis, CEO, British Association for Supported Employment, warned about the stereotype of superpowers, and said that autistic people have strengths and weaknesses as all people do.[249] Leo Capella, Training Consultant (Employment Specialist), National Autistic Society, stressed the importance of avoiding the 'The IT Crowd' stereotype of highly technical knowledge and attention to detail. He also warned against making autism out to be a superpower, saying it was more accurate for many to describe a 'spiky' or uneven profile.[250] Professor Rebecca Charlton, Professor of Psychology, Goldsmiths, University of London, pointed to a lack of understanding of the 'spiky profiles' of many autistic people, which means that social care services, for example, may make assumptions that someone does not need help because they are highly skilled in certain areas.[251]

166. A parent told us:

> "There is a lot of talk of autism being a superpower and something to be proud of. This has made us as parents feel completely alienated. Our son does not have that kind of autism, there is nothing to celebrate here. His 'severe' autism combined with a learning disability is profoundly life-limiting. It is very likely that he will be reliant on carers for the whole of his life."[252]

167. Autism Alliance UK said that "autistic people with high support needs and co-occurring conditions are seen as 'less' than other people, and autistic people with a high level of autonomy are more likely to be distrusted or disbelieved."[253] Dan Harris, Founder and Chairperson, Neurodiversity in Business, said that the non-speaking and minimally speaking community is "doubly marginalised".[254]

168. Some witnesses noted different perspectives within the autism community. One witness told us:

> "Whilst awareness of autism has greatly increased in recent years, that awareness has been raised primarily by two groups with the loudest 'voices'—namely, parents of autistic children with very obvious traits, who want to make it clear that these are difficult to live with, and also autistic adults that are able to speak publicly and have tried to increase acceptance of autistic people by fighting against the negative messages and focusing heavily on the positive whilst downplaying autistic struggles and challenges."[255]

248 Written evidence from Sheffield Autism Research Lab (ShARL), University of Sheffield (AAC0088)
249 Q 93 (Laura Davis)
250 Q 17 (Leo Capella)
251 Q 64 (Prof Rebecca Charlton)
252 Written evidence from Anonymous 19 (AAC0073)
253 Written evidence from Autism Alliance UK (AAC0143)
254 Q 120 (Dan Harris)
255 Written evidence from Cheryl Lewis (AAC0017)

169. Neurodiverse Connection said that the growing visibility of autistic voices and increasing influence of the neurodiversity movement is helping to challenge outdated stereotypes.[256]

Diversity of experience

170. Rotherham Parents Forum Limited (RPFL) highlighted a lack of recognition of the diversity of experience of autistic people:

> "Public understanding of autism still leans heavily on stereotypes. The reality is messier—and more human. It includes women, nonbinary people, people of colour, late-diagnosed adults … Acceptance … [is] letting us tell our own stories, in our own way, at our own pace."[257]

171. Several witnesses referred to gender stereotypes around autism. Essex County Council noted that "myths remain that autism only affects males".[258] Sheffield Autism Research Lab (ShARL), University of Sheffield, said that autistic women and girls are "less likely to be accepted as autistic and are more likely to have their needs minimised by others unless they fit a male stereotype of autism."[259]

172. A number of respondents stressed that public narratives must reflect the diversity of autistic lives, including autistic people who are LGBT+.[260] One witness said that autistic people who identify outside the gender binary "face compounded stigma and routinely experience dismissal in both autism and gender care pathways."[261] Disabled Students UK (DSUK) stated that, in a climate "where trans rights are increasingly politicised and access to gender-affirming care is under threat … recognising and respecting intersectional experiences of autistic people is essential to creating safe, inclusive futures free of discrimination and harm."[262]

173. Marsha Martin, Founder and CEO, Black SEN Mamas, shared her experience as someone who is black and autistic and supports largely black and autistic families: "When you exist as a minority within a minority—black and disabled—your experience of disability is significantly shaped by variables that the wider majority may never have to consider … many black autistic individuals still have to fight to prove they even exist."[263] She added that "woefully insufficient" training rarely acknowledges how autism presents across gender, race and culture.[264]

174. Brightstars Autistic Club referred to the work it is doing to tackle the stigma associated with autism in Afro-Caribbean communities.[265] Professor Mark Mon-Williams, Chair in Cognitive Psychology, University of Leeds, noted the disadvantages faced by children born to parents of south Asian heritage.[266]

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256 Written evidence from Neurodiverse Connection (AAC0103)
257 Written evidence from Rotherham Parents Forum Limited (RPFL) (AAC0113)
258 Written evidence from Essex County Council (AAC0191)
259 Written evidence from Sheffield Autism Research Lab (ShARL), University of Sheffield (AAC0088)
260 See for example QQ 118 and 122 (Char Bailey), written evidence from Penny Jackson (AAC0045) and Dr Keri-Michèle Lodge (AAC0320).
261 Written evidence from Anonymous 18 (AAC0067). See also written evidence from Lynette Morgan (AAC0150) and Fiona Hipkin (AAC0167).
262 Written evidence from Disabled Students UK (DSUK) (AAC0220)
263 Q 16 (Marsha Martin)
264 Q 17 (Marsha Martin)
265 Written evidence from Brightstars Autistic Club (AAC0341)
266 Q 31 (Prof Mark Mon-Williams)

175. Norwood, the UK's oldest Jewish charity, noted that, while the taboo around autism is being challenged, "in some cultural and religious settings, including parts of the Jewish community, there remains discomfort around neurodiversity." They said that providers of specialist services must understand and reflect the communities they serve.[267]

176. Professor Nusrat Husain, Professor of Psychiatry and Director of Research, Global Mental Health Division, Division of Psychology and Mental Health, University of Manchester, and Anum Farooq, PhD candidate, School of Psychology, University of Lincoln, and Research Assistant, Division of Psychology and Mental Health, University of Manchester, cited evidence that cultural norms, religious beliefs and expectations form the basis of many barriers faced by ethnic minorities in accessing autism-appropriate support. They stressed that representatives and leaders within each ethnic community can play a key role in advocating for autistic inclusion. They also stressed the importance of workforce diversity to reflect the communities they serve better.[268]

177. In Chapter 2 we explored how the Autism Act was concerned with the identification and support of autistic adults. However, witnesses told us that the needs of older adults are still often overlooked. Many referred to the compounded challenges of later life such as care needs and the impact of dementia and other age-related conditions.[269] Others referred to the challenges faced by older autistic women. One witness said that autistic women's experience of the menopause was "an overlooked crisis": "We are experiencing increased sensory issues, shutdowns, difficulties socialising, and emotional distress—yet there is no formal recognition or structured help."[270]

Uninformed public discourse

178. Witnesses drew attention to a vicious cycle whereby current political, media and public discourse around autism, fuelled by the gap between awareness and understanding, is driving the spread of misinformation. This in turn leads to increased stigma and lack of acceptance. Witnesses noted in particular the current focus on 'overdiagnosis' that we highlighted in Chapter 2. Autistic Parents UK said:

> "There are two common public misconceptions related to the rise in rates of autism diagnosis: either that autism and other forms of neurodiversity are 'overdiagnosed' or that there is an 'epidemic'. These incorrect ideas are being spread by prominent figures in society".[271]

179. Dr Jessica Ong, General Practitioner and Clinical Care Professional Lead for Autism, ADHD & SEND, South East London Integrated Care Board, et al, perceived a growing stigma around perceived overdiagnosis: "We hear too many professionals in schools, health services and elsewhere readily

267 Written evidence from Norwood (AAC0116)
268 Written evidence from Prof Nusrat Husain and Anum Farooq (AAC0161)
269 See for example Q 34 (Dr Conor Davidson), written evidence from Neurodiverse Connection (AAC0103), Christopher Barber (AAC0304) and Officers of Hertfordshire County Council (AAC0125).
270 Written evidence from Anonymous 56 (AAC0359). See also written evidence from Anonymous 5 (AAC0021), Anonymous 7 (AAC0023), Penny Jackson (AAC0045) and Lynette Morgan (AAC0150).
271 Written evidence from Autistic Parents UK (AAC0292). See also written evidence from Anonymous 8 (AAC0032) and Avenues Group (AAC0126).

expressing opinions such as 'everyone wants their child diagnosed' or, 'we're all a bit on the spectrum' which too easily lead people to conclude that the need for support is exaggerated."[272] Dr Ken Courtenay, Consultant Psychiatrist in Learning Disability, NHS England, pointed out that "people seem to believe that there is an overdiagnosis of autism occurring. In fact, when we have looked at the data more recently, there appears to be an underdiagnosis", in particular among older people.[273] We discussed the evidence on diagnosis rates in Chapter 2.

180. Witnesses said that recent comments by politicians from across the political spectrum about overdiagnosis were particularly damaging.[274] In Chapter 4 we reflect on the concerns of autism charities over recent ministerial comments about the need "to see the demand curve [for diagnosis] flatten out".[275]

Autism in the media

181. Several witnesses pointed to the unrealistic and tokenistic portrayal of autistic people in the media as a contributory factor to the lack of understanding.[276]

182. Dr Themis Karaminis, Lecturer in Psychology, City St George's, University of London, and his colleagues analysed the portrayal of autism and autistic people in British newspapers between 2011 and 2020. They found a focus on deficits and challenges faced by autistic people, coverage heavily skewed towards children (especially boys), reinforcement of gender stereotypes, and use of outdated language.[277] Asperger's Syndrome Self Advocacy (ASSA) West Sussex argued that "only exceptionally high functioning autistic people are represented in the media".[278] On the other hand, research by the Centre for Neurodiversity and Development at Durham University showed that media representations of autistic people are often biased towards tragedy, and stereotype autistic people as lacking both warmth and competence.[279] Hesley Group, a specialist autism care provider, noted that authentic representation of neurodivergent individuals in the media can challenge stereotypes and highlight the value of every person's unique perspective.[280] Other witnesses praised the increased representation of autistic people in the media and positive role models.[281]

183. Witnesses noted that social media can be helpful for autistic people in terms of finding a community, accessing services and providing support.[282] However, social media is also too often a source of damaging misinformation and stigma.[283]

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272 Written evidence from Dr Jessica Ong, Sonia Gannon, Katherine Smith and Louise Finer (AAC0229)
273 Q 160 (Dr Ken Courtenay)
274 See for example Q 193 (Adam Micklethwaite).
275 Q 185 (Stephen Kinnock MP)
276 See for example written evidence from Nancy Lowe (AAC0037), Lisa Lawton (AAC0054) and Mission Impossible Peer and Self-Advocacy Group (AAC0291).
277 Written evidence from Dr Themis Karaminis (AAC0216)
278 Written evidence from Asperger's Syndrome Self Advocacy (ASSA) West Sussex (AAC0317)
279 Written evidence from Centre for Neurodiversity and Development, Durham University (AAC0325)
280 Written evidence from Hesley Group (AAC0302)
281 See for example written evidence from Sandy Keenay (AAC0077), Simran Sidhu (AAC0059) and Riddley McDermott (AAC0155).
282 Written evidence from Prof Nelya Koteyko (AAC0086) and Alijan Kirk and Oscar Law-Jones (AAC0053). See also National Autistic Society (NAS), *The Online Community*.
283 See for example written evidence from Anonymous 3 (AAC0007), Anonymous 54 (AAC0344), Alijan Kirk and Oscar Law-Jones (AAC0053), Sunderland People First (AAC0093) and Care England (AAC0211).

The consequences of continued stigma and misunderstanding

184. The National Autistic Society said that surveys show that low public understanding of autism has a negative impact on the lives and wellbeing of autistic people, including: a lack of appropriate help given to autistic people when needed, such as when visibly distressed; experiences of taunting, mocking, and overt disapproval at distressed behaviours; and negative reactions to disclosure. Furthermore, according to National Autistic Society survey data:

- 55% of autistic people say they have avoided going out because they are worried about how people they meet will treat them. Only 5–13% of autistic people reported that they do not worry about going out due to concerns about how people they meet will treat them.[284]
- Almost eight in ten carers say the autistic person they care for has been unable to attend leisure activities due to other people's attitudes or perceptions of autism.
- Three quarters of carers say the autistic person they care for is lonely.
- Nine in ten autistic people have experienced poor mental health due to other people's attitudes or perceptions of autism.
- 84% of autistic people have experienced social isolation.[285]

185. Dr Sarah Cassidy, Associate Professor in Psychology, Nottingham University, said that autistic people may 'mask' or 'camouflage' their autistic characteristics in an attempt to try to access and cope in social spaces and services, creating stress, anxiety and pressure: "Lots of research studies now show that there is a consistent link between mental ill-health and camouflaging autistic traits or characteristics, regardless of whether a person has a diagnosis."[286]

Accessibility of public environments

The provisions of the Equality Act 2010

186. Box 5 sets out the relevant provisions of the Equality Act 2010.

187. Notwithstanding these provisions, we received compelling evidence of the continuing inaccessibility of a wide range of public environments. The accessibility concerns of many witnesses related to the core areas of focus of the current autism strategy: health and care, education, employment and the criminal justice system. We examine each of these in turn in Chapters 5–8. In this chapter we focus on case studies of other environments, including public facilities and spaces and transport.

284 Written evidence from UK Government (AAC0231)
285 Written evidence from National Autistic Society (NAS) (AAC0232)
286 Q 36 (Dr Sarah Cassidy)

Box 5: The Equality Act 2010 and reasonable adjustments

Section 6 of the Equality Act 2010 defines disability as a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on a person's ability to do normal daily activities. 'Substantial' is more than minor or trivial, for example it takes much longer than it usually would to complete a daily task like getting dressed. 'Long-term' means 12 months or more.[287] Statutory guidance to the Act gives autism as an example of an impairment that may give rise to disability.[288]

The Equality Act 2010 creates a positive duty to anticipate the needs of, and make reasonable adjustments for, disabled people. Section 20 of the Act ('Duty to make adjustments') sets requirements to "take such steps as it is reasonable to have to take" to:

- avoid putting disabled people at a substantial disadvantage where a provision, criterion or practice would put them at that disadvantage compared with people who are not disabled;
- remove, alter or provide means of avoiding physical features where those features put disabled people at a substantial disadvantage compared with people who are not disabled; and,
- provide an auxiliary aid where disabled people would, but for the provision of that aid, be put at a substantial disadvantage in comparison with people who are not disabled.[289]

The Act prohibits discrimination in relation to services and public functions, work, the management and disposal of premises, education, clubs and associations, and transport.[290]

Public facilities and spaces

Box 6: Testimonies from autistic people and those who support them about public facilities and spaces

"I have to pretend that yes, I'm fine to go for a drink in a noisy café and I really don't mind all the clattering and the sharpness of the noises and the different conversations that I can't focus in on."[291]

"I think neurotypical people don't realise that when we're trying not to show a sensory environment is affecting us, because we don't want to be perceived to be 'difficult' about asking for the lights to be turned off or for the radio to be turned down, it really drains us."[292]

"It's hard to access the community being autistic; I can't travel by myself and attend community support groups. I need support to even attend, so a lot of groups available are out of the question, as I can't get the support I need to attend."[293]

"We commonly hear of autistic children being banned from play areas."[294]

287 HM Government, *Definition of disability under the Equality Act 2010*
288 Equality Act, section 6. See Government Equalities Office and Women and Equalities Unit, *Disability: Equality Act 2010—Guidance on matters to be taken into account in determining questions relating to the definition of disability*, updated 8 March 2013.
289 Equality Act 2010, section 20 and House of Commons Library, *A short introduction to equality law and policy*, CBP 9448, 2 December 2024
290 House of Commons Library, *A short introduction to equality law and policy*, CBP 9448, 2 December 2024
291 Written evidence from Autistica (AAC0105)
292 Written evidence from Dr Catherine Manning (AAC0130)
293 Written evidence from Avenues Group (AAC0126)
294 Written evidence from Education Otherwise (AAC0069)

188. Autistica noted that around nine in ten autistic people experience sensory differences, but this has rarely been considered in building and venue design.[295] Hampshire Autism Partnership Board agreed that "autistic-friendly design is often an afterthought rather than integrated from the outset. This results in public spaces, services, and facilities that are overwhelming or inaccessible due to sensory challenges, poor signage, or inflexible layouts."[296] Care England reported that social isolation and loneliness are widespread because community spaces and activities are not designed with autistic people's needs in mind. Public spaces often lack sensory-friendly features, such as quiet areas, appropriate lighting or clear signage.[297]

189. Dr Catherine Manning, Associate Professor in Psychology, University of Birmingham, and giving evidence on behalf of the Sensory Street project and colleagues at the Universities of Birmingham and Reading, cited six reasons why spaces are commonly disabling for autistic people: the sensory environment, space constraints, unpredictability, misunderstanding, lack of suitable adjustments, and lack of space and time to recover and prepare.[298] Dr Samantha Friedman, Lecturer, University of Edinburgh, and Dr Keren MacLennan, Lecturer, University of Bath, noted that some of the most challenging spaces include supermarkets, restaurants, retail stores and high streets. Many autistic people experience sensory overload in these spaces. They said that the autism strategy makes no reference to sensory challenges in relation to community inclusion.[299]

190. One parent referred to the support that her autistic son received from shop workers, hairdressers and pub staff in his local community: "Because the staff treat him appropriately, after some guidance from my son's support staff, other people in the pub and shops also acknowledge him as well, thus broadening his horizons. They listen patiently to him even if what he says cannot be understood fully."[300] In contrast, another parent highlighted the difficulties their daughter faced when presented with a lack of flexibility to take account of her needs in public spaces.[301]

Social inclusion

191. Witnesses stressed the importance of support networks for autistic people.[302] Cheryl Simpson MBE cited the work of her Space4Autism charity, which has been running a range of social clubs for autistic children and adults since 2005. She highlighted the funding pressures that such charities face.[303] Autistic Nottingham observed that, while initiatives by autism-focused charities or community organisations are often impactful, they lack the scale and support to influence broader community inclusion.[304]

192. Officers of Hertfordshire County Council reported that autistic people are not always clear if they are welcome in community settings without specific

295 Written evidence from Autistica (AAC0105)
296 Written evidence from Hampshire Autism Partnership Board (AAC0352)
297 Written evidence from Care England (AAC0211)
298 Written evidence from Dr Catherine Manning (AAC0130)
299 Written evidence from Dr Samantha Friedman and Dr Keren MacLennan (AAC0112)
300 Written evidence from Susan Kirkman (AAC0180)
301 Written evidence from Anonymous 48 (AAC0281)
302 See for example supplementary written evidence from Dr Rachel Moseley (AAC0074) and written evidence from Jack Honey (AAC0273).
303 Written evidence from Space4Autism (AAC0314)
304 Written evidence from Autistic Nottingham (AAC0047)

instructions that they are welcome, and that services are themselves unclear how to support the autistic population.[305] Norfolk County Council observed that community inclusion is hindered by a lack of adjustments in leisure services and social groups open to all, such as Scouts and Girl Guiding.[306] We explore these issues in more detail in Chapter 5.

Transport

193. Witnesses drew attention to the particular importance of accessibility in the transport system. The Government noted:

> "The 2021 national autism strategy highlights that transport is a key enabler to autistic people and their families being included in their communities and being able to find employment, but anecdotal evidence tells us that many find public transport inaccessible because of how anxiety-inducing noisy and busy public environments can be."[307]

194. The Government cited interviews conducted by Ipsos MORI that highlighted that using public transport was important for autistic people because it provided independence, confidence, a sense of achievement and the freedom to commute, attend health appointments, lead full social lives, and travel farther afield. However, many experienced barriers when using transport. Participants had difficulties processing and retaining information and communicating with others, which resulted in anxiety, stress and a lack of self-confidence, especially if travelling alone.[308]

Box 7: Testimonies from autistic people and those who support them about transport

"For me travel is hard because of the overwhelming noise and need for social interaction … I have experienced staff members at train stations, airports and similar actively find my questions annoying, rather than helping to support me …. I have been shouted at, threatened to be removed for being rude when asking for help … Because of my experiences I now often don't use public transport alone, I want to travel and enjoy the things other people my age do but now I just am less independent."[309]

"I have been verbally harassed by train station staff for not making enough eye contact or conversation at ticket barriers … experiences like this discourage me from future work trips."[310]

"Public transport should be more accessible … and people who drive public transport should be given more training around autism awareness as they are very likely to come into contact with people who are autistic."[311]

195. The Transport Studies Unit, University of Oxford, said that transport system design rarely takes into account the requirements of autistic people, meaning

305 Written evidence from Officers of Hertfordshire County Council (AAC0125)
306 Written evidence from Norfolk County Council (AAC0285)
307 Department for Transport, *People with non-visible impairments' attitudes to and experiences of transport*, 26 September 2024
308 Written evidence from UK Government (AAC0231)
309 Written evidence from Anonymous 6 (AAC0022)
310 Written evidence from Anonymous 55 (AAC0356)
311 Written evidence from Mission Impossible Peer and Self-Advocacy Group (AAC0291)

they have to plan ahead for, manage, and modify the sensory environments of mobile spaces.[312]

196. Research by the Transport Studies Unit showed that one of the most persistent challenges for autistic children is the impact of their treatment in everyday public settings such as public transport on their emotional safety. They stated that autistic children and their families frequently experience stigma, impatience or judgement when behaviours diverge from neurotypical norms.[313]

Case studies of good practice

197. Nevertheless, there are case studies of good practice. Fazeela Hafejee, Representative, Association of Directors of Adult Social Services (ADASS), and Assistant Director for Adults with Disabilities, Bradford Council, referred to the development of "a neurodiverse-friendly district of Bradford", which aims to engage in sectors beyond health and social care to encourage recognition that people need to be supported in every part of their lives. Building on a previous Department of Health and Social Care (DHSC) initiative to support a dementia-friendly society, they held a successful event, including the arts, culture, leisure, tourism and transport sectors, involving "making a pledge to make the smallest of changes but have the biggest of impacts".[314]

198. Nigel Minns, Chair of Health, Care & Additional Needs Policy Committee, Association of Directors of Children's Services, and Executive Director for Children and Young People, Warwickshire County Council, gave the example in Warwickshire of the production of reasonable adjustment guides, which had spread from mental health services to other local services such as leisure centres.[315] Hampshire Autism Partnership Board highlighted successful local public awareness campaigns.[316]

Proposals for change

199. Witnesses made several proposals to improve acceptance and understanding and the accessibility of public environments. Five key elements emerged.

A Government-led public understanding and acceptance initiative

200. The 2021–26 autism strategy stated:

> "We will develop and test an autism public understanding and acceptance initiative, working with autistic people, their families and the voluntary sector … to help the public adapt their behaviour towards autistic people and recognise the diversity of the autistic community; that every autistic person is different. This includes improving understanding of the strengths and positives of being autistic, as well as the challenges people might face in their daily lives and how distressed behaviour can manifest itself. We will also ensure this covers the diversity of the autistic community."[317]

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312 Written evidence from Transport Studies Unit, University of Oxford (AAC0123)
313 *Ibid*.
314 Q 153 (Fazeela Hafejee)
315 Q 153 (Nigel Minns)
316 Written evidence from Hampshire Autism Partnership Board (AAC0352)
317 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 21 July 2021

201. The National Autistic Society noted that DHSC "proposed to trial and evaluate the impact of the initiative by May 2022. This still hasn't happened." They stressed that "any future strategy must have a clear commitment to improve public understanding and challenging negative and misleading perceptions of autism." They said that it must reflect the diversity of the autistic community, including the presentation of autism in women and girls, the LGBT+ community, and people from ethnic minority backgrounds.[318]

202. Autism Action said that 96% of their survey respondents endorsed a recommendation for the Government to run campaigns to promote public understanding and address misinformation about autism.[319] John Phillipson, CEO, North East Autism Society, said that "lots of snake oil salesmen say there is a cure, and people are making all sorts of comments about whether autism exists et cetera. It exists, and the Government need to have a publicity strategy."[320]

203. Numerous witnesses called for a national autism awareness campaign "featuring real autistic individuals".[321] In the words of one submission: "what I am really hoping for is that there comes a time when 'acceptance' becomes 'embracement' of autism within society."[322]

Training of public-facing staff

204. John Phillipson called for a national programme to train people at the front line of services so that they can better understand the needs of the people they are working for.[323] Nigel Minns said that training and awareness raising should be mandatory and formalised as part of a national scheme.[324] Jude Ragan CBE, a former special school headteacher, argued for accredited national training for all staff who interact with the public, including police, social services, healthcare, teachers, social care staff and housing support staff.[325] The Transport Studies Unit, University of Oxford, called for awareness training for public transport staff.[326] Others suggested training should be given to people in retail roles.[327]

205. Professor Anna Remington, Director, Centre for Research in Autism and Education (CRAE), University College London, noted evidence that 'one-size-fits-all' autism awareness training for employers and managers does not always make much difference.[328] Professor Will Mandy, Professor of Neurodevelopmental Conditions, University College London, said that specialist autism services should provide a consultancy training function as disseminators of knowledge to service providers interacting with autistic people.[329]

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318 Written evidence from National Autistic Society (NAS) (AAC0232)
319 Written evidence from Autism Action (AAC0233)
320 Q 66 (John Phillipson)
321 Written evidence from Ben Wise (AAC0024). See also written evidence from Connor Passey (AAC0003), Lisa Lawton (AAC0054), Victoria Bagnall (AAC0075), Steven John May (AAC0145), Wigan All Age Autism Partnership Board (AAC0106) and Q 90 (Anita Harrington).
322 Written evidence from Ivan Ambrose (AAC0068)
323 Q 64 (John Phillipson)
324 Q 158 (Nigel Minns). See also Q 169 (Tom Cahill).
325 Written evidence from Jude Ragan CBE (AAC0184). See also written evidence from Lisa Lawton (AAC0054) and Anonymous 41 (AAC0255).
326 Written evidence from Transport Studies Unit, University of Oxford (AAC0123)
327 Written evidence from Mission Impossible Peer and Self-Advocacy Group (AAC0291)
328 Q 94 (Prof Anna Remington)
329 Q 29 (Prof Will Mandy)

206. Some witnesses suggested that the Oliver McGowan Mandatory Training for all staff at registered health and social care providers could be rolled out to other organisations.[330] We discuss the Oliver McGowan Mandatory Training in more detail in Chapter 5.

The role of autistic people in promoting understanding and acceptance

207. Witnesses emphasised that meaningful engagement with, and leadership by, autistic people is essential to promoting greater understanding and acceptance.[331] One witness stressed that mandatory training must be "delivered by autistic people not just from textbooks or token one-hour sessions."[332] Autistic Nottingham called for investment in autistic people trained to share their experiences in schools, workplaces, and community settings, as authentic, first-hand stories have far more impact than theoretical training alone.[333] Witnesses called for the full diversity of autistic experience to be represented. Marsha Martin particularly highlighted the need to ensure that black autistic individuals and their families are "not just included in but actually leading conversations."[334]

208. Witnesses emphasised the vital role that encountering and working alongside autistic people on a daily basis plays in breaking down stigma and increasing acceptance (see Chapter 7).[335] NHS and local authority professionals noted the invaluable role that autistic employees can play in supporting autistic people they come into contact with in a professional capacity: "It's important for autistic people who are in distress and trying to access services to see others like them on the other side. The impact of this can be breathtaking."[336] Conversely, Dr Mary Doherty, Founder, Autistic Doctors International, highlighted the harmful impact in terms of perpetuating shame and stigma when autistic people feel unable to acknowledge being autistic.[337]

Accessibility and reasonable adjustments in public spaces

209. Fazilet Hadi, Head of Policy, Disability Rights UK, noted that accessibility duties in equality law are not consistently understood or met. Yet:

> "Often the responsibility for calling out the statutory sector—whether because we are not getting the services we need or because the Equality Act has been breached—is left to the disabled person. That is totally unacceptable. Why are the Government … leaving it to individual disabled people to fight for our rights?"[338]

210. In Chapter 2 we explored the importance of universal design as an underpinning principle. The Prince's Foundation for Building Community states that the built environment has a key role to play in encouraging

330 See for example written evidence from Birmingham Autism and ADHD Partnership Board (AAC0195).
331 See for example written evidence from Autistica (AAC0105), Lucy Cowap (AAC0041) and Q 54 (Dr Rachel Moseley).
332 Written evidence from Daniel White (AAC0152). See also written evidence from River Stone (AAC0091) and Anonymous 29 (AAC0164).
333 Written evidence from Autistic Nottingham (AAC0047). See also written evidence from Connor Passey (AAC0003) and Hogan (AAC0029).
334 Q 16 (Marsha Martin)
335 See for example written evidence from Anonymous 3 (AAC0007).
336 Appendix 5 and Autism Act 2009 Committee, *Note of meeting with NHS and local authority professionals*, 1 May 2025
337 QQ 45 and 51, footnote 9 (Dr Mary Doherty)
338 Q 3 (Fazilet Hadi)

social inclusivity and community connectivity, and combating loneliness and vulnerability.[339] Autistica noted that, in 2022, the British Standards Institution published guidance (PAS 6463) for the first time on designing buildings to be accessible to neurodivergent people.[340] Autistica called for this guidance to be adopted in the next autism strategy across publicly-owned spaces and services. They said that many adaptations, such as a dedicated quiet space, make a big difference and do not require large sums of money or a full rebuild.[341] Other recommendations included guidelines and rating services for autism inclusivity and the use of sensory audits in public settings.[342]

211. Hesley Group said that leisure providers such as cinemas, theme parks, and swimming venues should make reasonable adjustments (including sensory-friendly sessions, clear signage and quiet zones) to ensure their spaces are welcoming and accommodating to all.[343] Cheshire West All Age Autism and Neurodivergence Partnership Board called for the Government to encourage businesses such as supermarkets to create a more inclusive environment.[344]

212. Dr Ken Courtenay emphasised the importance of "actually asking autistic people what would suit and help them rather than prescribing how things should be done, particularly in the built environment … It is about us having to change, rather than expecting autistic people to do it."[345]

Conclusions and recommendations

213. **There has been a welcome increase in public awareness of autism since the Autism Act came into force. Younger people in particular are perceived to be embracing neurodiversity and demonstrating acceptance of autism. There are positive signs that these trends have created an environment where people are more willing to seek and be open about an autism diagnosis.**

214. **However, understanding of autism and acceptance of autistic people continue to lag behind. The aim of the current autism strategy for there to be a significant improvement in public understanding and acceptance by 2026 is unlikely to be met. There remain fundamental misunderstandings and misconceptions about autism, and autistic people remain subject to stereotyping, stigma and discrimination.**

215. **There is also a real fear among autistic people and those who support them that the misinformed public discourse about autism at the present time is increasing the stigma that autistic people face. In particular, rhetoric suggesting there is an overdiagnosis problem has had a damaging impact. The ambition that there comes a time when acceptance becomes embracement of autism remains far off.**

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339 Prince's Foundation for Building Community, *Community Connectedness: Building Resilient Harmonious Communities*

340 British Standards Institution, *PAS 6463:2022—Design for the mind—Neurodiversity and the built environment—Guide*, October 2022

341 Written evidence from Autistica (AAC0105). See also written evidence from Dr Letizia Palumbo (AAC0132) and Prof Andrew Hugill (AAC0138).

342 Written evidence from Kent and Medway NHS and Social Care Partnership Trust (AAC0337) and Sheffield Health and Social Care NHS Foundation Trust (AAC0326)

343 Written evidence from Hesley Group (AAC0302)

344 Written evidence from Cheshire West All Age Autism and Neurodivergence Partnership Board (AAC0354)

345 Q 166 (Dr Ken Courtenay)

216. **Against that backdrop, the failure by successive governments to meet the commitment in the current autism strategy to develop an autism public awareness and understanding initiative is both striking and unacceptable.**

217. ***The Government must as a matter of urgency implement a new initiative to improve understanding and acceptance of autism. This should be led at ministerial level and produced with autistic people and those who support them. This initiative should be designed to engage and inform both the public in general, and staff in public-facing roles in particular. It must reflect the diversity of experience of autistic people. It must also be evaluated robustly, including by autistic people.***

218. ***This initiative should be underpinned by regular polling, tracking changes to public attitudes to and understanding and acceptance of autism.***

219. ***As a key part of this, the Government must commission a national programme of accredited mandatory training in autism and neuroinclusion for public-facing staff in all public bodies and service providers. This training should also be developed with and led by autistic people and those who support them, and should be made available to private sector businesses and organisations.***

220. **Autistic people continue to face fundamental barriers to the accessibility of a wide range of public services and environments. This has a damaging impact not only on effective service provision, but also on the wellbeing of autistic people and those who support them.**

221. ***Strengthened and updated statutory guidance needs to set out how the NHS, local authorities and all public bodies and service providers must meet their duties in equality law to ensure that public services and environments are fully accessible to and inclusive of autistic people. This must take account of the principles of universal design and the British Standards Institution guidance (PAS 6463) on designing buildings to be accessible to neurodivergent people. It must also involve meaningful consultation with autistic people and those who support them about accessibility needs.***

CHAPTER 4: IDENTIFICATION, ASSESSMENT AND SUPPORT

Introduction

222. The Autism Act 2009 places a duty on the Secretary of State to provide guidance on the provision of services for diagnosing autism in adults and the identification of autistic adults. Statutory guidance to the Act sets out how NHS bodies and local authorities should ensure access to pathways to diagnosis and post-diagnostic support from health and social care services. NHS bodies should assure themselves that people's experiences of the local autism diagnosis process are acceptable.[346]

223. The 2021 autism strategy set a goal to make progress on reducing waiting times for autism diagnosis. For the first year of the strategy, it committed £10.5 million in funding to test and implement effective ways of reducing diagnosis waiting times for children and £2.5 million in funding for adult diagnostic services.[347] Since then, the numbers waiting have risen rapidly.[348]

224. We received overwhelming evidence that the autism assessment system is not fit for purpose and that fixing the system is critical to delivering better outcomes for autistic people. In this chapter, we examine the key challenges for the autism assessment system and consider what the Government needs to do to make it work.

The capacity gap

225. The most pressing challenge for the autism assessment system is the gap between referrals and capacity. Stephen Kinnock MP, Minister of State for Care, Department of Health and Social Care (DHSC), told us:

> "One of the most striking statistics that I have come across since I took up this position a year ago is that, between April 2019 and March 2025, the number of people with an open referral for suspected autism increased twelvefold from 17,411 to 224,382 … What we now have to do is figure out how to configure the system so that it is able to deal with this massive increase in the demand for assessments."[349]

226. This increase in referrals is part of a longer-term trend that has accelerated since the COVID-19 pandemic. Speaking about his experience in adult assessment services, Leeds clinician and Autism Champion at the Royal College of Psychiatrists, Dr Conor Davidson, told us:

> "When the referrals in Leeds used to go to Sheffield prior to the Act, there were about 12 a year. After we set up the Leeds service in 2011, pretty soon, we were getting 12 a month. Now, particularly since the COVID pandemic, it is not unusual to get 12 referrals a day, and that is the kind of pattern we have seen across the country … The situation now is of a real capacity-demand mismatch."[350]

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346 Autism Act 2009 and Department of Health and Social Care, *Adult autism strategy: supporting its use*, 26 March 2015

347 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021

348 NHS Digital, *Autism Waiting Time Statistics*. See further paras 225 and 240–43.

349 Q 179 (Stephen Kinnock MP)

350 Q 30 (Dr Conor Davidson)

227. We heard some sharp differences in view about how the Government should respond to this. Stephen Kinnock MP told us:

> "We will never get enough capacity in the system until we deal with the issue of exponentially rising demand … It is the right thing to do, to give people support that is not necessarily about getting an assessment but about early identification of need, early intervention and early support … If you get that right, you begin to see the demand curve flatten out. Demand and capacity start to balance, and you then get better-quality outcomes for the people who really need it, in terms of the assessment and diagnosis that is there."[351]

228. In this context, we note media reports in autumn 2025 that the Government plans to "launch a review of the prevalence of mental illness and neurodivergence, with a particular focus on whether some conditions are being overdiagnosed."[352]

229. Many witnesses disagreed with the Minister's framing of the issue. Dr James Cusack, CEO, Autistica, asked: "If we talked about suppressing demand so that people could receive other forms of diagnosis and care, would we consider that acceptable, ethical and the morally right thing to do when we have a nationalised health service?" Tim Nicholls, Assistant Director of Policy, Research and Strategy, National Autistic Society, said: "Improving needs-led support should not be used to try and drive down diagnosis waiting times. Diagnosis is for life. It will enable you to know so much about the future of your life and how you might approach, feel or experience certain things."[353]

230. This disagreement raises questions about what the purpose of the autism assessment system should be and what it would take to scale up the assessment system.

The purpose of an autism diagnosis

231. An autism diagnosis serves several important purposes. In medical terms, a diagnosis can enable clinicians to recommend interventions tailored to needs associated with autism (such as communication needs), as well as co-occurring physical and mental health needs. In personal and social terms, a diagnosis can help the autistic person and those around them to understand and respond to their needs. More broadly, a diagnosis can also help an autistic person access statutory support such as social care or reasonable adjustments at school or at work.[354]

232. Many autistic adults told us they found an autism diagnosis made sense of their experiences and gave them ways of managing their needs, often after many years of struggling with unmet mental health needs and sometimes precipitated by crisis.[355] Parents of pupils at Phoenix School, a large special school in the London Borough of Tower Hamlets, spoke of how early

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351 Q 185 (Stephen Kinnock MP)
352 HSJ, *Streeting orders probe of mental illness overdiagnosis*, 30 September 2025
353 Q 193 (Dr James Cusack, Tim Nicholls)
354 NHS England, *A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards*, 27 November 2023
355 See for example Box 8, written evidence from Anonymous 10 (AAC0042), Anonymous 20 (AAC0079) and Anonymous 38 (AAC0249).

diagnosis had developed their own understanding of their children's needs and said that the school had changed the lives of their families.[356]

Box 8: Testimonies from autistic people and those who support them about the role of autism diagnosis

"It gives you permission to be different. It gives you avenues to talk to other autistic people … and learn a little bit more about how other people cope with the problems they have."[357]

"Not knowing I was autistic … feeling broken and like a failure for not being able to do or be like others around me" [contributed to suicidality].[358]

"I would never have wanted to engage with the National Autistic Society, for example, without a diagnosis, because I wouldn't have felt valid, because I've been told my entire life that I just need to try more hard to be normal." [359]

"Without a diagnosis there is no support offered. A diagnosis is therefore the first step to getting any support but waiting lists are currently up to four years on the NHS. And then there are more waiting lists, in order to access the necessary support. I was diagnosed when I was eight. I am now 13 and I am still waiting for my EHCP to be confirmed."[360]

"If a child doesn't have a formal diagnosis, they are often left with no support at all. Even with a diagnosis, there's barely any meaningful post-diagnostic support."[361]

"In many ways my life [was] the same pre-diagnosis as it is now."[362]

233. There is academic evidence that delays in and barriers to autism diagnosis are linked to worse outcomes.[363] Dr Rachel Moseley, Principal Academic in Psychology, University of Bournemouth, told us:

> "We know from our research that autistic people who grow up undiagnosed have worse mental health and higher suicide rates. Our most recent work has clearly shown how being undiagnosed makes people feel lost, broken and like a failure for not being able to do or to be like others … We know about the immensely positive impacts of diagnosis, which some people in our study said had saved their lives; I can testify to that."[364]

234. For autistic people struggling with mental ill health, diagnosis can be vital to effective support and treatment. One person told us how receiving an autism diagnosis had offered them a path to recovery after years in hospital with an eating disorder.[365] Professor Will Mandy, Professor of Neurodevelopmental Conditions, University College London, referred to evidence that around

356 Appendix 9 and Autism Act 2009 Committee, *Note of Committee visit to Phoenix School, Bow, London Borough of Tower Hamlets*, 11 June 2025
357 Written evidence from Autistica (AAC0105)
358 Supplementary written evidence from Dr Rachel Moseley (AAC0074)
359 Written evidence from Autistica (AAC0105)
360 Written evidence from Riddley McDermott (AAC0155)
361 Written evidence from Celestine Fairhall (AAC0253)
362 Written evidence from Anonymous 40 (AAC0252)
363 NHS England, *A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards*, 27 November 2023
364 Q 59 (Dr Rachel Moseley)
365 Appendix 10 and Autism Act 2009 Committee, *Note of meeting with the House of Commons Autistic Champions*, 7 July 2025

20% to 30% of patients with anorexia nervosa are autistic or have high autistic traits, but that they usually present to services without an autism diagnosis:

> "It matters to know that they are autistic. It matters in terms of how you engage them with the service—whether you need to make adaptations just to make that service accessible to them, so they can get through the door and make use of the treatment. It can also have a big effect on how you understand and treat their eating disorder."[366]

235. At the same time, Dr Adrian James, Medical Director for Mental Health and Neurodiversity, NHS England, noted that not every autistic person will want a diagnosis: "We need to be careful that we are not manufacturing a system that forces people to get a diagnosis in order to get the help that they need."[367] Dr James Cusack warned against creating a culture "where a diagnosis is required to qualify for acceptance in some way: 'Why are you behaving differently? You don't have a diagnosis of something.'"[368]

236. Beyond healthcare, many witnesses expressed frustration that autistic people often in practice have to access a diagnosis to unlock any support, even where this ought not to be the case. Some suggested that this is an inevitable consequence of the ways that access to statutory support is structured. Dr Conor Davidson told us:

> "Special educational needs, reasonable adjustments in the workplace and even social care support are supposed to be needs-led rather than diagnosis-led. We are told by patients, carers and families that the reality is that you need a diagnosis to access most of that type of support. Given the pressures on the SEN system and social care, I cannot see that particularly changing very much in the future."[369]

237. Professor Jonathan Green, Professor of Child and Adolescent Psychiatry, University of Manchester, told us: "The diagnosis process as a gateway to care, SEND and other support is now a constraining bottleneck. We have got to somehow rethink how we do this to be much more agile to meet people's needs early on and not do one size fits all."[370]

238. Witnesses stressed the need for a stable identification, assessment, and support system, enabling access to timely needs-led support as well as equitable access to diagnosis. The PDA Society, a charity for autistic people with a pathological demand avoidance profile,[371] shared survey evidence showing that autistic people and family members wanted people working in universal services to be trained and empowered to respond to need without a diagnosis, so that the purpose of diagnosis is "to deepen our understanding of a person—not to serve as a barrier that must be passed before help can begin … The expertise and experience of diagnosticians has its greatest

366 Q 26 (Prof Jonathan Green)
367 Q 160 (Dr Adrian James)
368 Q 201 (Dr James Cusack)
369 Q 31 (Dr Conor Davidson). See also written evidence from Anonymous 4 (AAC0015), Down's Syndrome Association (AAC0101) and Isabelle Finn-Kelcey (AAC0072).
370 Q 25 (Prof Jonathan Green)
371 Pathological Demand Avoidance (PDA) is "widely understood to be a profile found within some autistic people. The most obvious characteristic of PDA is a determined avoidance of so-called 'common' demands of life, including expectations and things the person enjoys doing." The term was developed by psychologist Elizabeth Newson in the 1980s. See PDA Society, *What is PDA?* and National Autistic Society, *Demand avoidance*.

impact when it is used to inform how best to support someone, not whether they get support at all."[372]

239. Autism Alliance UK argued that the Government needs to build a better picture of why increasing numbers of people are seeking autism assessment to build an assessment system that is fit for the future.[373] Autism Action suggested that the Government could survey people on waiting lists to understand what their main reasons are for seeking a diagnosis.[374]

The capacity of the autism assessment system

240. Our witnesses also discussed the Minister's view that it is not realistic to scale up the autism assessment system to meet demand. Tim Nicholls told us this was not correct: "NHS England knows what it would take and how much investment it would take to bring down those waiting lists. By phrasing it as 'exponential' and saying that capacity will never catch up, we are undermining the ability to find solutions."

241. Tim Nicholls said that the main driver of increasing numbers of people waiting was not change in the rate of increase in referrals but the gap between numbers of new referrals and closed referrals: "There are not enough diagnostic assessments taking place to drive down those waiting lists."[375] Tom Cahill, National Director, Learning Disability and Autism Programme, NHS England, told us that Integrated Care Boards (ICBs) are making progress in increasing assessment capacity and "seeing more people than they have ever seen before."[376]

242. The autism assessment waiting times statistics are experimental and rely on data submitted by providers, so they need to be interpreted with care. Tim Nicholls told us that published statistics are likely to underestimate the number of the people waiting for autism assessment in 2019, suggesting that the true increase since then is less than the 12-fold rise that headline figures show.[377] The Government acknowledged that "some of this [increase] will be due to growth in the number of service providers submitting to MHSDS [the Mental Health Services Data Set]."[378]

243. Another key limitation of the waiting times statistics is that they count only children referred to mental health services for autism assessment: in March 2025, more than 137,000 in all. The majority of children who are assessed for autism are referred to community paediatric services instead. This means that the true number of children waiting for an autism assessment will be much higher. [379] There is no disaggregated data on autism assessment waiting times in community paediatric services. Based on the available data, the Children's Commissioner estimated that there were about 400,000 children

372 Written evidence from PDA Society (AAC0268)
373 Written evidence from Autism Alliance UK (AAC0143)
374 Supplementary written evidence from Autism Action (AAC0380)
375 Q 193 (Tim Nicholls)
376 Q 163 (Tom Cahill)
377 Q 193 (Tim Nicholls)
378 Further supplementary written evidence from UK Government (AAC0378)
379 See NHS Digital, *Autism Waiting Time Statistics*, Correspondence, *House of Commons Health and Social Care Committee to the Minister for Care*, 21 July 2025 and HC written answer 43191, Session 2024–26.

waiting for assessment for neurodevelopmental conditions (including autism) in community health services at the end of 2022/23.[380]

244. The National Autistic Society has proposed an investment of £1.3 billion over the next 15 years to address the gap between funding and demand and to "evolve" the assessment process.[381]

Assessment pathways

245. Against this backdrop, we asked witnesses to tell us about the strengths and the main problems with current autism assessment pathways.

Barriers to accessing assessment

Box 9: Testimonies from autistic people and those who support them about assessment pathways

"Having to wait this long to be taken seriously is an insult … It is obscene to leave so many people in distress."[382]

"We were told three years. That's three years of watching her spiral."[383]

"We were not given any specific ideas or options at diagnosis, so we did not know what would help."[384]

"We'd [have] liked to have come out of the diagnosis process with some idea of what my son can do, and what might support him to do that, rather than everything he can't do."[385]

246. A person is normally referred for an autism assessment by professionals working in health, social care, education or criminal justice. Following screening and triage, the person may join a waiting list for autism assessment.[386] Many autistic people and family members told us how they had struggled to secure a referral. At Phoenix School, a large special school in the London Borough of Tower Hamlets, parents of autistic children told us that they had faced battles with health visitors and GPs to access a referral before their children reached school age, despite obvious need. Some resorted to private assessment.[387] Children's autism assessment pathways are not always open to under-fives and often have long waiting lists, meaning opportunities for early help are missed.[388] Heath visitors, teachers, GPs, social workers and mental health professionals do not always identify when a person may be autistic or respond well to requests for referral. This can lead to failures to

380 Children's Commissioner, *Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions*, October 2024
381 Written evidence from National Autistic Society (NAS) (AAC0232)
382 Written evidence from Anonymous 43 (AAC0259)
383 Written evidence from North East and North Cumbria Integrated Care Board (AAC0355)
384 Q 85 (Anita Harrington)
385 Written evidence from Laura Quigley (AAC0265)
386 NHS England, *Operational guidance to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards*, 27 November 2023
387 Appendix 9 and Autism Act 2009 Committee, *Note of Committee visit to Phoenix School, Bow, London Borough of Tower Hamlets*, 11 June. See also written evidence from Transforming Autism and Guy Shahar (AAC0279).
388 Written evidence from Jenny Gilchrist (AAC0014), Space4Autism (AAC0314) and Horizon Care Supported Living (AAC0212)

offer timely, needs-led support to children and adults, as well as creating barriers to referral.[389]

247. Access on to a waiting list is a postcode lottery. Different services deal with high volumes of referrals in different ways.[390] Dr Conor Davidson told us:

> "You can have very strict triage procedures at the front door, so you are only letting in people with the highest need and risk—that is an approach they have taken in North Yorkshire, for example—or you can have a clinical prioritisation system, which is the approach we have taken in our team, where you still accept people for assessment but prioritise them according to the level of need and risk."[391]

248. Merseyside-based children's nurse Jenny Gilchrist told us that there are no standardised criteria for access on to a waiting list: some services use simple screening tests, while others ask for extensive evidence.[392] The Calderdale Branch of the National Autistic Society told us that in their area the waiting time to be referred on to the waiting list had reached a year. They noted that National Institute for Health and Care Excellence (NICE) guidelines do not support the use of screening tools alone to rule diagnosis in or out.[393]

249. Waiting times for autism assessment are very long. According to the autism assessment waiting times statistics, nearly 90% of people waiting for an assessment have been waiting for longer than the 13 weeks recommended by NICE. The average waiting time is more than 17 months.[394] In some parts of the country, waiting times are far longer. Many witnesses told us about waits of three years or more for assessment.[395] Kent and Medway NHS and Social Care Partnership Trust told us that waiting times for autism assessment there are five to seven years.[396] Sheffield Health and Social Care NHS Foundation Trust told us their waiting times are five to eight years for children; they are less than two years for adults due to a strict triage system.[397] In some places NHS referrals for adult autism assessment services have been suspended or closed, including in Oxfordshire, where the waiting list was closed when it had stretched to 18 years, and in Cheshire and the Wirral.[398]

250. Autism assessment services typically offer little or no support to people on waiting lists. This is a particular problem in children's services, where early support is key. Victoria Bates, Child autism assessment lead, Sirona Care & Health, told us that that service has a waiting time of more than five years, is seeing only those children with the highest level of need, and is

389 See for example written evidence from Rotherham Parents Forum Limited (RPFL) (AAC0113), Marta Dobrowolska (AAC0144), Anonymous 51 (AAC0315), Lisa Lawton (AAC0054), Kent and Medway NHS and Social Care Partnership Trust (AAC0337) and Anonymous 14 (AAC0056).
390 Written evidence from Royal College of Psychiatrists (AAC0298)
391 Q 31 (Dr Conor Davidson)
392 Written evidence from Jenny Gilchrist (AAC0014). See also written evidence from BeU North Yorkshire (AAC0343) and Andrew Barlow (AAC0238).
393 Written evidence from National Autistic Society, Calderdale Branch (AAC0222)
394 NHS Digital, *Autism Waiting Time Statistics* and National Autistic Society, *Autism assessment waiting times*, August 2025
395 See for example written evidence from Ryan Graham (AAC0011), Jenny Gilchrist (AAC0014), Autistic Nottingham (AAC0047), City & Hackney partnership, NHS North East London (AAC0219) and Anonymous 8 (AAC0032).
396 Written evidence from Kent and Medway NHS and Social Care Partnership Trust (AAC0337)
397 See written evidence from Sheffield Health and Social Care NHS Foundation Trust (AAC0326), Susan Kirkman (AAC0180) and Laura Johnson (AAC0241).
398 See written evidence from Kevin Taphouse (AAC0001), Victoria Shaw (AAC0010), West Cheshire Autism Hub (AAC0071) and Nicky Drury (AAC0260).

unable to move to early identification and support.[399] Some local authorities commission services to help adults and children waiting for an assessment manage their needs and navigate services.[400]

251. Dr Emma Bradley, Consultant Paediatrician, Sirona Care & Health, and Chair of the Royal College of Paediatricians specialist advisory committee for community child health, told us that once a child has reached the top of the waiting list their primary needs will often have changed. Young people are often taken off the waiting list for assessment when they age out of children's services, increasing risks that they will fall through gaps in service provision just as they embark on adulthood.[401] Some areas have all-age assessment pathways; most do not.[402]

252. Failures to identify and meet the needs of people who are waiting for an autism assessment may increase the risks of harm and mortality. Autism Action cited data from the National Child Mortality Database from 2019 to 2022 suggesting that, of 48 deaths among children who were waiting for an autism assessment or had autistic traits, more than half were by suicide or deliberate self-inflicted harm. This compared to one-third of 77 deaths among diagnosed autistic children without a learning disability and 14% of deaths among non-autistic children.[403] Some services try to manage these risks through triage. NHS Greater Manchester Integrated Care Board told us they were consulting on introducing a new triage system for adult ADHD assessment, following coronial investigations highlighting harms caused by inadequate prioritisation. They said that there were similar issues in autism services and wanted to see national backing for this approach.[404]

253. In the face of long waiting times or closed waiting lists, many turn to the NHS 'right to choose' route,[405] or pay privately for assessment. Many autistic people and family members told us that it had been vital to have these alternative routes and that they would not have been able to access a diagnosis otherwise.[406] However, we also heard that GPs do not always know about or promote access to 'right to choose', creating inconsistencies in access to referral.[407]

254. Barriers to referral may contribute to inequalities in access to diagnosis. Professor Mark Mon-Williams, Chair in Cognitive Psychology, University of Leeds, told us that data from Bradford shows that "children born to mothers of south Asian heritage are getting into the system two years behind their white British peers"; there are likewise delays for girls and for the children of mothers without educational qualifications.[408] City & Hackney partnership, NHS North East London, said that assessment services do not reliably collect data on the demographics of patients, but that black autistic children

399 QQ 111 and 117 (Victoria Bates)
400 Written evidence from Essex County Council (AAC0191) and Norfolk County Council (AAC0285)
401 Q 116 (Dr Emma Bradley). See also written evidence from Jenny Gilchrist (AAC0014).
402 Written evidence from Neurodiverse Connection (AAC0103)
403 Written evidence from Autism Action (AAC0233). See Autism Action, *'Suicide or deliberate self-inflicted harm' identified as the most common category of death in autistic children without a learning disability*, 18 July 2024.
404 See for example written evidence from NHS Greater Manchester Integrated Care Board (AAC0128).
405 If a GP refers a patient to a hospital or service, in most cases the patient has the legal right to choose the hospital or service that they go to (including private services). See NHS, *Your choices in the NHS*, 10 May 2023.
406 See for example written evidence from Charli Clement (AAC0122) and Anonymous 58 (AAC0369).
407 Written evidence from Officers of Hertfordshire County Council (AAC0125)
408 Q 31 (Prof Mark Mon-Williams)

and young people seem to be more likely to be referred for assessment only after being excluded from school.[409] Sheffield Health and Social Care NHS Foundation Trust stated that people in non-white ethnic groups were less likely than average to access assessment services.[410] Dr Ryan Woolhouse, a Senior Clinical Psychologist based in London, told us about data from a local adult assessment service evaluation showing that younger, white British and male patients are more likely to be referred for assessment but that those disparities disappear at assessment, suggesting relative under-referral of adults outside those groups.[411]

Consistency and reliability of assessment

255. The Centre for Applied Autism Research shared survey evidence showing that autistic adults often felt that just receiving a diagnosis was the most important part of going through assessment, and that they were more likely to be satisfied with the assessment itself than their experiences before or after the assessment.[412] However, some autistic adults told us that the assessment focused heavily on their deficits rather than their strengths and forced them to recall and recount difficult experiences. For some, this made the assessment highly stressful or traumatic.[413]

256. There is evidence of problems with the consistency and reliability of referral, screening and assessment. In 2024, Autistica found that people assessed for autism in some NHS trusts are up to seven times more likely to receive a diagnosis than in others. In the NHS trust with the highest conversion rate, 100% of children who were assessed for autism received a diagnosis, compared to just 18% in the trust with the lowest conversion rate. In adults, conversion rates ranged between 97% and 14%.[414] These disparities are likely to be the result of differences in processes at referral, screening and assessment. As we have seen, services apply different criteria for referral for assessment. There is also inconsistency at the assessment stage. Jenny Gilchrist told us that NICE guidelines on assessment are vague, enabling services to use different assessment tools and involve different professionals in the assessment process.[415]

257. Screening and assessment may not consistently and reliably identify autism in some groups.[416] This may contribute to lower diagnosis rates for women and girls, older people, and people from different ethnic groups and cultural backgrounds. Autistica said that autistic adults and clinicians wanted to see "assessment tools and criteria that more accurately reflect the full spectrum of autistic experience, including gendered, cultural, and age-related differences." They noted that NICE guidelines on autism are due to be updated, offering an opportunity to ensure they reflect the latest evidence. [417]

409 Written evidence from City & Hackney partnership, NHS North East London (AAC0219)
410 Written evidence from Sheffield Health and Social Care NHS Foundation Trust (AAC0326)
411 Written evidence from Dr Ryan Woolhouse (AAC0349)
412 Written evidence from Centre for Applied Autism Research (CAAR) (AAC0070)
413 Written evidence from Anonymous 2 (AAC0005) and Anonymous 3 (AAC0007)
414 Q 25 (Prof Will Mandy). See Autistica, *'Not a Priority' highlights crisis in autism assessment and support*, 25 October 2024 and The Guardian, *Positive assessment rates for autism vary widely between parts of England*, 27 October 2024.
415 Written evidence from Jenny Gilchrist (AAC0014)
416 See for example written evidence from I-RAP Research Group (AAC0131)
417 Written evidence from Autistica (AAC0105)

258. Some witnesses told us that it can be unhelpful that assessment demands a binary judgement on whether a person meets the diagnostic criteria, risking failures to identify and meet need if they do not. This can be a particular problem when a person is not given an autism diagnosis after waiting for years to be assessed. Victoria Bates told us:

> "Not all children and young people who present with difficulties will receive a diagnosis. We need to recognise that those needs are still present; they just do not meet very specific diagnostic criteria. It does not mean that their support and their needs are not valid."[418]

259. Dr Sophie Doswell, Consultant Clinical Psychologist, South London and Maudsley NHS Foundation Trust, told us that it can be "very challenging" when an adult is assessed and not given an autism diagnosis and that there needs to be more clarity on what support can be offered in this situation.[419]

260. There are problems with the quality of some assessment providers. Some families pay thousands of pounds for private assessments that are then not accepted on the NHS.[420] Children's assessment provider BeU North Yorkshire told us that NHS bodies are paying some providers to assess for autism through 'right to choose' and then judging those assessments clinically invalid, wasting public money and patients' time. They said that there needs to be consistent accreditation of 'right to choose' providers.[421] Several local authorities and NHS bodies raised similar concerns.[422] On the other hand, the Calderdale Branch of the National Autistic Society feared that the introduction of a quality standard for providers would further limit access to diagnosis.[423]

Fragmented pathways

261. Autism assessment services often do not offer clear pathways to assessment for co-occurring conditions. This is widely recognised as a problem. Dr Mary Doherty, Founder, Autistic Doctors International, told us most autistic people are neurodivergent in other ways too: "it does not make sense that the services are set up in such a way that this cannot be taken into account."[424] Professor Ashok Roy OBE, Consultant Psychiatrist and Associate Medical Director, Coventry and Warwickshire Partnership NHS Trust, said: "We have made our lives very difficult by creating very separate autism and ADHD services … we create situations where people have to go and wait again in another queue to have a fuller diagnosis."[425] Dr Ken Courtenay, Consultant Psychiatrist in Learning Disability, NHS England, agreed.[426] Earlier this year, the NHS England independent ADHD taskforce concluded that there needs to be a 'single front door' for support and assessment for ADHD,

418 Q 117 (Victoria Bates)
419 Written evidence from Dr Sophie Doswell (AAC0114)
420 Written evidence from Archbishop Ryan Cleminson (AAC0234). See also written evidence from Nicky Drury (AAC0260).
421 Written evidence from BeU North Yorkshire (AAC0343)
422 Written evidence from NHS Greater Manchester Integrated Care Board (AAC0128), Officers of Hertfordshire County Council (AAC0125), Essex County Council (AAC0191) and Birmingham Autism and ADHD Partnership Board (AAC0195)
423 Written evidence from National Autistic Society, Calderdale Branch (AAC0222)
424 Q 45 (Dr Mary Doherty)
425 Q 61 (Prof Ashok Roy OBE)
426 Q 164 (Dr Ken Courtenay)

co-occurring neurodevelopmental conditions, and associated mental health conditions.[427]

262. The separation of autism assessment services from mainstream mental health services is especially unhelpful. Professor Jonathan Green told us: "In some areas of CAMHS through the country, up to 80% of referrals now come with questions about neurodiversity—that includes autism."[428] Dr Conor Davidson drew attention to NHS England figures showing about one in 20 adults accessing secondary mental health services is autistic. The true scale of need is likely to be higher because many autistic people with mental health needs are excluded from secondary mental health services.[429] We were told that about half of autistic adults who are in mental health inpatient settings are identified only after admission.[430] Experienced psychiatrists in general mental health services are not always permitted to assess for autism because of local commissioning arrangements, meaning patients must be referred to a separate assessment provider. Dr Keri-Michèle Lodge, a Consultant Psychiatrist, told us that the same issue in learning disability services can delay diagnosis of autism in people with a learning disability.[431]

263. These barriers increase the risk of diagnostic overshadowing, where a person's needs are interpreted through a narrow or even harmful diagnostic lens.[432] Dr Charlotte Cox, Principal Clinical Psychologist, Wirral Complex Needs Service, said that autism and complex trauma can look similar, and frequently co-occur, but that most services are only equipped to recognise and help with one or the other. This can lead to failures to recognise and respond well to a person's needs.[433] The I-RAP Research Group told us that the diagnosis of complex mental health problems such as personality disorder is a "key barrier" to autism diagnosis, particularly for women and girls. Many undiagnosed autistic adults are diagnosed with borderline personality disorder, then "offered incorrect explanations for their experiences and given interventions that don't help, or even harm."[434] Conversely, Jenny Gilchrist said that children will often be referred for an autism assessment even with a significant trauma background or known alcohol use during pregnancy, but that there is no other pathway for them to be referred.[435]

264. The Royal College of Psychiatrists told us that there should be more integration between neurodevelopmental services and mainstream mental health services.[436] We return to the issue of improving mental health care for autistic people in Chapter 5.

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427 NHS England, *Report of the independent ADHD Taskforce: Part 1*, April 2025. See also NHS England, *Report of the independent ADHD Taskforce: Part 2*, November 2025.
428 Q 24 (Prof Jonathan Green)
429 See paras 328–30.
430 QQ 32 and 35 (Dr Conor Davidson)
431 Written evidence from Dr Keri-Michèle Lodge (AAC0320). See also written evidence from Royal College of Psychiatrists (AAC0298).
432 See National Institute for Health and Care Excellence (NICE), *Recommendations: Care and support of people growing older with learning disabilities*, 11 April 2018.
433 Written evidence from Dr Charlotte Cox (AAC0082). See also written evidence from Andrew Barlow (AAC0238).
434 Written evidence from I-RAP Research Group (AAC0131)
435 Written evidence from Jenny Gilchrist (AAC0014)
436 Written evidence from Royal College of Psychiatrists (AAC0298)

Post-diagnostic support in health

265. Most autistic people receive little support after assessment and almost no lifetime support. There is agreement that this needs to change.[437]

266. Part of the reason for this is that successive strategies have channelled limited funding into widening access to diagnosis. Professor Jonathan Green told us there was "a perverse situation where there are big waiting lists for diagnosis as a gateway to care, a majority of specialist personnel sucked into meeting this need, with relatively less personnel to provide the care after it."[438]

267. The NICE quality standard for autism sets out that everyone given a diagnosis should have a personalised plan developed in partnership between them, their families and carers, and the autism team. They should be offered a key worker to coordinate the care and support they need. For children and young people, the key worker could be a professional in the autism team or local community services. For adults who are not receiving specialist care, the key worker could be their GP.[439]

268. Professor Will Mandy said that post-diagnostic support is critical to realising the benefits, and mitigating any harms, of autism diagnosis.[440] Dr Sophie Doswell agreed that this "can help adults 're-author' and make sense of difficulties and help them to develop a positive self-identity and strategies for managing going forward. This should be mandatory to avoid any harm from people being given the diagnosis and then left to 'fend for themselves'."[441]

269. Access to immediate post-diagnostic support is a postcode lottery.[442] Professor Bryony Beresford, Professor of Social Policy, University of York, told us: "A lot of adults are diagnosed and that is all that happens … Evidence from our study suggests that for at least some, that can lead to a deterioration in outcomes for them, because it leaves them in a position of having to make sense of themselves and their lives to date."[443] Numerous autistic adults told us they had been offered no support at all, sometimes leaving them feeling abandoned.[444] There is academic evidence linking failures to provide post-diagnostic support to suicidality.[445]

270. In the years after diagnosis, autistic people, families and carers typically have little access to support to understand and manage their needs. Professor Bryony Beresford told us that failures to offer flexible, ongoing support can increase mental health risk, particularly during times of transition:

> "Children are diagnosed when they are five or six, and then they hit adolescence and there is work they have to do around, 'How do I feel about this?' … It can lead to a very explicit rejection of that autism identity, which perhaps previously they were quite proud of or had no

437 Written evidence from Autistica (AAC0105), Charli Clement (AAC0122) and Q 162 (Dr Ken Courtenay)
438 Q 24 (Prof Jonathan Green)
439 National Institute for Health and Care Excellence (NICE), *Autism Quality standard*, 21 January 2014
440 Q 23 (Prof Will Mandy)
441 Written evidence from Dr Sophie Doswell (AAC0114)
442 Written evidence from Rotherham Parents Forum Limited (RPFL) (AAC0113). See also written evidence from Norfolk County Council (AAC0285).
443 Q 23 (Prof Bryony Beresford)
444 See for example written evidence from Anonymous 23 (AAC0108) and Anonymous 60 (AAC0121).
445 Supplementary written evidence from Dr Rachel Moseley (AAC0074)

issue with, and that can be very distressing for them. The key thing is that typically they are not in contact with services any more."[446]

271. Steven Ingram, Founder, Neurodiversity Together, told us: "Once someone has a diagnosis, it does not mean they are able to a) know or understand how their autism presents; b) articulate what their autism means to them; and c) know or understand or articulate what adjustments they might need to help them."[447]

Post-diagnostic support beyond healthcare

272. Autistic people typically need support beyond healthcare, for example with school, work, housing or access to care. Accessing this support is often nearly impossible without a diagnosis, and still very difficult with one. The Royal College of Psychiatrists told us: "It is common for autistic people to not receive timely support on many life domains (e.g. mental health, social, employment, leisure) and then progressively deteriorate until they reach crisis point, sometimes resulting in psychiatric hospital admission."[448] We discuss access to healthcare and support in the community for autistic people in Chapter 5.

Reforming identification, assessment and support

273. There is broad consensus that the assessment system needs to change. Many witnesses agreed with the National Autistic Society that more funding is needed.[449] However, we also heard that increasing funding is unlikely to work on its own. Professor Jonathan Green said: "We need system redesign."[450] We note in this context that the interim report of the NHS England ADHD Taskforce concluded that an entirely specialist, single diagnosis model is not sustainable or evidence-informed. Instead, they said that there needs to be a holistic, joined-up, generalist approach to support.[451]

274. Adam Micklethwaite, Director, Autism Alliance UK, argued that as part of the next autism strategy: "the Government should commission a serious piece of work on assessment for the long term and treat this not as a cost but as an investment for better outcomes and more cost-effective spending." He said that a review could consider both "protecting access to clinical assessment because of the intrinsic value that it provides" and "breaking the false connection between diagnosis and services".[452]

275. Despite the challenges of limited resources, new models of identification, assessment and support are emerging across the country. Because services are locally and regionally commissioned, these initiatives are patchy. Autistica, Professor Jonathan Green and Professor Will Mandy called for a more centralised approach to testing new models for identification, assessment and support.[453]

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446 Q 28 (Prof Bryony Beresford)
447 Written evidence from Steven Ingram (AAC0353).
448 Written evidence from Royal College of Psychiatrists (AAC0298)
449 See for example written evidence from Royal College of Psychiatrists (AAC0298) and Hampshire Autism Partnership Board (AAC0352).
450 Q 25 (Prof Jonathan Green)
451 NHS England, *Report of the independent ADHD Taskforce: Part 1*, April 2025. See also NHS England, *Report of the independent ADHD Taskforce: Part 2*, November 2025 and Correspondence, *House of Commons Health and Social Care Committee to the Minister for Care*, 21 July 2025.
452 Q 200 (Adam Micklethwaite)
453 Q 29 (Prof Jonathan Green, Prof Will Mandy) and written evidence from Autistica (AAC0105)

Early identification and stepped support

276. Many of our witnesses told us about efforts to shift towards a model of earlier identification and needs-led support for autistic people. Professor Jonathan Green argued for "stepped care, not the one gateway model", enabling autistic people to access care that 'steps up' and 'steps down' throughout the lifespan as their needs evolve.[454] Tim Nicholls cautioned that such approaches should not become an excuse to restrict access to diagnosis.[455]

277. Since autism is a developmental difference, early identification can be significant.[456] Professor Jonathan Green told us that there is good evidence of efficacy for the early care model developed in Manchester and Stockport. Young children who show autistic traits are identified through routine health visitor screening. Professor Green explained that the early care model "uses video feedback with parents to help them … understand and 'read' their child's behaviour and communication most effectively." This helps parents to attune to their children, enabling the children to "become increasingly confident and communicative as they grow." Many children go on to receive an autism diagnosis; some do not. Evaluation has shown that the early care model is cost-effective by middle childhood.[457] We note that the Government is expanding Best Start Family Hubs. Each family hub will have a children and family services professional trained to support young children with additional needs. The House of Commons Education Select Committee has recommended that Best Start Family Hubs incorporate routine SEND screening and awareness as a core part of their early years services.[458]

278. For school-age children, there are emerging initiatives to use 'neuroprofiling' tools to identify strengths and needs. NHS Greater Manchester Integrated Care Board told us about efforts to develop a needs-led model for neurodevelopmental support for children and young people, including the development of support hubs in each of the 10 Greater Manchester localities; a holistic neuroprofiling tool to help identify a child's individual needs and support plan; and development of a clearer Greater Manchester-wide process for assessment, diagnosis and prescribing, aiming to focus on those with the greatest need.[459] Greater Manchester Autism Consortium told us this approach risked making diagnosis even harder, but if successful would enable access to support before a diagnosis and at the point of need.[460]

279. The Royal College of Psychiatrists told us that there is increasing interest in neuroprofiling, but warned that "the evidence base is lacking so it is currently

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454 Q 25 (Prof Jonthan Green). See Autistica, *Autistica Support Plan*: "In stepped care, autistic people would mostly manage independently or with support from family/carers. However, rather than being abandoned by public services, autistic people will have an ongoing link to a specialist service they can access support from if their needs begin to escalate, as well as constant access to a suite of supports that they and their family can use by themselves."

455 Q 200 (Tim Nicholls)

456 Q 200 (Dr James Cusack)

457 Q 25 (Prof Jonathan Green) and supplementary written evidence from Prof Jonathan Green (AAC0172)

458 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)

459 Written evidence from NHS Greater Manchester Integrated Care Board (AAC0128). See also House of Commons Health and Social Care Committee, *Inquiry into Autism and ADHD Diagnostic Pathways for Children and Young People*, 25 June 2025, Q 55 (Hayden Ginns), and Special Needs Jungle, *The neurodiversity "early help" profiling tool creating a very unhelpful barrier to diagnosis*, 15 July 2025.

460 Written evidence from Greater Manchester Autism Consortium (AAC0296)

difficult to identify opportunities and risks."[461] Dr James Cusack told us that it was "very positive" that the Department for Education is looking into the use of neuroprofiling. However, he noted that "we need to make sure that what we are doing is evidence-based."[462]

280. In adults, initiatives to identify autistic people without clinical assessment have been more limited. Professor Will Mandy told us that some eating disorder services now adapt interventions for patients who show autistic traits, even if they do not have a diagnosis.[463] Dr James Cusack supported the principle of early identification and support for adults who may be autistic. However, he cautioned that diagnosis is important to the accurate interpretation of need, especially after early childhood.[464]

281. There was some support for the principle of moving towards a more graded system for identification, assessment and support, enabling both sub-clinical and clinical needs to be identified and met. Autism Alliance UK argued that a future assessment system should "position strengths and needs, rather than diagnosis, as the basis for services, support and adaptations." They also said that the Government should commission development and testing of a strengths and needs profile that would "become the reference point for support and adaptations, rather than whether someone has a diagnosis."[465] Several witnesses called for the development and use of 'passports' to enable autistic people and those who support them to communicate their needs in different contexts.[466]

Integrating assessment and support into mainstream services

282. There are emerging efforts to integrate autism assessment and support into mainstream health and care services, enabling a wider range of professionals to carry out assessment and helping services to consider a person's needs in a more holistic way.

283. Dr Conor Davidson referred to a pilot project in Cambridge looking at whether it is feasible for autism assessments to be done in primary care or in the third sector, so that non-clinical and non-qualified clinical staff might do some of the assessment process. However, he said that such initiatives are "not particularly joined up."[467]

284. Professor Bryony Beresford said that some specialist services are moving towards a model of acting as consultants to mainstream services.[468] Professor Will Mandy suggested that training and accrediting a wider range of practitioners to assess for autism could help increase the capacity, sustainability and consistency of provision, in a similar way to the development of tiered standards for Cognitive Behavioural Therapy practitioners.[469] Dr Ken Courtenay told us about efforts to train more clinicians across different

461 Written evidence from Royal College of Psychiatrists (AAC0298)
462 Q 11 (Dr James Cusack). See also written evidence from Royal College of Psychiatrists (AAC0298)
463 Q 26 (Prof Will Mandy)
464 Q 200 (Dr James Cusack)
465 Written evidence from Autism Alliance UK (AAC0143). See also written evidence from Lee Robb (AAC0187).
466 See for example written evidence from North East and North Cumbria Integrated Care Board (AAC0355) and Steven Ingram (AAC0353).
467 Q 31 (Dr Conor Davidson)
468 Q 25 (Prof Bryony Beresford)
469 Q 29 (Prof Will Mandy)

services through the National Autism Trainer Programme.[470] In the longer term, the Royal College of Psychiatrists told us, there could be a "a 'tiered' approach to service provision … with lower-level need managed in primary care/third sector, intermediate need in mainstream mental health services, and specialist autism teams reserved for the highest level of complexity and need."[471]

285. There are also efforts to integrate autism assessment into services that undiagnosed autistic people already use. Dr Anna Crabtree and Dr Louise Rutter, on behalf of the Autism and Ageing Workstream at the British Psychological Society's Faculty of the Psychology of Older People, explained that many older people accessing mental health services were likely to be autistic but not diagnosed. They told us that they had worked with experts by experience to develop "a joint-working pathway, whereby older adult staff do the autism assessment with diagnostic scaffolding, oversight and decision-making by the adult diagnostic team."[472] Professor Mark Mon-Williams described how assessment teams had been brought into schools in Bradford, reducing barriers to diagnosis:

> "The families from very disadvantaged backgrounds did not have to catch two buses and take a day off work—which often means they do not eat that day—to get into our hospital. The multidisciplinary team could immediately draw on the insights of the teachers, the school leaders and the SENCOs [special educational needs coordinators] within those schools."[473]

286. Marilyn Jones told us about an adult assessment model developed by Shropshire Autism Hub and funded through NHSE Innovation. In this model, a third sector organisation is commissioned to provide non-clinical triage, pre-assessment and wraparound support, and input from people with lived experience. She said that this model reduces the stress and trauma of the lengthy clinical assessment pathway, while also freeing up clinicians' time and saving money.[474] Peter Hopkins cited similar services commissioned in Leeds, Sunderland, South Tyneside and Northumberland, and Cheshire and the Wirral.[475]

Conclusions and recommendations

287. **An effective autism assessment system is critical to improving lives. Diagnosis plays a vital role in enabling an autistic person and those that support them to understand and respond well to their needs. For many, diagnosis is life-changing. However, in practice the autism assessment system can also become a tool for public services to ration limited access to support, forcing some to pursue diagnosis to access even basic help.**

288. **The current autism assessment system is not fit for purpose. Access to autism assessment has widened, but the number of people coming forward for assessment has risen much more rapidly than services**

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470 Q 162 (Dr Ken Courtenay)
471 Written evidence from Royal College of Psychiatrists (AAC0298). See para 351.
472 Written evidence from Dr Anna Crabtree and Dr Louise Rutter (AAC0089)
473 Q 31 (Prof Mark Mon-Williams)
474 Written evidence from Marilyn Jones (AAC0165)
475 Written evidence from Peter Hopkins (AAC00176)

have been expanded. Thousands of people wait years for a diagnosis and are left with little to no support even when it comes.

289. **Successive Government strategies have focused on using limited capacity to increase the number of assessments carried out, at the expense of supporting autistic people before and after diagnosis. This means vital opportunities to offer timely support are routinely missed.**

290. **The Government is seeking to provide more needs-led support and reduce numbers of people seeking diagnosis. However, there is real fear among autistic people and those who support them that this could mean that the intrinsic benefits of diagnosis are lost and in practice make it even harder to access any support at all.**

291. **A new way forward is needed. To tackle unacceptable waiting times, the Government will need to continue to scale up autism assessment services. By itself, this will not be sustainable. To enable every autistic person to access the support they need in a timely way, the Government needs to build a stable, equitable model of identification, assessment and support that can be stepped up and down throughout life.**

292. ***The Government must immediately:***

- ***invest in driving down autism assessment waiting times, while also building up capacity to provide high-quality support both before and after diagnosis; and,***
- ***set up a commissioning framework to develop, test and scale up stepped, evidence-based identification, assessment and support pathways for autistic children and adults.***

293. ***In close partnership with autistic people and those who support them, the Government must establish the evidence and build a consensus on:***

- ***the reasons why people seek autism assessment;***
- ***the kinds of support that should be offered on the basis of need with and without an autism diagnosis, in healthcare and beyond;***
- ***how to shift away from a binary model of autism assessment towards a model of stepped identification of strengths and needs at clinical and sub-clinical levels;***
- ***how to ensure autism assessment services are not siloed, so that there is a 'single front door' for the assessment of autism and of associated neurodevelopmental and mental health conditions;***
- ***how to move towards a model of lifelong, stepped support for people across all services;***
- ***how to enable specialist autism assessment services to help build capability across mainstream services; and,***

- ***how to set training and quality assurance standards for autism assessment.***

294. ***The Government should use its findings as the basis of a new commissioning framework, workforce plan and funding settlement for autism assessment.***

CHAPTER 5: REDUCING HEALTH INEQUALITIES AND BUILDING SUPPORT IN THE COMMUNITY

Introduction

295. The 2021 autism strategy set a goal to reduce health inequalities for autistic people, "evidencing that we are making progress on improving autistic people's health outcomes and reducing the gap in life expectancy." Separately, the strategy committed to reduce the number of autistic people in mental health inpatient settings and to deliver "significant improvements to the provision and quality of community support, including social care, mental health and housing support."[476]

296. There are major pressures on health and social care services, leaving far too many people overall struggling to access the care they need.[477] We also received significant evidence that autistic people face further barriers to accessing NHS and social care services and to having their needs met effectively in those services.

297. Stephen Kinnock MP, Minister of State for Care, Department of Health and Social Care (DHSC), told us that key goals in the new autism strategy would be improving health outcomes for autistic people and moving autistic people from mental health inpatient settings into the community.[478]

298. In this chapter, we look at the evidence on the health inequalities that autistic people still face and what more the Government can do to ensure healthcare is accessible and meets their needs. Next, we consider how the Government could build a holistic model of integrated healthcare and community support for autistic people. Finally, we look at what the Government needs to do to stop autistic people being wrongly detained in mental health hospitals, suffering harm in relationships of care, and dying prematurely.

Health inequalities for autistic people

299. Autistic people live shorter lives. Life expectancy for people with a learning disability (including those who are also autistic) is particularly low. NHS England told us that according to GP records data for 2022 to 2023:

> "Life expectancy at birth for autistic people was 76 years, which is 5.4 years lower than the general population. For autistic people without a co-occurring learning disability, life expectancy was 1.9 years lower than for the general population …. For autistic people with a learning disability life expectancy was 10.6 years lower than the general population."[479]

300. Separate UK cohort study data has estimated that autistic people without a learning disability live six years less long than average. Given the low diagnosis rates in older adults, autistic people identified in this study are likely to have had higher support needs on average than the current diagnosed population. The same cohort study estimated that autistic women with a

476 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021

477 Department of Health and Social Care, *Independent investigation of the NHS in England*, 15 November 2024 and Adult Social Care Committee, *A "gloriously ordinary life": spotlight on adult social care* (Report, Session 2022–23, HL Paper 99)

478 Q 179 (Stephen Kinnock MP)

479 Written evidence from NHS England (AAC0360)

learning disability live more than 14 years less long, and autistic men with a learning disability seven years less long, than average.[480]

301. Health inequalities for autistic people start early and accumulate through the lifespan. Autistic children are more likely to have problems with sleep, eating and drinking.[481] About 40% of autistic people have a classifiable or diagnosable mental health problem recorded with their GP, compared to about 10% of people in the general population and a quarter of people with ADHD.[482] Autistic people are also more likely to have chronic health conditions that affect all systems of the body, including the brain, the central nervous system, the gastrointestinal system, the endocrine system, and connective tissue.[483] Professor Mark Mon-Williams, Chair in Cognitive Psychology, University of Leeds, told us about cohort study data showing that autistic people are over-represented among "the very large number of individuals within the NHS at middle age who have a really horrible combination of what we call internalising disorders—anxiety and depression plus cardiometabolic disease."[484] Older autistic people are more likely to develop heart disease, stroke, and Parkinson's disease.[485]

302. Mental and physical ill health put autistic people at higher risk of early death. Autistic people with a learning disability are at much higher risk of premature death than average, including from cardiovascular disease, respiratory infections and cancer as well as epilepsy.[486]

303. Autistic people are also at higher risk of dying by suicide and deliberate self-inflicted harm. Dr Sarah Cassidy, Associate Professor in Psychology, Nottingham University, drew our attention to systematic review evidence suggesting that about one in four autistic people attempt suicide during their lifetime.[487] Direct comparison with the general population is not possible; however, data from the Adult Psychiatric Morbidity Survey (APMS) suggests about one in 13 people in England have attempted suicide in their lifetime.[488] Importantly, the large majority of people in the general population who experience suicidality or have attempted suicide do not go on to take their own life. The overall suicide rate is about one in 10,000.[489] However, there is also evidence that autistic people are over-represented among people who die by suicide. Tom Purser, CEO, Autism Action, drew attention to data from the National Child Mortality Database indicating that suicide and deliberate self-inflicted harm represent the leading cause of death among autistic children without a learning disability.[490] Equivalent data is not available for adults, but analysis of a sample of inquest records in two regions of England showed evidence of autism or high autistic traits in 11% of people who died

480 *Ibid.*
481 Q 43 (Prof Jeremy Parr)
482 Q 36 (Prof Ailsa Russell)
483 See written evidence from Dr David Moore (AAC0227), Dr Jessica Ong, Sonia Gannon, Katherine Smith, and Louise Finer (AAC0229) and SEDSConnective (AAC0201), and Autistica, *Building happier, healthier, longer lives*, 2019.
484 Q 32 (Prof Mark Mon-Williams)
485 Autistica, *Building happier, healthier, longer lives*, 2019
486 King's College London, *LeDeR Report 2023*, 2 September 2025
487 Q 36 (Dr Sarah Cassidy)
488 NHS Digital, Adult Psychiatric Morbidity Survey, *Chapter 4: Suicidal thoughts, suicide attempts and non-suicidal self-harm*, 26 June 2025
489 Autistica, *Suicide Prevention*, March 2019, and Office for National Statistics, *Suicides in England and Wales: 2023 registrations*, 29 August 2024
490 Q 36 (Tom Purser)

by suicide. In follow-up interviews with the next of kin of a small number of the people who had died, this rose to more than 40%.[491]

304. Autistic people are disproportionately likely to suffer harm in health and care settings. There have been successive reports over many years of care failings, neglect and abuse of autistic people and people with a learning disability in health and care settings. Following a BBC investigation into abuse of autistic people and people with a learning disability at Winterbourne View in 2011, the Government committed to move all patients inappropriately placed in hospitals to community-based care.[492] This has not been achieved. In September 2025, there were 2,025 autistic people and people with a learning disability in mental health inpatient settings (including 1,100 autistic people without a learning disability, 370 autistic people with a learning disability, and 550 non-autistic people with a learning disability).[493]

Making healthcare accessible

305. Many autistic people struggle to access healthcare. Numerous autistic people and those who support them told us about problems making an appointment by phone or online; travelling to an appointment; coping with the crowded spaces, bright lights, noises and smells at the GP surgery or in hospital; communicating their needs; and being understood and believed.[494]

306. Autistic people who are also marginalised in other ways can be at particular risk of harm in healthcare settings. One NHS expert by experience told us that health and care staff had told them in the past that their sexuality and gender identity had been 'caused by their autism' and that they had 'naughty girl syndrome'.[495] Marsha Martin, Founder and CEO, Black SEN Mamas, told us: "Without access to proper care, black autistic people are left to navigate life with untreated conditions, worsening health and a poor quality of life overall. That is why we need to address the intersection of race and disability. It is not optional. It is urgent."[496]

Box 10: Testimonies from autistic people and those who support them about access to healthcare

"Just making a phone call to book an appointment is extremely stressful. The outcome of that is that I don't attend healthcare appointments, and I haven't done for many years."[497]

"I have felt the need to leave a medical waiting room, to abandon my appointment entirely, just because the sensory environment became intolerable. That was despite knowing, as a doctor, that my appointment was to arrange investigations to rule out a malignancy."[498]

491 Q 36 (Dr Sarah Cassidy) and Sarah Cassidy et al, 'Autism and autistic traits in those who died by suicide in England', *The British Journal of Psychiatry*, vol 221, pp 683–691 (2022): https://doi.org/10.1192/bjp.2022.21

492 Department of Health, *Transforming care: a national response to Winterbourne View hospital*, December 2012

493 NHS Digital, *Learning Disability Services Statistics*

494 See for example written evidence from Connor Passey (AAC0003), Jade McCullum (AAC0004), Victoria Shaw (AAC0010), Cheryl Lewis (AAC0017), Anonymous 6 (AAC0022), Kira Withers-Jones (AAC0026), Penny Jackson (AAC0045), Katie Roche (AAC0048) and Georgine Burnett (AAC0102).

495 Appendix 6 and Autism Act 2009 Committee, *Note of meeting with experts by experience*, 1 May 2025

496 Q 19 (Marsha Martin)

497 Written evidence from Jude Geddes (AAC0166)

498 Q 46 (Dr Mary Doherty)

> "If I need to call 111, I will try to use the online version, but I often need to call and then rehearse what I am going to say. When I visit appointments my pain or symptoms often aren't taken seriously as I don't display the typical expressions that they would be expecting. I am not diagnosed, so if I didn't tell the healthcare professional I had these difficulties they often assume I am just anxious."[499]
>
> "There does appear to be some unconscious bias where the health conditions of disabled people (particularly non-verbal) are not taken as seriously as those of people who can speak for themselves. For instance, frequent infections are treated with regular antibiotics rather than any attempt to find causes and reduce occurrence. Despite the NHS STOMP initiative,[500] psychotropic medications such as lorazepam are regularly used as chemical restraints to control the behaviour of autistic people rather than efforts made to understand the causes (which, in our experience, may be a physical and painful illness)."[501]

307. Barriers to accessing healthcare drive health inequalities for autistic people. Dr Mary Doherty, Founder, Autistic Doctors International, told us about her research in which 80% of autistic people reported problems accessing a GP; one in three said they had not sought help for a potentially life-threatening health problem:

> "We saw some serious medical issues, such as participants experiencing a heart attack and not being able to phone for an ambulance. Another participant found a breast lump and was unable to go to a doctor. Some people with a ruptured appendix were not presenting to an emergency department for 24 hours."[502]

Dr Adrian James, Medical Director for Mental Health and Neurodiversity, NHS England, cited evidence that only half of eligible autistic people access breast screening, compared to two-thirds of non-autistic people.[503]

The 2019 NHS Long Term Plan and the new NHS 10-Year Plan

308. The 2021 autism strategy and the 2019 NHS Long Term Plan made a set of commitments on improving access to healthcare to enable autistic people to live healthier, happier, longer lives.[504] A National Autism Team was set up in NHS England to oversee those commitments, as part of the mental health, learning disability and autism programme.[505]

309. Some warned that the Government's reforms to the NHS could put this progress at risk. Tim Nicholls, Assistant Director of Policy, Research and Strategy, National Autistic Society, noted that autism is not mentioned in the new NHS *10-Year Health Plan*, and said that there is a risk "we lose the focus on autism that has been built within NHS England over the past five to ten years, which was particularly reflected in the last NHS long-term

499 Written evidence from Jenny Gilchrist (AAC0014)
500 Stopping over medication of people with a learning disability and autistic people (STOMP) is a national NHS England work programme to stop the inappropriate prescribing of psychotropic medication. See NHS England, *Stopping over medication of people with a learning disability and autistic people (STOMP) and supporting treatment and appropriate medication in paediatrics (STAMP)*.
501 Written evidence from Anonymous 48 (AAC0281)
502 Q 43 (Dr Mary Doherty)
503 Q 166 (Dr Adrian James)
504 NHS England, *Autism*
505 NHS England, *National Autism team*

plan."[506] Professor Martin Knapp, Professor of Health and Social Care Policy, London School of Economics and Political Science, told us: "NHS England is prioritising bringing down waiting lists but, in doing that, the danger is that it then deprioritises supporting autistic people in getting their health needs identified and responded to, because the quicker wins are with the general population."[507]

310. The Government's decision to bring NHS England into DHSC means some uncertainty about the future of the National Autism Team. James Bullion, Interim Chief Inspector of Adult Social Care and Integrated Care, Care Quality Commission, told us that this is "a slight future worry on accountability".[508] Stephen Kinnock MP told us: "We are very keen to retain the expertise and experience that we have in the team and to have that continuity."[509]

311. The new Government *10-Year Health Plan* sets an ambition to deliver shifts in healthcare from sickness to prevention; hospital to community; and analogue to digital. As part of this, it sets a goal to create a neighbourhood health service to "bring care into local communities, convene professionals into patient-centred teams and end fragmentation."[510] Dr Adrian James suggested the Government has an opportunity to build more integrated, lifelong services for autistic people through this neighbourhood health model, bringing together primary care, secondary care and local authority services.[511]

Accessibility and reasonable adjustments

312. Dr Mary Doherty drew attention to the Autistic SPACE framework, a tool designed by autistic doctors on how healthcare professionals can make the adjustments autistic people need.[512] Tom Cahill, National Director, Learning Disability and Autism Programme, NHS England, told us: "If you are building something new such as an A&E, you have to think about [neurodivergent] people and what that might look like."[513] NHS England has published guidance about sensory-friendly hospital wards.[514]

313. We heard about some positive examples of healthcare providers making reasonable adjustments for autistic people, such as offering extra time for appointments, quiet rooms or home visits.[515] City & Hackney partnership, NHS North East London, told us how they co-produced an autistic-friendly checklist for primary care settings. The checklist has now been embedded in primary care contracts at the North East London Integrated Care Board level.[516] However, failures remain widespread. Dr Sarah Cassidy said that guidance on reasonable adjustments in healthcare for autistic people has been available for years, but mental health services still fail to make simple

506 Q 195 (Tim Nicholls)
507 Q 8 (Prof Martin Knapp)
508 Q 82 (James Bullion)
509 Q 188 (Stephen Kinnock MP)
510 Department of Health and Social Care, and Prime Minister's Office, *10 Year Health Plan for England: fit for the future*, 3 July 2025, CP 1350
511 Q 166 (Dr Adrian James)
512 Q 46 (Dr Mary Doherty)
513 Q 166 (Tom Cahill)
514 NHS England, *Sensory-friendly resource pack*, 12 April 2023
515 See for example written evidence from Horizon Care Supported Living (AAC0212).
516 Written evidence from City & Hackney partnership, NHS North East London (AAC0219). See also written evidence from Emma Sharp (AAC0269).

adjustments like offering ways to make an appointment without using the phone.[517]

Digital flags and hospital passports

314. The 2021 autism strategy set a commitment to develop a digital flag system for patients who need reasonable adjustments in healthcare. The digital flag has now been built into the NHS Spine records system. NHS and publicly funded social care organisations are meant to have processes in place to record and share the reasonable adjustments that patients need.[518] NHS England has also produced guidance on health and care passports for autistic people and people with a learning disability. Health and care passports contain information about a person to help staff deliver personalised care.[519]

315. Rollout of the digital flag has been patchy. Dr Jessica Ong, General Practitioner and Clinical Care Professional Lead for Autism, ADHD & SEND, South East London Integrated Care Board, et al, said that the "system is not functioning effectively at the frontline of care."[520] Dr Adrian James told us: "We do not have facts and figures around how much that has been taken up, but I think it has been really important."[521] The use of health and care passports is also inconsistent. Several autistic people and those who support them told us that health and care staff do not always read or act on them.[522]

Primary care health checks

316. The 2021 autism strategy committed to a randomised control trial of health checks for autistic adults in the North East, developed at Newcastle University and funded by Autistica and NHS England.[523] The results of the trial were published in September 2025. Professor Jeremy Parr, Professor of Paediatric Neurodisability, Newcastle University, told us that they showed the health check is feasible to deliver, acceptable to professionals and most autistic adults, and effective in identifying and meeting their health and care needs.[524] Furthermore, research has identified the most effective ways to incentivise primary healthcare providers to offer and use annual health checks with their autistic patients.[525]

317. People with a learning disability or a severe mental illness are already meant to be offered an annual health check.[526] Some autistic adults and those who support them told us those health checks helped them access the healthcare they need. However, we also heard frustration about people with a learning disability being referred for treatment following a health check and then

517 Q 37 (Dr Sarah Cassidy)
518 NHS England, *Reasonable adjustments*
519 NHS England, *Health and care passports: implementation guidance*, 18 June 2024
520 Written evidence from Dr Jessica Ong, Sonia Gannon, Katherine Smith and Louise Finer (AAC0229). See also written evidence from Martin Doddimeade (AAC0018) and Lucy Porte (AAC0162).
521 Q 166 (Dr Adrian James)
522 See for example written evidence from Susan Kirkman (AAC0180), Lisa Hesketh (AAC0008), Carol Ann Hardisty (AAC0283) and Anonymous 32 (AAC0203).
523 Newcastle University, *Health Checks for Autistic Adults*
524 Q 46, footnote 6 (Prof Jeremy Parr)
525 Dr Jade Davies, Prof Anna Remington, Dr Carole Buckley, Prof Laura Crane, Dr Katelyn Smalley, "It seems like a luxury to be able to offer that': Factors influencing the implementation of annual health checks for autistic people in England', *Autism*, vol 28(3), pp 656–73: https://doi.org/10.1177/13623613231182011
526 NHS, *Learning disabilities: Annual health checks*, and NHS, *Annual health check for people with severe mental health conditions*

unable to access that treatment because adjustments are not made.[527] About 75% of people with a learning disability are not on the register to have health checks.[528] A target to increasing uptake of learning disability health checks has been removed from NHS planning guidance.[529]

Box 11: Testimonies from autistic adults about accessing health checks

"The yearly health check ups for SMI [severe mental illness] and autism are important and it's paramount that funding continues to be provided to surgeries to carry these checks out. At my recent health check a blood test showed that I had an underactive thyroid, and this wouldn't have been found without this appointment as I wouldn't have been able to describe my symptoms to the GP or have the awareness to request a test."[530]

"I was also given an Easy Read diary plan following a learning disability check up appointment. This plan was to help me record a health plan (like changing diets and taking regular exercise) and to record my daily activities for 12 months until my next appointment."[531]

Mandatory training for health and care staff

318. Improving understanding of autism among health and care staff is critical to improving autistic people's health outcomes. Statutory guidance to the Autism Act 2009 sets out that local authorities, NHS bodies and NHS foundation trusts should ensure that all health and care staff undertake training on autism at a level commensurate to their role.[532]

319. Failures to understand autism among health and care staff have harmful and, at times, tragic consequences. Parent and advocate Dr Virginia Bovell OBE told us about the experiences of her autistic son Danny, who has a severe learning disability and suffered serious gastrointestinal problems. She told us how it had been very difficult to convince professionals that her son was hurting himself and others not because of his autism or learning disability but because he was in pain and needed major surgery.[533] Paula McGowan OBE, Founder, Oliver McGowan Mandatory Training on learning disability and autism, told us about her son Oliver, who lost his life after being admitted to hospital with seizures. When Oliver became agitated, scared and confused, staff prescribed him antipsychotic medication; had him detained under the Mental Health Act; used restraint; and failed to adjust the sensory environment or listen to the people who knew Oliver well. Oliver died in 2016 at the age of 18. An independent learning disability mortality review concluded his death was potentially avoidable.[534]

320. Following Oliver's death, Paula McGowan OBE successfully campaigned for training on learning disability and autism to be made mandatory for all staff at registered health and social care providers in the Health and Care

527 Written evidence from Anonymous 13 (AAC0055) and Susan Kirkman (AAC0180)
528 House of Commons Women and Equalities Committee, *Inequalities in healthcare and employment for people with a learning disability and autistic people* (4th Report, Session 2023–24, HC Paper 134), and HC written answer 21003, Session 2023–24
529 Mencap, *Mencap responds to NHS planning guidance*, 30 January 2025
530 Written evidence from Anonymous 13 (AAC0055)
531 Written evidence from Sarah Francis-Soutar (AAC0174)
532 Department of Health and Social Care, *Adult autism strategy: supporting its use*, 26 March 2015
533 Q 52 (Dr Virginia Bovell OBE)
534 Q 52 (Paula McGowan OBE), and Department of Health and Social Care, *The Oliver McGowan code of practice on statutory learning disability and autism training*, 18 September 2025

Act 2022.[535] Three million people have now completed the online Oliver McGowan Mandatory Training; 4,000 people have been trained to deliver the training.[536] Many witnesses told us that the Oliver McGowan Training is a vital step forward in building understanding of autism among health and care staff and paid tribute to the McGowan family for what they have done to make it a reality. We heard particular support for the role of experts by experience in co-producing and delivering the training.[537]

321. There are some limitations to the Oliver McGowan Mandatory Training. We heard that some NHS bodies are not offering the full-day Tier 2 training for frontline staff who provide care and support to autistic people or people with a learning disability, instead opting for the short online Tier 1 course.[538] The Local Government Association (LGA) told us that they support the mandatory training in social care, but "funding has only been recently agreed and is very limited."[539] Some witnesses told us that the mandatory training does not give staff the competence they need to care for and support autistic people and that it could, at worst, risk reinforcing misconceptions.[540] An independent evaluation of the training has been commissioned.[541]

322. There are also gaps in pre-service training and continuous professional development for healthcare staff who work with autistic people. GPs and dentists report low confidence in working with autistic patients.[542] Professor Ailsa Russell, Professor of Clinical Psychology, University of Bath, told us that there is nothing specific about autism in standard training for psychologists.[543] The Royal College of Nursing said that "mandatory training and core professional training often contains minimal autism-related content, and autism-related content is not specified in the NMC [Nursing and Midwifery Council] Future Nurse Standards."[544]

323. More broadly, mandatory training alone is not always enough to empower health and care staff to change established practice. Professor Ashok Roy OBE, Consultant Psychiatrist and Associate Medical Director, Coventry and Warwickshire Partnership NHS Trust, told us: "We send people on training—including Oliver McGowan training—and people come back to the same services they worked in the previous day, unable to make a change."[545]

Building capability in health services

324. Witnesses agreed that there is a need to build capability in meeting autistic people's needs across the NHS.

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535 Health and Care Act 2022, section 181
536 Q 166 (Dr Adrian James)
537 See for example Q 166 (Dr Adrian James), Q 53 (Virginia Bovell OBE), Appendix 6 and Autism Act 2009 Committee, *Note of meeting with experts by experience*, 1 May 2025, and written evidence from Laura Johnson (AAC0241) and Gabriela (Gabby) Horecka (AAC0230).
538 Appendix 4 and Autism Act 2009 Committee, *Note of meeting with the House of Commons Autistic Champions*, 24 April 2025. See also written evidence from Anonymous 25 (AAC0129).
539 Written evidence from Local Government Association (LGA) (AAC0198)
540 Written evidence from Steven Ingram (AAC0353). See also written evidence from Gabriela (Gabby) Horecka (AAC0230) and Anonymous 62 (AAC0027).
541 University of Leicester, *Leicester researchers to evaluate training for health and adult social care staff in England*, 23 January 2025
542 Written evidence from Centre for Research in Autism and Education (CRAE) (AAC0081)
543 Q 40 (Prof Ailsa Russell)
544 Written evidence from Royal College of Nursing (AAC0333)
545 Q 61 (Prof Ashok Roy OBE)

Meeting autistic people's support needs in healthcare

325. Some autistic people benefit from healthcare support with core features of autism, such as communication and sensory differences.[546] However, there are capacity shortages across speech and language therapy, occupational therapy and educational psychology. Access to such services is typically very limited for children and young people (see Chapter 6). It is even more limited for adults. Norfolk County Council told us that autistic people without a learning disability in their local area do not have access to specialist support from speech and language therapy, psychology, occupational therapy or nursing.[547] The Royal College of Speech and Language Therapists told us that the Government should fund models for autistic people to access speech and language therapy support for the longer term after diagnosis, including help to navigate healthcare, education and employment.[548]

326. More broadly, there is a need to develop and test more evidence-based, co-produced models of healthcare support for autistic people's needs. Many autistic people told us that interventions often focus too much on changing the autistic person's behaviour so they comply with neurotypical norms.[549] Long-standing controversy over the use of behaviour-based approaches persists.[550] Autistica called for the Government to fund a research initiative into effective ways of meeting autistic people's support needs.[551]

Mental health services

327. There are major pressures on NHS mental health services. Lord Darzi's independent investigation of the NHS highlighted that, as of June 2024, there were 345,000 referrals where people were waiting more than a year for first contact with mental health services. More than 100,000 of those were for children and young people under the age of 18.[552] We saw evidence to suggest that autistic people face an especially large gap between their mental health needs and access to services. Dr Sarah Cassidy drew attention to data from a study sample showing that 60% of autistic adults wanted help with their mental health, but only 20% got that help.[553] Autism Action shared data from a survey of autistic people and family members showing that nearly 90% thought NHS mental health care and suicide prevention services were bad or very bad.[554]

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546 NHS England, *A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards*, 27 November 2023

547 Written evidence from Norfolk County Council (AAC0285). See also written evidence from Officers of Hertfordshire County Council (AAC0125) and Martin Doddimeade (AAC0018).

548 Written evidence from Royal College of Speech and Language Therapists (AAC0197). See also written evidence from Greater Manchester Specialist Support Team (AAC0299), Neurodiversity in Business (AAC0370), Elizabeth Robillard (AAC0245) and Anonymous 36 (AAC0236).

549 Written evidence from Charli Clement (AAC0122)

550 See for example written evidence from Neurodiverse Connection (AAC0103), Positive Support Group Ltd (AAC0329) and Anonymous 37 (AAC0243).

551 Written evidence from Autistica (AAC0105)

552 Department of Health and Social Care, *Independent investigation of the NHS in England*, 15 November 2024

553 Q 36 (Dr Sarah Cassidy)

554 Written evidence from Autism Action (AAC0233)

Box 12: Testimonies from autistic people about accessing mental healthcare

"They told me I was too autistic for therapy. But my anxiety didn't come with a manual."[555]

"I've had multiple bad experiences with NHS 111 Option 2 [for urgent mental health support] over the past eight months. Each time I called during a mental health crisis, there was a major communication barrier. I was reaching out to stop myself from self-harming, but staff misunderstood and decided I wasn't at risk because I didn't use the exact words they expected. On one occasion, I explained that I'd already called every other number I'd been given (Samaritans, Release the Pressure, etc.), and I begged them not to refer me elsewhere, but they did anyway, escalating my distress to the point that I ended up self-harming."[556]

"The only person I wanted to talk to about my mental illnesses was the psychiatrist, not a 'care-coordinator'. I became extremely distressed and upset with this situation. I got very anxious before each time she visited. She asked too many open questions which is not helpful to autistic people. She would often ask me 'why?' … Autistic people very often do not know 'why?' about many things."[557]

"In my early 20s, with anorexia, a doctor once told me about all the NHS resources I was using up because I was failing to get better. That was very unfortunate because I was painfully aware of being a treatment failure and a burden, which is a mental state that we researchers have linked to suicide in autistic people."[558]

328. Statutory guidance to the Autism Act 2009 says that NHS bodies should ensure that autistic people have equal access to local psychological therapy services.[559] This ambition has not been achieved. Many witnesses told us about autistic people being turned away from mental health services.[560] The Royal College of Psychiatrists told us: "In some cases, legitimate referrals for mental health treatment are rejected solely because of the presence of an autism diagnosis—this constitutes potentially illegal discrimination under the Equality Act 2010."[561] One NHS professional explained that, in their experience, "some primary care services, including certain [talking therapy] services, do not accept referrals for neurodivergent individuals. As a result, these individuals are often referred to secondary care services, but many do not meet the strict referral criteria required."[562]

329. Adults are meant to be able to access NHS talking therapies for anxiety and depression through their GP or by self-referral. There is some evidence that talking therapies based on Cognitive Behavioural Therapy (CBT) can help autistic people with anxiety and depression, particularly if they are adapted

555 Written evidence from North East and North Cumbria Integrated Care Board (AAC0355)
556 Written evidence from Georgine Burnett (AAC0102)
557 Written evidence from Ivan Ambrose (AAC0068)
558 Q 52 (Dr Rachel Moseley)
559 Department of Health and Social Care, *Adult autism strategy: supporting its use*, 26 March 2015
560 See for example written evidence from Evolve Psychology Services (AAC0301), Anonymous 62 (AAC0027) and George Sutherland (AAC0225).
561 Written evidence from Royal College of Psychiatrists (AAC0298)
562 Written evidence from Anonymous 27 (AAC0149). See also written evidence from Dr Sophie Doswell (AAC0114), Jody Wheeler (AAC0248), and North East and North Cumbria Integrated Care Board (AAC0355).

to be accessible.[563] However, numerous autistic adults told us CBT had not been adapted to their needs and did not help them at all.[564] Professor Ailsa Russell said talking therapy providers have not been given the support they need to make adjustments for autistic patients.[565] Tom Cahill, National Director, Learning Disability and Autism Programme, NHS England, told us efforts are underway to change this.[566]

330. Autistic people's needs are also often unmet in community and secondary mental health services. The National Autistic Society drew attention to evidence that child and adolescent mental health services often fail to accept referrals for autistic children and young people or offer suitable interventions.[567] This also applies to autistic people without a diagnosis. Professor Ashok Roy OBE told us: "Mental health care is very hard to access once autism is suspected. It is not uncommon for people in that position to be discharged from mental health services and then be referred to a long autism waiting list, where the whole world goes into a limbo."[568]

331. Many witnesses told us professionals in mental health services need a much better understanding of autistic people's needs and how to meet them. Some progress has been made in recent years. More than 5,000 mental health professionals have now been trained to deliver autism training in their workplace through the National Autism Trainer Programme. The programme was co-designed, co-produced and co-delivered with more than 100 autistic people.[569]

332. Professor Ailsa Russell told us that routine screening tools for mental health conditions were not designed for autistic people and may fail to reflect their true needs. She said: "There have been efforts to make some specific measures for anxiety, for example, but these things are not then built in to be routinely used in the kinds of primary care mental health services where people generally get picked up."[570]

333. In places, mental health interventions adapted for autistic people have been developed and rolled out more widely. Dr Sarah Cassidy told us about the development of autism-adapted suicide safety plans developed in partnership with autistic people.[571] These have been recommended in the Government's suicide prevention strategy and are starting to be taken up by the NHS.[572] This is the exception, not the rule. We spoke to a lead expert by experience for the PEACE pathway, a clinical pathway for treating eating disorders in young people who are autistic or have high autistic traits. They told us that

563 Written evidence from Dr Alan Lovell, Kieran Becker, Dr Maxwell S Barnish, Dr Tom Arthur, Joelle Kirby, Prof Helen Dodd, Dr Vijaya Raghavan Dhandapani, G J Melendez-Torres and Dr Anna Price (AAC0357) and Q 40 (Prof Ailsa Russell)
564 See for example written evidence from Anonymous 58 (AAC0369), Anonymous 16 (AAC0060), Anonymous 22 (AAC0095), Anonymous 35 (AAC0235), Charli Clement (AAC0122) and Rebecca Roach (AAC0294).
565 Q 37 (Prof Ailsa Russell)
566 Q 166 (Tom Cahill)
567 Written evidence from National Autistic Society (NAS) (AAC0232)
568 Q 60 (Prof Ashok Roy OBE)
569 Anna Freud, *National Autism Trainer Programme*
570 Q 38 (Prof Ailsa Russell)
571 Q 40 (Dr Sarah Cassidy) and Jacqui Rodgers, et al, 'Feasibility and acceptability of autism adapted safety plans: an external pilot randomised controlled trial', 'The Lancet: *eClinicalMedicine*', vol 73 (July), Issue 102662 (2024), pp 1–9: https://doi.org/10.1016/j.eclinm.2024.102662
572 Q 40 (Dr Sarah Cassidy)

the pilot drove better and quicker identification and reduced the length of hospital stays, but had been stopped after three years.[573]

General health services

334. Autistic people also face significant barriers to having physical health needs identified and met.[574]

Box 13: Testimonies from autistic people and those who support them about accessing healthcare

"My daughter fractured her elbow and school staff did not recognise anything was wrong because she did not express pain conventionally … As a former crisis team clinical lead, I know current models rely on the person's ability to narrate distress—usually via phone. If someone says 'I don't know' or cannot articulate distress, they are often excluded from help."[575]

"A lot of my poor mental health is due to frustration about not being able to communicate clearly or be understood what my physical health issues [are]. I feel the miscommunication and lack of understanding is partly due to having autism."[576]

"Our daughter cannot tolerate some medical procedures or bloods being taken. The NHS seems to have no alternative strategy for autistic people and I am concerned that, were she to have a serious health condition such as cancer, there would be no mechanism whereby they could detect, diagnose and treat her."[577]

335. There are emerging efforts to improve outcomes for autistic people in general health services. Dr Adrian James told us about his role as the first medical director for mental health and neurodiversity at NHS England: "I … ask which individuals have the poorest outcomes, highlight who they are—autistic people are front and centre—and ask, 'What is it within your programme that is trying to meet their needs?'" He said that NHS leaders now understand and welcome this question in a way that they would not have in the past.[578]

336. There are serious gaps in specialist workforce capacity for meeting autistic people's general healthcare needs. For example, special care dentistry services are meant to be available to people who cannot access standard dentistry, including some autistic people and people with a learning disability.[579] Several family members told us it is now impossible or very difficult to access them.[580]

337. One approach is to make sure there are specialist professionals to hand when autistic people access general health services. Tom Cahill said: "We know

573 Appendix 4 and Autism Act 2009 Committee, *Note of meeting with the House of Commons Autistic Champions*, 24 April 2025. See also Martin Knapp et al, *The Economic Case for Prioritising Autism in Policy and Reform*, December 2024, and Kate Tchanturia et al, 'A novel approach for autism spectrum condition patients with eating disorders: Analysis of treatment cost-savings', *European Eating Disorders Review*, vol 29, Issue 3 (2021), https://doi.org/10.1002/erv.2760.

574 See for example written evidence from SEDSConnective (AAC0201), Joely Williams (née Colmer) (AAC0287) and Martin Corrie Quinnell (AAC0264).

575 Written evidence from Anonymous 18 (AAC0067)

576 Written evidence from Stephanie Lees (AAC0140)

577 Written evidence from Anonymous 48 (AAC0281)

578 Q 166 (Dr Adrian James)

579 See King's College Hospital NHS Foundation Trust, *Community special care dentistry*.

580 Written evidence from Joan Love (AAC0033), Rosalyn Lord (AAC0156) and Anonymous 11 (AAC0044)

that, for learning disabilities, outcomes are better where there are learning disability nurses." There is a national shortage of learning disability nurses.[581] Dr Ken Courtenay, Consultant Psychiatrist in Learning Disability, NHS England, cited the learning disability physician model used at North Middlesex University Hospital, where a senior consultant doctor specialises in providing support to professional colleagues in meeting the needs of autistic people.[582]

338. Maternity Autism Research Group (MARG) told us that the Royal Cornwall Hospital NHS Trust and East and North Hertfordshire NHS Trust have started to put in place specialist autism midwives and antenatal care pathways for autistic women.[583] Dr Char Goodwin, University of Exeter, et al, referred to an ongoing project to develop guidance for healthcare professionals treating autistic cancer patients.[584]

339. The relationships between autism, mental ill health and physical ill health are not well enough understood.[585] This can hinder effective treatment. SEDSConnective told us "autistic health is too often siloed", drawing attention to the co-occurrence of autism with joint hypermobility and centralising sensitivity syndromes.[586] Dr David Moore, Reader in Pain Psychology, Liverpool John Moores University, noted evidence that autistic people are over-represented in chronic pain services but that healthcare providers do not have any clear guidance on how to meet their needs. He suggested that better understanding of the relationship between mental ill health and experience of chronic pain could help.[587]

Conclusions and recommendations

340. **We welcome the Government's commitments to address unacceptable inequalities in health outcomes and life expectancy in the new autism strategy. NHS services are too often inaccessible for autistic people. Even when people do access NHS services, those services often lack the capability they need to offer the right support.**

341. **Important progress has been made in improving autistic people's access to healthcare in recent years, in particular through the introduction of the Oliver McGowan Mandatory Training. Building on this progress is vital.**

342. ***In the new autism strategy and statutory guidance, the Government should identify priority health outcomes for autistic people and actions to improve them. Local authorities and NHS bodies should be required to report on progress towards these outcomes.***

343. ***The Government must ensure that the requirement for all staff at registered health and care providers to undertake mandatory training on autism and learning disability is implemented in full.***

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581 Royal College of Nursing, *Learning disability nursing crisis leaving gaps in care, RCN says*, 23 December 2024
582 Q 169 (Tom Cahill, Dr Ken Courtenay)
583 Written evidence from Maternity Autism Research Group (MARG) (AAC0147)
584 Written evidence from Dr Char Goodwin, Prof Manuela Barreto, Prof Ginny Russell, Eleanor Jane Turner, Dr Mary Doherty and Dr Sebastian Shaw (AAC0307)
585 Written evidence from Autistica (AAC0105)
586 Written evidence from SEDSConnective (AAC0201)
587 Written evidence from Dr David Moore (AAC0227)

344. ***Subject to the forthcoming evaluation of the Oliver McGowan Mandatory Training, the Government must ensure that all health and care staff who may be required to provide a service to an autistic person or a person with a learning disability have completed Tier 2 of that training at a minimum.***

345. ***The Government should roll out health checks for autistic people across the NHS. The Government should immediately reinstate the target to increase uptake of health checks for people with a learning disability in NHS planning guidance. It should do the same for health checks for autistic people as they are rolled out.***

346. ***Using the priority health outcomes for autistic people as a basis, the Government must develop a plan to reduce health inequalities for autistic people. This must set out how the Government will:***

- ***build up capability to support autistic people in the health and care workforce, including enabling specialist services to advise and support mainstream services; and,***
- ***develop, test and scale up effective models for meeting the needs of autistic people across general and mental health services.***

Building the right support in the community

347. Autistic people need holistic, joined-up support to thrive, bringing together healthcare with support in the community.[588] Too many people in general struggle to access such support.[589] Autistic people can face specific barriers to accessing the right support at the right time. Jolanta Lasota, CEO, Ambitious about Autism, and Chair, Autism Alliance UK, told us: "What we see is young people's needs being shunted on to someone else. They get excluded from education, then they are on a waiting list for mental health services and then they are below a threshold for social care support. What we are seeing is cost-shunting."[590]

348. This can have devastating consequences. Professor Ashok Roy OBE told us that in mental health units:

> "What we pick up are burning wrecks. We pick up people who have broken down, who have had huge distress or who have attempted suicide. We should not be picking up people at that stage, but because of the threshold-based culture we live in, you have to be 'bad enough' to warrant a service, and that is not the way to help people who have got a developmental disorder such as autism, where early intervention makes a big, positive difference."[591]

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588 Written evidence from Kirklees Council, and Kirklees Health and Care Partnership (AAC0118), and Q 154 (Prof Asif Zia)

589 See Department of Health and Social Care, *Independent investigation of the NHS in England*, 12 September 2024, House of Commons Levelling Up, Housing and Communities Committee, *Disabled people in the housing sector* (7th Report, Session 2023–24, HC Paper 63), Department of Health and Social Care, *Independent commission into adult social care: terms of reference*, 11 July 2025, and House of Commons Education Committee, *Children's social care* (4th Report, Session 2024–25, HC Paper 430).

590 Q 197 (Jolanta Lasota)

591 Q 63 (Prof Ashok Roy OBE)

349. Crises cost money and lives. Zaynab (ZeZe) Sohawon, Young Ambassador, National Autistic Society, and Founder, Emotion Dysregulation in Autism, told us about how she spent four years in a mental health inpatient unit:

> "I racked up just over £1 million for my NHS trust to spend on me being in a mental health unit that was not actually helping me very much. When we put that into the context of lots of other young people who are autistic and have mental health needs, we are spending a lot of money but not in a very effective way."[592]

Box 14: Testimonies from autistic people and those who support them about trying to access joined-up support

"As a late-diagnosed autistic person with ADHD, trying to find support has often felt like trying to do a jigsaw puzzle with half the pieces missing—and no picture on the box. You don't know what you're looking for. You don't know what's out there. And by the time you realise you need help, you often don't have the energy left to chase it … Sometimes I've needed someone to walk me there, not just point from a distance."[593]

"Autism is not a mental illness, thus mental health services will say they cannot help because my primary diagnosis is autism. But equally, when my unsupported autism is causing mental health difficulties to present, social services are just as quick to say they cannot help."[594]

"Local authorities only intervene at the point that a major crisis has occurred. In our case, our requests for help were repeatedly ignored until the police became involved but then, suddenly, massive resources to pay for suitable accommodation far from home became available, when previously we had been refused any practical or financial help whatsoever."[595]

Specialist autism services

350. Some witnesses told us there is still a particular need to provide local services for autistic adults who are not eligible for learning disability services, social care, or mental health services. The Royal College of Psychiatrists told us:

> "There is still a cohort of autistic people who 'fall through the gap' in community support services. Typically these are young adults with learning difficulties (but not intellectual disability) and significant social interaction challenges who struggle to maintain paid work and become progressively more socially isolated and economically disadvantaged."[596]

351. Since the Autism Act was passed, some efforts have been made to develop services for autistic adults without a learning disability. Professor Bryony Beresford, Professor of Social Policy, University of York, told us: "There are localities where a specialist autism team is jointly staffed and jointly funded by local authorities and the NHS, but that is incredibly unusual."[597] Professor Ashok Roy OBE said: "I am a learning disability specialist and I can see the

592 Q 22 (Zaynab (ZeZe) Sohawon)
593 Written evidence from Anonymous 60 (AAC0121)
594 Written evidence from Bee Young (AAC0135)
595 Written evidence from Anonymous 48 (AAC0281)
596 Written evidence from Royal College of Psychiatrists (AAC0298). See also for example written evidence from Lisa Hesketh (AAC0008), Christopher Barber (AAC0304) and Nazmiye Raif (AAC0342).
597 Q 28 (Prof Bryony Beresford)

contrast between these two worlds where you have well-developed specialist teams working away, dealing with a whole range of problems, working with social care providers and partnerships, while in the autism context, that just does not exist." He called for local neurodevelopmental teams to be established more widely.[598]

352. At the same time, we also heard that creating specialised, siloed services may risk making it more difficult for autistic people to access help, particularly where they have co-occurring needs.[599] Professor Rebecca Charlton, Professor of Psychology, Goldsmiths, University of London, told us: "Autism in social care often either sits in the autism and learning disability team or in a mental health team." She drew attention to examples of people who had received an autism diagnosis and then been moved out of a mental health team, preventing them from accessing the support they previously had.[600] Dr Virginia Bovell OBE told us that eligibility criteria are useful to guide people into the right specialism, but they are not helpful when they shut people out.[601] Some witnesses made the point that autistic people who have not been diagnosed or are on a waiting list should not be excluded from support on that basis.[602]

353. Professor Asif Zia, Chief Medical Officer, Hertfordshire Partnership University NHS Foundation Trust, and Chair, Mental Health Medical Director Forum, NHS Confederation, told us that "providing kind and compassionate care, involving service users and carers in decision-making, and co-producing crisis plans" are important across all of health and care and warned against getting "tangled in some very specialist services and models that do not deliver the essential bits of care."[603] Dr Conor Davidson, clinician and Autism Champion, Royal College of Psychiatrists, said that many autistic people benefit more from flexible, responsive support than episodic, short-term care, as it provides "continuity of care and … somebody there in the background, almost, who can step back and then step up according to what is going on in the autistic person's life."[604]

Transitions to adulthood in health and care

354. The Autism Act requires that the Secretary of State issue statutory guidance about "planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults."[605]

355. We heard from many witnesses that, in practice, young autistic adults often face a 'cliff edge' in access to support.[606] This is in part a result of differences in eligibility criteria for support. Nigel Minns, Chair of Health, Care & Additional Needs Policy Committee, Association of Directors of Children's Services, and Executive Director for Children and Young People,

598 Q 65 (Prof Ashok Roy OBE)
599 See for example Q 24 (Prof Bryony Beresford) and Q 82 (Prof Sheila the Baroness Hollins).
600 Q 61 (Prof Rebecca Charlton)
601 Q 53 (Dr Virginia Bovell OBE)
602 Q 106 (Prof Amanda Kirby) and written evidence from Auticon (AAC0316)
603 Q 154 (Prof Asif Zia)
604 Q 33 (Dr Conor Davidson). See also written evidence from Bernadette Shrubshall (AAC0358).
605 Autism Act 2009
606 See for example Q 89 (Alice Willans, Anita Harrington), Q 77 (Sarah Wild), Q 99 (Prof Anna Remington), Q 116 (Dr Emma Bradley), written evidence from Aquayemi-Claude Akinsanya (AAC0046), Sharon Barrowman (AAC0181), Dr Karen Neil (AAC0244), Anonymous 4 (AAC0015) and Anonymous 45 (AAC0272).

Warwickshire County Council, told us: "There are very clear differences between the Children and Families Act and the Care Act in terms of what may or may not be valid in support terms."[607] We return to the role of education in bridging transitions to adulthood for autistic children and young people in Chapter 6.

356. Even where a young autistic person is still eligible for health or care services, there are routinely failures to plan for transition. There are also differences in approach and culture between children's and adults' services: for example, children's services tend to focus on managing risks, whereas adult services aim to promote independence.[608] Dr Emma Bradley, Consultant Paediatrician, Sirona Care & Health, and Chair of the Royal College of Paediatricians specialist advisory committee for community child health, said that more services could be commissioned for young adults, or on an all-age basis.[609]

Box 15: Testimonies from autistic people and those who support them about transitions from children's to adult services

"My son had a lot of CAMHS support from an early age, but it just literally stopped at 18. Nothing has been put in its place because he is not bad enough to need adult services."[610]

"I am going to give you the example of a family I know—that of a young man with autism plus [co-occurring conditions]. He has intellectually moderate learning difficulties, in the old language, but he got his GCSEs. He also has ADHD … His ADHD medication needs upping because he has bulked up, now that he is in young adulthood, but he is no longer eligible for CAMHS or the learning disability specialist psychiatrist, who could prescribe an increase in medication. The core psychiatric teams say that they do not deal with ADHD, and there is a waiting list of three years to access the adult ADHD service. His GP does not feel able to up the dose. The only alternative is to go private, but that might cost £4,000 for a reassessment. You could argue that, without the extra medical help, this young man, who probably needs just a small increase, is at risk of entering the criminal justice system and/or failing some exams that could make him eligible for employment in the long term."[611]

Lower-level support

357. Autistic people and their families and carers often benefit from the kinds of low-level support that are most vulnerable to funding cuts, such as peer support, social groups or befriending.[612]

358. Greater Manchester Autism Consortium told us: "No government has prioritised preventative support for autistic people who do not meet eligibility for statutory services and until this happens we do not feel that autistic people will feel any real improvements in their lives."[613] Tim Nicholls said: "Preventive support and universal support … are the things that we have lost in society. That includes the ability to go out and socialise, make friendships

607 Q 156 (Nigel Minns)
608 Written evidence from Local Government Association (LGA) (AAC0198) and Yair Domb (AAC0190)
609 Q 116 (Dr Emma Bradley)
610 Q 89 (Anita Harrington)
611 Q 53 (Dr Virginia Bovell OBE)
612 See for example written evidence from Anonymous 42 (AAC0257), Lee Sanderson (AAC0256) and Dr Paul Linehan (AAC0237).
613 Written evidence from Greater Manchester Autism Consortium (AAC0296)

and stay happy and well; all have left the system over the past few years because they were seen as a 'nice to have'."[614] Professor Ashok Roy OBE told us: "I have heard it being said, when we want to have a befriending scheme, 'I am not going to pay you to go and have friends and have a cup of tea. That is not a need or a service. That is a social thing' [not] realising that interventions like that can … make a huge difference to the lives of autistic people."[615]

Box 16: Testimonies from autistic people and those who support them about accessing lower-level support

"Attending the groups gives me a purpose and something to look forward to. I've made good friends, and it has given me more confidence. This is the first social group in my life that I feel relaxed in, I can be myself without any judgement or bullying. … The group is like gold dust. This group has saved me."[616]

"I am not aware of any community support for people who are autistic specifically late-diagnosed adults who have struggled their entire lives with feeling 'different' and out of place. The only support I have ever received is online and in women-only groups."[617]

"Autistic single mums … are often assumed to have a support network of family and friends that can step in which sadly isn't always the case. We have seen more than one woman be denied much needed surgery due to having no friends or family to care for their child."[618]

"I know one autistic young man who had been sectioned with multiple suicide attempts. He had no peer group, but he had a support worker who took him out to do fun things that built his self-worth. Then, funding for this support worker was cut, and the young autistic man was told, 'I am not paying for you to have friends.'"[619]

359. Under the Care Act 2014, local authorities have a duty to take steps to prevent or delay the development of care and support needs in adults.[620] Statutory guidance to the Autism Act says that "this could be done through providing 'lower level' local preventative support and enabling people with autism to be connected with peers and with other local community groups."[621] In practice, local authorities and NHS bodies have little incentive to do this.[622] James Bullion, Interim Chief Inspector of Adult Social Care and Integrated Care, Care Quality Commission, told us: "In our local authority work we do not see enough evidence of preventative activity in this particular area." He pointed by contrast to the Better Care Fund, where the NHS and local authorities receive mandatory integrated funding to support older people to live more independently and stay out of hospitals and care homes.[623] Similarly, Nigel

614 Q 198 (Tim Nicholls)
615 Q 64 (Prof Ashok Roy OBE)
616 Written evidence from Avenues Group (AAC0126)
617 Written evidence from Gillian Ashton (AAC0178)
618 Written evidence from Rotherham Parents Forum Limited (RPFL) (AAC0113)
619 Q 55 (Dr Rachel Moseley)
620 Care Act 2014, section 2
621 Department of Health and Social Care, *Adult autism strategy: supporting its use*, 26 March 2015
622 Q 154 (Nigel Minns). See also written evidence from Mark Evans (AAC0308).
623 Department of Health and Social Care, and Ministry of Housing, Communities and Local Government, *Better Care Fund policy framework 2025 to 2026*, 27 March 2025, and Q 81 (James Bullion)

Minns argued that there should be an equivalent to the Better Care Fund for children and young people.[624]

360. Autistic people and those who support them often face particular struggles to navigate multiple services at the same time and to have their needs understood and met.[625] Many autistic people and family members told us about feeling lost and not knowing where to turn for information and support.[626] Some witnesses said there could be better signposting for autistic adults and their families, building on the NHS Autism Central programme and the SEND local offer.[627] Autistic Nottingham noted that its previous community advocacy service demonstrated that short-term, practical support—such as assistance with benefits applications, housing issues, or arranging reasonable adjustments—can lead to long-term independence and significantly improved outcomes.[628] Autism in Mind told us about the successful use of health link workers for autistic people in Sunderland and South Tyneside, based in primary care hubs.[629] City & Hackney partnership, NHS North East London, said that autistic people locally wanted a hub "where people who are autistic or who care for autistic people can meet, socialise, learn, get peer support and build up a library of knowledge and guidance", but that they are unlikely to be able to fund a non-statutory service like this.[630]

361. We did receive some evidence about good local initiatives to commission and deliver lower-level support. Fazeela Hafejee, Representative, Association of Directors of Adult Social Services (ADASS), and Assistant Director for Adults with Disabilities, Bradford Council, told us that Bradford Council has created a social work service for people who are neurodivergent and do not have a learning disability:

> "We have been able to support 100 to 200 people, but I have provided paid support to only a handful of individuals. The reason for this is that most of the people who have come to us have not needed a massive amount of support. They have needed a short-term intervention to support them in getting to where they probably were before they got into crisis."[631]

362. Tim Nicholls told us: "At the National Autistic Society, we run social groups in Wales that are fully evaluated and have been hugely positive … It is about rolling that good stuff out and making sure that it is absolutely everywhere."[632] Jon Phillipson, CEO, North East Autism Society, told us: "Commissioners are not always aware that there are some really good services around in the community" provided by small organisations.[633] Simon Froud,

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624 Q 154 (Nigel Minns)
625 See for example written evidence from Anonymous 59 (AAC0372), Charli Clement (AAC0122), Karen Harrison (AAC0274), Sue Cook (AAC0154) and Christopher Burns (AAC0031).
626 See for example Appendices 8 and 9, Autism Act 2009 Committee, *Note of Committee visit to Phoenix School, Bow, London Borough of Tower Hamlets*, 11 June 2025 and *Note of meeting with the House of Commons Autistic Champions*, 7 July 2025.
627 Appendix 10 and Autism Act 2009 Committee, *Note of meeting with the House of Commons Autistic Champions*, 7 July 2025. See Autism Central, and Department of Health and Social Care, *SEND code of practice: 0 to 25 years*, 11 June 2014.
628 Written evidence from Autistic Nottingham (AAC0047)
629 Written evidence from Autism in Mind (AAC0271)
630 Written evidence from City & Hackney partnership, NHS North East London (AAC0219)
631 Q 154 (Fazeela Hafejee)
632 Q 198 (Tim Nicholls)
633 Q 62 (John Phillipson). See also written evidence from Autism in Mind Sunderland (AAC0176) and Autistic Spectrum Collective (AAC0016).

Representative, Association of Directors of Adult Social Services (ADASS), and Director of Adult Social Care and Statutory DASS, Telford & Wrekin Council, called for national standards around low-level and prevention services and information about how those standards can be applied across the country.[634]

Integrated mental health, social care and housing support

Box 17: Testimonies from those supporting autistic people about access to social care

"When I asked, three years running, for a [social care] assessment for my child, I was told that he needed an autism diagnosis before he could be assessed (despite other diagnosed disabilities and a clear social care need). During those three years his physical and mental health declined. His ability to engage with education was vastly reduced."[635]

"I applied for social care for my daughter. They could not decide whether to go with the learning disabilities team—she is not learning disabled—the mental health team or the physical disabilities team, so she got bounced around all three, which took several years. Eventually, they came back and said, 'Yes, you can have one, but we are going to charge you £60 a week'. This was said to a girl who lives on universal credit and PIP."[636]

"Z has a university degree and has an interest in legislation. When their physical health allows, they can read and understand complex documents and make articulate arguments about them. At the same time, they're unable to use a washing machine or work out the steps of making a simple meal. When professionals see how articulate and intelligent Z can be, they can sometimes believe that Z can't 'really' struggle in those other areas."[637]

363. Autistic people should be able to access integrated support across mental health, social care and housing. This is not currently happening. James Bullion said that there is little coordination of care around the person. He noted that the Government's independent commission into adult social care led by Baroness Casey is "already out of alignment" with the NHS 10-Year Plan.[638]

364. Overall demand for social care far exceeds capacity. Around a third of requests for social care result in no support.[639] There is a large gap between the number of autistic people who are eligible for social care and autistic people who are able to access it. Data is patchy. One modelling study has suggested there are more than 11,000 autistic adults who are eligible for adult social care and do not have any access to it, most with a moderate learning disability.[640]

634 Q 117 (Simon Froud)
635 Written evidence from Anonymous 52 (AAC0334)
636 Q 90 (Tania Tirraoro)
637 Written evidence from Dr Valeri Gladkova (AAC0226)
638 Q 80 (James Bullion)
639 King's Fund, *Social Care In A Nutshell*, 5 June 2024
640 Autism Alliance UK, *Mapping supply and demand for care services for autistic adults in England*, November 2023

365. Many autistic people with a mild or no learning disability also have care needs. Dr Rachel Moseley, Principal Academic in Psychology, University of Bournemouth, told us that in her academic research:

> "People said that there needs to be a service that helps autistic adults with everyday living—including things such as shopping, managing finances and understanding other people—because, for many of us, those are things that our parents, as our life supporters, help us with, but they will not be here for ever. As an adult in my 30s, I can say that this frightens me every day."[641]

366. There are not enough good care providers and social care staff to support autistic people. Professor Sheila the Baroness Hollins, former Chair, Oversight Panel review of Independent Care (Education) and Treatment Reviews, told us: "Social care providers can pick and choose … the straightforward easy people to support. They do not have to support people like my son."[642] Dr Virginia Bovell OBE said that better career pathways, recognition and pay are needed to support social care staff to build up the skills they need to work with autistic people. She suggested that partnerships between social care providers and training institutions could help achieve this.[643]

367. Statutory guidance to the Autism Act sets out that a local authority care needs assessment should take into account an autistic person's communication needs and that eligibility cannot be denied on grounds of intellectual ability. It says that this is "particularly important" for autistic people without a learning disability, who may still face significant challenges with daily life.[644] Yet barriers persist. We heard examples of autistic children and adults being denied access to social care.[645] City & Hackney partnership, NHS North East London, told us it is very difficult for them to source a social care provider that can support autistic adults without a learning disability.[646] We also heard that more thought needs to be given to how to meet the care needs of older autistic adults, particularly as the identified population of autistic people ages. Dr Conor Davidson said: "It seems to be particularly difficult if somebody needs a care package coming into their homes and they are autistic—you have people coming at perhaps unusual times or there are different staff members each time."[647]

368. Many witnesses told us that successive Government autism strategies have paid too little attention to ensuring autistic people can live in homes that meet their needs.[648] Autistic people are more likely not to have a safe home and to experience homelessness.[649]

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641 Q 59 (Dr Rachel Moseley). See also written evidence from George Sutherland (AAC0225), Bee Young (AAC0135), Danny Phillips (AAC0323), Antonia Borneo (AAC0305) and Anonymous 39 (AAC0251).
642 Q 80 (Prof Sheila the Baroness Hollins)
643 Q 55 (Dr Virginia Bovell OBE)
644 Department of Health and Social Care, *Adult autism strategy: supporting its use*, 26 March 2015
645 See Box 17.
646 Written evidence from City & Hackney partnership, NHS North East London (AAC0219)
647 Q 34 (Dr Conor Davidson)
648 See for example written evidence from Kent and Medway NHS and Social Care Partnership Trust (AAC0337), Cheshire West All Age Autism and Neurodivergence Partnership Board (AAC0354), Dr Gavin Hutchison (AAC0050), MAIN—taking autism personally (AAC0092) and Anonymous 15 (AAC0057).
649 See Q 60 (Prof Ashok Roy OBE) and written evidence from Dr Edith England, Dr Josie Henley and Dr Emma Sheppard (AAC0345).

Box 18: Testimonies from autistic people and those who support them about social housing and supported living

"Sensory-inclusive social housing must also be a priority. Without stable, comfortable housing, our needs are never met. Councils should include sensory needs in priority banding and act quickly to remove autistic people from unsafe or overstimulating environments, such as those with poor soundproofing or anti-social neighbours."[650]

"Housing should be its own priority area. We're struggling to find affordable accommodation suitable for our adult son. He might not need supported housing, but he needs appropriate, affordable housing that supports his needs; a familiar setting for the rest of his life."[651]

"Owing to funding constraints, fewer councils are supporting access to residential care homes as they cost more than supported living. Supported living arrangements are not the best or most appropriate solution, for many disabled people."[652]

369. Not having a safe place to live increases the risk of crisis and can make it more likely that an autistic person will end up in hospital. Paula McGowan OBE told us: "Many end up in settings that increase anxiety or reduce independence. As a result, many autistic people and those with a learning disability end up in institutions that they should never be in, often being physically and chemically restrained."[653] Professor Ashok Roy OBE said: "Homelessness can easily double or treble the length of stay in an inpatient unit."[654]

370. Part of the problem is that there are too few homes that meet autistic people's social and sensory needs. The Local Government Association (LGA) has commissioned co-produced guidance on meeting autistic people's sensory needs in housing;[655] however, building accessibility standards still focus on physical disability.[656] Autistic people who need a home and support to live in it face struggles to access both. We heard concerns about failures to enable autistic people to live in their own home with care and support; to provide suitable supported housing; and to fund good quality residential care for people who need it.[657] The LGA told us that the funding model for supported housing is not sustainable.[658]

Preventing unnecessary hospital admissions, harmful treatment, and premature deaths

371. Despite commitments by successive governments, autistic people are still disproportionately likely to be detained in mental health hospitals, to experience harm in care relationships, and to die early. Autism Action shared

650 Written evidence from Georgine Burnett (AAC0102)
651 Written evidence from Laura Quigley (AAC0265)
652 Written evidence from Joan Love (AAC0033)
653 Q 55 (Paula McGowan OBE)
654 Q 60 (Prof Ashok Roy OBE)
655 Local Government Association (LGA), *Considering and meeting the sensory needs of autistic people in housing*
656 House of Commons Levelling Up, Housing and Communities Committee, *Disabled people in the housing sector* (7th Report, Session 2023–24, HC Paper 63)
657 Written evidence from Joan Love (AAC0033), Dr Keri-Michèle Lodge (AAC0320) and Sarah Francis-Soutar (AAC0174)
658 Written evidence from Local Government Association (LGA) (AAC0198)

survey evidence showing strong support among autistic people and their families for the proposal that "the Government must … make it possible to raise concerns quickly in high-risk situations where local systems don't appear to be listening, such as autistic people being actively suicidal, being refused access to mental health support or social care, or being at risk of inappropriate inpatient detention."[659]

Reducing the use of inpatient treatment

372. NHS planning guidance for 2025/26 sets a target for the number of autistic people and people with a learning disability in mental health inpatient settings to be reduced by 10% in one year. Previous targets for a 50% reduction relative to the 2015 figure were not met.[660] Between March 2015 and July 2025, the overall number of autistic people and people with a learning disability in a mental health hospital fell by 31%. There was a reduction of 59% for people with a learning disability, but a rise of 84% for autistic people without a learning disability.[661] Part of the reason for this rise may be increasing rates of diagnosis. However, it is also the case that the overall use of detention under the Mental Health Act has increased in recent years.[662]

373. About 30% of autistic people and people with a learning disability in mental health hospitals stay longer than five years.[663] Witnesses told us about autistic people who have been in hospital for decades.[664] This happens in large part because of the disabling effect of being detained in hospital. One expert by experience told us how the environment in a mental health inpatient setting can be debilitating for an autistic person, causing constant meltdown or shutdown.[665] Dr Sarah Cassidy told us: "In response to that increased distress, there is a snowballing effect of increased restrictive practices and increased difficulty in being able to adjust or course correct to get people out of that snowballing."[666] Baroness Hollins said: "It is difficult to get better when you do not have anything to get better from; you have an environment that is wrong."[667]

659 Written evidence from Autism Action (AAC0233)
660 NHS England, *2025/26 priorities and operational planning guidance*, 30 January 2025, and Department of Health and Social Care, *Independent investigation of the NHS in England*, 12 September 2024
661 See NHS England, *Update on Learning Disability and Autism Programme*, September 2025 and NHS Digital, *Learning Disability Services Statistics*.
662 King's Fund, *Mental Health 360: acute mental health care for adults*, 21 February 2024
663 NHS Digital, *Learning Disability Services Statistics*
664 Appendix 6 and Autism Act 2009 Committee, *Note of meeting with experts by experience*, 1 May 2025
665 Appendix 6 and Autism Act 2009 Committee, *Note of meeting with experts by experience*, 1 May 2025. See also written evidence from Andew Barlow (AAC022438) and Yair Domb (AAC0190).
666 Q 39 (Dr Sarah Cassidy)
667 Q 82 (Prof Sheila the Baroness Hollins)

Box 19: Testimonies from autistic people about being in a mental health inpatient setting

"I was restrained for one and a half hours at a time when I was in a mental health unit, which is a really long time to be on the floor with lots of people on top of you. That is the reality of what autistic people are facing right now. I was only 14 at the time."[668]

"I was in crisis. Much of this time is a blur to me as I was so ill. Although my parents were able to visit me at any time, they found it extremely distressing. Not only because they felt sad and helpless, but they knew how much the environment was not good for me as an autistic patient …. There was so much sensory overload. Unfamiliar sounds from other patients, staff, alarms going off, phones ringing, doors shutting, furniture being moved about, a TV on loud. The lights were bright. Lots more people in one space than I was comfortable with. All these things are so distressing for people with autism at any time and even more so when they are in such a dark place and in desperate need of gentle, understanding and empathetic medical care."[669]

"I recall my first MHAA [Mental Health Act Assessment] where I sat hidden behind my brother in a bright and unfamiliar room, hearing the screams of other patients, with my hands covering my ears, eyes firmly closed, rocking back and forth repeating 'I want to go home'. I was not an immediate physical risk to anyone, and I was in a locked hospital so wasn't going to escape. Time should have been given to allow me to de-escalate and settle to ensure I had the ability to access my rational mind before the MHAA took place."[670]

"I have had two CTRs [Care and Treatment Reviews][671] … in the past, one in hospital, another in the community. At both reviews I felt supported and that good decisions were made which were [in] my best interests for the best care. Unfortunately, the recommendations from the CTRs were never put in place leading me to believe that the whole process is pointless and they are only recommendations so could be ignored."[672]

374. We did hear about some successful efforts to move and keep autistic people out of hospitals. John Phillipson, CEO, North East Autism Society, told us:

> "The charity that I work with supports a man who was in hospital for 43 years. He has now been living in a bungalow with his own team supporting him, and, as he described it to me, he is living his best life … It is £4,500 a week to support him in his own accommodation—versus £19,000 a week in the hospital that he was in before."[673]

375. Autism in Mind, and North East and North Cumbria Integrated Care Board, told us about the successful use of admission avoidance link workers.[674] The

668 Q 17 (Zaynab (ZeZe) Sohawon)
669 Written evidence from Ivan Ambrose (AAC0068)
670 Written evidence from Freya Box (AAC0158)
671 A Care (Education) and Treatment Review is a review into whether a patient with a learning disability or an autistic patient is safe, whether they are receiving the correct care and treatment, and whether they have any specific needs for social care, special education provision or medical treatment. The review panel makes recommendations based on these considerations. See House of Commons Library, *Mental Health Bill [HL] 2024–25*, CBP 10260, May 2025.
672 Written evidence from Stephanie Lees (AAC0140)
673 Q 61 (John Phillipson)
674 Written evidence from Autism in Mind (AAC0271) and North East and North Cumbria Integrated Care Board (AAC0355)

LGA and the NHS have agreed five key elements for discharging autistic people and people with a learning disability from hospital.[675]

376. The Mental Health Bill currently before Parliament would limit the length of time that autistic people can be detained under the Mental Health Act, if they do not have a co-occurring mental disorder that needs hospital treatment and have not committed a criminal offence. However, the Government has said this provision "will be commenced only where there are strong community services in place."[676] The Government has said it will lay before Parliament an annual written ministerial statement on the implementation of the Bill after Royal Assent until this has been done.[677]

377. Baroness Hollins warned that the Government does not have a plan to ensure those strong community services exist: "Without a costed plan—and I did try to introduce an amendment—to require sufficient community services, to be honest, the [updated Mental Health] Act will be a sham."[678] NHS Greater Manchester Integrated Care Board told us that there should be ringfenced funding to reduce the use of inpatient settings for people with a learning disability and autistic people.[679]

378. The Mental Health Bill will put the Dynamic Support Register (DSR) for autistic people and people with a learning disability at risk of admission and the Care (Education) and Treatment Review (C(E)TR) process on a statutory footing.[680] The DSR and C(E)TRs are not yet consistently used. The Calderdale Branch of the National Autistic Society told us that in their area the DSR is only used for people with a learning disability.[681] One witness told us that in West Sussex less than 30% of people flagged red on the DSR are receiving any support.[682]

379. Gaps in local and regional accountability for moving and keeping autistic people out of hospital will persist. Baroness Hollins told us that C(E)TRs are effective in increasing chances of discharge, but their recommendations are not taken seriously by commissioners and by providers.[683] Adam Micklethwaite, Director, Autism Alliance UK, told us that the DSR is a "positive process", but "unless commissioners and service leads are accountable for actually improving outcomes, both at the point of contact and in the long term, the focus will tend to be just on completing the process."[684]

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675 Written evidence from Local Government Association (LGA) (AAC0198). The five key elements are to agree that delayed discharge is a potential harm event; to use existing tools to set out agreed roles and responsibilities for all partners involved in the person's care; to show that decisions about the person have been co-produced with the person; to identify and engage with all relevant partners on restrictions about a person's care and discharge; and to ensure that care and treatment plans are based on a holistic assessment of need, to have a plan for discharge from the point of admission, to have a continued focus on the person's wellbeing, and to ensure that discharge planning properly considers any support needed through the transition from hospital to community living. See NHS England, *Five key elements for discharge: supporting people with a learning disability and autistic people to leave hospital*, January 2024.

676 Mental Health Bill

677 Stephen Kinnock MP (Q 189)

678 Q 82 (Prof Sheila the Baroness Hollins)

679 Written evidence from NHS Greater Manchester Integrated Care Board (AAC0128)

680 Dynamic support registers are registers of people with a learning disability and autistic people who are at risk of admission to a mental health hospital. See House of Commons Library, *Mental Health Bill [HL] 2024–25*, CBP 10260, May 2025.

681 Written evidence from National Autistic Society, Calderdale Branch (AAC0222)

682 Written evidence from Butterfly Hope (AAC0185)

683 Q 79 (Prof Sheila the Baroness Hollins)

684 Q 196 (Adam Micklethwaite)

380. Baroness Hollins drew attention to the findings of her 2023 report to the Government that too many autistic people in hospitals are in 'long-term segregation': in other words, solitary confinement. This has no therapeutic benefit.[685] She told us: "The problem is that as long as this pathway exists it will be used, and as long as seclusion rooms exist they will be used."[686] The Independent Care (Education) and Treatment Review (IC(E)TR) process is intended to reduce the use of long-term segregation. It is currently run by the Care Quality Commission. James Bullion told us that in 17 of the 55 IC(E)TRs the CQC has undertaken, the partnership has been able to work to reduce segregation and to start or get community support in place. Baroness Hollins told us: "Those IC(E)TRs are only funded until the end of the year and we believe that they should continue until long-term segregation becomes essentially a never event."[687]

Protecting autistic people from harm

381. Autistic people often experience harm in what should be relationships of care. Restrictive practice is making someone do something they do not want to do or stopping them from doing something they do want to do, by restricting or restraining them, or depriving them of their liberty. Health and care services must use restrictive practice only when it is lawful, for a legitimate aim, and the least restrictive way of meeting that aim.[688] Despite this, the Care Quality Commission acknowledges that health and care staff use restrictive practices on autistic people and people with a learning disability too often, including physical, chemical, and mechanical restraint; extreme restraint in the form of intubation; short-term seclusion; and long-term segregation.[689] Cases of shocking neglect and abuse persist.[690] There is also evidence that autistic children and adults are more likely to experience trauma, neglect and abuse in informal care relationships.[691] In some cases unsustainable pressures on autistic people and their carers may contribute to this risk. We heard that there is often little to no support for carers of autistic people who need help not to hurt themselves or others.[692]

382. At the same time, we heard that parents of autistic children (particularly if they are autistic themselves) can be at increased risk of unfair parental blame, safeguarding investigations, and having their children taken into care.[693] For some, fear of blame drives avoidance of services.[694] Cerebra explained that

685 Department of Health and Social Care, *Baroness Hollins' final report: My heart breaks—solitary confinement in hospital has no therapeutic benefit for people with a learning disability and autistic people*, 8 November 2023

686 Q 82 (Prof Sheila the Baroness Hollins)

687 QQ 79–80 (James Bullion, Prof Sheila the Baroness Hollins)

688 See Care Quality Commission, *Restrictive practice—a failure of person-centred care planning?*, 3 August 2023 and *Restrictive practices*, 13 March 2025.

689 Care Quality Commission, *The state of health care and adult social care in England 2023/24*, October 2024

690 See for example BBC News, *Autistic abuse case must never happen again, says No 10*, November 2024, BBC News, *'Toxic culture' of abuse at mental health hospital revealed by BBC secret filming*, September 2022 and BBC Panorama, *Undercover Hospital Abuse Scandal*, May 2019. See also written evidence from Anonymous 36 (AAC0236) and Jude Ragan CBE (AAC0184).

691 Written evidence from Dr Felicity Sedgewick (AAC0205)

692 See written evidence from Paul Whiteley (AAC0173), Danielle Moreton (AAC0090), Anonymous 48 (AAC0281) and Anonymous 44 (AAC0266).

693 Written evidence from Legal Action for Women, Disabled Mothers' Rights Campaign, and WinVisible (AAC0330), Autistic Parents UK (AAC0292) and Claire McNabb (AAC0263). See also Directors of Adult Social Services West Midlands, *Autism and parental blame project: blamed instead of helped*, November 2024.

694 Written evidence from Centre for Neurodiversity and Development, Durham University (AAC0325)

the parents of a disabled child can request a child in need assessment or a parent and carer needs assessment, but that these assessments fall under a legal safeguarding framework. They argued that, where there are no signs of neglect or abuse, a child in need assessment should be carried out under a different framework.[695] The Calderdale Branch of the National Autistic Society agreed and called for urgent implementation of the Law Commission's proposed reforms to children's social care to address this.[696] The House of Commons Education Select Committee has recommended the same.[697] Dr Virginia Bovell OBE referred to a staff training scheme in Islington pioneered by a family carer and based on videos and interviews with family carers, individuals and staff called 'Learn With Us' and 'Mind The Gap(s)' about the adversarial relationship that can develop with gatekeepers at service providers. She said that they are "really good at helping professional staff understand how they conduct themselves in very difficult interpersonal contexts."[698]

383. People who have experienced trauma often face barriers to accessing health and care services, including in feeling safe and in developing trusting relationships with health and care services and staff.[699] Dr Adrian James told us about the NHS Culture of Care programme, a programme meant to look at the culture of all mental health services and ensure they are autism-friendly, anti-racist and trauma-informed, describing this as a "game-changer".[700] There is a very long way to go. Baroness Hollins told us that the first IC(E)TRs often included nothing about an autistic person's life story:

> "In solitary confinement—somebody in long-term segregation—people's life stories were usually unknown … It is that lack of appreciation of the whole story that matters. We need to know what has happened for this person and how we can respond to them. What is called challenging behaviour is often a response to not feeling safe because so often one has been the victim."[701]

695 Written evidence from Cerebra (AAC0324). See also written evidence from Dr Fiona Gullon-Scott and Prof Luke Clements (AAC0104).
696 Written evidence from National Autistic Society, Calderdale Branch (AAC0222). See Law Commission, *Disabled Children's Social Care*.
697 House of Commons Education Committee, *Children's social care* (4th Report, Session 2024–25, HC Paper 430)
698 Q 56 (Dr Rachel Moseley)
699 See Office for Health Improvement and Disparities, *Working definition of trauma-informed practice*, 2 November 2022.
700 Q 167 (Dr Adrian James)
701 Q 81 (Prof Sheila the Baroness Hollins)

Learning from and preventing avoidable deaths

Box 20: Testimonies from family members about learning from and preventing future deaths

"[My daughter's] inquest concluded if the correct support was giving in a timely manner she would still be alive. She died because she wasn't supported by school, education or health services, however much I tried to advocate and get support for her."

"My late brother was autistic and had a learning disability, and was subject to the LeDeR process following his inquest. Although the local LeDeR panel did listen and made pertinent recommendations for learning, I was dismayed to learn that there is no mechanism for ensuring accountability for the changes local LeDeR reports and the national LeDeR reports call for. Without accountability for implementing actions for learning, nothing will change."

"My brother's death, and the deaths of all those people accounted for in all the LeDeR reports to date, must not be in vain. We can't simply keep reporting on things that have gone wrong and pockets of good practice. Real change will only come with establishing a mechanism of accountability at the ICB level for implementing LeDeR recommendations."[702]

384. The Government set up the Learning from Lives and Deaths Review (LeDeR) in 2017 to collate data on deaths among adults with a learning disability and identify changes that can be made. The 2021 autism strategy committed to include the deaths of autistic adults without a learning disability in the LeDeR.[703]

385. The LeDeR programme has serious limitations. Just 53 deaths of autistic people without a learning disability were included in the 2023 review. Publication of the report was also delayed.[704] Autism Action called for the Government to put completing the LeDeR into NHS planning guidance and to hold Integrated Care Boards (ICBs) to account if they do not improve reporting and reduce preventable deaths.[705] Stephen Kinnock MP has said: "It is crucial we improve our understanding of deaths of autistic people. We expect that with increased awareness of the ability to report these deaths, we can then take specific action to address issues raised."[706]

386. In certain investigations, a coroner must issue a prevention of future deaths report.[707] Tom Purser told us that services try to avoid prevention of future deaths reports being produced and responding to and implementing their recommendations:

> "The Chief Coroner recently wrote to a huge number that had not responded and published their names in an effort to shame them into responding; that is the step she felt she had to take. There is no proper

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702 Testimonies from Sharren Bridges and Dr Keri-Michèle Lodge in supplementary written evidence from Autism Action (AAC0381). See also written evidence from Tanya Baxby (AAC0153) and Anonymous 47 (AAC0276).

703 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021

704 King's College London, *LeDeR Report 2023*, 2 September 2025

705 Supplementary written evidence from Autism Action (AAC0381)

706 Written Statement, HCWS901, 2 September 2025

707 Courts and Tribunals Judiciary, *Reports to Prevent Future Deaths*

oversight mechanism to identify common themes from inquests and from prevention of future deaths reports."[708]

Conclusions and recommendations

387. **Too many autistic people are unable to access the support they need to live well in the community. Many still fall through gaps between mental health and social care services. Failures to provide early, timely support increase the risks of crisis.**

388. ***The Government should develop a national framework for the integration of healthcare and community support for autistic people to prevent care needs from developing and escalating, underpinned by a plan to develop capability in the health and care workforce.***

389. **We welcome the Government's commitment to make it a priority in the new autism strategy to ensure autistic people can leave and stay out of mental health inpatient settings.**

390. ***The Government must set a clear timeline and roadmap for strong community services to be put in place, so that provisions in the Mental Health Bill to prevent the unnecessary detention of autistic people and people with a learning disability can be commenced.***

391. **Autistic people are at unacceptable risk of harm in health and care settings and in informal care relationships. There is also concerning evidence to suggest that some carers of autistic people, and autistic carers, are unfairly blamed or treated with suspicion when they try to access help.**

392. ***In new statutory guidance to the Autism Act, the Government must make clear how it will ensure autistic people, their families and carers are able to raise and escalate concerns about risks of failures to keep people safe and how services will be held to account for such failures.***

393. **It is unacceptable that so many autistic people and people with a learning disability die prematurely.** ***The Government must make it mandatory for Integrated Care Boards to complete LeDeR reviews into the lives and deaths of autistic people and people with a learning disability. The Government must also set up an independent mechanism to oversee the implementation of recommendations made in LeDeR reviews.***

708 Q 41 (Tom Purser)

CHAPTER 6: ACCESS TO EDUCATION AND TRANSITIONS TO ADULTHOOD

Introduction

394. The 2021 autism strategy set a goal for "the SEND system to enable autistic children and young people to access the right support, both within and outside of education settings." The strategy also set a goal to improve transitions to adulthood for autistic children and young people.[709]

395. There is consensus that the SEND system is not financially sustainable and is failing to improve outcomes for autistic children and young people.[710] The Government has said that it will publish a white paper in the new year setting out its approach to reforming the SEND system.[711]

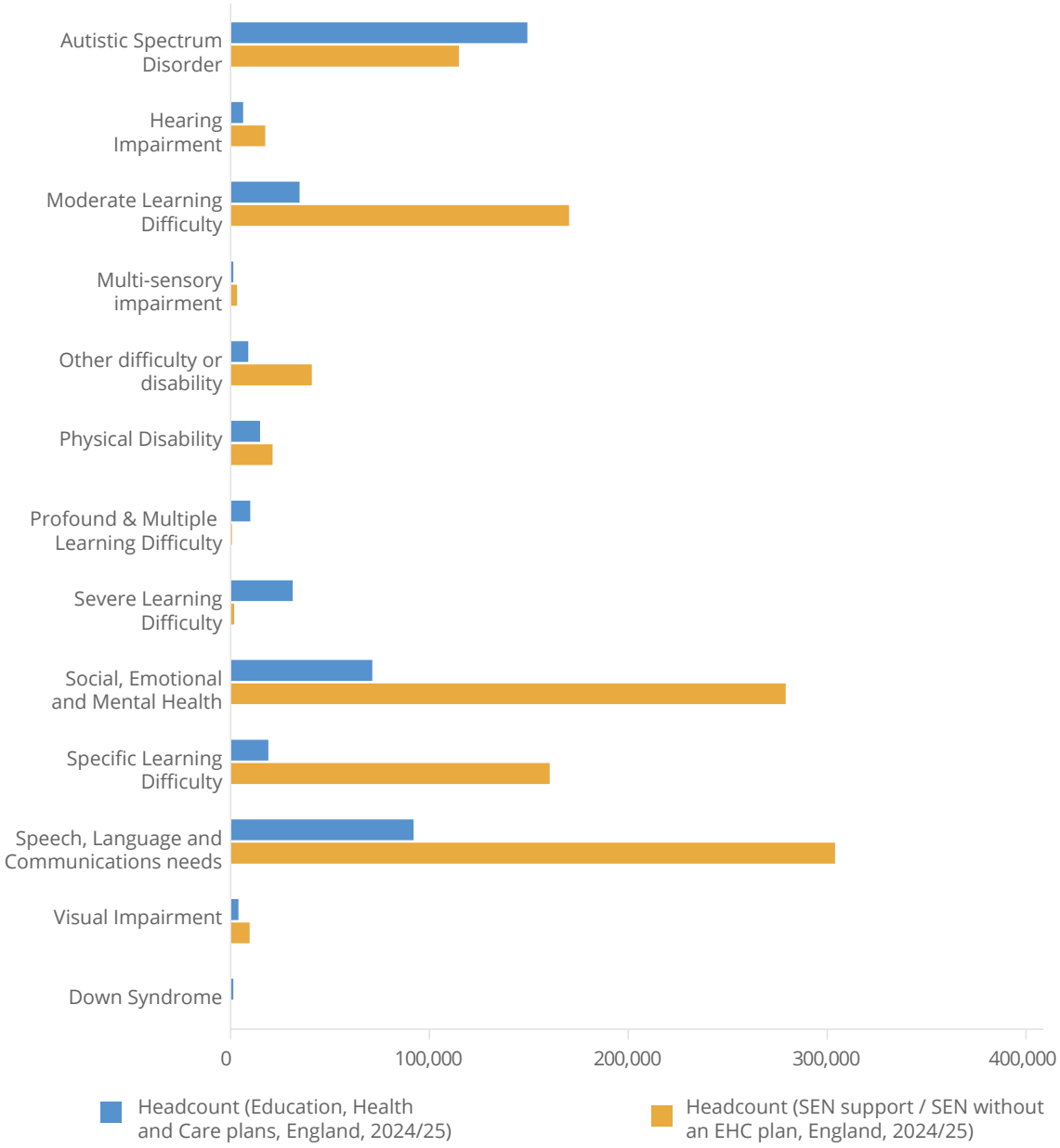
396. The question of what the Government should do to change the SEND system was beyond the remit of our inquiry. Nevertheless, we received strong evidence that autistic children and young people do not have equal access to education. In this chapter, we look at the evidence on access to education and transitions to adulthood for autistic children and young people and consider what the Government needs to do to put their needs at the heart of the education system.

Access to education

397. Most autistic children attend mainstream schools. The number of autistic children identified in schools has increased rapidly in recent years. In 2024/25, there were 149,217 pupils with an Education, Health and Care (EHC) plan whose primary need was autism, representing one third of all pupils with an EHC plan. There were a further 114,772 children receiving lower-level SEN support with a primary need of autism.[712] Overall, the number of pupils with an EHC plan has more than doubled since 2015/16. The number of pupils receiving SEN support has risen by about 20% over the same period.[713]

709 Department of Health and Social Care, and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021
710 House of Commons Public Accounts Committee, *Support for children and young people with special educational needs* (1st Report, Session 2024–25, HC Paper 353)
711 HM Treasury, *Spending Review 2025*, 11 June 2025, and Correspondence, *Secretary of State for Education to Chair of the Education Select Committee*, 22 October 2025
712 Department for Education, *Special educational needs in England*, 12 June 2025
713 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492) and Department for Education, *Special educational needs in England*, 12 June 2025

Figure 4: Number of pupils with EHC plan or SEN support by type of need



Source: Department for Education, Special educational needs in England, 12 June 2025

398. Most autistic children are not happy at school. Professor Karen Guldberg, Professor of Autism Studies, University of Birmingham, and Chair, Neurodivergence Task and Finish Group, Department for Education (DfE), told us: "In a quite recent National Autistic Society survey, only 5.7% said they felt excited about going to school or [were] enjoying it, only 8% said they get the support they need, and only 2% were confident in asking for support."[714] Autistic children are at increased risk of bullying, isolation, depression, anxiety and social isolation.[715] Surveys of parents and carers of autistic children in mainstream schools have also shown that most are not happy with their education.[716]

714 Q 67 (Prof Karen Guldberg)
715 Q 68 (Prof Karen Guldberg) and written evidence from UK Government (AAC0231)
716 Ambitious about Autism, *Written Off?*, November 2022

399. Autistic children do not have equal access to education. In 2023/24, 31% of autistic children were persistently absent, compared to 17% of children without identified SEN. In 2022/23, the permanent exclusion rate for autistic pupils was 0.15 (per 100 pupils). This compares to a rate of 0.07 for pupils with no listed SEN.[717]

400. These statistics represent the tip of an iceberg. Ambitious about Autism cited survey evidence showing that 71% of autistic pupils experience at least one form of lost learning in mainstream schools, including part-time timetables, persistent or severe absenteeism, and internal isolation.[718] Such social exclusion starts early. One parent told us how staff had told them their child could not participate in nursery tea parties because it would be too overwhelming for them.[719] There are few options for autistic children who do not thrive in mainstream schools. Specialist provision is limited, particularly for those working at or above age-related expectations. Professor Karen Guldberg told us: "many autistic children are not clearly suited to either specialist or mainstream education. They seem to fall in the gap and constantly be let down by both sides."[720]

401. Numerous parents and carers told us that schools routinely fail to meet the needs of autistic pupils, overlooking the needs of children who are seen as quiet or well-behaved and punishing children who are seen as disruptive because of distress and unmet need.[721] Schools and local authorities may issue parenting orders and fines where a child is deemed to be missing school without a good reason.[722] Marsha Martin, Founder and CEO, Black SEN Mamas, drew attention to the impact of attendance fines on autistic children and their families: "They are charging families for … protecting the mental health of their children. They do not address the root cause of why autistic children are struggling to attend in the first place."[723]

717 Written evidence from UK Government (AAC0231)
718 Written evidence from Ambitious about Autism (AAC0206) and Ambitious about Autism, *When will we learn: Lost learning report*, March 2025
719 Appendix 7 and Autism Act 2009 Committee, *Note of meeting with autistic young people and parents*, 12 May 2025
720 Q 69 (Prof Karen Guldberg). See also written evidence from Gemma Ladley (AAC0141) and Helen Gibson (AAC0312).
721 See for example Box 21, written evidence from Daniella Smith (AAC0028), Dr Jill Pluquailec (AAC0035) and Anonymous 21 (AAC0094).
722 Department for Education, *School attendance and absence*
723 Q 21 (Marsha Martin)

Box 21: Testimonies from parents and a child about access to education for autistic children and young people

"Attending a school is no longer an option for me. I know it will never be the right environment as I struggle with a huge amount of anxiety due to my autism and my past experiences in school."[724]

"In reception, [my son] entered a mainstream school due to being verbal, academically capable, and not meeting the more visible criteria often associated with complex needs. However, this placement was a nightmare. He was routinely punished for behaviours related to his autism such as verbal stimming and physical stimming (such as spinning in circles). Instead of support, these were treated as disciplinary issues."[725]

"My daughter's education was repeatedly disrupted by a lack of understanding … because of how successfully she masked, at the cost of her mental health. She experiences situational mutism (I do not like the term selective mutism as this implies the person has a choice in their response, and my daughter certainly does not have a choice when she shuts down. She physically cannot speak, eat or move). Schools use behaviour systems that punish, create trauma responses and overload."[726]

"My son spent 70 days in isolation last year at school. This is exclusion by stealth. How often is this being done to children because they are unable to follow behaviour policy?"[727]

402. Jude Ragan CBE, a former special school headteacher, raised particular concern about rules allowing excessive use of restraint in schools. She said that local authorities, academy trusts and Ofsted should be made responsible for oversight of the use of restraint and that schools should be required to log and report to parents, governors and/or trustees all incidences of restraint.[728] The Government has consulted on updates to guidance on the use of reasonable force and on mandating schools to record and report each significant incident where force is used.[729]

403. Increasing numbers of families of autistic children now pursue elective home education not because they want to but because they feel they have no other choice. A reported 153,300 children were in elective home education at any point during the 2023/24 academic year, up from an estimated 126,100 in the previous year.[730] Education Otherwise told us that the reasons that families choose home education have shifted since the pandemic: "The charity started to take increasing numbers of calls and support requests from parents whose child was displaying Emotionally Based School Avoidance (EBSA) in 2023, with almost all of those parents describing their child as having special needs, usually autism, most usually combined with anxiety." They said:

> "When we surveyed parents in early 2025, over 54% of those who had come new to home education during 2024 stated that they had done so

724 Written evidence from Riddley McDermott (AAC0155)
725 Written evidence from Melissa Shaw (AAC0107)
726 Written evidence from Anonymous 18 (AAC0067)
727 Written evidence from Samantha Bullock (AAC0261)
728 Written evidence from Jude Ragan CBE (AAC0184)
729 Department for Education, *Use of reasonable force and other restrictive interventions guidance: proposed amendments*, 4 February 2025
730 Department for Education, *Elective Home Education*, updated 9 May 2025

> as a result of school not being able to meet their child's needs. These children were almost uniquely autistic children. The parents were clear that they were not electing to home educate their child but that they felt forced to do so."[731]

404. The impact of lost learning is not felt equally. Ambitious about Autism cited survey data showing that, while white autistic children are more likely to be moved to elective home education, autistic children from an ethnic minority are more likely to be directed to off-site provision.[732] Marsha Martin told us:

> "In the absence of training and knowledge, teachers will, unfortunately, fall back on implicit biases that are shaped by the same societal stereotypes that disadvantage both autistic and black children … Those labels—"disruptive", "aggressive" and "challenging"—stick with these children; they follow black autistic children through their school years, impacting their self-esteem, opportunities and long-term life outcomes."[733]

405. Autistic children who have not been diagnosed or identified through the SEND system may face particular barriers to accessing education. Sarah Wild, Headteacher, Limpsfield Grange School, told us: "We know that a lot of the young people who fall out of school from about year 8 onwards are unidentified autistic young people. They cannot manage it. You are asking them to do something they cannot do, and then they do not get an education. That is not fair."[734]

406. Early failures to support autistic children and young people can have lifelong consequences. For many autistic people, isolation, social exclusion and mental ill health start at nursery or school and worsen over time.[735] Children with SEND who have been suspended or excluded from school may be at higher risk of involvement with the criminal justice system (see Chapter 8).[736] Failures to support autistic children also have knock-on effects on their families. Parents of autistic children told us about struggling to meet their needs without support from schools, sometimes being forced to give up their own work as a result.[737]

Making mainstream schools inclusive for autistic children and young people

407. The Government says it wants to enable more children with SEND to be educated in inclusive, mainstream schools.[738] Jolanta Lasota, CEO, Ambitious about Autism, and Chair, Autism Alliance UK, said: "The SEND reforms need to focus on autistic children. They have the highest number of EHCPs in the system, so we need to think about how the reforms will change those outcomes."[739]

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731 Written evidence from Education Otherwise (AAC0069). See also written evidence from Dr Jill Pluquailec (AAC0035).
732 Written evidence from Ambitious about Autism (AAC0206)
733 Q 17 (Marsha Martin)
734 Q 73 (Sarah Wild)
735 See for example written evidence from Anonymous 61 (AAC0282) and Anonymous 53 (AAC0336).
736 University of Exeter, *Neurodisability in children linked to increased vulnerability to 'school to prison pipeline'*, 26 June 2025
737 See for example written evidence from Lee Wardman (AAC0098), Helen Harverson (AAC0288), Isabelle Finn-Kelcey (AAC0072) and Liana Arampidou (AAC0179).
738 Written evidence from UK Government (AAC0231)
739 Q 194 (Jolanta Lasota)

408. Some witnesses suggested that making schools inclusive may reduce need for individualised support through the SEND system. Professor Sue Fletcher-Watson, Professor of Developmental Psychology, University of Edinburgh, told us: "If the default school package catered to … a more diverse range of young people … you would have fewer young people needing special modifications."[740] However, we also heard fears about moves to reduce access to specialist provision for autistic pupils. Alice Willans, who is autistic and has a learning disability and chairs the Ambitious about Autism Youth Council, told us: "Being left in mainstream might not give the best chance for children to thrive academically, socially and emotionally, and for them to have a sense of belonging."[741] Dr Nicola Crossley, Chief Executive Officer, Liberty Academy Trust, and SEND (Special Educational Needs) representative, Association of School and College Leaders, cited Department for Education data that two in three special schools are at or over capacity. She argued that the pause on the special free schools programme should be lifted.[742]

409. Dr Anne Heavey, Director of Insights, Ambition Institute, called on the Government "to interlock the curriculum and assessment review and the inspection framework review with the mission around making our system more inclusive".[743] This may not be straightforward. Dr Nicola Crossley noted: "Inclusion as a concept is hugely contested and much debated. The fact that both Ofsted and the Government are spending time and money on trying to get to an agreed definition speaks to that complexity … Trying to create a tick-box for inclusion is an unhelpful route to take."[744]

410. The House of Commons Education Select Committee recommended that the Government must publish a definition of inclusive education and rationale for this vision alongside examples of good practice across different phases of education and settings.[745]

Accountability

411. School accountability measures can discourage inclusion. Sarah Wild told us that, in the experience of headteachers in mainstream schools in Surrey, there is a "tension between the accountability measures that mainstream schools have to adhere to and the fact that they … effectively encourage schools to not be very inclusive."[746] Narrow accountability measures focusing on behaviour and attainment can encourage schools to adopt exclusionary practices, such as off-rolling and disproportionately excluding children with SEND.[747]

412. Ofsted has announced that 'inclusion' will be one of the criteria in the new inspection framework being introduced from November 2025.[748] Professor Sue Fletcher-Watson told us that there should be "an emphasis within Ofsted

740 Q 70 (Prof Sue Fletcher-Watson)
741 Q 87 (Alice Willans). See also written evidence from Lee Wardman (AAC0098).
742 Q 76 (Dr Nicola Crossley)
743 Q 74 (Dr Anne Heavey)
744 Q 74 (Dr Nicola Crossley)
745 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)
746 Q 74 (Sarah Wild)
747 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)
748 Schools Week, *'Inclusion' a key 'criterion' for new Ofsted report cards*, 3 September 2024, TES, *Ofsted set to stagger full inspection launch in November*, 15 July 2025, and Ofsted, *Improving the way Ofsted inspects education: consultation document*, updated 9 September 2025

evaluation criteria on schools meeting the needs of neurodivergent pupils and cultivating a sense of belonging in all pupils in the school. Neurodivergent young people should be key informants to inspectors when they are making those judgments."[749]

413. Academic benchmarking may also hinder inclusion. The Progress 8 accountability measure aims to track progress that pupils in a secondary school make from year 7 to year 11.[750] Dr Anne Heavey told us that Progress 8 means that "it might be more data lucrative for you as a school to put a child on to a GCSE that may not serve them."[751] Dr Nicola Crossley told us that in her special schools "we are not beholden to things like Progress 8 … I can prioritise my improvements on flexible pathways and preparation for adulthood in a way that many mainstream schools cannot offer."[752]

414. The Education Select Committee called for the Government to engage with Ofsted to ensure that the inclusion criterion within the new inspection framework is robust, measurable, and reflective of the experiences of all pupils, particularly those with SEND. The Committee also argued that the Government should introduce mandatory, comprehensive SEND training for all Ofsted inspectors.[753]

Curriculum and assessment

415. Shortly before we agreed our report, the Government set out its response to the Curriculum and Assessment Review. As part of this, it said that children with SEND are among those with "the most to gain from an ambitious, future-focused curriculum" and promised that the new curriculum "will take those children from forgotten to included, and set them up for success."[754]

416. We received strong evidence that the current curriculum and assessment system is too narrow and exam-focused and does not work well for many autistic students. In 2023/24, 50% of autistic pupils who entered GCSEs achieved a grade 4 in English and maths, compared to 65% of all pupils.[755] About one in five working-age autistic people have no qualifications.[756] Sarah Wild told us that the curriculum is "just wrong": "We have designed a curriculum offer that is basically for the top third of students in the school, and even neurotypical students who are just not that way inclined find it very heavy going."[757] This limits autistic students' options. Laura Davis, CEO, British Association for Supported Employment, told us: "Aspirations are way too low for young people within education. The focus is purely around how academically successful you are. We have to start building different mechanisms for evidencing people's competencies."[758]

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749 Q 72 (Prof Sue Fletcher-Watson)
750 Department for Education, *How to understand school performance – everything you need to know*, 19 October 2022
751 Q 74 (Dr Anne Heavey)
752 Q 74 (Dr Nicola Crossley)
753 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)
754 Department for Education, *Curriculum and Assessment Review Final Report: government response*, 5 November 2025
755 Written evidence from UK Government (AAC0231)
756 Department for Work and Pensions, *The employment of disabled people 2025*, 4 November 2025
757 Q 78 (Sarah Wild). See also written evidence from Learning in Harmony Trust (LiHT) (AAC0218).
758 Q 99 (Laura Davis)

417. We note in this context the Government's recent commitment to introduce "new, rigorous [post-16] qualifications so that all learners, including those with special educational needs and disabilities (SEND), will have access to high-quality study pathways and a clear line of sight to employment or further study."[759]

418. Professor Sue Fletcher-Watson told us: "One of the things that we fail to do with autistic people leaving school is to give them the self-advocacy skills they are going to need as adults."[760] Dr Felicity Sedgewick, Senior Lecturer in Psychology of Education, University of Bristol, drew attention to evidence that young autistic people are not typically offered relationships, sex and health education (RSE) that meets their needs. This is a particular issue because evidence suggests autistic people are at increased risk of domestic abuse, sexual assault and exploitation (see Chapter 8). She recommended that adapted, accessible RSE should be developed.[761] Statutory guidance provides that RSE must be accessible to all pupils; that it can be particularly important for students with SEND; and that there may be a need for RSE to be tailored to the needs of children with SEND.[762]

419. More broadly, the curriculum has a key role to play in fostering acceptance and understanding of autism among all pupils. Several witnesses told us effective teaching about autism and neurodiversity in schools is crucial not just to making schools more inclusive but to creating a more inclusive society.[763] Professor Sue Fletcher-Watson spoke about a newly developed programme to support mainstream primary schools to introduce pupils to neurodiversity in the classroom.[764] Catherine McKinnell MP, then Minister for School Standards, Department of Education (DfE), said that fostering understanding in children and young people is vital to "setting them up for a life of having a better understanding of difference."[765]

Workforce

420. Teachers and school staff often do not have the support they need to work effectively with autistic children and young people. In a National Autistic Society survey, nearly 90% of teachers felt confident supporting autistic pupils, but 70% of autistic pupils thought their teachers did not understand autism well enough. Only 14% of secondary school teachers had received more than a half day's training on autism.[766] We heard that there needs to be a coherent and consistent training offer to enable all school staff to develop the skills they need to support autistic pupils. Dr Anne Heavey said: "We cannot have individual teachers doing bits and bobs of training all over the

759 Department for Education, Department for Work and Pensions and Department for Science, Innovation and Technology, *Post-16 education and skills white paper*, 20 October 2025 and Department for Education, *Curriculum and Assessment Review Final Report: government response*, 5 November 2025

760 Q 71 (Prof Sue Fletcher-Watson)

761 Written evidence from Dr Felicity Sedgewick (AAC0205). See also written evidence from Dr Carly Jones MBE (AAC0246).

762 Department for Education, *Relationships Education, Relationships and Sex Education and Health Education*, 15 July 2025

763 See for example Q 69 (Prof Sue Fletcher-Watson), Q 153 (Prof Asif Zia), Q 196 (Adam Micklethwaite), written evidence from Lisa Lawton (AAC0054), Hesley Group (AAC0302), Rachel Winder (AAC0100), and Caren and Callum Gamble (AAC0267).

764 Q 108 (Prof Sue Fletcher-Watson). See University of Edinburgh, *Learning About Neurodiversity at School (LEANS): A resource pack for primary school teachers and pupils*, 20 October 2022

765 Q 184 (Catherine McKinnell MP)

766 National Autistic Society (NAS), *A Constant Fight*, 23 January 2024. See also written evidence from Rebecca Cox (AAC0159).

place. We need to think about how we rewire the school to be an inclusive culture and offer."[767] Sarah Wild drew attention to the need for better pay, training and career progression for learning support assistants and teaching assistants who work with pupils with SEND.[768]

421. The Government noted that the new Initial Teacher Training and Early Career Framework (ITTECF) includes "significantly more content related to adaptive teaching and supporting pupils with SEND."[769] School staff are not currently required to undertake Continued Professional Development (CPD) on SEND.[770]

422. The Education Select Committee recommended making CPD on SEND mandatory for school staff; strengthening initial teacher training on SEND; requiring that at least one member of the Senior Leadership Team in every school and every multi-academy trust holds SENCO qualifications; and addressing the crisis in recruiting and retaining teaching assistants and learning support assistants through a new strategy.[771]

Building support in education

423. Mainstream schools are required to offer high-quality, inclusive provision to all pupils; targeted support to pupils with SEND; and additional funded, statutory support to children with an EHC plan.[772] Failures at all of these levels are routine.

A whole-school approach

424. Including autistic children in mainstream schools starts with whole-school approaches. Professor Sue Fletcher-Watson told us we need to develop "authentically inclusive schooling … through the application of universal design principles in physical spaces and in approaches to learning and curriculum."[773] The Government has commissioned a Neurodivergence Task and Finish Group, chaired by Professor Karen Guldberg, to provide advice on how best to meet the needs of neurodivergent children and young people within mainstream education settings.[774]

425. For too many autistic children and young people, mainstream schools are inaccessible and even disabling:

- One young autistic adult told us about how they went from being academically successful to nearly being expelled when they moved to a new secondary school because of the sensory impact of the school uniform material on them. Staff did not listen when they tried to explain.[775]

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767 Q 74 (Dr Anne Heavey)
768 Q 74 (Sarah Wild)
769 Written evidence from UK Government (AAC0231)
770 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)
771 *Ibid*.
772 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)
773 Q 72 (Prof Sue Fletcher-Watson). See also written evidence from Marisa McKinlay, Dr Carol Jasper, Dr Lorna Camus and Prof Mary Stewart (AAC0217).
774 Department for Education, *Neurodivergence Task and Finish Group*
775 Appendix 10 and Autism Act 2009 Committee, *Note of meeting with the House of Commons Autistic ChampionsNote of 7 July private meeting with Autistic Champions*, 7 July 2025

- Another young autistic person told us about being taken out of class at primary school because the classroom environment was overwhelming for them, then given nothing else to do.[776]

426. Many autistic children and young people face social exclusion in mainstream schools. Alice Willans told us:

> "In mainstream schools, I felt socially isolated. I felt different to everyone else, and I was unable to learn, despite wanting to. I appeared passive, confused, disengaged and frustrated … Only then, when I went to my special school, did I learn how to make friends and experience the joy that friendship brings, and I really thrived."[777]

427. Professor Karen Guldberg told us that autistic children and young people "consistently make the point that what made the biggest difference to them in school was the relationship they had with their teacher."[778] Alice Willans said that "listening to the voices of autistic children and young people and their parents is a vital part of making the autistic learning environment inclusive."[779] Numerous witnesses told us that schools need to ensure that autistic children have a supportive peer group and staff who understand their needs, including role models who are autistic.[780] Dr Mary Doherty, Founder, Autistic Doctors International, said that "autistic kids need the chance to grow up confidently autistic, and they need to see that it is entirely possible to thrive as an autistic adult."[781] Some witnesses argued that neurodivergent staff could act as positive role models for pupils.[782] Inclusion also requires an accessible school environment. Sarah Wild said that falling school rolls may free up more space in mainstream school buildings, offering opportunities to make them more accessible to children with sensory needs.[783]

428. There are some initiatives underway to make schools more inclusive. The Government drew attention to the Partnerships for Inclusion of Neurodiversity in Schools (PINS) programme, which is backed by £22 million of investment and is being delivered in 10% of mainstream primary schools in 2024/25. The future of PINS is uncertain. Nigel Minns, Chair of Health, Care & Additional Needs Policy Committee, Association of Directors of Children's Services, and Executive Director for Children and Young People, Warwickshire County Council, told us that PINS is "really positive" but that such initiatives are usually short-term.[784] The PINS programme is being evaluated to "inform future policy development around how schools support neurodivergent children."[785]

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776 Appendix 7 and Autism Act 2009 Committee, *Note of meeting with autistic young people and parents*, 12 May 2025
777 Q 85 (Alice Willans)
778 Q 72 (Prof Karen Guldberg)
779 Q 88 (Alice Willans). See also for example written evidence from Chloe Frost (AAC0270).
780 See for example written evidence from Anonymous 3 (AAC0007), Horizon Care Supported Living (AAC0212), Dr Rebecca Wood (AAC0109), Dr Charlotte Hamilton Clark (AAC0139), and Bienias and Sadana (AAC0142).
781 Q 45 (Dr Mary Doherty)
782 See written evidence from Anonymous 3 (AAC0007) and Anonymous 7 (AAC0023).
783 Q 74 (Sarah Wild)
784 Q 150 (Nigel Minns)
785 Written evidence from UK Government (AAC0231)

Identification, support and reasonable adjustments

429. Schools should be able to identify and meet children's needs at an early stage, whether they have a diagnosis or not. This is important not only for timely support but for a truly needs-led approach. Professor Sue Fletcher-Watson said: "If [teachers and early years practitioners] can identify who is struggling to concentrate or who cannot sit still for a whole lesson, those are the kinds of immediate needs we should be catering to."[786] Dr Nicola Crossley told us: "Even in my [special] schools … where all the students share the same label as a result of a medicalised model that dictates provision and funding, the needs, the strengths and the interests of each child differ."[787]

430. Under the Equality Act 2010 and the SEND Code of Practice, mainstream schools must make reasonable adjustments and provide targeted SEN support for pupils with SEND who do not have an EHC plan.[788] Schools do not always have a good understanding of what constitutes a reasonable adjustment. Dr Anne Heavey told us: "If we can provide the guidance and exemplification for schools on implementing reasonable adjustments with confidence, that will … go a long way to building more inclusive cultures."[789]

431. Funding for SEN support is very limited and is not ringfenced, so families and schools often face incentives to push for an EHC plan to access any real support. Local authorities often challenge or delay the issue of EHC plans because of the costs they entail.[790] A diagnosis is not a precondition for an EHC plan, but in practice it is often treated as one. Outcomes First Group (OFG) told us:

> "The EHCP system … is binary, with support either hinging on having an EHCP or being largely unavailable. This has led to an unsustainable two-track system … with significant numbers of children unable to access flexible, low-level support in mainstream settings."[791]

432. Even when a child has an EHC plan, it does not always make much difference. Sarah Wild told us: "[EHC plans] are often very poorly written, the provision in them is often incredibly generic and schools do not get any money or resourcing to deliver any of the plan. In some instances, they just feel a bit meaningless and they do not add any value for the young person."[792]

433. The Education Select Committee called on the Government to publish a unified national framework for ordinarily available provision and SEN support, and to publish statutory requirements for the minimum SEN support offer. The Committee also said that the Government must not withdraw statutory entitlements for children with SEND, and must instead set out plans for reform that increase accountability across the whole of the

786 Q 70 (Prof Sue Fletcher-Watson). See also written evidence from Rebecca Cox (AAC0159).
787 Q 74 (Dr Nicola Crossley)
788 Department of Health and Social Care, *SEND code of practice: 0 to 25 years*, 11 June 2014 and House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)
789 Q 74 (Dr Anne Heavey)
790 Institute for Fiscal Studies, *England's SEND crisis: costs, challenges and the case for reform*, 12 September 2025
791 Written evidence from Outcomes First Group (OFG) (AAC0196)
792 Q 77 (Sarah Wild)

SEND system, so that children's needs will be met regardless of whether they have a diagnosis or EHC plan.[793]

Specialist provision

434. The Government is encouraging local authorities to set up SEN units and resourced provision in mainstream schools to help increase the number of children with SEND who are educated in mainstream settings.[794]

435. Dr Anna Cook, School of Psychology, University of Surrey, cited her evaluation of the National Autistic Society Cullum Centres for autistic children in mainstream schools. Compared to autistic pupils in other schools, pupils at Cullum Centre schools showed an increase in academic progress in core subjects over time; higher attendance; a lower exclusion rate; increased happiness; improved friendship satisfaction; and a stronger sense of school belonging.[795]

436. We heard about excellent examples of special schools supporting the development of SEN units and resourced provision in mainstream schools. We visited Phoenix School in the London Borough of Tower Hamlets, an outstanding special school with more than 500 autistic pupils and a waiting list of more than 200 children. Phoenix is now running a pilot of a specialist classroom model for more than 200 autistic pupils in 22 local mainstream schools. Each mainstream school runs its own specialist classroom, with intensive support from Phoenix including continuous professional development of staff and quality assurance.[796]

437. Such models could be expanded more widely. Sarah Wild told us: "Special schools are slightly excluded from the conversation … It would be great if we had a bit more voice so that we could help and be specialists and experts, which is what we are." Dr Nicola Crossley agreed.[797] Professor Karen Guldberg called for clear and enforceable national specifications for resourced provision, ensuring inclusion rather than segregation for autistic pupils.[798] We note the recommendation of the Education Select Committee that, as part of the expansion of specialist SEND, the highest-performing state specialist schools should be designated as Centres of Excellence to support the development of expertise across other schools, local authorities or multi-academy trusts.[799]

438. Tackling shortages of educational psychologists, speech and language therapists, and occupational therapists is also critical to improving access to education for autistic children and young people. One parent told us: "In

793 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)

794 Written evidence from UK Government (AAC0231). SEN units are special provisions within a mainstream school where the pupils with SEN are taught within separate classes for at least half of their time. Resourced provisions are places that are reserved at a mainstream school for pupils with a specific type of SEN, taught for at least half of their time within mainstream classes, but with a base and some specialist facilities around the school. See *Solving the SEND Crisis*.

795 Written evidence from Dr Anna Cook (AAC0063). See also written evidence from Niamh Dyer (AAC0065).

796 Appendix 9 and Autism Act 2009 Committee, *Note of Committee visit to Phoenix School, Bow, London Borough of Tower Hamlets*, 11 June 2025

797 Q 74 (Sarah Wild, Dr Nicola Crossley). See also written evidence from Witherslack Group (AAC0111).

798 Q 69 (Prof Karen Guldberg)

799 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)

my son's primary school, there was one occupational therapist who visited the school one day per week. This was for more than 100 children, each with [occupational therapy] in their EHCPs."[800] At Phoenix School, we heard that lack of speech and language therapy is the biggest barrier to educating autistic children with communication needs in mainstream schools.[801] There is widespread recognition that professionals are spending too much of their time carrying out assessments of and writing reports about children, as opposed to helping them.[802]

439. The Education Select Committee recommended that the Department for Education and Department of Health and Social Care should urgently develop a joint SEND workforce plan to address shortages and build capacity across education, health, and care services. The Committee said that this should include a shift in the deployment of educational psychologists, speech and language therapists and other allied health professionals away from undertaking assessments and writing reports and towards greater deployment in education settings. It also said the Department for Education must significantly improve cross-departmental coordination with the Department of Health and Social Care and NHS England to establish clear, consistent accountability for SEND at the Integrated Care Board (ICB) level.[803]

Supporting autistic children who are not in school

440. Several witnesses told us there is an urgent need to improve support for autistic children who are not in school or who could benefit from more flexible schooling.[804] Education Otherwise told us that autistic children experiencing emotionally based school avoidance will often need Education Other Than at School (ETAS) provision, but that this is increasingly inaccessible because of lack of funding.[805] Professor Karen Guldberg told us that children and young people can get stuck in a loop of suspensions and exclusions: "We do not have any kind of systematic response post-exclusion to starting a new school, or post-suspension to go back into the same school to reintegrate, learn from and correct the mistakes that led to the initial absence from school."[806]

Conclusions and recommendations

441. **Autistic children and young people do not have equal access to education. Most autistic children and young people attend mainstream schools; many are unhappy there. Increasing numbers of families of autistic children are turning to home education not because they want to but because school is no longer an option for them. Rates of suspension and exclusion are also too high. A new generation of young autistic people is being set up to struggle.**

800 Written evidence from Anonymous 9 (AAC0034). See also written evidence from Anonymous 17 (AAC0062).
801 Appendix 9 and Autism Act 2009 Committee, *Note of Committee visit to Phoenix School, Bow, London Borough of Tower Hamlets*, 11 June 2025
802 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)
803 *Ibid*.
804 See for example Q 69 (Prof Karen Guldberg) and written evidence from Joely Williams (née Colmer) (AAC0287).
805 Written evidence from Education Otherwise (AAC0069)
806 Q 69 (Prof Karen Guldberg)

442. **Mainstream schools need more support and stronger incentives to provide autistic children and young people with the support they need. We endorse the recommendation of the House of Commons Education Select Committee that an inclusive mainstream education system must be underpinned by principles that:**

- **"education settings and environments must be accessible, safe, and designed to meet a wide range of sensory and physical needs;**
- **"teachers and teaching assistants and other support staff should have the expertise, training, and confidence to support diverse learners, underpinned by regular access to embedded specialist professionals;**
- **"the curriculum must be flexible, relevant, and reflect the representation of young people with SEND; and the Government must ensure the curriculum itself and the assessment of it reflect and accommodate their needs;**
- **"accountability systems must examine and prioritise the progress and outcomes of all pupils, on a rounded set of indicators which include but are not limited to academic attainment, so that inclusion is embedded as an essential component of quality for all settings; and,**
- **"good inclusive practice must always ensure rigorous, systemic approaches to understanding the individual needs of every child and delivering personalised support."**[807]

443. **Improving outcomes for autistic children and young people must be a key measure of the success of any reform to the education system. *In the new autism strategy, the Government should set priority outcomes for better access to education for autistic children and young people and report regularly on progress towards those outcomes.***

444. ***To help achieve those outcomes, the Government should develop, test and scale up approaches to building capability to support autistic children and young people across all types of educational setting, including by enabling high-performing specialist schools to act as centres of excellence.***

Transitions in the education system and into adulthood

445. Under the Children and Families Act and the SEND code of practice, local authorities are under duties to prepare pupils with SEND for adulthood.[808] EHC plans are meant to be reviewed annually. From at least Year 9, the annual review must include consideration of preparation for adulthood, including employment or education, independent living and participation in society.[809]

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807 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)

808 See Department of Health and Social Care, *Adult autism strategy: supporting its use*, 26 March 2015, Children and Families Act 2014, and Department for Education, and Department of Health and Social Care, *SEND code of practice: 0 to 25 years*, 11 June 2014.

809 Department of Health and Social Care, *Adult autism strategy: supporting its use*, 26 March 2015

446. Numerous young autistic people and parents told us that they had received no support with transitions between different stages of education and into adulthood:

- One young autistic person told us how they had struggled with the transition from primary school and had been told it would not be possible for them to attend secondary school. They are now at college. So far, they have had no support with preparing to go to university.[810]

- A parent of an autistic child in key stage one told us how it terrified them to think about what their child's future will be like. A parent's natural worry is multiplied by a million for parents of neurodivergent children.[811]

447. Several witnesses suggested that there needs to be an effort to make transitions in the education system "more fluid and overlapping".[812] Tania Tirraoro, Founder and Co-Director, Special Needs Jungle Ltd, pointed to 'continuous provision' bridging nursery and reception as a good example of this, offering "a much gentler start to school than used to happen."[813] Sarah Wild suggested a bridging offer from school to college could be developed: "Could it be they stay at school for an additional year but they are sharing the provision with the new provider?"[814] Dr Jonathan Vincent, Lecturer in Higher Education, Lancaster University, told us that there is a particular need to invest in services for autistic people making the transition to adulthood: "This is a group of people who often fall between the cracks at a time that is the most important, when the risk of mental health, depression and anxiety is extremely high."[815] We note in this context the recent recommendation of the NHS England ADHD Taskforce that the Government should consider implementing, testing and evaluating integrated youth services in England.[816]

448. Schools play a critical role in preparing autistic children and young people for adulthood, including through functional skills education, careers advice and helping arrange work experience. Outcomes First Group (OFG) told us: "97% of our students who leave our [special] schools go on to meaningful destinations such as college, apprenticeships or jobs, significantly higher than the national average for students without SEND." The Group argued for "dedicated SEND support focused on employability, including accessible careers advice, structured exposure to different pathways, and opportunities to build workplace skills in a supported way."[817]

449. Many schools, particularly in the mainstream sector, do not provide this level of support to young people with SEND. Laura Davis told us: "There is a community of specialist providers and community partners who could come and work within schools to help them deliver this … alongside building really robust careers planning for young people."[818] Professor Anna Remington, Director, Centre for Research in Autism and Education (CRAE), University

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810 Appendix 7 and Autism Act 2009 Committee, *Note of meeting with autistic young people and parents*, 12 May 2025
811 *Ibid*.
812 Q 76 (Dr Anne Heavey). See also written evidence from Caren and Callum Gamble (AAC0267).
813 Q 88 (Tania Tirraoro)
814 Q 75 (Sarah Wild)
815 Q 72 (Dr Jonathan Vincent)
816 NHS England, *Report of the independent ADHD Taskforce: Part 2*, updated 6 November 2025
817 Written evidence from Outcomes First Group (OFG) (AAC0196)
818 Q 99 (Laura Davis)

College London, said that there should be "a new autism-specific programme of careers guidance for mainstream and special schools."[819] Dr Anne Heavey suggested that it could be a priority "to help schools build capacity, bring in experts, work closer with employers and add time to dig into these issues."[820]

Further education

450. Further education providers receive no extra money for young people receiving SEN support who do not have an EHC plan.[821] More than a quarter of people with an EHC plan are between the ages of 16 and 25, but less than 10% of the high-needs budget is spent on them.[822] Sarah Wild drew attention to failures to support autistic students in post-16 provision: "What often happens is that school is okay. They get through it … Then they go to college and they do not really have great support. The college is too big and too overwhelming and … they drop out. That happens a lot. Then, at 18, they do not have any high-level qualifications."[823] The Education Select Committee has recommended that the Government should introduce a dedicated and ring-fenced funding stream for SEN support beyond the age of 16.[824]

Box 22: Testimonies from young autistic people and those who support them about transitions to further and higher education

"I could have had access to high-need specialist provision at the expense of continuing to make progress academically, but I chose to go to a mainstream college with a small foundation learning department. Even going there, I felt a bit like a round peg in a square hole. I felt anxious, different and lonely. I felt I had lost all the independence I had at school—I was unable to access the learning that year, I missed my school terribly and it felt like a bereavement."[825]

"The school sixth form did a lot of meetings and workshops for both my son and for parents on what happens next and the options available. There was no mention at all of disability or DSA [Disabled Students' Allowance], let alone autism."[826]

"A lot of people who seem to get missed at school gain diagnoses (for example through educational psychologists) at university. The student support plans are quite general and not always tailored to the needs of each student. Alternatively, some students will only disclose in private to select, 'safe' members of staff. In both cases, I have seen students flourish at the opportunity to work even slightly differently; small changes by a few members of staff can make a big difference."[827]

819 Q 99 (Prof Anna Remington)
820 Q 75 (Dr Anne Heavey)
821 Q 89 (Tania Tirraoro); see House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492.
822 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)
823 Q 75 (Sarah Wild)
824 House of Commons Education Committee, *Solving the SEND Crisis* (5th Report, Session 2024–26, HC Paper 492)
825 Q 89 (Alice Willans)
826 Q 89 (Anita Harrington)
827 Written evidence from Anonymous 53 (AAC0336)

> "At school and college, no one explained what would happen next or helped me prepare for further education, employment, or adult services. I went to university under pressure, without adequate support, and dropped out within a year due to burnout and mental health issues. I then entered adult life already in crisis—with growing PTSD symptoms, emotional dysregulation, housing instability, and no working understanding of my disabilities."[828]

Higher education

451. The number of students who disclose that they are autistic in higher education has roughly tripled over the past decade, from less than 7,000 in 2014 to more than 22,000 in 2024.[829] Once an autistic student enters higher education, they stop receiving any support through the SEND system. Liberty Academy Trust told us: "An EHCP ceases to be maintained once a student goes to university. At perhaps one of the most important transitional periods of life, the support your family has fought for, and you have relied on, is taken away."[830] Students who previously received support through the SEND system have higher drop-out rates and lower progression rates.[831]

452. We did hear about some positive efforts to improve support for autistic and neurodivergent students in higher education. About half of identified autistic students access specialist mentoring.[832] Some witnesses told us about good experiences with the Disabled Students Allowance,[833] though delays in access to autism assessment can prevent this.[834] We also heard about universities that have developed approaches to supporting students who are autistic and neurodivergent, including Kingston University, Birmingham Newman University, the University of East London and the University of Warwick.[835]

453. However, many witnesses told us about struggles for autistic students with living independently, studying, making friends, and managing their mental health.[836] The Association of Graduate Careers Advisory Services (AGCAS) Disability Task Group said that many autistic people find the transition to higher education demands significant time and energy, making the idea of finding work experience overwhelming. The Group argued that universities need to offer autistic students proactive rather than reactive careers support.[837] Disabled Students UK (DSUK) noted that most universities do provide student mental health services, but that many autistic students are told their mental health needs are 'too complex' for them. They told us that the Government should include improving support for autistic students in higher education in the next autism strategy.[838]

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828 Written evidence from Anonymous 58 (AAC0369)
829 Written evidence from Disabled Students UK (DSUK) (AAC0220)
830 Written evidence from Liberty Academy Trust (AAC0208). See also written evidence from Joanne Cammish (AAC0171) and Anonymous 35 (AAC0235).
831 Q 73 (Dr Nicola Crossley)
832 Written evidence from Centre for Research in Autism and Education (CRAE) (AAC0081)
833 Disabled Students Allowances provides support to cover the study-related costs that a student has because of a mental health problem, long-term illness or any other disability. See UK Government, *Help if you're a student with a learning difficulty, health problem or disability: Disabled Students' Allowance*.
834 Q 89 (Anita Harrington) and written evidence from Disabled Students UK (DSUK) (AAC0220)
835 Q 75 (Sarah Wild) and written evidence from Dr Elisa Back (AAC0204)
836 Written evidence from Disabled Students UK (DSUK) (AAC0220) and Louise Mills (AAC0110)
837 Written evidence from Association of Graduate Careers Advisory Services (AGCAS) Disability Task Group (AAC0136). See also written evidence from Karen Coney (AAC0157) and Nazmiye Raif (AAC0342).
838 Written evidence from Disabled Students UK (DSUK) (AAC0220)

Conclusions and recommendations

454. **Young autistic people very often face a cliff edge in access to support in the transition to adulthood, just when they need that support most.** ***In the new autism strategy, the Government must set priority outcomes for better transitions to adulthood for young people and benchmarks by which progress will be measured. The Government must set clear lines of responsibility and ministerial accountability for progress.***

455. ***The Government must produce a commissioning framework for local authorities and NHS bodies to provide integrated, evidence-based services for young autistic people during the transition to adulthood, including support with education, mental health, housing and employment.***

CHAPTER 7: EMPLOYMENT

Introduction

456. Only about 3 in 10 autistic people are in work, compared to 5 in 10 disabled people and 8 in 10 people who are not disabled. Supporting more autistic people to find and stay in work would yield benefits both for autistic people and for society and the economy. Most autistic people who are not in work would like to be.[839] Those employers that support autistic people to thrive benefit significantly from their strengths.[840] Economic analysis suggests that doubling the employment rate for autistic people could generate economic benefits of up to around £1.5 billion per year.[841]

457. The 2021 autism strategy set out ambitions to make progress on closing the employment gap for autistic people and to improve support for autistic people to find and stay in work.[842] Statutory guidance to the Autism Act sets duties on local authorities and NHS bodies in relation to employment support for autistic adults. It is "good practice" for local authorities to "include the employment support needs of the local population of adults with autism, including those who are not eligible for care and support, in local autism plans as part of supporting their health and wellbeing, and commission relevant services."[843]

458. There have been successive reviews in recent years into how to enable autistic, neurodivergent and disabled people to find and stay in work.

- In 2023, the then Government commissioned Rt Hon Sir Robert Buckland KC to carry out a review into autism employment, "identifying the barriers to autistic people securing sustained and fulfilling employment and exploring how we can overcome those barriers." The report of the Buckland Review of Autism Employment was published in February 2024.[844]

- In January 2025, the Government announced the *Keep Britain Working* review, chaired by Sir Charlie Mayfield. The review examined the roles of UK employers and government in "tackling health related inactivity and creating and maintaining healthy and inclusive workplaces", including increasing recruitment, retention and return to work for disabled people and people with long-term health conditions.[845] Sir Charlie published an interim discovery report in March and a final report in November 2025.[846]

- The Government has also commissioned Professor Amanda Kirby to lead an expert panel on neurodiversity and employment. This is

839 National Autistic Society (NAS), *The Autism Employment Gap*, 27 October 2016
840 See Box 23.
841 Autistica and Pro Bono Economics, *Opening opportunities: Improving employment prospects for autistic people*, 13 December 2023
842 Department of Health and Social Care and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021
843 Department of Health and Social Care, *Adult autism strategy: supporting its use*, 26 March 2015
844 Department for Work and Pensions, *The Buckland Review of Autism Employment: report and recommendations*, 28 February 2024
845 Department for Work and Pensions and Department for Business and Trade, *Keep Britain Working: Terms of Reference*, 8 May 2025
846 Department for Work and Pensions and Department for Business and Trade, *Keep Britain Working Review: Discovery*, 20 March 2025 and *Keep Britain Working Review: Final report*, 5 November 2025

focusing on "what actions employers can take to foster a more inclusive workplace but also what actions the Government can introduce to break down barriers to opportunity for people with a [neurodivergent] condition".[847]

- On 10 November 2025, the Government announced that former Health Secretary Rt Hon Alan Milburn would lead an investigation "to tackle the persistently high numbers of young people out of work, education and training … with a particular focus on the impact of mental health conditions and disability."[848] We urge the investigation to take into account our findings on autistic people and employment.

459. Alison McGovern MP, then Minister for Employment, Department for Work and Pensions (DWP), told us that the Government's ambition is to reach an employment rate of 80% in the general population: "We do not want just to get the people who are closest to the labour market further towards it—we really want to focus on the people who and places that are furthest away from the labour market."[849]

460. The Government published the *Pathways to Work* welfare reform proposals during our inquiry.[850] Reform to the benefits system was beyond the remit of our inquiry. However, we did hear frustration at "the lack of distinction between autistic people who are able to work but are being shut out by discrimination; those who are temporarily unable to work and would benefit from tailored support; and those who are unlikely to ever be able to work."[851] Numerous autistic people shared their fears with us about income from benefits being taken away.[852]

461. In this chapter, we look first at the evidence on the employment of autistic people. We then look at the Government's plans to enable more disabled people to move into work and consider how the advantages of these changes can be realised for autistic people. Finally, we look at what employers are doing to help autistic people find and stay in work and how the Government could support and incentivise them to do more.

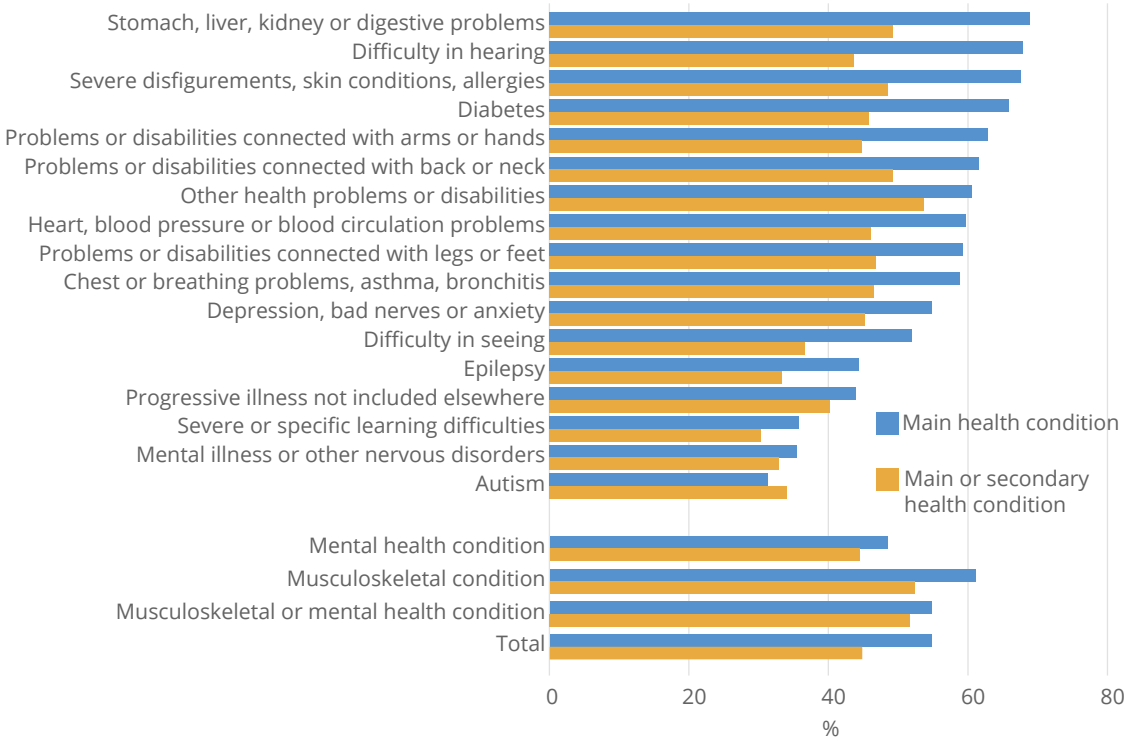
The employment of autistic people

462. According to official statistics, 31% of people whose main health condition is listed as autism were in employment in 2024/25. This compares to 53% of all disabled people and 83% of non-disabled people. This makes autistic people the group of people least likely to be in work by their disability or health condition. Part of the reason for this is that proportionally more autistic people are disabled and limited a lot by their disability than the average for

847 Department for Work and Pensions, *Employment prospects for neurodiverse people set to be boosted with launch of new expert panel*, 30 January 2025. See also HC Deb, 27 October 2025, col 19.
848 Department for Work and Pensions, *Independent investigation to be launched to tackle rising youth inactivity*, 10 November 2025
849 Q 170 (Alison McGovern MP)
850 Department for Work and Pensions, *Pathways to Work: Reforming Benefits and Support to Get Britain Working Green Paper*, updated 30 October 2025
851 Written evidence from Autistica (AAC0105)
852 See for example written evidence from Anonymous 12 (AAC0051), Sarah Leigh (AAC0085), Benjamin Scott (AAC0148), Jude Geddes (AAC0166), Fiona Hipkin (AAC0167), City & Hackney partnership, NHS North East London (AAC0219) and National Autistic Society, Calderdale Branch (AAC0222).

people with a health condition or disability. About half of autistic people report that they are disabled and limited a lot.[853]

Figure 5: Proportion of people in employment by main or secondary health condition, people aged 16 to 64 years, UK, 2024/25

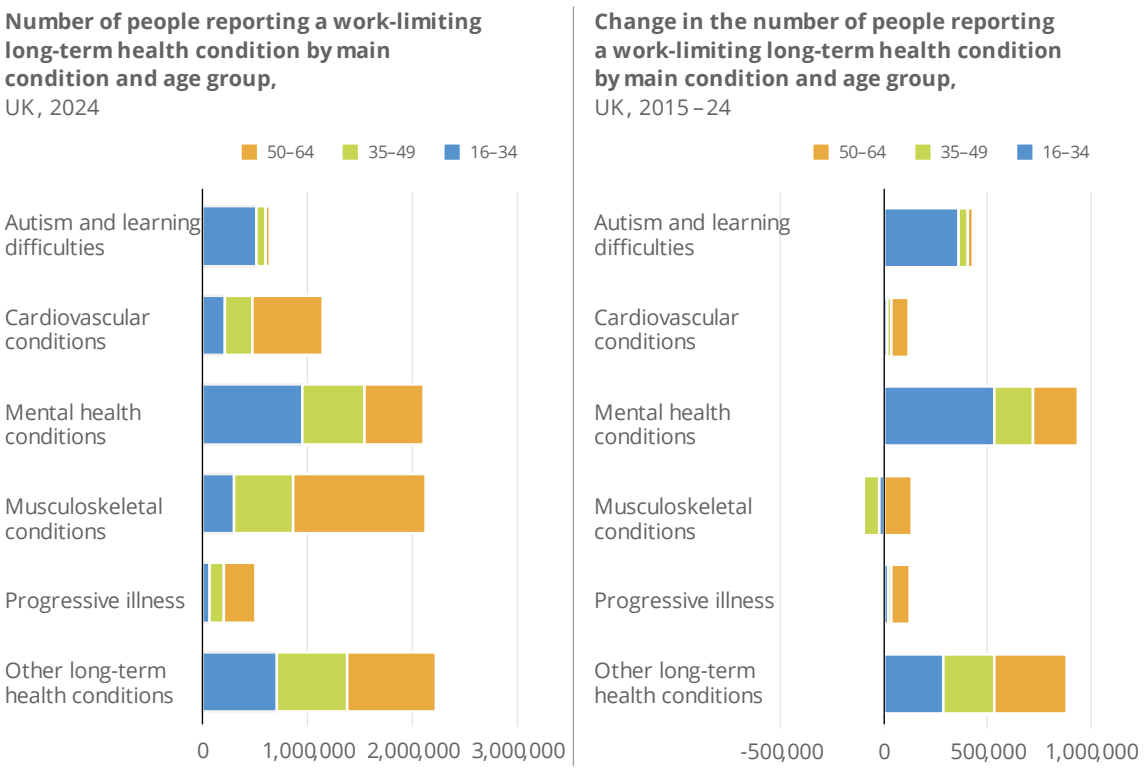


Source: Department for Work and Pensions, The employment of disabled people 2025, 4 November 2025

463. In 2024/25, nearly half of disabled people reporting autism as their main or secondary health condition were aged between 16 and 24. The overall share of young people aged between 16 and 24 who are not in education, employment or training (NEET) has increased in recent years to an estimated 13%. Just under half of young people who are NEET are classed as disabled. Among young disabled people who are NEET, 22% report that their main condition is autism.[854]

853 Department for Work and Pensions, *The employment of disabled people 2025*, 4 November 2025
854 *Ibid.*

Figure 6: People reporting a work-limiting long-term health condition between 2015 and 2024



Source: Department for Work and Pensions, Keep Britain Working Review: Discovery, 20 March 2025

464. Autistic graduates are also less likely to be in work than their peers. Data from the Graduate Outcomes Survey shows that 43% of autistic graduates who left higher education in 2021/22 were in full-time employment 15 months after leaving their course, compared to 60% of graduates with no known disability. Around 12% of autistic graduates were unemployed, compared to 5% with no known disability.[855]

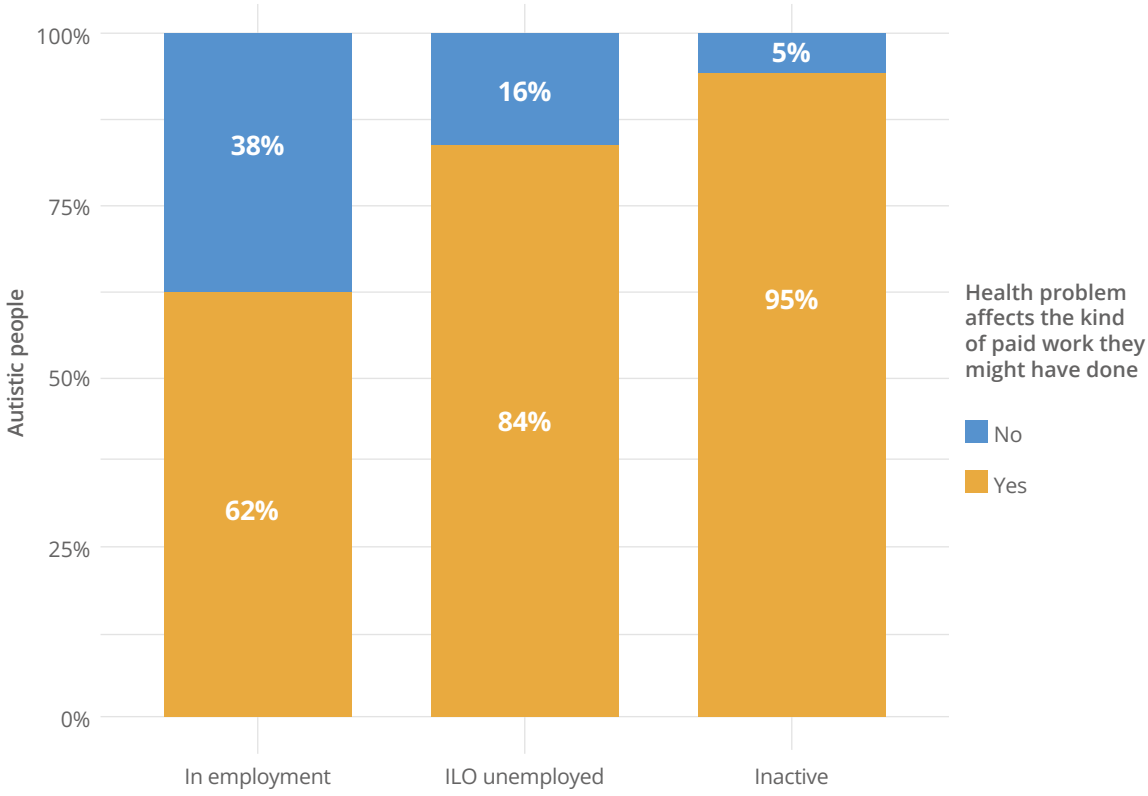
465. Autistic people who receive adult social care are much less likely to be in work. Laura Davis, CEO, British Association for Supported Employment, told us: "For people who are autistic and known to adult social care, that rate drops even lower to around 4.8% of people accessing paid employment, yet a piece of research by Mencap demonstrated that over 86% of people want to work." Data on the employment of adults who receive adult social care is not collected any more, so it is impossible to tell with any certainty if this is changing.[856]

466. Autistic people are also less likely to be in jobs that match their level of skills and experience. Professor Amanda Kirby drew attention to evidence that autistic people are significantly more likely to be in precarious or temporary employment.[857] Only 63% of autistic graduates were in highly skilled employment, compared to 79% of graduates with no known disability.[858]

855 Written evidence from Association of Graduate Careers Advisory Services (AGCAS) (AAC0099)
856 Q 92 (Laura Davis). See NHS Digital, *Measures from the Adult Social Care Outcomes Framework, England, 2022–23*, 7 December 2023.
857 Q 105 (Prof Amanda Kirby)
858 Written evidence from Association of Graduate Careers Advisory Services (AGCAS) (AAC0099)

Autistic people who are in work are much more likely than average to want to work more hours and to be looking for a different or additional paid job. Most autistic people report that their health affects the kind of work that they can do.[859] When autistic people are in work, they often face barriers to progression.[860]

Figure 7: Paid work and health



Source: Written evidence from Chartered Institute of Personnel and Development (CIPD) (AAC0200), based on analysis of the Labour Force Survey for October to December 2024.

467. Low employment rates drive worse outcomes for autistic people. Professor Anna Remington, Director, Centre for Research in Autism and Education (CRAE), University College London, told us that autistic people are twice as likely not to have the income to meet their basic needs. She said: "Employment is often a gateway to independence and to social and community participation. Research has shown that, for autistic people, employment significantly impacts on mental health and well-being."[861] Low employment for autistic people is also bad for our economy and society. Professor Kim Hoque, Professor of Human Resource Management, King's College London, told us: "There are over 800,000 vacancies in the economy … It stops firms being able to grow if they cannot get the staff that they need."[862] More broadly, witnesses told us that enabling autistic people to find, stay and thrive in jobs is critical to building public understanding of autism and creating an inclusive society, particularly through 'anchor organisations' like the NHS.[863]

859 Written evidence from Chartered Institute of Personnel and Development (CIPD) (AAC0200)
860 Q 98 (Prof Anna Remington)
861 Q 92 (Prof Anna Remington)
862 Q 92 (Prof Kim Hoque)
863 See Autism Act 2009 Committee, *Note of meeting with NHS and local authority professionals*, 1 May 2025, and *Note of Committee visit to St Thomas' Hospital, London Borough of Lambeth*, 19 May 2025.

Barriers to the employment of autistic people

468. Some employers do a good job of enabling autistic people to find, stay and thrive in work, with the support of initiatives including Autistica's Neurodiversity Employers Index accreditation scheme and guidance from professional bodies such as the Chartered Institute of Personnel and Development (CIPD).[864]

Box 23: Employer perspectives on employing autistic people

"It is something really important to me and I would love to see things being a lot easier for my children than they were for me getting to this point. Secondly, to me, it is just good business. As a business, we all want to attract and retain the best possible people, and there is every possibility that the best possible people for our business are people who have autism, as well as people who do not."[865]

"We have around 7,000 employees, and around 20% to 30% of them are neurodivergent. Over the last seven years, I have worked with some incredible people. I have seen some brilliantly talented people that challenge the stereotypes of autism—some of the most funny, most engaging, most talented people you can imagine. We have had engineers who have been able to resolve problems that no other engineers could. We have had analysts who have been able to support major savings in two contracts for our customers, and it was their autism that helped them to spot those changes and spot that data."[866]

"My main driver … is [that] the unemployment rates … are so dreadful, and providing an opportunity to tap into talent that is often overlooked, especially in my industry where financial analyst skills are in quite high demand. It is great to explore a different talent pool and … benefit from that.[867]

469. Rt Hon Sir Robert Buckland KC told us: "Time and time again, we heard this really positive evidence about the experiences in many different walks of life, from insurance right through to more blue-collar types of work, that autistic people make good workers. That message has to resonate time and time again."[868] Mayur Gondhea, Founder, CubeLynx, told us that some autistic people who have little or no work can go into highly skilled jobs with the right support.[869]

470. Such positive case studies remain the exception, not the rule. Many employers lack the support they need to enable more autistic people to find and stay in work. Sir Robert told us that there are "cultural barriers and problems, and a fear or reluctance on the part of employers to take on or promote people who have autism."[870] Persistent stigma against autistic people is one barrier. Professor Anna Remington told us: "There was a YouGov poll that surveyed a lot of employers and asked them, 'Would an autistic person be a likely fit in your team?'; 27% thought that an autistic person would be unlikely to fit in their team, down from 34% a few years earlier."[871]

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864 See written evidence from Autistica (AAC0105) and Chartered Institute of Personnel and Development (CIPD) (AC0200).
865 Q 125 (Rob Walters)
866 Q 125 (Peter Stokes)
867 Q 125 (Mayur Gondhea)
868 Q 105 (Rt Hon Sir Robert Buckland KC)
869 Q 131 (Mayur Gondhea)
870 QQ 101 and 105 (Rt Hon Sir Robert Buckland KC)
871 Q 94 (Prof Anna Remington)

471. Sir Charlie Mayfield told us that employers are more likely to employ an adequately qualified candidate who does not appear 'risky' than an excellent candidate who does:

> "The balance of incentives … is weighted against people who are different getting a job in the first place. Honestly, no amount of Equality Act or legislation will change that unless one addresses the actual cause of the fear, which is that the person I might employ, who might be fantastic but looks risky, could be a problem down the track."[872]

472. Employers also often lack the support and incentives they need to employ autistic people. Rt Hon Sir Robert Buckland KC drew attention to survey evidence showing that nearly 70% of employers thought that the cost and practicalities of making workplace adjustments were barriers to employing disabled people.[873] The CIPD told us about their survey evidence showing that less than half of employers said managers feel capable and confident to support neurodivergent people at work. Almost a quarter of employers said their organisation does not do anything to create a neuroinclusive culture.[874]

473. Autistic people likewise face barriers to finding and staying in work. As we set out in Chapter 6, the education system often fails to prepare autistic people well for work. The Association of Graduate Careers Advisory Services (AGCAS) Disability Task Group told us that autistic students and graduates often have low confidence about their ability to find work. This can be because of lack of confidence that they can show their competence, fear of discrimination, not knowing their rights, and not knowing how to ask for adjustments.[875]

474. This can all drive a wedge between employers and autistic applicants and employees. Sir Charlie Mayfield told us that there is:

> "a tremendous amount of fear in this whole landscape, both of individuals to disclose because they are concerned about potential discrimination … and simply how it would be received, and among employers—including line managers—who do not want to say the wrong thing or cause offence, let alone give reason to create a dispute or claim."[876]

Getting autistic people working

475. For too many autistic people, work is out of reach. For some young autistic people, education and unpaid work experience becomes a "roundabout that they cannot get off".[877] Alice Willans, who chairs the Ambitious about Autism Youth Council, told us: "When you leave education, an EHCP should change to a work, health and care plan and support people like me into work to be able to get an apprenticeship in which you are up against mainstream people."[878]

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872 Q 104 (Sir Charlie Mayfield)
873 Q 105 (Rt Hon Sir Robert Buckland KC)
874 Written evidence from Chartered Institute of Personnel and Development (CIPD) (AAC0200)
875 Written evidence from Association of Graduate Careers Advisory Services (AGCAS) Disability Task Group (AAC0136)
876 Q 101 (Sir Charlie Mayfield)
877 Q 122 (Sian Foster). See also written evidence from Christian Mallon (AAC0168).
878 Q 86 (Alice Willans)

Box 24: Testimonies from young autistic people about pathways into work

> "Doing a supported internship changed my life. I am now in sustainable employment and saving money to eventually buy my own first home, at the age of 23."[879]
>
> "As a result of my supported internship, I have gained a gardening job one day a week, volunteering. It gave me a weekly schedule. The claim of supported internships is that by the end of the internship, people with autism and/or a learning disability have employment. However, it is not quite like that. I have worked two days a week … but some of my friends who have similar needs to me have no work at all. I do not have a solution to go forward and no particular support to do anything about this."[880]

476. In the *Get Britain Working* white paper, the Government set out plans to reduce economic inactivity. It said it would fund all local areas in England to produce local Get Britain Working plans and support the development of an "integrated offer of local work, health and skills support".[881]

477. Our witnesses expressed particular support for the Government's decision to fund support for people to move towards and into work through the supported employment model. Supported employment schemes identify a person's needs, match them to a tailored role, and help their employer provide in-work support. They have a proven track record of enabling autistic people and people with a learning disability to move into and stay in work, enabling them to learn and demonstrate skills on the job and helping them move into sustainable employment.[882]

A partnership approach

478. The Government's *Get Britain Working* white paper acknowledged that "DWP funded employment support provision has focused overwhelmingly on the unemployed, while local help offered—by local councils, the NHS, voluntary sector, colleges and housing associations—is often fragmented and difficult to navigate."[883]

479. There are some good examples of local partnerships. Peter Stokes, Neurodiversity and Social Mobility Manager, Babcock International, told us how Babcock works with schools, the Jobcentre and the local authority in Plymouth to find the right people for the right roles.[884] For their part, Plymouth Jobcentres have commissioned an employment support offer for autistic and neurodivergent jobseekers, offering tailored one-to-one support and funded by the DWP.[885] Mayur Gondhea told us it would help smaller inclusive employers to have "a central way of accessing and forming partnerships" with local authorities across the country.[886] Dr Anne Heavey, Director of Insights, Ambition Institute, noted good examples of schools

879 Q 118 (Tegan Mulby)
880 Q 89 (Alice Willans)
881 Department for Work and Pensions, HM Treasury and Department for Education, *Get Britain Working White Paper*, 2 September 2024
882 British Association for Supported Employment, *About Supported Employment*
883 Department for Work and Pensions, HM Treasury and Department for Education, *Get Britain Working White Paper*, 2 September 2024
884 Q 128 (Peter Stokes)
885 Written evidence from Lynn McBain (AAC0362)
886 Q 130 (Mayur Gondhea)

modelling inclusive employment by providing apprenticeships for young people who received support through the SEND system.[887]

480. Autistic people need to participate in such partnerships on equal terms. Coach, consultant, youth mentor and speaker Char Bailey told us: "productivity should [not] be measured on how well I mimic neurotypical norms … I would like to build a system where autistic people are thriving, leading and changing things on our terms". She drew attention to successful neurodivergent-led initiatives to bring more autistic people into work.[888]

A new jobs and careers service

481. The Jobcentre is often unwelcoming and frequently inaccessible for autistic people.[889] In a 2019 survey for the All-Party Parliamentary Group (APPG) on Autism, just 4% of autistic adults said they thought Jobcentre staff had a good understanding of autism.[890] At present, only people who are in receipt of unemployment benefit can use the Jobcentre; the focus of appointments is on checking that benefit conditions are met and finding the jobseeker any job that is available.[891]

482. The Government has set out plans to reform the Jobcentre, building a service that will provide "support for anyone who is looking for work, who wants to get on in work, or who wants to change their career or retrain" and "prioritise providing genuine support for people over monitoring compliance and benefits administration." As part of this, the Government plans to merge the Jobcentre with the National Careers Service.[892]

483. Alison McGovern MP told us that the Government wants to "try to build a better relationship with employers … and try to help to offer a much more personalised service to autistic people and those with disabilities so we can improve the quality of match."[893] She said that the Government is building a work coach academy, which could be informed by "things like the Autistica index".[894] Autistica suggested that the Government should "develop an evidence-based curriculum for specialist neurodiversity work coaches, with a view to rolling this out across the country."[895]

484. There have been previous initiatives to make Jobcentres more accessible to autistic people. Under the previous Government, a pilot to improve support for autistic jobseekers was set up in 15 Jobcentres, in partnership with the National Autistic Society.[896] In June, the Government announced a

887 Q 76 (Dr Anne Heavey)
888 Q 124 (Char Bailey)
889 See QQ 93 (Prof Kim Hoque), 97 (Laura Davis), supplementary written evidence from Leo Capella (AAC0188) and House of Commons Work and Pensions Committee, *Get Britain Working: Reforming Jobcentres* (4th Report, Session 2024–25, HC Paper 353).
890 All Party Parliamentary Group on Autism, *The Autism Act: 10 years on*, 2019
891 House of Commons Work and Pensions Committee, *Get Britain Working: Reforming Jobcentres* (4th Report, Session 2024–25, HC Paper 353)
892 Department for Work and Pensions, *Pathways to Work: Reforming Benefits and Support to Get Britain Working Green Paper*, updated 30 October 2025, House of Commons Work and Pensions Committee, *Get Britain Working: Creating a new jobs and careers service* (5th Report, Session 2024–25, HC Paper 1286) and *Get Britain Working: Reforming Jobcentres* (4th Report, Session 2024–25, HC Paper 353).
893 Q 172 (Alison McGovern MP)
894 Q 173 (Alison McGovern MP)
895 Written evidence from Autistica (AAC0105)
896 HC Written Answer, 65876, Session 2022–23

Pathfinder of the new jobs and careers service in Wakefield.[897] We asked the Government to tell us how it would evaluate whether the jobs and careers service Pathfinder works well for autistic people. The Government told us that it was developing its evaluation strategy to ensure the development of the new service is evidence-based.[898]

Supported internships and work placements

485. Supported internships are structured, work-based study programmes for young people between the ages of 16 and 24. They are funded through education and are not paid. The aim is to support a transition into sustained paid work. Interns attend a learning provider (such as a college), but spend most of their time in the workplace. There is good evidence that supported internships are an effective way of supporting young disabled people into work, including young autistic people. About 60% of people who do a supported internship progress into work.[899]

486. Catherine McKinnell MP, then Minister for School Standards, Department of Education (DfE), told us that the Government wanted to double the number of supported internships to 4,500 per year. The Government said that indicative data suggests this number had already been reached by March 2025 and should be sustained in the 2025/26 academic year. The Minister also told us that the Government is piloting the extension of supported internships to students who do not have an EHC plan.[900]

487. Numerous NHS hospitals offer supported internships.[901] We visited The Autism Project (TAP) at St Thomas' Hospital in the London Borough of Lambeth, a full-time, two-year employability programme for young autistic people aged 18 to 25. Learners can try administrative office-based roles and physical roles like portering to learn what they do and don't like. Savita Rana, Deputy Director for Inclusion, Guy's and St Thomas' NHS Foundation Trust, told us that initiatives like TAP are crucial to delivering a pipeline of employees from schools and universities and to building the future workforce. She argued that the TAP model could be scaled up across NHS trusts in South East London and then applied more widely across the country, using the NHS as an anchor organisation.[902]

488. Capitalising on the benefits of supported internships is key. Supported internships remain underused and can be inaccessible to candidates who are deemed less ready for work.[903] A large minority of supported interns do not end up finding paid work.[904] Representatives of TAP called for more

897 Department for Work and Pensions, *Press Release:* Biggest shake-up of Jobcentres in decades gets underway, 5 June 2025
898 Further supplementary written evidence from UK Government (AAC0378)
899 Q 95 (Prof Kim Hoque)
900 Q 177 (Catherine McKinnell MP)
901 House of Lords Public Services Committee, *Think Work First: The transition from education to work for young disabled people* (1st RReport, Session 2024–25, HL Paper 12)
902 Appendix 8 and Autism Act 2009 Committee, *Note of Committee visit to St Thomas' Hospital, London Borough of Lambeth*, 19 May 2025
903 Written evidence from Susannah Trotter (AAC0240)
904 House of Lords Public Services Committee, *Think Work First: The transition from education to work for young disabled people* (1st Report, Session 2024–25, HL Paper 12). See also written evidence from Sarah-Jane Seaton-Norton (AAC0202).

support for young autistic people to take the next step into paid work through supported apprenticeships and employment schemes.[905]

Apprenticeships and vocational training

489. Apprenticeships are paid jobs combined with training and study. The Engineering Professors' Council told us that many autistic students have strengths that would benefit them in an engineering career, but the post-16 curriculum is not flexible enough to respond well to the needs of autistic students or employers in the sector. The Council argued that there should be more equitable routes for young people to access careers in engineering, including through apprenticeships and vocational training, as well as A-levels.[906] Rob Walters, Technical Director, PatronBase UK, told us that degree apprenticeships and T-levels are "really good for autistic people going into work", offering a lower threshold of expectations and a phased transition from education to work.[907]

490. Inflexible rules for apprenticeships can also present barriers to young autistic people and people with a learning disability. Supported apprenticeships operating in a similar way to supported internships do exist, but are very rare.[908] Alice Willans told us that she was prevented from doing a level 2 apprenticeship in horticulture because she already had a level 2 vocational qualification.[909] Laura Davis drew attention to evidence that young disabled people are disproportionately likely to drop out of apprenticeships: "We need to build different ways for people to be able to evidence their skills and talents."[910]

Supported employment and Connect to Work

491. The Government has said it will fund support for up to 100,000 people a year who are economically inactive[911] to move into work through Connect to Work, a new supported employment programme.[912] Laura Davis told us that this is "a phenomenal opportunity" and urged the Government to promote Connect to Work more effectively with autistic people, their families and employers.[913] She also said that training up enough specialised job coaches will be key to the programme's success.[914]

Access to Work

492. The Government's Access to Work scheme enables people with a disability or health condition to apply for grants to pay for help they need at work. Access to Work is intended to support workplace adjustments that go beyond the reasonable adjustments that employers must provide anyway by law (for

905 Appendix 8 and Autism Act 2009 Committee, *Note of Committee visit to St Thomas' Hospital, London Borough of Lambeth*, 19 May 2025
906 Written evidence from Engineering Professors' Council (AAC0192)
907 Q 127 (Rob Walters)
908 Written evidence from CareTrade (AAC0350)
909 Q 89 (Alice Willans). See also written evidence from Dr Susanne Lace (AAC0327) and Daisy Lapsey (AAC0351).
910 Q 92 (Laura Davis)
911 Economic inactivity is a term used in labour market statistics to describe when a person is not in work and has not been seeking work within the last four weeks, and/or is unable to start work within the next two weeks. See Office for National Statistics, *Economic inactivity*.
912 Department for Work and Pensions, HM Treasury and Department for Education, *Get Britain Working White Paper*, 2 September 2024
913 Q 96 (Laura Davis)
914 Q 98 (Laura Davis)

example, a support worker or job coach).[915] The Government has consulted on changes to the Access to Work scheme, noting that numbers of applications for support through the scheme have increased substantially in recent years and that it still only supports about 60,000 people in total.[916]

493. There are at present long delays for Access to Work. These are having a serious impact on employers and autistic employees. Rob Walters told us: "It might as well not exist at this point … and that is even with the nice little check box on the DWP website that says, 'I'm at risk of losing a job'. Even if you tick that, you could still be waiting months."[917] Mayur Gondhea told us that his company, CubeLynx, successfully supports autistic employees with job coaches funded through Access to Work, but "it takes a long time and is quite hard work."[918]

494. Reductions in Access to Work support could undercut efforts to widen access to supported employment. Sian Foster, Director of Service Development, DFN Project SEARCH, told us that supported employment organisations can now only claim Access to Work funding for 26 weeks, slightly less than the length of a standard six-month supported internship. She said: "We cannot remove [Access to Work] just at that transition point where they are moving out of a supported internship into paid employment … We are taking it away just at the point where it is absolutely imperative."[919] Many of our witnesses feared that the Government may seek to cut Access to Work to save money and urged the Government to see the scheme as an investment in the future.[920] Alison McGovern MP acknowledged that Access to Work applications are taking too long and told us that there is "more work" to do with the scheme.[921]

Conclusions and recommendations

495. **The Government's Get Britain Working plan offers opportunities to enable more autistic people to move towards and into work, in particular through the expansion of access to supported employment.**

496. ***In the new autism strategy, the Government should make a significant increase in the employment rate for autistic people a priority outcome and should report regularly on progress towards this goal. To achieve this, the Government should fund the expansion of evidence-based initiatives to support people to find and stay in work, including through supported internships and supported employment.***

497. ***In updated statutory guidance to the Autism Act, the Government should require that local authorities and NHS bodies work with the Department for Work and Pensions and employers to support autistic people to move into work and to collect evidence and data on progress against this goal.***

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915 UK Government, *Access to Work: get support if you have a disability or health condition*

916 Department for Work and Pensions, *Pathways to Work: Reforming Benefits and Support to Get Britain Working Green Paper*, updated 30 October 2025

917 Q 129 (Rob Walters). See also written evidence from Dr Anne Cockayne (AAC0303) and Martin Davis (AAC0189).

918 Q 129 (Mayur Gondhea)

919 Q 124 (Sian Foster)

920 Q 93 (Prof Kim Hoque) and Q 124 (Sian Foster)

921 Q 172 (Alison McGovern MP)

The role of employers

498. Under the Equality Act 2010, employers must make reasonable adjustments to support disabled job applicants and employees. However, employers do not always have the support they need to make sure this happens in practice.

499. Standard recruitment processes often put autistic people at a disadvantage. Most autistic job applicants do not disclose that they are autistic, often out of fear of discrimination.[922] Autistic graduates and employees often report limited confidence about demonstrating skills in recruitment.[923] Job descriptions are often vague, listing criteria like 'good communication' where autistic people are less likely to feel they excel. Autistic and neurodivergent applicants often do less well in multiple-choice psychometric tests.[924] There are emerging concerns that the use of AI tools to screen applications is systematically disadvantaging autistic candidates.[925] Interviews often assess normative social skills as much as or more than the ability to do a job.[926] Research consistently shows autistic applicants are rated on average less favourably at interview.[927]

Box 25: Testimonies from autistic people and those who support them about finding work

"My friend got a first class honours in computer science and has been unemployed for two years because he can't get past the interview."[928]

"If you are autistic and/or have a learning disability, you can often not be shortlisted or find the interview process too overwhelming, even with adjustments—which has happened to me on all my attempts at applying for jobs so far. Even among my friends and peers, all of them who have gone down the route of applying for jobs have applied for a number of jobs, such as working in a café, but have been unsuccessful without even getting to the interview stage. All five of them felt depressed about their situation and did not like being unemployed."[929]

"Completing timed psychometric tests does not give us processing time, and the questions do not make sense. Interviews can be really hard when you are autistic."[930]

"I have one example of an autistic graduate being advised they weren't a good fit for a role after completing a psychometric test. The attributes identified by the test were all related to autism. They asked to be assessed by an alternative method and were subsequently offered the job."[931]

922 Q 92 (Prof Anna Remington)
923 Written evidence from Association of Graduate Careers Advisory Services (AGCAS) (AAC0099). See also written evidence from Chartered Institute of Personnel and Development (CIPD) (AAC0200) and Fiona Gordon (AAC0361).
924 Written evidence from Dr Jan Lawler (AAC0295)
925 See Q 93 (Laura Davis) and written evidence from Dr Jan Lawler (AAC0295).
926 Written evidence from Autistica (AAC0105) and Dr Louise Nash, Dr Raysa Rocha and Dr Siddhartha Saxena (AAC0038)
927 Written evidence from Centre for Research in Autism and Education (CRAE) (AAC0081)
928 Written evidence from Autistica (AAC0105). See also written evidence from Anonymous 33 (AAC0214).
929 Q 90 (Alice Willans)
930 Q 123 (Tegan Mulby)
931 Written evidence from Association of Graduate Careers Advisory Services (AGCAS) Disability Task Group (AAC0136)

500. Once in work, autistic people can struggle to do well in busy, noisy environments and to navigate the social world of the workplace.[932]

Box 26: Testimonies from autistic employers and autistic employees about staying and progressing in work

"Sometimes the important conversations happen in the pub. That's not where I want to be. It's noisy, it's chaotic, people move to the bar, they buy drinks … So you get left out of those social interactions, which are important for the stuff you do between nine and five."[933]

"We put in office hours, which was something I pinched from universities. It is the idea that, between 9 and 10, you can hit me with questions, but from 10 onwards I have my head down and am concentrating on stuff. I found that really helpful and other colleagues did as well."[934]

"My employer, Positive Footprints, took the time to get to know me and I can self-advocate what I need to bring my hard-working self to work. They are understanding when I need to change my hours to avoid busy buses, and they let me try different start times as well, to find the best one for me. They can also contact my tutor, Sarah … and my job coach Maria for support."[935]

Work trials and targeted employment schemes

501. One approach is for employers to offer more targeted employment schemes for autistic and neurodivergent people, drawing on principles from the supported employment model. Laura Davis told us that employers could make more use of work trials instead of interviews to enable autistic applicants to demonstrate their competence effectively.[936] Numerous organisations offer targeted internships for young autistic people, including the civil service.[937] SAP, Microsoft, and GCHQ have developed autism-specific hiring pathways.[938]

A universal approach

502. Targeted employment schemes will not suit everyone. Many autistic applicants and employees do not disclose a disability. Professor Anna Remington told us: "As noted in the Buckland review, only 35% of autistic employees said that they were fully open about being autistic in the workplace. Some of our research showed that 40% of those who had disclosed it felt that there was a positive outcome."[939] Rt Hon Sir Robert Buckland KC told us: "If a disclosure is made, it is often after the job is offered, which … perhaps makes things a bit more difficult, because those early weeks of a new job are often the time when things can go really badly wrong."[940] Particularly outside younger age groups, many will not have a diagnosis at all. Professor Amanda Kirby said that employers sometimes think a diagnosis is required

932 Written evidence from Autistica (AAC0105)
933 Written evidence from Autistica (AAC0105)
934 Q 129 (Rob Walters)
935 Q 119 (Tegan Mulby)
936 Q 93 (Laura Davis). See also written evidence from Vocational Rehabilitation Association (AAC0224) and National Association of Disabled Staff Networks (AAC0335).
937 Ambitious Youth Network, *Employ Autism Opportunities (18+)*, 10 January 2025
938 Written evidence from Chartered Institute of Personnel and Development (CIPD) (AAC0200)
939 Q 92 (Prof Anna Remington)
940 Q 102 (Rt Hon Sir Robert Buckland KC)

to put adjustments in place. This can lead to delays in support and foster distrust and fear between the employer and employee.[941]

503. We heard that it is helpful for employers to take a universal approach to inclusion, severing the link between disclosure and adjustments.[942] Laura Davis said: "If employers have the right things in place, nobody ever has to disclose anything."[943] Rob Walters told us: "If someone who is autistic says that they need flexible time to work, why would you not offer that to other people you employ?"[944] Mayur Gondhea said that open-minded and considerate employers will reap benefits in better staff retention.[945]

504. There is evidence that offering simple adjustments to interviews as standard or on request, such as providing questions in advance, can often lead to better outcomes for autistic candidates.[946] Peter Stokes told us that being transparent about reasonable adjustments "stops that fear … and stops the othering of autistic individuals as well."[947] Rt Hon Sir Robert Buckland KC pointed out that many smaller businesses rely on recruitment agencies to hire staff and told us engagement with the Recruitment and Employment Confederation could help drive change.[948]

505. Employers could also do more to put in place proactive, universally offered adjustments in the workplace. Many autistic employees benefit from remote working, as it enables them to adapt their working environment to their sensory and social needs.[949] However, Professor Kim Hoque told us: "When you … look just at the jobs that are offered on the Government's Find a Job website on a working-from-home basis, we calculated it as 0.35%. Employers are just not offering working from home to new entrants to the organisation."[950] The Chartered Institute of Personnel and Development (CIPD) have recommended that employers should carry out sensory audits, provide quiet spaces, and allow for flexible scheduling.[951]

Making reasonable adjustments

506. Employers and autistic employees need to work together to identify the reasonable adjustments they need and put them in place in a timely way. This is key to successful employment. Professor Anna Remington told us about her research that "found that those who received adjustments were over three times more likely to be in a job that matched their skill level."[952]

507. Getting the right reasonable adjustments in place is not always easy. Professor Remington's research showed that almost a third of autistic employees felt unable to discuss what they might need as adjustments. Of those who requested them, a quarter were refused and 10% said that the adjustments

941 Q 102 (Prof Amanda Kirby)
942 See QQ 101 (Rt Hon Sir Robert Buckland KC), 102 (Prof Amanda Kirby) and 122 (Char Bailey).
943 Q 97 (Laura Davis)
944 Q 125 (Rob Walters)
945 Q 126 (Mayur Gondhea)
946 See Q 97 (Prof Anna Remington) and written evidence from Centre for Research in Autism and Education (CRAE) (AAC0081).
947 Q 126 (Peter Stokes)
948 Q 101 (Rt Hon Sir Robert Buckland KC)
949 Written evidence from Autistica (AAC0105)
950 Q 92 (Prof Kim Hoque)
951 Written evidence from Chartered Institute of Personnel and Development (CIPD) (AAC0200)
952 Q 98 (Prof Anna Remington)

they received were not properly implemented.[953] Many witnesses told us that employers need a better understanding of what reasonable adjustments for an autistic employee might be. Dan Harris, Founder and Chairperson, Neurodiversity in Business, said: "UK plc needs to come together and develop a gold standard, a menu, of what should be in place as default for autistic people."[954]

508. Part of the issue is that autistic applicants and employees do not always know what support they might need. Diagnosis alone does not unlock this information. Leo Capella, Training Consultant (Employment Specialist), National Autistic Society, told us: "I am someone who had support in school and university. Translating that experience into what I needed in employment was tricky. It is the same for other autistic people."[955] Professor Amanda Kirby said: "Assuming ability or lack of ability … is a problem. A checklist approach does not seem to work."[956] Steven Ingram cited the DWP's health adjustments passport, which is intended to support disabled people and people with health conditions to identity the support they need to move into or stay in a job. He suggested that an adapted passport could yield greater benefits.[957]

509. Some witnesses told us that there needs to be stronger accountability for employers that fail to provide reasonable adjustments. Professor Kim Hoque called for a two-week time limit within which employers need to provide a substantive response on reasonable adjustment requests, because "so often people's requests for reasonable adjustments simply disappear into the ether."[958]

Thriving and progressing at work

510. Professor Anna Remington cited recent research showing that less than half of the autistic people spoken to were satisfied with their employment status, compared to more than half of non-autistic participants. She said: "There are a few things getting in the way: underemployment and poor job matching … stigma and discrimination, a lack of institutional support and bias within the internal promotion procedures, and gaps in education and employment history."[959]

511. Professor Remington also drew attention to evidence suggesting that autistic employees often feel that their line manager does not know how to help them progress.[960] Mayur Gondhea told us:

> "Traditionally, people's careers are defined by stepping stones, progressing and doing different things such as client-facing roles … It is a bit of a mindset shift to make sure that we value people who are doing good work and allow them to flourish in their own way, rather than judge everyone's career on the traditional basis."[961]

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953 Q 92 (Prof Anna Remington)
954 Q 122 (Dan Harris)
955 Q 20 (Leo Capella)
956 Q 102 (Prof Kim Hoque)
957 Written evidence from Steven Ingram (AAC0353). See Department for Work and Pensions, *Health Adjustment Passport*, updated 12 June 2023.
958 Q 95 (Prof Anna Remington)
959 Q 98 (Prof Anna Remington)
960 *Ibid.*
961 Q 129 (Mayur Gondhea)

Managing ill health, performance and employment disputes

512. Many autistic people do thrive at work. However, autistic employees can experience difficulties too. These can result from failures to make timely adjustments at work, changes in relationships of care and support outside work, or ill health.[962] Over time, unmet needs can escalate. Leo Capella likened some autistic employees to "swans—people performing gracefully above the surface while paddling like 'anything'" or "sharks—relentless, hungry, overachieving people who fear stopping but will have difficulties slowing down."[963] Char Bailey told us: "Often, autistic employees will overextend themselves and overachieve … The result of that is burnout, which, from my own personal experience, is awful to go through."[964]

Box 27: Testimonies from autistic adults about problems at work

"Not having a diagnosis makes it very difficult to advocate for myself in the workplace. There are many areas in which I know I struggle in the workplace, but without a diagnosis, it is difficult to know what reasonable adjustments to request."[965]

"I knew I had autism, but I had no framework or guidance of how to understand how it presented in me. This led to me providing a sub-optimal narrative when I disclosed my condition; which led to misunderstandings between myself and people I disclosed to; which led me to be treated unfairly (as well as giving me a very low sense of self-worth); which led to me, my parents, teachers, managers, HR, Occupational Health, etc, recommending/providing incorrect and ineffective Reasonable Adjustments; which then led to me being asked why my performance wasn't improving; which led to me feeling stressed, anxious, low, depressed, burnt out, and much more; which meant I found it harder, and it took longer, to do all of my work and gave others the perception of poor performance; which led to a plethora of different things, including … being offered voluntary redundancy or being forced out of a company."[966]

"My first graduate role broke down due to unimplemented reasonable adjustments and a lack of workplace support. Communication challenges escalated into a disciplinary process and ultimately the termination of my contract. That experience led to severe autistic burnout and depression. At the same time, I was locked in a punishing battle to access basic services such as PIP, adult social care, and mental health support all while trying to live independently and remain in full-time work … Employment support means nothing if housing is insecure. Social care doesn't work without access to mental health services. None of it is effective if those services don't recognise the full diversity of who autistic people are."[967]

513. Sir Charlie Mayfield told us: "There is relatively little support of a practical and easily accessible nature for employers and employees who are navigating ill health, disability and [neurodivergence] and autism within the workplace … If there is not much support available, they often do not get handled very

962 Supplementary written evidence from Leo Capella (AAC0188) and written evidence from Association of Graduate Careers Advisory Services (AGCAS) Disability Task Group (AAC0136). See also written evidence from Anonymous 35 (AAC0235).
963 Supplementary written evidence from Leo Capella (AAC0188)
964 Q 123 (Char Bailey)
965 Written evidence from Anonymous 55 (AAC0356)
966 Written evidence from Steven Ingram (AAC0353)
967 Written evidence from Benjamin Hitimana (AAC0368)

well and therefore can get worse."[968] Long waits for healthcare in particular increase the risk that needs will escalate;[969] as we saw in Chapters 4 and 5, autistic people are at a particular disadvantage here. Char Bailey told us that there should be guaranteed mental health support as part of employment rights.[970] We note in this context the recommendation of Sir Charlie's *Keep Britain Working* review that the Government should develop a Healthy Working Lifecycle standard to define "the practices that drive the best outcomes in reduced sickness absence, improved return to work rates and better participation and inclusion of disabled people."[971]

514. Like other disabled employees, autistic employees typically face barriers to enforcing their rights in the workplace.[972] Unequal access to diagnosis may put undiagnosed autistic employees at a particular risk of not being able to access protections under the Equality Act.[973] When problems escalate, employment disputes can result. In practice, most disputes do not end up at tribunal.[974] However, Professor Amanda Kirby told us that fear of employment tribunal cases can put off employers that might otherwise employ disabled or neurodivergent people.[975] Leo Capella told us that there was a need for a need for a "more neutral hub" to offer advice to employers and autistic employees about disputes in the workplace. He drew our attention to the ACAS guidelines on neurodiversity at work.[976]

Supporting and incentivising employers to improve support

515. Witnesses agreed that more could be done to support and incentivise employers to enable autistic people to find and stay in work.

Guidance, awareness and training

516. First, employers need a better understanding of why they should employ autistic people and how they can do it well. Rt Hon Sir Robert Buckland KC told us that his review had recommended that there be an "a renewed campaign … to refocus employers on the benefits of employing autistic people."[977] Many witnesses told us too that there should be mandatory training for employers and line managers and referred us to positive examples of training programmes.[978]

517. Part of the challenge is in making sure managers have the right information and skills when they need it. Peter Stokes told us that Babcock International has a neurodiversity team and neurodiversity networks, which has led to a change in culture and given managers the confidence to seek advice.[979] Sir

968 Q 102 (Sir Charlie Mayfield)
969 Q 107 (Sir Charlie Mayfield)
970 Q 124 (Char Bailey)
971 Department for Work and Pensions and Department for Business and Trade, *Keep Britain Working Review: Final report*, 5 November 2025
972 House of Lords Public Services Committee, *Think Work First: The transition from education to work for young disabled people* (1st Report, Session 2024–25, HL Paper 12)
973 Q 108 (Prof Amanda Kirby)
974 House of Lords Public Services Committee, *Think Work First: The transition from education to work for young disabled people* (1st Report, Session 2024–25, HL Paper 12)
975 Q 108 (Prof Amanda Kirby)
976 Supplementary written evidence from Leo Capella (AAC0188); see ACAS, *Neurodiversity at work*, 5 March 2025.
977 Q 101 (Rt Hon Sir Robert Buckland KC)
978 See for example written evidence from Dr Anne Cockayne (AAC0303), Educating Edward (AAC0306), Lynn McBain (AAC0362), Sana Ali (AAC0347) and Sofie Day (AAC0043).
979 Q 125 (Peter Stokes)

Charlie Mayfield noted that a small- or medium-sized employer may not have the necessary advice to hand when they need it.[980]

Spreading good practice

518. Many witnesses told us the Government could do more to support employers to learn from each other, spread good practice, and gain voluntary accreditation. Rob Walters told us: "I found the Autistica Neurodiversity Employers Index really valuable. I would like to see government promoting things of that nature much more, because that does allow employers to earn a grade for how well they are doing these things."[981]

519. Laura Davis told us that the British Association for Supported Employment works with employers to help them become more inclusive, saying that they "intellectually get this", but often do not know what to do.[982] She called for a Government-supported mechanism for spreading good practice.[983] Professor Anna Remington told us how Deutsche Bank had shared experience with businesses across the sector after successfully running targeted internships for autistic graduates.[984]

520. Leadership is crucial. Autistic leaders in particular can play important roles both in championing good practice and in supporting and mentoring autistic staff.[985] Peter Stokes told us that at Babcock International: "We are lucky to have [autistic former Second Sea Lord] Sir Nick Hine as our lead and sponsor for neurodiversity."[986] Char Bailey told us: "We need to have autistic people in leadership roles. I have had the privilege of having neurodivergent leaders shape me, mould me and be role models, and that has allowed me to feel as though I am valuable and valid to take up the spaces that I have."[987] The Group for Autism, Insurance, Investment and Neurodiversity (GAIN) shared evidence from a survey of their network members showing that employees in firms with employee resource groups reported higher engagement, a greater sense of inclusion, and increased safety in disclosing their neurodivergence. Where there were neurodivergent role models, workplace culture was rated as significantly more inclusive.[988]

Financial incentives

521. Some witnesses suggested the Government could give employers more financial incentives to employ autistic and neurodivergent people. Professor Anna Remington suggested that the Government could "extend something like the apprenticeship levy, so that you are explicitly welcoming businesses to spend on initiatives that would support a neurodivergent or autistic workforce."[989] Mayur Gondhea suggested that the Government could compensate small businesses that champion inclusive employment for outreach to other employers.[990]

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980 Q 105 (Sir Charlie Mayfield)
981 Q 131 (Rob Walters)
982 Q 91 (Laura Davis)
983 Q 96 (Laura Davis)
984 Q 97 (Prof Anna Remington)
985 Written evidence from Chartered Institute of Personnel and Development (CIPD) (AAC0200)
986 Q 128 (Peter Stokes)
987 Q 122 (Char Bailey)
988 Written evidence from Group for Autism, Insurance, Investment and Neurodiversity (GAIN) (AAC0209)
989 Q 97 (Prof Anna Remington)
990 Q 126 (Mayur Gondhea)

522. Professor Kim Hoque said that public procurement policy could also be used to reward inclusive employers.[991] Mayur Gondhea suggested more social value marks could be awarded in bids for public sector contracts to businesses that employ autistic and neurodivergent people.[992] Another approach could be to offer businesses tax relief for supporting more disabled people towards and into work, building on the current National Insurance Contributions Relief for Veterans scheme.[993]

Protecting rights and strengthening accountability

523. There are often large gaps between how inclusive employers say they are and what they do in practice. Professor Kim Hoque drew attention to research into large private sector employers:

> "We looked at whether they monitor and review hiring and promotions by disability, whether they review pay by disability, whether they have put into place special recruitment procedures to reach out to disabled people in the hiring process, and whether they have conducted accessibility assessments. We looked at seven practices in total … on average, they have adopted just 1.1 out of those seven practices. This is despite the fact that about 84% of them have a formal disability equality policy statement."[994]

524. Many witnesses told us employers need to be held to account for failures to be inclusive. Char Bailey said: "Inclusion should be audited like health and safety is."[995]

525. The Government's Disability Confident scheme aims to help businesses hire and retain disabled employees. Employers can sign up to the scheme and attain three different levels of accreditation. It is only at the third level, Disability Confident Leaders, that employers are subject to external scrutiny.[996] Tegan Mulby told us the Disability Confident scheme was "nonsense": "So many companies claim to be disability confident but their recruitment process excludes autistic people. When you ask for reasonable adjustments, such as interview questions, they do not give them to you."[997] Numerous autistic people and others told us the same.[998] Professor Kim Hoque said: "There is hardly any evidence at all to suggest that Disability Confident organisations actually employ disabled people in greater numbers than non-Disability Confident organisations." He called for criteria to be reformed so that certification at Levels 2 and 3 depends on the employer meeting a requirement for a minimum percentage of their workforce being disabled.[999]

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991 Q 95 (Prof Kim Hoque)
992 Q 129 (Mayur Gondhea)
993 See Good Growth Foundation, *Employer NICs Holiday to tackle economic inactivity crisis could save up to £1.1 billion per year*, 4 April 2025 and HMRC, *Evaluation of the employer National Insurance contributions relief for veterans*, 28 May 2025.
994 Q 92 (Prof Kim Hoque)
995 Q 124 (Char Bailey)
996 House of Lords Public Services Committee, *Think Work First: The transition from education to work for young disabled people* (1st Report, Session 2024–25, HL Paper 12)
997 Q 122 (Tegan Mulby)
998 For example, written evidence from Charli Clement (AAC0122), Steven Ingram (AAC0353), Spenser Gray (AAC0363), Sarah-Jane Seaton-Norton (AAC0202), Anonymous 6 (AAC0022), Anonymous 16 (AAC0060) and Anonymous 40 (AAC0252).
999 Q 93 (Prof Kim Hoque). See also written evidence from Disability@Work (AAC0036).

526. Alison McGovern MP told us that there are "a range of views" about Disability Confident. However, she said: "The results we are looking for are to increase the disability employment rate and the autistic employment rate, so we definitely need to do more with schemes like Disability Confident."[1000] The Government has also consulted on how to introduce mandatory disability and ethnicity pay reporting for large employers.[1001] We heard support for this approach.[1002]

Conclusions and recommendations

527. **Employers have a vital role to play in enabling autistic people to find, stay and thrive in work, but they need more support and stronger incentives to do so.**

528. ***The Government should develop and publish standards on what employers should do in practice to enable autistic applicants and employees to access their legal rights to reasonable adjustments, drawing on evidence and experience from employers and employees.***

529. ***The Government should run a campaign to promote evidence-based voluntary peer-to-peer learning and accreditation schemes for employers, such as the Autistica Neurodiversity Employers Index.***

530. ***The Government should develop, test and scale up financial incentives for employers to support more autistic and disabled people to find and stay in work, for example through taking into account the percentage of an organisation's workforce that is disabled in the awarding of public contracts, or through the use of tax incentives and/or national insurance relief.***

531. ***The Government should reform the Disability Confident scheme so that certification at Levels 2 and 3 is based on objective criteria, including the percentage of the workforce that is disabled.***

1000 Q 173 (Alison McGovern MP)
1001 Office for Equality and Opportunity, *Equality (Race and Disability) Bill: mandatory ethnicity and disability pay gap reporting*, 18 March 2025
1002 Written evidence from Disability@Work (AAC0036)

CHAPTER 8: CRIMINAL JUSTICE

Introduction

532. The previous chapters of this report have examined the importance of effective support for autistic people in key aspects of life. The other area of focus of the current autism strategy, criminal justice, is of a different order. Interaction with the criminal justice system is by its nature undesirable. Sadly, evidence suggests that autistic people are more likely than average to come into contact with the criminal justice system. As we have seen, it appears that interaction with the criminal justice system, whether as victims, witnesses or perpetrators of crime, becomes more likely where there are failings in care and support for autistic people during the life course, including at key moments of transition between stages of life.[1003]

533. As we set out below, evidence on the causes of interaction of autistic people with the criminal justice system, numbers in the system, personal experiences, and effective strategies for reform is patchy. Our analysis of the criminal justice system should be measured in the context of these limitations. Nevertheless, the evidence we have received shows that criminal justice must remain a key area of focus in the new autism strategy.

The 2021–26 autism strategy

534. The autism strategy for 2021–26 stated:

> "By 2026, we want to have made improvements in autistic people's experiences of coming into contact with the criminal and youth justice systems, by ensuring that all staff understand autism and how to support autistic people. We want all parts of the criminal and youth justice systems, from the police to prisons, to have made demonstrable progress in ensuring that autistic people have equal access to care and support where needed. In addition, we want autistic people who have been convicted of a crime to be able to get the additional support they may require to engage fully in their sentence and rehabilitation."[1004]

Testimony of autistic people and those who support them

Box 28: Testimonies from autistic people and those who support them about criminal justice

"The criminal justice system can retraumatise victims and defendants alike—especially neurodivergent people. Long waits, confusing procedures, and abrupt interactions can cause lasting harm."[1005]

"Nobody understands how autism affects the ability to communicate with others. Their carer understands this but they are excluded from the process as the system dictates that the person accused of the offence must be the one that tells their story."[1006]

1003 See for example paras 406 and 418, and University of Exeter, *Neurodisability in children linked to increased vulnerability to 'school to prison pipeline'*, 26 June 2025.
1004 Department of Health and Social Care and Department for Education, *National strategy for autistic children, young people and adults: 2021 to 2026*, 22 July 2021
1005 Written evidence from Anonymous 60 (AAC0121)
1006 Written evidence from Anonymous 24 (AAC0124)

"People we support have been arrested and physically restrained when in meltdown due to misunderstandings from the police and the distress caused by this can be devastating. When police have had a true understanding of autism there have been much more positive and calmer outcomes."[1007]

"I know a young man with profound autism who, during a school holiday, became very distressed. His loving mother could not work out why. She took him to the doctor, who could not examine the young man as he was too distressed and would lash out. The police were called. This resulted in the young man being restrained by 11 police and him being detained in custody … This autistic young man spent three months in a secure psychiatric unit because he had tonsilitis and was unable to make anyone understand that."[1008]

"Our non-verbal daughter was handcuffed by police who, despite our explanation, misinterpreted her autism as drug use and took her off without support in an ambulance where she had blood taken forcibly against her will. This caused our daughter unimaginable distress. The police clearly had had no training whatsoever in managing a person with autism and had no understanding of what it might mean."[1009]

"Being an offender in the justice system is hard … The court process was extremely difficult and being in prison was more distressing than it should've been because nobody knew about my autism and therefore couldn't make any adjustments. … I was diagnosed with autism thanks to the justice system … If it wasn't for probation having the funding and capacity to provide services like this, I wouldn't have been diagnosed as autistic and would likely still be offending."[1010]

Statistics

535. Dr Katie Maras, Associate Professor of Psychology, University of Bath, drew attention to the patchy nature of statistics on the numbers of autistic people in the criminal justice system:

> "The studies are mixed and generally of quite poor quality … estimates of prevalence range from 0.9% to 60%, which is huge, but it very much depends on who you are asking and from what sample. Is it a forensic inpatient sample or a community sample? Are you asking whether they have had contact with the police or if they are actually in prison?"[1011]

536. Dr Chloe Holloway-George, Assistant Professor, School of Law, University of Nottingham, said that the lack of accurate data can be linked to the absence of routine recording and collection of data by criminal justice institutions.[1012] Dr Marie Tidball MP, Chair, All-Party Parliamentary Group (APPG) on Autism, noted inconsistencies in data collection and 'flagging systems' between different parts of the criminal justice system.[1013] John Nelson, Chair, National Police Autism Association, said that recording of autism on police crime systems and the police national computer is patchy.[1014]

1007 Written evidence from Rotherham Parents Forum Limited (RPFL) (AAC0113)
1008 Written evidence from Jude Ragan CBE (AAC0184)
1009 Written evidence from Anonymous 48 (AAC0281)
1010 Written evidence Anonymous 13 (AAC0055)
1011 Q 132 (Dr Katie Maras)
1012 Written evidence from Dr Chloe Holloway-George (AAC0379)
1013 Q 147 (Dr Marie Tidball MP)
1014 Q 138 (John Nelson)

537. The most frequently cited data comes from the Government-commissioned July 2021 Criminal Justice Joint Inspection (CJJI) report *Neurodiversity in the Criminal Justice System: a review of evidence*.[1015] This found that neurodivergence is more prevalent in the criminal justice system than in the wider community. Based on the evidence collated, His Majesty's Inspectorate of Prisons said, the report determined that as many as half of those entering prison may have "some form of neurodivergent condition": "However, with no reliable, consistent or systematic data gathering or monitoring within prisons, or across the criminal justice system, we cannot be certain." Nevertheless, they said that the estimate in the report "appears to reflect the reality in a number of prisons inspected. At HM Prison (HMP) Deerbolt around two-thirds of prisoners have been identified by the prison as having neurodivergent needs."[1016]

538. Evidence from Independent Monitoring Boards, who monitor the treatment and conditions of people detained in prisons across England and Wales, and Lay Observers, who carry out similar monitoring in court custody and during transfers, reported that at some prisons over 50% of the total population had neurodivergent needs.[1017] An inquiry into SEND and neurodiversity in Essex Youth Justice Service in June 2024 showed that at that point in time 53.8% of the cohort (141 in total) had identified SEND, and that 27 of the 141 had an autism diagnosis.[1018]

539. Dr Katie Maras pointed out that the CJJI data includes conditions other than autism[1019] and is very much an estimate. However, she and Dr Chloe Holloway-George both said that, notwithstanding the limits of data, there is evidence that autistic people are over-represented in the system as a whole.[1020] Despite this, Dr Maras emphasised that there is no evidence that autistic people are more likely than non-autistic people to be offenders overall.[1021]

1015 Criminal Justice Joint Inspection, *Neurodiversity in the Criminal Justice System: a review of evidence*, 15 July 2021

1016 Written evidence from HM Inspectorate of Prisons (AAC0210)

1017 Written evidence from Independent Monitoring Boards and Lay Observers (AAC0120)

1018 Written evidence from Essex County Council (AAC0191)

1019 The review uses "neurodivergence as an umbrella term to refer to the group of conditions that fall under the broader category of neurodevelopmental disorders (NDDs). These incorporate learning difficulties and disabilities (LDDs) which generally include: learning disability, dyslexia, dyscalculia, and developmental coordination disorder (DCD, also known as dyspraxia); other common conditions, such as attention deficit hyperactivity disorder (ADHD, including ADD), autism spectrum conditions, developmental language disorder (DLD, including speech and language difficulties), tic disorders (including Tourette's syndrome and chronic tic disorder); and cognitive impairments due to acquired brain injury (ABI)." See Criminal Justice Joint Inspection, *Neurodiversity in the Criminal Justice System: a review of evidence*, 15 July 2021.

1020 Q 132 (Dr Katie Maras) and written evidence from Dr Chloe Holloway-George (AAC0379)

1021 QQ 132 and 139 (Dr Katie Maras)

Autistic victims and witnesses of crime

Box 29: Statutory rights of vulnerable victims and witnesses

Under the Code of Practice for Victims of Crime in England and Wales (the Code), victims of crime have a number of rights including: "to be able to understand and be understood"; "to be referred to services that support victims"; and, "to be provided with" a range of information covering (but not limited to) compensation, the investigation and prosecution of the crime, the outcome of the trial, any subsequent appeals, and details about the perpetrator. The Code also includes "enhanced rights" for "vulnerable" victims. This includes those that "have a physical disability or are suffering from a physical disorder", but autistic people are not addressed directly.

Under the Youth Justice and Criminal Evidence Act 1999, vulnerable witnesses are entitled to special measures to enable them to give their best evidence.

Source: Ministry of Justice, Statutory guidance: Code of Practice for Victims of Crime in England and Wales, 29 January 2025; Youth Justice and Criminal Evidence Act 1999, Sections 16–33

540. Autistic people are more likely to be victims than perpetrators of crime.[1022] The Centre for Neurodiversity and Development at Durham University also noted that autistic people are more likely to be the victim of a crime than their non-autistic peers, with experiences of violence and victimisation particularly prevalent.[1023]

541. Dr Felicity Sedgewick, Senior Lecturer in Psychology of Education, University of Bristol, cited research studies showing that autistic people are especially vulnerable to 'mate crime' (where someone pretends to be your friend to enable them to commit a crime against you) and intimate partner violence. She said that there is some evidence that autistic people are at higher than average risk of sexual assault and domestic abuse. Her research showed that abusers often capitalise on difficulties in reading social cues, assumptions that others will act in good faith, and a lack of wider friendship circles who can intervene.[1024]

542. One witness said that "victims are often disbelieved. Autistic victims of crime are frequently not taken seriously—especially if they're overwhelmed, confused, unable to sequence events clearly, or unable to describe what happened in a 'neat' way. This leads to devastating injustice and secondary trauma."[1025] The Centre for Neurodiversity and Development at Durham University stated that autistic people report particular difficulties in interactions involving the police. Participants in a 2022 research project reported autistic characteristics (such as differences in use of eye contact or outward expression of emotions) being read by police as signs of dishonesty when attempting to report being the victim of a violent crime. Likewise, autistic participants in a 2025 study on accessing support and justice after experiences of intimate violence and abuse reported feeling traumatised by their experiences with the criminal justice system. They stated that autistic people often do not align with expectations of the 'ideal victim'

1022 Q 81 (Prof Sheila the Baroness Hollins) and Q 132 (Dr Katie Maras)
1023 Written evidence from Centre for Neurodiversity and Development, Durham University (AAC0325)
1024 Written evidence from Dr Felicity Sedgewick (AAC0205). See also written evidence from Anonymous 31 (AAC0183), Dr Carly Jones MBE (AAC0246) and Andrew Barlow (AAC0238).
1025 Written evidence from Anonymous 60 (AAC0121)

and may display distress in ways that are unusual or unfamiliar to frontline professionals.[1026]

543. The Government cited existing and planned protections for vulnerable witnesses, including: the Victims' Code (statutory guidance that sets out the minimum level of service that victims of crime should receive from agencies and organisations in the criminal justice system); Registered Intermediaries (who can support vulnerable and intimidated witnesses, including autistic people, to give their best evidence); and specialist support from an Independent Domestic Violence Adviser (IDVA), an Independent Sexual Violence Adviser (ISVA), or an Independent Stalking Advocate (ISA).[1027]

544. However, participants in the Autistica Insight Group focus groups reported that, although vulnerable victims and witnesses may be entitled to the use of special measures such as a Registered Intermediary to support two-way communication, access in practice is patchy and relies on individual professionals within the criminal justice system recognising vulnerability.[1028]

Box 30: Supporting autistic victims: good practice examples

In Humberside, a Neurodiverse Independent Sexual Violence Adviser (ISVA) works closely with local adult services to provide tailored support for victims of sexual violence who are autistic or have a learning disability. The ISVA can help victims to understand and engage with the criminal justice system. The ISVA also undertakes relevant institutional advocacy to represent and advocate for victims who are autistic within the criminal justice system.[1029]

SARSAS in Bristol is actively working to provide high quality neurodivergent-adapted support after sexual assault and abuse. Following conversations where the team recognised that a large number of the women and non-binary people they worked with were autistic or had learning difficulties, the organisation co-developed specialist training and a service pathway for these individuals. The training is always at least partly delivered by a neurodivergent survivor, they have neurodivergent counsellors, and the website has a clear set of information targeted specifically at these groups. This information and a guide to sexual consent are available in Easy Read format.[1030]

1026 Written evidence from Centre for Neurodiversity and Development, Durham University (AAC0325). See also written evidence from Dr Felicity Sedgewick (AAC0205).
1027 Written evidence from UK Government (AAC0231). Box 29 sets out provisions in relation to the Victims' Code and Registered Intermediaries.
1028 Written evidence from Autistica (AAC0105)
1029 Written evidence from UK Government (AAC0231)
1030 Written evidence from Dr Felicity Sedgewick (AAC0205)

Autistic suspects, defendants and convicted offenders

Box 31: Provisions on treatment of suspects, criminal culpability and sentencing

The Police and Criminal Evidence Act 1984 (PACE) includes a range of measures addressing "vulnerable suspects" and covers their detention, treatment and questioning by police officers. The bulk of these measures are set down in Code C of PACE, with Annex E addressing "vulnerable persons" directly. The accompanying guidance to PACE says that: "A person may be vulnerable as a result of a having a mental health condition or mental disorder." Those classed as "vulnerable" will be assigned an "appropriate adult" tasked with safeguarding "the rights, entitlements and welfare of 'vulnerable persons'" as they engage with the police and pass through the criminal justice system.

Annex A to the Sentencing Council's guidelines on *Sentencing offenders with mental disorders, developmental disorders, or neurological impairments* lists autism as an example of a developmental disorder that may have an impact on culpability and sentencing.

Among other provisions, the guidelines state that "the fact that an offender has an impairment or disorder should always be considered by the court but will not necessarily have an impact on sentencing", and "in assessing whether the impairment or disorder has any impact on sentencing, the approach to sentencing should be individualistic and focused on the issues in the case."

Courts are encouraged to "be alive to the impact of an impairment or disorder on an offender's ability to understand and participate in proceedings." Courts should also "ensure that offenders understand their sentence and what will happen if they reoffend and/or breach the terms of their licence or supervision."

Sources: Police and Criminal Evidence Act 1984; Home Office, Statutory guidance: PACE Code C 2019 (accessible), 20 December 2023; Sentencing Council, Sentencing offenders with mental disorders, developmental disorders, or neurological impairments, 1 October 2020

545. As we have seen, Dr Katie Maras said there is no evidence that autistic people are more likely than non-autistic people to be offenders overall. For those that do offend, "you can quite often link that back to the autism in some way or understand their offending behaviour in relation to their autism."[1031] Witnesses discussed the factors that made autistic people more likely to be engaged with the criminal justice system as suspects, defendants or convicted offenders.

546. The National Autistic Society said that many autistic individuals enter the justice system due to a lack of support from other agencies, particularly social care, mental health services, and housing.[1032] Dr Alexandra Lewis, Consultant Psychiatrist, Cambridgeshire and Peterborough Foundation NHS Trust, said that people often come into contact with the criminal justice system because it is the first agency that picks them up.[1033] Rt Hon Sir Robert Buckland KC made a similar point.[1034]

547. Participants in the Autistica Insight Group focus groups cited the particular vulnerability of young autistic people in complex social situations, leading

1031 QQ 132 and 139 (Dr Katie Maras)
1032 Written evidence from the National Autistic Society (NAS) (AAC0232)
1033 Q 134 (Dr Alexandra Lewis)
1034 Q 105 (Rt Hon Sir Robert Buckland KC). See also QQ 105 and 109 (Prof Amanda Kirby), 111 (Victoria Bates) and 143 (Dr Marie Tidball MP).

to actions that are inadvertently illegal or being taken advantage of in ways that amount to a crime.[1035] Wigan All Age Autism Partnership Board said that autistic people are vulnerable to bias and misjudgements and are often pressured into crimes without realising it.[1036]

548. Dr Alexandra Lewis said that it needs to be recognised that autistic people are all different and that the factors are different in each case. She cited emerging data that "actual social communication deficits and perhaps being gullible are not major drivers for people becoming involved in the criminal justice system." She said that characteristics such as hyper-focus on a certain topic and the ability to assimilate huge amounts of very complex knowledge may make some autistic people more vulnerable to some forms of offending.[1037]

549. Some witnesses highlighted risk factors that may prevent diversion out of the system. Dr Chloe Holloway-George pointed to evidence that autistic people's behaviour is more likely to be misinterpreted as non-compliant, violent or suspicious by police. Her research found autistic people may be arrested for 'accidental offending', where they engage in behaviour that is wrongly perceived as intentional when it is a reaction to external factors such as mental ill health or stress.[1038] Another witness stated that autistic communication styles (such as differences in eye contact) and expressions of distress (such as meltdowns or shutdowns) are frequently misinterpreted as non-compliance, aggression, or a threat.[1039]

550. Dr Katie Maras cited various reasons for the apparent higher prevalence of autism among people in the criminal justice system, including autistic people being more likely to confess or be caught, less able to advocate for themselves in court and more likely to enter a guilty plea, and the impact of autism on rehabilitation and risk assessments.[1040] Sunderland People First warned of the risk of autistic people making confessions because they want to get out of a situation.[1041]

Screening and diagnosis

551. Dr Katie Maras observed that one of the key problems is the identification of autistic people from first response and throughout the criminal justice system. It may not be known or immediately apparent that a person is autistic and, even where they have a diagnosis, they may be reluctant to share it.[1042] The National Autistic Society said that many autistic people in the criminal justice system remain undiagnosed or misdiagnosed, or face long waits for a diagnostic assessment.[1043]

552. Dr Maras noted that autistic women and girls may be less likely to have received a diagnosis prior to contact with the criminal justice system.[1044] The 2017 *Lammy Review* found that "in the youth system, young BAME [Black, Asian and Minority Ethnic] prisoners are less likely to be recorded as having

1035 Written evidence from Autistica (AAC0105)
1036 Written evidence from Wigan All Age Autism Partnership Board (AAC0106)
1037 QQ 134 and 140 (Dr Alexandra Lewis)
1038 Written evidence from Dr Chloe Holloway-George (AAC0379)
1039 Written evidence from Georgia Holliday (AAC0134). See also written evidence from Tameside Autism Network (AAC0286).
1040 Q 132 (Dr Katie Maras)
1041 Written evidence from Sunderland People First (AAC0093)
1042 Q 132 (Dr Katie Maras)
1043 Written evidence from National Autistic Society (NAS) (AAC0232)
1044 Q 132 (Dr Katie Maras)

problems, such as mental health, learning difficulties and troubled family relationships, suggesting many may have unmet needs."[1045]

553. HM Inspectorate of Prisons acknowledged that achieving positive outcomes for autistic individuals in the criminal justice system begins with identification and screening.[1046] However, access to screening and diagnosis within the criminal justice system is patchy at best. The Government conceded that prison health primary care services found it difficult to access neurodevelopmental assessment waiting lists.[1047] The National Autistic Society pointed out that some assessment providers will not conduct assessments while there is an ongoing court case or the potential for recall to custody.[1048]

554. Independent Monitoring Boards and Lay Observers said that there were often long waiting lists for those without a diagnosis to access autism assessment. They did point out that some autistic people arrive at prison with a diagnosis (either from another establishment or from the community), and some prisons have introduced new screening processes which aim to aid the identification of neurodivergent people on arrival. However, information on the needs of new arrivals is not always communicated from the sending prisons.[1049]

The experience of autistic people at each stage of the criminal justice system

555. We invited our witnesses to reflect on the experiences of autistic people at each stage in the criminal justice system. In so doing we acknowledge that the criminal justice system as a whole is under severe strain. The July 2025 report of the Justice and Home Affairs Committee on *Better prisons: less crime* observed:

> "Our prisons are currently operating in a state of crisis. They are overcrowded, often in bad and unsanitary condition, and face issues such as a shortage of funds, gangs operating with impunity, drones undermining security, an alarming availability of drugs and over-stretched, demoralised staff."[1050]

556. On top of this, as the July 2021 *Neurodiversity in the Criminal Justice System: a review of evidence*[1051] report found, some of the difficulties that neurodivergent people experience may place them at particular disadvantage upon arrest, at court, on community supervision, in prison and on release.[1052]

557. Too often there is a lack of coordination between the different parts of the criminal justice system. Martin Jones CBE, HM Chief Inspector of Probation, said that while national strategies appear to be the right ones:

1045 Rt Hon David Lammy MP, *The Lammy Review: An independent review into the treatment of, and outcomes for, Black, Asian and Minority Ethnic individuals in the Criminal Justice system*, 8 September 2017
1046 Written evidence from HM Inspectorate of Prisons (AAC0210)
1047 Written evidence from UK Government (AAC0231)
1048 Written evidence from National Autistic Society (NAS) (AAC0232)
1049 Written evidence from Independent Monitoring Boards and Lay Observers (AAC0120)
1050 House of Lords Justice and Home Affairs Committee, *Better prisons: less crime* (1st Report, Session 2024–26, HL Paper 153)
1051 Criminal Justice Joint Inspection, *Neurodiversity in the Criminal Justice System: a review of evidence*, 15 July 2021
1052 Written evidence from HM Inspectorate of Prisons (AAC0210)

> "Hand-offs create opportunities to lose information—to lose understanding of somebody's needs. A better join-up between the police, probation, prisons and other agencies would ensure that everybody has the potential to keep people out of the system—but also, where they are caught in the system, it would ensure that their needs are met by all the other agencies."[1053]

558. One member of a self-advocacy group who works as a prison officer observed that "most of what's needed already exists in existing policies. The issue could lie in an inconsistent application of them. Improvements should focus on pushing what we already have", including early identification, mandatory training, reasonable adjustments, peer support roles and proper involvement of lived experience experts.[1054]

559. There is also a lack of coordination with other service providers. Wigan All Age Autism Partnership Board noted that the footprint of the criminal justice system does not always mirror that of the NHS and local authorities.[1055]

560. Witnesses identified several case studies of good practice at each stage of the criminal justice system (which we outline in Boxes 30 and 32–36). However, these remain patchy and uncoordinated examples, and in many cases will need to be fully tested and evaluated. We therefore cannot vouch for them or for the overall standard and quality of support for autistic people in each setting referred to. We note, however, that some criminal justice settings have been awarded or are aspiring to accreditation under the National Autistic Society Autism Accreditation Programme.[1056]

Youth justice

561. Martin Jones CBE noted that the criminal justice system as a whole, and the probation system in particular, are better at identifying and supporting the needs of children than adults, partly because youth justice services have statutory partnerships built into their remit.[1057] The Government stated that mandatory screening of children for SEND or neurodivergence at police stations or by the Youth Offending Team (YOT) is common practice. In the children and young person's secure estate, the principles of the Framework for Integrated Care are being implemented. This aims to enable the right culture, right workforce, and right approach to intervention.[1058]

562. Dr Alexandra Lewis said that the Framework for Integrated Care will pick up if a child or young person might be autistic or have neurodivergent needs, although it will not produce a diagnosis. It also provides effective training for staff. However, this system is not being implemented in many Young Offender Institutions (YOIs), largely because of staffing issues.[1059]

1053 Q 140 (Martin Jones CBE)
1054 Written evidence from Asperger's Syndrome Self Advocacy (ASSA) West Sussex (AAC0317)
1055 Written evidence from Wigan All Age Autism Partnership Board (AAC0106)
1056 HMP Wakefield was accredited in 2022, National Probation Service Lancashire in 2023 and HMP Whatton in 2024. HMP Peterborough is aspiring to accreditation. These case studies are discussed in Emma Woodhouse, Jack Hollingdale, Lisa Davies et al., 'Identification and support of autistic individuals within the UK Criminal Justice System: a practical approach based upon professional consensus with input from lived experience', *BMC Medicine*, vol 22, Article number 157 (2024): https://doi.org/10.1186/s12916–024-03320-3
1057 QQ 133, 139–40 (Martin Jones CBE)
1058 Written evidence from the UK Government (AAC0231). See NHS England, *Health and justice framework for integration 2022–2025*, 3 November 2022.
1059 Q 136 (Dr Alexandra Lewis)

Box 32: Youth justice: good practice examples

City and Hackney Youth Offending Team have worked with the courts and those in the judicial system to make things more accessible for young people in court. This includes speech and language therapists advising the courts on how to make communication more accessible.[1060]

HM Inspectorate of Prisons cited examples of support for autistic children in the youth estate at HMYOI Feltham and Wetherby.[1061]

Police and custody

563. John Nelson said that training for officers to identify and respond appropriately to autism is still patchy across individual police forces. He said that autistic people may be unfairly targeted for stop and search due to their behaviour.[1062] Dr Chloe Holloway-George said that her research showed that problems with identification of autism in suspects arose because of a lack of understanding of autism among custody staff.[1063]

564. Dr Katie Maras noted that initial police contact "is when that person is under extreme distress, and they are not necessarily able to advocate for what their differences are and how they should be supported better."[1064] Mission Impossible Peer and Self-Advocacy Group said that "some of the police response to autistic people experiencing a meltdown is heavy handed and unnecessary and this needs to change."[1065]

565. Participants in the Autistica Insight Group focus groups reported concerns over racial inequalities in how autistic people in distress are treated by police.[1066] Marsha Martin, Founder and CEO, Black SEN Mamas, also referred to additional discrimination faced by black autistic people in the criminal justice system.[1067]

566. Dr Chloe Holloway-George said that her research found that autistic people can become overwhelmed and distressed by the sensory demands of the police station, such as bright lights and loud noises.[1068] Participants in the Autistica Insight Group focus groups reported anxiety around encounters with police and sudden, sharp demands for eye contact or verbal communication. They said that autistic individuals in custody may not be made aware of their rights in a way that they understand. They also highlighted unclear and indirect standard interview techniques, which can be misinterpreted by autistic people with a literal understanding of language. This can lead to the person being viewed as inconsistent or unreliable, undermining their credibility.[1069]

1060 Written evidence from City & Hackney partnership, NHS North East London (AAC0219)
1061 Written evidence from HM Inspectorate of Prisons (AAC0210)
1062 Q 138 (John Nelson)
1063 Written evidence from Dr Chloe Holloway-George (AAC0379)
1064 Q 132 (Dr Katie Maras)
1065 Written evidence from Mission Impossible Peer and Self-Advocacy Group (AAC0291)
1066 Written evidence from Autistica (AAC0105)
1067 Q 22 (Marsha Martin). The *Lammy Review* concluded that "BAME individuals still face bias, including overt discrimination, in parts of the justice system" It noted that a majority of BAME people (51%) believe "the CJS discriminates against particular groups and individuals", compared with 35% of the British-born white population. See Rt Hon David Lammy MP, *The Lammy Review: An independent review into the treatment of, and outcomes for, Black, Asian and Minority Ethnic individuals in the Criminal Justice system*, 8 September 2017.
1068 Written evidence from National Autistic Society (NAS) (AAC0232)
1069 Written evidence from Autistica (AAC0105)

567. Dr Chloe Holloway-George's research shows that autistic people have particularly negative experiences in police custody, including:

- two-way communication barriers which affect the understanding of questions asked during booking-in with custody staff;
- a lack of accessible information about what will happen during the custody process;
- being encouraged to acquiesce, or respond to police interview questions in a particular way, which may lead to inappropriate admissions of guilt; and,
- difficulties accessing legal safeguards such as legal advice, appropriate adults,[1070] and reasonable adjustments.[1071]

568. Dr Alexandra Lewis said that suspects may not understand the advice they are given: "A duty solicitor comes in with no knowledge, often late at night, to see a distressed person. That is the kind of scenario where there are few eyes on the situation and vulnerability is at its highest." She said that the level of training that appropriate adults have had is highly variable.[1072]

Box 33: Police and custody: good practice examples

John Nelson drew attention to a number of tools:

- the National Autistic Society guide 'Autism: a guide for police officers and staff';
- the use by the Metropolitan Police and Hampshire Police of autism alert cards and car stickers;[1073]
- the Metropolitan Police autism stop and search guide and a guide for first responders responding to autistic meltdowns; and,
- the National Security Agency's use of closed questions and breaks in interviews with autistic individuals suspected of involvement in cybercrime.[1074]

The Nottinghamshire Autism Police Partnership is a group of academics, autistic people and police staff who work together to improve the support of autistic people in police custody. They co-developed a role-specific autism training package for custody staff which includes a training video representing autistic people's lived experience of the custody process, an autism toolkit aimed at improving the practices of custody staff when interacting with autistic suspects, and accessible information about being detained in police custody.[1075]

Avon and Somerset Police have worked with Dr Katie Maras to redesign their custody suites to make them more autism-friendly, including lighting and blankets. They have seen a reduction in escalations and adverse incidents.[1076]

1070 See Box 31.
1071 Written evidence from Dr Chloe Holloway-George (AAC0379)
1072 Q 137 (Dr Alexandra Lewis)
1073 Q 138 (Dr Alexandra Lewis, John Nelson)
1074 Q 138 (John Nelson). See National Police Autism Association, *Met Police releases autism stop & search guide*, 31 December 2022.
1075 Written evidence from Dr Chloe Holloway-George (AAC0379)
1076 Q 138 (Dr Katie Maras)

The City of London Police provides training for custody officers and detention officers, including a video explaining 'Autism Passports'. Passports can be given to detainees who are in custody and contain important information such as how they communicate, their appropriate adult's name and medical conditions.[1077]

Courts and sentencing

569. Participants in the Autistica Insight Group focus groups highlighted traumatic experiences of attending court, with little to no support available for such an unpredictable, high-stress environment. This included a failure to provide timely information about court dates, what to expect or how long proceedings would take, and sudden changes.[1078] Lay Observers described instances of people held in court custody for excessive periods, creating anxiety and distress due to the poor quality of court custody cells.[1079]

570. Participants in the Autistica Insight Group also noted that while Registered Intermediary support is offered for victims and witnesses, it is not available on the same basis to autistic defendants, even though they have not yet been convicted of any crime.[1080] Vulnerable witnesses have clearer statutory rights than defendants to special measures such as an intermediary.[1081] Nevertheless, a court has an inherent jurisdiction to ensure that the defendant has a fair trial, and it may exercise this to allow a vulnerable defendant to be assisted by an intermediary.[1082]

571. The Government clarified that, rather than using Registered Intermediaries, intermediaries for vulnerable defendants in criminal proceedings (and parties in tribunals and the civil and family courts) are provided through a separate HM Courts and Tribunals Service Appointed Intermediary Scheme (HAIS).[1083] This scheme has been in place since 2022.[1084]

572. The Centre for Research in Autism and Education (CRAE) said that, although it is not part of the criminal justice system, autistic adults often face significant challenges in the family justice system. They reported feeling misunderstood, unsupported, and overwhelmed by the court processes, with limited adjustments made for their communication and sensory needs.[1085]

1077 Written evidence from City & Hackney partnership, NHS North East London (AAC0219)
1078 Written evidence from Autistica (AAC0105)
1079 Written evidence from Independent Monitoring Boards and Lay Observers (AAC0120)
1080 Written evidence from Autistica (AAC0105)
1081 See Box 29.
1082 House of Commons Library, *Treatment of adults with autism by the criminal justice system*, CDP-2018–0022, 26 January 2018
1083 Written evidence from UK Government (AAC0231)
1084 John Taggart, 'Vulnerable defendants and the HMCTS court appointed intermediary services', *Criminal Law Review*, Vol 6, pp 432–47
1085 Written evidence from Centre for Research in Autism and Education (CRAE) (AAC0081). See also written evidence from Anonymous 28 (AAC0163).

Box 34: Courts: good practice examples

In 2022, the Ministry of Justice funded a neurodiversity specialist to review how Community Sentence Treatment Requirements (CSTRs)[1086] could be more accessible to neurodivergent individuals. More accessible assessments and sensory aids are being rolled out to criminal courts for individuals sentenced to CSTRs (including Mental Health Treatment Requirements, Alcohol Treatment Requirements and Drug Rehabilitation Requirements).[1087]

The Advocate's Gateway provides online toolkits for lawyers about how to communicate with autistic individuals.[1088] However, the information is several years old and in need of updating.[1089]

Prison and detention

573. Dr Luke Paul Vinter, Senior Lecturer in Applied Criminology, University of Derby, said that his research showed that autistic people can experience prison as fundamentally more punitive than their non-autistic peers. While the predictability and structure of prison life can be helpful, it can also be a tremendous source of stress, anxiety and frustration. The transition from life outside of prison can be particularly traumatic. The reception process can be overwhelming, with little information on what to expect. Daily routines are subject to changes. The communication and application of rules can sometimes be inconsistent, ambiguous or unclear, leading to confusion about what to expect and what is expected of prisoners. Prison staff refer to a lack of specific training and information and to difficulties identifying autistic people in prison.[1090]

574. Dr Vinter highlighted complex prison social environments which autistic individuals find challenging to navigate:

> "This includes unwritten rules and nuanced communication (such as deception, manipulation, humour and sarcasm) which can lead to verbal and physical confrontations. … Autistic people often report feeling alienated, experience bullying or manipulation from others, feel less socially confident and sometimes will avoid interaction as a coping strategy."[1091]

575. Dr Vinter highlighted that there is limited opportunity in prison to avoid or escape aversive stimuli. Autistic people in prison report anxiety, stress, agitation, nausea and disorientation as a result of their sensory experiences. This can contribute to switching off or outbursts in prison activities. These inner experiences are not always immediately obvious on the surface, contributing to misunderstanding.[1092]

1086 Community Sentence Treatment Requirements (CSTRs) are court-ordered treatment programs designed to address the underlying causes of offending behaviour, such as mental health issues, substance misuse, and alcohol dependency. They serve as an alternative to short custodial sentences, aiming to reduce reoffending and improve health and social outcomes. These requirements are available to individuals aged 18 and above who have been convicted of an offence that falls within the sentencing threshold for a Community Order (CO) or Suspended Sentence Order (SSO).

1087 Written evidence from UK Government (AAC0231)

1088 Q 138 (Dr Alexandra Lewis)

1089 See The Advocate Gateway: Responding to communication needs in the justice system, *The Advocate's Gateway Toolkits*.

1090 Written evidence from Dr Luke Paul Vinter (AAC0076)

1091 *Ibid*.

1092 *Ibid*.

576. Independent Monitoring Boards and Lay Observers noted that prisoners told them that they struggled with the physical environment of the prison, including loud noises and being among large groups of people.[1093] The physical environment of the prison estate makes sensory adjustments very difficult to achieve. HM Inspectorate of Prisons were:

> "very concerned that many prisoners are living in poor conditions, with national population pressures meaning that far too many prisoners are currently sharing cells designed for one person. The ability to cater to individuals and support people with autism, for example to have their own cell or a quieter cell, is currently under significant strain."[1094]

577. HM Inspectorate of Prisons acknowledged that, despite some excellent work in some prisons and by some individuals, provision and tailored support is patchy.[1095] Lay Observers cited instances where casework documents failed to provide staff with adequate information on whether a person arriving in detention was autistic or neurodivergent.[1096]

578. Independent Monitoring Boards and Lay Observers said that at many prisons, autistic or neurodivergent prisoners are segregated in Care and Separation Units (CSUs) (previously known as segregation units) due to the lack of alternative provision. Concerns have been raised that these are inappropriate environments for prisoners with complex needs and contribute to a deterioration of mental health.[1097]

Neurodiversity Support Managers

579. A number of witnesses referred to the introduction by HM Prison and Probation Service (HMPPS) of the Neurodiversity Support Manager (NSM) role. The Government stated that this was trialled in 2021/22 before being rolled out across the prison estate in 2024. The Government stated that NSMs are:

- raising awareness of neurodiversity-supportive practices and providing staff with specialist training on autism;
- developing prison environments which are more supportive of needs (for instance designing accessible signage and providing sensory aids); and,
- supporting autistic individuals to engage with education, skills and work, and other rehabilitative activities (for instance providing tailored education opportunities and targeted one-to-one or group support).[1098]

580. Independent Monitoring Boards and Lay Observers said that this dedicated staff resource had a positive impact in supporting prisoners on a one-to-one basis and leading on staff training and inclusivity. At many prisons this led to an increased awareness of the specific needs of prisoners.[1099] HM

1093 Written evidence from Independent Monitoring Boards and Lay Observers (AAC0120)
1094 Written evidence from HM Inspectorate of Prisons (AAC0210)
1095 *Ibid.*
1096 Written evidence from Independent Monitoring Boards and Lay Observers (AAC0120)
1097 *Ibid.*
1098 Written evidence from UK Government (AAC0231)
1099 Written evidence from Independent Monitoring Boards and Lay Observers (AAC0120)

Inspectorate of Prisons welcomed NSM roles but said there has been a lack of evaluation of their impact.[1100]

Box 35: Prisons and detention: good practice examples

HMP Wakefield and HMP Whatton have been accredited under the National Autistic Society Autism Accreditation programme, and HMP Peterborough is aspiring to accreditation. HMP Wakefield has a dedicated unit (the Mulberry unit) for autistic individuals (or those considered extremely likely to be autistic). It has 14 cells and a three-to-one ratio of prisoners to staff. It is led by a clinical psychologist and all staff have specific training. The unit aims to support individuals to re-integrate into standard prison wings.

HMP Coldingley has neurodivergent prisoner champions on each wing, either to raise awareness of the needs of neurodivergent and autistic individuals or to provide direct support.

HMP Lancaster Farms has created a Complex Care Unit (CCU) for 18 neurodivergent prisoners, including a new garden and sensory room.[1101]

HMP Nottingham delivered neurodiversity awareness training to 170 staff members, and uses 'low sensory load' cells on each wing located in quieter areas and used by prisoners who are sensitive to sound or disruption.[1102]

HMP Pentonville has a neurodiversity wing, where people "can come in, have a 10-week assessment and then 12 weeks of support to help them move on and cope better when they go back into custody."[1103]

Probation and rehabilitation

581. Martin Jones CBE, HM Chief Inspector of Probation, said that the Probation Service is under acute pressure. As a result "we see a really patchy, difficult position on the ground, with pockets of good practice" such as in Yorkshire, where local autism groups support probation officers. He noted that the Inspectorate of Probation is currently carrying out inspection around safeguarding vulnerable adults and acknowledged that improvements are required.[1104]

582. The National Autistic Society noted that for some, being in prison or probation can be the first experience of structure and predictability in their lives. This may paradoxically lead some to prefer remaining in custody or probation to retain access to this 'support'.[1105] Essex County Council said that a lack of suitable programmes means prisons are not able effectively to address the offending behaviour of neurodivergent prisoners, such that they do not receive the correct preparation and support for release from prison.[1106]

583. Dr Luke Paul Vinter said that autistic people can find rehabilitation and offending behaviour programmes overwhelming, in particular group-based programmes and abstract exercises prompting exploration of past, present or future feelings. Autistic prisoners can be caught between mainstream programmes that are too fast-paced and adapted programmes for people

1100 Written evidence from HM Inspectorate of Prisons (AAC0210)
1101 Written evidence from Independent Monitoring Boards and Lay Observers (AAC0120)
1102 Written evidence from HM Inspectorate of Prisons (AAC0210)
1103 Q 138 (Dr Alexandra Lewis)
1104 QQ 133 and 138–40 (Martin Jones CBE)
1105 Written evidence from National Autistic Society (NAS) (AAC0232)
1106 Written evidence from Essex County Council (AAC0191)

with a learning disability, which can be experienced as stigmatising or patronising.[1107]

584. Birmingham Autism and ADHD Partnership Board noted that autistic individuals who are in contact with the criminal justice system or have a criminal record face major challenges in finding work, often lacking essential skills and support.[1108] Dr Marie Tidball MP noted that the Care Act 2014 refers to offenders coming out of prison where they have adult social care needs, and said that this could be used as a hook for "a really comprehensive piece of work around keeping people out of prison and keeping them in employment and in the community."[1109]

Box 36: Probation and rehabilitation: good practice examples

The Probation Service has commissioned neurodiversity specialist services in Yorkshire and the Humber, the North West, the West Midlands, the South West and Wales. These services offer direct support to people who are diagnosed or suspected to have a neurodivergent condition, supporting engagement with their orders or licences. They also provide briefings to probation staff, designed to help them to identify factors that may be related to neurodivergent conditions and guidance on how best to support rehabilitation.[1110]

National Probation Service Lancashire has been accredited under the National Autistic Society Autism Accreditation Programme.

HMP Brixton worked with the registered charity Certitude to provide coaching and mentoring opportunities for prisoners after release.[1111]

Proposals for reform

Overview

585. One witness stressed the need for a paradigm shift in the justice system's approach to autistic individuals, moving from misunderstanding and criminalisation to informed understanding, support, and genuine justice.[1112] Dr Alexandra Lewis suggested "trying to reframe the contact with the justice system as a pivotal moment, which can have a positive outcome and is not necessarily a catastrophic point of contact."[1113]

586. Dr Luke Paul Vinter stressed the importance of consistent information-sharing across the criminal justice system and centralised service-wide sources of information.[1114] Witnesses also agreed that a whole-system approach needs to include not only all parts of the criminal justice system

1107 Written evidence from Dr Luke Paul Vinter (AAC0076)
1108 Written evidence from Birmingham Autism and ADHD Partnership Board (AAC0195)
1109 Q 147 (Dr Marie Tidball MP). The statutory guidance to the Autism Act states: "Local authorities must under the Care Act, from April 2015, assess the care and support needs of adults (including those with autism) who may have such needs in prisons or other forms of detention in their local area, and meet those needs which are eligible; work with prisons and other local authorities to ensure that individuals in custody with care and support needs have continuity of care when moving to another custodial setting or where they are being released from prison and back into the community." See Department of Health, *Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy*, 26 March 2015.
1110 Written evidence from UK Government (AAC0231)
1111 Written evidence from HM Inspectorate of Prisons (AAC0210)
1112 Written evidence from Georgia Holliday (AAC0134)
1113 Q 138 (Dr Alexandra Lewis)
1114 Written evidence from Dr Luke Paul Vinter (AAC0076)

itself, but also wider services to stop people entering the criminal justice system and to prevent re-offending.[1115]

587. The July 2021 *Neurodiversity in the Criminal Justice System: a review of evidence*[1116] report made six key recommendations:

- A coordinated and cross-government national strategy.
- A common screening tool to help more accurately determine the prevalence of neurodivergence in the criminal justice system.
- Systematic collection and analysis of data to help more accurately determine the prevalence of neurodivergence in the criminal justice system.
- A programme of awareness-raising and specialist training for staff in the criminal justice system.
- Adjustments throughout the criminal justice system for those with neurodivergent conditions.
- A coordinated means for all criminal justice system agencies to work together and with other statutory and third sector organisations to understand and meet the needs of neurodivergent individuals in the community, preventing offending and supporting rehabilitation.[1117]

588. Notwithstanding the Government's publication in 2022 of a Neurodiversity Action Plan in response to the report,[1118] the evidence we received demonstrated the continued importance of these recommendations.[1119]

A coordinated national strategy

589. The National Autistic Society called for a coordinated, cross-government approach to improve outcomes for neurodivergent individuals within the criminal justice system.[1120]

590. The 2015 statutory guidance does not apply directly to the criminal justice system, although it recommends that bodies in the criminal justice system look to follow the guidance to help improve the delivery of the services they provide. In a chapter on working with the criminal justice system, it states:

> "Police, probation services, courts and prisons should be supported so that they are aware of the communication challenges experienced by people with autism. NHS bodies, Foundation Trusts and local authorities should work with the criminal justice system to achieve this."[1121]

However, the extent to which this happens in practice is unclear.

1115 Written evidence from National Autistic Society (NAS) (AAC0232)
1116 Criminal Justice Joint Inspection, *Neurodiversity in the Criminal Justice System: a review of evidence*, 15 July 2021
1117 Written evidence from HM Inspectorate of Prisons (AAC0210)
1118 HM Prison and Probation Service and Ministry of Justice, *A Response to the Criminal Justice Joint Evidence Review: Neurodiversity in the Criminal Justice System action plan*, 25 January 2023
1119 See for example written evidence from National Autistic Society (NAS) (AAC0232).
1120 *Ibid*.
1121 Department of Health, *Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy*, 26 March 2015

591. Dr Chloe Holloway-George and Dr Marie Tidball MP both said duties in any new iteration of the statutory guidance should be made mandatory for bodies in the criminal justice system, either by amending the Autism Act itself, or through the Equality Act 2010 or other legislation.[1122]

Identification, screening and assessment

592. Dr Luke Paul Vinter called for improved and more consistent autism screening approaches, which could be integrated into a mandatory neurodivergence screening process during the prison reception process, or earlier in the system.[1123] Other submissions called for mandatory autism screening at all justice system entry points.[1124] West Kent Autism Parents' Support Society argued that all young people entering the justice system should be screened for autism and ADHD, as early diagnosis and support can help break the cycle of reoffending.[1125] The Royal College of Speech and Language Therapists said that early identification of autism following entry to the criminal justice system was vital in identifying communication needs.[1126] Greater Manchester Specialist Support Team underlined the importance of access to diagnostic pathways within custody.[1127]

Data collection

593. Dr Marie Tidball MP recommended improving data collection and flagging, which she noted "was talked about in previous autism strategies but never really got off the ground."[1128] Dr Chloe Holloway-George agreed that police forces should take steps to improve the recording of the number of autistic people who enter the criminal justice system.[1129]

Awareness-raising and specialist training

Victims and witnesses

594. The Centre for Neurodiversity and Development at Durham University stressed the importance of training co-produced with or led by autistic people, including information on how to support victim-survivors who may struggle reliably to use speech when distressed, and offering alternative communication tools, an independent advocate or appropriate adult. They said that frontline workers should be aware of how the sensory environment may lead to heightened distress and difficulty in providing testimony.[1130]

Police and custody

595. Autistica Insight Group focus group participants called for initiatives to improve understanding of autism across the police force, including training, advisory groups with experts by experience, and an experienced champion in every police force to support with communication.[1131] Birmingham Autism and ADHD Partnership Board said that training for police is

1122 Written evidence from Dr Chloe Holloway-George (AAC0379) and Q 147 (Dr Marie Tidball MP)
1123 Written evidence from Dr Luke Paul Vinter (AAC0076)
1124 Written evidence from Anonymous 18 (AAC0067) and Anonymous 31 (AAC0183)
1125 Written evidence from West Kent Autism Parents' Support Society (AAC0340)
1126 Written evidence from the Royal College of Speech and Language Therapists (AAC0197)
1127 Written evidence from Greater Manchester Specialist Support Team (AAC0299)
1128 Q 147 (Dr Marie Tidball MP)
1129 Written evidence from Dr Chloe Holloway-George (AAC0379)
1130 Written evidence from Centre for Neurodiversity and Development, Durham University (AAC0325). See also QQ 138 (Dr Katie Maras) and 140 (John Nelson).
1131 Written evidence from Autistica (AAC0105)

crucial to ensure they understand autism and can effectively support autistic individuals, especially when alert cards are used.[1132]

596. John Nelson and Mission Impossible Peer and Self-Advocacy Group said that the police should have mandatory autism training because autistic people are more likely to come into contact with them. Training should focus on issues such as unhealthy relationships, coercion and coping strategies.[1133]

Prison and detention

597. Dr Luke Paul Vinter called for co-designed mandatory training reflective of the prison context to enhance autism awareness and neuroinclusive communication among staff, prisoners and autistic individuals themselves. He said that fixed points of contact with especially strong levels of autism awareness are a vital source of support for autistic prisoners and prison staff.[1134] Marilyn Jones called for lived experience education and information for autistic prisoners to help them understand why they struggled.[1135]

Support and adjustments

598. We have noted that section 20 of the Equality Act imposes a duty on service providers to make reasonable adjustments for disabled people.[1136] Witnesses advocated for reasonable adjustments to be made for autistic people throughout the criminal justice system, through both universal design and person-centred support.

599. Dr Luke Paul Vinter called for adjustments and accommodations in the sensory environment, learning from schools.[1137] Wigan All Age Autism Partnership Board likewise called for improved custody facilities (including sensory-friendly spaces, better accessibility and clearer guidance). They also stressed the importance of accessible information and guidance on appointments, legal processes, reasonable adjustments and support.[1138] Autistica Insight Group focus group participants called for basic adaptations to police communication (such as using direct, literal language) to ensure autistic people understand interview questions and their rights; and providing clear advance information about what to expect and the support available in court appearances, including access to intermediaries.[1139]

600. A parent of an autistic individual arrested and charged for serious offences called for changes including providing information in advance of a court hearing, providing questions in advance and in writing, not assuming guilt because of 'no comment' responses, asking interview questions about how autism affects the defendant, awareness of sensory aids, asking questions in a simple short form with a quiet voice, allowing support from an appropriate adult or carer, and reasonable adjustments when a prisoner is transferred.[1140]

1132 Written evidence from Birmingham Autism and ADHD Partnership Board (AAC0195)
1133 Q 138 (John Nelson) and written evidence from Mission Impossible Peer and Self-Advocacy Group (AAC0291). See also written evidence from Anonymous 20 (AAC0079).
1134 Written evidence from Dr Luke Paul Vinter (AAC0076)
1135 Written evidence from Marilyn Jones (AAC0165)
1136 See Box 5.
1137 Written evidence from Dr Luke Paul Vinter (AAC0076). See also written evidence from Dr Chloe Holloway-George (AAC0379).
1138 Written evidence from Wigan All Age Autism Partnership Board (AAC0106)
1139 Written evidence from Autistica (AAC0105)
1140 Written evidence from Anonymous 24 (AAC0124)

601. Mission Impossible Peer and Self-Advocacy Group, Sunderland People First and Asperger's Syndrome Self Advocacy (ASSA) West Sussex each said that people should be supported to understand their rights more and have access to advocates. They said that it is crucial that autistic people who are arrested are given the opportunity to have an appropriate adult present.[1141]

602. Dr Katie Maras stressed the importance of an individualised, needs-based approach throughout the process from police stages to court and prison.[1142] Dr Luke Paul Vinter also said that support needs to be tailored to the individual, including giving them the opportunity to convey their own needs. He said that co-produced documents can be a useful means of articulating an individual's needs and strengths, and follow their journey through the system.[1143] Mission Impossible Peer and Self-Advocacy Group said that police passports should be more widespread.[1144]

603. Autistica Insight Group focus group participants said that legal professionals and jurors should be informed, where appropriate, of how autism may affect an individual's communication and presentation.[1145] The Royal College of Speech and Language Therapists and Greater Manchester Specialist Support Team said that access to speech and language therapy services throughout the criminal justice system was vital.[1146]

A coordinated approach to prevention and rehabilitation

Prevention

604. The National Autistic Society said that it is crucial to improve support across all statutory services to prevent autistic people from entering the criminal justice system in the first place.[1147]

605. Greater Manchester Specialist Support Team called for an increased range of options to divert people at risk of entering the criminal justice system.[1148] John Nelson argued for initiatives used by Youth Offending Teams to try to keep children out of the court system to be applied to autistic adults through 'Vulnerable Persons Offending Teams'.[1149]

Rehabilitation

606. Dr Luke Paul Vinter called for improvements to prison-based rehabilitation, including alternatives to group-based programmes, such as one-to-one support. A pre-intervention foundational skills or induction programme could also help some autistic individuals become familiarised with what to expect and develop confidence.[1150] Birmingham Autism and ADHD Partnership Board said that there is a need for significant investment in

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1141 Written evidence from Mission Impossible Peer and Self-Advocacy Group (AAC0291), Sunderland People First (AAC0093) and Asperger's Syndrome Self Advocacy (ASSA) West Sussex (AAC0317)
1142 Q 140 (Dr Katie Maras)
1143 Written evidence from Dr Luke Paul Vinter (AAC0076). See also written evidence from Dr Chloe Holloway-George (AAC0379).
1144 Written evidence from Mission Impossible Peer and Self-Advocacy Group (AAC0291)
1145 Written evidence from Autistica (AAC0105)
1146 Written evidence from the Royal College of Speech and Language Therapists (AAC0197) and Greater Manchester Specialist Support Team (AAC0299)
1147 Written evidence from National Autistic Society (NAS) (AAC0232)
1148 Written evidence from Greater Manchester Specialist Support Team (AAC0299)
1149 Q 139 (John Nelson)
1150 Written evidence from Dr Luke Paul Vinter (AAC0076)

prison education and training to equip young adults with essential skills for employment, reducing reoffending.[1151]

607. West Kent Autism Parents' Support Society argued that every offender should be assigned a support worker trained in autism and ADHD to help with reintegration into society. They stressed that teaching life skills can help people build healthier relationships, behaviours and futures.[1152] Mission Impossible Peer and Self-Advocacy Group stressed the importance of support once an individual has left prison and transitioned back to the community.[1153]

Conclusions and recommendations

608. **The current autism strategy aims for all parts of the criminal justice system to have made demonstrable progress by 2026 in ensuring that autistic people have equal access to care and support where needed. This aim is unlikely to be met. While there are many pockets of good practice, support across the system as a whole is patchy and inconsistent. The system is not joined up in its support for and understanding of autistic people, and there is no effective mechanism for best practice in a particular institution or part of the system to be applied across the system as a whole.**

609. **We identify six specific problems:**

- **poor identification, screening and assessment pathways within the criminal justice system;**
- **poor and inconsistent collection and sharing of data on numbers of autistic people and the needs of individuals;**
- **a lack of understanding of autism and the specific difficulties that people may face in the criminal justice system;**
- **a lack of support and adjustments for autistic people across the system;**
- **continued cases of inappropriate treatment; and,**
- **inconsistent practice across the system as a whole.**

610. **The July 2021 *Neurodiversity in the Criminal Justice System: a review of evidence* report made six core recommendations:**

- **A coordinated and cross-government national strategy.**
- **A common screening tool to help more accurately determine the prevalence of neurodivergence in the criminal justice system.**
- **Systematic collection and analysis of data to help more accurately determine the prevalence of neurodivergence in the criminal justice system.**
- **A programme of awareness-raising and specialist training for staff in the criminal justice system.**

1151 Written evidence from Birmingham Autism and ADHD Partnership Board (AAC0195)
1152 Written evidence from West Kent Autism Parents' Support Society (AAC0340)
1153 Written evidence from Mission Impossible Peer and Self-Advocacy Group (AAC0291)

- **Adjustments throughout the criminal justice system for those with neurodivergent conditions.**

- **A coordinated means for all criminal justice system agencies to work together and with other statutory and third sector organisations to understand and meet the needs of neurodivergent individuals in the community, preventing offending and supporting rehabilitation.**

611. ***We endorse these recommendations. The Government must publish a full account of progress in each part of the criminal justice system towards meeting these objectives, and how it will seek to address them in the context of the next autism strategy.***

612. ***In particular, we call on the Government, working with all parts of the criminal justice system, the NHS and local authorities, to develop an evidence base on, test and roll out effective ways to identify and support autistic people. This should address support for victims, witnesses, suspects, defendants or those convicted of a crime. It should also focus on: preventing people entering the criminal justice system; screening, support and adjustments; tailored rehabilitation; and training for frontline staff.***

APPENDIX 1: LIST OF MEMBERS AND DECLARATIONS OF INTEREST

Members

Baroness Rock (Chair)
Lord Addington
Baroness Browning
Lord Crisp
Lord Elliott of Mickle Fell
Baroness Goudie
Baroness Hodgson of Abinger
Lord Hope of Craighead
Baroness Pitkeathley
Baroness Ritchie of Downpatrick
Lord Scriven
Lord Wigley

Declarations of interests

Baroness Rock (Chair)

Senior Adviser, Newton Europe (remunerated)

Lord Addington

I am currently the lead person on the Liberal Democrat benches on special educational needs and a member of the education team. I have a long history of being involved in disability matters having spoken for the Liberal Democrats on the subject for numerous years as a spokesperson on either education or Department for Work and Pensions (DWP) matters.

President, British Dyslexia Association (unpaid)

Chairman, MicroLink plc (remunerated): A firm specialising in support for disabled people in education and the workplace often involving technological solutions and adjustments to the workplace

Baroness Browning

Vice-Chair, All-Party Parliamentary Group (APPG) on Autism

Member, Autism Bill Committee in 2008–09 parliamentary session (House of Commons)

Vice President, National Autistic Society

Lord Crisp

No relevant interests declared

Lord Elliott of Mickle Fell

President, The Jobs Foundation (remunerated)

Baroness Goudie

No relevant interests declared

Baroness Hodgson of Abinger

No relevant interests declared

Lord Hope of Craighead

No relevant interests declared

Baroness Pitkeathley

Vice President, Carers UK

Baroness Ritchie of Downpatrick

Member, Advisory Board, PeopleHawk (remunerated): an online Human Resources platform for students and graduates

Lord Scriven

Liberal Democrat frontbench spokesperson in the House of Lords for health

Vice President, Local Government Association

Lord Wigley

Relevant former interests:

Vice President, Local Government Association (interest ceased 30 April 2024)

Vice President, MENCAP (interest ceased 30 April 2024)

A full list of Members' interests can be found in the Register of Lords' Interests: https://www.parliament.uk/hlregister

Specialist Adviser

Professor Laura Crane

I hold a salaried role as Professor of Autism Studies at the University of Birmingham, where I am Director of the Autism Centre for Education and Research (ACER) and Director of Research for the School of Education.

I hold an honorary position as Professor of Autism Research and Education at University College London.

I currently receive funding for autism research from the Economic and Social Research Council (ESRC), the National Institute for Health and Care Research (NIHR), the Sheila Coates Foundation and the Nuffield Foundation. These projects are:

- *'Measuring Special Measures: Supporting Access to Justice for Autistic People'. Funder: ESRC, awarded to Maras and Crane.*
- *'Peer-group intervention to promote successful transition to adulthood for autistic people: A feasibility RCT'. Funder: NIHR, awarded to Cooper, Mandy, Russell, Beresford, Crane, Worsley, Bater and Portway. This project is a collaboration with the charity Ambitious about Autism.*
- *'Making autism education research truly make a difference'. Funder: Sheila Coates Foundation, awarded to Crane.*
- *'EXAMINE: Exam inequality for neurodivergent students'. Funder: Nuffield Foundation, awarded to Remington, Bird, Crane, Richardson and Shepherd.*

I do not receive personal payments in relation to these research grants, but the University of Birmingham receives funding for part of my salary to enable me to work on these projects.

I also have PhD studentships funded via UKRI. Of note, I have been awarded a Collaborative PhD Studentship in partnership with the charity Ambitious about Autism, which began in October 2025.

I have previously received funding for autism research (as principal or co-investigator) from the following organisations: Ambitious about Autism, Autistica, British Academy, ESRC, NIHR, and the John and Lorna Wing Foundation. As above, I have not received any personal payments in relation to these research grants, but my employer has (depending on the funder) received funding for part of my salary to enable me to work on these projects.

Some of my research involves developing and/or evaluating supports and interventions for autistic people, their families, or the professionals who work with them. I do not receive any personal payments in relation to this work.

I occasionally receive royalties from sales of two co-edited books on autism.

I occasionally receive personal payments for academic dissemination of autism research (such as lectures) and for academic examinations (such as of PhD theses).

I currently hold (or have held during the course of the Committee's work) the following roles in relation to external boards and organisations, for which I do not receive any payment:

- *Editorial Board member at the academic journal Autism.*
- *Autism Advisor to the National Autistic Society.*
- *Partnership Board member of the Autism Alliance UK.*
- *Member of the Birmingham Autism and ADHD Partnership Board.*
- *Member of the Office of Qualifications and Examinations Regulation (Ofqual) Access Consultation Forum (ceased in May 2025).*
- *Member of the Trial Steering and Data Monitoring Committee of the OSI-Autism trial (University of Oxford, NIHR-funded).*
- *Member of the Scientific Advisory Board for the 'Conceptualisations of Neurodiversity and Barriers to Inclusive Pedagogy for Early Career Teachers (ConNECT)' project (University of Surrey, ESRC-funded).*
- *Member of the Advisory Group for the 'Neurodivergence at work: ensuring employment support systems meet the needs of neurodivergent people' project (University of Sheffield, NIHR-funded).*

I occasionally serve as an abstract reviewer for autism-related conferences, in exchange for which I may receive subsidies (such as free conference attendance). In 2025, I have served in this capacity for Autism Europe.

APPENDIX 2: LIST OF EVIDENCE AND COMMITTEE ACTIVITY

Evidence is published online at: https://committees.parliament.uk/committee/770/autism-act-2009-committee/publications/ and available for inspection at the Parliamentary Archives (0207 219 3074).

Evidence in alphabetical order

Aquayemi-Claude Akinsanya	AAC0046	
Sana Ali	AAC0347	
Ambitious about Autism	AAC0206	QQ 7–14 and QQ 193–201, Jolanta Lasota, CEO, Ambitious about Autism, and Chair, Autism Alliance UK
Ivan Ambrose	AAC0068	
Anonymous 1	AAC0280	
Anonymous 2	AAC0005	
Anonymous 3	AAC0007	
Anonymous 4	AAC0015	
Anonymous 5	AAC0021	
Anonymous 6	AAC0022	
Anonymous 7	AAC0023	
Anonymous 8	AAC0032	
Anonymous 9	AAC0034	
Anonymous 10	AAC0042	
Anonymous 11	AAC0044	
Anonymous 12	AAC0051	
Anonymous 13	AAC0055	
Anonymous 14	AAC0056	
Anonymous 15	AAC0057	
Anonymous 16	AAC0060	
Anonymous 17	AAC0062	
Anonymous 18	AAC0067	
Anonymous 19	AAC0073	
Anonymous 20	AAC0079	
Anonymous 21	AAC0094	
Anonymous 22	AAC0095	
Anonymous 23	AAC0108	
Anonymous 24	AAC0124	
Anonymous 25	AAC0129	

Anonymous 26	AAC0137
Anonymous 27	AAC0149
Anonymous 28	AAC0163
Anonymous 29	AAC0164
Anonymous 30	AAC0170
Anonymous 31	AAC0183
Anonymous 32	AAC0203
Anonymous 33	AAC0214
Anonymous 34	AAC0221
Anonymous 35	AAC0235
Anonymous 36	AAC0236
Anonymous 37	AAC0243
Anonymous 38	AAC0249
Anonymous 39	AAC0251
Anonymous 40	AAC0252
Anonymous 41	AAC0255
Anonymous 42	AAC0257
Anonymous 43	AAC0259
Anonymous 44	AAC0266
Anonymous 45	AAC0272
Anonymous 46	AAC0275
Anonymous 47	AAC0276
Anonymous 48	AAC0281
Anonymous 49	AAC0289
Anonymous 50	AAC0290
Anonymous 51	AAC0315
Anonymous 52	AAC0334
Anonymous 53	AAC0336
Anonymous 54	AAC0344
Anonymous 55	AAC0356
Anonymous 56	AAC0359
Anonymous 57	AAC0364
Anonymous 58	AAC0369
Anonymous 59	AAC0372
Anonymous 60	AAC0121
Anonymous 61	AAC0282

Anonymous 62	AAC0027	
Liana Arampidou	AAC0179	
Fuchsia Arnold	AAC0346	
Gillian Ashton	AAC0178	
Asperger's Syndrome Self Advocacy (ASSA) West Sussex	AAC0317	
Association of Directors of Adult Social Services (ADASS)		QQ 110–117, Simon Froud, Representative, Association of Directors of Adult Social Services (ADASS), and Director of Adult Social Care and Statutory DASS, Telford & Wrekin Council QQ 150–158, Fazeela Hafejee, Representative, Association of Directors of Adult Social Services (ADASS), and Assistant Director of Adults with Disabilities, Bradford Council
Association of Directors of Children's Services (ADCS)		QQ 150–158, Nigel Minns, Chair of Health, Care & Additional Needs Policy Committee, Association of Directors of Children's Services, and Executive Director for Children and Young People, Warwickshire County Council
Association of Graduate Careers Advisory Services (AGCAS)	AAC0099	
Association of Graduate Careers Advisory Services (AGCAS) Disability Task Group	AAC0136	
Auticon	AAC0316	
Autism Action	AAC0233, AAC0380, AAC0381	QQ 36–42, Tom Purser, CEO, Autism Action
Autism Alliance UK	AAC0143	QQ 1–6 and QQ 193–201, Adam Micklethwaite, Director, Autism Alliance UK
Autism in Mind	AAC0271	
Autism in Mind Sunderland	AAC0176	

Autistica	AAC0105	QQ 7–14 and QQ 193–201, Dr James Cusack, CEO, Autistica
Autistic Nottingham	AAC0047	
Autistic Parents UK	AAC0292	
Autistic Spectrum Collective	AAC0016	
Avenues Group	AAC0126	
Babcock International		QQ 125–131, Peter Stokes, Neurodiversity and Social Mobility Manager, Babcock International
Dr Elisa Back	AAC0204	
Victoria Bagnall	AAC0075	
Char Bailey		QQ 118–124, Char Bailey
Christopher Barber	AAC0304	
Andrew Barlow	AAC0238	
Sharon Barrowman	AAC0181	
Dr Adam Edward Barton	AAC0030	
Tanya Baxby	AAC0153	
George Bell	AAC0293	
Professor Bryony Beresford		QQ 23–29, Professor Bryony Beresford, Professor of Social Policy, University of York
BeU North Yorkshire	AAC0343	
Bienias and Sadana	AAC0142	
Birmingham Autism and ADHD Partnership Board	AAC0195	
Black SEN Mamas		QQ 15–22, Marsha Martin, Founder and CEO, Black SEN Mamas
Antonia Borneo	AAC0305	
Dr Virginia Bovell OBE		QQ 52–59, Dr Virginia Bovell OBE
Freya Box	AAC0158	
Heather Bridge	AAC0297	
Brightstars Autistic Club	AAC0341	
British Association for Supported Employment		QQ 91–100, Laura Davis, CEO, British Association for Supported Employment

Rt Hon Sir Robert Buckland KC		QQ 101–109, Rt Hon Sir Robert Buckland KC, former Chair, Buckland Review of Autism Employment
Samantha Bullock	AAC0261	
Georgine Burnett	AAC0102	
Christopher Burns	AAC0031	
Burton Street Foundation	AAC0331	
Butterfly Hope	AAC0185	
Joanne Cammish	AAC0171	
Leo Capella	AAC0188	QQ 15–22, Leo Capella, Training Consultant (Employment Specialist), National Autistic Society
Care England	AAC0211	
Care Quality Commission	AAC0366	QQ 79–84, James Bullion, Interim Chief Inspector of Adult Social Care and Integrated Care, Care Quality Commission
CareTrade	AAC0350	
Dr Sarah Cassidy		QQ 36–42, Dr Sarah Cassidy, Associate Professor in Psychology, Nottingham University
Centre for Applied Autism Research (CAAR)	AAC0070	
Centre for Neurodiversity and Development, Durham University	AAC0325	
Centre for Research in Autism and Education (CRAE)	AAC0081	QQ 91–100, Professor Anna Remington, Director, Centre for Research in Autism and Education (CRAE), University College London
Cerebra	AAC0324	
Lou Chandler	AAC0119	
Professor Rebecca Charlton		QQ 60–66, Professor Rebecca Charlton, Professor of Psychology, Goldsmiths, University of London
Chartered Institute of Personnel and Development (CIPD)	AAC0200	

Cheshire West All Age Autism and Neurodivergence Partnership Board	AAC0354	
James Christie	AAC0039	
Christina Lou	AAC0239	
City & Hackney partnership, NHS North East London	AAC0219	
Dr Charlotte Hamilton Clarke	AAC0139	
Charli Clement	AAC0122	
Archbishop Ryan Cleminson	AAC0234	
Cloverleaf Advocacy	AAC0199	
Dr Anne Cockayne	AAC0303	
Keren Coney	AAC0157	
Dr Anna Cook	AAC0063	
Sue Cook	AAC0154	
Lucy Cowap	AAC0041	
Dr Charlotte Cox	AAC0082	
Rebecca Cox	AAC0159	
Dr Anna Crabtree and Dr Louise Rutter	AAC0089	
CubeLynx		QQ 125–131, Mayur Gondhea, Founder, CubeLynx
Matthew Davies	AAC0186	
Martin Davis	AAC0189	
Sofie Day	AAC0043	
DFN Project SEARCH		QQ 118–124, Sian Foster, Director of Service Development, DFN Project SEARCH
Disability@Work	AAC0036	
Disability Rights UK		QQ 1–6, Fazilet Hadi, Head of Policy, Disability Rights UK
Disabled Students UK (DSUK)	AAC0220	
The Diversity Project	AAC0146	
Marta Dobrowolska	AAC0144	
Mary Docton	AAC0311	

Martin Doddimeade	AAC0018	
Dr Mary Doherty		QQ 43–51, Dr Mary Doherty, Founder, Autistic Doctors International
Yair Domb	AAC0190	
Dr Sophie Doswell	AAC0114	
Down's Syndrome Association	AAC0101	
Nicky Drury	AAC0260	
Niamh Dyer	AAC0065	
Educating Edward	AAC0306	
Education Otherwise	AAC0069	
Engineering Professors' Council	AAC0192	
Dr Edith England, Dr Josie Henley and Dr Emma Sheppard	AAC0345	
Jon-Paul Entwistle	AAC0182	
Essex County Council	AAC0191	
Mark Evans	AAC0308	
Evolve Psychology Services	AAC0301	
Celestine Fairhall	AAC0253	
Isabelle Finn-Kelcey	AAC0072	
Valerie Fitch	AAC0080	
Professor Sue Fletcher-Watson		QQ 67–73, Professor Sue Fletcher-Watson, Professor of Developmental Psychology, University of Edinburgh
Sarah Francis-Soutar	AAC0174	
Maurice Frank	AAC0277	
Dr Samantha Friedman and Dr Keren MacLennan	AAC0112	
Chloe Frost	AAC0270	
Caren and Callum Gamble	AAC0267	
Jasmine Garriga	AAC0117	
Jude Geddes	AAC0166	
Helen Gibson	AAC0312	
Jenny Gilchrist	AAC0014	
Dr Valeri Gladkova	AAC0226	

Dr Anita Z Goldschmied	AAC0194	
Dr Char Goodwin, Professor Manuela Barreto, Professor Ginny Russell, Eleanor Jane Turner, Dr Mary Doherty and Dr Sebastian Shaw	AAC0307	
Fiona Gordon	AAC0361	
Ryan Graham	AAC0011	
Spenser Gray	AAC0363	
Dr Corinne Greasley-Adams, Dr David Thorpe, Professor James Richards, Professor Katherine Sang and Professor Mary Stewart	AAC0215	
Greater Manchester Autism Consortium	AAC0296	
Greater Manchester Specialist Support Team	AAC0299	
Professor Jonathan Green	AAC0172	QQ 23–29, Professor Jonathan Green, Professor of Child and Adolescent Psychiatry, University of Manchester
Spencer Grennan	AAC0365	
Group for Autism, Insurance, Investment and Neurodiversity (GAIN)	AAC0209	
Professor Karen Guldberg		QQ 67–73, Professor Karen Guldberg, Professor of Autism Studies, University of Birmingham, and Chair, Neurodivergence Task and Finish Group, Department for Education (DfE)
Dr Fiona Gullon-Scott and Professor Luke Clements	AAC0104	
Helen Haddon	AAC0254	
Hampshire Autism Partnership Board	AAC0352	
Hampshire Autism Voice	AAC0160	
Hampshire County Council	AAC0321	
Carol Ann Hardisty	AAC0283	
Anita Harrington		QQ 85–90, Anita Harrington
Emma Harris	AAC0177	

Karen Harrison	AAC0274	
Helen Harverson	AAC0288	
Miguel Hayworth	AAC0066	
Dr Anne Heavey		QQ 73–78, Dr Anne Heavey, Director of Insights, Ambition Institute
Officers of Hertfordshire County Council	AAC0125	
Lisa Hesketh	AAC0008	
Hesley Group	AAC0302	
Fiona Hipkin	AAC0167	
Benjamin Hitimana	AAC0368	
HM Chief Inspector of Probation		QQ 132–141, Martin Jones CBE, HM Chief Inspector of Probation
HM Inspectorate of Prisons	AAC0210	
Hogan	AAC0029	
Georgia Holliday	AAC0134	
Professor Sheila the Baroness Hollins		QQ 79–84, Professor Sheila the Baroness Hollins, former Chair, Oversight Panel review of Independent Care (Education) and Treatment Reviews
Dr Chloe Holloway-George	AAC0379	
Jack Honey	AAC0273	
Gavin Hoole	AAC0338	
Peter Hopkins	AAC0374	
Professor Kim Hoque		QQ 91–100, Professor Kim Hoque, Professor of Human Resource Management, King's College London
Gabriela (Gabby) Horecka	AAC0230	
Horizon Care Supported Living	AAC0212	
Professor Andrew Hugill	AAC0138	
Professor Nusrat Husain and Anum Farooq	AAC0161	
Dr Gavin Hutchison	AAC0050	
Independent Monitoring Boards and Lay Observers	AAC0120	

Steven Ingram	AAC0353	
I-RAP Research Group	AAC0131	
Penny Jackson	AAC0045	
Sarah Jackson	AAC0019	
Laura Johnson	AAC0241	
Dr Carly Jones MBE	AAC0246	
Marilyn Jones	AAC0165	
Dr Themis Karaminis	AAC0216	
Sandy Keenay	AAC0077	
Kent and Medway NHS and Social Care Partnership Trust	AAC0337	
Professor Amanda Kirby		QQ 101–109, Professor Amanda Kirby, Chair, Neurodiversity employment academic panel
Alijan Kirk and Oscar Law-Jones	AAC0053	
Kirklees Council, and Kirklees Health and Care Partnership	AAC0118	
Susan Kirkman	AAC0180	
Professor Martin Knapp		QQ 7–14, Professor Martin Knapp, Professor of Health and Social Care Policy, London School of Economics and Political Science
Professor Nelya Koteyko	AAC0086	
Sarah Labovitch	AAC0247	
Dr Susanne Lace	AAC0327	
Gemma Ladley	AAC0141	
Daisy Lapsey	AAC0351	
Dr Jan Lawler	AAC0295	
Lisa Lawton	AAC0054	
Learning in Harmony Trust (LiHT)	AAC0218	
Stephanie Lees	AAC0140	
Legal Action for Women, Disabled Mothers' Rights Campaign, and WinVisible	AAC0330	
Sarah Leigh	AAC0085	

Usha Lekha	AAC0258	
Dr Alexandra Lewis		QQ 132–141, Dr Alexandra Lewis, Consultant Psychiatrist, Cambridgeshire and Peterborough Foundation NHS Trust
Cheryl Lewis	AAC0017	
Liberty Academy Trust	AAC0208	QQ 73–78, Dr Nicola Crossley, Chief Executive Officer, Liberty Academy Trust, and SEND (Special Educational Needs) representative, Association of School and College Leaders
Dr Paul Linehan	AAC0237	
Live! Cheshire	AAC0087	
Local Government Association (LGA)	AAC0198	
Dr Keri-Michèle Lodge	AAC0320	
Rosalyn Lord	AAC0156	
Joan Love	AAC0033	
Dr Alan Lovell, Kieran Becker, Maxwell S Barnish, Dr Tom Arthur, Joelle Kirby, Professor Helen Dodd, Dr Vijaya Raghavan Dhandapani, G J Melendez-Torres and Dr Anna Price	AAC0357	
Nancy Lowe	AAC0037	
Alice Mace	AAC0310	
MAIN—taking autism personally	AAC0092	
Christian Mallon	AAC0168	
Professor Will Mandy		QQ 23–29, Professor Will Mandy, Professor of Neurodevelopmental Conditions, University College London
Dr Catherine Manning	AAC0130	
Dr Katie Maras		QQ 132–141, Dr Katie Maras, Associate Professor of Psychology, University of Bath
Professor Nicola Martin	AAC0309	

Maternity Autism Research Group (MARG)	AAC0147	
Steven John May	AAC0145	
Sir Charlie Mayfield		QQ 101–109, Sir Charlie Mayfield, Chair, Keep Britain Working Review
Lynn McBain	AAC0362	
Jade McCullum	AAC0004	
Riddley McDermott	AAC0155	
Paula McGowan OBE		QQ 52–59, Paula McGowan OBE, Founder, Oliver McGowan Mandatory Training on learning disability and autism
Marisa McKinlay, Dr Carol Jasper, Dr Lorna Camus and Professor Mary Stewart	AAC0217	
Claire McNabb	AAC0263	
Louise Mills	AAC0110	
Veronica Milne	AAC0193	
Mission Impossible Peer and Self-Advocacy Group	AAC0291	
Professor Mark Mon-Williams		QQ 30–35, Professor Mark Mon-Williams, Chair in Cognitive Psychology, University of Leeds
Dr David Moore	AAC0227	
Danielle Moreton	AAC0090	
Lynette Morgan	AAC0150	
Dr Rachel Moseley	AAC0074	QQ 52–59, Dr Rachel Moseley, Principal Academic in Psychology, University of Bournemouth
Tegan Mulby		QQ 118–124, Tegan Mulby
Dr Louise Nash, Dr Raysa Rocha and Dr Siddhartha Saxena	AAC0038	
National Association of Disabled Staff Networks	AAC0335	

National Autistic Society (NAS)	AAC0232	QQ 1–6 and QQ 193–201, Tim Nicholls, Assistant Director of Policy, Research and Strategy, National Autistic Society
National Autistic Society, Calderdale Branch	AAC0222	
National Institute for Health and Care Excellence (NICE)	AAC0367	
National Police Autism Association		QQ 132–141, John Nelson, Chair, National Police Autism Association
Dr Karen Neil	AAC0244	
Neurodiverse Connection	AAC0103	
Neurodiversity in Business	AAC0370	QQ 118–124, Dan Harris, Founder and Chairperson, Neurodiversity in Business
NHS England	AAC0360	QQ 159–169, Dr Ken Courtenay, Consultant Psychiatrist in Learning Disability, NHS England QQ 159–169, Tom Cahill, National Director, Learning Disability and Autism Programme, NHS England QQ 159–169, Dr Adrian James, Medical Director for Mental Health and Neurodiversity, NHS England
NHS Greater Manchester Integrated Care Board	AAC0128	
Norfolk County Council	AAC0285	
North East and North Cumbria Integrated Care Board	AAC0355	
North East Autism Society		QQ 60–66, John Phillipson, CEO, North East Autism Society
Mike Nesbitt MLA, Minister of Health, Northern Ireland Executive	AAC0375	
Norwood	AAC0116	

Nottinghamshire Integrated Care System Learning Disability and Autism Operational Delivery Group, Nottinghamshire Healthcare NHS Foundation Trust	AAC0339	
Dr Jessica Ong, Sonia Gannon, Katherine Smith and Louise Finer	AAC0229	
Faith Ougham	AAC0078	
Outcomes First Group (OFG)	AAC0196	
Outside the Box	AAC0169	
Dr Letizia Palumbo	AAC0132	
Professor Jeremy Parr		QQ 43–51, Professor Jeremy Parr, Professor of Paediatric Neurodisability, Newcastle University
Connor Passey	AAC0003	
PatronBase UK	AAC0376	QQ 125–131, Rob Walters, Technical Director, PatronBase UK
PDA Society	AAC0268	
Danny Phillips	AAC0323	
Jo Phillips	AAC0278	
Stephanie Phillips	AAC0318	
Dr Jill Pluquailec	AAC0035	
Lucy Porte	AAC0162	
Positive Support Group Ltd	AAC0329	
Dr Lauren Powell and Jacob Lewis	AAC0058	
Priory Group	AAC0332	
Laura Quigley	AAC0265	
Martin Corrie Quinnell	AAC0264	
Jude Ragan CBE	AAC0184	
Nazmiye Raif	AAC0342	
Shaji Rajamony	AAC0223	
Fiona Regan	AAC0313	
Trevor Regan	AAC0300	
Relationship Development Intervention (RDI) Connect	AAC0213	

Rebecca Roach	AAC0294	
Lee Robb	AAC0187	
Elizabeth Robillard	AAC0245	
Katie Roche	AAC0048	
Rotherham Parents Forum Limited (RPFL)	AAC0113	
Dr Ashok Roy OBE		QQ 60–66, Dr Ashok Roy, Consultant Psychiatrist and Associate Medical Director, Coventry and Warwickshire Partnership NHS Trust
Royal College of Nursing	AAC0333	
Royal College of Psychiatrists	AAC0298	QQ 30–35, Dr Conor Davidson, Autism Champion, Royal College of Psychiatrists
Royal College of Speech and Language Therapists	AAC0197	
Professor Ailsa Russell		QQ 36–42, Professor Ailsa Russell, Professor of Clinical Psychology, University of Bath
Lee Sanderson	AAC0256	
Benjamin Scott	AAC0148	
Tom Arthur MSP, Minister for Social Care and Mental Wellbeing, Scottish Government	AAC0328	
Sarah-Jane Seaton-Norton	AAC0202	
Dr Felicity Sedgewick	AAC0205	
SEDSConnective	AAC0201	
Su Seymour	AAC0371	
Emma Sharp	AAC0269	
Valentine Sharpe	AAC0348	
Melissa Shaw	AAC0107	
Victoria Shaw	AAC0010	
Sheffield Autism Research Lab (ShARL), University of Sheffield	AAC0088	
Sheffield Health and Social Care NHS Foundation Trust	AAC0326	
Bernadette Shrubshall	AAC0358	
Simran Sidhu	AAC0059	

Sirona Care & Health		QQ 110–117, Dr Emma Bradley, Consultant Paediatrician, Sirona Care & Health, and Chair of the Royal College of Paediatricians specialist advisory committee for community child health QQ 110–117, Victoria Bates, Child autism assessment lead, Sirona Care & Health
Daniella Smith	AAC0028	
Zaynab (ZeZe) Sohawon		QQ 15–22, Zaynab (ZeZe) Sohawon, Young Ambassador, National Autistic Society, and Founder, Emotion Dysregulation in Autism
Space4Autism	AAC0314	
Speak Out Peterborough	AAC0284	
Sharon Stockley	AAC0250	
River Stone	AAC0091	
Professor André Strydom		QQ 43–51, Professor André Strydom, Professor in Intellectual Disabilities, King's College London, and Chief Investigator, Learning from Lives and Deaths Review
Sunderland People First	AAC0093	
George Sutherland	AAC0225	
Tameside Autism Network	AAC0286	
Kevin Taphouse	AAC0001	
Dr Marie Tidball MP		QQ 142–149, Dr Marie Tidball MP, Chair, All-Party Parliamentary Group (APPG) on Autism
Janine Timiney	AAC0262	
Tania Tirraoro		QQ 85–90, Tania Tirraoro, Founder and Co-Director, Special Needs Jungle Ltd
James Tomboline	AAC0009	
Transforming Autism and Guy Shahar	AAC0279	

Transport Studies Unit, University of Oxford	AAC0123	
Susannah Trotter	AAC0240	
Dr Peter Tyerman	AAC0064	
UK Government	AAC0231, AAC0377, AAC0378	QQ 170–192, Stephen Kinnock MP, Minister of State for Care, Department of Health and Social Care (DHSC) QQ 170–192, Alison McGovern MP, Minister for Employment, Department for Work and Pensions (DWP) QQ 170–192, Catherine McKinnell MP, Minister for School Standards, Department for Education (DfE)
Dr Jonathan Vincent		QQ 67–73, Dr Jonathan Vincent, Lecturer in Higher Education, Lancaster University
Dr Luke Paul Vinter	AAC0076	
Vocational Rehabilitation Association	AAC0224	
Lee Wardman	AAC0098	
Benjamin Waters	AAC0319	
Joanne, Kevin and Thomas Watson	AAC0097	
Chelsea Webster	AAC0115	
Dr Tom Welsh	AAC0175	
Sarah Murphy AS/MS, Minister for Mental Health and Wellbeing, Welsh Government	AAC0373	
West Cheshire Autism Hub	AAC0071	
West Kent Autism Parents' Support Society	AAC0340	
Jody Wheeler	AAC0248	
Daniel White	AAC0152	
Paul Whiteley	AAC0173	
Wigan All Age Autism Partnership Board	AAC0106	

Sarah Wild		QQ 73–78, Sarah Wild, Headteacher, Limpsfield Grange School
Alice Willans		QQ 85–90, Alice Willans, Chair, Youth Council, Ambitious about Autism
Joely Williams (née Colmer)	AAC0287	
Naomi Williams	AAC0006	
Professor Jane Wills	AAC0012	
Rachel Winder	AAC0100	
Ben Wise	AAC0024	
Kira Withers-Jones	AAC0026	
Witherslack Group	AAC0111	
Dr Rebecca Wood	AAC0109	
Dr Ryan Woolhouse	AAC0349	
Bee Young	AAC0135	
Professor Asif Zia		QQ 150–158, Professor Asif Zia, Chief Medical Officer, Hertfordshire Partnership University NHS Foundation Trust, and Chair, Mental Health Medical Director Forum, NHS Confederation
Elizabeth de Zoysa	AAC0242	

Published engagement and visit notes in chronological order

Note of meeting with the House of Commons Autistic Champions, 24 April 2025
Note of meeting with NHS and local authority professionals, 1 May 2025
Note of meeting with experts by experience, 1 May 2025
Note of meeting with autistic young people and parents, 12 May 2025
Note Of Committee visit to St Thomas' Hospital, London Borough of Lambeth, 19 May 2025
Note of Committee visit to Phoenix School, Bow, London Borough of Tower Hamlets, Wednesday 11 June 2025
Note of meeting with the House of Commons Autistic Champions, 7 July 2025

APPENDIX 3: CALL FOR EVIDENCE

Call for evidence launched to mark World Autism Acceptance Day, 2 April 2025

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.

Be aware that written evidence sent to the Committee will usually be published online. Your name will usually be published too.

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: HLAutismAct2009@parliament.uk
- via post: Clerk to the Select Committee on the Autism Act 2009, Committee Office, House of Lords, London SW1A 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: https://www.parliament.uk/business/lords/work-of-the-house-of-lords/lords-select-committees/

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:

https://committees.parliament.uk/committee/770/autism-act-2009-committee/#:~:text=Lords%20Select%20Committee,2009%20and%20to%20make%20recommendations.

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 *Autism Act 2009* 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 autism strategy 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 statutory guidance says what the NHS and local authorities should do to make sure the autism strategy works.

You might want to read the *Autism Act 2009*, the autism strategy and/or the statutory 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

Question 1

(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?

Question 3

(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?

Question 7

(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 and,
- 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?

Question 10

(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 11

(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.

Question 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?

Question 17

(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.

Question 20

(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 can:

- send us your written submission using the form available at https://committees.parliament.uk/call-for-evidence/3625/
- send your written submission or voice recording by email to HLAutismAct2009@parliament.uk. Please give your email the title 'Written Evidence' to make clear that you are submitting written evidence.

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 contact your local Member of 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.

APPENDIX 4: NOTE OF MEETING WITH THE HOUSE OF COMMONS AUTISTIC CHAMPIONS, 24 APRIL 2025

Introduction

The House of Lords Committee on the Autism Act 2009 held a private meeting on 24 April 2025 with the House of Commons Autistic Champions, a group of autistic adults working with Parliament.

The role of the Autistic Champions is to review and provide feedback on Parliament's public engagement services from the perspective of autistic people, looking at experiences like visiting Parliament, going on tours and finding information on the Parliamentary website.

The meeting was an opportunity for the Committee to learn about the work of the Autistic Champions and to discuss key issues for autistic people from their perspective and priorities for the Committee's inquiry.

Participants in the meeting had a range of experiences of advocating for and supporting autistic people, including delivering autism training for the NHS and other organisations (including the Oliver McGowan Mandatory Training on learning disability and autism); working with NHS, local authority services, employers and the police to improve support; working with heritage organisations to make visits more accessible; supporting autistic children and young people and their parents; carrying out research into autistic people's experiences; and creating online content sharing their experiences.

Participants had been diagnosed as autistic at different ages and had different experiences of autism and co-occurring conditions, including ADHD, learning disability, epilepsy, eating disorders and chronic illness.

1. Key issues for autistic people

Several participants said it was important to improve understanding and acceptance of autism. A participant said we are still too medicalised in our approach. There is othering: autistic people are viewed as less than human and the default is that their way of being is wrong. Lots of the challenges they face are avoidable. There is a massive shift required to get that to change. Otherwise, we will be going round in circles. We often say 'autistic people have communication challenges', but what that really means is that the professional doesn't have an adaptable skillset. We need to rehumanise the autistic experience. Autistic people have lost possession of the word autism: it's seen as a medical thing detached from the human. They are an autistic person and exist as part of society. Autistic people have the same wants and needs as most humans.

Participants said that the roots of why autistic people have autistic traits are differences in the processing of information. Autistic people process more information and prune irrelevant information less, leading to overwhelm. So, even at the baseline they are processing the world from a position of overwhelm. We should look at support through a lens of the processing of information, not through the lens of behavioural traits.

A participant spoke about the importance of understanding autism in people with co-occurring conditions. Better understanding of autism in women and girls is key. They were diagnosed with autism at 24, ten years after becoming very unwell with anorexia. They spent five years detained in hospital, two of them far from

family in Scotland. The care they received was inappropriate and traumatic. They managed to get out of hospital. A key part of their recovery was finding out they were autistic, under the care of an open-minded psychiatrist who referred them for assessment and a nurse who was willing to adapt their treatment before they had had a formal assessment. They are now in the final year of university. It would have been much better for them to be identified as autistic when first in contact with mental health services. They were medicated, restrained and secluded in ways they shouldn't have been. When you get an autism diagnosis, those experiences don't go away. It's key to have trauma-informed care for autistic people with co-occurring conditions. They are still in recovery from mental health problems that came about from unrecognised autism. Part of their care is processing what they went through in hospital.

The participant also raised the issue of pilot schemes that are good and then stop. They had worked on the PEACE pathway pilot in children's and adolescent services, as the lead expert by experience. The pilot was great to be involved with. It drove better and quicker identification, reducing admission times. There was an amazing three years and then the funding stopped. Why? It saved lives and got people who were stuck on wards home and into a stronger place.

Participants spoke about improving access to education for autistic children and young people. One participant was prescribed Fridays off school by their doctor due to sensory shutdowns. That enhanced their attendance and got them from F to A grades. There was no point sitting through hours of neurotypical-focused teaching and learning. Every day autistic people are shut down they are losing the ability to function the next day. Another participant spoke about how using strengths to overcome challenges can help autistic people immensely. For example, their child is a big fan of Formula One. They encouraged them to apply the structure of Formula One to school learning, creating spreadsheets to help with inference in English literature.

Participants discussed the need to improve support in employment. A participant spoke about how their child got good academic results and a first class degree at university. The only time they didn't know where to go further was employment. Now they run an employment consultancy with programmes for young people who encounter cliff-edges in support after education, providing mentoring with a focus on empowerment and taking positive opportunities from adversity. Another participant was diagnosed at 18 after they tried working but it didn't work out. They were academically successful but struggled with the world of employment.

Another participant got a good graduate job but lost out on an opportunity to thrive because of the open plan office. They were the only graduate that didn't get promoted. It was a great job, but they and their colleagues didn't realise the impact that the open plan office was having. They were bullied out of one of their jobs and it nearly went to tribunal. There is a lot of wasted cost and resources. Education could prevent that. The participant said that people say that they are unemployable but they have three jobs supporting and training others. Autistic people have a lot of untapped resource and potential. We shouldn't be waiting for more suicides: we need to be proactive and provide training for educational professionals and employers.

Another participant said they had two paid jobs, but this is the only time they have had that opportunity. They struggled to get employment for five years and were told that they wouldn't get a job due to autism and learning disability. They have received job-appropriate training. As part of their work, they help advocate for

non-speaking autistic people. There might be non-speaking autistic people who want to find work but need carers or advocates to support them.

A participant spoke about access to social housing and supported living. They were taken off the social housing list by the council because they needed supported living. They were hoping to go through the supported living process, but it didn't work out. That hurt them and knocked their independence.

2. Priorities for the Committee

Participants spoke about the need to improve public understanding and acceptance. Autistic people need understanding from people that they are humans and not lesser. It stems from education, training and media. It should be about giving people the benefit of the doubt and checking if people might be misunderstanding. The place to start would be education, so that everyone has exposure from the get-go and live their whole lives with an understanding of autistic people. To raise public awareness, there should be training in schools and for employers, drawing on people's real-life experiences. There also needs to be more training on abuse including covert abuse. Autistic people don't always process if they are being abused.

A participant spoke about the importance of self-understanding. They didn't have a diagnosis of autism until adulthood and still don't have a diagnosis of likely dyspraxia. That means missed opportunities for self-understanding. As a neurodivergent person, they get to explore their understanding of what it means to be them. We should start at age five and enable people to start understanding their own brains. It would be a great starting place to stop the negative ripple effect throughout individuals' lives and through society. We should focus on using autistic people's strengths and passions to enhance their abilities.

Participants spoke about improving access to healthcare and mental health support. It's important for there to be validation of the autistic experience, particularly in mental health care. Everyone in the mental health system should be screened for autism (albeit that there are problems with screening processes). All professionals should be thinking about it. Mental health difficulties are often a result of unaccommodated autism. Adjustments like changing lighting levels can make a big difference and save so much time. There should be more autism training by autistic people. One participant said they know from personal experience that GPs don't always do training on learning disability and autism because it takes time and resource. Participants also said there should also be tailored research into the links between autism and trauma and into the impact of autistic people's information processing on chronic pain, endocrine and gut issues.

Participants spoke about improving access to education. Education should be tailored to autistic people's needs. There is unintentional gaslighting of autistic people in neurotypical education settings. What helps neurotypical people doesn't help autistic people. Autistic people are told to deny their lived reality. There should be more training for parents and tutors for support at home.

Participants spoke about improving access to employment. There should be steps into paid work. An autistic person should be able to start a job on limited hours to establish the level of support they need. They should be given reasonable adjustments and eased into the full job description. The right adjustments should be in place by the time they start full time. Another participant said they were raising employment as an issue with their MP and local election candidates. They

highlighted the 'benefits trap' of losing benefits if you work more than 16 hours a week.

A participant said we need to start with accountability. There is no accountability at the moment. Committee members had said in the previous public evidence session that the Secretary of State is meant to ensure accountability, but that hasn't happened. There needs to be an independent body that reports to a panel of autistic people or is made up of autistic and non-autistic people. It needs to be independent of government and come from the top. Like a conductor in an orchestra, it would drive improvements in diagnosis, public understanding, and education, ensuring better allocation of funding and saving money.

APPENDIX 5: NOTE OF MEETING WITH NHS AND LOCAL AUTHORITY PROFESSIONALS, 1 MAY 2025

Introduction

On 1 May 2025 the House of Lords Committee on the Autism Act 2009 held a private meeting with professionals in the NHS and local authorities, facilitated by NDTi. This meeting was to discuss how effectively autistic people are involved in making decisions about NHS and local authority services and how this could be improved in the future. All the participants in this meeting had experience of developing and co-producing NHS and/or local authority services for autistic people. Some of the participants were autistic.

1. In your experience, how effectively do NHS and local authority services meet autistic people's needs? What are the main barriers to meeting autistic people's needs effectively?

The Committee is investigating how well the Autism Act 2009 is working. In your experience, what impact (if any) have the Autism Act, autism strategy and statutory guidance had on the provision of services for autistic people? Why have they been effective or not effective?

Participants said that there is a lot of variation. Some services are exemplary and others are far behind. It is a postcode lottery. One barrier is that autism is sometimes still viewed as something that affects children and young people, so the concept of autistic adults is novel and confusing. There is a big drop off in support beyond the age of 18. Some children's and young people's services extend to 25. Though this perpetuates the infantilisation of autistic people, it does provide some continuity. Many people make patronising assumptions about how to communicate with autistic people and expect autistic people to conform to them. There are ever-increasing waiting lists. Some people seek private diagnoses, but services do not always recognise them. This wastes services' and families' time and money. Local authority assessments are bureaucratic and intimidating. Paperwork, interviews and assessments can cause severe anxiety and affect quality of life. Mandatory training on learning disability and autism is quite narrow and doesn't cover much on sensory processing or interoception. There are very low levels of employment and many dream of a life where they can have a job and contribute. At the end of the day, we are all human beings. The duties in the statutory guidance are very positive steps, but they don't go far enough and aren't enforced so they do not have the effect we would all like to see.

There are both successes and failures in the NHS and local authorities. Systems often address people's needs reactively. Eventually, there are successful outcomes, but in the process there is unnecessary trauma and distress. This has a significant emotional cost. Services are weighted too heavily towards treatment rather than public health approaches. Rather than spending more money, services need to spend it differently and earlier. Non-autistic professionals recognise behavioural difference, but don't support understanding of what it means to experience the world in a subjectively different way. If people aren't actively supported to understand their own experience of the world, they rely on those around them. Culturally, we could do more to teach autistic people to understand and advocate for their needs. This would help wider society understand autism as a way of being.

The Autism Act gave local authorities and the NHS a statutory obligation to provide services. There is often agreement about what needs to happen. The Act and statutory guidance are used to guide us. For example, one participant said their local authority had carried out an autism review four years ago looking at services (primarily for adults) and how to improve them. They then developed an autism strategy and implementation plan, consulting with about 100 autistic people in the local area. The local strategy is aligned with the national strategy.

There are real challenges. There is a lack of community services and an over-reliance on mental health crisis services, which are not well-placed to help autistic people. Autistic people can fall between different services. Mental health services often feel an autistic person's needs are due to autism and refer them to social care, but colleagues in social care also under-equipped to help them. This is particularly challenging where someone is displaying behaviour which challenges, hoarding, Avoidant/Restrictive Food Intake Disorder (ARFID), and self-harm and what support or organisation would be best placed to meet the identified needs. Funding is another barrier. There used to be ring-fenced budgets as part of the Service Development Funding (SDF) via NHS England which has now stopped and this will likely result in a fall back to statutory obligations in services rather than being able to develop holistic services to meet the needs of the person as a whole. There are separate budgets for health and social care. This results in discussions between services about who is responsible and delays in a person getting the right services.

2. What are the main barriers to involving autistic people and their families/carers in making decisions about services the services they use? What would be the best ways to overcome those barriers?

Participants said they were passionate about co-production and making sure services meet the needs of their population, rather than making assumptions about what people need.

A participant spoke about the experience of their NHS trust. They were doing strategic work to identify why their services aren't working as well as they should be. At service level, the trust has moved from consultative to collaborative approaches. There is a board of autistic people paid a professional wage to carry out internal projects and build collaboration across health and care services. The board could be more diverse. The outcomes have been significant in terms of cultivating partnerships across different sectors, influencing organisational policy and practice, commissioning new services, and challenging services that are not neurodiversity-affirming. The board is bringing different voices to decisions. For example, the board identified that one service could be open for shorter hours later in the day, meeting people's needs better and saving money. Collaboration on children's and young people's services is less well-developed and the voices we need most are often missing. The participants wanted involvement of autistic people in services to become the rule, not the exception.

Another participant spoke about a community-led post-diagnostic peer support service. People in the local autistic community were involved in presenting the specification for the service and monitoring the contract. Now the contract is being reviewed and autistic people are involved in that. There is a local co-production board to keep commissioners on the right track. They act as a critical friend, advocating for their needs and how they can be met better. This is mostly focused on adults. There is a young commissioner programme to support children and young people's voice in services but this needs to be developed further.

Another participant said there is a lot of variation. Some NHS trusts have senior people who champion autistic people's voices being heard in all decisions. In other areas autistic people are widely ignored or told how their own lives should be. Overall, this drives anxiety and has a negative impact on people's experiences. There are horror stories of care failings, abuse and deaths. Autistic people can end up asking for services and having the door shut in their face. It can feel like betrayal, or like a stick is being used to beat you down with. But there can be recovery and hope too: involving autistic people in decisions, frontline innovation, getting people out of hospital after a number of years. There are opportunities to restructure staff teams to include autistic people as paid staff. It's important for autistic people who are in distress and trying to access services to see others like them on the other side. The impact of this can be breathtaking.

3. What are the main barriers to involving autistic people and their families/carers in making decisions about the services they use? What would be the best ways to overcome those barriers?

A participant said their local co-production board was very strong, but it only represented a small proportion of the population and it only had white men on it. Members of the board do not always agree on the best way forward. This can make it challenging for a commissioner to take their advice. It can be difficult to cater to people's different access needs—for example, some people find it easier to meet online and others find it more difficult. Another challenge in co-production is that not everyone is interested in all areas of policy and implementation. For example, the co-production board looked at the local supported living strategy but the board members weren't interested because it didn't apply to them. There is a need to collaborate with a wider range of people, including people from different cultural backgrounds and people with more severe learning disability. It's key not to forget about people who can't easily advocate for themselves.

Another participant said their Integrated Care System was partway through its journey on involving people. The barriers are not insurmountable but they are significant. There is a need for genuine diversity of voice, particularly among people with complex needs. The workforce needs to be supported to adapt to new ways of working. Consultation is sometimes mistaken for co-production. For this participant, the solutions lie in time, education, building clear evidence of the need for change, and standardising capabilities around the existing core capability framework.

Another participant said they felt that there was a lack of understanding of rights and responsibilities at all levels. Education, Health and Care (EHC) plans are an example of this: most families don't understand they have entitlements to support outside school too. There are staffing and funding constraints. If a service is focused on meeting key performance indicators, involving people is seen as a nice-to-have. There needs to be a change of values, towards a more collaborative and less hierarchical approach. There need to be honest conversations without defensiveness, which takes bravery on both sides. Autistic people need to be directly employed and become fully integrated as professionals, so that autism is integral, not an outside thing. Defensive and inflexible thinking are unhelpful. Ironically, this participant said, in this sense NHS service providers can be more stereotypically autistic than autistic people.

4. The Committee's final report will make recommendations about what the Government should do following the end of the national autism strategy for 2021 to 2026. What do you think is the most effective thing the Government could do to improve NHS and local authority services for autistic people?

A participant said they thought it was critical to bring in autistic people as a qualified and integral part of staff teams. Many autistic people still get bullied out of work. There are high barriers to employment due to a lack of understanding and stigma. Organisations can bring people from the outside in to help deliver services and make prioritisation decisions. This means people on the outside can see people like them on the inside fighting for them. This would have wider positive social and cultural effects. It comes back to hope and humanity.

Another participant said it would be helpful for there to be more clarity on the role of diagnosis. There are such long waiting lists that services shouldn't have to wait to support a person with an identified need. In mental health services, more clarity would help with challenging professionals for attributing a person's needs just to autism and writing them off as not needing treatment for mental health conditions. Mental health conditions may be more likely in autistic people but they can still be treated—it's just that a different approach may be needed. Local authorities are often working with rigid contracts. This can make it difficult to be flexible when new understanding comes to light about the population of autistic people and how to meet their needs. The Oliver McGowan Training is a great start, but there is a need for more in-depth training for professionals. For example, in their area there are very few speech and language therapists who are specifically qualified to work with autistic people. Specialisms for working with autistic people should be developed in different professions.

Another participant called for a shift from a reactive model to a preventative approach to services. All health and care staff should be trained before they enter the workforce in working with autistic people, and this should be based on the Core Capabilities Framework for Supporting Autistic People. There should also be training on neurodivergence in schools and for employers. There should be legislative requirements for authentic co-production in service design, commissioning and evaluation, moving beyond consultation to power sharing. This would help drive a culture shift, helping to reduce unnecessary costs, improve autistic people's quality of life, and develop public understanding of autism as a difference not a deficit.

APPENDIX 6: NOTE OF MEETING WITH EXPERTS BY EXPERIENCE, 1 MAY 2025

Introduction

The House of Lords Committee on the Autism Act 2009 held a private meeting on 1 May 2025 with experts by experience, facilitated by NDTi. The meeting was to discuss how effectively autistic people are involved in making decisions about NHS and local authority services and how this could be improved in the future.

All participants had lived experience of trying to access health and care services as an autistic person, or for autistic children. Some participants had previous lived experience of mental health inpatient admission.

All participants had experience of working with the NHS and other organisations to improve services for autistic services. Between them, participants' experiences included creating and delivering autism training for health and social care staff; developing an autistic led post-diagnostic support programme; acting as a panel member in Care (Education) and Treatment Reviews; supporting the parents of children diagnosed as autistic and/or having a learning disability; and being a school governor.

1. In your experience, how effectively do NHS and local authority services meet autistic people's needs? What are the main barriers to meeting autistic people's needs effectively?

The Committee is investigating how well the Autism Act 2009 is working. In your experience, what impact (if any) have the Autism Act, autism strategy and statutory guidance had on the provision of services for autistic people? Why have they been effective or not effective?

Participants said that there are still large numbers of NHS and local authority staff who have not had any training on practical approaches to working with autistic people. The training that they have is basic and does not provide practical skills on how to approach the person in front of you.

There are some very good services, driven by individual professionals who participate in training and actively involve autistic people. There is a postcode lottery. A participant gave an example of where they had been commissioned to deliver voluntary training for health and care staff. They hosted about 300 people for each webinar. This shows there are lots of staff who are truly personally invested in taking up the training.

Barriers to meeting autistic people's needs include time, money and staff resources. For example, there has been a concerted effort to implement training programmes, but there are barriers to rollout and uptake. Staff don't always understand that doing training isn't just a day out of their time, it's a tool they can use with patients in front of them. There is an idea that you can teach everyone what autism is. That's not really possible, as autistic people are all different. It would be very powerful to empower autistic people to learn their own profile of needs and their rights and to communicate their needs to professionals. Professionals also need to receive training on different profiles and how to respond to the needs of the person in front of them.

There is a need to address stigma and move away from the idea that autism is a disorder. This needs to happen in an intersectional way. Different community

services and hospitals serve local populations with different needs. Black autistic people and people from other ethnic minorities are less likely to access the support they need. There is a need to listen to autistic people's experiences and perspectives and to make sure that they can communicate their needs. People need to be supported to understand their rights and what the law says.

A participant spoke about their experience of trying to access services. As an autistic person with co-occurring conditions, they spent years in the NHS going round the houses. They interpret pain differently. Professionals told them they were making it up and it was all in their head. They were undiagnosed and unsupported until they had a mental health crisis. In emergency situations in physical and mental health services, no adjustments are made for autistic people's needs. Autistic people can become unable to respond in the ways that professionals want them to. There is little support for carers and advocates. This has become worse since the pandemic. The sensory environment in psychiatric wards is a cocktail for an extremely difficult and traumatic experience. They were not supported to transition back into the community after leaving hospital and couldn't use the bus for two years after discharge.

Some services are trying to move away from diagnosis-led support to needs-led support, but this is challenging. There are long delays in diagnosis. This is a longstanding problem. The NICE recommendation of 13 weeks from referral to diagnosis was not being achieved even ten years ago. There is a need to ensure people don't have to receive a diagnosis to access support. However, society relies on diagnosis for everything from welfare benefits to access to railcards and bus passes.

The Autism Act has helped make the NHS aware of its duties, but many aspects of the strategy don't seem to have manifested. Barriers include a lack of focus on implementation and funding; the fact that the Act covers adults only; and barriers to autistic people becoming true leaders of service change and being paid fairly to do so.

2. In your experience, how effectively do the NHS and local authorities involve autistic people and families/carers in making decisions about the services they use?

What impact does this have on how effectively services meet autistic people's needs?

Participants spoke about failures to involve autistic people and their families/carers in decisions about the support they need. For the families and carers of autistic children, it's not easy to deal with local authorities. An Education, Health and Care (EHC) plan might say that a child needs input from speech and language therapy, but then that doesn't happen in practice. This can mislead the family. During the transition to adulthood when the person is 17 or 18, services fight over who is responsible for what and move the goalposts, without really listening to the person or their family.

One participant said they needed a carer for almost all their appointments. They are very often patronised and their mother is spoken to instead of them. Decisions about the services they access are made about them, not for them. If they were given reasonable adjustments, their anxiety levels and communication needs would be completely different. They know services are under-funded and over-stretched, but even smaller adjustments feel like an unreasonable ask. Without adjustments, autistic people can become more insecure and likely to mask their needs. People in psychiatric wards (whether under section or not) lose their autonomy. They

said the changes to the Mental Health Act don't do enough to prevent traumatic admissions. The Autism Act does not prevent this either.

Another participant spoke about their experience of reviewing the care and treatment of autistic people in inpatient settings. This ranged from cases of teenagers who had been in the criminal justice system and ended up in hospital to a case of a late-diagnosed autistic adult who had a history of employment blocking cyber-crime. When a local authority needs to find a placement for a person or set up a discharge pathway from hospital, they don't always really listen to the person and their family and find the right placement. Services don't really do early intervention. Often people are admitted to hospital because local authority services have failed and not really listened to the person and their family. The money comes after the person has been sectioned. This is traumatic for the person and their family.

Participants gave good and bad examples of involving autistic people in decisions about how services are run. There are some amazing projects with shared power and co-production, that allow experts by experience to be part of every aspect of the project and support them to share traumatic experiences in a safe way. For example, one participant spoke about working with a local authority board on transforming neurodiversity. Autistic adults on the board are consulted and involved in how services are developed and go out to inspect services.

Another participant said that they had been mined for trauma and used to rubber-stamp projects, particularly when younger and more vulnerable. It's a postcode lottery. There is not enough vetting of organisations. Some organisations don't practise what they preach and cause long-term trauma to the autistic people that they bring in to do that work. For example, experts by experience can end up talking about traumatic experience and not getting the right support, doing intense emotional labour and not being compensated properly for their time, and being used in a tokenistic way.

There is still a need to bring autistic people into permanent, decision-making roles. There is also a need to build up knowledge of how to co-produce services, particularly with autistic people with different communication needs. In the meantime, there is a lack of access to diagnostic services and mental health services that meet autistic people's needs. There are some community support services that are provided by autistic people and their families, but they are outside wider service frameworks.

3. What are the main barriers to involving autistic people and their families/carers in making decisions about services the services they use? What would be the best ways to overcome those barriers?

Participants spoke about the 'double empathy' problem: autistic people and non-autistic people struggle to understand each other. Society puts all the pressure to resolve this problem on autistic people. The barriers are made by systems that are not set up for autistic people. When an autistic person is in crisis, involving the autistic person and their family in decisions isn't prioritised. In reality, the crisis would be less lengthy if there was less uncertainty and lack of structure. There is also a lack of knowledge. Sometimes healthcare interventions are taken off the table because professionals believe it would be too difficult to make adjustments. Autistic people know their own needs better than professionals do and often interpret their bodies differently. Understanding and listening to the autistic person is key. Professionals are more likely to dismiss and fail to listen to

autistic people who are also marginalised in other ways. A participant spoke about professionals telling them that their sexuality and gender identity were caused by their autism and being told they had 'naughty girl' syndrome when trying to access healthcare. There is a lack of use of alternative communication methods (including Easy Read and plain language versions). Adjustments are often not that difficult and expensive but they are not prioritised.

Another participant spoke about the need for more understanding of autism in the community. Their child finished university two years ago and has applied for hundreds of jobs but hasn't received any help from the local authority because of the label of autism. There is a need to prioritise jobs for autistic people more than others. They are put at the bottom at the moment. Local shops and supermarkets need support and training to employ autistic people. Without support, things can go in the wrong direction and autistic people can end up being admitted as mental health inpatients.

Services don't always invite autistic people to the table, or they do this in a tokenistic way. Sometimes they veto or knock back what autistic people say because it's not the way that things are done. It can take months for people even to be compensated for their time. Changes can take months or years to be implemented. An example was given of an autistic person who asked to be involved in panels for Care (Education) and Treatment Reviews. The process took a very long time and in the meantime panel meetings were not being held. Services need to do more to enable autistic people to tell services they have an idea and to listen to those ideas. Services don't listen to autistic people from different backgrounds enough. There are not enough non-white people and LGBTQ people in the room. There can be a lack of understanding of autistic people's behaviours and communication. Professionals can find autistic people difficult, angry and intimidating. This is also an intersectional issue: for instance, professionals are more likely to see a black autistic woman as angry.

To overcome these barriers, there is a need for more representation and for real decision-making roles to be held by autistic people. There is a need for real consultation with autistic people in the community, including people from marginalised communities and people with significant disability. Organisations need to be held to account for tokenistic gestures towards co-production and for exploitation of autistic people. There need to be better ways to get things across to the NHS. Reverse mentorship could be part of this, enabling professionals to learn directly from autistic people.

4. The Committee's final report will make recommendations about what the Government should do following the end of the national autism strategy for 2021 to 2026. What do you think is the most effective thing the Government could do to improve NHS and local authority services for autistic people?

Participants spoke about the need to spend money early. One participant spoke about their child not being able to access support from an educational psychologist even though they have an EHC plan because of a lack of funding. Earlier intervention would be more effective.

One participant called for autistic leadership to be embedded in service design and evaluation and for autistic people to be able to access support with identified needs regardless of whether they have a diagnosis. Struggling services should be

supported and services that are doing well should be rewarded. There should be more carrot and less stick.

Another participant called for more training. The mandatory training on learning disability and autism is fairly narrow, particularly on specialised aspects of healthcare and on working with autistic people who have co-occurring conditions and/or are multiply marginalised. In an ideal world, every autistic person would have an individualised sensory assessment and their care would reflect their priorities and experiences.

Participants agreed on the need to reduce the numbers of autistic people in mental health inpatient settings. Being a mental health inpatient can be debilitating for an autistic person if they are in constant meltdown or shutdown. The statistics on this are very bad and not improving. One participant had met an autistic person who had been in the same hospital room and bed for 16 years. Two participants knew of autistic people in their local area who had been in hospital for more than 30 years.

APPENDIX 7: NOTE OF MEETING WITH AUTISTIC YOUNG PEOPLE AND PARENTS, 12 MAY 2025

Introduction

The Committee on the Autism Act 2009 held a private meeting, facilitated by Ambitious About Autism, with young autistic people and parents on 12 May 2025 to discuss their experiences of education and transitions to adulthood. The parents in the group had autistic children between the ages of six and 14 with experience of both specialist and mainstream education. The young people in the group were currently attending mainstream college or university.

1. Experiences of access to and inclusion in education

A parent spoke about how their autistic child had had both positive and negative experiences in education. When their child was at nursery, the staff told the parent several times that it was best for the child not to attend social activities like tea parties because it would be too overwhelming. This wasn't discussed with the parent beforehand. There were times when the child became overwhelmed and the parent was told that if the 'negative behaviour' continued the child wouldn't be allowed to return. This continued even after the child received an autism diagnosis. The child has had more positive experiences since moving to a smaller school. The school is flexible and accommodating and the child attends for reduced hours because they would struggle with the full day. The child has their own space with favourite toys to calm them down, one-to-one support from a teacher, and a routine so they know where to sit. The other children also seem aware of and accommodating towards their needs.

Another parent said their child's mainstream school did try to be inclusive, but it couldn't provide what they needed. The child did okay during key stage 1, but the demands of the curriculum and the environment in key stage 2 were too much. There were concerns about not being able to support the child to participate in activities like swimming lessons and residential trips. The child's Education, Health and Care (EHC) plan didn't come with enough funding to enable the school to meet their needs. During key stage 2, the child moved to a hub in a different school, and they are loving it there. There are more members of staff per child and the staff have a high level of understanding.

Another parent said they had very similar sentiments. They went through the process of trying to get an EHC plan for their child and making sure it is in place. Despite that, they had been met with serious challenges on inclusion and on staff training and understanding of autism. There is so often box-ticking rather than meaningful and consistent support. Their child is now at secondary school and is in detention three times a week. The child is exhausted most of the time because they are masking and they don't want anyone to know they are autistic. At the moment there is not enough staff training or understanding of neurodiversity.

A young person said that when they had struggled with the mainstream class environment at primary school because it was overwhelming, they were taken out of class and given nothing else to do. There was no effort made to make the class more inclusive. At secondary school they couldn't access the cafeteria for the same reason. They were offered a separate room to eat in but they couldn't eat with their friends there, so they ended up having to eat outside in the cold. The school uniform code was strict and became a major source of stress. PE was also a huge stressor because it was overwhelming and loud. There weren't any alternative

quiet activities. The young person hadn't really had any positive experiences with inclusion or efforts made to make adjustments for their needs. Some of the teachers were kind to them.

Another young person said that they had had a similar experience at school. They weren't allowed to go on school trips because the school didn't adapt to meet their needs. They weren't able to participate in many activities. Teachers didn't understand their needs, leading to frustrations on both sides. In sixth form, they had a better experience. There were smaller class sizes and their teachers took an interest in some of their special interests.

Participants discussed how inclusion in education could be improved for autistic children and young people. They said that there is a need to increase acceptance as well as awareness, moving away from a stereotypical understanding of autism and towards an understanding of complexity. Better training to enable staff to support autistic students and more funding to enable schools to create more inclusive environments would help. There should be more sensory-friendly classrooms, staff support and mentoring, and involvement from children and young people in decisions. There should be a transdisciplinary team approach around the child with support from different professionals. At the moment EHC plans don't seem to be implemented fully. There should be more accountability for the delivery of EHC plans.

2. Experiences of identification and support

A young person said that at primary school they were part of a social and emotional learning support programme for anyone with an identified need. They could talk to peers who understood them, using writing, talking and puppets. They could also do activities to help them feel like they had achieved something. At secondary school, they weren't supported. The environment was overwhelming, partly because of noisy building work. The school said they should move elsewhere but not until it was too late to do so. They were allowed to go to the school office if they were overwhelmed. In sixth form, they had a better experience. They had a form tutor who understood their needs in a more in-depth way. Their teaching staff were briefed about them and their needs. They were allowed to miss assembly, allowing them to focus more on the school day.

Another young person said that their primary school hadn't understood their needs. Their parent had to contact the school repeatedly to ask for support. This continued in secondary school. For their GCSE mock exams, they notified the school that they needed a smaller separate room. The school didn't do this and it was left up to their subject teachers to sort it out. The quiet room for SEND students was too small and eventually they were excluded from it. The school eventually opened a separate building, which was more accessible. They had a better experience at college. The college approached them first and asked about their needs. The college showed the young person round before they started, introduced them to the SEND team and discussed how to meet their needs.

A parent said that they had been surprised that their child's nursery had been very helpful with getting an EHC plan. They had heard horror stories about this but they felt very supported, although they did have to resolve some coordination issues.

Another parent said they had received quite a lot of support from their child's mainstream school. Their child had one-to-one support from a member of staff who was paid to go on extra training courses. The school helped with referrals

to speech and language services and getting an EHC plan, but it still became very difficult because there wasn't sufficient funding. For example, their child loves music, but there are very few resources for that. Music provision in primary schools is probably not as good as it should be in general, let alone for children with SEND. They fought for access to a music specialist to be in the child's EHC plan to unlock funding. A lot depends on whether schools and families know what to do to unlock support. Local specialist schools in their area now go around mainstream schools to share best practice. The SEN coordinator was brilliant but was also a class teacher and deputy head. Being an SEN coordinator is a full-time role.

Participants discussed how identification and support in education could be improved for autistic children and young people. They said there should be more funding for adaptations to sensory environments, early identification and staff support. There should be better training for staff with good frameworks and examples of how to help. Being believed is key. School and college SEND teams also need to talk to students and their families about transitions.

3. Experiences of transitions to adulthood

A young person said their school had said multiple times that they would not be able to go to university, despite having the grades they needed. The school even suggested that the young person sit out of university preparation sessions. Now, they are at university. The Disabled Students' Allowance is brilliant: it provides a lot more support and it is a lot easier to get than support at school. They have been able to access equipment, education support and a study skills mentor. University is very tricky in some ways. The structure of university learning is too standard. Being talked at in a lecture doesn't work for them. It's very hard to make adaptations to that, unlike in a school.

Another young person said they had experienced a lack of support with the transition from primary school to secondary school, and they had been told they wouldn't be able to go to secondary school. Now they were at college and they hadn't had any support with leaving and going to university yet.

A parent said their child was in key stage 1, but the parent was already worried about transitions. They just didn't think the world or a job setting was equipped for autistic young people. It terrifies them to think about what their child's future will be like. They know parents worry anyway, but that worry is multiplied by a million for parents of neurodivergent children. They wonder how their child will be able to lead a fulfilling life and contribute to society like everyone else can.

Parents discussed their experiences with children moving from key stage 3 to key stage 4. In their EHC plan for Year 9, they are meant to look at transitions and set outcomes and targets to meet their needs. They felt worried about their children's future. One parent said they were aware of support available from peers, parent trainers and charities, but not of sources of legal, financial and housing support. They thought things had probably been improving over the past decade. They hear more now about adults being helped to live on their own with support provided. Another parent said their child in Year 9 was already anxious about finishing school, getting a job and becoming independent. There doesn't seem to be any structure in schools around this. Nobody has discussed a career pathway with them.

Participants discussed how transitions to adulthood could be improved for autistic children and young people. There should be better guidance for young people,

parents, teachers and support staff. There should be more college and university practice days and more job support and guidance. Some universities have an autism week. This is a good idea to help familiarise incoming students with the environment. There needs to be early career development support at school. Children and young people need mentoring and counselling through transitions to provide emotional support. It's about giving children the right support at a critical time. There is a need for a deeper understanding of what autistic people are like and what they need. An autistic person with a high level of educational attainment may still need help with social and emotional needs or executive function.

APPENDIX 8: NOTE OF COMMITTEE VISIT TO ST THOMAS' HOSPITAL, LONDON BOROUGH OF LAMBETH, 19 MAY 2025

On 19 May 2025, a delegation of the House of Lords Committee on the Autism Act 2009 visited St Thomas' Hospital in the London Borough of Lambeth.

The Committee delegation comprised:

- Baroness Rock (Chair)
- Lord Addington
- Lord Crisp

The delegation visited St Thomas' Hospital to hear about the partnership between Guy's and St Thomas' NHS Foundation Trust and CareTrade, a charity founded in 2009 to support autistic people into employment, including through The Autism Project (TAP), a full-time, two-year employability programme for autistic young people aged 18-25 with an Education, Health and Care (EHC) plan.

Baroness Rock and the other members of the Committee introduced themselves. Baroness Rock summarised the work of the Committee.

Katherine Dymond, Engagement Officer, The Autism Project (TAP) and Job Coach at CareTrade, spoke about CareTrade's work with employers through TAP, and her role in providing a link between the Learner and placement host.

Karen Edwards, Chief Executive Officer, CareTrade, said that CareTrade had a strong relationship with the Trust that has changed over time. She noted that attitudes to and understanding of autism had changed in that time, for instance through the Autism Act, changes to approaches to education and the pandemic.

Jacintha M said that she worked at the Trust. Her department had hosted a placement which was supposed to be for six weeks but had in fact lasted for three months. It had been a positive and rewarding experience both for the employer and the Learner.

Judith Kerem, Development Director, CareTrade, said that she had worked for CareTrade for 13 years. She had undertaken lots of work with over 25s and with employers to upskill them to be neuroinclusive and to support people in the workplace in relation to access to work.

George Byford said that he had come through the TAP project as a Learner. He was now a full time employee with the NHS in the portering department. He had worked at the hospital for nine years.

Elliott Ayling said that he had also been a CareTrade client, and they had helped him find a position at the hospital in the dental records departments. He had worked there for 19 years.

Savita Rana, Deputy Director for Inclusion, Guy's and St Thomas' NHS Foundation Trust, said that she welcomed the opportunity to think about equipping the future workforce and providing a pipeline of talent.

Jo Young, Widening Participation Manager, Guy's and St Thomas' NHS Foundation Trust, said that in 2020 the Trust took six interns a year. There was

now capacity to take 25, working with CareTrade and other partners. They took on autistic Learners and people with a learning disability. She said that CareTrade do so much more than supporting internships. They provide support for managers, training, and promote the Access to Work scheme.

Ciara MacKay, Director of Nursing, Guy's and St Thomas' NHS Foundation Trust, said that she was leading work to develop a Trust strategy. This began as an autism strategy and was now being expanded into a neurodivergence strategy. To its credit, the Trust charity provided funding to appoint a project manager and develop a co-production strategy. This is the first time the Trust has paid patients, carers and families to be committee members. The strategy is now entering stage two.

Harriett Rossouw said that she had previously worked at Royal Brompton Hospital for ten years and had recently joined Guy's and St Thomas' NHS Foundation Trust as the Project Manager for its autism and neurodivergence strategy. She said that she is neurodivergent and co-chair of the staff neurodiversity network.

Hilary Fertig said that she is Executive Manager of Employment Autism, a separate charity which was taken on by CareTrade.

Baroness Rock asked how TAP works in practice at the Trust, and how the knowledge and experience of the project could be rolled out more widely among other employers in both the public and private sectors.

Jo Young said that her role is Trust-wide. The Trust has a Memorandum of Understanding with CareTrade. However, because CareTrade has been working with the Trust for so long they know who to speak to in order to get things done. They have free rein to source placements in dialogue with Trust managers. There are struggles. This work is not the Trust's primary focus—it is a health care organisation, and during times of backlogs or emergencies like the COVID pandemic managers will focus on their primary purpose. There is therefore always that challenge of keeping the work with CareTrade and other partners at the forefront of managers' attention. When they engage with TAP, managers realise that the interns are not a burden but rather a very useful free extra pair of hands. Then they are converted to come back year after year to host an intern. The Trust employs 25,000 people and the aim is to chip away manager by manager to debunk myths, and to show that autistic people are no easier or harder to manage than anyone else. People like Katherine Dymond provide a bridge to get the relationship going.

Lord Crisp asked what the conversion rate is for TAP Learners in terms of gaining employment in the Trust or elsewhere.

Jo Young said that TAP Learners usually get paid employment subsequently if there is a vacancy in the department but it can be a challenge if they have to go back into a recruitment pool. They are doing a lot of work with managers on recruitment adjustments.

Judith Kerem said that 22 TAP Learners had moved into paid employment at the Trust over the past 13 years. Others had gained employment in other NHS trusts or in other jobs. Some young people go back into education or are not quite ready for work. There is an alumni job club for people not quite ready to go into work.

Karen Edwards said that the difficulty is in banding of jobs and finding the right match. It is different with each employer. CareTrade place quite a lot of Learners with other organisations.

Katherine Dymond said that Learners develop transferable skills. TAP is a two-year project. The Trust is a good option for people with less experience because of the variety of potential roles. Learners can try administrative office-based roles and physical roles like portering and get an idea of what they like and don't like. In the final year it is more like a supported internship with a focus on roles the Learner may want to go into in the future. If someone prefers an administrative role then they may go and work with another local employer in the local area in the second year. Katherine said that she looks around the local area to find organisations that would be a good fit and then works with them on training. This can be used as a work trial as opposed to a work placement—it provides an opportunity to volunteer and demonstrate skills, which may then lead into a paid job. That has happened on several occasions.

Karen Edwards gave examples of working with the hospitality, retail and transport sectors.

Baroness Rock asked how CareTrade identify employers who are willing to use the supported internship model, and how they get employers to be excited about these opportunities.

Karen Edwards said that this was why working with the Trust is such a strength—there are lots of opportunities in one large organisation. The capacity can vary widely depending on the employer.

Savita Rana said that there was the potential to scale up TAP with NHS trusts across South East London. It is about showing employers what the future workforce will look like in terms of diversity and inclusion. There was a case for a consistent approach across the NHS, beginning in South East London and then applying more widely across the country using the NHS as an anchor organisation. They want to scale it up. Data shows that such initiatives are crucial in terms of the future workforce and delivering a pipeline of employees from schools and universities. The NHS has recruitment criteria in terms of education qualifications. That needs to be reviewed and the NHS needs to look at that. No-one is questioning the appropriateness of entry level requirements.

Jo Young said that they are working with the recruitment team around the concept of transferable skills in recruitment, for instance considering work in retail in relation to numeracy. It is about ensuring managers understand that when they are shortlisting. They are undertaking a piece of work around knowing what 'or equivalent' means in a recruitment exercise.

Hilary Fertig said that it is not about getting round the recruitment process but rather having one that is flexible enough.

Elliott Ayling said that the NHS is very flexible in terms of how the internship system works. Other employers may be more fearful or hesitant to take on someone who is different.

Judith Kerem said that it is key to have flexibility. It works at the Trust because CareTrade is embedded in the system. When the Trust is thinking about recruitment adjustments CareTrade will get a phone call. Judith has advised the Trust around making recruitment adjustments. The Trust is open to this because

they recognise the value of taking on neurodivergent staff. There needs to be a holistic approach with buy-in and resources from the organisation. The best thing to do is ask, but you need to know who to ask or have someone to ask. There is a strong support network in the Trust.

Savita Rana said that the Trust could not have achieved what they have without CareTrade.

Harriett Rossouw said that CareTrade are approached by a lot of individuals looking for employment. They are also approached by employers who want to employ autistic people and take advantage of their neurodivergent abilities. CareTrade is the thread between them.

Judith Kerem said that there is a lot of trust between the hospital and CareTrade. CareTrade also works with a hospital in North London and other trusts have similar set-ups. It is about the information and the knowledge—telling people that CareTrade are there.

Elliott Ayling said that CareTrade are trying to educate employers so they understand about autism. Autism is an obscure, hidden disability. It is a spectrum condition and people have different levels of need.

Jo Young said that the Trust was commendably forward thinking. Her role doesn't exist in every trust, although Bart's also has a dedicated team. In other trusts the tasks that Jo undertakes may be added on to existing posts. A trust needs to recognise its role as an anchor organisation, creating resource. There is a lack of understanding among parents of school-aged children that supported internships are a route. They will look at college routes, but supported internships are not well known. There would be a huge demand if they were known about, but as it is there is not so much demand for them. We need to ensure communities know it is an option available to them.

George Byford said that he went straight from sixth form into the CareTrade project. At the start, it was nerve-wracking. He said that he has learned over the years not to worry too much. At the start, he was worrying that he had upset people. It took him a long time to realise that he could come and do his job and didn't have to get to know everybody. That has helped him to understand who he is. George said he also has a strong network of friends who love him for who he is. On the second placement at CareTrade, he worked with one person who showed him all the ropes, and another who subsequently became a good friend.

Judith Keren said that the model CareTrade use teaches resilience. George's confidence came from his own determination and because he was embedded in the workplace. It is about future-proofing the support and giving Learners the opportunity to practice these things.

Jo Young said that not every placement works out at the beginning. CareTrade can recognise when something is not working and switch the Learner to another placement.

Lord Crisp asked about the sustainability and resourcing of the model, and whether all employers can do this.

Jo Young said not every trust has a partnership like this. She said that CareTrade is a small organisation.

Judith Kerem said that TAP is funded through education – all Learners have an EHCP. That is great but it is also a barrier. They are grant funded for work with over 25s. Supported employment should not stop at 25.

Karen Edwards said that CareTrade receive charitable grant funding. That is really important. The benefit of TAP is that it lasts for two years whereas a typical internship lasts a year. There is a focus on education in the first year and longer exposure to the workplace. DWP Access to Work funding is also available, providing continuity with training offered to employers. Many organisations do supported internships.

Savita Rana said that there should be a focus on sustainability and scalability. Wraparound support is so fundamental at the moment, and expansion would present a risk. There is a need to consider education, awareness and cultural barriers. We have moved forward with awareness of mental health and we are still at the beginning of the journey in relation to autism, and considering sustainability and scalability. There are some conversations going on. They would welcome a dialogue about how the Trust's model and Jo Young's role can be used elsewhere to scale up and educate others.

Judith Kerem talked about the knock-on benefits. People who get a job will need less access to Access to Work support because of the skills they have learned. They are a phone call away to anyone who needs them for support.

Dylan joined the meeting. He is in his final year as a TAP Learner and is part of the bank staff for the portering team. In his previous placement at Royal Brompton he worked with the stores team. He applied for bank work at St Thomas' and was successful, starting a few months ago. He said that he is enjoying the work.

Ciara MacKay said that in the first phase of the Trust's autism and neurodivergence strategy they engaged with 200 members of the public, including patients, carers and family members. They stressed the Trust's responsibility to employ autistic and neurodivergent people and also to help manage employees' health conditions to enable them to attend work. There is scope to apply the things they have learned across the country, including through the Job Centre network.

Baroness Rock asked what recommendations the Committee should make to the Government.

George Byford stressed the importance of facilitating the work of organisations such as CareTrade in working with businesses to try to get more people with different disabilities and situations into a workplace that they can enjoy.

Harriett Rossouw said that it is important to stress to employers that if you are going to employ someone who is neurodivergent, autistic and/or has a learning disability, it is an investment but you get a return. Neurodivergent people are representative of the community, which is particularly important in the healthcare sector. If you can see yourself in the workforce you will engage more. That is an investment and a return.

Karen Edwards stressed the importance of changes to make for smoother avenues into work. If 50–60% of autistic people go into work, you still have 40–50% who don't. Many are ready for work but if you don't make that journey into the workforce in a certain period of time you start to de-skill. CareTrade do work to give people confidence, and that is key. Young people come to CareTrade and don't realise they already have the skills they need. One interesting area to explore

is supported apprenticeships. These provide a longer period of support but in work, enabling people to move from unpaid work experience into a stronger, paid support structure.

Savita Rana said that thought needed to be given to making apprenticeships accessible.

Judith Kerem said that it is important to make employers aware that you can adapt or extend traditional apprenticeships.

Baroness Rock asked what the barriers to this are.

Jo Young said that it is the same as employment. She gets told that employment law says every job must be advertised, and employers wrongly think the Equality Act means people need to be treated exactly the same. Apprenticeships should be ringfenced. There is a need to break through misunderstandings of employment law and show employers that they won't be taken to a tribunal.

Savita Rana stressed the importance of developing skills for the future, such as cyber-skills. People with neurodivergent conditions often have the best skill sets. There is a need to look at different routes for developing these skills, for instance through apprenticeships.

Hilary Fertig said that there is a cohort of people stuck in their bedrooms. So many people say they have given up when they are unsuccessful in applying for hundreds of jobs. Parents ask how that can be changed.

Jo Young said that the key is finding a way to make an individual known to the organisation so that managers know how good they are. Manager will find a way to make adjustments for someone who is known to them, but won't always make those adjustments for someone they don't know.

Karen Edwards said that some neurodivergent people may appear over-qualified for an apprenticeship (for instance if they entered university), but that may be exactly what they need.

Judith Kerem said that people in their bedrooms may have skills around tech and gaming, for example. There is not enough joined-up thinking. CareTrade get referrals from job centres. They have built relationships with local job centres and get emails from a wide variety of organisations, but they have invested in developing these relationships: they do not exist organically.

Savita Rana said that she had an issue with unpaid employment. Why shouldn't they pay people to work? These are colleagues supporting their organisations. Paid employment has to be the way forward. It empowers people in a different way by providing a sense of worth.

Jo Young said that there is a problem in the way that jobs are designed. She gave an example of inflexibility in the domestic team to meet the requirements of a potential employee. She said that jobs are designed around how we envisage they have to be rather than around the individuals who might do them.

Judith Kerem said that there is a need to scrutinise traditional jobs and see if they are fit for purpose.

Lord Crisp asked about how to transition from policy into practice.

Harriett Rossouw said that the discussion had been about chipping away one manager at a time. That is a very slow way but it is the only way you can do it. It is about hearts and minds. To scale up, a way needs to be found to engage with multiple managers at a time. A way needs to be found to change people's fundamental views, using a carrot approach as much as a stick.

Savita Rana said that it is about holding employers to account as well as educating them.

Lord Addington asked if they have quantified the benefits to the Trust of the TAP project and such internship models.

Jo Young said that they talk about this but haven't written it down. Because every autistic person is different it is difficult to generalise. However you can look at the people the Trust have employed and see how reliable they are in terms of longevity and a low absence record, for example.

Savita Rana said that there was a case to do some modelling on this.

Harriett Rossouw gave the example of a neurodivergent person who put on their records not to be taken to A&E because of sensory overload. But if they saw someone who they could identify with and who would look after them, would that enable them to see healthcare in a more positive way?

Savita Rana asked if the Committee have spoken to any large employers who are not following best practice.

Baroness Rock said that the Committee is looking at autism policy and why it is not being implemented.

Jo Young said that the education sector leaves a lot to be desired. Autistic people and others are coming out of the education system broken.

Lord Addington asked how good the nursing profession is at employing autistic people.

Ciara MacKay said that nurses are recruited having trained at universities, so they are dependent on what qualifications universities require. However, there are also associate and apprenticeship role opportunities. There is an openness to look at this but it is not a focused piece of work on autism, but rather the broader neurodivergence strategy. She said that they should be challenging themselves on this.

Jo Young said that they now have interns in clinical roles but not nursing. She would love to see an intern on every ward.

Harriett Rossouw said that the neurodiversity staff network is looking at neurodiversity within the nursing and midwifery cohort. Many autistic people also had other conditions such as ADHD. She praised the work of Autistic Doctors International.

Jo Young stressed that trusts are beholden to universities and who they recruit to their courses.

Judith Kerem said that one of the benefits of CareTrade's work with the Trust is that it becomes embedded. Five years ago TAP Learners had not taken on clinical roles in their internship, but that is now happening more and more.

Jo Young said that they are just about to launch a new declaration campaign to get data on neurodivergence among employees.

Harriett Rossouw said it is about creating a safe space to declare.

Karen Edwards said that the neurodiversity movement has helped with this. People didn't know what autism was but people have an understanding that neurodivergence means that someone will think differently. This helps employers be less anxious.

Elliott Ayling said that there was still a huge degree of uncertainty around autism and what people need in terms of support. It's not right for the Government to tell someone that because they have a job they don't need any support and their benefits can be cut. People get forgotten about.

Baroness Rock thanked all participants for their contribution and closed the meeting.

APPENDIX 9: NOTE OF COMMITTEE VISIT TO PHOENIX SCHOOL, BOW, LONDON BOROUGH OF TOWER HAMLETS, 11 JUNE 2025

Introduction

On 11 June 2025, a delegation of the House of Lords Committee on the Autism Act 2009 visited Phoenix School in Bow, in the London Borough of Tower Hamlets.

The Committee delegation comprised:

- Lord Addington
- Lord Crisp
- Lord Elliott of Mickle Fell
- Lord Hope of Craighead (who acted as Chair of the delegation)

Introductory meeting with Veronica Armson, Executive Headteacher

The visit began with an introductory meeting with the Executive Headteacher of the school, Veronica Armson, and other members of staff. Ms Armson introduced herself and provided the following background information:

- Phoenix is an all-aged special school for children and young people from 3 to 19. All children have a diagnosis of autism or have been assessed and are waiting for one.
- The school has over 500 students across three sites and has five Satellite classroom provisions in two mainstream schools with children on the Phoenix roll.
- Phoenix children have a wide range of complex needs and are academically working below their equivalent year group.
- Overall, 60% of students at Phoenix use alternative and augmented communication systems to support their language and communication.
- They have an extremely successful Phoenix Outreach Team which is trusted and well respected within the Local Authority, and has been working within schools for over ten years and is based at the school.
- The Outreach Team work across all schools in Tower Hamlets and are a free service offering training and advice through modelling and face to face discussions and mentoring.
- The school is recognised by the National Autistic Society with Advanced Status (March 2023).
- The school had an Ofsted inspection in April 2024 and continues to be recognised as Outstanding.
- The school has a highly experienced team of staff who are well trained and specialised in the field of autism.
- The school is piloting a Specialist Classroom project with mainstream schools. Twenty-two schools (including two secondary and 20 primary) are working in partnership with Phoenix, having set up classroom provisions for their autistic young people. Phoenix are supporting all schools with advice, training, practical support and buddy teaching both in the mainstream and staff visits to Phoenix. Phoenix have led on peer learning to quality assure, teaching and learning, the curriculum offer and assessment. Phoenix have

offered an action plan and follow up for training and support in the schools and at Phoenix.

Ms Armson said that there were currently 220 children on the Phoenix waiting list. Demand exceeds supply, an increasing number of cases are being taken to Tribunal, and classes are getting bigger. This showed why the Specialist Classroom model was so important, as it allows mainstream schools to operate a specialist classroom for their autistic children under the guidance of Phoenix through specialist training, thereby widening capacity and expertise in educating autistic pupils across the Borough.

Tower Hamlets has the highest proportion of children with an autism diagnosis in the country, and there is a waiting list of two to three years for diagnosis. There are 2,500 students with a diagnosis across the Borough. As well as having 520 children on site, the school supports another 900 children across the Borough.

Ms Armson stressed the importance of early diagnosis and intervention. She also noted that many autistic children had co-occurring conditions such as global developmental delay, being d/Deaf, dyslexia, dyspraxia and ADHD. The rates of diagnosis of ADHD are also increasing rapidly. Some children therefore have more complex needs, and their parents are anxious for them to get a place at Phoenix. Obtaining a diagnosis is key.

The school has an experienced team of 420 members of staff, including 62 teaching staff in 52 classrooms, and other specialist staff including Speech and Language-Trained Teaching Assistants and six Speech and Language therapists. These posts are self-funded, and have been hugely successful in helping students with communication skills. There is also a team of chefs with a focus on being healthy and preparing specialist food for some of the children who have eating and drinking challenges.

There are five or six members of staff per room, and between 10/11 students per class. Each class will usually have a teacher, a Speech and Language-Trained Teaching Assistant and three or four Teaching Assistants. Staff aim to provide an emotional support to students and prioritise helping them understand their autism as well as an effective curriculum to meet their needs.

The school has a constant stream of people wanting to work at the school, whereas mainstream schools often struggle with retention. A key aspect of Phoenix's work is upskilling staff in mainstream schools. It is important to train the whole school in the basics of autism, and to ensure that the school leadership and specialist staff have the greater depth of knowledge required. This work is important to bring about a culture change in mainstream schools. This has been the impact of the Specialist Classroom work.

The school trains its own staff internally. Staff have a range of experience, and for some it will be their first job in teaching. The school employs three or four trainees each year through LETTA teacher training SCITT programme in Tower Hamlets. Many of these will stay if they are good enough and show the necessary passion for the job. The school does well in terms of retention of staff.

The school's priority goals for educating autistic children and young people reflect the SCERTS model developed by Emily Rubin: Social Communication; Emotional Regulation; and Transactional Support (preparing students for the transition to adulthood). Phoenix is part of the Pan London Autism Schools Network (Plasn), a network of 16 schools that use this model. Each school adapts the model for the

specific needs of its cohort of children. Phoenix prioritises helping children to learn about their autism.

Under SCERTS there are three partner styles reflecting methods of communication: social partners; language partners and conversation partners. Ms Armson said that 60% of students use alternative and augmented communication systems. These include: objects of reference; symbol exchange; core boards; and hi-tech partners. Many students will be able to converse through iPads. Support is individualised to the student.

The Early Years curriculum is based on play and exploratory learning through free-flow. From Primary, the curriculum has different routes. The routes are known as explorers, discoverers and pioneers. Children stay in their age groups and are taught according to which stage they are in. The explorer route is based on an engagement model of teaching through exploring. This will be play-based for children of primary age, and at secondary age will focus on functional skills for everyday life. This may include skills such as brushing teeth or making a cup of tea. After leaving Phoenix, young people tend to move on to a college environment or to day centres. Phoenix has an internship programme through DFN Project SEARCH which leads to employment or further education. Students may receive Level 2 or Level 3 accreditation rather than GCSEs. A key component of the curriculum is life skills to prepare students for adulthood. For example, primary age children have recently been putting recycling into practice. The curriculum prioritises creative, play-based, work-related learning. There is a focus on multi-sensory and outdoor learning. The school has a sensory room (where lessons sometimes take place), two gardens, ponds, and a greenhouse. The school does not engage in one-to-one teaching, but rather constant support and more generalised learning to students in class. The focus is on teaching as well as therapy—children are educated, not just looked after.

Children have a wide range of sensory and occupational therapy needs. There are low arousal classrooms. Many students have high behavioural needs. Staff plan ahead and look at students' profiles and likely triggers for dysregulation. The school aims for children to be in a 'Green Zone' where they feel at their calmest and regulated for learning. Some students may choose to wear headphones if noise sensitive and are encouraged to ask for their own regulation tools. Many of the students enjoy sensory play.

The school operates a School Council comprised of students from across the school. They discuss issues such as the colour of the school uniform, which was recently changed in the secondary setting. The school also has a strong network of parent partnerships, and an effective governing body. The school also undertakes visits to the local area and further afield, such as to play cricket at Arundel. There are also girls' groups, after-school clubs, a Saturday club and a youth club which are all self-funded.

Phoenix School works with DFN Project SEARCH in facilitating an internship at Queen Mary University of London, where students learn skills through work experience at the university. They learn a skill in a department for a six-week period and then rotate to another skill. They are taught about work and their coaches help them to find employment. There is also an internship partnership with a construction firm and a legal firm. Phoenix School has employed some of its former students and also given some of them apprenticeships. This project has won awards and has an 85% employment rate for those who have undertaken an internship.

The National Autistic Society undertakes observations at the school every three years. In its most recent assessment in March 2023, the school was given Advanced status. The school is now aiming to achieve Beacon status. The school also has regular Ofsted inspections. Its most recent inspection in 2024 saw it recognised as Outstanding. The inspectors had a good knowledge of autism and Special Educational Needs and Disabilities (SEND).

The school has operated satellite classes in mainstream schools since 2015. This supports students who are able to cope in a mainstream environment with support. It has been hugely successful. It has enabled Phoenix students with higher academic ability to interact with mainstream students. Although the goal is happiness and helping students to cope in social environments rather than academic attainment, two pupils have recently gone on to take some GCSEs through this model. The students have their own Phoenix classroom but are based within the mainstream school, and wear the mainstream school uniform. At the same time, students still feel that they are part of Phoenix and come back for Assembly and some specialist lessons. While Phoenix run satellite classes, the model has inspired the idea of Specialist Classrooms which are the same model but run by mainstream schools with intensive support from Phoenix.

Parents often say they feel lucky that their child obtains a place at Phoenix, but it shouldn't be a question of luck. Ms Armson said that it is so important to help mainstream schools and to provide more training for their staff. It is also important to recognise that the needs of each child are different. The funding for the current Specialist Classrooms model was for two years. This has got to continue because mainstream schools are changing for the better. The impact has been better progress for the students but also the knowledge and understanding of autism has improved. At present 221 children are being taught in Specialist classrooms and over 600 staff have had training across the schools. The biggest problem in mainstream schools is speech and language therapy and the consistency of practice to support the young people with their communication for receptive and expressive language. The focus in mainstream tends to be on bringing autistic people into the neurotypical world rather than adapting to their world. The Specialist Classroom project has adapted the focus and is now providing an education that is teaching the young people rather than just occupying them.

Tour of the secondary and primary campuses

The delegation were then taken on a tour of the secondary and primary campuses, when they met students and staff members, saw classrooms and observed the school sports day.

Meeting with parents

The delegation then met a group of parents of students at the school, who shared their experiences.

A parent shared their struggles with obtaining a diagnosis for their child. It is difficult to get a diagnosis and takes a long time. They said that the process was a constant battle and a mental challenge. Early diagnosis is so important: it is beneficial for the child and gives parents direction, whereas it is much more difficult to put support in place later on. They engaged with lots of different health visitors, but in spite of repeated requests a referral was not made. The parent decided to go private. The diagnosis had made it possible for their child to join Phoenix. They had seen a major positive change in him and the family dynamic, and the parent was full of praise for the school. They referred to coffee mornings for parents

of neurodivergent children. They also said that non-specialist professionals such as GPs often inadvertently passed on misinformation, and engagement with specialists in autism through the school network had helped to correct this.

A parent said that the Government needs to meet autistic children's needs. Their needs are not met in mainstream schools because teachers are not trained in SEN or speech and language. Phoenix is in high demand, and parents are constantly looking for a private diagnosis or to appeal a decision to ensure their child is able to secure a place. Some parents have more than one autistic child, and this involves so much time with GPs, healthcare professionals and engaging with Education, Health and Care (EHC) plans.

A parent said that they did not know how to help their child until the child received an autism diagnosis. Since the diagnosis was received four or five years ago, the child had blossomed at school. They did not use spoken language, but their communication skills had increased significantly. They were able to show affection, use eye contact and were toilet trained. The parent said that at the school people were on hand to offer advice. They said that communication is so important, and after diagnosis they had realised that there are so many ways to communicate, not just words. There is so much that autistic children and young people can bring to this world, and the school is helping to equip them to do so.

A parent said that their child had been diagnosed during the COVID period and this had made things more difficult because it was not possible to meet professionals. It was only when the child started school that they were able to have effective speech and language training and become toilet trained. Diagnosis during COVID provided peace of mind but also a sense of isolation. Phoenix opened doors. Their child's communication skills had developed so much because of the staff at the school. The parent said that mainstream schools are not a safe environment. Safety is important. The parent said that Phoenix School was the best thing that had happened to them in their care for their child.

A parent said that there was a WhatsApp Group of parents of autistic children in the Borough. Many parents shared their struggles at mainstream schools. There was a feeling that their children were babysat rather than taught, left with agency workers, and not permitted to engage with the rest of the class or go on school trips. There was a fear in mainstream schools when they encountered autistic children.

A parent said that their child had not used verbal language until they were four or five. They had attended a mainstream nursery, and the SENCO recommended Phoenix School. The head of the mainstream school they attended said they couldn't help because the curriculum was geared to verbal communication, and also recommended Phoenix. Since starting at the school, the child has started to talk and communicate, and is now toilet-trained. There had been a big positive change since the child started at the school. The school provides daily feedback through the school App, Class Dojo and parents' questions were answered immediately.

A parent shared their struggles prior to the diagnosis of their child. They saw signs of autism but they had to seek a second opinion before a diagnosis was given. This placed them as parents under mental strain. There are problems with lack of funding and the long wait for diagnosis. Their child was doing much better since they started at Phoenix. They are able to show affection and communicate their needs.

A parent summarised the discussion by saying that Phoenix has changed the lives of children, parents and families.

Concluding discussion with Veronica Armson, Executive Headteacher, Leanne Woodward, Assistant Head of Primary, Ciara Mc Cone, Head of Speech and Language Therapy (SaLT)

Committee members asked what Veronica Armson and her colleagues would call on the Committee to recommend to the Government in its final report.

Veronica Armson stressed the importance of the Specialist Classrooms project and rolling it out across mainstream schools. She also stressed that mainstream schools need funding to provide effective speech and language support, but they also need to be linked to a special school for effective change to take place in the setting and the workforce.

Leanne Woodward said that there was no structural organisation to training of mainstream school staff. Each school does it differently. Special schools could operate as a learning hub. Mainstream schools often say that they don't know how to do a good job with autistic students, and special schools can show them how. Specialist skills and expertise are crucial. It is important to build a network and community. Phoenix School had set up resources evenings where teachers could meet and learn from each other. The focus is on how to help teachers as a cohort rather than only on SEND teachers, who often carry a heavy burden of responsibility.

Veronica Armson referred to a Borough-wide consultation which is seeking to establish the level of need. Parents fight for support in so many areas. For so many parents it is the luck of the draw, and many children with higher needs are in unsuitable mainstream school settings. It is vital that teaching expertise expands across the community rather than being concentrated in one place. Only two out of nine secondary schools in Tower Hamlets were currently part of the Specialist Classroom model, in part because they are reluctant to go down the route of accreditation rather than GCSEs.

Ms Armson said that Phoenix School would recommend the Specialist Classroom model. It may be called different things, but the crux of the model is that a special school provides for and ensures high standards in mainstream settings in a quality assurance role, including through Continuous Professional Development of staff. The main barrier is how to fund Specialist Classrooms. There is an overall budget envelope of nearly £300,000, and all the schools involved have said that they have spent the allocation already. However, the Local Authority argues that the model is over-costed.

Ms Armson also stressed the importance of early intervention and pre-diagnosis input and support. Early intervention centres do important work as an assessment base. The school has good links with NHS providers but there are inconsistencies because of the high turnover of staff and the high level of bureaucracy in the NHS system. It is particularly important that education and healthcare providers provide coordinated support in speech and language development. The model of NHS-funded speech and language therapists being based in a school setting was very effective but they need to be linked with education so there is consistency of practice and it is linked to the child's learning She stressed the value of education and healthcare professionals being trained together. Occupational therapy is more

of a challenge. Only a few children get it, and then only for a period of six weeks. There is not a perfect match between education and healthcare services.

Ms Armson also stressed the importance of effective adult support services, and in particular helping autistic people with the transition from education to adulthood, including employment, post-19. This really is lacking and needs training and support.

Lord Hope of Craighead thanked Veronica Armson and her colleagues for their hospitality, and concluded the visit.

APPENDIX 10: NOTE OF MEETING WITH THE HOUSE OF COMMONS AUTISTIC CHAMPIONS, 7 JULY 2025

The Committee held a private meeting on 7 July 2025 with the House of Commons Autistic Champions, a group of autistic adults working with Parliament. This followed a previous meeting with the Autistic Champions on 24 April.

The role of the Autistic Champions is to review and provide feedback on Parliament's public engagement services from the perspective of autistic people, looking at experiences like visiting Parliament, going on tours and finding information on the Parliamentary website.

The meeting was an opportunity for the Committee to hear reflections from the Autistic Champions on the evidence heard in its inquiry, including the evidence from Government ministers on 30 June and from representatives of autism charities earlier in the meeting on 7 July.

Participants in this meeting had a range of experiences of advocating for and supporting autistic people, including acting as an expert by experience to improve mental health services; advocating for and supporting autistic children and young adults; training employers about autism; supporting autistic people in the workplace; and creating online content sharing their experiences.

Baroness Rock asked what the Autistic Champions thought of the evidence from Government ministers on 30 June, and what was helpful or unhelpful in that evidence.

A participant said that when they read the transcript of the evidence, they felt at first that it was refreshing to see that the Government is aware of the issues and that at least two of the government departments work together. But they were also disappointed because there was no real commitment. In the evidence session on 7 July, the representatives of autism charities said a lot of things that resonated with the participant. Jolanta Lasota said right at the end that parents need support. The participant really felt that as the parent of an autistic adult. There is little support and no real responsibility or accountability. Another participant said that they felt the evidence session with the ministers showed things were moving in the right direction and that they were aware of all the issues, but accountability was missing.

Another participant said that when they first read the transcript of the ministers' evidence session, they were quite impressed. On reflection and after hearing the response from representatives of the autism charities, the participant thought that it was very wishy-washy. There was nothing concrete and there were no metrics or timescales. It seemed like the ministers don't yet know what the autism strategy is going to be.

Lord Hope of Craighead said that the Committee could play a role in recommending to the Government what the focus of the strategy should be.

A participant said that they work as a diversity, equity and inclusion specialist at an accountancy firm, supporting about 40 neurodivergent members of staff at any one time. They thought that there was a lot that was encouraging in the ministerial evidence session, in particular the commitment to produce a new autism strategy after 2026. They greatly welcomed the focus on needs-led approaches, but they wished that there was a focus on diagnosis, which they believed to be key too.

The participant works for a company that funds private autism assessments for employees and this can be really valuable. The assessment and the follow-up meeting to discuss the results help give the person an understanding of their neurotype and of their strengths and needs. This can then give the person the confidence and validation to ask for reasonable adjustments at work. This can be particularly important for people who are not identified as autistic until later in life. In practical terms, a diagnosis is necessary to access reasonable adjustments in professional qualifying exams in accountancy for apprentices hired by the participant's firm. If we shift towards more self-identification, we can end up putting more pressure on neurodivergent people to understand their neurotype and advocate for their own needs. The participant thought that relying on diagnosis wasn't necessarily the best solution in the longer term. We need to see big social shifts in acceptance, access to adjustments that don't depend on diagnosis, and more access to forms of support like counselling and coaching for employees. But there are big challenges that make access to diagnosis critical at the moment, and we need to take that into account.

Another participant said that it was great that the ministers had said there would be a new autism strategy, but they were concerned that there weren't specific enough recommendations coming out of the discussion. They were worried that there would be a great discussion but little would change in practice. The participant said that they know there is a conversation about whether diagnosis is always necessary. For them, they absolutely did need an autism diagnosis for several years. If they had been screened for autism when they first came into contact with mental health services, 12 years of mistreatment might have been avoided and things would certainly have been very different for them. Instead, they internalised everything and developed serious mental health problems. They reported experiencing very high sensitivity to noises in hospital as a patient. They had a sensory screening assessment and scored very highly, so people could have put the pieces together. There aren't enough people who understand or are thinking about autism early enough in any person's journey. They thought there was a huge difference in what's changing—where people do understand and where people don't. There is still a lot of social stigma that causes shame, and people don't speak about being autistic so they don't get adjustments. If people don't feel able to say they are autistic, that is a problem.

Another participant said that their priorities at the moment are education and employment. Last week they looked at debates on education and SEND in mainstream schools, including a recent House of Commons Education Select Committee evidence session on these matters. They are concerned about possible changes to Education, Health and Care (EHC) plans and Disability Living Allowance (DLA). Their nephew only received an autism diagnosis a few months ago. Their concern was that people could lose DLA as a result of the Government's forthcoming Autumn Statement. They would like to see the Disability Confident scheme and reasonable adjustments addressed as well.

Baroness Rock asked what the first steps might be to drive improvements, for example to improve understanding.

A participant said that the Committee has a real opportunity in the language used in writing its report. In recent years we've had more awareness, but we don't have enough drivers of true inclusion. Stereotypes are prevalent. So there is an opportunity to set a marker from a Parliamentary perspective on how the public view of autistic people, how we challenge medicalisation and infantilisation, and how we empower and celebrate autistic people.

Another participant said it was key to have autistic people represented in the room in conversations like this one. Autistic people may need simple reasonable adjustments to participate, but they're simple and not expensive. They come from understanding, patience and compassion.

For example, when a participant experienced a meltdown on the train because of the noise it was really important to have their mum there to help calm them down, including taking them outside for some fresh air.

Baroness Pitkeathley asked this participant whether they would have appreciated a hug from her during this meltdown.

This participant responded that they do wear a sunflower lanyard. A hug would have been overwhelming, but they would have been comforted if a stranger simply smiled at them during the train meltdown, as they would have felt reassured that everything was going to be okay. Sometime a small sign like a friendly smile can be much more powerful than a corporate message of support for autistic people that isn't backed up by action.

When they tell people what they have achieved as an expert by experience improving mental health services, people say it's amazing. The participant said that they don't feel like it is enough because it's not a PAYE (Pay As You Earn) job. They have had reasonable adjustments integrated into their roles and they have made a big difference. The participant also said training for professionals was very important. GPs need to understand they may need to give more time to an autistic person explaining physical symptoms.

Lord Hope of Craighead asked if there could be more trainers with lived experience. As a supplementary question to this, he asked how autism awareness training is arranged and whether payment is taken by trainers

A participant said that they and their adult child are paid lived experience trainers who go into companies and schools. It is very important that people do not see autism as a label and that it is humanised. They have been through it and bring their experiences to others. They come in and do role play and people really get engaged. Clients say it's the best training they have had. There is not much training out there at the moment. They pick up business through their marketing and networking (for example, at autism and ADHD shows). Recently, because of the higher costs for employers, they have had less business. Unfortunately, autism training is still seen as an extra.

Another participant said that having reasonable adjustments is vital. There is an important link between reasonable adjustments and the Disability Confident scheme. People shouldn't be afraid to sit down and have a bit of a chat about it.

Another participant said that, when it comes to reasonable adjustments and training, we put the burden on autistic people. The autistic person has to work out what the challenges are that they face, what adjustments might be reasonable, and how to advocate for them but they not may necessarily be equipped with this know-how. You can't just rely on autistic staff to advocate for themselves.

Lord Addington asked about needs-led support and the roles of line managers and business leaders. He also asked a supplementary question on whether legal enforcement would help with reasonable adjustments.

A participant said that when it comes to getting the best performance from an employee it is a collaboration between the individual, their line manager and Human Resources. Their company has a neurodiversity policy which has been updated numerous times. The person needs to have the confidence to say what their challenge is, and then their line manager and HR can work with them to figure out what adjustments would help. That requires a focus on need, not just the disclosure of a diagnosis. They said that 70% of autistic people could be in work and their potential could be tapped into by employers. There is so much value in autistic people being in employment. Leaders should focus on the benefits of employing autistic people. It's the right thing to do organisationally as well as morally.

Lord Hope of Craighead asked about school staff not always having the time to understand a student's needs, for example if they find school uniform distressing for sensory reasons.

A participant said that when they moved schools they really experienced distress because of the uniform. They went from being very academically successful to nearly being expelled. The participant articulated that the change in material was the problem but school staff didn't hear them when they tried to tell staff. Listening is very important. The participant found it encouraging that Minister McKinnell said Special Educational Needs and Disabilities (SEND) training would be mandatory in initial teacher training from September this year. The participant thought that would enable teachers to listen.

Another participant said that lack of time for school staff is a problem. They had one teacher at their child's secondary working overtime offering extra sessions for children like them. Not everyone can be that selfless.

Another participant said that they attended mainstream school. Uniform was never an issue for them. Even though the school had a SEND department they didn't have a good experience. They were thinking about creating a project for students with SEND to talk about puberty and menstruation because they have had a lot of feedback about that. They didn't have support going through puberty. They were never told properly how to use a menstrual pad and it was really awful. Schools need to understand that. They were told by one SEND teacher that they would never get a paid job or own a house. They wish there were more autistic people trained to do one-to-one support with children with SEND.

Baroness Rock asked what the Autistic Champions thought the Committee should recommend.

A participant said that the Government should be accountable for delivering the autism strategy to a committee of people with lived experience like there has been in Scotland, so there are incentives to stick to the strategy. The rest will follow from that. The formation of such a committee would not be too bureaucratic.

Another participant said they would focus on signposting. There seem to be lots of people doing great work all over the place, but there is no central place where all the information is brought together and trying to navigate the support that is available is nigh-on impossible. Sometimes you get a lot of information all at once but it's very difficult to find the right information about help for specific situations, like moving towards independent living in the case of their adult child.

Another participant said their focus was employment. There has been a lot of discussion about enabling more autistic people to find work and that's very

important. They would like there to be a review of the impact of job application screening processes and the use of AI on autistic applicants. But career pathways are important as well. It's key to empower employers to provide the right reasonable adjustments and not put the burden on the autistic person, so we can get the most out of autistic people's talents. The Access to Work scheme needs to be maintained and improved. It's been scary to see recent media reports suggesting the scheme could be cut back. There are also gaps in awareness of Access to Work.

Another participant said their focus was on understanding and acceptance of autistic people as valuable people in society. When an autistic person understands themselves and is understood by the people around them, they can feel like themselves and can then connect with society. They wanted to see things like screening for autism in mental health services, particularly for autistic people with a more internalised or hidden presentation.

Another participant said their priority would be benefits at the moment because of their worry about DLA, as well as Personal Independence Payments (PIP) and universal credit which is affecting them and their family and many autistic people more broadly. They would like to talk to the Minister for Social Security and Disability, Sir Stephen Timms MP, who is leading a review of the PIP assessment.

Another participant said that they and their parent advocate in their consultancy for teamwork between employers and autistic employees. Following this spirit of teamwork, the Government should do more to support employers. Employers are being left in the dark about making recruitment processes accessible and how to make reasonable adjustments. They need incentives to change, including hiring more neurodivergent employees.