

By Library specialists

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Autism - overview of policy and services



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Summary

Terminology

This briefing uses terminology recommended by the [National Autistic Society](#). While autism is classed as [a developmental disability](#), not all people on the autism spectrum consider themselves to be disabled.

People who are neurodivergent are covered by the Equality Act 2010 under the definition of disability (substantial and long-term impact on your ability to carry out day-to-day activities).

This briefing uses language around autism and disability when discussing policy and disability data.

The Autism Act 2009

The Autism Act 2009 is currently the only disability-specific legislation in England. The Act requires the Government to introduce and keep under review an [adult autism strategy](#). The initial strategy was published in 2010 and refreshed in 2014. The accompanying [statutory guidance](#) is aimed at supporting the NHS and local authorities in implementing the strategy in areas such as staff training, identification and diagnosis, transition planning when people move from children to adult services, employment and criminal justice.

The 2019 review and a new strategy

In 2019 the Government undertook a comprehensive review of the autism strategy and planned to extend it to include children and young people for the first time. A [call for evidence](#) was launched in March 2019 with a [summary of the findings](#) published in July 2021.

The findings from this and other reports were used to inform a new autism strategy, [The national strategy for autistic children, young people and adults: 2021 to 2026](#).

NHS policies

There have been successive health policies aimed at improving outcomes for people with autism. The [NHS Long Term Plan](#) (2019) has several objectives for people with autism, including: the introduction of a ‘digital flag’ in the patient record by 2023/24 to ensure staff know a patient has autism; ensuring reasonable adjustments are made so wider NHS services can support people with learning disabilities or autism; and piloting the introduction of a specific health check for people with autism.

There are ongoing concerns around diagnosis, particularly for children, with increasing waiting times from referral to diagnostic assessment in some areas. [NICE guidance](#) recommends a maximum waiting time of three months from referral to assessment. The latest [local authority self-assessment](#) (2018) found the median reported waiting time to be over seven months. During a Commons debate in 2019, the Minister for Care acknowledged geographical disparities and said “[this postcode lottery must end.](#)” She said new data on autism waiting times would help hold local authorities to account.

The Government and NHS have also focused on reducing levels of inpatient care for people with a learning disability and/or autism. The Department of Health and Social Care (DHSC) has said long-term residence in hospitals is not appropriate, and committed to move people to community-based support. However, ambitions have been postponed. The most recent target, as detailed in the NHS Long Term Plan, is for a reduction in inpatient provision of 50% (compared to 2015 levels) by 2023/24.

The Government has committed to introducing “Oliver McGowan” (named after Oliver McGowan whose death highlighted the need for health and social care staff to have better training in learning disability and autism) mandatory training on learning disabilities and autism for health and social care staff. Trials were due to begin in health and social care settings by April 2020 with a report by March 2021. The trial was subsequently extended due to the Covid-19 pandemic with the report now due in February 2022, after which wider roll-out of training is expected for all staff.

The impact of Covid on autistic people

Several reports on research into the impact of Coronavirus on autistic people and their families have been published. They show significant impacts on people on the autistic spectrum including on their education, mental and physical health, and care and support.

Devolved executives

This paper focuses on policies in England. Health is a devolved matter so each of the devolved executives are responsible for developing their own policies. Section 9 provides an overview of strategies implemented in Scotland, Wales and Northern Ireland.

1 Government policies on autism in England

1.1 The 2010 strategy for adults on the autistic spectrum

The [Autism Act 2009](#) placed statutory requirements on the Government to publish an adult autism strategy and associated statutory guidance for local authorities and NHS bodies.

The 2009 Act was a Private Member's Bill introduced by Cheryl Gillan with backing from the National Autistic Society and other autism charities. It was the first, and at this point remains, the only disability-specific Act of Parliament.

The Department of Health (DH) published the first autism strategy for England in March 2010 - [Fulfilling and rewarding lives: the strategy for adults with autism in England](#).¹

The strategy focused on five core areas of activity:

- Increasing awareness and understanding of autism among frontline professionals;
- Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment;
- Improving access for adults with autism to the services and support they need to live independently within the community;
- Helping adults with autism into work; and
- Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.²

¹ Department of Health, [Fulfilling and rewarding lives': the strategy for adults with autism in England](#), 3 March 2010 (now archived)

² [Ibid.](#), pp18-19

In December 2010, the DH published [statutory guidance](#) for local authorities and NHS organisations to accompany the strategy.³ This provided guidance on the following areas:

- Training for staff who provide services to adults with autism;
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services;
- Planning in relation to the provision of services to people with autism as they move from being children to adults; and
- Local planning and leadership in relation to the provision of services for adults with autism.⁴

1.2

Think Autism strategy 2014

In April 2014, the DH published an update to the 2010 autism strategy: [Think Autism - fulfilling and rewarding lives, the strategy for adults with autism in England: an update](#).⁵ It built-on, rather than replaced, the 2010 strategy.

Think Autism set out fifteen priority challenges for action from the perspective of people with autism and carers. The strategy focused on the following areas:

- Building communities that are more aware of and accessible to the needs of people with autism, which have autism champions for change;
- Promoting innovative local ideas, services or projects which can help people in their communities through new models of care; and
- Focusing on how advice and information on services can be joined up better for people.⁶

The Coalition Government announced national investment in 2014/15 of £4.5million to deliver the objectives in the strategy.

In January 2016, the DH produced a progress report on Think Autism: [Progress Report on Think Autism: the updated strategy for adults with autism in England](#).⁷ The report summarised progress since the 2014 strategy and set

³ Department of Health, [Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy](#), 17 December 2010 (now archived)

⁴ [Ibid.](#), p9

⁵ Department of Health and Social Care, ['Think Autism': an update to the government adult autism strategy](#), 2 April 2014

⁶ [Ibid.](#), p9

⁷ Department of Health and Social Care, [Strategy for adults with autism: progress report](#), 2016

a number of new actions, focusing on education, employment, the criminal justice system and better data reporting.

In March 2015, the Government produced updated [statutory guidance](#) for local authorities and NHS organisations to support the implementation of Think Autism. Guidance was added on the following areas:

- Preventative support and safeguarding in line with the Care Act 2014 from April 2015;
- Reasonable adjustments and equality;
- Supporting people with complex needs, whose behaviour may challenge or who may lack capacity;
- Employment for adults with autism; and
- Working with the criminal justice system.⁸

The guidance was revised to take account of responses to [a related consultation](#).⁹ It also took account of progress made since the 2010 guidance, and related legislation, including the Health and Social Care Act 2012, the Care Act 2014, and the Children and Families Act 2014, which introduced new duties for people with autism.

1.3

The national strategy for autistic children, young people and adults: 2021 to 2026

In July 2021, The Department of Health and Social Care and the Department of Education published the [National strategy for autistic children, young people and adults: 2021 to 2026](#).¹⁰ This strategy builds on and replaces the 2014 Think Autism strategy and covers children and young people, as well as adults, for the first time.

The Government committed to invest £74.88 million towards the objectives in the first year of the strategy.¹¹ How this money will be spent is set out in the [implementation plan for 2021-22](#), published alongside the strategy.¹²

⁸ Department of Health and Social Care, [Adult autism strategy: supporting its use](#), 26 March 2015, pp36-55

⁹ Department of Health and Social Care, [The Government response to the consultation on revised statutory guidance to implement the Strategy for Adults with Autism in England](#), 26 March 2015

¹⁰ 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

¹¹ Department of Health and Social Care Press Release, [New landmark strategy to improve the lives of autistic people](#), 21 July 2021

¹² Department of Health and Social Care and Department of Education, [Autism strategy implementation plan: 2021 to 2022 \(Annex A\)](#), updated 22 July 2021

Subsequent implementation plans will be developed in line with future Spending Reviews.

The strategy is informed by a [review of the Think Autism strategy](#), which included a public consultation on the care and support experiences of autistic people and their families and carers.¹³

Evidence was also drawn from a 2019 report by the All-Party Parliamentary Group on Autism (APPGA) and the National Autistic Society, [The Autism Act: 10 Years On](#). The report found “71% (2 in 3) of autistic adults in England aren’t getting the support they need.”¹⁴

Independent research was commissioned from the Policy Innovation Research Unit to understand the [impact of the Covid-19 pandemic on autistic people](#) (PDF, 2.39MB) (see section 8 for more details).¹⁵

The new Strategy sets out the Government’s vision for next five years and focuses on six key themes:

- Improving understanding and acceptance of autism within society
- Improving autistic children and young people’s access to education, and supporting positive transitions into adulthood
- Supporting more autistic people into employment
- Tackling health and care inequalities for autistic people
- Building the right support in the community and supporting people in inpatient care
- Improving support within the criminal and youth justice systems¹⁶

The Strategy also sets out plans for the improvement of data quality and collection, with the aim to decrease reliance on self-assessments and build a cross-government approach to data collection and reporting. A National Executive group will be established to monitor progress and attend bi-annual accountability meetings with the Minister for Children and Families and The Minister of State for Care.¹⁷

¹³ Department of Health and Social Care and Department for Education, [Review of the National Autism Strategy ‘Think Autism’: call for evidence and summary of responses](#), 14 March 2019

¹⁴ All Party Parliamentary Group on Autism and the National Autistic Society, [The Autism Act: 10 Years On](#), September 2019, p5

¹⁵ Policy Innovation and Evaluation Research Unit, [The Impact of COVID-19 on Autistic People in the United Kingdom: Final Report](#) (PDF, 2.39MB) July 2021

¹⁶ 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, p10

¹⁷ [Ibid.](#), p40

Response to the 2021-2026 autism strategy

The response to the new strategy was generally positive on its aims and the amount of money committed in year one. However, there were concerns about sustaining the funding throughout the full five years and the knock-on impact of unresolved problems in the social care sector. Caroline Stevens, Chief Executive of the National Autistic Society said:

The strategy recognises many of the biggest challenges autistic people of all ages face.

We and our supporters have long campaigned for a fully-funded public understanding campaign, significant investment in reducing diagnosis waiting times and better post-diagnostic support. No-one should feel judged for being autistic, or to have to wait many months for a potentially life changing diagnosis and vital help and support.

So, we're really pleased to finally see these as concrete actions in the first year of the new strategy, alongside other important commitments for autistic people and their families.

But the true success of the strategy will depend on the Government investing in autistic people each year, as well as the Prime Minister honouring his promise to fix the social care crisis. If this happens, this strategy could be a significant step forward in creating a society that really works for autistic children, adults and their families.¹⁸

In the [Autumn budget and Spending Review 2021](#)¹⁹ on 27 October 2021, no new money was announced for the autism strategy. The National Autistic Society commented in a press release:

We're pleased that there will be more money for the NHS and long-term funding for social care, which will help many autistic people and families. But we're worried about the lack of immediate funding for social care and will be following this up with the Government.

The Spending Review did not specifically set out how the new [autism strategy](#) for England will be funded, beyond its first year. We urge the Government to tell autistic people and families how they will use the money announced to meet the important commitments they made in the autism strategy. We will continue to [call on the Government](#) to properly fund the promises made in the five-year strategy, over the next four years and beyond.²⁰

¹⁸ National Autistic Society News, [Government invests millions in better support for autistic people in England](#), 21 July 2021.

¹⁹ HM Treasury Press Release, [Budget and Spending Review – October 2021: What you need to know](#), 27 October 2021

²⁰ National Autistic Society News, [Our calls for funding the autism strategy](#), 28 October 2021

The Autism strategy also relies on several other pieces of Government work including: the SEND review;²¹ the National Disability Strategy;²² and the health and disability support green paper.²³

²¹ Department for Education Press Release, [Major review into support for children with special educational needs](#), 6 September 2021

²² Disability Unit, Equality Hub, Department of Work and Pensions, [National Disability Strategy](#), 28 July 2021

²³ Department of Work and Pensions, [Shaping future support: the health and disability green paper](#), July 2021.

2 Health policies

Autism has been related to [a range of health conditions](#)²⁴, including mental health problems, insomnia, ADHD, gastrointestinal problems, and problems with joints. Epilepsy is also more likely to occur in people on the autistic spectrum and is a major cause of death among those with severe autism.

A 2015 [Swedish study](#) (PDF, 1.23MB) suggested those with severe autism face a reduced life expectancy and adults on the autistic spectrum without a learning disability are nine times more likely to die from suicide relative to the general population.²⁵

People on the autistic spectrum can also face significant difficulties in accessing healthcare.²⁶

The Covid-19 pandemic disrupted usual care and support for people with autism. In March 2021, the Government published a [Covid-19 mental health and wellbeing recovery action plan](#).²⁷ The plan is intended to respond to, and mitigate, the impacts of the pandemic on the mental health of the public. One-off funding initiatives for groups particularly affected by the pandemic were announced, including:

£31 million to address particular challenges faced by individuals with a learning disability and autistic people who are struggling with their mental health, and support faster discharge from mental health settings back into the community. Specifically, funding will be used to address the diagnostic backlog in autism services and investment in early identification and intervention, to prevent children and young people with learning disability, autism or both, escalating into crisis.²⁸

This section details health policies intended to reduce the health gap between people on the autistic spectrum and the general population, as directed in the Government's mandates to the NHS.²⁹ It also details successive programmes of work to improve diagnosis rates, reduce rates of inpatient care and introduce mandatory staff training.

²⁴ NHS.UK, [Other conditions that affect autistic people](#), (accessed 20 January 2022)

²⁵ Hirvikoski, T. et al. Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, Vol 207 No 5, 2015. Referred to in Autistica, [Personal tragedies public crisis](#) (PDF, 1.23MB), 2016, p4

²⁶ Autistica, [Personal tragedies public crisis](#) (PDF, 1.23MB), 2016, p6

²⁷ Department of Health and Social Care, [COVID-19 mental health and wellbeing recovery action plan](#), 27 March 2021

²⁸ Department of Health and Social Care, [Policy paper overview: COVID-19 mental health and wellbeing recovery action plan](#), March 2021, p51

²⁹ Department of Health and Social Care, [NHS mandate 2018 to 2019](#), 20 March 2018

2.1

The NHS Long Term Plan

The 2019 [NHS Long Term Plan](#) contains a commitment to do more across the NHS “to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives.”³⁰ Specific areas of action for autism include tackling the causes of morbidity and preventable deaths in people by:

- Piloting the introduction of a specific health check for people with autism, and if successful, extending it more widely.
- Expanding stopping overmedication of people with a learning disability, autism or both, and Supporting Treatment and Appropriate Medication in Paediatrics (STOMP-STAMP) programmes to stop the overmedication of those groups.

Improving understanding in the NHS of the needs of people with learning disabilities and autism, and working together to improve their health and wellbeing by:

- Training NHS staff to support people with a learning disability and/or autism.
- Ensuring reasonable adjustments are made so that wider NHS services can support people with learning disabilities and their families.
- Implementing national learning disability improvement standards over the next five years which will apply to all services funded by the NHS. These standards will promote greater consistency, addressing themes such as rights, the workforce, specialist care and working more effectively with people and their families.
- Introducing a ‘digital flag’ by 2023/24 in the patient record to ensure staff know a patient has a learning disability or autism.
- Working with the Department for Education and local authorities to improve their awareness of, and support for, children and young people with learning disabilities.
- Working with partners to bring hearing, sight and dental checks to children and young people with a learning disability, autism or both in special residential schools.

Working to reduce waiting times for specialist services by:

- Including autism diagnosis alongside work with children and young people’s mental health services.
- Developing joint packages with children’s social care and education services to support children with autism or other neurodevelopmental disorders including attention deficit hyperactivity disorder (ADHD) and their families, throughout the diagnostic process.

³⁰ NHS England, [The NHS Long Term Plan](#), January 2019, p41

- Ensuring by 2023/4 children and young people with a learning disability, autism or both with the most complex needs have a designated keyworker to support them.

Moving more care to the community and supporting local systems to take greater control over how budgets are managed by:

- Giving local providers control of budgets to reduce avoidable admissions, enabling shorter lengths of stay and ending out of area placements.
- Enabling, where possible, people with a learning disability, autism or both to have a personal health budget (PHB).
- Reducing the levels of adults, children and young persons with a learning disability and/or autism that are cared for in an inpatient unit.

Increasing investment in intensive, crisis and forensic community support:

- By enabling more people to receive personalised care in the community, closer to home, and reducing preventable admissions to inpatient services.
- Through community health services investment to have a seven-day specialist multidisciplinary service and crisis care.
- Working with partners to develop specialist community teams for children and young people, such as the [Ealing Model](#).³¹

The Long Term Plan commits to halving inpatient provision for people with a learning disability and/or autism by 2023/24, compared to 2015 levels (on a like for like basis and taking into account population growth). The initial target, set in 2015, was for a 35-50% reduction in inpatient care by March 2019.³² However, the Government said although people were being moved into the community as planned, more people were being placed in secure settings.³³

Concurrent targets are also set out in the Plan for the maximum numbers of adults and children in inpatient units - for every one million adults, there will be no more than 30 people with a learning disability and/or autism in inpatient care. For children and young people, the maximum is 12 to 15 children per one million.

Further information on reducing inpatient care is provided in section 2.4.

³¹ [Ibid.](#), pp52-53

³² Department of Health and Social Care, [The Government's revised mandate to NHS England for 2018-19 \(PDF, 293KB\)](#), para 6.3

³³ [HC Deb 7 January 2019 c70](#)

NHS Long Term Plan Implementation Framework

The [Implementation Framework](#) (June 2019) set out how commitments in the NHS Long Term Plan will be delivered.³⁴ Each local area should develop a five-year plan setting out:

- Their share of the required further reduction inpatient usage and beds;
- Learning disability and autism physical health checks for at least 75% of people aged over 14 years;
- How proposals for people with learning disabilities and/or autism align with their plans for mental health, special educational needs and disability (SEND), children and young people's services and health and justice;
- The local offer for autistic young people, people with a learning disability and their families;
- How NHS-led provider collaboratives will be developed locally and should ensure that digital plans use the reasonable adjustment 'digital flag' in the patient record or, where this is not available, use the Summary Care Record as an alternative.³⁵

Box 1: STPs and ICSs

STPs (Sustainability & Transformation Partnerships) and ICSs (Integrated Care Systems) are new collaborative models of care to deliver integration of health and social care services. The Health and Care Bill 2021-22 seeks to establish ICSs on a statutory footing. See the Library briefing on the Health and Care Bill.

The Framework also highlights that STP and ICS (see Box 1) areas should designate a **senior responsible officer for learning disability and autism** to deliver on these commitments.

The framework details **targeted funding**, including specific investment to roll out keyworkers for children and young people with the most complex needs and their carers/families from 2020/21, and capital investment to develop new housing options and suitable accommodation in the community, as an alternative to inpatient care.³⁶

2.2

Mandatory staff training

The 2014 Think Autism strategy focused on making autism training available to all staff working in health and social care, as well as across public services.³⁷ The Care and Support Act 2014 placed a statutory duty on local authorities to ensure staff undertaking an assessment of an adult's care and support needs are appropriately trained. Assessors are required to consult a

³⁴ NHS England, [NHS Long Term Plan The Implementation Framework](#), 27 June 2019

³⁵ NHS England, [NHS Long Term Plan The Implementation Framework](#), 27 June 2019, para 5.10

³⁶ [Ibid.](#), para 5.13

³⁷ Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p11

person who has expertise in relation to the condition being assessed or circumstances of the individual, where they consider the needs of the individual require this.³⁸

In February 2019, the Government consulted on mandatory learning disability and autism training for all health and care staff. The Government's response to the consultation, [Right to be heard](#), was published in November 2019. Over 5,000 responses were received, the vast majority of which were supportive of the principle of mandatory training.³⁹

The Government has since committed £1.4 million to developing the [Oliver McGowan Mandatory Learning Disability and Autism Training](#) for staff who work in 'regulated activities' (see box 2). Oliver's death and [his parents' campaign](#) highlighted the need for improved training on learning disabilities and autism for health and social care professionals.

This training is currently being trialled with the final report expected by Spring 2022. Subject to the evaluation of the trial, the Government intends to complete a wider roll-out. The content of the training is informed by the Core Capabilities Framework for Supporting People with a Learning Disability⁴⁰ and the Core Capabilities Framework for Supporting Autistic People.⁴¹

Box 2 Regulated Activities

Regulated Activities are described in Schedule 1 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. These broadly cover the following areas:

1. Personal care
2. Accommodation for people who require nursing or personal care
3. Accommodation for people who require treatment for substance misuse
4. Treatment of disease, disorder or injury
5. Assessment or medical treatment for persons detained under the Mental Health Act 1983
6. Surgical procedures
7. Diagnostic and screening procedures
8. Management of supply of blood and blood-derived products

³⁸ [Care and Support \(Assessment\) Regulations 2014](#) (SI 2014/2827), Regulation 5

³⁹ Department of Health and Social Care, ['Right to be heard': The Government's response to the consultation on learning disability and autism training for health and care staff](#), 5 November 2019

⁴⁰ Health Education England, [Core Capabilities Framework for Supporting People with a Learning Disability](#), October 2019

⁴¹ Health Education England, [Core Capabilities Framework for Supporting Autistic People](#), October 2019

9. Transport services, triage and medical advice provided remotely
10. Maternity and midwifery services
11. Termination of pregnancies
12. Services in slimming clinics
13. Nursing care
14. Family planning services

Alongside the continuation of the Oliver McGowan mandatory learning plans, the latest Autism Strategy introduces plans to publish a Capability Statement for social workers working with autistic children (there is an existing Capability Statement for working with autistic adults).⁴² New materials for simulated practice and knowledge assessment for social workers working with autistic children will be introduced to the National Assessment and Accreditation System (NAAS).⁴³

2.3

Assessment and diagnosis

The National Institute for Health and Care Excellence's (NICE) guidance on [Autism spectrum disorder in under 19s: recognition, referral and diagnosis](#) (December 2017) says an autism diagnostic assessment should start within three months of the referral to the autism team.⁴⁴ Statistics indicate in many cases this target is not met – see waiting times statistics below.

There have been successive programmes of work to reduce delays in autism assessment and diagnosis.

The Think Autism (2014) strategy established that each local area should have a clear pathway to diagnosis and each Clinical Commissioning Group (CCG) should designate a health lead responsible for developing, maintaining and promoting a diagnostic and treatment pathway.⁴⁵

Increased public awareness of autism, subsequent increased referrals and the impact of the Coronavirus pandemic have also contributed to delays in autism services. The latest Strategy sets out the Government's plans to invest

⁴² 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, p27

⁴³ [Ibid.](#), p27

⁴⁴ NICE guidance is not mandatory but provides best-practice and health practitioners are expected to take guidance into consideration.

⁴⁵ Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p16

£13 million to start reducing waiting times by testing diagnostic pathways and addressing the backlog of assessments.⁴⁶

To monitor the progress of the new strategy, the Government is changing the way in which it collects data about diagnosis times.

Autism self-assessment framework

Between 2011-2019, Public Health England carried out annual self-assessment exercises with local authority areas on progress made in implementing the autism strategy. Local authorities worked with their local partners, including CCGs, to informally answer a range of questions.⁴⁷ On diagnosis, the following results were reported for 2018:

The median reported waiting time from referral to diagnostic assessment was 30 weeks (up from 16 weeks reported in 2016). Among the 74% of responding authorities that provided figures for both years, 23% reported a fall in waiting time, 63% reported an increase. A substantially higher proportion of local areas reported that they were unable to foresee when they would be able to meet the recommended NICE standards.⁴⁸

NHS Digital autism waiting time statistics

In November 2019, NHS Digital published experimental statistics on the number of new autism referrals and waiting times for appointments and diagnoses.⁴⁹ This is a quarterly release. However, the dataset has a number of [limitations](#)⁵⁰ meaning it is not straightforward to infer trends in waiting times. No average waiting time is available from the dataset.

The data shows a substantial proportion of those referred in 2019 and 2020 with suspected autism are yet to receive a care contact or diagnosis. For example, 28% of those referred in the quarter ending June 2019 (the earliest data available) are still waiting for a care contact or diagnosis. 49% of those referred in the quarter ending March 2021 (the most recent data available) are still waiting. This means final waiting time statistics for people referred in each quarter are not comprehensive.

The data suggests a lower proportion of referrals received a first appointment within 13 weeks during the early stages of the pandemic. 8% of referrals had a first appointment within 13 weeks in the quarter ending June 2020, compared with 16% in the quarter ending June 2019. Similarly, 12% of those referred had a first appointment within 26 weeks in the quarter ending June 2020,

⁴⁶ 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, p26

⁴⁷ [PQ HL6524 \[on Autism\]](#), 14 March 2016

⁴⁸ Public Health England, [Autism self-assessment exercise 2018: executive summary](#), para 5

⁴⁹ NHS Digital, [Autism Waiting Time Statistics](#), (accessed 20 January 2022)

⁵⁰ NHS Digital, [Limitations of the statistics and interpretation issues](#), (accessed 20 January 2022)

compared with 21% in the quarter ending June 2019. Both measures have since recovered near to their previous levels.⁵¹

2.4 Reducing inpatient care

In 2011, the BBC's Panorama programme exposed the abuse of patients at Winterbourne View, an independent hospital for people with learning disabilities and/or autism.

The Department of Health's national policy response, [Transforming care: A National response to Winterbourne View Hospital](#) (December 2012) said people with learning disabilities or autism should not live in hospitals, and pledged that everyone inappropriately placed in hospital would move to community-based care as quickly as possible, and no later than 1 June 2014.⁵² The review was accompanied by the [Winterbourne View Review: Concordat](#); an agreement signed by the NHS, statutory organisations and stakeholders committing themselves to provision of appropriate services for people with learning disabilities and/or autism.⁵³

After the pledge to move people to community care by June 2014 was missed, the [Winterbourne View - Time for Change](#) (2014) report found people with learning disabilities or autism were still being placed inappropriately in long-term institutional care. The report found there were still more people being admitted to such institutions than were being discharged and recommended urgent closure of unsuitable in-patient care institutions.⁵⁴

The subsequent report, [Winterbourne View - Time is Running Out](#) (2015), found progress had been made as the number of people being discharged from inpatient institutions was greater than the number admitted. However, it said the pace of change had been slow, and the Transforming Care programme had not yet delivered tangible benefits in terms of new community facilities or closures.⁵⁵

The next report, [Time for Change: The Challenge Ahead](#) (2016) recommended a commissioner for learning disabilities to promote and protect the rights of all people with learning disabilities and/or autism in England.⁵⁶ The Government said it would consider the recommendations but "new statutory

⁵¹ These figures are calculated as a percentage of all referrals with suspected autism. This total includes some people who are discharged from the service without a diagnosis or care contact.

⁵² Department of Health, [Transforming care: A National response to Winterbourne View Hospital](#), December 2012

⁵³ Department of Health, [Winterbourne View Review: Concordat](#), December 2012

⁵⁴ Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb, [Winterbourne View - Time for change](#), November 2014

⁵⁵ Transforming Care and Commissioning Steering Group, [Winterbourne View: Time is Running Out](#), July 2015

⁵⁶ Transforming Care and Commissioning Steering Group, [Time for Change: The Challenge Ahead](#), February 2016

roles and legislation are not necessarily the answer to promoting and protecting the rights of people with learning disabilities and their families.”⁵⁷

In January 2015, the Government published [Winterbourne View: Transforming Care Two Years On](#), to report on progress against their original report. The report said a significant number of recommendations had been achieved, including improved accountability arrangements; DH guidance on minimising restrictive interventions; and a more rigorous inspection process.⁵⁸

During a Public Accounts Committee session in February 2015, the Chief Executive of NHS England announced there would be a planned closure programme for NHS mental health hospitals, and a change in commissioning practices for NHS inpatients within the independent sector.⁵⁹ This was to be accompanied by a transition plan for people with learning disabilities and challenging behaviour within these hospitals, from 2016–17.⁶⁰

In October 2015, NHS England, in partnership with the Local Government Association (LGA) and the Directors of Adult Social Services (ADASS), published a national action plan to develop community services and close inpatient facilities for people with a learning disability and/or autism. The [Building the Right Support](#) plan aimed to shift money from inpatient services to the community and reduce the use of inpatient beds by 35% - 50% over three years, alongside the closure of the last standalone learning disability hospital in England.⁶¹

The [Government’s Mandate to the NHS 2018-19](#) set an objective to achieve the 35-50% bed reduction by March 2019.⁶² The Government noted in October 2017 that the total number of people in inpatient units had fallen 14% since March 2015, and 164 inpatient beds closed in 2016/17, “ahead of plan”.⁶³

However, as noted above, the 2019 [NHS Long Term Plan](#) target for reducing inpatient provision by 50% is delayed until 2023/24. This has been criticised by charities such as Mencap, who have described the continuation of people in inpatient care as a “domestic human rights scandal”.⁶⁴

As of September 2021, there were 2,085 learning disability or autism inpatients, down 28% from 2,895 in March 2015. However, a higher number of these inpatients are now categorised with autism (either on its own or with a learning disability): 1,220 in September 2021 compared with 1,100 in March

⁵⁷ [PQ 28525 \[on Learning Disability\] 1 March 2016](#)

⁵⁸ Department of Health, [Winterbourne View: Transforming Care Two Years On](#), January 2015

⁵⁹ Public Accounts Committee, [Care services for people with learning disabilities and challenging behaviour](#), 27 March 2015, HC 973 2014-15, para 15

⁶⁰ Public Accounts Committee, [Care services for people with learning disabilities and challenging behaviour](#), 27 March 2015, HC 973 2014-15, page 5

⁶¹ NHS England, [Building the right support](#), October 2015

⁶² Department of Health and Social Care, [Government’s Mandate to the NHS 2018-19](#), March 2018, p25

⁶³ [PQ 108577 \[on Health Services: Learning Disability\], 26 October 2017](#)

⁶⁴ Mencap Press Release, [Government due to miss deadline for releasing people with a learning disability locked away in inpatient units, warns Mencap](#), 21 March 2019

2015. There was also an increase in inpatients for autism on its own, from 440 in March 2015 to 710 in September 2021.⁶⁵

The Government plans to address this rise by increasing support for autistic children and young people at school and during their transition into adulthood. By preventing autistic people from falling into crisis, they will be less likely to require hospital admission.⁶⁶

2.5

Mental Health Act Reform

In 2018, an Independent Review of the Mental Health Act 1983 was conducted to understand rising rates of detention under the Act; the disproportionate numbers of people from black, Asian and minority ethnic groups in the detained population; and investigate concerns about some processes in the Act being out of step with a modern mental health system. The resulting report, [Modernising the Mental Health Act](#), found:

[...] the Mental Health Act isn't providing the right type of support and care for people with learning disabilities, autism or both. The Mental Health Act is being used in a way that is not in line with its intended purpose, and is too often being used compensate for the lack of adequate and meaningful support within the community.⁶⁷

In response to the review, the Government published a [White Paper on Reforming the Mental Health Act](#) in January 2021.⁶⁸ The proposed changes to the Act would mean autism and learning disabilities cannot be considered as mental disorders requiring compulsory treatment under Section 3 of the Act.

In practice this would mean autistic people could be detained under Section 2 of the Act for assessment of their mental health if there is a “substantial risk of significant harm to self or others (as for all detentions) and a probable mental health cause to that behaviour that warrants assessment in hospital.”⁶⁹ Detention under Section 3 of the Act may only be pursued if a mental health condition is identified for treatment. Autism and learning disabilities cannot be removed through treatment, but some autistic people may also have a mental illness that requires treatment.

Where a person on the autistic spectrum is detained under Section 3 for the treatment of a mental health condition, the Government proposes establishing recommendations from Care Treatment Reviews (CTR) (for adults) or Care, Education and Treatment Reviews (CETR) (for children) on a

⁶⁵ NHS Digital, [Learning disability services monthly statistics from Assuring Transformation dataset: Data tables](#).

⁶⁶ 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, p12

⁶⁷ Department of Health and Social Care, [Modernising the Mental Health Act – final report from the independent review](#), December 2018, p31

⁶⁸ Department of Health and Social Care, [Reforming the Mental Health Act](#), January 2021

⁶⁹ [Ibid.](#), p82

statutory footing. The White Paper also proposed such recommendations should form part of the person's Care and Treatment Plan, with any deviations justified by the Responsible Clinician.⁷⁰

62% of respondents to the [consultation on proposed changes](#) agreed or strongly agreed with the proposed reforms to the application of the Act for autistic people or people with a learning disability.⁷¹ However, 48% of respondents felt there could be unintended consequences.⁷² Concerns included: lack of adequate community care provision; clinicians wrongfully diagnosing a mental health condition to justify detention, or wrongfully attributing behaviour to neurodivergence (diagnostic overshadowing); and increased use of the Mental Capacity Act 2005.⁷³

Further consultations on the application of the Mental Health Act for neurodivergent people within the criminal justice system are ongoing.

⁷⁰ [Ibid.](#), p84

⁷¹ Department of Health and Social Care, [Reforming the Mental Health: Government response to consultation](#), July 2021, p79

⁷² [Ibid.](#), p84

⁷³ [Ibid.](#), pp84-86

3 Social care services

3.1 Adult social services

Under the Care Act 2014, local authorities have a range of duties relating to the provision of adult social care services which apply to all adults, including adults on the autism spectrum. They include duties:

- to undertake an assessment of any adult with an appearance of need for care and support, or any carer with an appearance of need for support, regardless of their financial situation or whether the authority thinks the individual is eligible for support (sections 9 and 10); and
- to meet an adult's assessed care and support needs, or the support needs of a carer, where those needs meet prescribed eligibility criteria.⁷⁴ Authorities also have the power to meet needs not meeting the eligibility criteria (sections 18-20).

Under Regulation 5 of the Care and Support (Assessment) Regulations 2014, local authorities are required to ensure a person carrying out a social care needs assessment has the skills, knowledge and competence to carry out the assessment in question and is appropriately trained. Local Authorities must therefore ensure assessors carrying out assessments of people with autism have the skills, knowledge, competence and training to carry out such assessments.⁷⁵

Guidance for professionals involved in delivering social work to autistic adults is provided in Government-commissioned [Capability Statement](#) (PDF, 2.2MB) published by the British Association of Social Workers.⁷⁶

2015 statutory guidance for local authorities and NHS organisations to support implementation of the 2010 Autism Strategy states local authorities should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of care and support services for adults with autism.⁷⁷ It adds that local commissioning plans should describe how local authorities will make sure adults with autism are able to access direct payments (where

⁷⁴ [The Care and Support \(Eligibility Criteria\) Regulations 2015](#), SI 2015/313

⁷⁵ Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy \(PDF, 925KB\)](#), March 2015, p18

⁷⁶ British Association of Social Workers, [Capabilities Statement for Social Work with Autistic Adults](#).

⁷⁷ Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy \(PDF, 925KB\)](#), March 2015, p29

appropriate).⁷⁸ Individuals who qualify may choose to have either a direct payment or a personal budget:

- **Direct payments:** Adults, including those with autism, who qualify for state-funded care services may be entitled to receive payments instead of a care package from the local authority. The payments, known as direct payments, are then used by the recipient to arrange and pay for their own, independently contracted, care and support services.
- **Personal budgets:** Personal budgets are an allocation of funding given to people after an assessment of their needs. People can either take their personal budget as a direct payment, or - while still choosing how their care needs are met and by whom - leave councils with the responsibility to commission the services. Or they can have a combination of the two.

The statutory guidance also says people on the autism spectrum should benefit from personalisation and be involved in decisions about their care and decisions about shaping local services:

Local commissioning plans should set out how local authorities will ensure that adults with autism are able to access direct payments (where appropriate) and benefit from the personalisation of health and social care. Local partners should already have a local autism partnership board in place, which brings together different organisations, services and stakeholders and adults with autism and their families to set a clear direction for improved services. Autism partnership boards have proved to be a highly effective means for stakeholders to shape and monitor local delivery of the strategy and statutory guidance. It is therefore essential for their partnership arrangements to be established in areas where they are not currently.⁷⁹

Autism Strategy 2021-2026

The Autism Strategy 2021-2026 identifies “improving health and care staff’s understanding of autism” as crucial in enabling progress on reducing health inequalities for autistic people. The Strategy says in 2021 to 2022 the Government will continue to trial and develop the [Oliver McGowan Mandatory Training](#) in learning disability and autism for all health and adult social care staff across England.⁸⁰

Noting “commissioners need the right skills and tools to develop services that work for autistic people”, the Strategy says the Local Government Association (LGA), Skills for Care and the Association of Directors of Adult Social Services (ADASS) will roll out their qualification for commissioners who work with autistic people to 120 more NHS and local authority commissioners. In addition, [Government-commissioned guidance](#) to “help commissioners identify local demand and develop the right services for autistic people”,

⁷⁸ Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy \(PDF, 925KB\)](#), March 2015, p29

⁷⁹ Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy \(PDF, 925KB\)](#), March 2015, p29

⁸⁰ Department of Health and Social Care and Department for Education, [The national strategy for autistic children, young people and adults: 2021 to 2026](#), 21 July 2021, p27.

developed by Skills for Care and the National Development Team for Inclusion (NDTi), was published alongside the strategy.⁸¹

The Strategy argues “too many autistic people” are being admitted to inpatient mental health settings “because they often struggle to access community support, including social care, mental health and housing support before their needs escalate.” As part of a plan to prevent avoidable admissions, the Strategy says the Government “will...improve autistic people’s access to housing and social care that meets their needs, by increasing the provision of supported housing, enabling more people to access adaptations to their homes and reforming the social care system so it is fit for purpose.” It adds that the LGA and ADASS are “leading work to review best practice models of support for autistic people, people with a learning disability or both.”⁸²

Regarding the plans for adult social care reform, the Strategy says:

We are committed to sustainable improvement of the adult social care system and will bring forward proposals in 2021. The objectives for reform are to enable an affordable, high quality adult social care system that meets people’s needs, while supporting health and care to join up services around them. We want to ensure that everyone, including autistic people, receive the care they need to enable them to live full and independent lives.⁸³

Further information on the Government’s proposals adult social care reform is provided in the Library briefing: [Proposed reforms to adult social care announced in September 2021 \(including cap on care costs\)](#).

3.2

Children’s social services

Under section 17 of the Children Act 1989, local authorities are under a general duty “to safeguard and promote the welfare of children within their area who are in need...by providing a range and level of services appropriate to those children’s needs.”

The legislation defines a child in need as a child who:

(d) [is] unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision...of services by a local authority...;

(e) [whose] development is likely to be significantly impaired, or further impaired, without the provision of such services; or

⁸¹ Department of Health and Social Care and Department for Education, [The national strategy for autistic children, young people and adults: 2021 to 2026](#), 21 July 2021, p27.

⁸² Department of Health and Social Care and Department for Education, [The national strategy for autistic children, young people and adults: 2021 to 2026](#), 21 July 2021, p30-33.

⁸³ Department of Health and Social Care and Department for Education, [The national strategy for autistic children, young people and adults: 2021 to 2026](#), 21 July 2021, p32.

(f) [is] disabled.⁸⁴

A local authority is responsible for assessing whether a child is in need. Where, following an assessment, a local authority decides to provide services, a multi-agency child in need plan should be developed, setting out which organisations and agencies will provide which services to the child and family.

The type of services that can be provided include:

- advice, guidance and counselling
- occupational, social, cultural, or recreational activities
- home help
- facilities for, or assistance with, travelling to and from home for the purpose of taking advantage of any other service provided under the 1989 Act or of any similar service
- assistance to enable the child concerned and their family to have a holiday
- such steps that are practicable to enable a child in need (who is not a looked after child) who is living apart from their family to live with their family, or to promote contact between them and their family (if necessary in order to safeguard or promote their welfare)
- day care for a child if they are under 5 years of age but not yet attending school
- care or supervised activities (either outside school hours or during school holidays) for a child attending any school
- accommodation
- assistance in kind or in cash

Any service may also be provided to any member of the child in need's family, "if it is provided with a view to safeguarding or promoting the child's welfare".

Further information is available in the Library briefing paper, [Local authority support for children in need \(England\)](#).

During a debate on 21 March 2019, Members raised issues with securing adequate care plans for children with autism. Dr Drew said:

What parents find most frustrating are instances in which a care plan has been agreed and is in place, and the local authority then tries to renegotiate downwards the sum that has been agreed. That causes problems for the parents and, obviously, for the person with autism, but is also causes problems for, in particular, specialist units.⁸⁵

⁸⁴ Children Act 1989, section 17.

⁸⁵ [HC Deb 21 March 2019 c1276](#)

Autism Strategy 2021-2026

Noting the important role social workers play in “identifying the support autistic people need throughout their lives”, the Autism Strategy says the Government will:

- publish a Capability Statement for social work with autistic children and their families in line with the existing Capability Statement for Social Work with Autistic Adults (see above); and
- introduce a new National Assessment and Accreditation System (NAAS) simulated practice and knowledge assessment materials for social workers working with autistic children.⁸⁶

The Strategy also notes the launch of the Independent Review of Children’s Social Care in January 2021 and says the review “will take a fundamental look at what is needed to make a real difference to children who need social care.”⁸⁷

⁸⁶ Department of Health and Social Care and Department for Education 21 July 2021, [The national strategy for autistic children, young people and adults: 2021 to 2026](#), p27.

⁸⁷ Department of Health and Social Care and Department for Education 21 July 2021, [The national strategy for autistic children, young people and adults: 2021 to 2026](#), 21 July 2021, p32.

4 Education policy

The legislative basis of the system of support for children with special educational needs (SEN) in England is Part 3 of the [Children and Families Act 2014](#).

Under the 2014 Act, local authorities have a duty to identify needs in their area and to commission, together with partner agencies (eg schools), services to support children and young people with SEN. This includes children and young people with autism. As part of this, authorities are required to publish a Local Offer, which must set out, among other things, a description of the special educational provision it expects to be available for children in its area who have special educational needs from schools and other educational providers.

In January 2015, the Government published a new [Special educational needs and disability code of practice](#)⁸⁸ for children and young people aged between 0 to 25 years and provides statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities.

4.1 Types of support

The type of support children and young people with SEN receive may vary widely, as the types of SEN and the impact they may have are very different. This applies particularly with regard to autism spectrum conditions. However, two broad levels of support are in place: SEN support, and Education, Health and Care Plans.

- **SEN support** - support given to a child or young person in their pre-school, school or college. In schools, it replaces the previously existing 'School Action' and 'School Action Plus' systems. For children of compulsory school age the type of support provided might include extra help from a teacher, help communicating with other children, or support with physical or personal care difficulties.
- **Education, Health and Care Plans** - for children and young people aged up to 25 who need more support than is available through SEN support. They aim to provide more substantial help for children and young people through a unified approach that reaches across education, health care,

⁸⁸ Department for Education and Department for Health and Social Care, [SEND code of practice: 0 to 25 years](#), Last updated 30 April 2020

and social care needs. They are the replacement for SEN statements and Learning Difficulty Assessments (LDAs).

4.2 SEN support system

Support for pupils with autism is provided within the broader system of support for pupils with special educational needs.

The statutory [SEND Code of Practice](#) makes particular reference to autism and the challenges it produces. See for instance:

Special educational provision should be matched to the child's identified SEN. Children's SEN are generally thought of in the following four broad areas of need and support – see Chapter 6, paragraph 6.28 onwards, for a fuller explanation:

- communication and interaction
- cognition and learning
- social, emotional and mental health
- sensory and/or physical needs

These areas give an overview of the range of needs that providers should plan for. However, individual children often have needs that cut across all these areas and their needs may change over time. For instance speech, language and communication needs can also be a feature of a number of other areas of SEN, and children with an Autism Spectrum Disorder may have needs across all areas. The special educational provision made for a child should always be based on an understanding of their particular strengths and needs and should seek to address them all, using well-evidenced interventions targeted at areas of difficulty and, where necessary, specialist equipment or software. This will help to overcome barriers to learning and participation. Support should be family centred and should consider the individual family's needs and the best ways to support them.

[...]

6.29 Children and young people with ASD, including Asperger's Syndrome and Autism, are likely to have particular difficulties with social interaction. They may also experience difficulties with language, communication and imagination, which can impact on how they relate to others.⁸⁹

In [response to a Parliamentary Question](#) in December 2017, the Education Minister Lord Agnew summarised the Government's wider approach to autism in education and future plans:

⁸⁹ Department for Education, [Special educational needs and disability code of practice: 0 to 25 years \(PDE_93.3MB\)](#), January 2015, p85 and p97

Lord Agnew: Local councils have a statutory duty, under the Children and Families Act 2014, to identify needs in their local area and to commission, together with partner agencies, services to support children and young people with SEND and their families. This includes services for children and young people with autism. These services must be included in each council's 'local offer' of available services, which must be reviewed regularly, in consultation with local families, taking their views into consideration.

The department has funded the [Autism Education Trust \(AET\)](#)⁹⁰ since 2012 to deliver autism training to early years, schools and post-16 education professionals in England. The AET has now trained more than 150,000 education staff. This includes head teachers, teachers and teaching assistants, as well as support staff such as receptionists and dining hall staff, encouraging a 'whole school' approach to supporting children and young people with autism. The department will shortly begin discussions with the AET to consider an extension to their current contract.

The department published a new framework for Initial Teacher Training (ITT) content in July 2016. The framework, attached, includes specific content on SEND, including autism, and is available for training providers to use. This twin approach of ongoing work in schools to increase awareness of autism through training, while also ensuring that new teachers are equipped to support pupils with autism from the outset, is designed to ensure that children and young people can succeed in their education. The department does not hold data on the numbers of teachers who have been trained by the AET or who have been through ITT courses that reflect the new ITT framework.

All academies and local authority maintained schools in England are expected to admit children and young people with SEND, including those with autism, whether or not they have an Education, Health and Care (EHC) plan. They cannot refuse to admit a pupil simply because he or she has a SEND. In 2016, there were 630 maintained special schools and 32 non-maintained special schools in England approved to make provision for pupils with autistic spectrum disorder. In addition, under the department's free schools programme, there are now 29 special free schools open in England, including 17 which cater specifically for children with autism. These include the Rise Free School in Hounslow and the Lighthouse Free School in Leeds. A further 22 special free schools are due to open in future, 12 of which will specialise in provision for children with autism, including the Cumbria Academy for Autism and a second National Autistic Society free school, the Vanguard School in Lambeth. The other schools will offer some places for children with autism.

In March, the government announced that it would make available £215 million of capital funding to support the expansion of existing provision as well as the development of new schools for pupils with EHC plans.⁹¹

A Library Briefing provides further information on the [system of special educational needs support in England](#). Section 5 of the paper discusses reports that have been published on the effectiveness of the system.

⁹⁰ [Autism Education Trust](#), (accessed 20 January 2022)

⁹¹ [HL4113 \[Written Question\] 27 December 2017](#)

Disagreement resolution

If a disagreement between parents of pupils with SEN and schools or local authorities has not been resolved at the local level, under sections 496 and 497 of the [Education Act 1996](#) complaints can be made to the Secretary of State for Education that either the governing body of a maintained school or a local authority has acted unreasonably, or has failed to carry out one of its duties under the Education Acts, including their SEN duties.

State-funded school pupils known to have ASD

The Department for Education publishes the number of state-funded pupils in England with an EHC plan or SEN support broken down by type of need.

The most recent data available is as of the 2020/21 school year when there were around 70,500 pupils with SEN support and with Autistic Spectrum Disorder (ASD).⁹² This was around 7% of pupils with SEN support.

A further 92,600 pupils with ASD had EHC plans, this was the most common type of need and made up around 30% of pupils with an EHC plan.

4.3

Special Educational Needs and Disability Review

In September 2019, five years after the introduction of the current system of support for children and young people with SEND, the Government [announced a review](#) of the system's effectiveness.

The review aimed “to improve the services available to families who need support, equip staff in schools and colleges to respond effectively to their needs as well as ending the ‘postcode lottery’ they often face.” It intended to look at how the system has evolved since its introduction, links with health and social care, and would “conclude with action to boost outcomes and improve value for money.”⁹³

The review has not yet been published. The Government has said the Coronavirus pandemic has affected the timing of the review, and also the content of the review will be reconsidered in light of the crisis.⁹⁴

⁹² Department for Education, [Special educational needs in England academic year 2020/21](#), June 2021

⁹³ Department for Education, [Major review into support for children with Special Educational Needs](#), 6 September 2019

⁹⁴ See, for example, [PQ 30349 \[Special Educational Needs: Reviews\], 14 July 2021](#).

In November 2021, the Education Secretary, Nadhim Zahawi, [told the Education Committee](#) he hoped the review would be published in the first quarter of 2022.⁹⁵

4.4 Teachers

Teachers are required to have a clear understanding of the needs of pupils with SEND, including autism, as part of the [Teachers' standards](#).⁹⁶ In July 2016 the Department for Education adopted a [framework of core content for initial teacher training \(PDF, 420 KB\)](#), which gives direction to training providers on what should be prioritised to ensure their programmes enable trainees to meet the Teachers' Standards in full. This includes specific content on SEND and makes specific reference to autism:

Providers should equip trainees to analyse the strengths and needs of all pupils effectively, ensuring that they have an understanding of cognitive, social, emotional, physical and mental health factors that can inhibit or enhance pupils' education. Providers should ensure that trainees understand the principles of the SEND Code of Practice, are confident working with the four broad areas of need it identifies, and are able to adapt teaching strategies to ensure that pupils with SEND (including, but not limited to, autism, dyslexia, attention deficit hyperactivity disorder (ADHD), sensory impairment or speech, and language and communication needs (SLCN)) can access and progress within the curriculum. Providers should ensure that SEND training is integrated across the ITT programme.⁹⁷

In addition, since 2011 the Department for Education has funded the Autism Education Trust to deliver autism training to teachers. In response to a PQ in June 2018, the Schools Minister said the Trust had trained 175,000 staff “to encourage a whole school approach to supporting children and young people with autism.” He added the Department had extended the contract with the Trust for another two years in March 2018.⁹⁸

The 2021-26 National strategy for autistic children, young people and adults includes, as part of the first year (2021-22) of the strategy, a commitment of £600,000 for staff autism training and professional development in schools and colleges, to improve understanding of autism amongst educational professionals.⁹⁹

⁹⁵ Education Committee, [Accountability Hearings](#), HC 82, 3 November 2021, Q1028

⁹⁶ Department for Education, [Teachers' standards](#), 1 July 2011

⁹⁷ Department for Education, [A framework of core content for initial teacher training \(ITT\)](#) (PDF, 420 KB), July 2016, p17

⁹⁸ [PQ 151018, 12 June 2018](#)

⁹⁹ Department of Health and Social Care and Department for Education, [National strategy for autistic children, young people and adults: 2021 to 2026](#), July 2021, p18

4.5

National Autistic Society and APPGA report

In January 2018 the National Autistic Society and the All-Party Parliamentary Group on Autism (APPGA) launched a joint report on [Autism and education in England 2017](#) (PDF, 6.2 MB). The report recommended the Government should develop a national autism and education strategy by the end of 2019. This includes: training for school staff, reasonable adjustments for pupils on the autism spectrum in schools, provision of a specialist curriculum for all pupils who need one, measures to reduce bullying and promote inclusion, and guidance for local authorities on commissioning the full range of educational provision and support.¹⁰⁰ The report was [debated](#) in the House of Commons on 6 February 2018.¹⁰¹

In May 2018, Lord Agnew said the Government was “carefully considering the recommendations [of the report], including creating a national autism strategy.”¹⁰²

On 5 December 2018, the Minister Nadhim Zahawi, issued [a formal response to the APPG’s report](#) (PDF, 171 KB) with responses to the recommendations around autism awareness and training in schools, collecting data to improve planning and making the SEND system more accountable.¹⁰³ He acknowledged the “important” recommendations of the report and said the Government is in the progress of addressing “many” of them.

One recommendation in particular related to autism awareness and training of school staff, the Minister said the Government “will be enhancing the package of support available for newly qualified teachers” in order to “support all pupils in their classrooms, including those with SEND” with further details about these enhancements due to be announced in “early 2019”. He also confirmed the Government’s Adult Autism Strategy, [Think Autism](#) would be extended to cover children.¹⁰⁴

2021-26 Autism strategy

As noted in section 4.4, the 2021-26 National strategy for autistic children, young people and adults includes a commitment of £600,000 for staff autism training and professional development in schools and colleges in 2021-22, to improve understanding of autism amongst educational professionals.¹⁰⁵

The strategy also set out that, in the first year, the Government would launch a new anti-bullying programme, and put in place new Mental Health Support

¹⁰⁰ All-Party Parliamentary Group on Autism (APPGA), [Autism and education in England 2017](#), (PDF, 6.2 MB), January 2018,

¹⁰¹ [HC Deb 6 February 2018 c1465](#)

¹⁰² [HC Deb 16 May 2018](#)

¹⁰³ Department of Education, [Response to APPG report](#), (PDF, 171KB), 5 December 2018

¹⁰⁴ Department of Education, [Response to APPG report](#), (PDF, 171KB), 5 December 2018

¹⁰⁵ Department of Health and Social Care and Department for Education, [National strategy for autistic children, young people and adults: 2021 to 2026](#), July 2021, p18

Teams and training for Designated Senior Mental Health Leads within schools, which it stated would “also benefit autistic pupils who are more likely to experience poor mental health.”¹⁰⁶

On SEND issues, the strategy said the forthcoming SEND review (see section 4.3) would include proposals to improve support systems, including for children on the autistic spectrum. The strategy also set out the Government’s commitment to opening 37 new special free schools, of which 24 would have provision specifically for autistic children and young people, expected to start operating from September 2022.¹⁰⁷

4.6 Permanent exclusions and suspensions of pupils with ASD

A permanent exclusion refers to a pupil who is excluded and who will not come back to that school (unless the exclusion is overturned). The Autism Spectrum Disorder (ASD) exclusion rate is the number of permanent exclusions of pupils with ASD as a percentage of pupils with ASD.

The latest Department for Education (DfE) exclusion statistics are for the 2019/20 school year.¹⁰⁸ However, figures for the ASD exclusion rate have not been published since the 2016/17 release.

In 2016/17 pupils with an identified primary SEN need of ASD had a permanent exclusion rate of 0.12% (125 exclusions for approximately 108,400 pupils with ASD as their primary SEN need).¹⁰⁹

This is above the permanent exclusion rate for all pupils without identified SEN, nationally (0.06%). Of pupils with special educational needs (SEN), pupils with social, emotional and mental health difficulties had the highest rate of permanent exclusion (1.09%).

In 2016/17 the one or more suspension rate (previously known as a fixed period exclusion) for those with ASD as their primary SEN need was 4.46%. This is higher than the one or more suspension rate for pupils with no identified SEN (1.63%). Again, of pupils with SEN, pupils with social, emotional and mental health difficulties as their primary SEN need had the highest one or more suspension rate (17.46%).¹¹⁰

¹⁰⁶ Ibid.

¹⁰⁷ Ibid., p18-19

¹⁰⁸ Department for Education, [Permanent and fixed-period exclusions in England: 2019 to 2020](#), July 2021.

¹⁰⁹ Pupils attending state-funded primary, special and secondary schools in England.

¹¹⁰ Department for Education, [Permanent and fixed-period exclusions in England: 2016 to 2017](#), July 2018.

Exclusions policy and Timpson review

School exclusions

Statutory guidance is in place on [School exclusion](#). The guidance makes clear that it is unlawful to exclude a pupil for a non-disciplinary reason.¹¹¹

Review

[The Timpson review](#), as well as a Government response, was published in May 2019.¹¹² The review set out 30 recommendations for Government on exclusions. Some of the key recommendations were:

- The DfE should make schools responsible for the children they exclude and accountable for their educational outcomes, and consult on how to do this
- Ofsted should recognise schools who use exclusion appropriately and effectively
- Where Ofsted finds off-rolling, this should always be reflected in inspections reports and in all but exceptional cases should result in a judgement that the school's leadership and management is inadequate
- The DfE should look carefully at the timing and amounts of any adjustments to schools' funding following exclusion, to make sure they neither act as an incentive for schools to permanently exclude, nor discourage a school from admitting a child who has been permanently excluded from elsewhere
- Pupil moves should be systematically tracked, to increase transparency on when children move out of schools, where they move to and why
- In making changes that strengthen accountability around the use of exclusion, DfE should consider any possible unintended consequences and mitigate the risk that schools seek to remove children from their roll in other ways. This should include:
 - - reviewing a 'right to return' period where children could return from home education to their previous school, and other approaches that will ensure that this decision is always made in the child's best interests
 - - considering new safeguards and scrutiny that mitigate the risk of schools avoiding admitting children where they do not have the grounds to do so.¹¹³

Government response

The [Government responded \(PDF, 756KB\)](#) positively to the review and said a consultation on how to make schools accountable for the outcomes of

¹¹¹ Department for Education, [Exclusion from maintained schools, academies and pupil referral units in England](#), July 2017, p9

¹¹² Department for Education, [Edward Timpson publishes landmark exclusions review](#), 7 May 2019

¹¹³ Department for Education, [Timpson Review of School Exclusion \(PDF, 2.68MB\)](#), CP 92, May 2019. Full list of recommendations pages 12-15

permanently excluded children would be opened in autumn 2019. The response also said the Government would rewrite its guidance on exclusions, and behaviour and discipline in schools by summer 2020.¹¹⁴

The response further stated the Department for Education would work with Ofsted to define and tackle off-rolling. Ofsted would respond to the review's relevant recommendations separately.¹¹⁵

In June 2021, the Minister for School Standards, Nick Gibb, [responded to a Parliamentary Question](#) about progress in implementing the recommendations of the Timpson Review:

[...] Since the publication of the Timpson Review and agreeing the recommendations in principle, the Government has been pursuing a programme of work on school behaviour across the school system. In April we commenced the Behaviour Hubs programme, investing £10 million that will help schools to develop and sustain a culture where good behaviour is the norm. Training is also being reformed as part of the Early Career Framework, so that all new teachers will be shown how to effectively manage behaviour in their first two years in the profession from September 2021. The Department will continue to work with Ofsted to tackle the practice of 'off-rolling' which is an unacceptable practice. Additionally, the Department will be consulting on how to help head teachers remove phones in schools, and other revisions to the Department's behaviour and discipline and expulsions guidance, later in the year.

The Department intends to go further and is committed to improving outcomes for children and young people in alternative provision who are most at risk of expulsion and disengaging from education. The Department will set out its plans in the forthcoming SEND review.¹¹⁶

Off-rolling

Related concerns about children leaving school rolls are discussed in the Library briefing paper [Off-rolling in English schools](#).

¹¹⁴ Department for Education, [The Timpson Review of School Exclusion: Government Response \(PDF, 757KB\)](#), CP 95, May 2019, p5-6

¹¹⁵ Ibid., p6-7

¹¹⁶ [PQ 8678 \[School Exclusions Review\], 11 June 2021](#).

5 Employment policies

Since January 2020, the Office for National Statistics (ONS) have collected data on people with autism through the [Annual Population Survey](#).

In February 2021, the ONS published a report comparing the employment rates for disabled people depending on the type of disability. For this report, a person is considered disabled if they have a self-reported long-standing illness, condition or impairment, which causes difficulty with day-to-day activities.¹¹⁷

They reported disabled people on the autistic spectrum as among disabled people with the lowest proportion in employment. 22% of disabled people on the autistic spectrum were in employment in the 6 months to June 2020, which compared to 54% for all disabled people and 81% of non-disabled people.

The National Autistic Society reported in 2016 that 77% of unemployed autistic people wanted to work.¹¹⁸

In their September 2019 report [The Autism Act, 10 Years On \(PDF, 2.7MB\)](#), the All-Party Parliamentary Group on Autism found only 12% of autistic adults were receiving employment support, despite 42% needing it, while only 13% said the support they were receiving helped them find or stay in work. Only 4% said Jobcentre Plus staff have a good understanding of autism.¹¹⁹

5.1 Autism national strategy: 2021 to 2026

In the July 2021 [Autism national strategy](#), the Government said by the end of the strategy in 2026, it will have improved the support provided to autistic people to help them find and stay in work:

By the end of the strategy, we will have improved the support autistic people can access to find and stay in work. This includes making sure that existing services and work programmes are more autism-inclusive and better able to help autistic people find the right employment opportunity for them. In addition, we will have improved welfare support for autistic people who are

¹¹⁷ Office for National Statistics, [Outcomes for disabled people in the UK: 2020](#), 18 February 2021

¹¹⁸ National Autistic Society, [The autism employment gap \(PDF, 17.MB\)](#), October 2016

¹¹⁹ National Autistic Society, [The Autism Act, 10 Years On: A report from the All-Party Parliamentary Group on Autism on understanding, services and support for autistic people \(PDF, 2.7MB\)](#), 15 September 2019
and their families in England

unable to work, so they can get the support they need to live well in their communities.¹²⁰

The Government has made various commitments to supporting autistic people in employment in 2021/22. These include:

- Improving employer awareness of autism: developing a better understanding of the benefits of employing autistic people and the adjustments needed to recruit and properly support them.
- Improving the accessibility of employment programmes for autistic people.
- Making Jobcentres more autism-inclusive.¹²¹

The strategy also outlines some of the programmes currently in place to meet these commitments.¹²²

The [Disability Confident](#) scheme aims to help organisations “improve how they attract, recruit and retain disabled workers”. This will include webinars focused specifically on supporting autistic people in the workplace.¹²³

The [Access to Work](#) programme provides support to meet the needs of disabled people in the workplace. Access to Work grants are available to both employees and to the self-employed, and aim to provide practical and financial support to help disabled people find or stay in work.¹²⁴

The [Intensive Personalised Employment Support programme](#) provides personalised support to those with more complex needs or barriers. People on this programme will have a dedicated support worker who will provide one-to-one support and training to help them get into work. They will usually receive this support for 15 months, as well as 6 months of on-the-job support if they find employment.¹²⁵

Information on all these schemes is provided in the Library briefing, [Disabled people in employment](#).

The Department for Work and Pensions (DWP) is also working with the National Autistic Society to test how Jobcentre Plus services can be more accessible to, and supportive of, autistic customers. This test is due to conclude in March 2020.¹²⁶ Some of the improvements made to Jobcentres in

¹²⁰ Department for Health and Social Care and Department for Education, [National strategy for autistic children, young people and adults: 2021 to 2026 \(PDF, 529KB\)](#), 21 July 2021

¹²¹ Department for Health and Social Care and Department for Education, [National strategy for autistic children, young people and adults: 2021 to 2026 \(PDF, 529KB\)](#), 21 July 2021, p22

¹²² Department for Health and Social Care and Department for Education, [National strategy for autistic children, young people and adults: 2021 to 2026 \(PDF, 529KB\)](#), 21 July 2021, pp 22-23

¹²³ HM Government, [Disability Confident](#). (accessed 26 January 2022)

¹²⁴ GOV.UK, [Access to Work: get support if you have a disability or health condition](#). (accessed on 19 January 2022)

¹²⁵ GOV.UK, [Intensive Personalised Employment Support](#). (accessed on 19 January 2022)

¹²⁶ Department for Health and Social Care and Department for Education, [Autism strategy action plan: 2021 to 2022 \(Annex A\) \(PDF, 184KB\)](#), 22 July 2021, p9; [PQ 57492](#), 20 October 2021

England and Wales are outlined in the July 2021 [Health and Disability Green Paper \(PDF, 1.2MB\)](#).¹²⁷

The [Autism Exchange Internship Programme](#) aims to provide autistic young people with experience of working in the Civil Service. The Government has committed to expanding this programme outside of London and the South East.¹²⁸

5.2 Other developments

The DWP has worked with various autism support groups and charities to develop a series of tools aiming to help autistic people find sustained employment.

They worked with Autism Alliance UK to produce an [Autism and Neurodiversity toolkit in April 2017](#). The aim of this toolkit is to support awareness and understanding of Autism Spectrum Conditions and provide guidance to support autistic people into employment. The toolkit is updated regularly by Autism Alliance UK.¹²⁹

The Government has previously reported it is unable to assess the effectiveness of this training due to the lack of robust employment figures for autistic people.¹³⁰

The DWP and Autism Alliance UK also worked together to deliver an Autism training programme to over 1,200 staff members in Jobcentre Plus.¹³¹

The DWP worked with the Hidden Impairment National Group to produce the [Hidden Impairments Toolkit](#). The toolkit “provides comprehensive information to enable staff to anticipate the reasonable adjustment solutions of individuals with [...] hidden impairments”.¹³²

A number of autism support groups worked with the DWP to develop an ‘[About Me](#)’ (PDF, 264KB) Disability Passport in March 2017. The aim of the passport is to improve the experience for autistic people (or other ‘invisible’ conditions) when visiting job centres, interviews and work placements.¹³³

¹²⁷ Department for Work and Pensions, [Shaping Future Support The Health and Disability Green Paper \(PDF, 1.2MB\)](#), July 2021, p28

¹²⁸ Department for Health and Social Care and Department for Education, [Autism strategy action plan: 2021 to 2022 \(Annex A\) \(PDF, 184KB\)](#), 22 July 2021, p9

¹²⁹ [PQ 252853](#), 17 May 2019

¹³⁰ [PQ 203312](#), 8 January 2019

¹³¹ [PQ 7308](#), 12 September 2017

¹³² Hidden Impairment National Group, [Uncovering Hidden Impairments Toolkit \(PDF, 622KB\)](#), September 2015

¹³³ Autism East Midlands, [New Disability Passport & Autism and Neurodiversity Toolkit launches](#), 27 March 2017

In addition to this, in December 2017 the DWP said a further initiative would be put in place called the Local Supported Employment (LSE) proof of concept ‘place and train’ model. This aims to move disabled people, notably those with learning disability and on the autism spectrum, into real jobs at the going rate of pay, with support for both individual and employer.¹³⁴ Following a “successful” proof of concept, the Government intends to trial this model in 20 LAs; this trial is expected to begin in 2022.¹³⁵

5.3 Statutory guidance for local authorities/Think Autism

In March 2015, the Government produced updated [statutory guidance](#) for local authorities and NHS organisations to support the implementation of the Government’s [Think Autism](#) programme of action. This set out legal duties for local authorities to improve employment outcomes for autistic people:

Local Authorities must:

- Ensure that the assessment and care planning process for adult needs for care and support considers participation in employment as a key outcome, if appropriate, and looks at the ways that any such needs may be met in a way which could support adults with autism to become ‘work ready’;
- when carrying out a needs assessment, consider whether matters other than the provision of care and support could contribute to the achievement of the outcomes an adult with autism wishes to achieve in day-to-day life, and whether the adult would benefit from the provision of anything under section 2 or 4 of the Care Act (preventative services or information and advice services) ,or anything that may be available in the community, including signposting, as appropriate, to Access to Work for interview support, and to other appropriate benefits and agencies that can help people with autism to find and keep a job.
- Ensure that employment is promoted as a positive outcome for the majority of children and young people with autism who have EHC plans and that routes to employment are fully explored during the reviews of those plans from Year 9 (age 13-14) onwards and included in plans where appropriate. Information on preparing for and finding employment must be included in the local authority’s Local Offer under the Children and Families Act 2014.¹³⁶

¹³⁴ [PQ 119261](#), 18 December 2017

¹³⁵ [PQ HL1096](#), 21 June 2021; Department of Health and Social Care, [People at the Heart of Care: adult social care reform white paper](#), 1 December 2021, p64

¹³⁶ Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy \(PDF, 925KB\)](#), March 2015, p51

5.4

Anti-discrimination legislation

People who are neurodivergent are covered by the Equality Act 2010 under the definition of disability. In the Act, a person is defined as having a disability if they have a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.¹³⁷

The Equality Act prohibits both direct and indirect disability discrimination in employment and recruitment.¹³⁸

The Act also prohibits employers from harassing or victimising disabled people.

Reasonable adjustments

Under the [Equality Act 2010](#), employers must make reasonable adjustments to support disabled job applicants and employees.¹³⁹ As stated in the Department for Work and Pensions (DWP) guidance:

This means ensuring disabled people can overcome any substantial disadvantages they may have doing their jobs and progressing in work.¹⁴⁰

Examples of reasonable adjustments are included in the guidance and on the gov.uk page [Reasonable adjustments for workers with disabilities or health conditions](#).¹⁴¹ Access to Work funding can be applied for towards the cost of making such reasonable adjustments.¹⁴²

The Equality and Human Rights Commission has provided [Examples of reasonable adjustments in practice](#).¹⁴³

¹³⁷ Section 6, [Equality Act 2010](#)

¹³⁸ Section 39, [Equality Act 2010](#)

¹³⁹ Ibid.

¹⁴⁰ Department for Work and Pensions, [Employing disabled people and people with health conditions](#), 25 March 2020

¹⁴¹ GOV.UK, [Reasonable adjustments for workers with disabilities or health conditions](#), (accessed 13 January 2022)

¹⁴² GOV.UK, [Access to Work: get support if you have a disability or health condition](#), (accessed 13 January 2022)

¹⁴³ Equality and Human Rights Commission, [Examples of reasonable adjustments in practice](#), (accessed 26 January 2022)

6 Social security

People with autism may potentially be entitled to a range of different benefits including:

- Benefits to help with the extra costs of a disability, such as [Personal Independence Payment \(PIP\)](#), which is replacing [Disability Living Allowance \(DLA\)](#) for working-age adults.
- ‘Income replacement’ benefits to cover day to day living costs. This includes benefits such as [Employment and Support Allowance](#), but increasingly the main source of support will be [Universal Credit](#).

6.1 Personal Independence Payment

Personal Independence Payment (PIP) is replacing Disability Living Allowance (DLA) for people of working age. Like DLA, PIP is non-means-tested and is intended to help with the extra costs arising from ill health or disability. It has two components: a mobility component, based on an individual’s ability to get around; and a ‘daily living’ component, based on ability to carry out various day to day activities. Each component has two rates.

PIP was introduced for new claims from April 2013, and DWP is reassessing all existing working age DLA claimants for the benefit. Young people in receipt of DLA are also reassessed for PIP when they reach 16. Full rollout of PIP is not expected to be achieved until 2025.¹⁴⁴

The PIP assessment was intended to provide a more ‘holistic’ assessment of the impact of a health condition on an individual’s ability to participate in everyday life, compared with that for DLA. PIP was also intended to target support more closely on those most in need. The Coalition Government assumed initially that PIP would ultimately cost 20% less than DLA, but the Office for Budget Responsibility (OBR) has shown that expenditure on PIP is exceeding that on DLA. In December 2019 the OBR noted that, despite its July 2015 forecast expecting spending on working-age disability benefits to fall in cash terms between 2014-15 and 2018-19, spending actually increased by 36% over the period, amounting to a £4 billion underestimate of disability benefits spending in 2018-19, with PIP rollout 75% complete.¹⁴⁵

¹⁴⁴ Office for Budget Responsibility, [Economic and Fiscal Outlook](#), November 2020, para A.37

¹⁴⁵ Office for Budget Responsibility, [Welfare trends report](#), December 2019, paras 2.28-2.31

The Department for Work and Pensions (DWP) is responsible for handling claims for, PIP and making decisions on entitlement to benefit. Contracted assessment providers are however a key element in the claims process. Atos Healthcare holds the contracts for undertaking assessments in Northern England and Scotland; and in London and Southern England. Capita Business Services Ltd holds the contracts covering Wales and Central England; and Northern Ireland. These are separate from the contract under which Maximus undertakes Work Capability Assessments for ESA and Universal Credit claims.

PIP statistics

As of October 2021, **127,399** recipients of PIP had an autistic spectrum disorder as their main disabling condition – these accounted for 4.5% of all PIP recipients.

The main disabling conditions of PIP recipients recorded in the autistic spectrum disorder group were as follows:

- Autism (96,029 recipients, 75.4%)
- Asperger's syndrome (30,959 recipients, 24.3%)
- Retts disorder (408 recipients, 0.3%)

77% of PIP recipients with an autistic spectrum disorder as their main disabling condition are male (97,638).

These figures include only those whose autistic spectrum disorder is their main disabling condition. Other PIP claimants may have such a condition as a secondary/other condition in addition to their main condition.

The most common award type for those with an autistic spectrum disorder main disabling condition is a combination of enhanced daily living and enhanced mobility components (63,561 recipients).

PIP claims in payment to people with autistic spectrum disorders as main disabling condition, October 2021

	Total: Autistic spectrum disorders	<i>of which:</i>		
		Autism	Asperger syndrome	Retts disorder
Total	127,399	96,029	30,959	408
<i>of which: type of award:</i>				
Daily Living - Enhanced	104,217	82,235	21,581	396
<i>of which - in combination with:</i>				
Mobility Award - Enhanced	63,561	54,409	8,784	375
Mobility Award - Standard	30,419	21,596	8,806	13
Mobility Award - Nil (a)	10,237	6,232	3,998	6
Daily Living - Standard	20,686	12,218	8,454	12
<i>of which - in combination with:</i>				
Mobility Award - Enhanced	2,041	1,355	685	..
Mobility Award - Standard	8,888	5,383	3,501	..
Mobility Award - Nil (a)	9,756	5,477	4,272	5
Daily Living - Nil	2,494	1,572	922	..
<i>of which - receiving:</i>				
Mobility Award - Enhanced	505	350	154	..
Mobility Award - Standard	1,916	1,180	738	..
Mobility Award - Nil (a)	75	42	31	..

Notes

Statistical disclosure control has been applied to this table at source to avoid the release of confidential data. **Components may not sum to totals due to the disclosure control applied.**

".." denotes a nil or negligible number of claimants or award amount based on a nil or negligible number of claimants.

(a) A very small proportion of the caseload at any given time are reported as nil-nil - these are claims temporarily recorded as nil rate pending a claim review. These cases should be treated with caution and may be subject to revision in future.

Source

DWP Stat-Xplore PIP cases with entitlement dataset

[Link to source](#)

People with autistic spectrum disorders have varying levels of success when it comes to applying for PIP. Between April 2013 and October 2021, 48% of new claims made by those with a recorded main disabling condition of autism were awarded PIP, while the remaining 50% were disallowed. For those with a main disabling condition of Asperger's syndrome, the award rate for new claims was 44%.

For people who were previously on Disability Living Allowance (DLA) and who underwent reassessment to determine entitlement to PIP, 78% of those with a main disabling condition of autism were awarded PIP. The award rate for reassessed DLA claimants with Asperger's syndrome was 55%.

Clearances of PIP new claim applications and DLA-to-PIP reassessments, by main disabling condition and initial DWP decision

April 2013 to October 2021 inclusive

	Total	<i>of which: outcome (a)</i>			
		Awarded		Disallowed	
New claim applications					
All claims where disabling condition is recorded	3,847,147	1,696,389	44%	2,150,761	56%
<i>of which - main disabling condition:</i>					
Total: Autistic spectrum disorders	42,437	20,183	48%	22,256	52%
<i>of which:</i>					
Autism	25,382	12,685	50%	12,698	50%
Asperger syndrome	17,020	7,477	44%	9,539	56%
Retts disorder	37	22	59%	16	43%
DLA-to-PIP reassessment cases					
All claims where disabling condition is recorded	1,941,382	1,384,368	71%	557,017	29%
<i>of which - main disabling condition:</i>					
Total: Autistic spectrum disorders	129,062	92,845	72%	36,214	28%
<i>of which:</i>					
Autism	93,778	73,342	78%	20,432	22%
Asperger syndrome	34,853	19,098	55%	15,755	45%
Retts disorder	433	406	94%	26	6%

Notes

Statistical disclosure control was applied to this table at source to avoid release of confidential data. **Components may not sum to totals due to the disclosure control applied.**

Source

DWP Stat-Xplore PIP clearances dataset

[Link to source](#)

PIP mobility component and psychological distress

In March 2017 the DWP introduced regulations to reverse the effect of two Upper Tribunal judgments relating to the PIP eligibility criteria.¹⁴⁶ The most significant change made was to tighten the rules on access to the mobility component for people unable to undertake journeys due to “overwhelming psychological distress.” This would potentially affect people with a wide range of conditions, including autism. Disability organisations called on the Government not to proceed with the changes.

On 21 December 2017, the High Court ruled the March 2017 regulations were unlawful because they discriminated against people with disabilities in breach of Human Rights Act 1998 obligations, and declared that the Secretary of State did not have lawful power to make the regulations (i.e. they were ‘ultra vires’) and should have consulted before making them.¹⁴⁷

The Government did not contest the High Court’s decision. The Secretary of State for Work and Pensions said her Department would “take all steps necessary to implement the judgment in MH [the Upper Tribunal decision that had prompted the change to the regulations] in the best interests of our claimants, working closely with disabled people and key stakeholders over the coming months.”¹⁴⁸

In June 2018 the DWP began to review around 1.6 million existing PIP awards, and PIP claims submitted since the original Upper Tribunal judgment in November 2016, to see who could be affected.¹⁴⁹

It was originally expected that the review would result in around 25,000 claimants by 2022-23 receiving a PIP award who would not have done so otherwise, and around 165,000 receiving a higher award.¹⁵⁰ DWP statistics suggest however that far fewer arrears payments than expected are being awarded. By 1 November 2021, the DWP had reviewed 980,000 PIP cases against the MH Upper Tribunal decision, but only around 4,200 resulted in additional payments being made.¹⁵¹ Some have suggested the relatively small number of awards casts doubt on whether the DWP review is a genuine and effective attempt to identify underpaid PIP claimants.¹⁵²

¹⁴⁶ See [Changes to the Personal Independence Payment eligibility criteria](#), Commons Library briefing CBP-7911

¹⁴⁷ [Rf v Secretary of State for Work and Pensions \[2017\] EWHC 3375 \(Admin\)](#)

¹⁴⁸ [HCWS414, 19 January 2018.](#)

¹⁴⁹ See Department for Work and Pensions, [Personal Independence Payment \(PIP\): Implementation of legal decisions MH and RJ: Frequently Asked Questions \(FAQ\)](#), DEP 2020-0061, February 2020

¹⁵⁰ Office for Budget Responsibility, [Economic and fiscal outlook](#), March 2018, para 4.112

¹⁵¹ Department for Work and Pensions, [PIP administrative exercise: progress on cases cleared, at 1 November 2021](#), 14 December 2021; see also DWP, [Personal Independence Payment \(PIP\): Progress update on completion of the MH and RJ administrative exercise: Frequently Asked Questions \(FAQ\)](#), DEP 2021-0987, 14 December 2021

¹⁵² [Update: LEAP Review May Be Unlawful Leading Barrister Tells Us, Now We Need Your Help](#), Benefits and Work Newsletter, 23 June 2021

6.2 Benefit assessments

A key concern of organisations working with people with autism is benefit assessors' knowledge and understanding of the condition, and how it affects people. In its September 2019 report 'The Autism Act, 10 Years On', the All-Party Parliamentary Group on Autism recommended the new autism strategy should:

- include a requirement in contracts for benefits assessment providers to provide all frontline assessors with autism training, and regularly monitor compliance; and
- ...develop guidance – working with autistic people and their families – to be disseminated to all providers carrying out benefits assessments on how to properly identify autistic people's needs and ensure assessments truly capture their circumstances.¹⁵³

While acknowledging some autistic people struggle to access the support they need because they feel benefit assessors may not understand their needs, or because they find the assessment process difficult to engage with, the Government's [Autism Strategy](#) published in July 2021 did not include any specific commitments on benefit assessments. It did however say the DWP's upcoming Health and Disability Support Green Paper would consider how the welfare system could better meet the needs of disabled people, including autistic people.¹⁵⁴

Asked whether assessors undertaking Work Capability Assessments were required to undertake training on autism and autistic spectrum disorders, the then Minister for Disabled People, Sarah Newton, said in a written answer in November 2017:

All Healthcare Professionals conducting Work Capability Assessments receive extensive training regarding autism spectrum disorders as part of their initial new entrant training. This training programme includes simulated assessments covering claimants with autism and learning disabilities to allow Healthcare Professionals to develop appropriate consultation skills. All Healthcare Professionals have access to condition specific information on autism which is quality assured by external reviewers. Healthcare Professionals are further supported by Functional Champions who are available to provide advice to Healthcare Professionals on particular conditions including autism before, during or after an assessment.¹⁵⁵

¹⁵³ All-Party Parliamentary Group on Autism, [The Autism Act, 10 Years On](#), September 2019, p52

¹⁵⁴ 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, chapter 5

¹⁵⁵ [PQ 112878 \[Work Capability Assessment: Autism\], 20 November 2017.](#)

The DWP's [Work Capability Assessment Handbook](#) for Healthcare Professionals gives further guidance in relation to the assessment of people with autistic spectrum disorder.¹⁵⁶

Asked what training disability training medical professionals undertaking PIP assessments are required to have in respect to autism, the then Minister for Disabled People Justin Tomlinson said in January 2020:

All health professionals carrying out assessments are clinically qualified and registered practitioners in their own field.

DWP requires health professionals to have a broad training in disability analysis as well as awareness training in specific conditions which include autistic spectrum disorder.

While preparing to undertake an assessment, health professionals have access to a range of resources as well as experienced clinicians to support them in assessing claimants with conditions that they may not be familiar with.

Additionally, assessment providers engage with medical experts, charities and relevant stakeholders to strengthen their training programmes.¹⁵⁷

Both PIP assessment providers also have 'Health Condition Insight Reports' that cover autism specifically. These are completed by representative groups and provide "insights from real life examples to describe common issues faced by the people they support". One provider has also developed a podcast on ADHD available to all their Health Professionals.¹⁵⁸

Health Transformation Programme and the Health and Disability Green Paper

In March 2019 the then Secretary of State for Work and Pensions, Amber Rudd, announced that her Department had launched a 'Health Transformation Programme' to develop a new, integrated service, supported by a single digital system, for both Personal Independence Payment assessments and Work Capability Assessments.¹⁵⁹ In March 2020 the then Minister for Disabled People, Work and Health, Justin Tomlinson, announced that the Department would initially develop the new service on a small scale "in a defined part of the country, a Transformation Area". In the Transformation Area, assessments are being conducted directly by the DWP.¹⁶⁰

Further information on the Government's plans for improving assessments for disability and incapacity benefits, including how it is exploring different ways to conduct assessments and reduce unnecessary assessments, and initiatives

¹⁵⁶ Department for Work and Pensions, [Work Capability Assessment handbook: for healthcare professionals](#), updated 10 December 2021

¹⁵⁷ [PQ 235 \[Personal Independence Payment: Medical Examinations\], 8 January 2020.](#)

¹⁵⁸ [PQ 79458 \[Autism and Hyperactivity: Females\], 30 November 2021.](#)

¹⁵⁹ [HCWS1376 5 March 2019](#)

¹⁶⁰ [HCWS138 2 March 2020](#)

to improve decision making on benefit claims more broadly, is given in chapter 3 of [Shaping Future Support: the Health and Disability Green Paper](#), published by the DWP on 20 July 2021.¹⁶¹ This includes an overview of progress towards developing the new integrated ‘Health Assessment Service’ under the Health Transformation Programme:

The integrated service will bring the assessments for PIP and UC/ESA onto a single, digital system. This will help make our processes more effective and efficient and improve people’s experience. For example, where people are willing to provide consent, the new system will allow us to share medical evidence more easily. This will help reduce the need for people to provide the same information more than once.

We will develop this new service on a small scale to begin with in a small area called the Departmental Transformation Area (DTA). The DTA will be a safe environment to test, adapt and learn from new ideas and processes. This approach will allow us to continually improve the new service and systems in a controlled way. We then plan to roll out improvements gradually at a greater scale, including with assessment providers. The first DTA location is in London and was launched on 21 April 2021.

The full scale of what the Health Transformation Programme can achieve is still developing. It will support the delivery of many of the improvements we have outlined in this Green Paper. For example, for some time, people going through a WCA have been able to have their face-to-face assessment audio-recorded. The Programme has now developed an approach to ensure PIP face-to-face assessments can also be audio-recorded, where a request is made in advance. In addition, we have started to offer audio-recording of telephone assessments for ESA, UC and PIP. We believe that audio-recording assessments will help improve trust in our decisions. Action is also being taken to test video assessments through the integrated assessment service...¹⁶²

Further information on plans to develop the integrated Health Assessment Service, and on other proposals set out in the Green Paper to deliver improvements to the health and disability benefits system, is given in the DWP’s November 2021 submission to the Work and Pensions Committee’s inquiry on health assessments for benefits.¹⁶³ This confirms the Department has begun work to procure contracted health assessment services for the period 2023-2028, and it has “no plans to in-house the assessment service beyond the small Health Transformation Area”.

6.3 Accessing Jobcentre Plus offices and services

The Government’s [Autism Strategy](#) published in July 2021 acknowledged concerns that some people with autism struggle to get the right support

¹⁶¹ Department for Work and Pensions, [Shaping future support: the health and disability green paper](#), CP 470, July 2021

¹⁶² Ibid., paras 173-175

¹⁶³ Department for Work and Pensions, [Written Evidence for the Health Assessments for Benefits inquiry](#), HAB0079, November 2021

because they feel Jobcentre staff do not understand their needs, or the adaptations they need to make to engage with autistic people, and that for some people the Jobcentre environment can be anxiety-inducing or distressing.

The Strategy said that the Government would continue efforts to make the Jobcentre network more welcoming and supportive to autistic customers, developing and testing new approaches to provide intensive support through ‘Health model Offices’.¹⁶⁴ Further information on Health Model Offices and other local initiatives to support autistic people can be found in paras 126-130 of the [Health and Disability Green Paper](#).

For DWP staff, there is also a ‘[Hidden Impairments Toolkit](#)’ (PDF, 622KB).¹⁶⁵ The purpose of this resource is to “help DWP colleagues understand how they can provide better support to claimants and people with autism and associated hidden impairment conditions”.

Starting from October 2021, 15 Jobcentre Plus sites have been testing an ‘autism framework’, designed with the National Autistic Society, to “transform the service available to jobseekers on the autism spectrum”. The framework pilot is aiming to help people on the autistic spectrum “find, retain and progress in fulfilling jobs”. It involves assessing the current state of knowledge and practices for dealing with autistic customers within those offices, and developing a new service delivery framework “that ensures those customers get the support they need, in the way they need it”. A DWP press release explains:

The framework explores how best to support autistic people into employment, including ensuring jobcentre appointments with autistic customers take place in the right environment and educating local employers in the additional requirements of autistic workers.

For example, many autistic people become distressed in busy, bright or noisy environments. As part of the pilot, jobcentre staff will therefore be asked to carry out appointments with customers triggered in this way in quieter rooms, with more appropriate lighting.

Work coaches will also be able to help providers and employers in the local communities understand the additional needs required by autistic employees, which should in turn create more opportunities for autistic jobseekers in settings where they can thrive.¹⁶⁶

The pilot will be completed by 31 March 2022. If the results are positive, the DWP will explore how the framework can be rolled out to jobcentres across Great Britain.

¹⁶⁴ 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, chapter 5

¹⁶⁵ Hidden Impairment National Group, [Uncovering Hidden Impairments Toolkit \(PDF 622KB\)](#), March 2017 (cited in a [DWP Freedom of Information response of 14 October 2019](#), DWP Ref: FOI2019/32844)

¹⁶⁶ Department for Work and Pensions press release, [New government support package to help more disabled people into work](#), 29 December 2021

6.4

Universal Credit

Universal Credit (UC) is replacing tax credits and means-tested benefits (including income-related ESA and Housing Benefit) for working age individuals and families, in or out of work. Eventually, around 7 million households are expected to be claiming UC.¹⁶⁷

For some people on the autistic spectrum, navigating the Universal Credit system may be a challenge, if they do not have an appointee to act on their behalf.¹⁶⁸ An autistic person could, for example, face challenges making and managing their claim online, interacting (either online, or in person) with their Work Coach, and satisfying ‘conditionality’ requirements. The removal of ‘implicit consent’ in UC may also make it harder for advisers and support workers to advocate for their clients with autistic spectrum disorders.¹⁶⁹

All Universal Credit claimants are required to agree to a [Claimant Commitment](#). This will record the activities they are required to undertake, including, where appropriate, doing all that can reasonably be expected of them to find work or prepare for work.

The DWP should have in place procedures to identify Universal Credit claimants with complex needs – including those with learning disabilities – so that they can get the support they need throughout the ‘customer journey’, and be subject to conditionality requirements that reflect their needs and circumstances. Identifying claimants with complex needs can also be important in determining whether the person needs extra help with making and maintaining their claim, whether they would benefit from alternative payment arrangements, in deciding whether there is ‘good cause’ for failing to comply with conditionality, or whether they should be offered home visits.¹⁷⁰

Further information on arrangements for helping people unable to access UC via the standard online process can be found in the DWP UC guidance chapter [Assisted digital overview](#) (PDF, 209KB).¹⁷¹

¹⁶⁷ [Budget measures bring number of families entitled to Universal Credit to 7 million](#), Institute for Fiscal Studies, 8 November 2021

¹⁶⁸ When a claimant lacks the capacity to manage their benefit affairs, the Secretary of State may appoint a person to act on their behalf for benefit purposes. For further information see the DWP UC guidance chapter on [Appointees, Personal Acting Bodies and Corporate Acting Bodies](#) (PDF, 170KB), Version 10.0, current October 2021

¹⁶⁹ Where implicit consent is accepted, a third party can deal with the DWP on behalf of a claimant in the absence of valid written authority, or where the claimant is not present at the time to confirm their consent verbally. In UC, the claimant must provide explicit consent before information can be disclosed to a representative – although an exception has been made for Members of Parliament. For further information see the DWP UC guidance chapter [Consent and disclosure including when to share with third parties](#) (PDF, 134KB), Version 19.0, current October 2021

¹⁷⁰ DWP UC guidance chapter [Complex needs overview](#) (PDF, 135KB), Version 17.0, current October 2021

¹⁷¹ Version 14.0, current October 2021

Information on the Help to Claim service – which provides “tailored, practical support to help people make a Universal Credit claim up to receiving their first full correct payment on time”¹⁷² – is available on the Citizens Advice website – see [Get help applying for Universal Credit](#).

Guidance for DWP staff states that when a UC claimant with complex needs contacts the Department, their customer journey “must be equal in quality and outcome to those whose needs are not complex” and that it is important to ask them and record what additional support they need “to make sure it’s available every time the claimant needs it”. The guidance states that this “will provide them with equal access to products and services and enable them to follow the standard claimant journey, if appropriate”.¹⁷³ However, there have been concerns that arrangements for identifying those needing support have not always worked as intended.¹⁷⁴

For UC claimants, their Work Coach is the key point of contact within the DWP. A DWP microsite giving [information for prospective applicants](#) for these posts explains:

As a Work Coach you hold a vital role in the Department, helping individuals and their families towards financial independence through work and enabling them to claim the support they need as they progress.

Work Coaches are customer-focused, dedicated individuals and able to deliver exceptional service with empathy and compassion to people who need their support.

As a Work Coach, you will use sound judgement to help people through some difficult, challenging times in their lives, and your tailored coaching can make a huge difference to their ability to find, stay in, and progress in a job.

A Commons written answer September 2020 gives information of the training and support for Work Coaches to enable them to support claimants with autistic spectrum disorders:

Jobcentre and Service Centre staff undergo a comprehensive learning journey designed to equip them with the tools, skills and behaviours required to provide a high quality service to all claimants, including those with Asperger’s syndrome and autism. They receive on-going learning in their roles and have access to guidance which is refreshed at regular intervals.

Part of our training programme advises Universal Credit Work Coaches to consult with their Disability Employment Adviser (DEA) if the claimant has complex personal circumstances which need to be better understood, including Autistic Spectrum Disorders (ASD) which is complemented with a specific online training product. This has been designed so Universal Credit Work Coaches can refer to it whenever they need to.

Additionally, Universal Credit Work Coaches are equipped with guidance to enable them to provide a high quality service to all claimants including those

¹⁷² [PQ 6510 \[Universal Credit\], 31 October 2019](#)

¹⁷³ Ibid.

¹⁷⁴ See [UC and complex needs](#), Owen Stevens, CPAG Welfare Rights Bulletin, August 2019

in need of specific support. Universal Credit guidance includes examples of life events, personal circumstances, health issues and disabilities which could affect the claimant's ability to access and use Universal Credit services.¹⁷⁵

¹⁷⁵ [PQ 94432 \[Universal Credit: Autism\], 28 September 2020](#)

7 Criminal justice

7.1 The national strategy

The Government's [National strategy for autistic children, young people and adults: 2021 to 2026](#) includes measures intended to improve understanding of autism and support for autistic people within the criminal and youth justice systems.

The strategy says available evidence indicates autistic people may be over-represented as people who come into contact with the criminal and youth justice systems, as victims, witnesses or defendants.¹⁷⁶

The strategy refers to the [All-Party Parliamentary Group \(APPG\) on Autism's 2019 report \(PDF, 2.7MB\)](#), which found autistic people often have poor experiences when they come into contact with these systems.¹⁷⁷ The strategy notes a lack of understanding of autism can cause staff to misinterpret autistic people's behaviour, resulting in missed opportunities to divert them from the criminal and youth justice systems. The strategy also refers to evidence from the APPG on Autism's inquiry which highlighted that autistic people often find prison environments overwhelming.

The strategy committed to developing a better view of existing provision for neurodivergent adults, including autistic adults, through a call for evidence on neurodiversity in the criminal justice system.

It also committed to taking further steps in 2021/22 to:

- improve staff awareness and understanding of autism across the criminal and youth justice systems, including prison and probation staff, and youth custodial specialists
- undertake work to improve autistic people's access to adjustments and support and help make environments like prisons and probation services more autism friendly

¹⁷⁶ 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, p35

¹⁷⁷ See: APPG on Autism, [The Autism Act, 10 Years On: A report from the All Party Parliamentary Group on Autism on understanding, services and support for autistic people and their families in England \(PDF, 2.7MB\)](#), 2019

- drive better access to health and social care services for those in contact with the criminal and youth justice systems, including the support they may need as they leave custody.¹⁷⁸

7.2

Neurodiversity in the criminal justice system: A call for evidence

The Ministry of Justice's September 2020 White Paper [A Smarter Approach to Sentencing \(PDF, 639KB\)](#) repeated these commitments. It said the Ministry of Justice would launch a national 'Call for Evidence' to obtain a clearer picture of prevalence and the current national provision to support offenders with neuro-divergent conditions in the criminal justice system.¹⁷⁹ It also said the Government would be improving awareness, understanding and training on neurodiversity across the system and would develop a national training toolkit to increase the skills of frontline staff on neurodiversity.

In December 2020 then-Justice Secretary, Robert Buckland, commissioned HM Inspectorate of Prisons, with support from HM Inspectorate of Probation and HM Inspectorate of Constabulary and Fire & Rescue Services, to undertake an independent review of neurodiversity in the criminal justice system.¹⁸⁰

The report [Neurodiversity in the criminal justice system: A review of evidence](#) was published in July 2021.¹⁸¹ It said evidence received as part of the review suggests neurodivergence is more prevalent in the criminal justice system than in the wider community.¹⁸²

The review focused on four main themes:

- screening to identify neurodivergence in criminal justice system service users
- adjustments that have been made to existing provision to support those with neurodivergent needs
- programmes and interventions which have been specifically designed or adapted for neurodivergent needs; and

¹⁷⁸ 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, p36

¹⁷⁹ Ministry of Justice, [A Smarter Approach to Sentencing, September 2020 \(PDF, 639KB\)](#), CP 292, p57

¹⁸⁰ Gov.uk, press release, [Fairer justice system for neurodivergent people to reduce crime](#), 18 December 2020

¹⁸¹ Criminal Justice Joint Inspection, [Neurodiversity in the criminal justice system: A review of evidence](#), 15 July 2021

¹⁸² Criminal Justice Joint Inspection, [Neurodiversity in the criminal justice system: A review of evidence](#), 15 July 2021, para 2.11

- training and support available to staff to help them support people with neurodivergent needs.¹⁸³

While the review found evidence of good local partnerships and was told of simple adjustments that could easily be made to support neurodivergent people in the criminal justice system, the Chief Inspectors concluded:

...such provision is patchy, inconsistent and uncoordinated, and that too little is being done to understand and meet the needs of individuals.¹⁸⁴

The report made six recommendations, including an overarching recommendation about coordination. The main recommendation was for the Ministry of Justice to work with the Home Office, Department for Health and Social Care and the Department for Education and the Welsh Government to develop an overarching national strategy. The other recommendations were:

- A common screening tool for universal use within the criminal justice system should be introduced
- Screening data should be systematically collected and aggregated to provide a more accurate assessment of the prevalence of neurodivergence
- A programme of awareness-raising and specialist training should be developed and delivered to staff working within criminal justice services
- Adjustments to meet the needs of those with neurodivergent conditions should be made throughout the criminal justice system
- Criminal justice system agencies should work together and with other statutory and third sector organisations in a coordinated way, to understand and meet the needs of neurodivergent individuals in the community, prevent offending and support rehabilitation.¹⁸⁵

The inspectorates said the Ministry of Justice should provide an action plan to address these recommendations within three months, followed by updates on progress at six and 12 months.

Government response

The Government welcomed the report and in September 2021 said an action plan in response would be published in October 2021.¹⁸⁶ In November 2021 Minister, Victoria Atkins, said the Ministry of Justice was drafting the action plan.¹⁸⁷

¹⁸³ Criminal Justice Joint Inspection, [Neurodiversity in the criminal justice system: A review of evidence](#), 15 July 2021, para 2.4

¹⁸⁴ Criminal Justice Joint Inspection, [Neurodiversity in the criminal justice system: A review of evidence](#), 15 July 2021, p4

¹⁸⁵ Criminal Justice Joint Inspection, [Neurodiversity in the criminal justice system: A review of evidence](#), 15 July 2021, p6

¹⁸⁶ [PQ 45267 \[Offenders\], 15 September 2021](#).

¹⁸⁷ [PQ 69119 \[Offenders: Hyperactivity\], 3 November 2021](#).

The commitment to develop a national toolkit for frontline staff was repeated in the [Prisons Strategy White Paper](#) (PDF, 577KB) published in December 2021.¹⁸⁸

The Ministry of Justice has said it is committed to providing a supportive environment for neurodivergent prisoners. Answering a [PQ in October 2021](#), Minister, Victoria Atkins, set out work undertaken in prisons. She said some prisons already have specialist wings which are designed to cater for the needs of neurodivergent individuals. She said the programme to build new prisons will be informed by available evidence on design principles, including the Call for Evidence on Neurodiversity.¹⁸⁹

She also noted that prisons can work with the National Autistic Society to achieve Autism Accreditation and said the Ministry of Justice is committed to promoting autism accreditation across the estate.¹⁹⁰ Finally, she said the prison service is currently testing a new Neurodiversity Support Manager role in some prisons; role-holders will be responsible for liaising with education and skills teams and ensuring departments across the prison are aware of prisoners' individual needs.

¹⁸⁸ Ministry of Justice, [Prisons Strategy White Paper \(PDF, 577KB\)](#), CP 581, December 2021, para 172

¹⁸⁹ [PQ 60374 \[Prisons: Mental Health Services\], 29 October 2021](#).

¹⁹⁰ See, National Autistic Society, [Autism Accreditation](#)

8

Coronavirus impacts: the research

Research suggests the Coronavirus pandemic has had positive and negative impacts on autistic people. Some negative impacts were pre-existing issues which have been exacerbated, while benefits have included working or studying from home, which has acted to reduce stress.

8.1

Women and Equalities Committee inquiry

Although not specifically about autism, the issues raised by the Women and Equalities Committee inquiry, [Unequal impact? Coronavirus, disability, and access to services](#) (2020) are relevant to some people with autism.

The interim report of the inquiry (September 2020) addressed the impacts of temporary legislative changes in response to the pandemic.¹⁹¹

The final report (December 2020) considered the wider impacts of the pandemic on people with disabilities.¹⁹² Committee chair Caroline Noakes said:

Disabled people who already faced substantial barriers to equal participation in society have suffered a range of profoundly adverse effects. They have faced problems with unequal access to food, and potentially discriminatory practices in health and social care services.

Existing systemic problems in education for children and young people with special educational needs have worsened.

The Government has been far too slow to address concerns about engagement and communications: we need genuinely effective mechanisms by which disabled people can influence policies and practices which affect them, and ensure that hard-won rights and equalities are not eroded.

Our inquiry heard extensive evidence from disabled people of the profoundly unequal adverse effects: our report makes the case for an independent inquiry into the causes.¹⁹³

The report called for:

¹⁹¹ Women and Equalities Committee, [Unequal impact? Coronavirus, disability and access to services: interim Report on temporary provisions in the Coronavirus Act](#), 25 September 2020, HC 386 2019-21

¹⁹² Women and Equalities Committee, [Unequal impact? Coronavirus, disability and access to services: Full Report](#), 22 December 2020, HC 1050 2019-2021

¹⁹³ Woman and Equalities Committee news, [Coronavirus: pandemic has had “profoundly adverse effects” on disabled people’s access to services](#), 22 December 2020

an Independent Inquiry for an independent inquiry into the causes of adverse outcomes for disabled people, including the decisions and policies of the Government and public authorities, to take place as soon as the pandemic is more clearly under control.¹⁹⁴

8.2 National Autistic Society research

In September 2020 the National Autistic Society published [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#) in association with Ambitious about Autism, Autistica, Scottish Autism, Mind and the Autism Alliance.¹⁹⁵ The findings were based on online surveys asking autistic people and their families about their experiences of coronavirus and lockdown. Reacting to the report Caroline Stevens, Chief Executive of the National Autistic Society said:

Autistic people and their families have been struggling to get the care, support and understanding they need for years and things have been made even harder by coronavirus. They've been left completely stranded.

If you're autistic, small changes and unexpected events can trigger intense anxiety. So the disruption and pace of change during the coronavirus outbreak has been incredibly hard. On top of this, support from some public services disappeared overnight, leading to impossible pressures on families and many feeling abandoned.

[...]

The inequalities that autistic people and their families face aren't new. We've been highlighting them for years. But coronavirus has laid them bare and deepened them.

[...]

And as we rebuild our society, governments need to look beyond the immediate effects of coronavirus too and invest in the understanding, support and services autistic people need. Only then will we create a society that works for autistic people and their families.¹⁹⁶

8.3 Policy Innovation Research Unit (PIRU)

As part of the review into the National Autism Strategy, the Department of Health and Social Care commissioned additional independent research from

¹⁹⁴ Woman and Equalities Committee news, [Coronavirus: pandemic has had "profoundly adverse effects" on disabled people's access to services](#), 22 December 2020

¹⁹⁵ The Autistic Alliance are an umbrella organisation for 16 separate autism charities, (see [Autism Alliance: Network of specialist autism charities in the UK](#) for full details)

¹⁹⁶ National Autistic Society Press Release, [Left stranded: our new report into the impact of coronavirus](#), 7 September 2020

the [Policy Innovation Research Unit \(PIRU\) into the impact of the pandemic on autistic people and their families](#).¹⁹⁷

The authors concluded:

The COVID-19 pandemic has both immediate and enduring effects. Ongoing attention to the longer-term implications for autistic people and their families is imperative; particularly in relation to educational opportunity, health, employment and social inclusion, all of which can have profound effects on quality of life.¹⁹⁸

The sections that follow outline the main issues highlighted by research in this area.

Government Communications

Communication is a significant problem for many autistic people in everyday life. Communications during the pandemic caused confusion and stress to people on the autistic spectrum. The Women and Equalities Committee sub-inquiry found:

The way the Government has communicated with disabled people during the pandemic has, on occasions, caused confusion and compounded already keenly felt anxiety. Communications have sometimes been poorly thought out, with insufficient consideration given to the psychological effects on recipients and their families. Ministers and officials involved in communicating public health messages to disabled people should undergo training in psychologically informed communications which take fully into account and empathise with disabled people's lived experiences.¹⁹⁹

The PRIU research found similar issues:

Government messages were found to be difficult both to understand and follow, and rule changes were confusing. Autistic people in the insight group felt strongly that if the message was not coherent or did not make sense, it was almost impossible for them to follow. In addition, written instructions for the COVID-19 test were challenging to understand.²⁰⁰

There was a lack of 'Easy read'²⁰¹ versions of communications or they were hard to find. For instance:

The Prime Minister's letter of 23 March to every household in the UK, explaining the gravity of the situation and the need for the first national lockdown, was

¹⁹⁷ Policy Innovation and Research Unit, [The Impact of COVID-19 on Autistic People in the United Kingdom: Final Report](#), May 2021

¹⁹⁸ Ibid.

¹⁹⁹ Women and Equalities Committee, [Unequal impact? Coronavirus, disability and access to services: Full Report](#), 22 December 2020, HC 1050 2019-2021, Summary p4

²⁰⁰ Policy Innovation and Research Unit, [The Impact of COVID-19 on Autistic People in the United Kingdom: Final Report](#), May 2021, p10

²⁰¹ A version of a document written in a clear and easier to understand way often with pictures, less dense text, and a good structure. (see [Easy Read Online: making information easy to understand so that people can do more for themselves - Easy-Read-Online Limited](#))

not initially available in any accessible formats. A large print version was published on 3 April and an Easy Read version, for people with learning disabilities and others who have difficulty reading, on 8 April.²⁰²

Education

For people on the autistic spectrum, education provides them with important life skills, a routine that supports them and important social contact. Many autistic children struggled without this and found home learning extremely difficult:

7 in 10 parents say their child has had difficulty understanding or completing school work and around half said their child's academic progress was suffering.²⁰³

According to the National Autistic Society survey

68% of family members said their autistic child was anxious at the loss of routine and 65% couldn't do online work.²⁰⁴

Many autistic children have Special Educational needs (SEN) and some will have Education Health and Care plans. The Women and Equalities Committee sub-inquiry found:

Delivering effective support for children and young people with SEND during a public health crisis was inevitably a massive challenge, to which some local authorities were unable to rise. The pandemic demonstrated and exacerbated a widely acknowledged pre-existing crisis in SEND provision. As set out in our interim Report, many children and young people received little or no support for three months. *The Government must now prioritise its SEND review, launched over a year ago, and bring forward as a matter of urgency reforms which address fundamental problems of funding, consistency of support, accountability and integration of services, identified by the Education Committee and the National Audit Office in 2019. The outcome of the SEND review must be published no later than the first quarter of 2021 and set out the Government's plan to reach a sustainable funding model while achieving the core aims of the 2014 reforms.*²⁰⁵

In addition, the committee was concerned that promised catch up funding did not specifically target children with SEND who were particularly affected by the educational disruption caused by the pandemic:

We agree that catch up funding should be weighted towards children who have been "hardest hit" by disruption to their education. We know that many children with special educational needs and disabilities (SEND) will be in the hardest hit group; many received little or no support earlier this year. We know

²⁰² Women and Equalities Committee, [Unequal impact? Coronavirus, disability and access to services: Full Report](#), 22 December 2020, HC 1050 2019-2021, para 118

²⁰³ National Autistic society Press Release, [Left stranded: our new report into the impact of coronavirus](#), 7 September 2020

²⁰⁴ National Autistic society, [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#), 7 September 2020, p7

²⁰⁵ Women and Equalities Committee, [Unequal impact? Coronavirus, disability and access to services: Full Report](#), 22 December 2020, HC 1050 2019-2021, para 98

that pupils with SEND are likely to fall further behind without commensurate help. Pupils with SEND in mainstream schools have often borne the brunt of the dysfunctional SEND system, missing out on support for their needs through a lack of ring-fenced funding. We are very concerned that catch up funding allocations do not adequately reflect this. In the light of experiences earlier this year, it is unacceptable that the £1 billion catch up premium does not include ring-fenced funding for pupils with SEND in mainstream schools. *We recommend that funding for the remaining tranches of the universal catch up allocation be increased by around £211 million, to allow mainstream schools to receive £240 per pupil with an EHC plan or receiving SEN Support, ring-fenced for their catchup support in this academic year. We further recommend the Department procure an additional strand of specialist provision in the National Tutoring Programme, designed to support pupils with EHC plans and those receiving SEN Support, across all schools.*²⁰⁶

The return to school was also traumatic for many autistic children after being out of school so long and with associated changes to routines and procedures required for Covid safety.

The return to school has been equally fraught. Some schools have refused to allow autistic young people to come back for risk reasons, even when schools have re-opened. Others haven't put in place the individual plans that autistic children need to cope with another massive change to their routines. This needs to happen for each autistic pupil. While schools are under huge pressure, there are other simple steps they could take that will help. They could provide visual guides showing the changes that have been made to the school and early tours for autistic children before term starts so they can understand changes to handwashing or playtime.²⁰⁷

Food shopping

All the reports refer to autistic people struggling to access food at the start of the first lockdown. The National Autistic Society survey observed autistic people said buying food was their biggest difficulty during lockdown.²⁰⁸

Some of the problems mentioned included:

- Carers or support networks not available to help due to restrictions and reduced numbers allowed in shops.
- Changes to the layout of stores and queuing.
- Lack of understanding of shop staff about autism.
- Difficult for some autistic people to wear masks.
- Priority for online delivery given to Clinical Extremely Vulnerable but not all autistic people fell into this category and those who did still found it difficult to access at the beginning.
- Lack of independence and worry.
- Lack of reasonable adjustments in supermarkets

²⁰⁶ Women and Equalities Committee, [Unequal impact? Coronavirus, disability and access to services: Full Report](#), 22 December 2020, HC 1050 2019-2021, para 105

²⁰⁷ National Autistic society, [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#), 7 September 2020, p8

²⁰⁸ National Autistic society, [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#), 7 September 2020, p9

- Difficulty understanding rules and upset caused by people not following rules

However some autistic people, who did manage to shop in person, found it less stressful than usual:

I did the majority of our shopping, and found it much more relaxing than usual. The queues outside were a good time to read, with no one too close, though I was concerned so few people wore masks – it is such a good protection for others and also provides the wearer an amount of protection.²⁰⁹

Mental health

Autistic people are more likely to suffer from mental illness and find it more difficult to access health care than the general population.

For many autistic people, the pandemic has had a negative effect on their mental health. Some have struggled with the loss of regular routines and a lack of contact with family and friends who provide support.

For some people on the autistic spectrum, not having to socialise brought some relief.²¹⁰ However, others felt isolated or fell into crisis without their usual support. A majority reported experiencing loneliness and anxiety as significant problems. The National Autistic Society found 90% of autistic people worried about their mental health during lockdown.²¹¹

For autistic people detained in hospital for the assessment or treatment of their mental health, efforts to prevent the spread of Covid-19 caused further disruption. According to a report published by The Joint Committee on Human Rights:

Unlawful blanket bans on visits, the suspension of routine inspections, the increased use of restraint and solitary confinement, and the vulnerability of those in detention to infection with Covid-19 (due to underlying health conditions and the infeasibility of social distancing) mean that the situation is now a severe crisis.²¹²

Access to health services

The impact of the pandemic on health services exacerbated long waiting times between referral and receiving an autism diagnosis. See section 2.3 for statistics. It also reduced the amount and type of support that people on the

²⁰⁹ Policy Innovation and Research Unit, [The Impact of COVID-19 on Autistic People in the United Kingdom: Final Report](#), PIRU, May 2021, p15

²¹⁰ Policy Innovation and Research Unit, [The Impact of COVID-19 on Autistic People in the United Kingdom: Final Report](#), PIRU, May 2021, p16

²¹¹ National Autistic Society, [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#), September 2020, p5

²¹² Joint Committee on Human Rights, [Human Rights and the Government's response to COVID-19: The detention of young people who are autistic and/or have learning disabilities](#), 12 June 2020, HC 395 / HL 72 2019-21, Summary p3

autistic spectrum and their carers could access. Many face-to-face services were suspended, and alternative telephone or online support was hard for some people with communication difficulties to use. The National Autistic Society have called for more research into the barriers to digital and online support faced by autistic people.²¹³

Carers and support

The disruption of regular support services during the pandemic had a significant impact on the lives of the people who cared for an autistic person. Family members and carers faced increased care responsibilities and but support services and access respite services were severely reduced if available at all. Added to that the lack of informal support due to lockdown and many carers, already under pressure, are simply exhausted.

Some autistic people need very little support while others need fulltime 24-hour care. The National Autistic society research found that those needing full time care were much more negatively affected by lock down than those who needed less support.²¹⁴ Those living in residential care went months without seeing relatives during lockdown, home visits at weekends were not possible and visiting was severely restricted if it happened at all.

The National Autistic Society found that one in five family members had to reduce their working hours due to caring responsibilities.²¹⁵ They found social care services were overstretched and underfunded:

Coronavirus has placed an added strain on autistic people, the available social care services and in particular on the families of autistic people as they are often relied upon when no other options are available. Social care services are stretched and funding has been cut over many years, nor has enough research been carried out about what support works best. Experts have warned that a £3.5 billion funding gap will exist by 2024 / 2025 if action is not taken now.²¹⁶

The PIRU report found:

Service provision and respite care during lockdown were described as patchy and fragmented. Social distancing requirements in day services and transport to those services restricted capacity, reducing the numbers of people who could access services and the amount of time spent there.²¹⁷

²¹³ National Autistic Society, [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#), September 2020, p5

²¹⁴ National Autistic Society, [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#), September 2020, p6

²¹⁵ National Autistic Society, [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#), September 2020, p7

²¹⁶ National Autistic Society, [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#), September 2020, p7

²¹⁷ Policy Innovation and Research Unit, [The Impact of COVID-19 on Autistic People in the United Kingdom: Final Report](#), PIRU, May 2021, p18

With respite and day services unavailable many carers of autistic people reported fatigue and exhaustion. One parent quoted by The Left stranded report said:

In normal times [my son] goes for respite 36 overnights a year which gives me a chance to sleep and usually attends a day service five days a week. I am now being told there will be no respite for the foreseeable. I can't go on for much longer in this situation. My son is unpredictable, he has severe meltdowns. I have no one. My mum died in February just weeks before lockdown. If I don't get a rest soon, I really don't know how I can continue.²¹⁸

Schools closing, dramatically increased pressure on parent carers as well:

I feel completely alone and unsupported with a child who is regressing further into his own bubble on a daily basis. I haven't got him outside in 11 weeks and I haven't had a break in as long. He has not been able to do any schooling as home is home and school is school, causing massive meltdowns and trauma.²¹⁹

This also impacted siblings as well the PIRU report mentions a survey about this:

A separate parental survey looking specifically at the siblings of disabled children (including children with a diagnosis of autism) shed a further light on the effects of lockdown on siblings. Parents reported being unable to take the sibling physically away from the home while the disabled child was having a 'meltdown'. The lack of respite or opportunity for breaks was also felt by parents to have a significant impact on siblings.²²⁰

²¹⁸ National Autistic Society, [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#), September 2020, p6

²¹⁹ National Autistic Society, [Left stranded: The impact of coronavirus on autistic people and their families in the UK](#), September 2020, p8

²²⁰ S Policy Innovation and Research Unit, [The Impact of COVID-19 on Autistic People in the United Kingdom: Final Report](#), PIRU, May 2021, p18

9 Scotland, Wales and Northern Ireland

Health is a devolved matter so each of the devolved administrations are responsible for setting their own policies in this area.

9.1 Scotland

Scottish strategy for autism

The Scottish Government published the [Scottish Strategy for Autism](#) in November 2011. The strategy aims to ensure that progress is made across Scotland in delivering quality services for people on the autistic spectrum and their families. The strategy was backed up with funding of £10m over four years.

The strategy contained 26 recommendations, under the following overarching themes:

- The Scottish Government will provide strategic leadership on improving the lives of people affected by autism. It will lead on creating a strategic vision for the development of services and support for people on the autistic spectrum, their families and carers.
- Achieving best value for services for people affected by autism will ensure that resources are effectively targeted and that the outcomes in improving people's lives are the best we can achieve.
- Autistic people, and their families and carers, should be involved at all levels in decision making.
- The capacity for cross-agency working will be developed through stronger networks, best practice and training. This will help deliver cost-effective support and interventions.
- For adults, getting a good quality diagnosis is the key foundation that will lead them to understanding their condition and for the best support to be made available to them.
- There are many autistic people who would like to work but who face significant barriers to getting and sustaining a job. We will support them through training, creating opportunities and improving access to the workplace.

The Scottish Government ran a [consultation](#) from 18 October to 29 November 2017 to refresh the 2011 strategy. This sought views on what the actions for the final stage of the strategy should be in the context of changes since 2011, including devolved employability and social security powers.

The refreshed strategy, [Scottish Strategy for Autism: outcomes and priorities 2018-2021](#), was published in March 2018. Research into [The microsegmentation of the autism spectrum: research project](#) was also published in March 2018. It covers economic research on autism and implications for Scotland, including how the economic cost of autism can inform strategy and planning. Scottish Autism responded to this report.²²¹

During a debate on ‘services for people with autism’ on 21 March 2019, David Linden referred to an announcement by Scottish Mental Health Minister, Clare Haughey, on 19 March 2019 of a “complete review of mental health legislation and autism legislation.”²²²

A review of the Mental Health (Care and Treatment) (Scotland) 2003 Act began in early 2020 with a 12-week consultation and is ongoing - more information is available at [Scottish Mental Health Law Review](#).²²³

Learning/Intellectual disability and autism: transformation plan

In March 2021 the Scottish government and COSLA²²⁴ published [Learning/intellectual disability and autism: transformation plan](#), ‘Towards Transformation’.

The report lays out 32 actions the Scottish Government and COSLA plan to take over the following 2 years, it contained actions on human rights, actions for both learning disability and autism and separate actions for learning disability and autism:

Human Rights

There are two actions in the transformation plan on human rights:

Action 1 - The Scottish Government is clear that the needs of autistic people and people with learning/intellectual disabilities and their carers are to be actively considered as part of the ongoing independent review of the Mental Health Act. This legislative reform²²⁵ work will help inform the shape of our future legislation.

Action 2 - The Scottish Government will explore further the proposals for a commission or commissioner to help protect people's rights.²²⁶

²²¹ Scottish Autism, [Scottish Autism: Service Provider’s Response to the Microsegmentation Report 2018](#), July 2018

²²² [HC Deb 21 March 2019 c1298](#)

²²³ [Scottish Mental Health Law Review](#) (accessed 14 December 2021)

²²⁴ The voice of local government in Scotland

²²⁵ Scottish government, [The Independent Review of Learning Disability and Autism in the Mental Health Act Scotland](#), December 2019

²²⁶ Scottish Government and COSLA, [Learning/intellectual disability and autism: transformation plan](#), 24 March 2021

Both learning/intellectual disability and autism

There are 19 actions that apply to both learning/intellectual disability and Autism and five specifically for autism. These actions include the following topics:

- Exploring how the delivery of the Mental Health Transition and Recovery Plan can better meet the needs of autistic people and people with a learning/intellectual disability.
- Investigating the possible of introducing mandatory autism training for all NHS staff, as well as other improvements to health care for people on the autistic spectrum.
- Work to “ensure that people with lived experience are listened to and better supported to initiate and influence programmes and initiatives which will impact on their lives.”²²⁷ Empower people to have their voices heard as active citizens through the new autism campaign – [Different minds. One Scotland.](#)^{228 229}
- Marketing to enable people to recognise that they are in a caring role and the support they can access.
- Work towards halving disability employment gap as stated in A Fairer Scotland for Disabled People and [A Fairer Scotland for Disabled People: Employment Action Plan.](#)^{230 231}
- Work towards “improving educational experiences and outcomes for all children and young people who need support with their learning”²³² and develop “meaningful additional support for learning outcome measures which capture indicators of the achievements and progress of autistic children... beyond solely academic and destination data.”²³³ And aim to “support more parents to have access to the information, skills, support and advocacy they need to be active and equal participants in their child's education.”²³⁴ And improve understanding of autism in Initial teacher training.
- Actions to improve digital access for autistic people so they can be more involved and connected in their communities.
- Improve autism and ADHD diagnosis services, develop an indicator to monitor these services and piloting a post diagnostic support service for autistic people

²²⁷ Scottish Government and COSLA, [Learning/intellectual disability and autism: transformation plan](#), 24 March 2021, Action 15

²²⁸ [Different Minds One Scotland](#) (accessed 12/01/2022)

²²⁹ Scottish Government and COSLA, [Learning/intellectual disability and autism: transformation plan](#), 24 March 2021, Action 30

²³⁰ Scottish Government, [A Fairer Scotland for Disabled People: employment action plan](#), 11/12/2018

²³¹ Scottish Government and COSLA, [Learning/intellectual disability and autism: transformation plan](#), 24 March 2021, Action 20

²³² Scottish Government and COSLA, [Learning/intellectual disability and autism: transformation plan](#), 24 March 2021, Action 22

²³³ Scottish Government and COSLA, [Learning/intellectual disability and autism: transformation plan](#), 24 March 2021, Action 25

²³⁴ Scottish Government and COSLA, [Learning/intellectual disability and autism: transformation plan](#), 24 March 2021, Action 27

- “Explore the barriers to autistic people living a healthier life.”²³⁵

Evaluation of the Scottish Strategy for Autism

In September 2021, the Scottish Government published an [Evaluation of the Scottish Strategy for Autism](#). The Evaluation examined the strategy’s recommendations and priorities, its impact on autistic people and services that support them, and lessons learnt that could inform future policy. The future policy lessons for the Scottish Government are listed below:

- Narrow the focus of future work which will mean less might be achieved but there is more likelihood of effective delivery and sustainability;
- Provide clarity about actions and implementation so that there are identified achievements within a clear plan;
- Explore what evidence or data could be routinely collected to inform a picture of what is happening locally and nationally;
- Provide clarity on where autism sits within government policy – lack of consensus of how autism should be considered, the disability vs neurodiversity debate;
- Consider focusing on areas that need to see the greatest change – diagnosis, transitions, support for autistic adults, employment;
- Place stronger requirements on local authorities to deliver, especially if funding is provided to support them;
- Review who is contributing to the discussions and influencing policy so that the usual suspects are not always around the table and the contributors are from a wider pool to reflect the small and large charities supporting autistic people, and individuals with a lived experience from across the ages; and
- Build on the positive relationships that exist – the nature of the dialogue has on many occasions been acrimonious and hostile, require a standard of acceptable engagement if people want to genuinely be involved in progressing this agenda in a more positive way.²³⁶

The Scottish Government funds the [Autism network](#) and the [Autism Toolbox](#).

²³⁵ Scottish Government and COSLA, [Learning/intellectual disability and autism: transformation plan](#), 24 March 2021, Action 14

²³⁶ Scottish Government, [Evaluation of the Scottish Strategy for Autism](#), 24 September 2021, Chapter 5: Discussions and Conclusions, Lessons gleaned for future policy direction, pp52-3

9.2

Wales

Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales

In 2008, the Welsh Assembly Government published the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales.²³⁷ The plan set out a number of actions to improve services and outcomes for people with autism in Wales under the following themes:

- Mapping prevalence, needs and services
- Commissioning services
- Transitional arrangements
- Services for adults
- Awareness raising, information and training

In May 2015, the Welsh Government announced a [one-year plan for children, young people and adults with autism spectrum disorder](#). As well as looking to refresh their autism strategy, the interim delivery plan also promised to take forward the ‘most pressing actions identified by a stakeholder advisory group’. These included:

- Addressing delays in diagnosis and improving ASD diagnostic pathways;
- Developing options for an integrated service to identify unmet need and address the most acute gaps in services and support;
- Improving education and employment outcomes including transition; and
- Developing awareness raising and professional training materials and resources.

Health and Social Services Minister, Mark Drakeford, said at the time:

I’m very pleased to announce a number of new measures to improve the process of diagnosing children, young people and adults with ASD and the services available to support them.

This plan, which is backed by more than £600,000 funding from the Welsh Government, sets out what we want to achieve over the next 12 months and its outcomes will inform decisions about longer-term goals.

We’re also making a £2m investment to develop specific services to better diagnose and support young people with ADHD and ASD. This will cut waiting times in specialist child and adolescent mental health services so those with highest levels of clinical need are seen in a more timely manner.²³⁸

²³⁷ Welsh Assembly Government, [The Autism Spectrum Disorder \(ASD\) Strategic Action Plan for Wales: Executive summary and actions](#) (PDF, 73KB), April 2008

²³⁸ Welsh Government, [New measures to improve autism services in Wales](#), 18 May 2015

In November 2016, the Welsh Government published a new [Strategic Action Plan for Autism Spectrum Disorder](#), which set out three priority areas for the coming years:

- Awareness raising, information and training;
- Assessment and diagnosis; and
- Meeting support needs.

The first annual report on the [Autistic Spectrum Disorder Strategic Action Plan 2017/18](#) outlined how the Welsh Government viewed its progress in implementing the strategy.

An [updated delivery plan](#) was published for 2018-21, which lists the commitments of the 2016 plan alongside a number of newer goals.

Autism (Wales) Bill

Paul Davies AM introduced the [Autism \(Wales\) Bill](#) on 13 July 2018.²³⁹ The Bill did not proceed but it prompted the Welsh Government to issue a detailed statement on 18 February 2019 on action taken to drive service improvement.²⁴⁰

Progress of the ASD Strategic Action Plan

The Welsh Government published a second comprehensive annual report in 2019, [Autism spectrum disorder: annual report 2018 to 2019](#). A shorter report followed in 2021 during the COVID pandemic, [Autistic Spectrum Disorder \(ASD\) strategic action plan – delivery plan: annual report 2019 to 2020](#).

In July 2021 the Welsh government published an updated plan for the first year of the new Senedd term, [Autism delivery plan 2021 to 2022](#), alongside the Code of Practice. There were eight priority areas identified (see box below)

Autism delivery plan: priority areas 2021 to 2022

1. Delivering the priorities for action
 - We will continue to support the provision of expert advice and guidance on the delivery of autism services and the delivery of the Code of Practice
2. Awareness raising

²³⁹ National Assembly for Wales Research Service, [Autism \(Wales\) Bill Summary](#) (PDF, 932KB), January 2019

²⁴⁰ Welsh Government, [Written Statement: Improving Autism Services](#), 18 February 2019

- We will raise public and employers’ awareness of autism and the Code of Practice
- 3. Training
 - We will work with partners to support training needs analysis and raise awareness of the duties in the Code of Practice
- 4. Assessment and Diagnosis services
 - We will support the improvement of autism assessment and support services.
 - We will support the Together for Children and Young People Programme 2²⁴¹ Neurodevelopmental work stream to improve children and young people’s assessment services.
- 5. Health and Social Care
 - We will drive inclusion of the Welsh language in service delivery.
- 6. Recovery, Inclusion and Well-being
 - We will support autistic people impacted by Covid-19 pandemic to recover
 - We will support and include autistic people who identify as Black, Asian and Minority Ethnic and/or identify as LGBTQ+.
- 7. Stakeholder involvement
 - We will ensure that autistic people, parents and carers are involved in all future policy and service development for autism services.
- 8. Planning, Data Collection and Monitoring
 - We will provide funding for Regional Partnership Boards to support the development of autism infrastructure, Population Needs Assessment and Area Plans²⁴²

The Welsh Government plan to revisit these priorities after the conclusion of the demand and capacity review of neurodevelopmental services for children and adults which is due to be completed in March 2022.²⁴³

The Code of Practice on the delivery of autism services

The Welsh Government consulted on a [Code of Practice for the Delivery of Autism Services \(PDF, 736 KB\)](#). This consultation closed on 1 March 2019 and

²⁴¹ A multi-agency programme ‘set up in 2015 to consider ways to reshape, remodel and refocus the emotional wellbeing and mental health services provided for children and young people in Wales.’ [Together for Children and Young People \(2\) - NHS Wales Health Collaborative](#), (accessed 16 December 2021)

²⁴² Welsh Government, [Autism delivery plan 2021 to 2022](#), July 2021

²⁴³ Welsh Government, [Autism delivery plan 2021 to 2022](#), July 2021, p1, para1

the draft code of practice was published for consultation in September 2020.²⁴⁴

The Welsh Government laid the Statutory Code of Practice on the Delivery of Autism Services on 24 March 2021, accompanied by a written statement:

It is so important that the way in which autistic people and those with other neurodiverse conditions communicate and interact with the world is understood. We need to create a kinder, more sensitive society that can respond positively and support autistic people, their families and carers. Today we have laid the Statutory Code of Practice on the delivery of Autism Services delivering on a Welsh Government commitment to publish the Code in this Senedd term. It will support the delivery of our on-going improvement programme set out in our autism strategy published in 2016. The Code describes how services and support should be planned and delivered to meet autistic people's identified needs and to ensure services are accessible in local communities.

The [Code](#) (published on the Welsh Parliament website) and [accompanying guidance](#) have been developed in partnership with our stakeholders, most importantly autistic people and their parents and carers, and with third sector organisations, practitioners and services providing support. We held two public consultations on our proposals and organised technical briefings to discuss the detail of the Code. We have sought engagement with all stakeholders across Wales, seeking their views on the services and support they want to see. I want to thank all those who took the time to work with the Welsh Government, providing advice and guidance on the priorities for the Code.

This Code and guidance will re-inforce and strengthen existing duties to support autistic people contained in the Social Services and Wellbeing (Wales) Act 2014 and the NHS (Wales) Act 2006. Its aim is to inform autistic people about the support they can expect to be available, to raise awareness of the needs of autistic people and their parents and carers to enable them to live fulfilling lives. The Code and guidance also provides direction for statutory services on how they should plan to ensure autism services are available and how they are delivered and monitored.

Subject to the will of the next Senedd, the Code will come into force from 1 September 2021 and will be supported by an updated delivery plan for the autism strategy, which will be published in the new Senedd Term. The delivery plan will acknowledge the enormous pressures faced by services as they recover from the impact of the COVID-19 pandemic. Early priorities will be on raising awareness of the Code and to support Regional Partnership Boards we are providing a grant of £4,000 per region to assist in developing an autism infrastructure from which they can build sustainable improvement. Regions will also be supported by the National Autism Team, and local autism leads, which working in partnership with autistic people will directly support the implementation of the Code, providing advice, training and resources.

Our strong commitment to improving the lives of autistic people and others who are neurodiverse will continue and develop. We are also publishing the [annual report](#) for the delivery of the autism strategy 19/20 which

²⁴⁴ Welsh Government, [Consultation document: Code of Practice on the Delivery of Autism Services](#), 21 September 2021

summarises the progress we are making. Although we have achieved significant improvements we recognise gaps in provision remain we need to gather new evidence and best practice as it emerges. Therefore this year we are undertaking a demand and capacity review of all age neurodevelopmental services. This will help us understand where we can build on existing services which are working well and where we need to take action to address identified gaps to create a sustainable system of support across sectors.

We will achieve this by continuing to work in partnership with autistic people and their parents and carers and with services across Wales over the next Senedd Term.²⁴⁵

Concerns about how the code could be enforced, were expressed by many stakeholders during the consultation, these were addressed in the final code, published in July 2021:

[...] with monitoring requirements and robust powers enabling Welsh Ministers to intervene if services do not meet satisfactory standards.²⁴⁶

The code came in to force 1 September 2021.

9.3

Northern Ireland

[The Autism Act \(Northern Ireland\) 2011](#) requires the Northern Ireland Executive to publish an Autism Strategy (for all ages) and to report on the implementation of that strategy to the Assembly at three yearly intervals.

The Autism Strategy (2013-2020) and Action Plan (2013-2016) were subsequently approved by the Northern Ireland Executive and launched in January 2014.

The structure of the Action Plan sets out thirty-four cross-Governmental actions reflecting the following eleven themes and associated strategic priorities:

- Awareness
- Accessibility
- Children, young people and family
- Health and wellbeing
- Education
- Transitions
- Employability
- Independence, choice and control
- Access to justice
- Being part of the community

²⁴⁵ Welsh Government, [Written Statement: Laying of the Statutory Code of Practice on the Delivery of Autism Services](#), 24 March 2021

²⁴⁶ Welsh Government, [Code of Practice on the delivery of autism services](#), updated 16 November 2021, p2, para2

- Participation and active citizenship

A progress report on the implementation of the strategy was published in September 2015: [The Autism Strategy \(2013 – 2020\) and Action Plan \(2013 – 2016\) Progress Report September 2015](#).

In 2016, The National Autistic Society Northern Ireland and Autism NI published [Broken Promises](#), which considered evidence on the impact of the 2011 Act, Strategy and Action Plan. The research found evidence of life getting more difficult for people on the autistic spectrum and of services “failing to deliver.”²⁴⁷ The report called on the Government to fulfil commitments made in 2011. The Northern Ireland Department of Health publish [autism statistics on their website](#).

In March 2021 the Minister of Health published an [interim autism strategy for action for 2021-22](#); due to the COVID pandemic it was not possible to plan a longer term strategy. The interim strategy has three strategic outcomes.

- A healthy life with access to services on an equal and timely basis to provide early intervention and support to best meet the needs for individuals and families
- A life with opportunities to live as an active citizen to support autistic people and their families through continued support in education and employment and as they transition through life stages
- An independent life with greater understanding and choices which provides opportunity for autistic people to live safe and independent lives within our communities and where they are met with respect and understanding.²⁴⁸

The [Autism Strategy 2023-2028](#) is currently in development. A consultation with stakeholders took place between August 2021 and 8 October 2021.²⁴⁹

The Education Authority in Northern Ireland has an [Autism Advisory and intervention service](#).

²⁴⁷ The National Autistic Society Northern Ireland & Autism NI, [Broken Promises](#), 2016

²⁴⁸ Department of Health Northern Ireland, [Minister of Health publishes cross departmental interim autism strategy](#), 8 March 2021

²⁴⁹ Department of Health Northern Ireland, [Autism Strategy 2023-2028](#), 23 August 2021 (accessed 16 December 2021)

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