



## BRIEFING PAPER

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# Autism – overview of policy and services

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## Summary

This briefing provides an overview of policies and services for people with autism spectrum disorder in England.

It is now over ten years since the passing of the *Autism Act 2009*, which is still the only disability-specific piece of legislation in England. The Act required the Government to introduce an [adult autism strategy](#), which was published in 2010 and refreshed in 2014. The accompanying [statutory guidance](#) sets out requirements for the NHS and local authorities to implement the strategy, in areas such as training for staff, identification and diagnosis, transition planning when people move from children to adult services, employment and criminal justice.

The Government is now undertaking a comprehensive review of the autism strategy and will be extending it to include children and young people for the first time. A [consultation](#) was launched in March 2019, and the Government is due to publish its response. The revised strategy was originally due to be published towards the end of 2019, however no update has yet been given for an expected publication date.

There have been successive health policies to improve outcomes for people with autism. Most recently, the [NHS Long Term Plan](#) (2019) provides 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 that 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 however 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 3 months from referral to assessment however the latest [local authority self-assessment](#) (2018) found that the median reported waiting time from referral to diagnostic assessment was 30 weeks. In a recent debate, the Minister for Care said that this "postcode lottery" must end and explained that new data on autism waiting times would help hold local authorities to account.<sup>1</sup>

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 has said that hospitals are not where people should live and committed to move people to community-based support. However, ambitions for this 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 also committed to introducing mandatory training on learning disabilities and autism for health and social care staff. Trials will begin in health and social care settings by April 2020, and report by

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<sup>1</sup> [HC Deb 21 March 2019 c1304](#)

March 2021, after which wider roll-out of training is expected for all staff.

This note focuses on policies in England. Health is a devolved matter so each of the devolved administrations are responsible for setting their own policies in this area. However, the note briefly outlines strategies implemented by the Governments in Scotland, Wales and Northern Ireland in section 8.

This note also describes policies in the areas of employment, education and social security.

# 1. Government policies on autism in England

## 1.1 Strategy for adults with autism 2010

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 *Autism Act 2009* 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 remains the only, disability-specific piece of legislation.

As required under the *Autism Act 2009*, the Department of Health published the first autism strategy for England in March 2010 - [Fulfilling and rewarding lives: the strategy for adults with autism in England](#).<sup>2</sup>

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.<sup>3</sup>

In December 2010, the Department of Health published statutory guidance for local authorities and NHS organisations to accompany the adult autism strategy.<sup>4</sup> This provided guidance on the following key 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.

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<sup>2</sup> Now archived.

<sup>3</sup> Department of Health, '[Fulfilling and rewarding lives': the strategy for adults with autism in England](#)', 3 March 2010, para 1.8 (now archived)

<sup>4</sup> [Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy](#).

## 1.2 Think Autism strategy 2014

In April 2014, the Department of Health published an update to the 2010 autism strategy: [Think Autism - fulfilling and rewarding lives, the strategy for adults with autism in England: an update](#). 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.

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

As part of this, the Government launched an Autism Innovation Fund to develop creative and cost-effective solutions and find new models of good practice. Local authorities, NHS organisations, third sector organisations and commercial organisations could bid for:

- £1 million of revenue funding for autism innovation project bids.
- £200,000 representing 6 months revenue funding for national co-ordination of autism awareness and the champions network. This funding was for third Sector/voluntary groups only.<sup>5</sup>

In January 2016, the Department of Health produced a progress report on *Think Autism*: [Progress Report on Think Autism: the updated strategy for adults with autism in England](#). The report summarised progress since the 2014 strategy and set a number of new actions, focusing on education, employment, the criminal justice system and better data reporting. It also detailed successful Autism Innovation Fund projects.

## 1.3 Statutory guidance 2015

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

- training for staff who provide services to adults with autism;

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<sup>5</sup> Department of Health, [The Autism Innovation Fund, national co-ordination of awareness and the champions network 2014/15](#).

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- identification and diagnosis of autism in adults, leading to assessment of needs for relevant services;
- planning in relation to the provision of services for people with autism as they move from being children to adults;
- local planning and leadership in relation to the provision of services for adults with autism;
- 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.

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

### 1.4 2019 review of the autism strategy

The Department of Health and Social Care and the Department for Education is now undertaking a comprehensive review of the adult autism strategy. The Government has committed to extending the strategy to cover children and young people, as well as adults, for the first time. It was initially due to be published towards the end of 2019.<sup>6</sup>

In March 2019, the Government launched a [public consultation](#) to inform the review of the autism strategy and is now due to publish their response.

The National Autistic Society, which has campaigned for a national strategy to meet the needs of children on the autism spectrum, welcomed the review:

It is absolutely right that the Government's upcoming autism strategy will cover autistic people of all ages as everyone deserves better support and understanding. This is an opportunity to drive forward improvements in education, health, care and public understanding - and make sure that no autistic child or adult is held back from reaching their potential. The strategy must put in place the right health, care and education services, reduce social isolation and open up opportunities for autistic people of all ages.<sup>7</sup>

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<sup>6</sup> [HC Deb 21 March 2019 c1303](#)

<sup>7</sup> NAS, [Big news: national autism strategy to be extended to children](#),

## 2. Health policies

The Government's 2018/19 [Mandate to NHS England](#) directs the NHS to reduce the health gap between people with mental health problems, learning disabilities and autism and the population as a whole, and support them to live full, healthy and independent lives.

The Government's 2019/20 Mandate is included in the [accountability framework for NHS England and NHS Improvement](#), and directs the two organisations to take forward the objectives in the Long Term Plan, many of which are autism specific – see below.

This section also details successive programmes of work to improve outcomes for people with autism, with objectives such as improving diagnosis rates, reducing rates of inpatient care and introducing mandatory staff training.

### 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”<sup>8</sup> 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.

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<sup>8</sup> NHS England, [The NHS Long Term Plan](#), January 2019, p41



- 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.
- Ensuring that 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 [Faling Model](#).<sup>9</sup>

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). There are concurrent targets for the maximum numbers of adult 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

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<sup>9</sup> Ibid, pp52-53

in inpatient care. For children and young people, the maximum is 12 to 15 children per one million.

The initial target set in 2015 was for a 35-50% reduction in inpatient care by March 2019, as most recently detailed in the Government's Mandate to NHS England 2018-2019.<sup>10</sup> During a debate on the NHS Long Term Plan, Health Secretary Matt Hancock was questioned about postponing this target to 2023/4 and said:

The target for this March [2019], which I inherited, was for a reduction of a third to a half. We are at a reduction of over 20%. The challenge has been that, while the number of people who are being moved into community settings has proceeded as per the plan, more people have been put into secure settings.<sup>11</sup>

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

## Implementation Framework

The [Implementation Framework](#) (June 2019) sets out how the commitments in the NHS Long Term Plan will be delivered. Each local area should develop a five-year plan, and to achieve the targets for people with learning disability and autism, these system plans should set 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.<sup>12</sup>

It also highlights that STP and ICS (see Box 2) areas should designate a **senior responsible officer for learning disability and autism** to deliver on these commitments.

The framework also details **targeted funding**, including specific investment to roll out keyworkers for children and young people with the most complex needs and their carers/families

### 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. ICSs (which are developing from STPs) should be in place across England by April 2021. See the Library briefing on [Health and Social Care Integration](#) (December 2019).

<sup>10</sup> Department of Health and Social Care, [The Government's revised mandate to NHS England for 2018-19](#), para 6.3

<sup>11</sup> [HC Deb 7 January 2019](#), NHS Long Term Plan, c70

<sup>12</sup> [The NHS Long Term Plan Implementation Framework](#), June 2019, para 5.10

from 2020/21, and capital investment to develop new housing options and suitable accommodation in the community, as an alternative to inpatient care.<sup>13</sup>

### 2.2 Mandatory staff training

The 2014 Think Autism strategy focused on autism training and made recommendations for improved staff training in health and care, welfare, employment, education, criminal justice and transport services. The associated statutory guidance made it clear that basic autism training should be available to all staff working in health and social care.<sup>14</sup>

Since 2015, as introduced by regulations under the *Care and Support Act 2014*, there has also been a statutory duty on local authorities to ensure that staff undertaking an assessment of an adult's care and support needs are appropriately trained. Local authorities are also required, when carrying out an assessment, to consult a person who has expertise in relation to the condition being assessed or circumstances of the individual, where it considers the needs of that individual require it to do so.<sup>15</sup>

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. This noted that over 5,00 responses were received, and the vast majority were supportive of the principle of mandatory training.<sup>16</sup>

The Government has since confirmed its intention to introduce mandatory learning disability and autism training for staff who work in 'regulated activities' (see box 1), by amending the *Health and Social Care Act 2008 (Regulated Activities) Regulations 2014*.

The Government will be looking at how training can also be strengthened for health and social care staff who do not work in regulated activities and will report back on this by 2021.<sup>17</sup>

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<sup>13</sup> [The NHS Long Term Plan Implementation Framework](#), June 2019, para 5.13

<sup>14</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p11

<sup>15</sup> [Care and Support \(Assessment\) Regulations 2014](#) SI 2014/2827 f

<sup>16</sup> Department of Health & 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

<sup>17</sup> Department of Health & 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, para 32

### Box 1 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:

- Personal care
- Accommodation for people who require nursing or personal care
- Accommodation for people who require treatment for substance misuse
- Treatment of disease, disorder or injury
- Assessment or medical treatment for persons detained under the Mental Health Act 1983
- Surgical procedures
- Diagnostic and screening procedures
- Management of supply of blood and blood-derived products
- Transport services, triage and medical advice provided remotely
- Maternity and midwifery services
- Termination of pregnancies
- Services in slimming clinics
- Nursing care
- Family planning services

The Government will be working with all professional bodies and Devolved Administration to agree a common 'core curriculum' based on the [Core Capabilities Framework for Supporting People with a Learning Disability](#) and the new [Core Capabilities Framework for Supporting Autistic People](#). Training requirements will however vary according to staff roles and interactions with people with a learning disability and/or autism. The Government has committed £1.4million to develop and test a learning disability and autism training package. A trial of the training is due to begin in April 2020 and will report by March 2021, after which wider roll-out to all staff is expected.<sup>18</sup>

## 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) states that an autism diagnostic assessment should start within 3 months of the referral to the autism team.<sup>19</sup> However, the latest local authority self-assessment found that the median reported waiting time from referral to assessment was 30 weeks – see below.

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

<sup>18</sup> Department of Health & 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, para 27

<sup>19</sup> NICE guidance is not mandatory but provides best-practice and health practitioners are expected to take guidance into consideration.

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Think Autism (2014) states that each local area is expected to 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.<sup>20</sup>

Public Health England also carries out an annual self-assessment exercise with local authority areas on progress they are making in implementing the autism strategy. Local authorities work with their local partners, including CCGs, to informally answer a range of questions.<sup>21</sup> On diagnosis, the following results were reported for 2018:

For the first time, all local authorities responded that they had a diagnostic pathway. However many downgraded their rating of their local diagnostic service from 'green' to 'amber', most commonly because the waiting time had risen to exceed the 3-month limit specified in NICE guidelines. There was a slight increase in the number of areas using out-of-area diagnoses (from 18% to 26%) and in these areas the proportion of their diagnostic work handled this way also appeared to be increasing.

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.<sup>22</sup>

In November 2019, NHS Digital first published data on the number of new autism referrals and waiting times to first appointment:

On 14 November 2019, NHS Digital published statistics that present the number of new referrals to mental health services for which the referral reason was suspected autism, as well as their waiting times to first appointment. These are experimental statistics and have been published by NHS Digital to involve users and stakeholders in the future development of the data, including work to improve the quality of the data. The data is available at the following link: <https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/autism-statistics><sup>23</sup>

The [NHS Long Term Plan](#) also explains that over the next three years, autism diagnosis will be included alongside work with children and young people's mental health services to test and implement the most effective ways to reduce waiting times for specialist services.<sup>24</sup>

Issues with the diagnosis of autism attracted comment during a House of Commons debate on autism in March 2019. In response to calls for

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<sup>20</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p16

<sup>21</sup> [PO HL6524 \[on Autism\], 14 March 2016](#)

<sup>22</sup> Public Health England, [Autism self-assessment exercise 2018: executive summary](#), para 5

<sup>23</sup> [PO 3857 \[on autism: diagnosis\], 20 January 2020](#)

<sup>24</sup> NHS England, [The NHS Long Term Plan](#), January 2019, para 3.33

the establishment of regional centres of excellence for diagnosis,<sup>25</sup> the Minister for Care said:

No one should have to face a long wait for an autism diagnosis, but we hear far too often that the NICE recommendation of a wait of no more than three months is exceeded. There is a geographical disparity, and this postcode lottery must end. The NHS long-term plan commits to testing and implementing the most effective ways to reduce those waiting times. Critically, we are collecting data to support that, which will be published later this year for the first time. This will mean that each area can be held to account and action can be taken.<sup>26</sup>

## 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) stated that people with learning disabilities or autism should not live in hospitals, and pledged that everyone inappropriately placed in hospital will move to community-based care as quickly as possible, and no later than 1 June 2014. 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.

In 2014, NHS England commissioned Sir Stephen Bubb to consider how a new national framework could expand community provision in order to move people with a learning disability or autism out of unsuitable institutional care. This came after the pledge to move people to community care by June 2014 was missed.<sup>27</sup>

Sir Stephen's report [Winterbourne View - Time for Change](#) (2014), found that people with learning disabilities or autism were still being placed inappropriately in long-term institutional care rather than being supported in the community. The report found that there were still more people being admitted to such institutions than were being discharged and he recommended the urgent closure of unsuitable inpatient care institutions.<sup>28</sup>

The subsequent report - [Winterbourne View - Time is Running Out](#) (2015) – found that progress had been made, with the number of people being discharged from inpatient institutions greater than the number admitted. However, it said that 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. The successive report [Time for Change: The Challenge Ahead](#) (2016)

<sup>25</sup> [HC Deb 21 March 2019 c1289](#)

<sup>26</sup> [HC Deb 21 March 2019 c1304](#)

<sup>27</sup> A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb, [Winterbourne View - Time for change](#), November 2014, page 8

<sup>28</sup> A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb, [Winterbourne View - Time for change](#), November 2014

recommended a commissioner for learning disabilities to promote and protect the rights of all people with learning disabilities and/or autism in England. The Government said it would consider the recommendations of the report, but that “new statutory roles and legislation are not necessarily the answer to promoting and protecting the rights of people with learning disabilities and their families”.<sup>29</sup>

In January 2015, the Government published [Winterbourne View: transforming care 2 years on](#), to report on progress against their original report. The report said that a significant number of the recommendations had been achieved, including:

- We know how many people are in inpatient settings, where they are and who is responsible for them.
- We have strong accountability and corporate responsibility arrangements in place via the Duty of Candour and Fit and Proper Person Test to assure the quality and safety of care services that people receive.
- We have new DH guidance on minimising restrictive interventions, complemented by a suite of information by Skills for Care and Skills for Health setting the foundation for a broader new programme Positive and Safe launched by the Department of Health in 2014. Work is underway to improve and report on data about the use of restraint.
- A more rigorous registration, assessment and inspection approach is in place for learning disability services, involving experts by experience and ratings are being published from inspections taking place since October 2014.
- The Care Act 2015 underpins and reinforces the importance of good quality, independent advocacy and will play an important part in supporting people, their families and carers to raise concerns when these arise.<sup>30</sup>

However, the report also said that not as much progress has been made as was intended – for example it recognised that the June 2014 target to transfer people to community care was missed.<sup>31</sup>

During a Public Accounts Committee session in February 2015, the Chief Executive of NHS England announced that 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.<sup>32</sup> This would be accompanied by a transition plan for the people with learning disabilities and challenging behaviour within these hospitals, from 2016–17.<sup>33</sup>

In October 2015, NHS England, in partnership with the Local Government Association (LGA) and the Directors of Adult Social Services

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<sup>29</sup> [PQ 28525 \[on Learning Disability\] 1 March 2016](#)

<sup>30</sup> Department of Health, [Winterbourne View: Transforming Care Two Years On](#), January 2015, page 6

<sup>31</sup> *ibid*

<sup>32</sup> Public Accounts Committee, [Care services for people with learning disabilities and challenging behaviour](#), 27 March 2015, HC 973 2014-15, para 15

<sup>33</sup> Public Accounts Committee, [Care services for people with learning disabilities and challenging behaviour](#), 27 March 2015, HC 973 2014-15, page 5

(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.<sup>34</sup> Transformation was based on 49 'Transforming Care Partnerships', comprising CCGs, NHS England commissioners, and local authorities. This was accompanied by £40 million of transformation funding from 2015/16 to 2018/19, to be matched by CCGs, and £20 million in capital funding.<sup>35</sup>

The [Government's Mandate to the NHS 2018-19](#) set an objective to achieve the 35-50% bed reduction by March 2019. 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'.<sup>36</sup>

However, as noted above, the 2019 [NHS Long Term Plan](#) provides that the 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'.<sup>37</sup>

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<sup>34</sup> NHS England, [Building the right support](#), October 2015

<sup>35</sup> NHS England, [NHS England to invest in building the right support for people with a learning disability](#), 20 June 2017

<sup>36</sup> [PO 108577 \[on Health Services: Learning Disability\], 26 October 2017](#)

<sup>37</sup> Mencap, [Government due to miss deadline for releasing people with a learning disability locked away in inpatient units, warns Mencap](#), 21 March 2019



## 3. Social care services

### Adult social services

The *Care Act 2014* brought in new duties for local authorities with regards to care and support services. The following duties came into force on 1 April 2015 and local authorities must carry them out in relation to adults with autism as with all other adults.

Local authorities have a duty:

- under Section 1 of the *Care Act*, to promote an individual's well-being;
- under Section 3 of the *Care Act*, to ensure the integration of care and support provision with health and health-related provision where this would, in its area, promote well-being, help prevent or delay the development of care and support needs, and improve the quality of care and support;
- under Section 4 of the *Care Act*, to establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and support for carers and in particular on how to access the care and support that is available;
- under Section 6 of the *Care Act*, to co-operate in general, in exercising functions relating to adults with care and support needs and carers with support needs, between local authorities and other relevant bodies, such as NHS bodies in its area, other local authorities, and specified persons responsible for exercising functions in relation to social security, employment and training, probation services, prisons and the police;
- under Section 7 of the *Care Act*, to co-operate with the same relevant bodies in specific cases relating to individuals with needs for care and support;
- under the *Care and Support (Assessment) Regulations 2014*, to give information about the assessment process to the individual being assessed;
- under Regulation 5 of the *Care and Support (Assessment) Regulations 2014*, to ensure that a person carrying out an assessment has the skills, knowledge and competence to carry out the assessment in question and is appropriately trained. Local Authorities must therefore ensure that assessors carrying out assessments of people with autism have the skills, knowledge, competence and training to carry out such assessments.<sup>38</sup>

The 2015 statutory guidance also states that local authorities should allocate responsibility to a named joint commissioner/senior manager to

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<sup>38</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p18

lead commissioning of care and support services for adults with autism.<sup>39</sup>

Local commissioning plans should describe how local authorities will make sure that adults with autism are able to access direct payments (where appropriate).<sup>40</sup> Individuals who qualify may choose to have either a direct payment or 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.

Under the *Health and Social Care Act 2012*, local authorities have a duty to provide direct payments for people who qualify for social care services. The *Care Act 2014* introduced a legislative basis for personal budgets for social care. The 2010 Government's [Mandate to NHS England](#) states that from 2015 personal health budgets, including direct payments for healthcare, should be available for anyone who could benefit from one.<sup>41</sup>

The statutory guidance also states that people with autism 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.<sup>42</sup>

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<sup>39</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p29

<sup>40</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p29

<sup>41</sup> Department of Health, [The Mandate: A mandate from the Government to NHS England: April 2015 to March 2016](#), March 2014, p11

<sup>42</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p29

## Children’s social services

Under section 17 of the *Children Act 1989* as amended, disabled children are among those who are classed as “children in need”, where the phrase “disabled” means if a child is “blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed”.

A local authority is responsible for assessing whether a child is need, and for children in need a range of services may be provided by a local authority to support the child and their family, as set out in Schedule 2 of the *Children Act 1989* (as amended).

In terms of the level of statutory support that a local authority needs to provide to children with autism, the Family Rights Group (FRG), a charity, notes in an advice sheet entitled [Family Support:](#)

Can I decide what support my child gets?

Not exactly. Generally, families don’t have the right to insist on a particular type of support being provided and, in practice, final decisions on what help will be offered to meet the assessed needs of children in need, are often made at internal funding panels within Children’s Services. You won’t be invited to this meeting.

Whatever help is offered, social workers are expected to agree a plan for support with the child and their family and it is good social work practice for the plan to be provided in writing and signed by both the family and the social worker.

However, there are some circumstances when families do have a right to support for their children:

- Families of eligible disabled children have a right to direct payments ... ; and
- Families of children with special educational needs who have an education, health and social care plan (EHC plan) have a right to the support identified in the statement/plan for their children.<sup>43</sup>

During the debate on 21 March 2019, Members raised issues with securing adequate care plans. 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.<sup>44</sup>

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

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<sup>43</sup> Family Rights Group, [Family Support](#), March 2019, pp21–22

<sup>44</sup> [HC Deb 21 March 2019 c1276](#)

## 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 (e.g. 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](#) 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 that 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, 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:

5.32 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:

## 21 Autism – overview of policy and services

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

5.33 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.<sup>45</sup>

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:

**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) 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

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<sup>45</sup> Department for Education, [Special educational needs and disability code of practice: 0 to 25 years](#), January 2015, p85 and p97

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.<sup>46</sup>

Library Briefing 7020 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.

## 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.

### 4.3 Teachers

Teachers are required to have a clear understanding of the needs of pupils with SEND, including autism, as part of the [Teachers' standards](#). In July 2016 the Department for Education adopted a [framework of core content for initial teacher training](#), which gives direction to training providers on what should be prioritised to ensure that 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

<sup>46</sup> [HL4113 \[Written Question\] 27 December 2017](#)

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.

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 stated that the Trust had trained 175,000 staff “to encourage a whole school approach to supporting children and young people with autism.” He added that the Department had extended the contract with the Trust for another two years in March 2018.

## 4.4 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](#). The report recommended that 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. The report was [debated](#) in the House of Commons on 6 February 2018.<sup>47</sup>

In May 2018, Lord Agnew [stated](#) that the Government was “carefully considering the recommendations [of the report], including creating a national autism strategy.”

On 5 December 2018, the Minister Nadhim Zahawi, issued a [formal response](#) to the APPG’s [report](#) with responses to the recommendations around autism awareness and training in schools, collecting data to improve planning and making the SEND system more accountable.<sup>48</sup> He acknowledged the “important” recommendations of the report and stated the Government is in the progress of addressing “many” of them. One recommendation in particular was regarding autism awareness and training of school staff, the Minister stated that 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 that the Government’s Adult Autism Strategy, [Think Autism](#) would be extended to cover children.<sup>49</sup>

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<sup>47</sup> [HC Deb 6 February 2018 c1465](#)

<sup>48</sup> Nadhim Zahawi’s Letter, 5 December 2018: [Download a PDF](#)

<sup>49</sup> Nadhim Zahawi’s Letter, 5 December 2018: [Download a PDF](#)

## 4.5 Permanent and fixed term exclusions of pupils with ASD

The most useful measure for assessing the prevalence of school exclusions among different pupil groups is the exclusion rate. This is calculated by expressing the number of exclusions as a percentage of all pupil enrolments sharing the same characteristic.

The latest Department for Education (DfE) exclusion statistics are for the 2016/17 school year. These figures are for state-funded primary, secondary and special schools. They show:

- Pupils with an identified primary SEN need of Autistic Spectrum Disorder (ASD) had a **permanent exclusion rate of 0.12 per cent** (125 exclusions for approximately 108,400 pupils with ASD as their primary SEN need). This is above the permanent exclusion rate for all pupils without identified SEN, nationally – **0.06 per cent**. Pupils with social, emotional and mental health difficulties had the highest rate of permanent exclusion, at **1.09 per cent**.
- In terms of pupils experiencing **one or more fixed term exclusions**, the rate for those with ASD as their primary SEN need was **4.46 per cent**. This is higher than the one or more fixed term exclusion rate nationally for pupils with no identified SEN, of **1.63 per cent**. Again, pupils with social, emotional and mental health difficulties as their primary SEN need had the highest rate, at **17.46 per cent**.<sup>50</sup>

### 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.<sup>51</sup>

#### Timpson review

In March 2018 the Government established a [review of school exclusions practice](#), led by the former Children's Minister Edward Timpson. The review has not yet been published.

The review is in part a response to concerns as to why some children with particular characteristics, such as SEN, are excluded at higher rates than other children. The Schools Minister Nick Gibb has stated that the review "will consider how schools use exclusion overall and how this impacts their pupils, and in particular, why some groups of pupils are more likely to be excluded from school. It will also consider practice in relation to behaviour management and alternative interventions schools take in place of exclusion."<sup>52</sup>

#### Off-rolling

Related concerns about children leaving school rolls are discussed in the Library briefing paper [Off-rolling in English schools](#), CBP 8444.

<sup>50</sup> [Permanent and fixed-period exclusions in England: 2016 to 2017](#), Department for Education, July 2018.

<sup>51</sup> Department for Education, [Exclusion from maintained schools, academies and pupil referral units in England](#), July 2017, p9

<sup>52</sup> [PO 163072, 20 July 2018](#)



## 5. Employment policies

Although the Government does not collect data specifically on employment rates for people with Autistic Spectrum Conditions, the Department of Health have said that adults with autism are significantly underrepresented in the labour market.<sup>53</sup> The National Autistic Society estimates that only 16% of working-age people with autism are in full time employment, and only 32% are in some kind of paid work. They also report that 79% of people with autism on out-of-work benefits want to work.<sup>54</sup>

The Government is considering how it can collect robust data on the employment rate for autistic people.<sup>55</sup>

### 5.1 Recent developments

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

They 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”.

The DWP has also worked with Autism Alliance UK to produce an [Autism and Neurodiversity toolkit](#). The aim of this toolkit is to support awareness and understanding of Autism Spectrum Conditions and provide guidance to support people with autism into employment. The two organisations also worked together to deliver an Autism training programme to over 1,200 staff members in Jobcentre Plus.<sup>56</sup>

The Government has reported that it is currently unable to assess the effectiveness of this training due to the lack of robust employment figures for autistic people.<sup>57</sup>

A number of autism support groups worked with the DWP to develop an ‘[About Me](#)’ Disability Passport. The aim of the passport is to improve the experience for people with autism (or other ‘invisible’ conditions) when visiting job centres, interviews and work placements.<sup>58</sup>

In 2015, the Government set up an Access to Work Hidden Impairments Specialist team to provide employment support to those with hidden impairments such as autism. People with hidden impairments are offered an Access to Work holistic workplace assessment to assess the

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<sup>53</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p51

<sup>54</sup> National Autistic Society, [Our Employment Campaign](#)

<sup>55</sup> [PO 203312](#), 8 January 2019

<sup>56</sup> [PO 7308](#), 12 September 2017

<sup>57</sup> [PO 203312](#), 8 January 2019

<sup>58</sup> Autism East Midlands, [New Disability Passport & Autism and Neurodiversity Toolkit launches](#), 27 March 2017

support they require in the workplace, and the Access to Work advisor will help put these support plans in place. This team supported 2,150 people in 2017.<sup>59</sup>

In addition to this, in December 2017 the DWP stated 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 autism, into real jobs at the going rate of pay, with support for both individual and employer. This is currently being tested in nine local authorities.<sup>60</sup>

In January 2016, the DWP set out areas of work that had been put in place to help adults on the autism spectrum into work:

- the development of an Autism/ Hidden Impairment Network across Jobcentre Plus;
- the expansion of the Access to Work Mental Health specialist advisory team to cover people with autism and associated hidden impairment conditions;
- work to implement autism specific opportunities on LMS, Jobcentre Plus's IT system;
- the introduction of a Job-Shadowing Work Placement Initiative for young disabled people (65% of participants in the first tranche had autistic spectrum conditions)
- The formation of an Autism Taskforce involving disability organisations and disabled people.<sup>61</sup>

In December 2018, the Government announced a new support programme aimed at helping long-term unemployed disabled people find work. The Intensive Personalised Employment Support programme will provide personalised support for those who are at least a year away from moving into work. This programme will roll out in 2019 and will support those on the autism spectrum.<sup>62</sup>

During the debate on 21 March 2019, the Minister commented on the need to improve employment prospects for people with autism:

The hon. Member for Bristol West (Thangam Debbonaire) and many other Members highlighted the need to do more to support autistic people into employment. It is a lost opportunity all round that only a relatively small number of autistic people are in work either full time or part time. Through the Disability Confident scheme, we are helping employers to promote the talents and abilities of autistic people, and Access to Work has a hidden impairments group that gives guidance to employers.<sup>63</sup>

There is information on [Disability Confident](#) online.

## 5.2 Think Autism

In March 2014, the DWP hosted an event prior to the publication of *Think Autism* in partnership with the Department of Health and the

<sup>59</sup> [PO 201149](#), 18 December 2018

<sup>60</sup> [PO 119261](#), 18 December 2017 and [PO 226195](#), 4 March 2019

<sup>61</sup> [PO 23990 \[on Employment: Autism\], 28 January 2016](#)

<sup>62</sup> Ibid

<sup>63</sup> [HC Deb 21 March 2019 c1304](#)

National Autistic Society. Discussions took place on ways to improve DWP services for people with autism and recommendations were made which helped to develop an Autism Strategy Action Plan, which became part of *Think Autism*. That plan focused on three strategic areas:

- autism awareness training for DWP staff/managers;
- promotion of the autism agenda to the employment support provider community to ensure that reasonable adjustment solutions are identified/ implemented at the earliest possible stage;
- promotion of the autism agenda to the business community, seeking to increase work opportunities for people with autism and associated hidden impairment conditions.

The DWP subsequently undertook an internal survey to help Jobcentre Plus managers assess their local capacity to fully support people with autism and associated hidden impairment conditions. The survey enabled DWP to capture information that can be used to better support the development of improved services for claimants. Utilising the findings from the survey, DWP reported that it was working in collaboration to:

- build an Autism Network across all Jobcentre Plus offices, to be completed during 2015/16 and 2016/17;
- upskill the autism knowledge and awareness of staff involved in the Personalisation Pathfinder pilots, to be completed during 2015/16;
- develop an autism e-learning tool for staff/managers, to be completed in 2016/17.<sup>64</sup>

In the summer of 2015, the DWP and the Department of Health also established a new unit to improve employment outcomes for people with health conditions and who are disabled, in order to contribute towards halving the disability employment gap. The Work and Health Joint Unit was to explore how best to support people with autism to find and stay in work, while also improving their health.<sup>65</sup>

## Statutory guidance 2015

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

### 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’;

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<sup>64</sup> Department of Health, [Progress Report on Think Autism: the updated strategy for adults with autism in England](#), January 2016, p60

<sup>65</sup> Department of Health, [Progress Report on Think Autism: the updated strategy for adults with autism in England](#), January 2016, p61

- 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.<sup>66</sup>

### 5.3 1 million more disabled people in employment by 2027

The Conservative Party 2017 manifesto pledged to get “1 million more people with disabilities into employment over the next ten years”.<sup>67</sup>

To meet this target there would have to be 4.5 million people in employment with disabilities by 2027, an increase of almost 600,000 people from current levels.

In November 2017, the Government set out its strategy on how it intends to get a million more disabled people into employment in the [Improving lives: the future of work, health and disability](#) White Paper. The strategy is partly based on supporting disabled people and people with long-term health conditions to find work, but also to provide investment to support these people to stay in work.

The Library briefing paper [People with disabilities in employment](#) provides a summary of the policies and proposals in the White Paper.

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<sup>66</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#). March 2015, p51

<sup>67</sup> Conservative Party, [Forward Together: Our plan for a stronger Britain and a prosperous future](#), p57

## 6. Welfare and benefits

People with autism may be entitled to a range of different benefits. This includes income-replacement benefits, such as [Employment and Support Allowance \(ESA\)](#) and [Universal Credit](#) or benefits to help with the extra costs of a disability, such as [Disability Living Allowance \(DLA\)](#) which is being replaced by [Personal Independence Payment \(PIP\)](#) for working-age adults.

### 6.1 Welfare changes

People with autism may be affected by recent welfare changes, including changes provided for in the [Welfare Reform and Work Act 2016](#).

#### Employment and Support Allowance

Employment and Support Allowance (ESA) replaced incapacity benefits for new claimants from 27 October 2008. It replaced Incapacity Benefit, Severe Disability Allowance and Income Support for people judged incapable of work.

To be eligible for ESA, a person must undergo a Work Capability Assessment (WCA). Claimants are assessed to determine whether they have a “limited capability for work”, and also whether they are capable of engaging in “work-related activity.” This second part of the assessment determines whether the person is placed in the “Support Group” or the “Work-Related Activity group”. For claimants placed in the Work-Related Activity Group, access to the full rate of benefit may be conditional on participation in work focused interviews and mandatory “work-related activity”, such as work experience or training programmes. Claimants are not however expected to apply for jobs or undergo medical treatment.

The *Welfare Reform and Work Act 2016* introduced changes to ESA. Since April 2017, new Employment and Support Allowance claimants who are placed in the “Work Related Activity Group” (WRAG) are no longer eligible for the additional Work-Related Activity Component, currently worth £29.05 a week. The corresponding limited capability for work element in Universal Credit has also been abolished for new claims. The changes only affect new claims from that date – people who were already getting the ESA Work-Related Activity Component or the UC limited capability for work element at April 2017 can continue to receive it.

An overview of ESA and the changes to the WRAC is available in the Library briefing note [Abolition of the ESA Work-Related Activity Component](#) CBP-7649.

#### The assessment process

Health professionals undertaking WCAs are required to undergo training in order to conduct assessments of claimants with autism spectrum disorders. The following [response](#) to a parliamentary question in November 2017 provides further details:

**Thangam Debbonaire:** To ask the Secretary of State for Work and Pensions, whether people administering work capability assessments are required to undertake training on autism and autistic spectrum disorders; and if he will make a statement.

**Sarah Newton:** 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.<sup>68</sup>

The [Work Capability Assessment Handbook](#) for Healthcare Professionals highlights that some of the activities assessed during the WCA may be particularly difficult for an individual with autism to undertake. For example, one of the activities that is tested as part of the WCA is an individual's ability to cope with change, with points awarded to individuals assessed as meeting the following descriptors:

- Cannot cope with change to the extent that day to day life cannot be managed – 15 points
- Cannot cope with minor planned change (such as a pre-arranged change to the routine time scheduled for a lunch break), to the extent that overall, day to day life is made significantly more difficult – 9 points
- Cannot cope with minor unplanned change (such as the timing of an appointment on the day it is due to occur), to the extent that, overall, day to day life is made significantly more difficult – 6 points
- None of the above applies – 0 points.

The Handbook states that this activity is intended to include difficulties that people with autism spectrum disorder may encounter:

This activity reflects the flexibility needed to cope with changes in normal routine. It is intended to include difficulties that may be encountered by people with moderate/severe learning disability, autistic spectrum disorder, brain injury, OCD, severe anxiety or psychotic illness. It is not intended to reflect simple dislike of changes to routine, but rather the inability to cope with them.

A further activity concerns an individual's ability to cope with social engagement due to cognitive impairment or mental disorder, with points awarded to individuals assessed as meeting the following descriptors:

- Engagement in social contact is always precluded due to difficulty relating to others or significant distress experienced by the claimant – 15 points
- Engagement in social contact with someone unfamiliar to the claimant is always precluded due to difficulty relating to

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<sup>68</sup> [Written question - 112878, 14 November 2017](#)

others or significant distress experienced by the claimant – 9 points.

- Engagement in social contact with someone unfamiliar to the claimant is not possible for the majority of the time due to difficulty relating to others or significant distress experienced by the claimant – 6 points
- None of the above applies – 0 points

The Handbook states that those with autism may have problems in this area:

This activity is intended to reflect a significant lack of self-confidence in face-to-face social situations that is greater in its nature and its functional effects than mere shyness or reticence. Clarifications from the DWP confirm that the ability to interact must be in person rather than through any “virtual face to face interaction” such as Skype. Those with conditions such as significant anxiety, autism, personality disorder, psychosis, significant depression or learning disability may have problems in this area.

It reflects levels of anxiety that are much more severe than fleeting moments of anxiety such as any person might experience from time to time.<sup>69</sup>

### The Improving Lives Green and White papers

Alongside the changes to the WRAC in 2016, the Government made an announcement to provide “new funding for additional support to help claimants return to work.” The subsequent October 2016 Green Paper, [Improving Lives](#)<sup>70</sup> contained a series of measures to provide additional help for people with health conditions and disabilities get into work. They included:

- An extra 300 Disability Employment Advisers and around 200 new Community Partners with disability expertise to support Jobcentre work coaches to offer tailored employment support as part of a new Personal Support Package for people with health conditions
- investing £115 million of funding to develop new models of support to help people into work when they are managing a long-term health condition or disability.

In the 2017 *Improving Lives* White Paper, published in [response](#) to the Green Paper consultation, the Government stated that employment support for those with learning disabilities and other health conditions should be available to all groups who needed it including groups with the lowest employment rates, such as those people with ‘neurodiverse conditions’ like autism.<sup>71</sup> The Government has proposed a 10-year

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<sup>69</sup> DWP, [Work Capability Assessment handbook: for healthcare professionals](#), February 2019, p134

<sup>70</sup> Department for Work & Pensions and Department of Health, *Improving Lives – The Work, Health and Disability green paper*, Cm 9342, October 2016

<sup>71</sup> Department for Work & Pensions and DoH, [Improving Lives: The Future of Work, Health and Disability](#), Cm 9526, November 2017; p9

strategy to “break down employment barriers for disabled people and people with health conditions”.<sup>72</sup> The strategy includes proposals to:

- Improve advice and support for employers by working with them and disabled people, as well as other stakeholders;
- Introduce an “enhanced training offer” for DWP work coaches – developed in conjunction with a national mental health charity – to help them work with benefit claimants with mental health conditions;
- Provide an additional £39 million to more than double the number of employment advisors in an existing NHS programme treating people with depression and anxiety disorders.

On 28 March 2019 the National Audit Office published a report looking at the DWP’s strategy, working across government, for supporting disabled people to work, and what is currently being achieved.<sup>73</sup>

## Personal Independence Payment

The *Welfare Reform Act 2012* provided that Disability Living Allowance (DLA) would be replaced with Personal Independence Payment (PIP) for working-age disabled adults starting from April 2013. The changes will affect existing working age DLA claimants, as well as those making a new claim. For those existing DLA claimants found not to satisfy the conditions for PIP on reassessment, DLA will stop. Existing DLA claimants are being reassessed for PIP. PIP was introduced for new claims from April 2013, and it was originally expected that by late 2017 remaining working age DLA claimants would have been “invited” to claim PIP, but the Department for Work and Pensions now expects that full roll-out of PIP will not be achieved until October 2020.

PIP is the “extra costs” benefit for people of working age who have daily living and/or mobility needs as a result of a disability or health condition. PIP does not depend upon the person being diagnosed as having a particular health condition or disability, but on how their condition or disability affects what they can and cannot do, as determined by the PIP assessment. The assessment for PIP looks at an individual’s ability to carry out a series of key everyday activities. The assessment considers the impact of a claimant’s health condition or impairment on their functional ability rather than focusing on a particular diagnosis.

Further detail on PIP and the assessment process is available in the Library briefing paper [Mental health and the benefits assessment process](#).<sup>74</sup>

<sup>72</sup> Department for Work & Pensions and DoH, [Improving Lives: The Future of Work, Health and Disability](#), Cm 9526, November 2017

<sup>73</sup> NAO, [Supporting disabled people to work](#), HC 1991 2017-19. See also Commons Library briefing CBP-7540, [People with disabilities in employment](#), 15 February 2019

<sup>74</sup> CDP-2019-0005, 21 January 2019



### **Personal Independence Payment (PIP) statistics**

As of January 2019, **79,305** recipients of PIP had an autistic spectrum disorder as their main disabling condition – these accounted for 3.9% of all PIP recipients.

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

- Autism (56,382 recipients, 71.1%)
- Asperger's syndrome (22,634 recipients, 28.5%)
- Retts disorder (292 recipients, 0.4%)

78% of PIP recipients with an autistic spectrum disorder as their main disabling condition are male (62,118).

These figures 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 (35,458 recipients).

<b>Personal Independence Payment (PIP) claims in payment to people with autistic spectrum disorders as main disabling condition, January 2019</b>				
	Total: autistic spectrum disorders	of which:		
		Autism	Asperger syndrome	Retts disorder
<b>Total</b>	<b>79,305</b>	<b>56,382</b>	<b>22,634</b>	<b>292</b>
<i>of which: type of award:</i>				
Daily Living - Enhanced	64,111	48,331	15,494	282
<i>of which - in combination with:</i>				
Mobility Award - Enhanced	35,458	30,084	5,112	257
Mobility Award - Standard	17,971	12,079	5,880	10
Mobility Award - Nil	10,675	6,169	4,502	10
Daily Living - Standard	13,605	7,192	6,406	6
<i>of which - in combination with:</i>				
Mobility Award - Enhanced	909	526	381	..
Mobility Award - Standard	4,479	2,527	1,958	..
Mobility Award - Nil (III)	8,212	4,139	4,065	..
Daily Living - Nil	1,593	854	732	5
<i>of which - receiving:</i>				
Mobility Award - Enhanced	249	146	102	..
Mobility Award - Standard	1,305	687	617	5
Mobility Award - Nil (a)	38	18	21	..

**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 claims in payment dataset

[Link to source](#)

People with autistic spectrum disorders have varying success when it comes to applying for PIP. Between 2013 and 2019, 58% of new claims made by those with a recorded main disabling condition of autism were awarded PIP, while 42% were disallowed. For those with a main disabling condition of Asperger's syndrome, the award rate for new claims was 50%.

For people who were previously on Disability Living Allowance (DLA) and who underwent reassessment to determine entitlement to PIP, 79% of those with a main disabling condition of autism were awarded PIP. The award rate for reassessed DLA claimants with Asperger's syndrome was 57%.

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

April 2013 to January 2019 inclusive

	Total	<u>of which: outcome (a)</u>			
		Awarded		Disallowed	
<b>New claim applications</b>					
All claims where disabling condition is recorded	1,866,130	1,136,435	61%	729,694	39%
<i>of which - main disabling condition:</i>					
Autistic spectrum disorders: Total	25,012	13,509	54%	11,509	46%
<i>of which:</i>					
Autism	12,898	7,497	58%	5,401	42%
Asperger syndrome	12,092	5,991	50%	6,101	50%
Retts disorder	26	19	73%	10	38%
<b>DLA-to-PIP reassessment cases</b>					
All claims where disabling condition is recorded	1,360,129	1,069,866	79%	290,265	21%
<i>of which - main disabling condition:</i>					
Autistic spectrum disorders: Total	82,073	59,615	73%	22,455	27%
<i>of which:</i>					
Autism	56,807	45,089	79%	11,714	21%
Asperger syndrome	24,973	14,251	57%	10,722	43%
Retts disorder	290	278	96%	13	4%

#### 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](#)

### Legal challenge to changes to the PIP Regulations

In March 2017 the DWP introduced regulations to reverse the effect of two Upper Tribunal judgments relating to the PIP eligibility criteria from November 2016. The [Social Security \(Personal Independence Payment\) \(Amendment\) Regulations 2017](#)<sup>75</sup> were introduced to amend the PIP eligibility criteria from 16 March 2017 to “clarify the drafting and

<sup>75</sup> [SI 2017/194](#)

reverse the effect” of the Upper Tribunal judgments.<sup>76</sup> The Government claimed that the judgments had interpreted the Schedule setting out the assessment criteria “in ways which the Government did not intend.” The regulations amended the PIP assessment criteria to make it clear that people who found it difficult to make journeys due to psychological distress (rather than a physical or mobility issue) were entitled to less support under PIP.

Further details of the judgments and the effect of the regulations is set out in the Library briefing paper: [Changes to the Personal Independence Payment eligibility criteria](#).

In the subsequent High Court case of *RF v the Secretary of State for Work and Pensions & Others*<sup>77</sup>, the claimant brought judicial review proceedings against the Secretary of State for Work and Pensions seeking to quash parts of the 2017 regulations on the basis that they were unlawful. RF’s claim was supported by The National Autistic Society, Inclusion London, Revolving Doors and Disability Rights UK, Mind and the Equality and Human Rights Commission (EHRC).

On 21 December 2017, the High Court ruled that the *Social Security (Personal Independence Payment) (Amendment) Regulations 2017* (GB) were unlawful because they discriminate 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 and should have consulted before making them.<sup>78</sup>

Responding to the judgment, Sarah Lambert, Head of Policy and Public Affairs at the National Autistic Society said:

This ruling is hugely significant for many autistic adults, who struggle to make new and unfamiliar journeys because of anxiety and psychological distress.<sup>79</sup>

### ***The Government response to the RF judgment***

On 19 January 2018 the Government announced that it would not contest the High Court’s decision in *RF*, and that it would also drop its appeal against the original Upper Tribunal decision that had prompted the change to the regulations.<sup>80</sup> The Secretary of State for Work and Pensions said that the DWP would “take all steps necessary to implement the judgment in *MH* in the best interests of our claimants, working closely with disabled people and key stakeholders over the coming months.”<sup>81</sup>

The DWP is reviewing all 1.6 million existing PIP awards as well as PIP claims submitted since the original Upper Tribunal judgment in

<sup>76</sup> *MH v Secretary of State for Work and Pensions (PIP)* [2016] UKUT 531 (AAC) and *Secretary of State for Work and Pensions v LB (PIP)* [2016] UKUT 530 (AAC)

<sup>77</sup> [2017] EWHC 3375 (Admin)

<sup>78</sup> Further information can be found in the Public Law Project press release, [High Court finds 2017 Personal Independence Payment \(PIP\) Regulations unlawful](#), 21 December 2017.

<sup>79</sup> NAS, [Victory in legal case on Personal Independence Payment](#), 21 December 2017

<sup>80</sup> *MH v Secretary of State for Work and Pensions* [2016] UKUT 0531 (AAC)

<sup>81</sup> [Written Statement HCWS414](#), 19 January 2018

November 2016 to see who could be affected. On 25 June 2018, the Government announced that the review was underway, and that new guidance required to implement the change had been published.<sup>82</sup>

It was 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 than would otherwise have been the case.<sup>83</sup>

The DWP Minister Sarah Newton updated the House on progress reviewing cases affected by the Upper Tribunal decision in MH in a [written statement on 20 December 2018 \(HCWS1224\)](#):

My Written Statement of 25 June 2018 (HCWS793) informed the House that my Department had begun an exercise to identify anyone who may be entitled to more support under PIP as a result of the MH and RJ decisions of the Upper Tribunal. The MH decision broadened the interpretation about how symptoms of overwhelming psychological distress should be assessed for the purpose of mobility activity 1 in PIP. The RJ decision concerned how the Department considers a claimant to be carrying out an activity safely and whether they need supervision to do so. I committed to regularly updating the House of developments regarding this administrative exercise.

The Department has today published an ad hoc release of Management Information on the administrative exercise: <https://www.gov.uk/government/collections/dwp-ad-hoc-analyses#2018>

As at 23 November 2018, 140,000 cases had been cleared, of which 1,000 had been paid arrears. The average payment made is approximately £4,500. We are monitoring the numbers of, and reasons for, revised awards closely and making regular quality checks in order to ensure that our decision making is accurate and fair.

Given the complexity of the exercise we have started at a relatively small scale to test our processes and ensure they are effective before ramping up. At the same time we have recruited over 250 additional staff to increase resources available for this exercise, with more to follow over the coming months.

In addition, we are redirecting resource from other areas of PIP. This means the administrative exercise will conclude in 2020. Some DLA to PIP reassessments that would have taken place in 2019/2020 will move to the following year. I believe that prioritising cases where claimants are entitled to arrears is the correct approach.

Further information on how the administrative exercise is being undertaken is set out in an updated Frequently Asked Questions. I will deposit a copy of this document in the Library.<sup>84</sup>

Further details of the review process are given in the FAQs Deposited Paper.<sup>85</sup>

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<sup>82</sup> [Written Statement HCWS793](#), 25 June 2018

<sup>83</sup> Office for Budget Responsibility, [Economic and fiscal outlook](#), March 2018, para 4.112

<sup>84</sup> [Written Statement HCWS1224](#), 20 December 2018

<sup>85</sup> [DEP 2018-1299](#)

## 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.

Benefit and tax credit claimants not experiencing a change in circumstances will transfer to UC by a process known as “managed migration.” Under the latest Government plans, a managed migration pilot involving around 10,000 claimants will begin in July 2019. The DWP will then seek parliamentary approval for the main phase of managed migration, which is expected to get underway in late 2020 and be completed by December 2023.

Universal Credit rationalises support for disabled people and does not include any of the disability premiums currently payable with means-tested benefits. Disability organisations have expressed particular concern that the Severe Disability Premium (SDP) currently received by over half a million people will not be carried over into Universal Credit. In response to a High Court judgment in June 2018, the Government introduced regulations preventing people in receipt of SDP from moving onto UC until the final managed migration stage, when they can receive transitional protection. People who have already moved to UC and lost their SDP are to receive additional payments – both backdated and on an ongoing basis – although these may not fully compensate individuals for the amounts lost. Draft regulations providing for these “SDP transitional payments” (and for the managed migration pilot) are currently before Parliament. Further information can be found in Commons Library briefing CBP-8494, [Universal Credit and the Severe Disability Premium](#).

Most claimants are expected to make and manage their Universal Credit claim online. In its December 2018 report [Universal Credit: support for disabled people](#),<sup>86</sup> the Work and Pensions Committee noted that some disabled people would never be able to use all online systems independently and recommended that the DWP offer proactively ongoing support to claimants who cannot use the online system, and ensure the funding necessary to deliver this. In its response, the Government said that from 1 April 2019 the new “Universal Support; Help to Claim Universal Credit” service delivered by Citizens Advice and Citizens Advice Scotland would provide tailored assistance to those requiring additional support to make and manage their UC claim.<sup>87</sup>

All Universal Credit claimants will be required to agree 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.<sup>88</sup>

Unlike ESA, claimants for Universal Credit who are waiting for a Work Capability Assessment (WCA) will, with some exceptions, be subject to

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<sup>86</sup> HC 1770 2017-19

<sup>87</sup> [Universal Credit: support for disabled people: Government Response](#), HC 1998 2017-19, 5 March 2019

<sup>88</sup> [Explanatory Memorandum to the Universal Credit Regulations 2013](#), para 7.10

the all-work related requirements level of conditionality. These requirements should be personalised to their circumstances. The DWP stated that:

This approach is intended to support more claimants by keeping them in touch with the labour market to reduce the damage caused by labour market detachment.<sup>89</sup>

In its recent report, the Work and Pensions Committee recommended that UC claimants awaiting a WCA who can present a valid Fit Note should not be subject to any conditionality. In response, the DWP said that starting from summer 2019 it would “explore the possibility” of a general policy that conditionality would not be imposed on people before their WCA, but that it would remain the responsibility of the Work Coach to consider each case individually.

For further information on how Universal Credit will affect disabled people, see Commons Library Debate Pack CDP-2018-0278, [Impact of changes to disability support](#). The DWP have produced a guide on [Universal Credit if you have a disability or health condition](#).

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<sup>89</sup> Work and Pensions Select Committee, *Employment and Support Allowance and Work Capability Assessments*, 23 July 2014, HC 302-I 2014-15, [Ev 17 WCA0196](#)

## 7. The criminal justice system

Making sure that people with autism are understood and supported by the criminal justice system was one of the priority areas in *Think Autism*:

If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.<sup>90</sup>

The statutory guidance sets out legal duties and recommendations for local authorities, NHS bodies and Foundation Trusts for adults with autism who come into contact with the criminal justice system, and how they can support police, probation services, courts and prisons.<sup>91</sup> For example, the guidance states that local authority-based Community Safety Partnerships should be used as a forum to bringing agencies together to develop plans to support the Autism Strategy, and should include the local authority, police, probation, CCGs and the fire and rescue authority.

The Department of Health's 2016 progress report on *Think Autism* outlined work to better support people with autism in the criminal justice system:

A Cross-Criminal Justice System Government Group, chaired by the MoJ, was set up in spring 2014 and now meets quarterly to discuss work across the criminal justice system to improve services for people with autism, including progress with commitments under the autism strategy. Membership includes MoJ, the Home Office, the Crown Prosecution Service (CPS), the Youth Justice Board, the National Offender Management Service (NOMS), the National Police Chiefs' Council (NPCC) which was formerly the Association of Chief Police Officers or ACPO, DH and NHS England, as well as a number of special interest bodies (including NAS) and self-advocates. Meetings cover issues such as training and awareness, screening, reasonable adjustments, and the use of IT systems to better support people with autism.<sup>92</sup>

The 2016 progress report also outlines work undertaken by the Crown Prosecution Service, the College of Policing, the Police National Computer, the police service and other national bodies to identify and support people with autism in contact with the criminal justice system.<sup>93</sup>

Liaison and diversion services have been developed to identify people who may have specific needs such as people with mental health problems, a learning disability and autism, so that offenders can either be supported through the criminal system pathway or diverted into treatment, health and care services or other relevant interventions. The Government supports a policy of liaison and diversion.

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<sup>90</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives. the strategy for adults with autism in England: an update](#), April 2014, p7

<sup>91</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p55

<sup>92</sup> Department of Health, [Progress Report on Think Autism: the updated strategy for adults with autism in England](#), January 2016, p64

<sup>93</sup> See Department of Health, [Progress Report on Think Autism: the updated strategy for adults with autism in England](#), January 2016, p65



In March 2014, the Minister for Care Services made a commitment for a nationwide liaison and diversion service by 2017:

We have started to roll out the Government's liaison and diversion service, which I announced back in January. By 2017 we aim to have a nationwide service for people with mental health problems, autism and learning disabilities who end up in the criminal justice system, often inappropriately and unnecessarily. Getting people diverted to diagnosis, which Members have talked about, and to the right treatment can often prevent further offending and potentially thereby transform someone's life while protecting others.<sup>94</sup>

In March 2019, the Minister said roll-out would be completed by 2021:

In the initial police learning and development programme, police officers are already given training, and many police forces have developed their own. Liaison and diversion schemes are being rolled out with 100% coverage expected by 2021.<sup>95</sup>

The 2015 statutory guidance sets out legal duties that local authorities have for supporting people with autism in the criminal justice system:

Local Authorities must:

- Under the *Care Act*, from April 2015, assess the care and support needs of adults (including those with autism) who may have such needs in prisons or other forms of detention in their local area, and meet those needs which are eligible;
- Work with prisons and other local authorities to ensure that individuals in custody with care and support needs have continuity of care when moving to another custodial setting or where they are being released from prison and back into the community.<sup>96</sup>

In March 2015, the Ministry of Justice announced that it is encouraging prisons and young offender institutes in England and Wales to apply for the National Autistic Society's Autism accreditation. The accreditation process has a clear framework to help institutions and services work systematically towards good quality autism practice and is intended to improve rehabilitation support for prisoners with autism.<sup>97</sup>

The National Autistic Society has published: [Autism: A guide for police officers and staff](#).

The National Autistic Society also states that some people with autism may also be more vulnerable to criminal acts against them, due to difficulties with social interaction.<sup>98</sup> *Think Autism* sets out work being done to improve support for vulnerable or intimidated victims and witnesses to crime giving evidence to the police and courts, including

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<sup>94</sup> [HC Deb 5 March 2014, c307WH](#)

<sup>95</sup> [HC Deb 21 March 2019 c1305](#)

<sup>96</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p56

<sup>97</sup> Ministry of Justice, [Prisons seeking National Autistic Society help to improve support for prisoners](#), 27 March 2015

<sup>98</sup> National Autistic Society, [Position statement: crime and autism](#) [last accessed 2 April 2015]

information provided by the Crown Prosecution Service to help and support vulnerable victims and witnesses.<sup>99</sup>

On 30 January 2018, there was a debate on the [Criminal Justice System: Adults with Autism](#). The Library published a corresponding debate pack on the [Treatment of adults with autism by the criminal justice system](#), which goes into more detail.

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<sup>99</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, p20

## 8. Scotland, Wales and Northern Ireland

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

### 8.1 Scotland

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 with autism 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 with autism, 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.
- People with autism, 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 people with autism 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 how 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 [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.

During the debate on 21 March 2019, David Linden referred to the announcement by Scottish Mental Health Minister, Clare Haughey, on 19 March 2019 of a “complete review of mental health legislation and autism legislation.”<sup>100</sup>

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

## 8.2 Wales

In 2008, the Welsh Assembly Government published the [Autistic Spectrum Disorder \(ASD\) Strategic Action Plan for Wales](#). 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:

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

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<sup>100</sup> [HC Deb 21 March 2019 c1298](#)

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.<sup>101</sup>

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](#) outlines how the Welsh Government views its progress in implementing its strategy.

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

Paul Davies AM introduced the [Autism \(Wales\) Bill](#) on 13 July 2018.<sup>102</sup> The Bill did not proceed but it prompted the Welsh Government to issue the following detailed statement on 18 February 2019:

The National Assembly's scrutiny of the Autism (Wales) Bill provided a welcome and valuable opportunity to consider whether autism-specific legislation would add value to the current autism services available in Wales.

I recognise there will be many people who will be disappointed this Bill is not proceeding further. However, over the course of the last year, it has highlighted the everyday experiences of people with autism and their families and carers of their interaction with services in Wales – both good and bad.

As the National Assembly committees, which examined the legislation, acknowledged, the Welsh Government is reforming services. This improvement programme needs to be accelerated and the remaining gaps in provision need to be addressed.

I have been clear that although the Welsh Government does not support legislation at this time – we agree with the need to speed up the pace of improvement.

Many clinicians and professional organisations – including the Royal College of Psychiatrists; the Royal College of Speech and Language Therapists; the Royal College of Paediatrics and Child Health; the Royal College of Occupational Therapists; the Royal College of General Practitioners and the Welsh NHS Confederation – support the need to allow these reforms to become embedded and reviewed before considering new legislation.

We have all the laws and powers we need to drive reform – in the Social Services and Wellbeing (Wales) Act 2014 and the NHS (Wales) Act 2006; in the Future Generations Act 2015 and the Additional Learning Needs and Education Tribunal (Wales) Act 2018.

Our programme of reform includes the roll out of the national integrated autism service, which will be available in every region

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<sup>101</sup> Welsh Government, [New measures to improve autism services in Wales](#), 18 May 2015

<sup>102</sup> [National Assembly Research Service Briefing on the Autism \(Wales\) Bill](#), 2019

of Wales by April 2019. To make sure this service is addressing identified gaps in provision, an independent evaluation will be completed in the coming weeks and the preliminary findings will be available in February.

I have also commissioned a review of the barriers to reducing diagnostic waiting times and on how wider neurodevelopmental services can be aligned to address any emerging gaps in services for people with other or co-existing conditions. This will be completed by the end of March 2019.

To strengthen and underpin existing duties, we are consulting on proposals for a statutory Code of Practice on the Delivery of Autism Services under the Social Services and Wellbeing (Wales) Act 2014 and NHS (Wales) Act 2006.

The code will be delivered this year and will set out how local authorities and the NHS should adapt their services to meet autistic people's needs. Public engagement events have been organised in Llandrindod Wells, Swansea, Llandudno and Cardiff during February 2019 and the consultation is open until 1 March.

This code will have as much or greater force and remedies than the proposed Autism (Wales) Bill. In addition to existing local complaints procedures, the Welsh Government can directly intervene in both health and local authority services where services are found to be failing. The clear services standards the code will set out provide the context within which these powers can be used in the future.

In other areas we have already taken such action to issue warning notices to a local authority when services have not met expected standards. There are similar powers to intervene in health services which we have also used.

I understand many parents concerns about the support their children receive at school and college. We are consulting separately on the Additional Learning Needs Code and proposed regulations to support the implementation of the Additional Learning Needs and Education Tribunal (Wales) Act 2018. This consultation will end on 22 March.

The second annual report about the delivery of the ASD Strategic Action Plan, which will be published by June 2019, will provide an update about assessment waiting times; the development of referral pathways; updating housing management guidance; preparing for the roll out of the new additional learning needs system and improving data through the development of a GP autism register. It will also provide feedback on the delivery of the integrated autism service.

Our improvement work continues to be supported by the National Autism Team, which is hosted jointly by the Welsh Local Government Association (WLGA) and Public Health Wales. The team plays a vital role in facilitating collaboration, supporting service delivery and raising awareness of autism, including providing tools and resources.

Visits to the ASDinfo.wales website, which the team maintains, have increased by 30,000 since 2017, to more than 108,000 in 2018. More than 30,000 people have completed the ASD Aware scheme – 8,000 of these during 2018. Almost 4,500 primary school teaching staff have completed the Learning with Autism programme and more than 26,500 children are now Autism 'super heroes'. To ensure this support continues uninterrupted, I

have renewed staff funding for the National Autism Team until March 2022.

We have introduced a new 26-week waiting time standard for neurodevelopment assessments for children and young people, data will be published when it is available. This new standard will measure waiting times from referral to the first face-to-face appointment, rather than just signalling the start of assessment.

There will always be more to be done and the reforms we are putting in place need to be implemented with energy and pace. A national conference for autistic people, their parents and carers will be held on 3 April in Swansea aimed at improving wellbeing outcomes.

A further independent evaluation will be commissioned this year which will be based on the recommendations arising from the current evaluation and those made by Assembly Committees during the Autism (Wales) Bill's scrutiny. This additional work will provide us with the evidence we need to ensure our reforms are delivering for people with autism in Wales or whether we need to consider a change of course later in this Assembly term.

The Welsh Government has consulted on a [Code of Practice for the Delivery of Autism Services](#). Consultation closed on 1 March 2019.

## 8.3 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) was 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
- 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 and Strategy and Action Plan. The research argued that they “had failed to deliver on promises of help for autistic people, their families and carers.” The [report called](#) for the government to fulfil the obligations promised in 2011. Statistics on autism in Northern Ireland can be [found online](#).

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



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