

#### **Research Briefing**

28 April 2023

By Katherine Garratt, Laura Abreu Autism: Overview of policy and services

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# Summary

### What is autism?

The National Autistic Society describes autism as a developmental disability that affects how people communicate and interact with the world. Autism is a spectrum condition that affects people in different ways. Autistic people may have:

- Challenges with social communication and interaction
- Repetitive and restrictive behaviours
- Over- or under-sensitivity to noise, touch, smells or tastes
- Highly focused interests or hobbies

Some autistic people also have a learning disability.

### Terminology

This briefing uses <u>terminology recommended by the National Autistic</u> <u>Society</u>. It uses the term "autistic people" unless quoting text from another publication.

Autism is sometimes referred to as "autism spectrum disorder", "autistic spectrum disorder" or "autism spectrum condition". These terms are often used in relation to medical diagnoses and data reporting. Where these terms are used in the briefing, it is to reflect the data or text source they are referring to.

The term "neurodiversity" refers to the normal range of variation in the way people's brains work, including how they perceive and respond to the world. A person whose brain works differently from the "typical" person may refer to themselves as neurodivergent; some, but not all, autistic people identify as neurodivergent.

# The Autism Act 2009 and autism strategies

The <u>Autism Act 2009</u> requires the Government to introduce and keep under review an adult autism strategy. <u>Fulfilling and rewarding lives: the strategy</u> for adults with autism in <u>England</u> was published in 2010 and was accompanied by <u>statutory guidance for NHS organisations and local</u> <u>authorities</u> (updated in 2015).

<u>The strategy was refreshed in 2014</u>, and in 2021 the Government published a <u>new strategy for 2021-2026</u> including children and young people, alongside

adults, for the first time. It focuses on autism awareness, education, employment, health, reducing inpatient care, community support and the criminal justice system.

An <u>implementation plan for 2021-22</u> set out how the strategy would be funded in the first year. In February 2023 the Government said there is no confirmed publication date for an updated implementation plan. The Department of Health and Social Care (DHSC) is working on updating the statutory guidance.

### Health policy and autism

The <u>NHS Long Term Plan</u> (2019) includes objectives for improving access to autism diagnosis and post-diagnostic support, as well as improving autistic people's mental and physical health.

The National Institute for Health and Care Excellence (NICE) has said <u>people</u> <u>referred for an autism assessment should be seen within three months</u>. In July 2022, there were 130,000 people waiting for a clinical autism assessment. Most of these people (84%) had been waiting for 13 weeks or more.

The <u>Health and Care Act 2022</u> introduced a new legal requirement for all health and social care service providers registered with the Care Quality Commission to provide employees with training on autism and learning disabilities (called <u>Oliver McGowan Training</u>).

The Long Term Plan set a target to reduce inpatient provision for autistic people and people with a learning disability by 50% (compared to 2015 levels) and support more people in the community by 2023/24. In January 2023, 2,020 autistic people and people with a learning disability were inpatients, down 30% from 2,905 inpatients in March 2015. However, a higher proportion of inpatients were on the autism spectrum, compared to overall numbers, in 2023 compared to 2015.

In July 2022, the DHSC published an updated <u>Building the right support for</u> <u>people with a learning disability and autistic people: action plan</u>, focusing on six areas to develop community services and reduce reliance on inpatient mental health beds.

The Government also proposed in the Draft Mental Health Bill 2022 to amend the criteria for detention under the Mental Health Act, so a person could not be subject to long-term detention for treatment for autism or learning disability.

### Social care and autism

Under the Care Act 2014, local authorities have duties relating to the provision of adult social care services, which apply to everyone including autistic adults. <u>Guidance for social workers</u> (PDF) is provided in a Governmentcommissioned Capabilities Statement. The Government is also rolling out a qualification for commissioners who work with autistic people. <u>Guidance on</u> <u>identifying local demand and developing services for autistic people</u> was published alongside the 2021-26 autism strategy.

In December 2021, the Government set out its plans for wider reform of adult social care in a white paper: <u>People at the Heart of Care: adult social care</u> reform white paper. In the <u>Autumn Statement 2022</u>, the Chancellor said the reforms would be delayed by two years.

### Education and autism

Under the <u>Children and Families Act 2014</u>, local authorities have a duty to identify needs in their area and commission services to support children and young people with special educational needs and disabilities (SEND). In January 2015, the Government published a <u>SEND code of practice</u>.

In March 2022, the Government published the results a <u>review of the SEND</u> <u>system's effectiveness</u> as a green paper for consultation. In March 2023, the Government published a <u>SEND and alternative provision improvement plan:</u> <u>right support, right place, right time</u>. The plan included intentions to establish national standards for SEND and alternative education provision and to standardise and digitise Education, Health and Care Plans.

Teachers are required to have a clear understanding of the needs of pupils with SEND, including autism, as part of the <u>Teachers' standards</u>. The 2021-26 autism strategy commits £600,000 for staff autism training and professional development in schools and colleges in 2021/22.

### **Employment and autism**

According to the Office for National Statistics, 29.9% of disabled people on the autism spectrum were in employment in 2021/22, compared to 54.3% of all disabled people and 81.1% of non-disabled people.

The National Autistic Society has said that <u>77% of unemployed autistic people</u> want to work.

The 2021-26 autism strategy says that by 2026, the Government will have improved support to help autistic people find and stay in work. This will be

through improving employer awareness of autism, improving the accessibility of employment programmes and making Jobcentres more autism-inclusive.

In April 2023, the Department of Work and Pensions announced a <u>review</u> considering how to improve autistic people's employment prospects.

Schemes aimed at supporting autistic people with employment include the Disability Confident scheme, the Access to Work programme, the Intensive Personalised Employment Support programme and the Local Supported Employment initiative.

Under the Equality Act 2010, employers must make reasonable adjustments to support disabled job applicants and employees.

### Social security and autism

Autistic people may be entitled to a range of benefits including benefits to help with the extra costs of a disability. These might include <u>Personal</u> <u>Independence Payment (PIP)</u>, which is replacing <u>Disability Living Allowance</u> (DLA) and 'Income replacement' benefits to cover day-to-day living costs, such as Universal Credit (UC).

The Department for Work and Pensions published <u>Transforming support: the health and disability White Paper</u> alongside the Spring Budget on 15 March 2023. This included an aim to make "the [benefit] claim journey more of a two-way conversation", communicate decisions in a simple and compassionate way and get more decisions right first time.

The white paper outlined plans to abolish the Work Capability Assessment. This assessment helps determine whether someone is entitled to extra amounts in UC and Employment and Support Allowance, as well as any workrelated requirements people must meet as a condition of their claim.

Under these plans a new "UC health element" will be available to claimants who also receive PIP, replacing the existing extra amount for those assessed as having "limited capability for work and work-related activity."

### The criminal justice system and autism

The 2021-26 autism strategy says autistic people may be over-represented among people who come into contact with the criminal and youth justice systems, as victims, witnesses or defendants. It references evidence that autistic people often have poor experiences of these systems, can find prison environments overwhelming and that staff do not always understand their needs. The strategy commits to developing a better view of existing provision for neurodivergent adults, including autistic adults, through a call for evidence on neurodiversity in the criminal justice system.

<u>Neurodiversity in the criminal justice system: A review of evidence</u> was published in July 2021. The review found too little is being done to understand and meet the needs of neurodiverse people in the system.

The Ministry of Justice responded by publishing a <u>neurodiversity action plan</u> (PDF) in June 2022, which was <u>updated in January 2023</u> (PDF). The updated plan says neurodiversity support managers have been introduced in prisons and the Government plans to have one in every prison across England and Wales by 2024. It also notes autism accreditation is being promoted across the prison estate.

### Devolved executives

This paper focuses on policies in England. Health is a devolved matter so each of the devolved executives is responsible for developing its own policy. Section 9 provides an overview of autism strategies implemented in Scotland, Wales and Northern Ireland. 1

# Government policies on autism in England

### 1.1 Autism Act 2009 and 2010 strategy

The <u>Autism Act 2009</u> placed statutory requirements on the Government to publish an adult autism strategy and associated statutory guidance for local authorities and NHS bodies.<sup>1</sup>

The 2009 Act was a Private Member's Bill introduced by Cheryl Gillan with backing from the National Autistic Society and other autism charities.

The Department of Health (DH) published the first autism strategy for England in March 2010 - <u>Fulfilling and rewarding lives: the strategy for adults</u> 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.
- 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 DH published <u>statutory guidance for local authorities</u> and NHS organisations to accompany the strategy.<sup>4</sup>

<sup>&</sup>lt;sup>1</sup> Autism Act 2009 (legislation.gov.uk)

<sup>&</sup>lt;sup>2</sup> DH, <u>Fulfilling and rewarding lives': the strategy for adults with autism in England</u>, 3 March 2010 (now archived)

<sup>&</sup>lt;sup>3</sup> As above, pp18-19

<sup>&</sup>lt;sup>4</sup> DH, Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy, 17 December 2010 (now archived)

# 1.2 Think autism strategy 2014

In April 2014, the DH published an update to the 2010 strategy: <u>Think autism -</u> <u>fulfilling and rewarding lives, the strategy for adults with autism in England:</u> <u>an update</u>.<sup>5</sup> It built-on, rather than replaced, the 2010 strategy.

Think autism set out fifteen priority challenges for action from the perspective of autistic people and carers, across 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.
- Focusing on how advice and information on services can be joined up better for people.<sup>6</sup>

In March 2015, the Government updated the statutory guidance for local authorities and NHS organisations.<sup>7</sup> The guidance took into account responses to a consultation<sup>8</sup> and related legislation, including the Health and Social Care Act 2012, the Care Act 2014, and the Children and Families Act 2014, which introduced new duties for autistic people.

In January 2016, the DH produced a progress report on Think autism: <u>Progress</u> <u>Report on Think Autism: the updated strategy for adults with autism in</u> <u>England.</u><sup>9</sup> The report summarised progress since the 2014 strategy and included a number of new actions, focusing on education, employment, the criminal justice system and better data reporting.

1.3

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

In July 2021, The Department of Health and Social Care (DHSC) and the Department for Education (DfE) published the <u>National strategy for autistic</u> children, young people and adults: 2021 to 2026.<sup>10</sup> It builds on and replaces the 2014 Think autism strategy and covers children and young people, as well as adults, for the first time.

<sup>7</sup> DHSC, <u>Adult autism strategy: supporting its use</u>, 26 March 2015, pp36-55

<sup>&</sup>lt;sup>5</sup> DHSC, <u>'Think Autism': an update to the government adult autism strategy</u>, 2 April 2014

<sup>&</sup>lt;sup>6</sup> As above, p9

DHSC, <u>The Government response to the consultation on revised statutory guidance to implement the</u> <u>Strategy for Adults with Autism in England</u>, 26 March 2015

<sup>&</sup>lt;sup>9</sup> DHSC, <u>Strategy for adults with autism: progress report</u>, 2016

<sup>&</sup>lt;sup>10</sup> DHSC and DfE, <u>National strategy for autistic children</u>, <u>young people and adults: 2021 to 2026</u>, 21 July 2021

The strategy was informed by a <u>review of the Think autism strategy</u>, which included a public consultation on the care and support experiences of autistic people and their families and carers.<sup>11</sup>

Evidence was also drawn from a 2019 report by the All-Party Parliamentary Group on Autism (APPGA) and the National Autistic Society, <u>The Autism Act:</u> <u>10 Years On</u>. The report found "71% (2 in 3) of autistic adults in England aren't getting the support they need."<sup>12</sup>

Independent research was commissioned from the Policy Innovation Research Unit to understand the <u>impact of the Covid-19 pandemic on autistic people</u> (PDF).<sup>13</sup>

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

- Improving understanding and acceptance of autism within society.
- Improving autistic children and young people's access to education, and supporting positive transitions into adulthood.
- Supporting more autistic people into employment.
- Tackling health and care inequalities for autistic people.
- Building the right support in the community and supporting people in inpatient care.
- Improving support within the criminal and youth justice systems.<sup>14</sup>

The strategy also sets out plans for the improvement of data quality and collection, with the aim to decrease reliance on self-assessments and build a cross-government approach to data collection and reporting.<sup>15</sup>

The Government committed to invest £74.88 million towards the objectives in the first year of the strategy.<sup>16</sup> An <u>implementation plan for 2021-22</u>, published alongside the strategy, set out how the money would be spent.<sup>17</sup>

<sup>&</sup>lt;sup>11</sup> DHSC and DfE, <u>Review of the National Autism Strategy 'Think Autism': call for evidence and</u> <u>summary of responses</u>, 14 March 2019

<sup>&</sup>lt;sup>12</sup> All Party Parliamentary Group on Autism and the National Autistic Society, <u>The Autism Act: 10 Years</u> On, September 2019, p5

<sup>&</sup>lt;sup>13</sup> Policy Innovation and Evaluation Research Unit, <u>The Impact of COVID-19 on Autistic People in the</u> <u>United Kingdom: Final Report (PDF, 2.39MB)</u> July 2021

<sup>&</sup>lt;sup>14</sup> DHSC and DfE, <u>National strategy for autistic children</u>, <u>young people and adults</u>: 2021 to 2026, 21 July 2021, p10

<sup>&</sup>lt;sup>15</sup> As above, p40

<sup>&</sup>lt;sup>16</sup> DHSC Press Release, '<u>New landmark strategy to improve the lives of autistic people</u>', 21 July 2021

<sup>&</sup>lt;sup>17</sup> DHSC and DfE, <u>Autism strategy implementation plan: 2021 to 2022 (Annex A)</u>, updated 22 July 2021

#### Response to the 2021-2026 autism strategy

Responses were generally positive in relation to the strategy's aims and the amount of money committed in year one. There were concerns about sustaining the funding throughout the full five years and the knock-on impact of unresolved problems in the social care sector. Caroline Stevens, chief executive of the National Autistic Society, said:

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

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

Following the Autumn spending review in 2021, The National Autistic Society urged the Government to "properly fund the promises made in the five-year strategy".<sup>19</sup>

In response to the Spring 2023 budget, the National Autism Society said it is "really worried the Government has missed another opportunity to fund its all-important Autism Strategy".<sup>20</sup>

In February 2023 the Government said there is no confirmed publication date for an updated implementation plan and the DHSC is working on updating the statutory guidance.<sup>21</sup>

<sup>&</sup>lt;sup>18</sup> National Autistic Society News, '<u>Government invests millions in better support for autistic people in England</u>', 21 July 2021.

<sup>&</sup>lt;sup>19</sup> National Autistic Society News, '<u>Our calls for funding the autism strategy</u>', 28 October 2021

<sup>&</sup>lt;sup>20</sup> National Autistic Society News, '<u>Our response to the Spring Budget and Health and Disability White</u> <u>Paper</u>', 15 March 2023

<sup>&</sup>lt;sup>21</sup> PQ 135349 [on <u>Autism: Health services</u>], 3 February 2023

# 2 Health policy and autism

# 2.1 The NHS Long Term Plan 2019

The 2019 <u>NHS Long Term Plan</u> 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>22</sup>

Specific areas of action include:

- Tackling the causes of morbidity and preventable deaths through piloting a health check for autistic people and expanding the Stopping overmedication of autistic people and people with a learning disability and Supporting Treatment and Appropriate Medication in Paediatrics (STOMP-STAMP) programmes.
- Continuing to fund the Learning from Life and Death Reviews Programme (LeDeR) (formally known, and referred to in the Long Term Plan, as the Learning Disabilities Mortality Review).<sup>23</sup> LeDeR looks at the lives and deaths of people with a learning disability and autistic people to identify how care can be improved, health inequalities reduced and early deaths prevented. Learning from the reviews is disseminated in <u>Action from</u> <u>learning reports</u> and <u>Annual reports</u>, which from 2023 onwards include information on autistic people.
- Improving understanding in the NHS of autistic people's needs by delivering awareness training to staff and introducing a "digital flag" in patient records to ensure staff are aware of autistic patients and patients with a learning disability.
- Testing and implementing the most effective ways to reduce waiting times for children and young people to be assessed for autism.
- Assigning designated keyworkers to autistic children and young people with or without a learning disability with the most complex needs. Initially, keyworkers would support those in hospital or at risk of admission, then expand to children facing other vulnerabilities, such as looked after children.

<sup>&</sup>lt;sup>22</sup> NHS England, <u>The NHS Long Term Plan</u>, January 2019, p41

<sup>&</sup>lt;sup>23</sup> Since January 2022, <u>LeDeR has reviewed the lives and deaths of autistic adults</u> (without a learning disability).

- Halving inpatient provision for autistic people and people with a learning • disability by 2023/24, compared to 2015 levels (on a like for like basis and taking into account population growth).<sup>24</sup>
- Improving the experience of inpatient care and speeding up the discharge process.
- Increasing investment in intensive, crisis and forensic community support including seven-day specialist multidisciplinary service and crisis care in every system.<sup>25</sup>

The Long term plan implementation framework (June 2019) sets out how commitments in the NHS Long Term Plan will be delivered and funded.<sup>26</sup> It says each local area should develop a five-year plan, overseen by a responsible officer, setting out how the above actions will be met and outlining the local offer for autistic young people and their families.<sup>27</sup>

# Mandatory staff training

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 was published in November 2019. Over 5,000 responses were received, the vast majority of which were supportive of the principle of mandatory training.<sup>28</sup>

The Government invested £1.4 million to develop the Oliver McGowan Mandatory Learning Disability and Autism Training for health and care staff.<sup>29</sup> The training is named after Oliver McGowan, whose death highlighted the need for improved training and led his parents to campaign for legislative change.30

The training has been trialled and evaluated and an e-learning package has been produced. Interactive and face-to-face training will become available in 2023.<sup>31</sup> The content of the training is informed by the Core capabilities

A previous target had been set to reduce inpatient care by 35-50% by March 2019 (see section 2.4)

<sup>25</sup> NHS England, The NHS Long Term Plan, January 2019, pp52-53

<sup>&</sup>lt;sup>26</sup> NHS England, <u>NHS Long Term Plan The Implementation Framework</u>, 27 June 2019

<sup>&</sup>lt;sup>27</sup> As above, para 5.10

<sup>28</sup> DHSC, '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>29</sup> DHSC, All inpatients with learning disability or autism to be given case reviews, 5 November 2019

<sup>30</sup> See the campaign website: Oliver McGowan - Oliver's Campaign for more information

Health Education England, The Oliver McGowan Mandatory Training on Learning Disability and Autism, updated 22 December 2022

framework for supporting people with a learning disability<sup>32</sup> and the Core Capabilities Framework for Supporting Autistic People.<sup>33</sup>

The Health and Care Act 2022 introduced a new legal requirement for all health and social care service providers registered with the Care Quality Commission to ensure their employees receive training on autism and learning disability at a level appropriate to their role.<sup>34</sup> It also placed a duty on the Secretary of State to issue a Code of Practice setting out requirements for the content, delivery and accreditation of training.<sup>35</sup>

### 2.3 Assessment and diagnosis

#### Waiting time standards

The National Institute for Health and Care Excellence's (NICE) guidance on Autism spectrum disorder in under 19s: recognition, referral and diagnosis (December 2017) says an autism diagnostic assessment should start within three months of the referral to the autism team.<sup>36</sup>

The <u>NICE Quality Standard on autism</u>, which covers health and social care services for autistic adults, young people and children, says autism diagnostic assessments should start within three months of a referral.<sup>37</sup>

Statistics indicate in many cases this target is not met – see waiting times statistics below.

#### Improving waiting times

The 2021-26 autism strategy says increased public awareness of autism, a resulting increase in referrals and the Covid-19 pandemic have contributed to delays in autism assessments. The strategy includes an investment of £13 million to reduce waiting times by piloting diagnostic pathways and addressing the backlog of assessments. £3.5 million is dedicated to identifying children and young people on waiting lists for assessment who may be at risk of crisis.<sup>38</sup>

<sup>&</sup>lt;sup>32</sup> Health Education England, <u>Core Capabilities Framework for Supporting People with a Learning Disability</u>, October 2019

<sup>&</sup>lt;sup>33</sup> Health Education England, <u>Core Capabilities Framework for Supporting Autistic People</u>, October 2019

<sup>&</sup>lt;sup>34</sup> Health and Care Act 2022 (legislation.gov.uk), s181

<sup>&</sup>lt;sup>35</sup> Health and Care Act 2022 (legislation.gov.uk), s181

<sup>&</sup>lt;sup>36</sup> NICE, <u>Clinical guideline [CG128] Autism spectrum disorder in under 19s: recognition, referral and diagnosis</u>, updated 20 December 2017. NICE guidance is not mandatory but provides best-practice and health practitioners are expected to take guidance into consideration.

<sup>&</sup>lt;sup>37</sup> NICE, <u>Quality standard [QS51] autism</u>, 21 January 2014

<sup>&</sup>lt;sup>38</sup> Department of Health and Social Care and Department for Education, <u>National strategy for autistic</u> <u>children</u>, <u>young people and adults</u>: 2021 to 2026, 21 July 2021, p26

The strategy also includes the expansion of a school-based programme piloted in Bradford involving health and education staff in identifying and assessing children who may be autistic. The expansion would see the programme rolled out to over 100 schools over three years.<sup>39</sup>

In a February 2023 debate on waiting times for autism and attention deficit hyperactivity disorder (ADHD) diagnosis, Maria Caulfield, Parliamentary Under-Secretary of State for Health and Social Care, gave an update on diagnostic pathway pilots and said a national framework is in development:

> NHS England has developed a framework that is transforming learning from autism pilot schemes into scalable action, which will improve support and care for people across the country. Last year, part of the £13 million autism funding enabled 72 pilot tests for improvements in diagnostic pathways, and these pilots are now helping NHS England to develop a national framework on autism that will improve assessment across the country for people of all ages.

> [...] We now expect integrated care boards, which were set up in July of last year, to lead the charge on how pathways can be best delivered in local areas. The guidance will provide signposting at each stage of the assessment process, helping to map out a clear route for diagnosis. We now expect every integrated care board to have an executive lead for learning disabilities and autism, and there was talk in the debate about having a national lead. Actually, we want leads at every single local integrated care board to be the lead person to whom MPs can go if assessments are not being done on time, to hold local services to account, to compare best practice and to make sure it is happening in every part of the country. We are putting in the investment needed to meet the demand, because further investment will be needed. This year, we have committed an extra £2.5 million to the scheme, which will help roll it out further.<sup>40</sup>

In April 2023, NHS England published <u>A national framework to deliver</u> improved outcomes in all-age autism assessment pathways: guidance for integrated care boards. The framework acknowledges that waiting lists for autism assessments in England have reached "unsustainable levels". It sets out principles underpinning assessment services and how these should be applied by Integrated Care Boards when commissioning services. The framework focuses on the "effective and efficient use of existing resource" and notes increasing workforce supply and resource allocation are outside the scope of the framework.<sup>41</sup>

Alongside the framework, NHS England published <u>Operational guidance</u> for Integrated Care Boards, which includes:

• an overview of key components of the autism diagnostic pathway;

<sup>&</sup>lt;sup>39</sup> Department of Health and Social Care and Department for Education, <u>National strategy for autistic</u> <u>children, young people and adults: 2021 to 2026</u>, 21 July 2021, p27

<sup>&</sup>lt;sup>40</sup> <u>HC Deb 6 February 2023</u>, c243WH. <u>Corrections to this statement</u> were made after the debate, this extract uses the corrected Hansard text.

<sup>&</sup>lt;sup>41</sup> NHS England, <u>A national framework to deliver improved outcomes in all-age autism assessment</u> pathways: guidance for integrated care boards, 5 April 2023

- considerations for conducting assessments outside of standard service delivery, for example in hospitals or the forensic settings;
- guidance on non-clinical tasks such as training and consultation and liaison across services.<sup>42</sup>

### Monitoring waiting times

Between 2011-2019, Public Health England carried out annual self-assessment exercises with local authority areas on progress made in implementing the Think autism strategy. Local authorities worked with their local partners to informally answer a range of questions.<sup>43</sup> On diagnosis, the following results were reported for 2018:

The median reported waiting time from referral to diagnostic assessment was 30 weeks (up from 16 weeks reported in 2016). Among the 74% of responding authorities that provided figures for both years, 23% reported a fall in waiting time, 63% reported an increase. A substantially higher proportion of local areas reported that they were unable to foresee when they would be able to meet the recommended NICE standards.<sup>44</sup>

NHS Digital started publishing experimental statistics on the number of new autism referrals and waiting times for appointments and diagnoses in November 2019.<sup>45</sup> The dataset has a number of limitations meaning it is not straightforward to infer trends in waiting times.<sup>46</sup>

The statistics have been impacted by cyber incident in 2022, meaning national figures are only available to July 2022.<sup>47</sup>

In July 2022, there were 130,000 people waiting for a clinical autism assessment. The majority of these (84%) had been waiting for 13 weeks or more. The data does not include average waiting times or any further information indicating how long people are waiting for their assessment to be completed.<sup>48</sup>

The number of people waiting for an autism assessment has grown steadily: in the year from July 2021 to July 2022, it increased by 41,700 people (+47%).

This is due to a greater number of new referrals for suspected autism being made each month relative to the number of referrals being closed. For

<sup>&</sup>lt;sup>42</sup> NHS England, <u>Operational guidance to deliver improved outcomes in all-age autism assessment</u> pathways: <u>Guidance for integrated care boards</u>, 5 April 2023

<sup>&</sup>lt;sup>43</sup> <u>PQ HL6524 [on Autism], 14 March 2016</u>

<sup>&</sup>lt;sup>44</sup> Public Health England, <u>Autism self-assessment exercise 2018: executive summary</u>, 20 June 2019, para 5

Experimental statistics are official statistics that have recently developed and are undergoing evaluation. NHS Digital, <u>Autism Waiting Time Statistics</u>

<sup>&</sup>lt;sup>46</sup> NHS Digital, <u>Autism Statistics</u>, <u>January to December 2022</u>: <u>Limitations of the statistics and interpretation issues</u>, 9 March 2023

<sup>&</sup>lt;sup>47</sup> NHS Digital, <u>Autism Statistics</u>, <u>January to December 2022</u>, 9 March 2023

<sup>&</sup>lt;sup>48</sup> As above

example, in July 2022 there were around 8,600 new referrals compared with 5,200 closed referrals.

Only a small proportion of the people waiting for an autism assessment have a care contact (a post-referral appointment) each month. For example, in July 2022 around 5,600 people waiting for an autism assessment had at least one care contact, representing just 4.3% of the total number waiting for an assessment. Having had a care contact does not mean the autism assessment is complete.

### 2.4 Reducing inpatient care

### Winterbourne View and Transforming Care

In 2011, the BBC's Panorama programme exposed abuse of patients at Winterbourne View, an independent hospital for autistic people and people with learning disabilities. In response, the DH published the Transforming Care programme, which pledged to move people inappropriately placed in hospital to community-based care no later than 1 June 2014.<sup>49</sup> This target was missed; a report by the Transforming Care Steering Group found there were more people being admitted to long-term institutions than those discharged.<sup>50</sup>

A subsequent report by the group in 2015 found progress was being made, but the programme had not yet delivered tangible benefits in terms of new community facilities or closures.<sup>51</sup> In 2016 the group recommended a commissioner to promote and protect the rights of all people with learning disabilities and autistic people in England.<sup>52</sup> The Government said statutory roles and legislation are "not necessarily the answer" to providing this protection.<sup>53</sup>

### **Building the Right Support (2015)**

In October 2015, NHS England, the Local Government Association and the Directors of Adult Social Services, published a national action plan to close inpatient facilities for autistic people and people with a learning disability. The <u>Building the Right Support</u> plan aimed to shift money from inpatient

<sup>&</sup>lt;sup>49</sup> DH, <u>Transforming care: A National response to Winterbourne View Hospital</u>, December 2012

<sup>&</sup>lt;sup>50</sup> Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb, <u>Winterbourne</u> <u>View - Time for change</u>, November 2014

<sup>&</sup>lt;sup>51</sup> Transforming Care and Commissioning Steering Group, <u>Winterbourne View: Time is Running Out</u>, July 2015

<sup>&</sup>lt;sup>52</sup> Transforming Care and Commissioning Steering Group, <u>Time for Change: The Challenge Ahead</u>, February 2016

<sup>&</sup>lt;sup>53</sup> PQ 28525 [on Learning Disability] 1 March 2016

services to the community and reduce the use of inpatient beds for people with a learning disability and autistic people by 35% - 50% over three years.<sup>54</sup>

In 2019, the <u>NHS Long Term Plan</u> included a commitment to achieve the 50% reduction (compared to the 2015 figure) by 2023/24.<sup>55</sup> The new deadline was criticised by charities such as Mencap, who described the situation as a "domestic human rights scandal".<sup>56</sup>

The Care Quality Commission (CQC) has published <u>reports on the use of</u> <u>restraint, segregation and seclusion</u> in care services for autistic people, people with a learning disability or a mental health condition.<sup>57</sup>

### National autism strategy 2021-26

The 2021-26 autism strategy recommits to achieving the Long Term Plan goal and reports a net decrease in inpatient numbers of autistic people and people with a learning disability of 28% as of June 2021.<sup>58</sup> It notes the decrease in inpatient numbers of autistic people has been slower compared to overall numbers. The strategy says that although progress is being made on discharging autistic people from hospital, "too many" autistic people are being admitted to hospital because they are not receiving adequate social care, mental health and housing support.<sup>59</sup>

The strategy includes actions across the following areas to reduce the number of autistic people and people with a learning disability in inpatient settings:

- Making legislative changes to the Mental Health Act (see section 2.5 below).
- Improving community support to prevent crises and avoidable admissions to hospital.
- Improving inpatient care for autistic people, including reducing restrictive practice, and speeding up discharges.<sup>60</sup>

### Building the right support action plan (2022)

In July 2022, the DHSC published an updated <u>Building the right support for</u> people with a learning disability and autistic people: action plan. Progress

- <sup>59</sup> As above, p30
- <sup>60</sup> DHSC and DfE, <u>National strategy for autistic children</u>, <u>young people and adults: 2021 to 2026</u>, 21 July 2021, pp31-34

<sup>&</sup>lt;sup>54</sup> NHS England, <u>Building the right support</u>, October 2015, para 1.9

<sup>&</sup>lt;sup>55</sup> PQ 274584 [on Learning disability: Hospital beds], 15 July 2019

<sup>&</sup>lt;sup>56</sup> Mencap Press Release, <u>Government due to miss deadline for releasing people with a learning</u> <u>disability locked away in inpatient units, warns Mencap</u>, 21 March 2019

<sup>&</sup>lt;sup>57</sup> CQC, <u>Out of sight – who cares?: Restraint, segregation and seclusion review</u>, 22 October 2022; CQC, <u>Restraint, segregation and seclusion review</u>: Progress reports, Updated March 2022

<sup>&</sup>lt;sup>58</sup> DHSC and DfE, <u>National strategy for autistic children</u>, <u>young people and adults: 2021 to 2026</u>, 21 July 2021, p30

against commitments in the plan is monitored by the Building the Right Support Delivery Board, chaired by the Minister of State for Care and Mental Health.<sup>61</sup>

The action plan focuses on six areas to develop community services and reduce reliance on inpatient mental health beds:

- Ensuring people are safe and that they receive quality health and social care through improving the experience of mental health settings, supporting people to move out of long-term segregation, improving advocacy and training the workforce.
- Making it easier to leave hospital by refreshing the policy for Care (Education) and Treatment Reviews, using the <u>Community Discharge</u> <u>Grant</u> and improving outcomes for neurodivergent people in the criminal justice system.
- Ensuring people receive the right housing, care and support in the community by reviewing best practice, investing in supported housing and ensuring the right services are commissioned.
- Supporting children and young people by ensuring quicker diagnosis, improving Special Educational Needs and Disabilities (SEND) provision and training educational staff in autism awareness.
- Making cross-government changes to improve system collaboration, including by reforming the Mental Health Act and integrating health and care.
- Ensuring local and national accountability by the Board holding commitment owners accountable for delivery.<sup>62</sup>

Providers of specialist services for autistic people and people with a learning disability are assessed against <u>guidance by the CQC</u>. From September 2022, providers registering with the CQC who do not plan to provide these services must agree to a condition that they "must not" provide these services. Should the provider decide to provide the services, they must apply to have the condition removed.<sup>63</sup>

### Monitoring mental health inpatient bed use

As of January 2023, there were 2,020 inpatients who had a learning disability and/or autism, down 30% from 2,905 inpatients in March 2015. However, a higher number of these inpatients are autistic (with or without a learning disability): 1,280 in January 2023 compared with 1,100 in March 2015. There

<sup>&</sup>lt;sup>61</sup> DHSC, <u>Building the right support for people with a learning disability and autistic people</u>, July 2022

<sup>&</sup>lt;sup>62</sup> DHSC, <u>Building the right support for people with a learning disability and autistic people</u>, July 2022

<sup>&</sup>lt;sup>63</sup> CQC, 'We are strengthening regulation of services for people with a learning disability and autistic people to improve people's experiences and outcomes', 31 August 2022

was also an increase in autistic inpatients without a learning disability, from 445 in March 2015 to 800 in January 2023.<sup>64</sup>

### 2.5 Mental Health Act Reform

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

[...] the Mental Health Act isn't providing the right type of support and care for people with learning disabilities, autism or both. The Mental Health Act is being used in a way that is not in line with its intended purpose, and is too often being used compensate for the lack of adequate and meaningful support within the community.<sup>65</sup>

In January 2021, the Government published a series of proposals for legislative change, including on how the Act would apply to autistic people and people with a learning disability, in a <u>white paper on Reforming the</u> <u>Mental Health Act</u>.<sup>66</sup> The Government held a <u>consultation on the proposed</u> <u>changes</u> between January and April 2021, before publishing its response in August 2021.<sup>67</sup>

### **Proposed reforms**

In June 2022, the Government published the <u>Draft Mental Health Bill 2022</u>. The draft Bill would amend the criteria for detention under the Act so autism and learning disability would not be conditions for which a person could be subject to longer term detention for treatment (section 3). This would mean people with a learning disability or autistic people could only be detained for treatment if they are suffering from a co-occurring mental disorder. The changes would not apply to patients in the criminal justice system.<sup>68</sup>

Measures in the draft Bill would place Care (Education) and Treatment Reviews (C(E)TRs) for persons with learning disability and autistic people on a statutory footing. C(E)TRs are part of current NHS policy and aim to reduce unnecessarily long hospital stays. They focus on whether the patient is safe and receiving the right care and treatment. By placing the reviews on a

<sup>&</sup>lt;sup>64</sup> NHS Digital, <u>Learning disability services monthly statistics from AT dataset: Data tables – January</u> 2023, 16 February 2023, Table 2.2

<sup>&</sup>lt;sup>65</sup> DHSC, <u>Modernising the Mental Health Act – final report from the independent review</u>, December 2018, p31

<sup>&</sup>lt;sup>66</sup> DHSC, <u>Reforming the Mental Health Act</u>, January 2021

<sup>&</sup>lt;sup>67</sup> DHSC, <u>Reforming the Mental Health Act: government response</u>, 24 August 2021

<sup>&</sup>lt;sup>68</sup> DHSC and MoJ, <u>Draft Mental Health Bill 2022</u>, 27 June 2022, clause 1

statutory footing, the draft Bill seeks to ensure outcomes from reviews are followed up and barriers to progress are overcome.<sup>69</sup>

The draft Bill would also require Integrated Care Boards (ICBs) to create and maintain a "risk register" for their area of autistic people and people with a learning disability at risk of hospital admission. The register would be used to put in place preventative measures to avoid admission and inform local commissioning. ICBs and local authorities would have a duty to seek to ensure they meet the needs of people with a learning disability and autistic people without detaining them.<sup>70</sup>

#### **Pre-legislative scrutiny**

In July 2022 a <u>Joint Select Committee was established</u> to consider the draft Bill. Following a call for evidence and a series of evidence sessions, <u>the</u> <u>Committee published its report</u> on 19 January 2023.<sup>71</sup>

The Committee said it heard from witnesses that hospitals are not the correct environment in which to provide support for people with learning disabilities and autistic people. Most witnesses supported changing the definition of "mental disorder" to exclude learning disability and autism in principle.<sup>72</sup>

The Committee also received evidence about a lack of community alternatives for those diverted away from hospital, with provision described as "worryingly low".<sup>73</sup> The Committee said it is clear there will need to be a "sustained programme of investment" to expand community services, but it was "still not clear to [the Committee] whether the Government is able to deliver on these commitments in the long term."

There were concerns that limiting how the Act would apply to autistic people and people with a learning disability could lead to unintended consequences, such as detention under the Mental Capacity Act or diagnosing alternative mental health conditions to justify using the Mental Health Act.

Another concern was that individuals from this group could be diverted into the criminal justice system.<sup>74</sup> The Government told the Committee they have introduced neurodiversity support managers in prisons and are improving staff training, including developing an autism accreditation.<sup>75</sup>

The Committee made the following recommendations to the Government:

<sup>&</sup>lt;sup>69</sup> As above, clause 2

<sup>&</sup>lt;sup>70</sup> As above, clause 2

<sup>&</sup>lt;sup>71</sup> Joint Committee on the Draft Mental Health Bill, <u>Report - Draft Mental Health Bill 2022</u>, 19 January 2023

<sup>&</sup>lt;sup>72</sup> As above, para 150

<sup>&</sup>lt;sup>73</sup> Joint Committee on the Draft Mental Health Bill, <u>Report - Draft Mental Health Bill 2022</u>, 19 January 2023, paras 108-110

<sup>&</sup>lt;sup>74</sup> Paras 164-175

<sup>&</sup>lt;sup>75</sup> Para 173

- Changes to the criteria should be the same for both civil patients and those in the criminal justice system.
- Review the Building the right support action plan (see section 2.4) to reflect how the needs of those no longer eligible for long-term detention under the Act will be met in the community.
- Review the Mental Capacity Act to ensure it cannot be used as an alternative detention route.
- Monitor the outcomes for those no longer eligible for long-term detention for a rise in use of the Mental Capacity Act or detention in the criminal justice system.
- Introduce a provision in the Bill to extend the detention of people with learning disabilities and autistic people under section 2 of the Act in "exceptional circumstances".
- Reduce the maximum interval between C(E)TRs from twelve to six months and strengthen the wording of the legislation to emphasise the duty on ICBs and Local Authorities to action the outcomes.
- Rename the "risk register" as the "Dynamic Support Register" and impose a "firm duty" on ICBs and Local Authorities to ensure an adequate supply of community provision.
- Review eligibility for section 117 aftercare,<sup>76</sup> to consider its extension to those detained under other sections of the Act.<sup>77</sup>

More information can be found in the Library's briefing paper on <u>Reforming</u> the <u>Mental Health Act.</u>

<sup>&</sup>lt;sup>76</sup> Section 117 of the Mental Health Act 1983 entitles people who have been detained in hospital under Section 3 of the Mental Health Act to receive free aftercare services to reduce the risk of future admission.

<sup>&</sup>lt;sup>77</sup> Joint Committee on the Draft Mental Health Bill, <u>Report - Draft Mental Health Bill 2022</u>, 19 January 2023, paras 178-182, 191-192, 208-213

# 3 Social care and autism

The main legislation and guidance relating to local authority provision of social care services is framed in general terms. The emphasis is on a person's care and support needs rather than any specific condition they may have.

### 3.1 Adult social services

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

- to undertake an assessment of any adult with an appearance of need for care and support, or any carer with an appearance of need for support, regardless of their financial situation or whether the authority thinks the individual is eligible for support (sections 9 and 10); and
- subject to certain conditions, to meet an adult's assessed care and support needs, or the support needs of a carer, where those needs meet prescribed eligibility criteria.<sup>78</sup> Authorities also have power to meet needs not meeting the eligibility criteria (sections 18-20).<sup>79</sup>

If a local authority is required, or chooses, to meet a person's social care needs, it must produce a care and support plan setting out how those needs will be met. This should include a statement setting out the cost to the local authority of meeting the person's needs (their "personal budget"), including the amount the person must pay themselves (on the basis of a financial assessment) and the amount the local authority must pay.

Adults qualifying for state-funded care services may be entitled to receive payments instead of a care package from the local authority. They can then use these direct payments to arrange and pay for their own, independently contracted, care and support services.

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

<sup>&</sup>lt;sup>78</sup> The Care and Support (Eligibility Criteria) Regulations 2015, SI 2015/313

<sup>&</sup>lt;sup>79</sup> <u>Care Act 2014</u>, sections 9-10 and 18-20.

the skills, knowledge, competence and training to carry out such assessments.  $^{\mbox{\tiny 80}}$ 

#### **Government guidance**

Guidance for professionals involved in delivering social work to autistic adults is provided in the Government-commissioned <u>Capability Statement</u> (PDF) published by the British Association of Social Workers.<sup>81</sup>

2015 statutory guidance for local authorities and NHS organisations to support implementation of the 2010 Autism strategy says local authorities should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of care and support services for autistic adults.<sup>82</sup> It adds that local commissioning plans should describe how local authorities will make sure autistic adults are able to access direct payments where appropriate (see above).<sup>83</sup>

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

> Local commissioning plans should set out how local authorities will ensure that adults with autism are able to access direct payments (where appropriate) and benefit from the personalisation of health and social care. Local partners should already have a local autism partnership board in place, which brings together different organisations, services and stakeholders and adults with autism and their families to set a clear direction for improved services. Autism partnership boards have proved to be a highly effective means for stakeholders to shape and monitor local delivery of the strategy and statutory guidance. It is therefore essential for their partnership arrangements to be established in areas where they are not currently.<sup>84</sup>

#### Autism strategy 2021-2026

The Autism strategy 2021-2026 identified "improving health and care staff's understanding of autism" as crucial in enabling progress on reducing health inequalities for autistic people. The strategy said the Government would continue to trial and develop the <u>Oliver McGowan Mandatory Training</u> in learning disability and autism for all health and adult social care staff across England.<sup>85</sup> As set out in section 2.2 above, this training has now been launched and the Government has said it is its "preferred and recommended

<sup>&</sup>lt;sup>80</sup> DH, <u>Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (PDF)</u>, March 2015, p18

<sup>&</sup>lt;sup>81</sup> British Association of Social Workers, <u>Capabilities Statement for Social Work with Autistic Adults</u>.

<sup>&</sup>lt;sup>82</sup> DH, <u>Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (PDF)</u>, March 2015, p29

<sup>&</sup>lt;sup>83</sup> As above, p29

<sup>&</sup>lt;sup>84</sup> As above, p29

<sup>&</sup>lt;sup>85</sup> DHSC and DfE, <u>The national strategy for autistic children</u>, young people and adults: 2021 to 2026, 21 July 2021, p27.

training for health and social care staff" to meet the mandatory training requirement under the Health and Social Care Act 2022.<sup>86</sup>

Noting "commissioners need the right skills and tools to develop services that work for autistic people", the strategy said the Local Government Association (LGA), Skills for Care, and the Association of Directors of Adult Social Services (ADASS) would roll out their qualification for commissioners who work with autistic people to 120 more NHS and local authority commissioners.<sup>87</sup> The Government's <u>Building the right support action plan</u>, published in July 2022, said Skills for Care had committed to roll out the qualification for current and aspiring commissioners by April 2023. It added the aim was to have a health and a social care commissioner per local area to have completed the qualification by April 2025.<sup>88</sup>

In addition, <u>Government-commissioned guidance</u> to "help commissioners identify local demand and develop the right services for autistic people", developed by Skills for Care and the National Development Team for Inclusion (NDTi), was published alongside the Autism strategy.<sup>89</sup>

The strategy argued "too many autistic people" are being admitted to inpatient mental health settings "because they often struggle to access community support, including social care, mental health and housing support before their needs escalate." As part of a plan to prevent avoidable admissions, the strategy said the Government "will...improve autistic people's access to housing and social care that meets their needs, by increasing the provision of supported housing, enabling more people to access adaptations to their homes and reforming the social care system so it is fit for purpose." It adds the LGA and ADASS are "leading work to review best practice models of support for autistic people, people with a learning disability or both."<sup>90</sup>

#### Adult social care reform

Regarding plans for adult social care reform, the strategy said:

We are committed to sustainable improvement of the adult social care system and will bring forward proposals in 2021. The objectives for reform are to enable an affordable, high quality adult social care system that meets people's needs, while supporting health and care to join up services around

<sup>&</sup>lt;sup>86</sup> Health and Social Care Act 2022, section 181; NHS Health Education England, <u>The Oliver McGowan</u> <u>Mandatory Training on Learning Disability and Autism</u>, last updated 22 December 2022.

<sup>&</sup>lt;sup>87</sup> DHSC and DfE, <u>The national strategy for autistic children</u>, young people and adults: 2021 to 2026, 21 July 2021, p27.

<sup>&</sup>lt;sup>88</sup> DHSC, <u>Building the right support for people with a learning disability and autistic people. Table of Commitments (Annex A)</u>, July 2022, Commitment 3h.

<sup>&</sup>lt;sup>89</sup> DHSC and DfE, <u>The national strategy for autistic children</u>, young people and adults: 2021 to 2026, 21 July 2021, p27.

<sup>&</sup>lt;sup>90</sup> As above, p30-33.

them. We want to ensure that everyone, including autistic people, receive the care they need to enable them to live full and independent lives.<sup>91</sup>

In December 2021, the Government set out its plans for wider reform of adult social care in a white paper: <u>People at the Heart of Care: adult social care</u> reform white paper.<sup>92</sup> The white paper set out a range of specific commitments up to 2024/25, including:

- At least £300 million to integrate housing into health and care strategies.
- At least £150 million "to drive greater adoption of technology and achieve widespread digitisation across social care".
- At least £500 million to support the adult social care workforce, so that it has "the right training and qualifications, and feel recognised and valued for their skills and commitment." Further information is provided in the Library briefing on the <u>adult social care workforce</u>.<sup>93</sup>
- Up to £25 million to "kick start a change in the services provided to unpaid carers."
- £30 million to "help local areas innovate around the support and care they provide in new and different ways."
- At least £5 million to "pilot new ways to help people understand and access the care and support available."
- More than £70 million to "increase the support offer across adult social care to improve the delivery of care and support services."<sup>94</sup>

The Government said it would publish a plan for adult social care system reform in "spring 2023" which will set out how it "will build on the progress so far to implement the vision for adult social care set out in the People at the Heart of Care white paper."<sup>95</sup>

In September 2021, the Government also set out plans to reform how people pay for adult social care, including the introduction of a cap on care costs from October 2023. At <u>Autumn Statement 2022</u> delivered on 17 November 2022, the Chancellor, Jeremy Hunt, said the reforms would be delayed by two

<sup>&</sup>lt;sup>91</sup> DHSC and DfE, <u>The national strategy for autistic children</u>, young people and adults: 2021 to 2026, 21 July 2021, p32.

<sup>&</sup>lt;sup>92</sup> DHSC, <u>People at the Heart of Care: adult social care reform white paper</u>, 1 December 2021.

<sup>&</sup>lt;sup>93</sup> Commons Library briefing CBP-9615, <u>Adult social care workforce in England</u>.

<sup>&</sup>lt;sup>94</sup> DHSC, <u>People at the Heart of Care: adult social care reform white paper</u>, 1 December 2021, p8.

<sup>&</sup>lt;sup>95</sup> PQ HL5577 [on <u>social services: Reform</u>], 15 February 2023.

years.<sup>96</sup> Further information is provided in the Library briefing: <u>Proposed adult</u> social care charging reforms (including cap on care costs).<sup>97</sup>

### 3.2 Children's social services

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

A child in need is defined as a child who:

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

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

(f) [is] disabled.<sup>98</sup>

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

The type of services that can be provided include:

- advice, guidance and counselling
- occupational, social, cultural, or recreational activities
- home help
- facilities for, or assistance with, travelling to and from home for the purpose of taking advantage of any other service provided under the 1989 Act or of any similar service
- assistance to enable the child concerned and their family to have a holiday
- such steps that are practicable to enable a child in need (who is not a looked after child) who is living apart from their family to live with their

<sup>&</sup>lt;sup>96</sup> <u>HC Deb 17 November 2022, c850</u>.

<sup>&</sup>lt;sup>97</sup> Commons Library briefing CBP-9315, Proposed adult social care charging reforms (including cap on care costs).

<sup>&</sup>lt;sup>98</sup> Children Act 1989, section 17.

family, or to promote contact between them and their family (if necessary in order to safeguard or promote their welfare)

- day care for a child if they are under 5 years of age but not yet attending school
- care or supervised activities (either outside school hours or during school holidays) for a child attending any school
- accommodation
- assistance in kind or in cash

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

Further information is available in the Library briefing paper, <u>Local authority</u> support for children in need (England).

During a debate on 21 March 2019, Members raised issues with securing adequate care plans for autistic children. 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>99</sup>

### National autism strategy 2021-2026

Noting the important role social workers play in "identifying the support autistic people need throughout their lives", the 2021-26 autism strategy said the Government would:

- Publish a Capability Statement for social work with autistic children and their families in line with the existing Capability Statement for Social Work with Autistic Adults (see above). At the time of writing, the Capability Statement had not been published.
- Introduce a new National Assessment and Accreditation System (NAAS) simulated practice and knowledge assessment materials for social workers working with autistic children.<sup>100</sup> The NAAS programme closed in March 2022 and the Government has set out details of a new integrated assessment for social workers post-qualification (see below).<sup>101</sup>

<sup>&</sup>lt;sup>99</sup> HC Deb 21 March 2019 c1276

<sup>&</sup>lt;sup>100</sup> DHSC and DfE, <u>The national strategy for autistic children</u>, <u>young people and adults</u>: 2021 to 2026, 21 July 2021, p27.

<sup>&</sup>lt;sup>101</sup> DfE, <u>National assessment and accreditation system (NAAS)</u>; Community Care, <u>Government scraps</u> <u>NAAS social work accreditation scheme</u>, 14 January 2022.

#### Reform of children's social care

The 2021-26 autism strategy also noted the launch of the Independent Review of Children's Social Care in January 2021 and said the review "will take a fundamental look at what is needed to make a real difference to children who need social care."<sup>102</sup>

The final report of the Independent Review was published in May 2022. The Government's response, comprising a consultation on reform proposals, was published in February 2023: <u>Stable homes, built on love: implementation</u> strategy and consultation.<sup>103</sup> The Government also published separate consultations on the child and family social worker workforce and the creation of a children's social care national framework and dashboard.<sup>104</sup>

The Government's consultation documents set out a wide range of reforms, including proposals for a new model of early intervention services, referred to as Family Help. The Stable Homes: Built on Love consultation said the Government wanted "to see much more support available for families who need extra help". It added the aim was for "every area in England to provide families with supportive and welcoming Family Help services, delivered by a skilled multi-disciplinary workforce."<sup>105</sup> Chapter two of the consultation document provides more details.

The consultation documents did not set out any commitments specifically related to autistic children. However, the broader reforms are clearly relevant.

<sup>&</sup>lt;sup>102</sup> DHSC and DfE, <u>The national strategy for autistic children</u>, young people and adults: 2021 to 2026, 21 July 2021, p32.

<sup>&</sup>lt;sup>103</sup> DfE, <u>Children's social care: Stable Homes, Built on Love</u>, 2 February 2023.

<sup>&</sup>lt;sup>104</sup> DfE, <u>Child and family social worker workforce</u>, 2 February 2023; Department for Education, <u>Children's social care national framework and dashboard</u>, 2 February 2023.

<sup>&</sup>lt;sup>105</sup> DfE, <u>Stable Homes, Built on Love: Implementation Strategy and Consultation</u>, February 2023, p17.

# 4 Education and autism

The legislative basis of the system of support for children with special educational needs and disabilities (SEND) in England is Part 3 of the <u>Children</u> and Families Act 2014.

Under the 2014 Act, local authorities have a duty to identify needs in their area and to commission, together with partner agencies (eg, schools), services to support children and young people with SEND. This includes autistic children and young people. 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 <u>Special educational needs and</u> <u>disability code of practice</u><sup>106</sup> for children and young people aged between 0 to 25 years and provides statutory guidance for organisations working with and supporting children and young people who have special educational needs and disabilities.

# 4.1 Types of support

The type of support children and young people with SEND receive varies widely, as the types of SEND and the impact they have are very different. This applies particularly with regard to autism. However, two broad levels of support are in place: SEN<sup>107</sup> support, and Education, Health and Care Plans.

- **SEN support** support given to a child or young person in their preschool, 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 (EHCPs) 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 reaching across education,

<sup>&</sup>lt;sup>106</sup> DfE and DHSC, <u>SEND code of practice: 0 to 25 years</u>, Last updated 30 April 2020

OPT Children with special educational needs may not have disabilities (or vice versa), and this support is focused on a child's special educational needs

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

### 4.2 Support system for children with SEND

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

The statutory <u>SEND Code of Practice</u> makes particular reference to autism and the challenges it produces. See for instance:

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

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

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

[...]

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>108</sup>

A Library Briefing provides further information on the <u>system of support for</u> <u>children and young people with special educational needs in England.</u> Section 6 of the paper discusses reports published on the effectiveness of the system.

<sup>&</sup>lt;sup>108</sup> DfE, <u>Special educational needs and disability code of practice: 0 to 25 years (PDF, 93.3MB)</u>, January 2015, p85 and p97

#### **Disagreement resolution**

If a disagreement between parents of pupils with SEND and schools or local authorities has not been resolved at the local level, under sections 496 and 497 of the <u>Education Act 1996</u> 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 SEND duties.

#### Autistic pupils in state-funded schools

As in previous years, the most commonly recorded primary need for pupils with an EHC plan was Autistic Spectrum Disorder (ASD). This was around 103,000 pupils in January 2022 (which made up around 31% of pupils with EHC plans). A further 79,000 pupils whose primary need was ASD had SEN support (around 8% of pupils with SEN support).<sup>109</sup>

Section 4.1 outlines the difference between EHC plans and SEND support.

# 4.3 Special Educational Needs and Disability Review

In September 2019, five years after the introduction of the current system of support for children and young people with SEND, the Government announced <u>a review of the system's effectiveness</u>.

The review aimed "to improve the services available to families who need support, equip staff in schools and colleges to respond effectively to their needs as well as ending the 'postcode lottery' they often face." It intended to look at how the system has evolved since its introduction, links with health and social care, and would "conclude with action to boost outcomes and improve value for money."<sup>110</sup>

The review was published as a green paper consultation: <u>SEND review: right</u> support, right place, right time in March 2022.

The green paper envisages, among other proposals:

- A new integrated national SEND and alternative provision system setting statutory, nationally consistent standards.
- Establishing new local SEND partnerships, bringing together education (including alternative provision), health and care partners with local

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<sup>&</sup>lt;sup>109</sup> DfE, <u>Special educational needs in England academic year 2021/22</u>, 16 June 2022

<sup>&</sup>lt;sup>110</sup> DfE, <u>Major review into support for children with Special Educational Needs</u>, 6 September 2019

government and other partners to produce a local inclusion plan, setting out how each local area will meet the national standards.

- Introducing a standardised and digitised EHCP process and template.
- Local authorities providing a tailored list of settings to support parents and carers to express their preference for a suitable placement.
- Introducing a streamlined process for redress, including mandatory mediation. <u>The SEND Tribunal</u>, responsible for handling appeals against local authority decisions regarding special educational needs, would remain in place.
- A planned consultation on a new Special Educational Needs Coordinator (SENCo) National Professional Qualification (NPQ) for school SENCos, and to increase the number of staff with an accredited Level 3 SENCo qualification in early years settings.
- Revised and clarified accountability for responsible bodies, such as schools and local authorities.
- A new national framework of banding and price tariffs for high needs funding, which covers SEND and alternative provision.

A Library briefing on <u>The Special Educational Needs and Disabilities and</u> <u>Alternative Provision Green Paper</u> provides more detail.

A consultation on the green paper was undertaken in summer 2022.

### **Improvement Plan**

The Government published its <u>SEND and alternative provision improvement</u> <u>plan: right support, right place, right time</u> in March 2023. The plan responded to the green paper consultation and confirmed the Government's future plans.

A roadmap was published alongside the Plan, setting out timelines for key aspects of the Government's proposals.  $^{\rm m}$ 

The Plan confirmed the Government's intention to, among other changes:

- Establish National Standards for SEND and alternative provision.
- Create local SEND and alternative provision partnerships to work with local partners to commission provision for SEND and alternative provision, in line with the National Standards.
- Standardise and digitise Education, Health, and Care Plans.

<sup>&</sup>lt;sup>111</sup> DfE, <u>SEND and alternative provision roadmap</u>, 2 March 2023

- Introduce a new leadership level SENCo (Special Educational Needs Coordinator) NPQ (National Professional Qualification) for schools.
- publish a local and national inclusion dashboard to support the development of local inclusion plans.

In a <u>written statement to the House of Commons</u>, the Children's Minister, Claire Coutinho, said what the Government had heard in the consultation responses "gives us confidence to establish a new national SEND and alternative provision system."<sup>112</sup> The Minister also published a letter to parents providing <u>an overview of the Government's plans</u>.<sup>113</sup>

The Department for Education also published <u>a short blog with an overview of</u> the Plan.<sup>114</sup>

### 4.4 Teachers

Teachers are required to have a clear understanding of the needs of pupils with SEND, including autism, as part of the <u>Teachers' standards</u>.<sup>115</sup> The Department for Education has adopted a <u>framework of core content for initial</u> <u>teacher training</u>, which gives direction to training providers on what should be prioritised to ensure their programmes enable trainees to meet the Teachers' Standards in full.

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 January 2022, the Schools Minister said the training had been given to more than 305,000 people.<sup>116</sup>

### National autism strategy 2021-26

The 2021-26 autism strategy includes a commitment of £600,000 for staff autism training and professional development in schools and colleges in 2021-22, to improve understanding of autism amongst educational professionals.<sup>117</sup>

The strategy also set out that, in the first year, the Government would launch a new anti-bullying programme, and put in place new Mental Health Support Teams and training for Designated Senior Mental Health Leads within

<sup>&</sup>lt;sup>112</sup> HC Deb 2 March 2023 c42WS

<sup>&</sup>lt;sup>113</sup> DfE, <u>Message to parents of children with SEND from Claire Coutinho MP, Minister for Children,</u> <u>Wellbeing and Families</u>, 2 March 2023

<sup>&</sup>lt;sup>114</sup> DfE, <u>How we are improving support for children with Special Educational Needs and Disabilities</u> (<u>SEND</u>), 2 March 2023

<sup>&</sup>lt;sup>115</sup> DfE, <u>Teachers' standards</u>, 1 July 2011

<sup>&</sup>lt;sup>116</sup> <u>PQ 106798 [Teachers: training], 26 January 2022</u>

<sup>&</sup>lt;sup>117</sup> DHSC and DfE, <u>National strategy for autistic children</u>, young people and adults: 2021 to 2026, July 2021, p18

schools, which it said would "also benefit autistic pupils who are more likely to experience poor mental health."<sup>118</sup>

The strategy set out the Government's commitment to opening 37 new special free schools, of which 24 would have provision specifically for autistic children and young people, expected to start operating from September 2022.<sup>119</sup>

#### 4.5

## Exclusions policy and Timpson review

#### **School exclusions**

Statutory guidance is in place on <u>School suspensions and permanent</u> <u>exclusions</u>. The guidance makes clear that it is only lawful to exclude a pupil for disciplinary reasons, and states explicitly that it is "unlawful to exclude a pupil simply because they have SEN or a disability that the school feels it is unable to meet."<sup>120</sup>

#### Review

<u>The Timpson review</u>, as well as a Government response, was published in May 2019.<sup>121</sup> The review set out 30 recommendations for Government on exclusions. Some of the key recommendations were:

- The Department for Education (DfE) should make schools responsible for the children they exclude and accountable for their educational outcomes, and consult on how to do this.
- Ofsted should recognise schools who use exclusion appropriately and effectively.
- Where Ofsted finds off-rolling, this should always be reflected in inspections reports and in all but exceptional cases should result in a judgement that the school's leadership and management is inadequate.
- The DfE should look carefully at the timing and amounts of any adjustments to schools' funding following exclusion, to make sure they neither act as an incentive for schools to permanently exclude, nor discourage a school from admitting a child who has been permanently excluded from elsewhere.

<sup>&</sup>lt;sup>118</sup> DHSC and DfE, <u>National strategy for autistic children</u>, young people and adults: 2021 to 2026, July 2021

<sup>&</sup>lt;sup>119</sup> 16 special free schools have opened since September 2022. See Gov.uk, <u>Get information about</u> <u>schools</u>.

<sup>&</sup>lt;sup>120</sup> DfE, <u>School suspensions and permanent exclusions</u>, September 2022, p15

<sup>&</sup>lt;sup>121</sup> DfE, <u>Edward Timpson publishes landmark exclusions review</u>, 7 May 2019

- Pupil moves should be systematically tracked, to increase transparency on when children move out of schools, where they move to and why.
- In making changes that strengthen accountability around the use of exclusion, DfE should consider any possible unintended consequences and mitigate the risk that schools seek to remove children from their roll in other ways. This should include:
  - reviewing a 'right to return' period where children could return from home education to their previous school, and other approaches that will ensure that this decision is always made in the child's best interests
  - considering new safeguards and scrutiny that mitigate the risk of schools avoiding admitting children where they do not have the grounds to do so.<sup>122</sup>

#### **Government response**

The Government responded positively to the review and said a consultation on how to make schools accountable for the outcomes of permanently excluded children would be opened in autumn 2019. The response also said the Government would rewrite its guidance on exclusions, and behaviour and discipline in schools by summer 2020 (the most recent guidance is linked on the previous page).<sup>123</sup>

The response further said the Department for Education would work with Ofsted to define and tackle off-rolling. Ofsted would respond to the review's relevant recommendations separately.<sup>124</sup>

In November 2021, the then Minister for School Standards, Robin Walker, <u>responded to a parliamentary question</u> about progress in implementing the recommendations of the Timpson Review:

The government is actively taking forward the recommendations from the Timpson Review of School Exclusion through its ambitious programme of action on behaviour, exclusion and alternative provision, which will back head teachers' powers to use exclusion when they need to, enable schools to support children at risk of exclusion, and ensure that excluded children continue to receive a good education.

The department published a call for evidence on behaviour management strategies, in-school units and managed moves in June this year and will shortly be consulting on new statutory guidance on suspensions and permanent exclusions. In addition, as part of the special educational needs and disabilities (SEND) Review, we will be setting out our plans for reforming alternative provision so it can provide leadership and expertise across the

<sup>124</sup> As above, p6-7

<sup>&</sup>lt;sup>122</sup> DfE, <u>Timpson Review of School Exclusion (PDF, )</u>, CP 92, May 2019. Full list of recommendations pages 12-15

<sup>&</sup>lt;sup>123</sup> DfE, <u>The Timpson Review of School Exclusion: Government Response (PDF)</u>, CP 95, May 2019, p5-6

whole school system to incentivise early support, and to ensure stable and high-quality provision for those children and young people most at risk of disengaging from education.  $^{\rm 125}$ 

#### **Off-rolling**

Related concerns about children leaving school rolls are discussed in the Library briefing paper <u>Off-rolling in English schools.</u>

## 4.6 Support in higher education

England's statutory Special Educational Needs and Disabilities (SEND) system does not extend to higher education, which is education generally undertaken in universities. Providers are instead bound by different statutory duties under the <u>Equality Act 2010</u> when it comes to supporting autistic students in higher education. There is also different funding in place known as the <u>Disabled</u> <u>Students' Allowance</u> (DSA).

#### Equality Act 2010

Publicly funded higher education providers have a duty under the <u>Equality Act</u> 2010 not to discriminate against potential or current students if they have a disability.

Not all autistic students will use the word "disabled" about themselves, but autistic students would be protected under the Equality Act if their autism meets the definition of disability set out in the Act.

A disability is defined in the Act as: "a physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities."<sup>126</sup>

Higher education providers must not discriminate against a student with a disability in relation to admissions, how education is provided, exclusion, and any other disadvantage or denial of opportunity or choice. How education is provided includes:

- teaching
- assessments and exams
- facilities, including lecture halls, libraries, and IT
- leisure, recreation, entertainment, and sports facilities

<sup>&</sup>lt;sup>125</sup> PQ 72621 [School Exclusions Review], 16 November 2021.

<sup>&</sup>lt;sup>126</sup> Disability Rights UK, <u>Factsheet F56. Understanding the Equality Act: Information for disabled</u> <u>students</u>, June 2020

- the physical environment
- disciplinary procedures.

#### **Reasonable adjustments**

The Equality Act 2010 requires higher education providers to make "reasonable adjustments" for disabled people.<sup>127</sup> The duty aims to ensure disabled people do not face "substantial disadvantage" compared to nondisabled people.<sup>128</sup>

- The first requirement of the duty covers changing the way things are done (such as changing a practice).
- The second covers making changes to the built environment (such as providing access to a building).
- The third covers providing auxiliary aids and services (such as providing special computer software or providing a different service).<sup>129</sup>

The aim is to prevent disabled people being from disadvantaged and to encourage greater equality in participation and outcomes among all students. The Office for Students, which regulates higher education in England, has published information on effective practice and resources to assist higher education providers in supporting disabled students.<sup>130</sup>

The <u>Disabled Students' Commission</u> is an independent group established by the Office for Students in March 2020 that provides advice and information to higher education providers to improve support for disabled students.

Universities have student support advisers, and many will also have specific disability advisers, who can discuss with autistic students what reasonable adjustments might be available to them depending on their personal situation.<sup>131</sup> Many universities will also publish information on their websites setting out what support is available to autistic students.<sup>132</sup>

#### **Disabled Students' Allowance**

<u>Disabled Students' Allowance</u> (DSA) helps to cover the extra costs a student might incur because of a disability, including a long-term health condition,

<sup>&</sup>lt;sup>127</sup> Equality Act 2010, Section 20 and Schedule 13

<sup>&</sup>lt;sup>128</sup> See the National Autistic Society's webpage on <u>Disability discrimination in further and higher</u> <u>education (GB)</u>, which provides information on discrimination and reasonable adjustments in higher education for autistic students

<sup>&</sup>lt;sup>129</sup> Equality Act 2010, Section 20

<sup>&</sup>lt;sup>130</sup> Office for Students, <u>Disabled students</u>, 27 July 2020

<sup>&</sup>lt;sup>131</sup> Disability Rights UK has a factsheet on some common adjustments for disabled students: Disability Rights UK, <u>Factsheet F11. Adjustments for disabled students</u>, April 2020

<sup>&</sup>lt;sup>132</sup> See for example University of Brighton, <u>Students with autistic spectrum conditions</u> (accessed 5 April 2023); University of Kent, <u>Autism Support</u> (accessed 5 April 2023)

mental health condition, physical disability, sensory disability, or specific learning difficulty.<sup>133</sup> Autistic students are eligible for DSA.

DSA can help to pay for:

- specialist equipment, such as a computer or disability-related software;
- a non-medical helper, such as a British Sign Language interpreter;
- the day-to-day costs of study related to the student's disability; and
- travel costs.

The amount of DSA a student is entitled to will depend on their individual needs. Students may need to provide evidence of their disability and attend a Study Needs Assessment to establish the necessary support. For autistic students, evidence could be a formal medical diagnosis, or a 'working diagnosis' from a doctor.

In England, undergraduate and postgraduate students can get up to £26,291 of support for the 2023/24 academic year.<sup>134</sup> Students apply through Student Finance England and the money is generally paid directly to the organisation providing the service or equipment, but may also be paid into the student's bank account depending on the support required.

The Government's SEND Improvement Plan said the Department for Education and the Welsh Government are working with the Student Loans Company to reduce the length of time between a student making a DSA application and having their support agreed. It also said the Government would "seek to set expectations" on how students should be supported to apply for DSA.<sup>135</sup>

#### **Transitioning into higher education**

The consultation period for the Government's 2022-23 SEND review revealed some young people with SEND do not feel effectively supported to transition into higher education. Delays to receiving support through the Disabled Students' Allowance (DSA) were highlighted, as were differences in the levels and types of support available at different higher education providers.<sup>136</sup>

The transition to higher education can be especially challenging for neurodiverse students. Rachel Nowicki, Disability Support Advisor at the Dyson Institute of Engineering and Technology, has said coping strategies

<sup>&</sup>lt;sup>133</sup> GOV.UK, <u>Help if you're a student with a learning difficulty, health problem or disability</u> (accessed 16 March 2023)

<sup>&</sup>lt;sup>134</sup> GOV.UK, <u>Help if you're a student with a learning difficulty, health problem or disability</u> (accessed 16 March 2023)

<sup>&</sup>lt;sup>135</sup> DfE, <u>SEND and alternative provision improvement plan: right support, right place, right time</u>, CP 800, March 2023, p46

<sup>&</sup>lt;sup>136</sup> DfE, <u>SEND and alternative provision improvement plan: right support, right place, right time</u>, CP 800, March 2023, p46

"can crumble in the face of increased independence, the removal of existent scaffolding and a new routine."<sup>137</sup>

The <u>2021-26 autism strategy</u> identifies "improving autistic children and young people's access to education and supporting positive transitions into adulthood" as a priority area. By 2026, the Government wants transitions into adulthood to improve, so that more autistic young people can, among other things, access higher education opportunities.

The Government's SEND Improvement Plan states the Department for Education is developing "good practice guidance" to support transitions for children and young people with SEND and in alternative provision between all stages of education from early years education.<sup>138</sup> This will focus initially on transitions into and out of post-16 settings, including transitions into employment, adult services, and out of alternative provision.

A <u>blog post on the Department for Education's teaching blog</u> by Leila Morne, an Advanced Autism Practitioner and Lecturer in Autism at Weston College, highlights the increase in the number of autistic university students and outlines how they can be better supported so their university experience is improved. It suggests immersive learning experiences to teach money management and study and social skills, as well as individualised training programmes so students can access tailored support.<sup>139</sup>

<sup>&</sup>lt;sup>137</sup> Advance HE, <u>A proactive approach to neurodiversity in higher education</u>, 21 March 2022

<sup>&</sup>lt;sup>138</sup> DfE, <u>SEND and alternative provision improvement plan: right support, right place, right time</u>, CP 800, March 2023, p45

<sup>&</sup>lt;sup>139</sup> DfE teaching blog, <u>Supporting students with SEND transition into higher education</u>, 29 March 2022

5

## **Employment and autism**

Since January 2020, the Office for National Statistics (ONS) have collected data on autistic people through the <u>Annual Population Survey</u> (APS).

The Department for Work and Pensions publishes an annual set of <u>statistics</u> on the employment of disabled people which uses the APS data, and includes a breakdown of employment rates for disabled people depending on the type of disability. These statistics use the <u>Government Statistical Service (GSS)</u> <u>Harmonised Standard definition of disability</u>, in line with the Equality Act 2010 (EA) core definition. A person is considered disabled if they have a selfreported long-standing illness, condition or impairment, which causes difficulty with day-to-day activities.<sup>140</sup>

These statistics show that disabled people on the autism spectrum were amongst the least likely to be in employment of all disabled people. 29.9% of disabled people with autism as a main or secondary health condition were in employment in the 2021/22 financial year, which compared to 54.3% for all disabled people and 81.1% of non-disabled people.

The National Autistic Society reported in 2016 that 77% of unemployed autistic people wanted to work.<sup>141</sup>

The ONS have reported that disabled employees with autism as their main impairment have a wider pay gap in comparison with non-disabled employees than disabled people with other types of main impairment. Median pay in 2021 for disabled employees with autism was 33.5% less than that for non-disabled employees.<sup>142</sup>

The Association of Graduate Careers Advisory Services (AGCAS) <u>Disability</u> <u>Task Group</u> produces an annual report on the employment outcomes of disabled graduates. In the 2022 report they have reported the following outcomes for graduates with autism in 2019:<sup>143</sup>

- They were least likely to be in paid employment of all the disability groups.
- They were most likely to be in insecure work.

<sup>&</sup>lt;sup>140</sup> DWP, <u>The employment of disabled people</u>, 26 January 2023

<sup>&</sup>lt;sup>141</sup> National Autistic Society, <u>The autism employment gap (PDF)</u>, October 2016

<sup>&</sup>lt;sup>142</sup> ONS, <u>Disability pay gaps in the UK: 2021</u>, 25 April 2022

<sup>&</sup>lt;sup>143</sup> AGCAS Disability Task Force, <u>What Happens Next? 2022 (A report on the outcomes of 2019 disabled</u> <u>graduates</u>), 26 May 2022

- They were least likely to have supervisory responsibilities.
- They were more likely to be over-qualified for their job.

In their September 2019 report <u>The Autism Act, 10 Years On (PDF)</u>, the All-Party Parliamentary Group on Autism found only 12% of autistic adults were receiving employment support, despite 42% needing it and only 13% said the support they were receiving helped them find or stay in work. Only 4% said Jobcentre Plus staff have a good understanding of autism.<sup>144</sup>

## 5.1 National autism strategy 2021-26

In the 2021-26 autism strategy, the Government said by the end of the strategy in 2026, it will have improved the support provided to autistic people to help them find and stay in work:

By the end of the strategy, we will have improved the support autistic people can access to find and stay in work. This includes making sure that existing services and work programmes are more autism-inclusive and better able to help autistic people find the right employment opportunity for them. In addition, we will have improved welfare support for autistic people who are unable to work, so they can get the support they need to live well in their communities.<sup>145</sup>

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

- Improving employer awareness of autism: developing a better understanding of the benefits of employing autistic people and the adjustments needed to recruit and properly support them.
- Improving the accessibility of employment programmes for autistic people.
- Making Jobcentres more autism-inclusive.<sup>146</sup>

The strategy also outlines some of the programmes currently in place to meet these commitments.<sup>147</sup> These include:

• The <u>Disability Confident</u> scheme aims to help organisations "improve how they attract, recruit and retain disabled workers". This will include

<sup>&</sup>lt;sup>144</sup> National Autistic Society, <u>The Autism Act</u>, <u>10 Years On: A report from the All-Party Parliamentary</u> <u>Group on Autism on understanding, services and support for autistic people (PDF)</u>, <u>15 September</u> 2019

 <sup>&</sup>lt;sup>145</sup> DHSC and DfE, <u>National strategy for autistic children</u>, young people and adults: 2021 to 2026 (PDF),
21 July 2021

<sup>&</sup>lt;sup>146</sup> As above, p22

<sup>&</sup>lt;sup>147</sup> As above, pp22-23

webinars focused specifically on supporting autistic people in the workplace.<sup>148</sup>

- The <u>Access to Work</u> programme provides support to meet the needs of disabled people in the workplace. Access to Work grants are available to both employees and to the self-employed, and aim to provide practical and financial support to help disabled people find or stay in work.<sup>149</sup>
- The Intensive Personalised Employment Support programme provides personalised support to those with more complex needs or barriers. People on this programme will have a dedicated support worker who will provide one-to-one support and training to help them get into work. They will usually receive this support for 15 months, as well as six months of on-the-job support if they find employment.<sup>150</sup>
- The <u>Autism Exchange Internship Programme</u> aims to provide autistic young people with experience of working in the Civil Service. The Government has committed to expanding this programme outside of London and the South East.<sup>151</sup>

Information on these schemes is provided in the Library briefing, <u>Disabled</u> people in employment.

In April 2023, the Department of Work and Pensions announced a <u>review</u> <u>considering how to improve autistic people's employment prospects</u>. The review will be led by Sir Robert Buckland KC MP and supported by the charity Autistica. The review will seek to identify the barriers autistic people face to entering, sustaining and progressing in employment. Recommendations will be reported to the Secretary of State in September 2023.<sup>152</sup>

## 5.2

## Accessing Jobcentre Plus offices and services

The 2021 strategy also acknowledged concerns that some autistic people struggle to get the right support because they feel Jobcentre staff do not understand their needs, or the adaptations they need to make to engage with autistic people, and that for some people the Jobcentre environment can be anxiety-inducing or distressing.

The strategy said the Government would continue efforts to make the Jobcentre network more welcoming and supportive to autistic customers, developing and testing new approaches to provide intensive support through

<sup>&</sup>lt;sup>148</sup> HM Government, <u>Disability Confident</u>, (accessed 2 March 2023)

<sup>&</sup>lt;sup>149</sup> GOV.UK, <u>Access to Work: get support if you have a disability or health condition</u>, (accessed 2 March 2023)

<sup>&</sup>lt;sup>150</sup> GOV.UK, <u>Intensive Personalised Employment Support</u>, (accessed 2 March 2023)

<sup>&</sup>lt;sup>151</sup> DHSC and DfE, <u>Autism strategy action plan: 2021 to 2022 (Annex A) (PDF)</u>, 22 July 2021, p9

<sup>&</sup>lt;sup>152</sup> DWP press release, 'New review to boost employment prospects of autistic people', 2 April 2023

'Health Model Offices'.<sup>153</sup> Further information on Health Model Offices and other local initiatives to support autistic people can be found in paragraphs 126-130 of the <u>Health and Disability Green Paper</u>.

For Department for Work and Pensions (DWP) staff, there is also a '<u>Hidden</u> <u>Impairments Toolkit</u>' (PDF).<sup>154</sup> The purpose of this resource is to "help DWP colleagues understand how they can provide better support to claimants and people with autism and associated hidden impairment conditions".

The Government has previously reported it is unable to assess the effectiveness of this training due to the lack of robust employment figures for autistic people.<sup>155</sup>

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

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

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

Work coaches will also be able to help providers and employers in the local communities understand the additional needs required by autistic employees, which should in turn create more opportunities for autistic jobseekers in settings where they can thrive.<sup>156</sup>

All 15 Jobcentres involved "achieved accreditation"<sup>157</sup> and the Government is "exploring whether this framework and these improvements can be rolled out across the wider network."<sup>158</sup>

 <sup>&</sup>lt;sup>153</sup> DHSC and DfE, <u>National strategy for autistic children</u>, young people and adults: 2021 to 2026, 22
July 2021, chapter 5

<sup>&</sup>lt;sup>154</sup> Hidden Impairment National Group, <u>Uncovering Hidden Impairments Toolkit (PDF 622KB)</u>, March 2017 (cited in a <u>DWP Freedom of Information response of 14 October 2019</u>, <u>DWP Ref: FOI2019/32844</u>)

<sup>&</sup>lt;sup>155</sup> PQ 203312, 8 January 2019

<sup>&</sup>lt;sup>156</sup> DWP press release, <u>New government support package to help more disabled people into work</u>, 29 December 2021

<sup>&</sup>lt;sup>157</sup> PQ65876, 26 October 2022

<sup>&</sup>lt;sup>158</sup> DWP, <u>Transforming Support: The Health and Disability White Paper, CP 807</u>, 15 March 2023, para 82

## 5.3 Other developments

In August 2022, following a "successful" proof of concept, the Government launched the Local Supported Employment (LSE) initiative in 24 local authorities in England and Wales. The Government has announced it will provide funding of £7.6 million and this is intended to help over 2,000 adults with learning disabilities and autism move into employment.<sup>159</sup>

The proof of pilot concept was run in 9 local authorities from November 2017 for 18 months.

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

It worked with Autism Alliance UK to produce an <u>Autism and Neurodiversity</u> toolkit in April 2017. The aim of this toolkit is to support awareness and understanding of Autism Spectrum Conditions and provide guidance to support autistic people into employment. The toolkit is updated regularly by Autism Alliance UK.<sup>160</sup>

## 5.4

## Statutory guidance for local authorities/Think Autism

In March 2015, the Government produced updated <u>statutory guidance for</u> <u>local authorities and NHS organisations</u> to support the implementation of the Government's <u>Think autism</u> programme of action. This set out legal duties for local authorities to improve employment outcomes for autistic people:

#### Local Authorities must:

- Ensure that the assessment and care planning process for adult needs for care and support considers participation in employment as a key outcome, if appropriate, and looks at the ways that any such needs may be met in a way which could support adults with autism to become 'work ready';
- when carrying out a needs assessment, consider whether matters other than the provision of care and support could contribute to the achievement of the outcomes an adult with autism wishes to achieve in day-to-day life, and whether the adult would benefit from the provision of anything under section 2 or 4 of the Care Act (preventative services or information and advice services) ,or anything that may be available in the community, including signposting, as appropriate, to Access to Work for

<sup>&</sup>lt;sup>159</sup> BASE, Local Supported Employment (LSE) funding announced by DWP, 18 August 2022

<sup>&</sup>lt;sup>160</sup> <u>PQ 252853</u>, 17 May 2019

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>161</sup>

## 5.5 Anti-discrimination legislation

People who are neurodivergent are covered by the Equality Act 2010 under the definition of disability. In the Act, a person is defined as having a disability if they have a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.<sup>162</sup>

The Equality Act prohibits both direct and indirect disability discrimination in employment and recruitment.<sup>163</sup>

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

#### **Reasonable adjustments**

Under the <u>Equality Act 2010</u>, employers must make reasonable adjustments to support disabled job applicants and employees.<sup>164</sup> As stated in the DWP guidance:

This means ensuring disabled people can overcome any substantial disadvantages they may have doing their jobs and progressing in work.<sup>165</sup>

Examples of reasonable adjustments are included in the guidance and on the gov.uk page <u>Reasonable adjustments for workers with disabilities or health</u> conditions.<sup>166</sup> Access to Work funding can be applied for towards the cost of making such reasonable adjustments.<sup>167</sup>

<sup>&</sup>lt;sup>161</sup> DH, <u>Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (PDF)</u>, March 2015, p51

<sup>&</sup>lt;sup>162</sup> Section 6, <u>Equality Act 2010</u>

<sup>&</sup>lt;sup>163</sup> Section 39, <u>Equality Act 2010</u>

<sup>&</sup>lt;sup>164</sup> As above

<sup>&</sup>lt;sup>165</sup> DWP, Employing disabled people and people with health conditions, 1 September 2022

<sup>&</sup>lt;sup>166</sup> GOV.UK, <u>Reasonable adjustments for workers with disabilities or health conditions</u>. (accessed 2 March 2023)

<sup>&</sup>lt;sup>167</sup> GOV.UK, <u>Access to Work: get support if you have a disability or health condition</u>, (accessed 2 March 2023)

The Equality and Human Rights Commission has provided <u>Examples of</u> reasonable adjustments in practice.<sup>168</sup>

<sup>&</sup>lt;sup>168</sup> Equality and Human Rights Commission, <u>Examples of reasonable adjustments in practice</u>, (accessed 2 March 2023)

6

## Social security and autism

Autistic people may potentially be entitled to a range of different benefits including:

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

## 6.1 Personal Independence Payment

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

PIP was introduced for new claims from April 2013, and Department for Work and Pensions (DWP) is reassessing all existing working age DLA claimants for the benefit. Young people in receipt of DLA are also reassessed for PIP when they reach 16. Full rollout of PIP is not expected to be achieved until 2025.<sup>169</sup>

The PIP assessment was intended to provide a more 'holistic' assessment of the impact of a health condition on an individual's ability to participate in everyday life, compared with that for DLA. PIP was also intended to target support more closely on those most in need. The Coalition Government assumed initially that PIP would ultimately cost 20% less than DLA, but the Office for Budget Responsibility (OBR) has shown that expenditure on PIP is exceeding that on DLA. In December 2019 the OBR noted that, despite its July 2015 forecast expecting spending on working-age disability benefits to fall in cash terms between 2014-15 and 2018-19, spending increased by 36% over the period, amounting to a £4 billion underestimate of disability benefits spending in 2018-19, with PIP rollout 75% complete.<sup>170</sup>

<sup>&</sup>lt;sup>169</sup> Office for Budget Responsibility, <u>Economic and Fiscal Outlook</u>, November 2020, para A.37

<sup>&</sup>lt;sup>170</sup> Office for Budget Responsibility, <u>Welfare trends report</u>, December 2019, paras 2.28-2.31

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

Other extra-costs disability benefits provide support for children (DLA) and people of State Pension age (Attendance Allowance). All these benefits are being replaced with new Disability Assistance benefits in Scotland.<sup>171</sup>

#### **PIP statistics**

A PIP claimant's "main disabling condition" is recorded during their assessment. The disability categories used are based on DWP data standards.<sup>172</sup>

As of October 2022, 154,871 PIP claimants had an autistic spectrum disorder recorded as their main condition.<sup>173</sup> These accounted for 4.9% of all PIP recipients.

The specific disabilities recorded for these claimants were as follows:

- Autism (121,646 recipients, 79%)
- Asperger syndrome (32,800 recipients, 21%)
- Retts disorder (427 recipients, 0.3%)

75% of PIP claimants with an autistic spectrum disorder as their main condition were male (97,638).

These figures include only those for whom an autistic spectrum disorder was recorded as their main condition on their PIP claim. Other PIP claimants may have an autistic spectrum disorder in addition to their main recorded condition.

The table below shows the total number of PIP claimants with an autistic spectrum disorder as their main condition, broken down by type of disorder and PIP award level.

<sup>&</sup>lt;sup>171</sup> See <u>Disability Assistance</u> on the Scottish Government website (accessed 1 March 2023)

<sup>&</sup>lt;sup>172</sup> Stat-Xplore, <u>PIP disability metadata</u>

<sup>&</sup>lt;sup>173</sup> Autistic Spectrum Disorder is a data standard used by the DWP. It includes autism, Asperger Syndrome and Retts Disorder.

Just over half (53%) of claimants with an autistic spectrum disorder were receiving the highest level of award (both the daily living and mobility component at the enhanced rate).

# PIP claims in payment to people with an autistic spectrum disorder as main disabling condition

By award level: October 2022 (Great Britain)

	Total: Autistic		Of which:	
	spectrum	Autism	Asperger	Retts
	disorders		syndrome	disorder
Daily Living - Enhanced	128,118	104,400	23,306	418
In combination with:				
Mobility Award - Enhanced	81,717	71,345	9,974	392
Mobility Award - Standard	35,772	26,339	9,414	20
Mobility Award - not awarded	10,640	6,716	3,915	7
Daily Living - Standard	23,473	14,936	8,529	12
In combination with:				
Mobility Award - Enhanced	2,641	1,895	745	
Mobility Award - Standard	10,347	6,718	3,626	
Mobility Award - not awarded	10,492	6,325	4,154	8
Daily Living - not awarded In combination with:	3,276	2,305	965	
Mobility Award - Enhanced	718	535	185	
Mobility Award - Standard	2,520	1,746	773	
Mobility Award - not awarded	33	28	8	
Total	154,871	121,646	32,800	427

Notes: Components may not sum to totals due to statistical disclosure control, which has been applied at source to avoid the release of confidential data. ".." denotes a nil or negligible number of claimants.

Source: <u>DWP Stat-Xplore</u>, PIP cases with entitlement dataset

#### **Application success rates**

The table overleaf shows that between April 2013 and October 2022, 48% of new claims made by those with an autistic spectrum disorder as their main condition were awarded PIP, while the remaining 52% were disallowed. This was higher than the award rate for all conditions (44%). For those whose main condition was Asperger syndrome, the award rate for new claims was lower at 43%.

For people who were previously receiving Disability Living Allowance (DLA) and who underwent reassessment to determine entitlement to PIP, 74% of those with an autistic spectrum disorder were awarded PIP, compared with

71% for all conditions. Again, the award rate for reassessed DLA claimants with Asperger syndrome was lower at 55%.

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

Great Britain: April 2013 to October 2022

		Of which:			
	Total	Awarded		Disallowed	
New claim applications					
All claims where disabling condition is recorded	4,662,110	2,054,761	44%	2,607,347	56%
Total: Autistic spectrum disorders	57,438	27,378	48%	30,061	52%
Autism	37,930	18,977	50%	18,956	50%
Asperger syndrome	19,459	8,379	43%	11,085	57%
Retts disorder	43	22	51%	22	51%
DLA-to-PIP reassessments					
All claims where disabling condition is recorded	2,030,665	1,446,767	71%	583,892	29%
Total: Autistic spectrum disorders	151,810	112,111	74%	39,699	26%
Autism	114,542	91,295	80%	23,247	20%
Asperger syndrome	36,813	20,384	55%	16,427	45%
Retts disorder	452	429	95%	26	6%

Notes: Components may not sum to totals due to statistical disclosure control, which has been applied at source to avoid the release of confidential data.

Source: DWP Stat-Xplore, PIP clearances dataset

### PIP mobility component and psychological distress

In March 2017 the DWP introduced regulations to reverse the effect of two Upper Tribunal judgments relating to the PIP eligibility criteria.<sup>174</sup> The most significant change made was to tighten the rules on access to the mobility component for people unable to undertake journeys due to "overwhelming psychological distress." This would potentially affect people with a wide range of conditions, including autistic people. Disability organisations called on the Government not to proceed with the changes.

On 21 December 2017, the High Court ruled the March 2017 regulations were unlawful because they discriminated against people with disabilities in breach of Human Rights Act 1998 obligations and declared that the Secretary of State did not have lawful power to make the regulations (ie, they were 'ultra vires') and should have consulted before making them.<sup>175</sup>

<sup>&</sup>lt;sup>174</sup> See Commons Library briefing CBP-7911, <u>Changes to the Personal Independence Payment eligibility</u> <u>criteria</u>

<sup>&</sup>lt;sup>175</sup> <u>RF v Secretary of State for Work and Pensions [2017] EWHC 3375 (Admin)</u>

The Government did not contest the High Court's decision. The Secretary of State for Work and Pensions said her Department would "take all steps necessary to implement the judgment in MH [the Upper Tribunal decision that had prompted the change to the regulations] in the best interests of our claimants, working closely with disabled people and key stakeholders over the coming months."<sup>176</sup>

In June 2018 the DWP began to review around 1.6 million existing PIP awards, and PIP claims submitted since the original Upper Tribunal judgment in November 2016, to see who could be affected.<sup>177</sup>

It was originally expected that the review would result in around 25,000 claimants by 2022-23 receiving a PIP award who would not have otherwise done so, and around 165,000 receiving a higher award.<sup>178</sup> DWP statistics suggest that far fewer arrears payments than expected are being awarded. By 30 November 2022, the DWP had reviewed 990,000 PIP cases against the MH Upper Tribunal decision, but only around 4,300 resulted in additional payments being made.<sup>179</sup> Some have suggested the relatively small number of awards casts doubt on whether the DWP review is a genuine and effective attempt to identify underpaid PIP claimants.<sup>180</sup>

## 6.2 Benefit assessments

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

- include a requirement in contracts for benefits assessment providers to provide all frontline assessors with autism training, and regularly monitor compliance; and
- ...develop guidance working with autistic people and their families to be disseminated to all providers carrying out benefits assessments on how to properly identify autistic people's needs and ensure assessments truly capture their circumstances.<sup>181</sup>

<sup>178</sup> Office for Budget Responsibility, <u>Economic and fiscal outlook</u>, March 2018, para 4.112

<sup>&</sup>lt;sup>176</sup> HCWS414, 19 January 2018.

<sup>&</sup>lt;sup>177</sup> See DWP, <u>Personal Independence Payment (PIP): Implementation of legal decisions MH and RJ:</u> <u>Frequently Asked Questions (FAQ)</u>, DEP 2020-0061, February 2020

<sup>&</sup>lt;sup>179</sup> DWP, <u>PIP administrative exercise: progress on cases cleared, at 30 November 2022</u>, 15 December 2022

<sup>&</sup>lt;sup>180</sup> Update: LEAP Review May Be Unlawful Leading Barrister Tells Us, Now We Need Your Help, Benefits and Work Newsletter, 23 June 2021

<sup>&</sup>lt;sup>181</sup> All-Party Parliamentary Group on Autism, <u>The Autism Act. 10 Years On</u>, September 2019, p52

While acknowledging some autistic people struggle to access the support they need because they feel benefit assessors may not understand their needs, or because they find the assessment process difficult to engage with, the <u>2021-26 autism strategy</u> did not include any specific commitments on benefit assessments. It did say the DWP's upcoming Health and Disability Support Green Paper would consider how the welfare system could better meet the needs of disabled people, including autistic people.<sup>182</sup>

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

> All Healthcare Professionals conducting Work Capability Assessments receive extensive training regarding autism spectrum disorders as part of their initial new entrant training. This training programme includes simulated assessments covering claimants with autism and learning disabilities to allow Healthcare Professionals to develop appropriate consultation skills. All Healthcare Professionals have access to condition specific information on autism which is quality assured by external reviewers. Healthcare Professionals are further supported by Functional Champions who are available to provide advice to Healthcare Professionals on particular conditions including autism before, during or after an assessment.<sup>183</sup>

The DWP's <u>Work Capability Assessment Handbook</u> for Healthcare Professionals gives further guidance in relation to the assessment of autistic people.<sup>184</sup>

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

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

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

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

Additionally, assessment providers engage with medical experts, charities and relevant stakeholders to strengthen their training programmes.<sup>185</sup>

<sup>&</sup>lt;sup>182</sup> DHSC and DfE <u>National strategy for autistic children, young people and adults: 2021 to 2026</u>, 22 July 2021, chapter 5

<sup>&</sup>lt;sup>183</sup> PQ 112878 [Work Capability Assessment: Autism], 20 November 2017.

<sup>&</sup>lt;sup>184</sup> DWP, <u>Work Capability Assessment handbook: for healthcare professionals</u>, updated 21 December 2022

<sup>&</sup>lt;sup>185</sup> PQ 235 [Personal Independence Payment: Medical Examinations], 8 January 2020.

Both PIP assessment providers also have 'Health Condition Insight Reports' that cover autism specifically. These are completed by representative groups and provide "insights from real life examples to describe common issues faced by the people they support". One provider has also developed a podcast on attention deficit hyperactivity disorder (ADHD) available to all their Health Professionals.<sup>186</sup>

# Health Transformation Programme and the Health and Disability Green Paper

In March 2019 the then Secretary of State for Work and Pensions, Amber Rudd, announced her Department had launched a 'Health Transformation Programme' to develop a new, integrated service, supported by a single digital system, for both Personal Independence Payment assessments and Work Capability Assessments.<sup>187</sup>

In March 2020 the then Minister for Disabled People, Work and Health, Justin Tomlinson, announced the Department would initially develop the new service on a small scale "in a defined part of the country, a Transformation Area". In the Transformation Area, assessments are being conducted directly by the DWP.<sup>188</sup>

The Government gave further information on plans for improving assessments for disability and incapacity benefits, including how it is exploring different ways to conduct assessments and reduce unnecessary assessments, and initiatives to improve decision making on benefit claims more broadly, in chapter 3 of <u>Shaping Future Support: the Health and Disability Green Paper</u>, published by the DWP on 20 July 2021.<sup>189</sup> This includes an overview of progress towards developing the integrated 'Health Assessment Service' under the Health Transformation Programme, bringing "the assessments for PIP and UC/ESA onto a single, digital system."<sup>190</sup>

Further information on plans to develop the integrated Health Assessment Service, and on other proposals set out in the green paper to deliver improvements to the health and disability benefits system, is given in the DWP's November 2021 submission to the Work and Pensions Committee's inquiry on health assessments for benefits.<sup>191</sup> This confirms the Department has begun work to procure contracted health assessment services for the period 2023-2028, and it has "no plans to in-house the assessment service beyond the small Health Transformation Area".

The DWP published <u>Transforming Support: The Health and Disability White</u> <u>Paper</u> alongside a Spring Budget on 15 March 2023. This noted an ongoing

<sup>&</sup>lt;sup>186</sup> PQ 79458 [Autism and Hyperactivity: Females], 30 November 2021.

<sup>&</sup>lt;sup>187</sup> HCWS1376 5 March 2019

<sup>&</sup>lt;sup>188</sup> HCWS138 2 March 2020

<sup>&</sup>lt;sup>189</sup> DWP, <u>Shaping future support: the health and disability green paper</u>, CP 470, July 2021

<sup>&</sup>lt;sup>190</sup> As above, paras 173-175

<sup>&</sup>lt;sup>191</sup> DWP, <u>Written Evidence for the Health Assessments for Benefits inquiry</u>, HAB0079, November 2021

commitment to developing services in the Health Transformation Area, working towards:

- Making the claim journey more of a two-way conversation. This involves building a holistic picture of the person by seeking relevant evidence and clarifying our understanding at every stage;
- Telling people about our decisions in a simple, straightforward and compassionate way. This will help people understand the outcome we have reached and why, and also help us understand if we can provide further support; and
- Increasing the number of decisions we get right first time by engaging people throughout their journey and ensuring we are obtaining more relevant evidence earlier. This should lead to a reduction in mandatory reconsiderations and appeals and make it more straightforward to challenge the outcome of a claim.<sup>192</sup>

The white paper also said the DWP is "evaluating how well telephone and video assessments are working compared to face-to- face assessments," and is "progressing a move to an IT system that will have the capability to record all assessments, including telephone and video."<sup>193</sup>

#### **Plans to abolish the Work Capability Assessment**

Chapter 4 of the white paper also outlined further plans for disability assessment reform.

The main proposal is to abolish Work Capability Assessment, which currently helps determine entitlement to extra amounts in Universal Credit and Employment and Support Allowance, as well as any work-related requirements people have to meet as a condition of their claim. Instead, a new "UC health element", available to claimants who also receive PIP, will replace the existing element for claimants who are assessed as having "limited capability for work and work-related activity".<sup>194</sup> Conditionality groups will no longer be assigned automatically following assessment, but will be decided individually through a "new personalised health conditionality approach"<sup>195</sup>

The Government argues that determining entitlement this way will "enable people to try to work without the fear of losing their benefits", and conditionality changes will "give people confidence that they will receive support, for as long as it is needed, regardless of whether they are working."<sup>196</sup>

<sup>&</sup>lt;sup>192</sup> DWP, <u>Transforming Support: The Health and Disability White Paper, CP 807</u>, 15 March 2023, paras 108-109

<sup>&</sup>lt;sup>193</sup> As above, paras 110-113

<sup>&</sup>lt;sup>194</sup> As above, paras 144-150

<sup>&</sup>lt;sup>195</sup> As above, paras 158-162

<sup>&</sup>lt;sup>196</sup> HCWS 636, 15 March 2023

These reforms will require new primary legislation, which will be brought forward in a future Parliament. The white paper says once legislation is passed:

These reforms would then be rolled out, to new claims only, on a staged, geographical basis from no earlier than 2026/27. We would expect the new claims roll-out to be completed within three years (so by 2029 at the earliest), when we would then begin to move the existing caseload on to the new system.<sup>197</sup>

## 6.3 Universal Credit

Universal Credit is replacing tax credits and means-tested benefits (including income-related Employment and Support Allowance and Housing Benefit) for working age individuals and families, in or out of work. Eventually, around 7 million households are expected to be claiming Universal Credit.<sup>198</sup>

For some people on the autism spectrum, navigating the Universal Credit system may be a challenge if they do not have an appointee to act on their behalf.<sup>199</sup> An autistic person could, for example, face challenges making and managing their claim online, interacting (either online, or in person) with their Work Coach, and satisfying 'conditionality' requirements. The removal of 'implicit consent' in Universal Credit may also make it harder for advisers and support workers to advocate for autistic clients.<sup>200</sup>

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

The DWP should have in place procedures to identify Universal Credit claimants with complex needs – including those with learning disabilities – so they can get the support they need throughout the 'customer journey' and be subject to conditionality requirements that reflect their needs and circumstances. Identifying claimants with complex needs can also be important in determining whether the person needs extra help with making

 <sup>&</sup>lt;sup>197</sup> DWP, <u>Transforming Support: The Health and Disability White Paper, CP 807</u>, 15 March 2023, para 156
<sup>198</sup> <u>Budget measures bring number of families entitled to Universal Credit to 7 million</u>, Institute for

Fiscal Studies, 8 November 2021

<sup>&</sup>lt;sup>199</sup> When a claimant lacks the capacity to manage their benefit affairs, the Secretary of State may appoint a person to act on their behalf for benefit purposes. For further information see the DWP UC guidance chapter on <u>Appointees</u>. Personal Acting Bodies and Corporate Acting Bodies (PDF, 170KB), Version 10.0, current November 2023

<sup>&</sup>lt;sup>200</sup> Where implicit consent is accepted, a third party can deal with the DWP on behalf of a claimant in the absence of valid written authority, or where the claimant is not present at the time to confirm their consent verbally. In UC, the claimant must provide explicit consent before information can be disclosed to a representative – although an exception has been made for Members of Parliament. For further information see the DWP UC guidance chapter <u>Consent and disclosure including when to share with third parties</u> (PDF, 134KB), Version 19.0, current October 2021

and maintaining their claim, whether they would benefit from alternative payment arrangements, in deciding whether there is 'good cause' for failing to comply with conditionality, or whether they should be offered home visits.<sup>201</sup>

Further information on arrangements for helping people unable to access Universal Credit via the standard online process can be found in the <u>DWP</u> <u>Universal Credit guidance chapter Assisted digital overview</u> (PDF).<sup>202</sup>

Information on the Help to Claim service – which provides "tailored, practical support to help people make a Universal Credit claim up to receiving their first full correct payment on time"<sup>203</sup> – is available on the Citizens Advice website – see <u>Get help applying for Universal Credit</u>.

Guidance for DWP staff says that when a Universal Credit claimant with complex needs contacts the Department, their customer journey "must be equal in quality and outcome to those whose needs are not complex" and it is important to ask them and record what additional support they need "to make sure it's available every time the claimant needs it". The guidance says this "will provide them with equal access to products and services and enable them to follow the standard claimant journey, if appropriate".<sup>204</sup> There have been concerns that arrangements for identifying those needing support have not always worked as intended.<sup>205</sup>

For Universal Credit claimants, their Work Coach is the key point of contact within the DWP. <u>A DWP microsite giving information for prospective</u> <u>applicants</u> for these posts explains:

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

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

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

A Commons written answer September 2020 provided information on training and support for Work Coaches to enable them to support autistic claimants:

> Jobcentre and Service Centre staff undergo a comprehensive learning journey designed to equip them with the tools, skills and behaviours required to provide a high quality service to all claimants, including those with Asperger's

<sup>&</sup>lt;sup>201</sup> DWP UC guidance chapter <u>Complex needs overview</u> (PDF,135KB), Version 18.0, current October 2022

<sup>&</sup>lt;sup>202</sup> Version 14.0, current October 2023

<sup>&</sup>lt;sup>203</sup> PQ 6510 [Universal Credit], 31 October 2019

<sup>&</sup>lt;sup>204</sup> As above

<sup>&</sup>lt;sup>205</sup> See <u>UC and complex needs</u>, Owen Stevens, CPAG Welfare Rights Bulletin, August 2019

syndrome and autism. They receive on-going learning in their roles and have access to guidance which is refreshed at regular intervals.

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

Additionally, Universal Credit Work Coaches are equipped with guidance to enable them to provide a high quality service to all claimants including those in need of specific support. Universal Credit guidance includes examples of life events, personal circumstances, health issues and disabilities which could affect the claimant's ability to access and use Universal Credit services.<sup>206</sup>

<sup>&</sup>lt;sup>206</sup> PQ 94432 [Universal Credit: Autism], 28 September 2020

## 7 The criminal justice system and autism

7.1

# Review of neurodiversity in the criminal justice system

The Ministry of Justice's (MoJ) September 2020 white paper <u>A Smarter</u> <u>Approach to Sentencing (PDF)</u> said the MoJ would launch a national 'Call for Evidence' to obtain a clearer picture of prevalence and the current national provision to support offenders with neurodivergent conditions in the criminal justice system.<sup>207</sup> It also said the Government would be improving awareness, understanding and training on neurodiversity across the system and would develop a national training toolkit to increase the skills of frontline staff on neurodiversity.

In December 2020 the then-Justice Secretary, Robert Buckland, commissioned HM Inspectorate of Prisons, with support from HM Inspectorate of Probation and HM Inspectorate of Constabulary and Fire & Rescue Services, to undertake an independent review of neurodiversity in the criminal justice system.<sup>208</sup>

The report, <u>Neurodiversity in the criminal justice system: A review of evidence</u> was published in July 2021.<sup>209</sup> It said evidence received as part of the review suggests neurodivergence<sup>210</sup> is more prevalent in the criminal justice system than in the wider community.<sup>211</sup>

The review focused on four main themes:

- screening to identify neurodivergence in criminal justice system service users;
- adjustments that have been made to existing provision to support those with neurodivergent needs;

<sup>&</sup>lt;sup>207</sup> MoJ, <u>A Smarter Approach to Sentencing, September 2020 (PDF, 639KB)</u>, CP 292, p57

 <sup>&</sup>lt;sup>208</sup> Gov.uk, press release, <u>Fairer justice system for neurodivergent people to reduce crime</u>,
18 December 2020

 <sup>&</sup>lt;sup>209</sup> Criminal Justice Joint Inspection, <u>Neurodiversity in the criminal justice system: A review of evidence</u>,
15 July 2021

<sup>&</sup>lt;sup>210</sup> Neurodiversity is defined in the review as an umbrella term for conditions under the broader category of neurodevelopmental disorders, including: learning difficulties and disabilities, attention deficit hyperactivity disorder, autism spectrum conditions, developmental language disorder, tic disorders and cognitive impairments due to acquired brain injury.

<sup>&</sup>lt;sup>211</sup> As above para 2.11

- programmes and interventions which have been specifically designed or adapted for neurodivergent needs; and
- training and support available to staff to help them support people with neurodivergent needs.<sup>212</sup>

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

...such provision is patchy, inconsistent and uncoordinated, and that too little is being done to understand and meet the needs of individuals.  $^{\rm 213}$ 

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

- A common screening tool for universal use within the criminal justice system should be introduced
- Screening data should be systematically collected and aggregated to provide a more accurate assessment of the prevalence of neurodivergence
- A programme of awareness-raising and specialist training should be developed and delivered to staff working within criminal justice services
- Adjustments to meet the needs of those with neurodivergent conditions should be made throughout the criminal justice system
- Criminal justice system agencies should work together and with other statutory and third sector organisations in a coordinated way, to understand and meet the needs of neurodivergent individuals in the community, prevent offending and support rehabilitation.<sup>214</sup>

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

#### Government response

The Government welcomed the report and in September 2021 said an action plan in response would be published in October 2021.<sup>215</sup>

 <sup>&</sup>lt;sup>212</sup> Criminal Justice Joint Inspection, <u>Neurodiversity in the criminal justice system: A review of evidence</u>, 15 July 2021, para 2.4

<sup>&</sup>lt;sup>213</sup> As above, p4

<sup>&</sup>lt;sup>214</sup> As above, p6

<sup>&</sup>lt;sup>215</sup> PQ 45267 [Offenders], 15 September 2021.

The <u>action plan (PDF</u>) was published in June 2022.<sup>216</sup> It set out which of the recommendations in the review had been agreed, partly agreed or not agreed by the Government. For those recommendations agreed or partly agreed, the action plan also set out steps to be taken. <u>The action plan was updated in</u> <u>January 2023 (PDF</u>) and a further update is due in Summer 2023.

Following a six-month exploration phase, the Government concluded that a neurodiversity strategy specifically for the criminal justice system was not needed and that existing policies and strategies for neurodivergent people could be expanded to cover any gaps relating to the criminal justice system.

The January 2023 updated action plan noted that a Cross Government Working Group, led by the Ministry of Justice and an Operational Working Group, had been established to monitor and support the delivery of the action plan.<sup>217</sup>

The updated action plan states that neurodiversity support managers have been introduced in prisons and says that the Government plans to have one in every prison across England and Wales by 2024. It notes that Autism Accreditation is being promoted across the prison estate and states that a 'National Neurodiversity Training Toolkit' is now available for all frontline staff within prison and probation.

Regarding the recommendation for a common screening tool, the updated action plan said that having thoroughly examined the use of screening tools across the criminal justice system, the Government had concluded that whilst consistency of approach is necessary, it would be "inappropriate to use a single tool universally across all agencies because the time available to identify an individual's needs and the types of reasonable adjustment available will vary at every stage of the system".<sup>218</sup>

The updated action plan notes that the Police Working Group is producing a best practice directory to highlight examples of training, reasonable adjustments and innovations.<sup>219</sup>

## 7.2

## National autism strategy 2021-26

The Government's <u>National strategy for autistic children</u>, young people and <u>adults</u>: 2021 to 2026 includes measures intended to improve understanding of autism and support for autistic people within the criminal and youth justice systems.

- <sup>218</sup> As above, p11
- <sup>219</sup> As above, p8

<sup>&</sup>lt;sup>216</sup> Gov.uk, <u>A Response to the Criminal Justice Joint Evidence Review: Neurodiversity in the Criminal Justice System action plan</u>, published 30 June 2022, last updated 25 January 2023

<sup>&</sup>lt;sup>217</sup> MoJ, <u>Action Plan</u> (PDF), updated 25 January 2023, p7

The strategy says available evidence indicates autistic people may be overrepresented as people who come into contact with the criminal and youth justice systems, as victims, witnesses or defendants.<sup>220</sup>

The strategy refers to the <u>All-Party Parliamentary Group (APPG) on Autism's</u> <u>2019 report (PDF)</u>, which found autistic people often have poor experiences when they come into contact with these systems.<sup>221</sup> The strategy notes a lack of understanding of autism can cause staff to misinterpret autistic people's behaviour, resulting in missed opportunities to divert them from the criminal and youth justice systems. The strategy also refers to evidence from the APPG on Autism's inquiry which highlighted that autistic people often find prison environments overwhelming.

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

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

- improve staff awareness and understanding of autism across the criminal and youth justice systems, including prison and probation staff, and youth custodial specialists
- undertake work to improve autistic people's access to adjustments and support and help make environments like prisons and probation services more autism friendly
- drive better access to health and social care services for those in contact with the criminal and youth justice systems, including the support they may need as they leave custody.<sup>222</sup>

 <sup>&</sup>lt;sup>220</sup> DHSC and DfE, <u>National strategy for autistic children</u>, <u>young people and adults</u>: 2021 to 2026,
21 July 2021, p35

<sup>&</sup>lt;sup>221</sup> See: APPG on Autism, <u>The Autism Act</u>, <u>10 Years On</u>: <u>A report from the All Party Parliamentary Group on Autism on understanding</u>. <u>services and support for autistic people and their families in England (PDF)</u>, 2019

 <sup>&</sup>lt;sup>222</sup> DHSC and DfE, <u>National strategy for autistic children</u>, young people and adults: 2021 to 2026, 21 July 2021, p36

## 8 Scotland, Wales and Northern Ireland

## Scotland

8.1

#### Scottish strategy for autism

The Scottish Government and COSLA (Convention of Scottish Local Authorities) published the <u>Scottish strategy for autism</u> in November 2011, backed up with funding of £10m over four years.<sup>223</sup> The strategy contained 26 recommendations including on leadership and cross-agency working, improving access to diagnosis and supporting people with employment.<sup>224</sup>

In 2014, the Scottish Government reported on the progress and noted the publication of a "menu of interventions" to help autistic people and their families to identify support. It also said a one-off £35,000 investment was given to each local authority to develop local autism strategies.<sup>225</sup>

In 2015 the strategy was reframed to become outcome focused. In 2017, the Scottish Government ran a consultation to refresh the strategy.<sup>226</sup> The updated strategy, <u>Scottish strategy for autism: outcomes and priorities 2018-</u>2021, was published in March 2018 and set out actions through to 2021.<sup>227</sup>

Research into <u>the microsegmentation of the autism spectrum: research</u> <u>project</u> was also published in March 2018. It covers economic research on autism and implications for Scotland, including the "escapable" economic costs of not providing the appropriate support for autistic people. Scottish Autism produced a series of "calls to action" in response to the report.<sup>228</sup>

In September 2021, the Scottish Government published an <u>Evaluation of the</u> <u>Scottish strategy for autism</u>. The Evaluation examined the strategy's recommendations and priorities, its impact on autistic people and services that support them, and lessons learnt that could inform future policy. The future policy lessons for the Scottish Government included narrowing the

<sup>&</sup>lt;sup>223</sup> Scottish Government, <u>The Scottish Strategy for Autism</u>, 2 November 2011

<sup>&</sup>lt;sup>224</sup> As above

 <sup>&</sup>lt;sup>225</sup> Scottish Government, <u>The Scottish Strategy for Autism Progress Report - Foundation Stage (2 Years)</u>,
31 October 2014

<sup>&</sup>lt;sup>226</sup> Scottish Government, <u>Scottish Strategy for Autism consultation</u> (Accessed 13 March 2023)

 <sup>&</sup>lt;sup>227</sup> Scottish Government, <u>Scottish Strategy for Autism: outcomes and priorities 2018-2021</u>, 26 March
2018

<sup>&</sup>lt;sup>228</sup> Scottish Autism, <u>Scottish Autism: Service Provider's Response to the Microsegmentation Report</u> <u>2018</u>, July 2018

focus of future work and placing strong requirements on local authorities to deliver, especially where funding is provided.<sup>229</sup>

## Learning/intellectual disability and autism: Transformation plan

In March 2021 the Scottish Government and COSLA published the <u>Learning/intellectual disability and autism: transformation plan</u>, 'Towards Transformation'.

The plan set out 32 actions for the Scottish Government and COSLA over the following 2 years, as summarised below.<sup>230</sup>

#### **Human rights**

- Considering the needs of autistic people and people with learning/intellectual disabilities as part of the <u>independent review of the Mental Health Act</u>.
- Exploring proposals for a commission or commissioner to protect the rights of autistic people and people with learning/intellectual disabilities.

#### Mental health, health and social care

- Improving how mental and physical health services can meet the needs of autistic people by piloting a Nurse/AHP Consultant for Autism and learning/intellectual disabilities and exploring mandatory training for NHS staff.
- Improving diagnostic services and monitoring, piloting a national post diagnostic support service and exploring community asset mapping.
- Involving people with lived experience in future policy work.
- Supporting autistic people and their carers to access their rights under the Social Work (Self Directed Support) (Scotland) Act 2013 and the Carers (Scotland) Act 2016.

#### Employment

 Working towards halving disability employment gap as stated in A Fairer Scotland for Disabled People and <u>A Fairer Scotland for Disabled People:</u> <u>Employment Action Plan.</u>

 <sup>&</sup>lt;sup>229</sup> Scottish Government, <u>Evaluation of the Scottish Strategy for Autism</u>, 24 September 2021, Chapter 5:
Discussions and Conclusions, Lessons gleaned for future policy direction, pp52-53

 <sup>&</sup>lt;sup>230</sup> Scottish Government and COSLA, <u>Learning/intellectual disability and autism: transformation plan</u>,
24 March 2021

• Involving autistic people and people with a learning/intellectual disability in the review of supported employment provision in Scotland.

#### Education

- Working to implement the <u>Additional support for learning: action plan</u> (2020).
- Developing training on autism for trainee teachers and producing guidance on physical intervention and seclusion for schools.
- Developing learning outcome measures that capture autistic children's and children with a learning/intellectual disability's progress beyond solely academic indicators.

#### Digital exclusion and communication

- Improving digital access for autistic people.
- Campaigning to change how autistic people are understood and empowering autistic people to have their voices heard, including through the <u>Different minds. One Scotland</u> campaign and supporting self advocacy initiatives.
- Engaging with autistic people from Black, Asian and Minority Ethnic communities. <sup>231</sup>

More information on Scottish policy affecting autistic people can be found on the Scottish Government website.

## 8.2 Wales

## Autism spectrum disorder (ASD) strategic action plan for Wales

In 2008, the Welsh Government published the Autism spectrum disorder (ASD) strategic action plan for Wales.<sup>232</sup>

In May 2015, the Welsh Government published an <u>Interim delivery plan for</u> <u>children, young people and adults with autism spectrum disorder 2015-16</u>. The plan highlighted priority actions to be taken whilst the ASD strategy was refreshed. It focused on diagnosis, gaps in services and support, education, training and employment support, and training for professionals.<sup>233</sup>

 <sup>&</sup>lt;sup>231</sup> Scottish Government and COSLA, <u>Learning/intellectual disability and autism: transformation plan</u>,
24 March 2021

<sup>&</sup>lt;sup>232</sup> Welsh Government, The Autism Spectrum Disorder (ASD) Strategic Action Plan for Wales: Executive summary and actions, April 2008

<sup>&</sup>lt;sup>233</sup> Welsh Government, <u>ASD Interim Delivery Plan 2015</u>, April 2015

In November 2016, the Welsh Government published a <u>Refreshed autism</u> <u>spectrum disorder strategic action plan</u>, which set out three priority areas for the coming years:

- Awareness raising, information and training;
- Assessment and diagnosis; and
- Meeting support needs.<sup>234</sup>

The plan included a commitment to publish a delivery plan and to report annually on progress in relation to the specific actions within the plans.<sup>235</sup> Annual reports on progress were published in 2018, 2019, 2020.<sup>236</sup>

In 2018, the Welsh Government published the <u>Autism spectrum disorder</u> <u>delivery plan 2018 to 2021</u>, which included new actions on providing access to services to address unmet needs in education, employment and health and social care. It also included a new awareness raising campaign, updating housing guidance and establishing a GP register for autism.<sup>237</sup>

In 2021, an updated <u>Autism delivery plan 2021 to 2022</u> was published reflecting the new statutory code of practice on the delivery of autism services (see below). It outlined priorities for 2021-22 and said future priorities would be informed by the outcomes of a demand and capacity review of neurodevelopmental services.<sup>238</sup>

The priorities for 2021-22 were:

- Continuing to fund the National Autism Team (NAT) to support the implementation of the Code of practice.
- Raising awareness of autism and the Code of practice through promotion of the Autism Aware campaign.
- Training the local authorities local health board (LHB) workforce on autism and the Code of practice.
- Improving diagnostic services through the duties placed LHBs in the Code, funding the Integrated Autism Service and working with the Together for Children and Young People Programme 2 neurodevelopmental workstream.
- Including the Welsh language in service delivery.
- Supporting autistic people's recovery from Covid-19.

<sup>&</sup>lt;sup>234</sup> Welsh Government, <u>Autism spectrum disorder: strategic action plan 2016</u>, 5 December 2016

<sup>&</sup>lt;sup>235</sup> As above, p25

<sup>&</sup>lt;sup>236</sup> Annual reports can be downloaded from <u>Autism and neurodivergence (GOV.WALES)</u>

<sup>&</sup>lt;sup>237</sup> Welsh Government, <u>Autism spectrum disorder delivery plan 2018 to 2021</u>, September 2018

<sup>&</sup>lt;sup>238</sup> Welsh Government, <u>Autism delivery plan 2021 to 2022</u>, 15 July 2021

- Supporting and including autistic people from Black, Asian and Minority Ethnic backgrounds and/ or LGBTQ+ autistic people.
- Involving autistic people and their carers in policy making through the Welsh Government Autism Advisory Group and Autistic Champions on Regional Partnership Boards (RPBs).
- Ensuring the needs of autistic people are captured in population needs assessments and developing autism infrastructure through funding for RPBs.<sup>239</sup>

#### The Code of Practice on the delivery of autism services

In July 2021, the Welsh Government published a statutory <u>Code of Practice on</u> <u>the delivery of autism services</u>. The Code of Practice is intended to reinforce the duties of the Social Services and Wellbeing (Wales) Act 2014 and the NHS (Wales) Act 2006 as an alternative to a separate Autism Bill.<sup>240</sup>

The Code of Practice aims to inform autistic people about the support they should expect and provide guidance to statutory services to plan, deliver and monitor autism services. It covers the following areas:

- Arrangements for autism assessment, diagnosis and post-diagnostic support.
- Arrangements for accessing health and social care services including advocacy, preventative services, local authority care, mental health services and carer assessments.
- Arrangements for awareness training and training on autism including in health, social care and educational settings.
- Arrangements for planning and monitoring services, including data collection, and ensuring stakeholder involvement.<sup>241</sup>

The Code of Practice came into force on 1 September 2021.

More information can be found on the Welsh Government website.

<sup>&</sup>lt;sup>239</sup> Welsh Government, <u>Autism delivery plan 2021 to 2022</u>, 15 July 2021

<sup>&</sup>lt;sup>240</sup> Welsh Government, <u>Code of Practice on the delivery of autism services</u>, 16 July 2021

<sup>&</sup>lt;sup>241</sup> As above

## 8.3 Northern Ireland

<u>The Autism Act (Northern Ireland) 2011</u> requires the Northern Ireland Department of Health to publish an autism strategy (for all ages) and to report on its implementation at three yearly intervals.<sup>242</sup>

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

The structure of the Action Plan set 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<sup>243</sup>

A progress report on the implementation of the strategy was published in September 2015.<sup>244</sup> A second progress report was published in 2019.<sup>245</sup>

In 2016, The National Autistic Society Northern Ireland and Autism NI published <u>Broken Promises</u>, which considered evidence on the impact of the 2011 Act, strategy and action plan. The report said life was getting more

<sup>&</sup>lt;sup>242</sup> Autism Act (Northern Ireland) 2011 (legislation.gov.uk)

 <sup>&</sup>lt;sup>243</sup> Northern Ireland Executive, <u>The Autism Strategy (2013-2020) and Action Plan (2013-2016) (PDF)</u>,
2014

<sup>&</sup>lt;sup>244</sup> Department of Health NI, <u>Autism Strategy (2013 – 2020) Action Plan (2013 – 2016) Progress Report</u>, September 2015

<sup>&</sup>lt;sup>245</sup> Department of Health NI, <u>The Autism Strategy (2013 – 2020) - Second Progress Report 2018</u>, July 2019

difficult for autistic people and services were failing to deliver. It called on the Assembly and government to fulfil commitments made in 2011.<sup>246</sup>

In March 2021 the then-Minister of Health, Robin Swann MLA, published an <u>Interim autism strategy for action for 2021-22</u>, noting that the Covid-19 pandemic had delayed the development of a longer strategy.<sup>247</sup> The interim strategy had three strategic outcomes:

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

In 2022, the <u>Autism (Amendment) Act (Northern Ireland) 2022</u> was passed. The legislation introduces:

- Data collection on how many adults and children are on the autism spectrum.
- Additional components to the autism strategy, including provision for:
  - training for staff of Northern Ireland departments and other public bodies;
  - an autism support and early intervention service;
  - an autism information service;
  - meeting the needs of autistic adults; and
  - reducing diagnostic waiting times.
- Requirements for the strategy to take a cross-departmental approach, be developed with the autism community and include measurable targets.
- A requirement for the Minister to produce a report each financial year on the funding for autism.

<sup>&</sup>lt;sup>246</sup> The National Autistic Society Northern Ireland & Autism NI, <u>Bro4ken Promises</u>, 2016

<sup>&</sup>lt;sup>247</sup> Department of Health NI, <u>Autism – Interim Strategy 2021-2022</u>, 8 March 2021

 <sup>&</sup>lt;sup>248</sup> Department of Health NI, <u>Minister of Health publishes cross departmental interim autism strategy</u>,
8 March 2021

• An 'autism reviewer' appointed by the Department to monitor and report on the effectiveness of the strategy.<sup>249</sup>

The Autism strategy 2023-2028 is currently in development. In 2021, a public questionnaire was made available to determine priorities for the strategy.<sup>250</sup> A further <u>public consultation on the new strategy</u> was held between December 2022 and March 2023. The strategy is due to be published in spring 2023 and will reflect the 2022 Act.

<sup>&</sup>lt;sup>249</sup> Autism (Amendment) Act (Northern Ireland) 2022 (legislation.gov.uk)

<sup>&</sup>lt;sup>250</sup> Department of Health Northern Ireland, <u>Autism Strategy 2023-2028</u>, 23 August 2021 (accessed 16 December 2021)

## 9 Further reading

The House of Commons Library has published briefing papers on the following related topics:

- Mental health policy in England
- <u>Reforming the Mental Health Act</u>
- Support for children and young people's mental health (England)
- The NHS workforce in England
- The National Disability Strategy 2021: Content and reaction
- <u>Disability discrimination</u>
- Adult Social Care Funding (England)
- Children's social care workforce
- Adult social care workforce in England
- The Special Educational Needs and Disabilities and Alternative Provision Improvement Plan
- Special Educational Needs: support in England
- Disabled people in employment

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