



## BRIEFING PAPER

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# Autism – overview of UK policy and services

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## Summary

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

It is estimated that more than half a million people in England have autism, which is equivalent to more than 1% of the population. There is however no national register or exact count kept of the number of people with the condition.

Successive Governments have pledged to improve outcomes for people with autism. The *Autism Act* was passed in 2009 and committed the Government to producing a strategy for adults with autism. In 2010, the Government produced the first autism strategy for England, *Fulfilling and rewarding lives*. The associated statutory guidance for local authorities and NHS organisation supported the strategy's implementation, and included duties and recommendations on areas including training of staff, identification and diagnosis of autism, and local service provision. The strategy was updated in 2014 – *Think Autism* built on the 2010 strategy and set a renewed focus on three key areas: building communities that are aware of autism; promoting innovation in service provision; and providing integrated care.

*Think Autism* and the revised statutory guidance contain duties and recommendations for service providers and Government departments across areas including employment, welfare, criminal justice, transport and education services. A progress report on the implementation of *Think Autism* was published in January 2016.

Recent legislation has also provided for new duties for services for people with autism, including the *Care Act 2014* which provides that all staff who undertake autism assessments must have appropriate training, and the *Children and Families Act 2014* which provides for a new special education needs and disability support system, covering education, health and social care.

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

# 1. What is autism?

Autism is a lifelong developmental disability that affects how people communicate and interact with others. It is a spectrum condition, meaning it affects people in different ways.

People with autism may experience differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours. In addition, people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems. These can include a need for routine and difficulty understanding other people, including their intentions, feelings and perspectives.<sup>1</sup>

It is estimated that more than half a million people in England have autism, which is equivalent to more than 1% of the population.<sup>2</sup>

There has been a 25-fold increase in the diagnosis of autism in the last 30 years. However, the diagnosed prevalence remains lower than population-level estimates, as only about two-thirds of children and 1 in 10 adults with autism have a diagnosis. Around 4 times more men than women have diagnosed autism, although this may be due in part to under-recognition of autism in women.<sup>3</sup>

Some people with autism also have other learning difficulties and mental health problems. It is estimated that 50% of people with autism have a learning difficulty. Approximately 70% of people with autism also meet diagnostic criteria for at least 1 other (often unrecognised) mental and behavioural disorder, and 40% meet diagnostic criteria for at least two disorders, mainly anxiety, attention deficit hyperactivity disorder and oppositional defiant disorder.<sup>4</sup>

Further information can be found on the National Autistic Society's page on [About autism](#).

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<sup>1</sup> [NICE quality standard \[QS51\]. Autism](#), January 2014

<sup>2</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives. the strategy for adults with autism in England: an update](#), April 2014, page 4

<sup>3</sup> NICE, [NICE support for commissioning for autism](#), January 2014

<sup>4</sup> NICE, [NICE support for commissioning for autism](#), January 2014

## 2. Government policies on autism in England

### 2.1 Autism Act 2009

The [Autism Act 2009](#), which received Royal Assent in November 2009, placed statutory requirements on the Government to publish an adult autism strategy by April 2010, and associated statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism by 31 December 2010.

Clause 2(5) of the *Autism Act* stated that the guidance must cover, among other areas: the provision of relevant services for diagnosing autism; identification of the numbers of adults with autism at a local level and; training of staff who provide relevant services to adults with autism.

The *Autism Act 2009* was a Private Members Bill introduced by Cheryl Gillan with backing from the National Autistic Society and other autism charities. It was the first disability-specific piece of legislation.

### 2.2 Adult autism strategy for England

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

The strategy focused on five core areas of activity:

- increasing awareness and understanding of autism among frontline professionals
- developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment
- improving access for adults with autism to the services and support they need to live independently within the community
- helping adults with autism into work, and
- enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.<sup>5</sup>

A first year delivery plan was published on 2 April 2010, [Towards fulfilling and rewarding lives: the first-year delivery plan](#). This set out the governance structure and the actions, with timescales and responsibilities, to be taken in the first year to support the implementation of the adult autism strategy.

The Government committed to formally review the strategy after three years.

### 2.3 Statutory Guidance 2010

Following the General Election 2010 the Coalition Government confirmed that it would fulfil the commitment in the *Autism Act* to

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<sup>5</sup> Department of Health, '[Fulfilling and rewarding lives: the strategy for adults with autism in England](#)', 3 March 2010, para 1.8

consult on and publish statutory guidance for local authorities and NHS organisations to support the strategy's implementation.

In December 2010, the Department of Health published [Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy](#). This provided guidance to local authorities, NHS bodies and NHS Trusts on the following key areas:

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

## 2.4 Think Autism strategy 2014

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

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

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

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

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

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

Examples of successful Autism Innovation Fund projects are provided in the [Think Autism progress report](#) (January 2016).

The 2014 strategy also contained a commitment to improve the data available on autism. The Department of Health committed to work with

<sup>6</sup> Department of Health, [The Autism Innovation Fund, national co-ordination of awareness and the champions network 2014/15](#).

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Public Health England to establish a data and information working groups, including the Department for Work and Pensions, the Department for Education and others to report to the National Autism Programme Board to compile a list of data sources for local authorities on people with autism.

The strategy is overseen by the [Adult Autism Programme Board](#) and will be reviewed in five years.

In January 2016, the Department of Health produced a progress report on *Think Autism: Progress Report on Think Autism: the updated strategy for adults with autism in England*. The report summarises progress since the 2014 strategy and sets a number of new actions, focusing on education, employment, the criminal justice system and better data reporting.

### 2.5 Statutory guidance 2015

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

- Training of staff who provide services to adults with autism;
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services;
- Planning in relation to the provision of services for people with autism as they move from being children to adults;
- Local planning and leadership in relation to the provision of services for adults with autism;
- Preventative support and safeguarding in line with the *Care Act 2014* from April 2015;
- Reasonable Adjustments and Equality;
- Supporting people with complex needs, whose behaviour may challenge or who may lack capacity;
- Employment for adults with autism; *and*
- Working with the criminal justice system.

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

### 2.6 'No voice unheard, no right ignored' consultation

In March 2015, the Government published the consultation paper - ['No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions.'](#)

The consultation examined how people's rights and choices can be strengthened. The then Minister for Care Services, Norman Lamb, said the Government want to see four key things:

- People in charge, supported by family and friends – not as passive patients or “prisoners” of a system, as they so often feel they are;
- Inclusion and independence in the community – people should not routinely be sent away from their homes and communities or to institutions which restrict access to their community or to inappropriate care;
- The right care in the right place –there should be real person centred planning with the individual themselves at the heart; and
- Very clear accountability and responsibility throughout the system – there can be no excuses for a lack of clarity over responsibility or for people falling through the gaps between services.<sup>7</sup>

The consultation also looked at issues raised during the 2014 consultation on the *Mental Health Act Code of Practice* regarding the *Mental Health Act* primary legislation.

The scope of the consultation primarily related to:

- assessment and treatment in mental health hospitals for people (all age) with learning disability or autism;
- adult care and support, primarily for those with learning disability but also for adults with autism (and the links to support for children and young people); *and*
- all those to whom the Mental Health Act currently applies (including children and young people).<sup>8</sup>

The Government provided its response to the consultation in November 2015: [Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions](#). The Government set a series of proposals grouped into three implementation phases:

- early actions that seek to sustain momentum generated, chiefly through the use of existing powers and building on work currently underway ;
- further changes, including proposed legislative changes that cannot be achieved via existing powers (and which relate principally to the *Mental Health Act 1983*); *and*
- a third phase, which explores more radical solutions to longer-term issues, as well as ongoing monitoring and review, and a commitment that the Government will intervene further, including through legislation if necessary, if the improvements sought continue not to be realised in practice.<sup>9</sup>

Detailed information on each of the above proposals is available in the Government’s response.

The Minister for Community and Social Care also outlined further areas of work to improve care for people with learning disabilities, autism and mental health problems:

<sup>7</sup> [HCWS355 \[on No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions\]](#), 6 March 2015

<sup>8</sup> *ibid*

<sup>9</sup> Department of Health, [Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions](#), November 2015 para 6



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The proposals in this document go hand in hand with the substantial programmes of work being put in place under the Transforming Care Programme, including the recently announced “Building the Right Support” national transformation plan. This was published on 30th October by NHS England, the Local Government Association and the Association of Directors of Adult Social Services to reduce reliance on inpatient capacity and increase community-based provision. A national NHS England fund of £45 million will be available to Transforming Care Partnerships over the next three years to aid the transition, focussing on ensuring that the right support is available in local areas to enable the first discharges. Central to the progress set out by the plan over the next three years will be new, high-quality, community-based services. The plan predicts that, as these services are put in place, there will be a reduction of up to 50% in the number of inpatient beds, meaning that some units will close altogether.<sup>10</sup>

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<sup>10</sup> [Written Statement HCWS302 \[on Government response to ‘No voice unheard, no right ignored’ consultation\], 10 November 2015](#)

## 3. Health and care services

### 3.1 Diagnosis

The Department of Health has said that many people with autism are likely to be undiagnosed or misdiagnosed.<sup>11</sup> Research by the National Autistic Society in 2012 found that 34% of people reported that they had waited three years or more for a diagnosis after first raising concerns, with a further 30% saying that it had taken between one and two years.<sup>12</sup>

A key action from the *Think Autism* strategy was that NHS England would help improve autism diagnostic services. The strategy set this as one of its 15 priority challenges for action:

I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.<sup>13</sup>

The National Institute for Health and Care Excellence's (NICE) *Quality Standard on autism* recommends that people should have a diagnostic assessment for autism within three months of referral:

#### **Quality statement**

People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

#### **Rationale**

There are several different routes by which someone with possible autism can be referred to an autism team for a diagnostic assessment. It is important that the assessment is conducted as soon as possible so that appropriate health and social care interventions, advice and support can be offered.<sup>14</sup>

*Think Autism* states that each local area is expected to have a clear pathway to diagnosis and each Clinical Commissioning Group (CCG) should designate a health lead responsible for developing, maintaining and promoting a diagnostic and treatment pathway.<sup>15</sup> Local authorities, NHS bodies and Foundation Trusts are asked to undergo a self-assessment evaluation of their diagnosis pathway:

In every local area, the NHS is expected to have a pathway to diagnosis, just as the local authority should have a clear framework for assessing the care and support needs of adults with autism. We will continue to ask local authorities, NHS bodies and Foundation Trusts to assess their progress on developing and

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<sup>11</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 34

<sup>12</sup> The National Autistic Society, [The way we are: autism in 2012](#), page 8

<sup>13</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 7

<sup>14</sup> NICE, [NICE quality standard \[QS51\]. Quality statement 1: Diagnostic assessment by an autism team](#), January 2014

<sup>15</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 16

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maintaining a pathway to diagnosis through the autism local area self-evaluation exercise.<sup>16</sup>

The statutory guidance states that the NICE guidance and NICE Quality Standard on autism represent best practice when developing diagnostic services.<sup>17</sup>

No formal statistics are collected of autism referrals, initial assessments or diagnoses. The Department of Health does however commission Public Health England each year to carry out a self-assessment exercise with local authority areas on progress they are making in implementing the Autism Strategy for Adults in England. Local authorities work with their local partners including CCGs to informally answer a range of questions.<sup>18</sup> As committed to in *Think Autism*, work is being undertaken to improve data sources of autism, including diagnosis. Further information is available in the *Think Autism Progress Report* (see page 12).

The Department of Health has supported the work of the Joint Commissioning Panel (JCP) for Mental Health, co-chaired by the Royal College of Physicians and the Royal College of GPs. They are developing a guide to encourage commissioners to use a values-based commissioning model when planning diagnostic services, which was a recommendation in *Think Autism*. The JCP will issue the practical guide on autism by April 2016.<sup>19</sup>

The autism statutory guidance states that NHS England local audit teams will assess the quality of autism diagnostic pathways and people's experiences of using them. Further information was given in a recent debate:

Diagnosis is of course a process which should be driven locally by clinical commissioning groups, working in partnership with their local authorities, to develop the right pathways to assessment and packages of care which result from a diagnosis. The noble Lord, Lord Hunt, and my noble friend Lady Browning talked about meeting targets and holding CCGs to account. The Department of Health and NHS England, along with the Association of Directors of Social Services, are visiting CCGs and local authorities. These visits aim to develop a better oversight of the challenges in securing timely diagnosis across all ages. They will consider data on waits, which are so essential, and the design of pathways [...]. They will also consider many of the critical issues raised so that they can make an effective assessment of how information is made available to the public, the links to mental health services and social care services, how initial referrals are triaged, and who provides leadership locally for autism support. NHS England will

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<sup>16</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 15 [The results from the 2013 self-assessment exercise, overseen by Public Health England, which reported across all 152 local authority areas in England, is available at [www.ihal.org.uk/projects/autism2013](http://www.ihal.org.uk/projects/autism2013).]

<sup>17</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 16

<sup>18</sup> [PQ HL6524 \[on Autism\], 14 March 2016](#)

<sup>19</sup> Department of Health, [Progress Report on Think Autism: the updated strategy for adults with autism in England](#), January 2016, page 38

complete its work in April and then report to the cross-government autism programme board.<sup>20</sup>

In January 2015, the Royal College of General Practitioners also launched a training programme for its members to improve the diagnosis of autism and support.<sup>21</sup>

## 3.2 Co-existing mental health problems and learning disabilities

Mental health problems can be more common among people with autism. For example, research in 2014 found that about 40% of people with autism have symptoms of at least one anxiety disorder at any time, compared with up to 15% in the general population.<sup>22</sup>

It is also estimated that about half of people with autism also have a learning disability.<sup>23</sup>

*Think Autism* sets as one of its priority challenges for people with autism to have support adapted to their needs if they have a co-existing mental health problem, learning disability or display challenging behaviour:

I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.<sup>24</sup>

The NICE *Quality Standard* on autism states that people who undergo an assessment for autism should also be assessed for co-existing physical and mental health problems:

### Quality Standard

People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

### Rationale

People with autism may have coexisting physical health conditions and/or mental health problems that, if unrecognised and untreated, will further impair the person's psychosocial functioning and could place additional pressure on families and carers. Because of their social communication difficulties, some people with autism may find it particularly difficult to communicate their needs and to access mainstream health and social care services.<sup>25</sup>

The 2015 statutory guidance states that many people with autism have difficulty in accessing mental health services and refers to the National

<sup>20</sup> [HL Deb 22 March 2016 cGC350](#)

<sup>21</sup> [HC Deb 5 January 2015 c130](#)

<sup>22</sup> National Autistic Society, [Mental health and autism](#) – based on an article that first appeared in the Mental Health supplement of Your Autism Magazine, Vol 8(4), Winter 2014.

<sup>23</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 36

<sup>24</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 7

<sup>25</sup> NICE, [NICE quality standard \[QS51\], Quality Statement 2, Assessment and diagnosis](#), January 2014

Development Team for Inclusion’s practical materials designed to help improve mental health services for adults with autism and learning disabilities.<sup>26</sup>

### Reducing inpatient care

*Think Autism* states that a priority is to reduce inpatient admission for people with co-existing mental health problems or a learning disability:

Most importantly is the aim for there to be a substantial reduction on reliance on inpatient care for this group of people. This requires personalised care planning, the provision of alternative community based settings and crisis intervention and support. NHS England is taking a lead on delivering this with health commissioners, working in partnership with local government and the LGA to secure transfers into the community.<sup>27</sup>

The Government and NHS England committed to an overhaul of inpatient and community services for people with autism and learning disabilities, following the abuse uncovered at Winterbourne View Hospital. A third of people within Winterbourne View had autism.<sup>28</sup>

The Department of Health’s review [Transforming care: A National response to Winterbourne View Hospital](#) found that many people were being kept in hospital when they were clinically ready to be discharged back into community care:

The review has highlighted a widespread failure to design, commission and provide services which give people the support they need close to home, and which are in line with well established best practice.

People with learning disabilities or autism may sometimes need hospital care but hospitals are not where people should live. Too many people with learning disabilities or autism are doing just that.<sup>29</sup>

The report set out significant milestones to be achieved by June 2014. This included a commitment that all current in-patient placements will be reviewed by 1 June 2013, and everyone inappropriately in hospital will move to community based support as quickly as possible, and no later than 1 June 2014.<sup>30</sup>

In March 2015, the Minister for Care Services, Norman Lamb, stated that NHS England have ensured that more than 1300 care and treatment reviews of adults and children with learning disability or autism in inpatient settings have been carried out.<sup>31</sup>

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<sup>26</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 43

<sup>27</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 36

<sup>28</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 36

<sup>29</sup> Department of Health, [Transforming care: A national response to Winterbourne View Hospital](#), page 8

<sup>30</sup> Department of Health, [Transforming care: A national response to Winterbourne View Hospital](#), page 9

<sup>31</sup> Department of Health, [No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions](#), March 2015, page 3

Further information on the commitment to move people from inpatient settings to living in the community can be found in the Library briefing on [Learning Disability - policies and issues](#).

### 3.3 Training for health and care professionals

*Think Autism* highlighted the importance of staff training on autism across all public services, and made recommendations for improved training for health and care, welfare, employment, education, criminal justice and transport staff.

Ensuring that all health and care professionals have an understanding of autism was included as one of the priority challenges in *Think Autism*:

I want staff in health and social care services to understand that I have autism and how this affects me.<sup>32</sup>

The strategy emphasised the importance of health and care staff understanding autism and being able to communicate effectively:

When professionals do understand autism, the positive impact on the lives of adults with autism can be immense. Health and social care professionals must be able to communicate effectively with people with autism if they are to be able to manage their own care and exercise genuine choice and control. The 2010 statutory guidance for local authorities and the NHS made it clear that basic autism training should be available to all staff working in health and social care. This remains a key requirement of this updated statutory guidance.<sup>33</sup>

The 2015 statutory guidance contained a list of recommendations for local authorities, NHS Trusts and NHS Foundation Trusts for staff training, for example each organisation should ensure that autism awareness training is included within general equality and diversity training programmes for all staff working in health and care.<sup>34</sup>

The Government mandated Health Education England to work with the Royal Colleges and other stakeholders to support autism awareness training.<sup>35</sup>

The Department of Health currently supports the Royal College of General Practitioners (RCGPs) Autism Initiative to improve understanding of autism amongst GPs. In 2015, the Department of Health also provided funding to a number of organisations, including the Royal College of Nursing, the Royal College of General Practitioners and the National Autistic Society, to upgrade their autism e-learning training tools and materials. The Department has also funded the development of two e-learning tools which can help people working

<sup>32</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 27

<sup>33</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 11

<sup>34</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 12

<sup>35</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 28

with autistic children, young people and young adults to provide better services.<sup>36</sup>

The Department of Health has also stated that it is considering the inclusion of autism in a proposed additional year of GP training.<sup>37</sup>

Autism training for GPs was emphasised in the 2015 statutory guidance:

NHS England should: Ensure that GPs, as the gatekeepers to diagnostic services, have adequate training specifically in autism beyond general awareness training.<sup>38</sup>

The strategy also contained a commitment for all Department of Health staff to undergo autism training, and for the Department's arm's length bodies to include autism in their equality and diversity training.

The *Care Act 2014* provided that all staff who are undertaking autism assessments must have appropriate training:

From April 2015, the Care and Support (Assessment) Regulations 2014 will require local authorities to ensure that a person undertaking an assessment of an adult's care and support needs has suitable skills, knowledge and competence in the assessment they are undertaking, and is appropriately trained, and require local authorities, when carrying out an assessment, to consult a person who has expertise in relation to the condition or other circumstances of the individual whose needs are being assessed where it considers the needs of that individual require it to do so.<sup>39</sup>

The Department of Health has also commissioned the College of Social Work to produce a Continuing Professional Development curriculum guide on autism, which will be linked to the Professional Capability Framework and a set of learning materials for social workers.<sup>40</sup>

A list of autism training links for professionals is included as an appendix to *Think Autism*.

### 3.4 NICE guidance

The National Institute for Health and Clinical Excellence (NICE) has published clinical guidelines on autism:

- [Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum](#);
- [Autism: The management and support of children and young people on the autism spectrum](#));

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<sup>36</sup> [HL Deb 22 March 2016 cGC351](#)

<sup>37</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives. the strategy for adults with autism in England: an update](#), April 2014, page 28

<sup>38</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 17

<sup>39</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 11

<sup>40</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 14

- [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](#).<sup>41</sup>

The NICE guidance states that the local services (including health, mental health, learning disability, education and social care services) for children and young people with autism, should be coordinated by a local autism multi-agency strategy group and that the coordination of care should be provided through local specialist community-based multidisciplinary teams ('local autism teams') which should include professionals from health, mental health, learning disability, education and social care services. A recent self-assessment exercise to map progress locally and nationally with delivery of the adult autism strategy showed that structures are in place in many areas, including the creation of diagnostic leads.<sup>42</sup>

NICE has also published a [Quality Standard \(QS51, January 2014\)](#) to help inform the commissioning of autism services for children, young people and adults, focusing on the key areas for improving the quality of existing services.

NICE guidelines describe best practice to help reduce variations in service provision for people with autism, but they are not mandatory. However, the *Health and Social Care Act 2012* sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

### 3.5 Social care services

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

Local authorities have a duty:

- Under Section 1 of the *Care Act*, to promote individual's well-being;
- Under Section 3 of the *Care Act*, to ensure the integration of care and support provision with health and health-related provision where this would, in its area, promote well-being, help prevent or delay the development of care and support, or support, needs and improve the quality of such care and support;
- Under Section 4 of the *Care Act*, to establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and support for carers and in particular on how to access the care and support that is available;

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<sup>41</sup> NICE guidance on adults with autism is available at: <http://guidance.nice.org.uk/CG142/Guidance>

<sup>42</sup> In April 2011, the Department of Health issued a template which local authorities could use to assess their progress towards Autism Strategy goals. Information from the templates submitted has been collated by the Learning Disabilities Public Health Observatory, and is available at: <http://www.improvinghealthandlives.org.uk/projects/autsaf2011>



- Under Section 6 of the *Care Act*, to co-operate in general, in exercising functions relating to adults with care and support needs and carers with support needs, between local authorities and other relevant bodies, such as NHS bodies in its area, other local authorities, and specified persons responsible for exercising functions in relation to social security, employment and training, probation services, prisons and the police;
- Under Section 7 of the *Care Act*, to co-operate with the same relevant bodies in specific cases relating to individuals with needs for care and support;
- Under the *Care and Support (Assessment) Regulations 2014*, to give information about the assessment process to the individual being assessed;
- Under Regulation 5 of the *Care and Support (Assessment) Regulations 2014*, to ensure that a person carrying out an assessment has the skills, knowledge and competence to carry out the assessment in question and is appropriately trained. Local Authorities must therefore ensure that assessors carrying out assessments of people with autism have the skills, knowledge, competence and training to carry out such assessments.<sup>43</sup>

The statutory guidance 2015 also states that local authorities should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of care and support services for adults with autism.<sup>44</sup>

Local commissioning plans should also describe how local authorities will make sure that adults with autism are able to access direct payments (where appropriate).<sup>45</sup> Individuals who qualify may choose to have either a direct payment or personal budget:

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

Under the *Health and Social Care Act 2012*, local authorities have a duty to provide direct payments for people who qualify for social care services. The *Care Act 2014* introduced a legislative basis for personal budgets for social care. The 2010 Government's *Mandate to NHS*

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<sup>43</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 18

<sup>44</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 29

<sup>45</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 29

*England* states that from 2015 personal health budgets, including direct payments for healthcare, should be available for anyone who could benefit from one.<sup>46</sup>

The statutory guidance also states that people with autism should benefit from personalisation and be involved in decisions about their care and decisions about shaping local services:

Local commissioning plans should set out how local authorities will ensure that adults with autism are able to access direct payments (where appropriate) and benefit from the personalisation of health and social care. Local partners should already have a local autism partnership board in place, which brings together different organisations, services and stakeholders and adults with autism and their families to set a clear direction for improved services. Autism partnership boards have proved to be a highly effective means for stakeholders to shape and monitor local delivery of the strategy and statutory guidance. It is therefore essential for their partnership arrangements to be established in areas where they are not currently.<sup>47</sup>

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<sup>46</sup> Department of Health, [The Mandate: A mandate from the Government to NHS England: April 2015 to March 2016](#), March 2014, page 11

<sup>47</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 29

## 4. Education policy

The *Children and Families Act 2014* provides for a new special educational needs and disability (SEND) support system, covering education, health and social care.

In England, the dual system of SEN statements for children and Learning Difficulty Assessments for 16 to 25 year olds is being replaced by a new single system of birth-to-25 assessments and Education, Health and Care Plans. The reformed system was introduced in September 2014, with transitional arrangements for those who already have plans in place. Transition to the reformed system is intended to be complete by April 2018. In January 2015, the Government published a new [Special educational needs and disability code of practice](#) for children and young people aged between 0 to 25 years and provides statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities.

The statutory guidance for *Think Autism* provides further information on the new SEND system brought about under the *Children and Families Act 2014*:

A young person (someone over compulsory school age and under 25) can ask the local authority to assess their Education, Health and Care (EHC) needs. Others, including schools and colleges, can also make such a request. This is with a view to an EHC plan being drawn up for the young person that sets out the special EHC provision required. The young person can further expect, when an EHC plan is being drawn up, to be able (subject to certain limited criteria being met) to choose which school or further education (FE) college they are to attend. They will also be given the opportunity of a Personal Budget to control some of the provision set out in an EHC plan.<sup>48</sup>

The Parliamentary under Secretary of State for Health, Dan Poulter, explained how the new system was intended to benefit children and young people with autism:

The Children and Families Act 2014 introduced, from September, new joint arrangements for assessing, planning and commissioning services for children and young people with special educational needs and disabilities.

In the past, many children and their families have encountered a disconnected and fragmented system. Families, particularly those with a child with complex needs, have often faced a battle to secure all the necessary support services, finding themselves repeating the same story over and over again to different providers who are not integrated or working together properly.

The new framework will change that. It is designed greatly to improve integrated working across health, education and social care, and to deliver improved outcomes for children and their families. CCGs and local authorities will work together to agree a local package of support services for children with special

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<sup>48</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 22

educational needs and to develop personalised education, health and care plans for each child who needs one, focusing on the outcomes that will make a real difference to the individual child and their family and friends.

Each child, and each young person up to the age of 25, who needs an individual education, health and care plan will have one tailored to their individual needs, including their options for future employment and independent living. Involving the child and the family at every stage of the process is, of course, essential. The plan must be developed in collaboration with the child and the family, and should cover the range of services that the child will receive and the specific outcomes each service will deliver. The plans will also have a section for the child and the family to talk about themselves, their wishes and their aspirations, to set the context for the assessment of need. I am confident that this new approach will be a powerful tool to better join up and integrate services across the local NHS, education services and local authorities for the benefit of both children and adults with autism.<sup>49</sup>

The statutory guidance also stated that young people with autism, whether or not they have an EHC plan, can expect help with their transition from school or college to adulthood and independent living.<sup>50</sup>

The Library standard note, [The reformed system for children and young people with Special Educational Needs in England](#), provides information on the revised system.

In response to a PQ in April 2016, the Department for Education outlined work to ensure that all teachers in England are able to understand and respond to the needs of pupils with an autism spectrum disorder:

The Department has contracted with the Autism Education Trust since 2012 to deliver autism training to education staff. To date, the Trust has trained over 90,000 education staff. This training will continue to be funded in 2016-2017 to a value of £750,000. The contract extension with the Autism Education Trust will build on previous grant funding from the Department for two other projects (2013-16): a project by the National Autistic Society to provide information and advice to parents and professionals on exclusions and a project by Ambitious about Autism on strategies for supporting transition from school to college.

Our support also includes the National Association for Special Educational Needs' Special Educational Needs and Disabilities Gateway ([www.sendgateway.org.uk](http://www.sendgateway.org.uk)). This offers education professionals free, easy access to high quality information, resources and training for meeting the needs of children with SEND, including those with autism. The Department has also funded National Association for Special Educational Needs (2015-16) to develop a free universal offer of SEND Continuous Professional Development for teachers.

The National College for Teaching and Leadership has produced a series of specialist online courses, one of which focuses on autism. The training materials are designed to support teachers in

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<sup>49</sup> [HC Deb 5 January 2015 c130](#)

<sup>50</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 23

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mainstream schools who want to improve their skills in teaching pupils with SEND. The training materials can be found at: [www.education.gov.uk/lamb](http://www.education.gov.uk/lamb).

In order to be awarded qualified teacher status, trainees must satisfy the Teachers' Standards, which include a requirement that they have a clear understanding of the needs of all pupils, including those with SEND, and are able to use and evaluate distinctive teaching approaches to engage and support them.

Following Sir Andrew Carter's independent review of the quality and effectiveness of Initial Teacher Training (ITT) courses, the Secretary of State appointed an independent working group made up of expert representatives from the sector to develop a framework of core ITT content. The working group includes two SEND experts and will consider Sir Andrew's recommendations on the SEND content of the proposed framework. The group is expected to report to DfE in spring 2016.<sup>51</sup>

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<sup>51</sup> [PQ 33545 \[on Pupils: Autism\], 19 April 2016](#)

## 5. Employment policies

Although the Government does not collect data specifically on employment rates for people with Autistic Spectrum Conditions, the Department of Health have said that adults with autism are significantly underrepresented in the labour market.<sup>52</sup> The National Autistic Society estimates that only 15% of working-age people with autism are in full time employment, yet 79% of people with autism on out of work benefits want to work.<sup>53</sup>

In March 2014, the Department of Work and Pensions (DWP) hosted an event prior to the publication of *Think Autism* in partnership with the Department of Health and the National Autistic Society. Discussions took place on ways to improve DWP services for people with autism and recommendations were made which helped to develop an Autism Strategy Action Plan, which became part of *Think Autism*. That plan focused on three strategic areas:

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

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

- build an Autism Network across all Jobcentre Plus offices, to be completed during 2015/16 and 2016/17;
- upskill the autism knowledge and awareness of staff involved in the Personalisation Pathfinder pilots, to be completed during 2015/16;
- develop an autism e-learning tool for staff/managers, to be completed in 2016/17.<sup>54</sup>

In January 2016, the Department for Work and Pensions set out further areas of work to help adults on the autism spectrum into work:

Department for Work and Pensions (DWP) is taking a number of steps to help adults on the autism spectrum into work, including:

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<sup>52</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 51

<sup>53</sup> National Autistic Society, [Support for employers](#) [last accessed 2 April 2015]

<sup>54</sup> Department of Health, [Progress Report on Think Autism: the updated strategy for adults with autism in England](#), January 2016, page 60

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

DWP has worked in close partnership with the Hidden Impairment National Group (HING) to produce an 'Uncovering Hidden Impairments' toolkit, which helps employers to recruit and retain people with hidden impairment conditions.<sup>55</sup>

In the summer of 2015, the Department of Work and Pensions and the Department of Health also established a new unit to improve employment outcomes for people with health conditions and who are disabled, in order to contribute towards halving the disability employment gap. The Work and Health Joint Unit will explore how best to support people with autism to find and stay in work, while also improving their health.<sup>56</sup>

The 2015 statutory guidance also set out legal duties for local authorities to improve employment outcomes for people with autism:

Local Authorities must:

Ensure that the assessment and care planning process for adult needs for care and support considers participation in employment as a key outcome, if appropriate, and looks at the ways that any such needs may be met in a way which could support adults with autism to become 'work ready';

When carrying out a needs assessment, consider whether matters other than the provision of care and support could contribute to the achievement of the outcomes an adult with autism wishes to achieve in day-to-day life, and whether the adult would benefit from the provision of anything under section 2 or 4 of the Care Act (preventative services or information and advice services) ,or anything that may be available in the community, including signposting, as appropriate, to Access to Work for interview support, and to other appropriate benefits and agencies that can help people with autism to find and keep a job.

Ensure that employment is promoted as a positive outcome for the majority of children and young people with autism who have EHC plans and that routes to employment are fully explored during the reviews of those plans from Year 9 (age 13-14) onwards and included in plans where appropriate. Information on preparing for and finding employment must be included in the

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<sup>55</sup> [PO 23990 \[on Employment: Autism\], 28 January 2016](#)

<sup>56</sup> Department of Health, [Progress Report on Think Autism: the updated strategy for adults with autism in England](#), January 2016, page 61

local authority's Local Offer under the Children and Families Act 2014.<sup>57</sup>

The Budget 2016 provided an update on progress towards halving the disability employment gap and announced new employment support for people with mental health problems and young disabled people:

1.133 The government is delivering on its manifesto pledge to halve the disability employment gap. The number of disabled people in employment has increased by 150,000 to over 3.25 million people over the last year and the government is taking action to increase this further. At Summer Budget 2015, the government allocated funding to provide additional help for those on Employment and Support Allowance to move closer to the labour market.

1.134 This Budget announces that the government is accepting the recommendations of an independent stakeholder group and will offer new peer and specialist support for those suffering from mental health conditions and young disabled people. Later this year, the government will publish a White Paper focusing on the roles that the health, care and welfare sectors can play in supporting disabled people and those with health conditions to get into and stay in work.<sup>58</sup>

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<sup>57</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 51

<sup>58</sup> HM Treasury, [Budget 2016](#), March 2016, page 40



## 6. Welfare and benefits

Social security policy is a matter reserved to the UK, meaning that policies generally apply to England, Scotland, Wales and Northern Ireland.

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

*Think Autism* states that some people with autism think the social security system could have made better adjustments for their needs.<sup>59</sup> The strategy describes the work undertaken by the 2010 – 2015 Government to ensure that reasonable adjustments are made to the process for claiming social security benefits for people with autism. The strategy explains that the claims process for Personal Independence Payment was developed in consultation with disabled people and disability organisations, and that adjustments that have been made to the assessment process. The strategy also states that people can bring a relative, friend or a professional to help them manage the anxiety caused by face to face assessments, and provide additional information about the person's difficulties. It also highlights that key staff involved in assessments should receive training on autism.<sup>60</sup>

### 6.1 Welfare changes

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

#### Employment and Support Allowance

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

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

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<sup>59</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 2

<sup>60</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 18

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

The Government has announced a package of measures to provide additional help people with health conditions and disabilities get into work. Further details will be set out in a forthcoming White Paper on improvements to back to work support for people with health conditions and disabilities.

For general background on the ESA changes, the rationale for them and initial reactions from disability organisations and others see [section 7 of Library briefing paper CBP-7252 produced for the Commons Second Reading of the Welfare Reform and Work Bill 2015-16](#).

Developments during the Lords stages are covered in the Library’s briefing [Welfare Reform and Work Bill 2015-16: Lords amendments](#). This also details the various concerns voiced about the impact of the changes, and the main findings from the report [Halving The Gap? A Review into the Government’s proposed reduction to Employment and Support Allowance and its impact on halving the disability employment gap](#), published by disability charities on 8 December 2015.

### **The assessment process**

Concerns have been raised about the suitability of the assessment process for people with mental health conditions and with autism. The fifth and final Independent Review of the Work Capability Assessment, carried out by Dr Paul Litchfield, contains 33 recommendations for the Government to improve the WCA. This includes a recommendation that autism should be given specific consideration in assessment interviews:

Particular attention should be paid to interview practices for those with mental health conditions, learning disabilities and autism, and this should be reflected in the guidance and training developed.<sup>61</sup>

This recommendation was accepted by the Government.<sup>62</sup>

The first Independent Review of the Work Capability Assessment, carried out by Professor Harrington, also raised concerns about the expertise of assessors in autism, mental health conditions and learning disabilities:

Some conditions are more difficult to assess than others, particular those that are more subjective such as mental health

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<sup>61</sup> Dr Paul Litchfield, [An Independent Review of the Work Capability Assessment – year five](#), November 2014, page 32

<sup>62</sup> DWP, [Government’s response to the Independent Review of the Work Capability Assessment – year five](#), page 10

conditions. People with mental health conditions also make up the largest group of individuals who go through the WCA (37 per cent). Atos HCPs [Healthcare Professionals] are mostly drawn from generalist medical professions and so are less likely to have insight into some mental health conditions, learning disabilities or autism.<sup>63</sup>

The Government accepted a recommendation that mental, intellectual and cognitive champions are present in each medical assessment centre, to spread best practice amongst healthcare professionals in mental, intellectual and cognitive disabilities. Mental Function Champions have been in place since May 2011.<sup>64</sup>

The National Autistic Society submitted evidence to the fifth Independent Review, and called for changes including improved information for claimants at different stages of the process and better use of a range of written evidence for people with autism.<sup>65</sup> The National Autistic Society outlines the changes made to the WCA through its work with the independent reviews:

During our engagement with these reviews, the following changes have been made to the process:

- increased support for claimants throughout the process of applying for ESA
- the appointment of ‘champions’ with expertise in intellectual and cognitive conditions to support assessors in assessing people with autism, mental health problems or a learning disability
- an increased focus on additional evidence provided by professionals
- revised guidance to ensure that individual's companions are involved in the assessment process.

In addition, Professor Harrington asked us to work with the mental health charity Mind and the learning disability charity Mencap to redraft the criteria for ESA to make sure that the assessment recognises the difficulties people with autism, mental health problems and learning disabilities may face in getting in to work. We are now working with the Government to ‘test out’ our alternative criteria. We are still working with government to take account of the findings of this work.

In response to the National Autistic Society, Mind and Mencap’s review of the WCA – the “Evidence Based Review” – the DWP concluded that “there is no evidence that changes to the WCA descriptors would significantly improve the overall assessment”.<sup>66</sup> However, the Government did state that it might be possible to make practical improvements to the assessment process, including building on the

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<sup>63</sup> Professor Malcolm Harrington, [An Independent Review of the Work Capability Assessment](#), November 2010, page 46

<sup>64</sup> Dr Paul Litchfield, [An Independent Review of the Work Capability Assessment – year four](#) - Annex 2: Review of year one to three recommendations, December 2013, page 89

<sup>65</sup> National Autistic Society, Response to review of work capability assessment

<sup>66</sup> [Government’s response to the year four independent review of the Work Capability Assessment](#), March 2014, Chapter 3, para 14

experience of using a semi-structured interview topic guide to promote “purposeful, open discussions”.<sup>67</sup>

### **Jobseekers’ Allowance**

People who apply for ESA but are not deemed to have “limited capability for work” due to an illness or disability may apply for JSA. To get JSA, a person has to sign on as available for and seeking work, and must be prepared to accept any reasonable offer of work, even though reconsideration/appeal is pending.<sup>68</sup> A JSA claimant with a health condition or disability may however be allowed to restrict their availability for work if it is reasonable in light of their condition.

### **Personal Independence Payment**

The *Welfare Reform Act 2012* provided that Disability Living Allowance (DLA) would be replaced with Personal Independence Payment (PIP) for working-age disabled adults starting from April 2013. The changes will affect existing working age DLA claimants, as well as those making a new claim. For those existing DLA claimants found not to satisfy the conditions for PIP on reassessment, DLA will stop. Existing DLA claimants are being reassessed for PIP, but the new benefit is not expected to be fully introduced until 2018.

The 2010 Government’s stated intention was that PIP will focus support on those “who face the greatest challenges to living independently”. The Government estimated that by 2018, 607,000 fewer people will receive PIP than would have got DLA under the existing rules, saving £2.5 billion a year.<sup>69</sup>

### **Withdrawn PIP changes**

The Government announced on 11 March 2016, and confirmed in Budget 2016, its intention to change the assessment criteria for the daily living component of Personal Independence Payment.

The Government reached this decision following consultation on the way in which points are assigned for use of, and costs incurred by, aids and appliances within the PIP claimant assessment. It reached this decision as:

Further work by DWP health professionals has found that aids and appliances are not a reliable indicator of extra costs in all cases. In 96% of the cases they reviewed their view was that claimants were likely to have low, minimal or nil on-going extra costs. Many of the aids and appliances likely to be used are also often provided free of charge by the NHS and local authorities or can be purchased for a low one-off cost.<sup>70</sup>

<sup>67</sup> [Government’s response to the year four independent review of the Work Capability Assessment](#), March 2014, Chapter 3, para 15

<sup>68</sup> See Work and Pensions Committee, [Employment and Support Allowance and Work Capability Assessments](#), 23 July 2014, HC 302-I 2014-15, paras 103-109

<sup>69</sup> DWP, [Personal Independence Payment: Reassessment and Impacts](#), 13 December 2012

<sup>70</sup> DWP, [The Government response to the consultation on aids and appliances and the daily living component of Personal Independence Payment](#); page 4

In Budget 2016 the Chancellor confirmed that the Secretary of State for Work and Pensions will continue to deliver PIP in line with its original intentions and to ensure support is better targeted.<sup>71</sup>

Specifically, the DWP decided to halve the number of points awarded for aids and appliances used in relation to activity five of the PIP claimant assessment, dressing and undressing, and for activity six, managing toilet needs.<sup>72</sup> The Department regarded these activities as less reliable indicators of extra, repeat costs incurred by claimants.

However, following the resignation of Iain Duncan Smith as Secretary of State for Work and Pensions on 18 March and the appointment of Stephen Crabb as his successor, the Government announced that it would not be proceeding with the PIP changes and has no further plans to make welfare savings beyond the savings already legislated for by Parliament, which it would now focus on implementing.

In his statement on welfare to the House on 21 March, Mr Crabb said:

The commitment that I am making today, based on some very long conversations with the Chancellor of the Exchequer and the Prime Minister over the weekend, is that we will not go ahead with the proposed PIP cuts, that we will not be seeking alternative offsetting savings, and that as a Government we are not seeking further savings from the welfare budget.<sup>73</sup>

## Universal Credit

Under the *Welfare Reform Act 2012*, from April 2013 Universal Credit began to replace a range of means-tested benefits and tax credits for working age families. Universal Credit will replace income-related Employment and Support Allowance, income-based Jobseeker's Allowance, Income Support, Child Tax Credit, Working Tax Credit and Housing Benefit. Contributory ESA will remain as a separate benefit. The DWP have stated that Universal Credit aims to simplify the current system of benefits and tax credits associated with disability.

For further information on how the introduction of Universal Credit will affect disabled people, see Library briefing SN06548 [Draft Universal Credit Regulations 2013](#).

Disability organisations have expressed concerns that the "Severe Disability Premium" which is currently payable with means-tested benefits will not be carried over into Universal Credit, meaning that some disabled people will be worse off. Further information is available from Citizen's Advice - "[Half a million disabled people could lose out under universal credit](#)<sup>74</sup>" – and the Disability Benefits Consortium [response to the Legislation Scrutiny Committee](#).<sup>75</sup>

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<sup>71</sup> HM Treasury, [Budget 2016, Chancellor's speech](#); also see page 26 of the [Budget 2016 red book](#)

<sup>72</sup> DWP; [The Government response to the consultation on aids and appliances and the daily living component of Personal Independence Payment](#); page 5

<sup>73</sup> [HC Deb 21 March 2016 c1279](#)

<sup>74</sup> Citizen's Advice Bureau, "[Half a million disabled people could lose out under universal credit](#)", 16 October 2012

<sup>75</sup> Disability Benefits Consortium, [Legislation Scrutiny Committee examination of the Statutory Instruments on Universal Credit \(UC\): DBC submission](#)

All Universal Credit claimants will be required to agree to a Claimant Commitment. This will record the activities they are required to undertake, including, where appropriate, doing all that can reasonably be expected of them to find work or prepare for work.<sup>76</sup>

Unlike ESA, claimants for Universal Credit who are waiting for a Work Capability Assessment or waiting for the outcome of an appeal will, with some exceptions, be subject to the all work related requirements level of conditionality. These requirements will be personalised to their circumstances. The DWP stated that:

This approach is intended to support more claimants by keeping them in touch with the labour market to reduce the damage caused by labour market detachment.<sup>77</sup>

The DWP have produced a guide on [Universal Credit if you have a disability or health condition](#).

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<sup>76</sup> [EXPLANATORY MEMORANDUM TO THE UNIVERSAL CREDIT REGULATIONS 2013](#), para 7.10

<sup>77</sup> Work and Pensions Select Committee, *Employment and Support Allowance and Work Capability Assessments*, 23 July 2014, HC 302-I 2014-15, [Ev 17 WCA0196](#)

## 7. The criminal justice system

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

If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.<sup>78</sup>

The statutory guidance sets out legal duties and recommendations for local authorities, NHS bodies and Foundation Trusts for adults with autism who come into contact with the criminal justice system, and how they can support police, probation services, courts and prisons.<sup>79</sup> For example, the guidance states that local authority-based Community Safety Partnerships should be used as a forum to bringing agencies together to develop plans to support the Autism Strategy, and should include the local authority, police, probation, CCGs and the fire and rescue authority.

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

A Cross-Criminal Justice System Government Group, chaired by the MoJ, was set up in spring 2014 and now meets quarterly to discuss work across the criminal justice system to improve services for people with autism, including progress with commitments under the autism strategy. Membership includes MoJ, the Home Office, the Crown Prosecution Service (CPS), the Youth Justice Board, the National Offender Management Service (NOMS), the National Police Chiefs' Council (NPCC) which was formerly the Association of Chief Police Officers or ACPO, DH and NHS England, as well as a number of special interest bodies (including NAS) and self-advocates. Meetings cover issues such as training and awareness, screening, reasonable adjustments, and the use of IT systems to better support people with autism.<sup>80</sup>

The 2016 progress report also outlines work undertaken by the Crown Prosecution Service, the College of Policing, the Police National Computer, the police service and other national bodies to help identify and support people with autism in contact with the criminal justice system.<sup>81</sup>

Liaison and diversion services have been developed to identify people who may have specific needs such as people with mental health problems, a learning disability and autism, so that offenders can either be supported through the criminal system pathway or diverted into

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<sup>78</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 7

<sup>79</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 55

<sup>80</sup> Department of Health, [Progress Report on Think Autism: the updated strategy for adults with autism in England](#), January 2016, page 64

<sup>81</sup> See Department of Health, [Progress Report on Think Autism: the updated strategy for adults with autism in England](#), January 2016, page 65

treatment, health and care services or other relevant interventions. The Government supports a policy of liaison and diversion.

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

We have started to roll out the Government's liaison and diversion service, which I announced back in January. By 2017 we aim to have a nationwide service for people with mental health problems, autism and learning disabilities who end up in the criminal justice system, often inappropriately and unnecessarily. Getting people diverted to diagnosis, which Members have talked about, and to the right treatment can often prevent further offending and potentially thereby transform someone's life while protecting others.<sup>82</sup>

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

Local Authorities must:

- Under the *Care Act*, from April 2015, assess the care and support needs of adults (including those with autism) who may have such needs in prisons or other forms of detention in their local area, and meet those needs which are eligible;
- Work with prisons and other local authorities to ensure that individuals in custody with care and support needs have continuity of care when moving to another custodial setting or where they are being released from prison and back into the community.<sup>83</sup>

In March 2015, the Ministry of Justice announced that it is encouraging prisons and young offender institutes in England and Wales to apply for the National Autistic Society's Autism accreditation. The accreditation process has a clear framework to help institutions and services work systematically towards good quality autism practice, and is intended to improve rehabilitation support for prisoners with autism.<sup>84</sup>

The National Autistic Society also states that some people with autism may also be more vulnerable to criminal acts against them, due to difficulties with social interaction.<sup>85</sup> *Think Autism* sets out work being done to improve support for vulnerable or intimidated victims and witness to crime giving evidence to the police and courts, including information provided by the Crown Prosecution Service to help and support vulnerable victims and witnesses.<sup>86</sup>

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<sup>82</sup> [HC Deb 5 March 2014, c307WH](#)

<sup>83</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, page 56

<sup>84</sup> Ministry of Justice, [Prisons seeking National Autistic Society help to improve support for prisoners](#), 27 March 2015

<sup>85</sup> National Autistic Society, [Position statement: crime and autism](#) [last accessed 2 April 2015]

<sup>86</sup> Department of Health, [Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#), April 2014, page 20



## 8. Scotland, Wales and Northern Ireland

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

### 8.1 Scotland

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

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

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

### 8.2 Wales

In May 2015, the Welsh Government announced a one-year plan for children, young people and adults with autism spectrum disorder. The interim delivery plan will take forward the most pressing actions identified by a stakeholder advisory group. These include:

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

Health and Social Services Minister Mark Drakeford said:

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

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

We're also making a £2m investment to develop specific services to better diagnose and support young people with ADHD and ASD. This will cut waiting times in specialist child and adolescent mental health services so those with highest levels of clinical need are seen in a more timely manner.<sup>87</sup>

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

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

### 8.3 Northern Ireland

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

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

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

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

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<sup>87</sup> Welsh Government, [New measures to improve autism services in Wales](#), 18 May 2015

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

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