



BRIEFING PAPER

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Support for people with a learning disability

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Summary

Coronavirus: Section 1 provides a summary of the impact of coronavirus on people with learning disabilities in England. New data shows a significant increase in deaths of people with a learning disability during the coronavirus outbreak.

This House of Commons Library briefing describes recent changes to policy and services for people with a learning disability in England.

Over 1.2 million people in England have a learning disability. The Government and NHS England are working to reduce health inequalities for people with a learning disability and have established national programmes to improve treatment and outcomes. The *Government's Mandate to the NHS 2018-19* set an objective for the NHS to close the health gap between people with mental health problems, learning disabilities and autism and the population as a whole.

Most recently, the *NHS Long Term Plan* (published in January 2019) recognised learning disabilities and autism as clinical priority areas. The *Long Term Plan* committed to increasing annual health checks for people with a learning disability, introducing designated keyworkers for children and young people and halving inpatient care for this group by 50% by 2023/24.

The Government has also committed to introducing mandatory training on learning disabilities and autism for health and social care staff. Trials will begin in health and social care settings by April 2020, and report by March 2021, after which wider roll-out of training is expected for all staff.

In June 2015, NHS England commissioned the *National Learning Disability Mortality Review Programme* (LeDeR), to review and learn from deaths of people with a learning disability with the aim of improving services, care and support nationally. The third annual report was published in May 2019, which found that in a large number of cases, people received poor standards of healthcare which significantly impacted on their well-being or directly contributed to their death. The report made twelve recommendations for the education, and health and care systems; the [Government's response](#) to the recommendations was published in February 2020.

The NHS has also announced £5 million in funding to accelerate the pace of LeDeR reviews. The NHS [Action from Learning report](#) (May 2019) described national and local actions to improve outcomes in response to reviews, such as targeted action in clinical areas including cancer and sepsis, and initiatives in hospitals to improve reasonable adjustments and the update of medical tests.

The Government and NHS have focused on reducing levels of inpatient care for people with a learning disability and/or autism. The Department of Health and Social Care has said that hospitals are not where people should live and has committed to move people to community-based support. However, ambitions for this have been postponed – the most recent target, as set out in the *NHS Long Term Plan*, is for a reduction in inpatient provision of 50% (as compared to 2015 levels) by 2023/24. In February 2020, the Equalities and Human Rights Commission launched a legal challenge against the Secretary

of State for Health and Social Care over the failure to move people with learning disabilities and autism into appropriate accommodation.¹

The briefing also looks at recent policy changes in the areas of employment, welfare and education.

¹ Equality and Human Rights Commission, [Health Secretary faces legal challenge for failing patients with learning disabilities and autism](#), 12 February 2020

1. Coronavirus update

This section briefly outlines the impact of coronavirus on people with learning disabilities in England.

What does the data show?

On 2 June 2020, the Care Quality Commission (CQC) published [data on deaths of people with a learning disability](#). The figures included deaths reported by services who provide care for people with a learning disability and/or autism. This includes adult social care, independent hospitals and community care.

Between 10 April and 15 May 2020, 386 people who were receiving care from learning disability and/or autism services died. In the same period last year 165 people died. This represents a 134% increase.

Of the 386 people who died this year, 206 were as a result of suspected or confirmed Covid-19.

Testing for people with a learning disability

Current Government guidance is that anyone [who has symptoms of Covid-19](#) in England may be tested. But there have been concerns about access to testing for people with learning disabilities in care homes.

Care homes can order testing kits for their residents and staff. In the Cabinet Office's [COVID-19 recovery strategy](#) (published 11 May 2020), the Government said that they were offering a COVID-19 test to staff members and residents in every care home in England. However, until 5 June 2020, care homes [could only order testing kits if they were looking after people aged over 65 or people with dementia](#).² This left care homes for younger people with learning disabilities without access to testing kits.

[The CQC said](#) its data on increased deaths (published 2 June) for people with learning disabilities should be considered when making decisions on testing priorities:

We already know that people with a learning disability are at an increased risk of respiratory illnesses, meaning that access to testing could be key to reducing infection and saving lives.

These figures also show that the impact on this group of people is being felt at a younger age range than in the wider population – something that should be considered in decisions on testing of people of working age with a learning disability.

[Mencap said:](#)

We've been telling the Government for weeks that it is putting people with a learning disability at risk by not giving them priority testing; it's time the Government acted to make sure that everyone who needs social care, regardless of their age, disability

² The Government guidance on [Coronavirus: Getting tested](#) was changed on 5 June 2020, and on 8 June the Secretary of State for Health and Social Care announced the change in the [Government's daily briefing](#).

or care setting, is prioritised for testing. This is a matter of life or death, yet people with a learning disability continue to be forgotten.

The Government set a target that by 6 June, every care home for the over 65s will have been offered testing for residents and staff.³ In early June, the Secretary of State for Health and Social Care said this target was met by the deadline, and so the Government would subsequently be rolling out testing to care homes for working age adults.⁴

The CQC is also [calling for priority testing to be extended](#) to people with learning disabilities who don't live in care homes, saying that the majority live in the community with support.

Further information on testing is available in the Library briefing on [Coronavirus: Testing for Covid-19](#) (May 2020).

Social care assessments

Under the *Coronavirus Act 2020* the obligations on local authorities under the *Care Act 2014* have been relaxed. In particular, local authorities don't have to carry out care and support needs assessments. The relaxation of local authority obligations are referred to as '*Care Act easements*'. Local authorities in England and Wales may instead prioritise the most urgent and acute needs. See the Library briefing on [Coronavirus: Local authorities' adult social care duties \(the Care Act easements\)](#) (6 May 2020).

Mencap said this might result in "more people with a learning disability [falling through the gap](#) when it comes to accessing vital social care support."

Eight local authorities used easements between 31 March and 15 May.⁵ However, as of 1 June 2020, [only two local authorities were using the easements](#).

On 26 March 2020, new and existing complaints to the Local Government and Social Care Ombudsman were suspended. On 5 June, some existing investigations were restarted, but new complaints are still not being accepted.⁶

Benefit assessments

The Department for Work and Pensions (DWP) has made a series of changes to the benefits system in response to the coronavirus pandemic, including suspending all work-related requirements for benefit claimants and mandatory face-to-face Jobcentre appointments.

On 17 March, the Department also suspended all face-to-face assessments for sickness and disability benefits for three months, and on

³ Cabinet Office, [Our plan to rebuild: The UK Government's COVID-19 recovery strategy](#), 11 May 2020

⁴ [Health and Social Care Secretary's statement on coronavirus \(COVID-19\)](#), 8 June 2020

⁵ National Audit Office, [Readying the NHS and adult social care in England for COVID-19](#), para 3.5

⁶ Local Government and Social Care Ombudsman, [Coronavirus update](#) [last accessed 12 June 2020]

23 March it announced that reviews and reassessments for all disability benefits were suspended for at least three months. Where benefit awards are due to expire, the DWP is automatically extending the payment period by six months so that people continue to receive their existing level of support.

Assessments are still taking place for new claimants and for existing claimants who request a reassessment (e.g. because their condition has deteriorated), but in the form of paper-based reviews or by telephone. The DWP says that it is adopting a “sympathetic, claimant-supportive view” on assessments in these circumstances, in recognition of the challenges in getting adequate evidence. It emphasises that “companions are also able to join the telephony assessment, as they would have done for the face-to-face assessment”⁷, although welfare rights advisers have reported that claimants have experienced problems arranging this.⁸

At the time of writing, there has been no announcement on whether the three-month suspension of face-to face assessments will be extended. The DWP is “reviewing this measure in light of the latest public health advice and will confirm next steps as soon as possible.”⁹

Further information on the benefits changes can be found in Commons Library briefing CBP-8894, [Coronavirus: Support for household finances](#), 29 May 2020.

What’s next?

[Weekly data](#) on deaths of patients with a learning disability where Covid-19 is suspected or confirmed as the cause of death is being reported to NHS England.

On 8 June, the Government created a [social care taskforce](#) to support the care sector and prevent further transmission.

The Government is also working with the Care Quality Commission and [Think Local, Act Personal](#) to [understand the impact on disabled people](#) and carers, and are giving [additional funding to learning disability charities](#).

Joint Committee on Human Rights

On 12 June, the Joint Committee on Human Rights (JCHR) published their Report on [Human Rights and the Government’s response to COVID-19: the detention of young people who are autistic and/or have learning disabilities](#).

The Committee said that the Government’s response to coronavirus had “resulted in human rights abuses”:

Unlawful blanket bans on visits, the suspension of routine inspections, the increased use of restraint and solitary

⁷ [PO 45409 \[on Personal Independence Payment: Coronavirus\]](#), 18 May 2020

⁸ See the Rightsnet discussion thread [Sickness and disability benefit reviews and reassessments suspended](#) [accessed 12 June 2020]

⁹ [PO 52251 \[on Social Security Benefits: Medical Examinations\]](#), 9 June 2020

confinement, and the vulnerability of those in detention to infection with Covid-19 (due to underlying health conditions and the infeasibility of social distancing) mean that the situation is now a severe crisis.¹⁰

The report makes a series of recommendations:

- NHS England must write immediately to all hospitals, including private ones in which it commissions placements, stating that they must allow families to visit their loved ones, unless a risk assessment has been carried out relating to the individual's circumstances which demonstrates that there are clear reasons specific to the individual's circumstances why it would not be safe to do so.
- Figures on the use of restrictive practices, including physical and medical restraint and any form of segregation, detailing any incidences which go beyond 22 hours per day and amount to solitary confinement, must be published weekly by the institutions. These figures must be provided to the Secretary of State for Health and Social Care and reported to Parliament.
- The Care Quality Commission (CQC) should carry out all their inspections unannounced; this is particularly important where any allegation of abuse is reported by a young person, parent, or whistle-blower.
- The CQC must prioritise in-person inspections at institutions with a history of abuse/malpractice, and those which have been rated inadequate/requires improvement.
- The CQC should set up a telephone hotline to enable all patients, families, and staff to report concerns or complaints during this period.
- The CQC must report on reasons for geographical variation in practice with resultant harmful consequences
- Now, more than ever, rapidly progressing the discharge of young people to safe homes in the community must be a top priority for the Government. The recommendations from the Committee's 2019 report must be implemented in full.
- Comprehensive and accessible data about the number of those who are autistic and/or learning disabled who have contracted and died of Covid-19 must be made available and include a focus on those in detention, for whom the state has heightened responsibility for their right to life.

The Library briefing on the [Care Quality Commission](#) (April 2020) has further information on the changes to the CQC's operations in response to coronavirus.

¹⁰ House of Commons, House of Lords, Joint Committee on Human Rights, [Human Rights and the Government's response to COVID-19: The detention of young people who are autistic and/or have learning disabilities](#), 8 June 2020

2. Health policies

Over 1.2 million people in England have a learning disability and face severe health inequalities and poorer access to healthcare compared with the rest of the population. On average, adults with a learning disability die 16 years earlier than the general population – 13 years for men and 20 years for women.¹¹ In 2017, the *Learning Disabilities Mortality Review Programme* identified that 31% of deaths in people with a learning disability were caused by respiratory conditions and 16% were caused by circulatory system conditions.¹²

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

There are various current programmes of work to improve outcomes for people with learning disabilities, with objectives such as reducing rates of inpatient care, increasing annual health checks, and reviewing the premature deaths of people with a learning disability.

2.1 The NHS Long Term Plan

Learning disabilities is one of the clinical priority areas in the *NHS Long Term Plan* (January 2019). This commits the NHS to tackling the causes of morbidity and premature death for people with these conditions, and sets several targets:

The uptake of **annual health checks** for people with a learning disability will be increased to at least 75% of those who are eligible - see Box 1.

The NHS and partners will introduce **hearing, sight and dental checks to children and young people** with a learning disability, autism or both in special residential schools

The NHS will expand the **Stopping over medication** of people with a learning disability, autism or both and Supporting Treatment and Appropriate Medication in Paediatrics (STOMP-STAMP) programmes to end the overmedication of people with a learning disability or autism. This is in light of evidence that psychotropic medicine is more likely to be inappropriately prescribed to people with a learning disability or autism.¹⁴

Box 1: Learning disability health check scheme

The [health check scheme](#) is an enhanced service for General Practice, who receive an additional payment of £140 (for 2018/19) from NHS England for each qualifying health check.

These checks are available to patients aged 14 and over and should be offered to everyone on a GP learning disability register. To support practices and to ensure that they have an accurate and complete register of these patients, NHS England and Improvement have published guidance on [Improving identification of people with learning disability](#).

In 2017/18, 55.1% of patients with a learning disability received an annual learning disability health check.¹³

¹¹ University of Bristol, [Confidential Inquiry into Premature Deaths of People with Learning Disabilities, Full final report](#), March 2013

¹² University of Bristol, [The Learning Disabilities Mortality Review Programme: Second annual report](#), December 2017, page 19

¹³ NHS England and NHS Improvement, [Improving identification of people with a learning disability: guidance for general practice](#), para 3

¹⁴ Public Health England, [Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England](#), 2015

The NHS will continue to fund the **Learning Disabilities Mortality Review Programme**. This supports local areas to review the deaths of people with learning disabilities, to understand factors leading to premature mortality and what actions are needed to address health inequalities (see section 1.3).

By 2023/24, a '**digital flag**' in the **patient record** will ensure staff know a patient has a learning disability or autism.

By 2023/24 children and young people with a learning disability, autism or both with the most complex needs will have a **designated keyworker**. This will be initially rolled out to children and young people who are inpatients or at risk of being admitted to hospital. It will also be extended to vulnerable children with a learning disability or autism, such as looked after and adopted children and those in transition between services.

NHS **staff will receive training** on learning disabilities and autism. Further information on recently introduced mandatory training is provided below (see section 1.3).

The *Long Term Plan* also commits to halving **inpatient provision** for people with a learning disability and/or autism by 2023/24, compared to 2015 levels (on a like for like basis and taking into account population growth). There are concurrent targets for the maximum numbers of adult and children in inpatient units - for every one million adults, there will be no more than 30 people with a learning disability and/or autism in inpatient care. For children and young people, the maximum is 12 to 15 children per one million.

The initial target set in 2015 was for a 35-50% reduction in inpatient care by March 2019, as most recently detailed in the *Government's Mandate to NHS England 2018-2019*.¹⁵ During a debate on the *NHS Long Term Plan*, Health Secretary Matt Hancock was questioned about postponing this target to 2023/4 and said:

The target for this March [2019], which I inherited, was for a reduction of a third to a half. We are at a reduction of over 20%. The challenge has been that, while the number of people who are being moved into community settings has proceeded as per the plan, more people have been put into secure settings.¹⁶

Further information on reducing inpatient care is provided in section 1.4.

The *Long Term Plan* also outlines the expectation that all NHS funded care providers will introduce the **learning disability improvement standards** by 2023/24.¹⁷ These standards will be included in the *NHS Standard Contract 2019/20*, which is mandated by NHS England for all commissioners of NHS services except primary care.

¹⁵ Department of Health and Social Care, [The Government's revised mandate to NHS England for 2018-19](#), para 6.3

¹⁶ [HC Deb 7 January 2019](#), NHS Long Term Plan, c70

¹⁷ See NHS Improvement, [Learning disability improvement standards](#)

Implementation Framework

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

- their share of the required further reduction inpatient usage and beds;
- learning disability and autism physical health checks for at least 75% of people aged over 14 years;
- how proposals for people with learning disabilities and/or autism align with their plans for mental health, special educational needs and disability (SEND), children and young people's services and health and justice;
- the local offer for autistic young people, people with a learning disability and their families;
- how NHS-led provider collaboratives will be developed locally and should ensure that digital plans use the reasonable adjustment 'digital flag' in the patient record or, where this is not available, use the Summary Care Record as an alternative.¹⁸

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

The framework also details **targeted funding**, including specific investment to roll out keyworkers for children and young people with the most complex needs and their carers/families from 2020/21, and capital investment to develop new housing options and suitable accommodation in the community, as an alternative to inpatient care.¹⁹

Box 2: STPs and ICSs

STPs (Sustainability & Transformation Partnerships) and ICSs (Integrated Care Systems) are new collaborative models of care, to deliver integration of health and social care services. ICSs (which are developing from STPs) should be in place across England by April 2021. See the Library briefing on [Health and Social Care Integration](#) (December 2019).

2.2 Mandatory staff training

The second annual report of the *Learning Disability Mortality Review Programme* (December 2017) recommended that mandatory learning disability training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families.²⁰

The Government accepted the report's recommendations in its response. It noted that despite the introduction of the *Learning Disability Core Skills Education and Training Framework* in 2016, some staff still do not possess the required knowledge and skills. The Government therefore committed to introducing mandatory training:

¹⁸ [The NHS Long Term Plan Implementation Framework](#), June 2019, para 5.10

¹⁹ [The NHS Long Term Plan Implementation Framework](#), June 2019, para 5.13

²⁰ The Learning Disabilities Mortality Review (LeDeR) Programme, [Annual Report](#), December 2017, Summary of recommendations, page 31.

We agree that health and care staff should have access to learning disability awareness training. We will consult by the end of March 2019 on options for delivering this to staff.

35. We are committed to basic training in, and awareness of, learning disability for health and care staff. Furthermore, we accept the advantage of delivering such training in conjunction with people with lived experience. We strongly recommend that all employers involve people with lived experience in the development and deployment of training.

36. All employers already have a clear responsibility set out in legislation to make sure that staff are competent to perform their role. The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, require that any person employed by a regulated service must 'receive the support, training, professional development, supervision and appraisal as is necessary to enable them to carry out the duties they are employed to perform.' In practice, for people and services which care for and treat people with a learning disability, the nature of the necessary skills and competencies are set out in the Learning Disability Core Skills Education and Training Framework (2016).

37. This Framework describes the core skills and knowledge required in three 'tiers':

- Tier 1 - for roles that require general awareness of learning disabilities;
- Tier 2 - for roles that will have some regular contact with people (children, young people and adults) with a learning disability, and;
- Tier 3 - for those staff directly providing care and support for people (children, young people and adults) with a learning disability.

38. While in principle employers are required to ensure that their staff have the core skills and knowledge to care for, treat and support people with a learning disability, the LeDeR report and campaigns such as Mencap's Treat me well, demonstrate that in practice this isn't always the case. We will take immediate steps (detailed below) to remind employers of their responsibilities to raise the profile of the Framework²¹, stimulate provision of training generally and to measure uptake. But persistent inequalities have endured for some of our most vulnerable citizens for too long. **For this reason, we will consult on options for delivering mandatory learning disability training for all relevant staff.** Consultation will take place with people with lived experience, the wider learning disability sector, NHS and social care providers and the general public to ensure that proposals are practicable and effective and to avoid any training becoming a 'box-ticking exercise'. The consultation will be completed by March 2019.²²

The Government's response to the consultation - "[Right to be heard](#)" - was published in November 2019. This noted that over 5,00 responses

²¹ The [Learning Disability Core Skills Education and Training Framework](#) was published in July 2016

²² Department of Health & Social Care, NHS England, [The Government response to the Learning Disabilities Mortality Review \(LeDeR\) Programme Second Annual Report](#), para 35-38

were received, and the vast majority were supportive of the principle of mandatory training.²³

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

The Government will be looking at how training can also be strengthened for health and social care staff who do not work in regulated activities and will report back on this by 2021.²⁴

Box 1 Regulated Activities

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

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

The Government will be working with all professional bodies and Devolved Administration to agree a common ‘core curriculum’ based on the [Core Capabilities Framework for Supporting People with a Learning Disability](#) and the new Core Capabilities Framework for Supporting Autistic People. Training requirements will however vary according to staff roles and interactions with people with a learning disability and/or autism. The Government has committed £1.4 million to develop and test a learning disability and autism training package. A trial of the

²³ Department of Health & Social Care, ‘[Right to be heard’: The Government’s response to the consultation on learning disability and autism training for health and care staff](#)’, 5 November 2019

²⁴ Department of Health & Social Care, ‘[Right to be heard’: The Government’s response to the consultation on learning disability and autism training for health and care staff](#)’, 5 November 2019, para 32

training is due to begin in April 2020 and will report by March 2021, after which wider roll-out to all staff is expected.²⁵

2.3 Learning Disabilities Mortality Review Programme

In 2013, the Department of Health established a [*Confidential Inquiry into the Premature Deaths of People with Learning Disabilities*](#). The Inquiry investigated the avoidable or premature deaths of people with learning disabilities through retrospective reviews of individual deaths. The aim was to review the patterns of care that people received in the period leading up to their deaths, to identify errors or omissions which may have contributed, to illustrate evidence of good practice, and to provide improved evidence on avoiding premature death. The inquiry focused on five Primary Care Trust (PCT) areas of South West England.

It found that the most common reasons for deaths being assessed as premature were delays or problems with diagnosis or treatment, and problems with identifying needs and providing appropriate care in response to changing needs:

for 29% there was significant difficulty or delay in diagnosis, further investigation or specialist referral, and for 30% there were problems with their treatment. The lack of reasonable adjustments to facilitate healthcare of people with learning disabilities, particularly attendance at clinic appointments and investigations, was a contributory factor in a number of deaths...²⁶

The inquiry made recommendations, such as introducing named professionals to coordinate patient care across different services, and proactively using annual health check and health action plans to identify and plan for health and care needs.

The [*Government's response to the Confidential Inquiry into premature deaths of people with learning disabilities*](#) (July 2013), stated that it was committed to addressing the issues identified. The Department of Health, NHS England, Public Health England and other statutory organisations, subsequently developed programmes of work to address each of recommendations. The Government published a progress update in September 2014, [*Premature Deaths of People with Learning Disabilities: Progress Update*](#) which summarised action taken or underway against each of the recommendations.

In June 2015, NHS England announced a three-year national review of premature deaths of people with learning disabilities. The *Learning Disability Mortality Review Programme* was commissioned by Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and similarly focused on retrospective reviews of individual deaths, to help

²⁵ Department of Health & Social Care, '[Right to be heard': The Government's response to the consultation on learning disability and autism training for health and care staff](#)', 5 November 2019, para 27

²⁶ [Confidential Inquiry into the Premature Deaths of People with Learning Disabilities \(CIPOLD\), March 2013, page 4](#)

reduce early deaths and health inequalities for people with a learning disability.²⁷

The 2016-17 annual report found that in 13% of its reviews into the deaths of people with learning disabilities, the person's health had been adversely affected by factors such as delays in treatment, organisational dysfunction and gaps in service provision. In response it set out nine national recommendations, including:

- Strengthening collaboration and information between care providers, including integration of health and care records;
- All people with learning disabilities with two or more long-term conditions should have a local, named care coordinator;
- Mandatory learning disabilities awareness training provided to all staff, delivered in conjunction with people learning disabilities and their families.²⁸

The Government provided its response in September 2018 and accepted the report's recommendations. It committed to several actions, including completing a public consultation on proposals for mandatory learning disability training by March 2019.

The third annual report was published in May 2019. The reviews found that in 71 cases (8% of reviews), a patient's received care fell so far short of expected good practice that it significantly impacted on their well-being or directly contributed to their cause of death. The report made twelve recommendations for the education, health and care systems, including:

- Support to recognise deteriorating health in people with learning disabilities
- Care co-ordination and better communication between agencies
- Transition planning for young people
- Training for staff²⁹

In May 2019, the NHS announced £5million funding to accelerate the pace at which reviews are completed.³⁰ NHS England and NHS Improvement also published a report outlining activity that is taking place locally and nationally in response to reviews - [Learning Disability Mortality Review \(LeDeR\) Programme: Action from Learning](#) (May 2019). This described national action in clinical areas such as cancer and sepsis, as well as initiatives in individual hospitals, such as targeted schemes to

²⁷ NHS England, [NHS launches world's first national review of deaths of people with learning disabilities](#), 18 June 2015

²⁸ The Learning Disability Mortality Review (LeDeR) Programme, [Annual Report 2016-17](#), December 2017, page 8

²⁹ The Learning Disability Mortality Review (LeDeR) Programme, [Annual Report 2018](#), May 2019

³⁰ NHS England, [NHS invests £5 million to improve care for people with a learning disability](#), 21 May 2019

improve reasonable adjustments and increase uptake of medical tests for this group.

The Government's response to the third annual report was published in February 2020, which responds to each of the 12 recommendations. For example, the Government committed to publishing a review of care-coordination for people with learning disabilities by summer 2020.³¹

2.4 Reducing inpatient care

In 2011, the BBC's Panorama programme exposed the abuse of patients at Winterbourne View, an independent hospital for people with learning disabilities and/or autism. Further inspections by the CQC of 150 hospitals and care homes for people with a learning disability found inadequate practice in inpatient services, included poor person-centred care, limited appropriate activities and a lack of monitoring and learning from incidents of restraint.³²

The Department of Health's national policy response, [*Transforming care: A National response to Winterbourne View Hospital*](#) (December 2012) stated that "hospitals are not where people should live" and pledged that everyone inappropriately placed in hospital will move to community-based care as quickly as possible, and no later than 1 June 2014. The review was accompanied by the [*Winterbourne View Review: Concordat*](#), an agreement signed by the NHS, statutory organisations and stakeholders committing themselves to provision of appropriate services for people with learning disabilities.

In 2014, NHS England commissioned Sir Stephen Bubb to consider how a new national framework for learning disability services could be implemented. This came after the pledge to move people to community care by June 2014 was missed.³³

Sir Stephen's report [*Winterbourne View - Time for Change*](#) (2014), found that people with learning disabilities were still being placed inappropriately in long-term institutional care rather than being supported in the community. The report found that there were still more people being admitted to such institutions than were being discharged and recommended the urgent closure of inappropriate inpatient care institutions.³⁴

The subsequent report - [*Winterbourne View - Time is Running Out*](#) (2015) – found that progress had been made, with the number of people being discharged from inpatient institutions greater than the number admitted. However, it said that the pace of change had been slow, and the *Transforming Care* programme has not yet delivered

³¹ Department of Health & Social Care, [The Government response to the third annual Learning Disabilities Mortality Review \(LeDeR\) Programme report](#), 12 February 2020

³² Care Quality Commission, [Learning Disability reports](#) [last accessed 5 November 2014]

³³ A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb, [Winterbourne View - Time for change](#), November 2014, page 8

³⁴ A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb, [Winterbourne View - Time for change](#), November 2014

tangible benefits in terms of new community facilities or closures. The successive report *Time for Change: The Challenge Ahead* (2016) recommended a commissioner for learning disabilities to promote and protect the rights of all people with learning disabilities and/or autism in England. The Government said it will consider the recommendations of the report, but that “new statutory roles and legislation are not necessarily the answer to promoting and protecting the rights of people with learning disabilities and their families”.³⁵

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

- We know how many people are in inpatient settings, where they are and who is responsible for them.
- We have strong accountability and corporate responsibility arrangements in place via the Duty of Candour and Fit and Proper Person Test to assure the quality and safety of care services that people receive.
- We have new DH guidance on minimising restrictive interventions, complemented by a suite of information by Skills for Care and Skills for Health setting the foundation for a broader new programme Positive and Safe launched by the Department of Health in 2014. Work is underway to improve and report on data about the use of restraint.
- A more rigorous registration, assessment and inspection approach is in place for learning disability services, involving experts by experience and ratings are being published from inspections taking place since October 2014.
- The Care Act 2015 underpins and reinforces the importance of good quality, independent advocacy and will play an important part in supporting people, their families and carers to raise concerns when these arise.³⁶

However the report also said that not as much progress has been made as was intended – for example it recognised that the June 2014 target to transfer people to community care was missed.³⁷

In February 2015, the National Audit Office (NAO) published its report *Care Services for People with Learning Disabilities and Challenging Behaviour*. The report found that the Government had not met its central goal of moving people out of hospital by June 2014 because it “underestimated the complexity and level of challenge in meeting the commitments in its action plan”.

During a Public Accounts Committee evidence session on the NAO report in February 2015, the Chief Executive of NHS England announced that there would now be a planned closure programme for NHS mental health hospitals, and a change in commissioning practices for NHS

³⁵ [PO 28525 \[on Learning Disability\] 1 March 2016](#)

³⁶ Department of Health, [Winterbourne View: Transforming Care Two Years On](#), January 2015, page 6

³⁷ *ibid*

inpatients within the independent sector.³⁸ This would be accompanied by a transition plan for the people with learning disabilities within these hospitals, from 2016–17.³⁹

In October 2015, NHS England, in partnership with the Local Government Association (LGA) and the Directors of Adult Social Services (ADASS), published a national action plan to develop community services and close inpatient facilities for people with a learning disability and/or autism. The *Building the Right Support* plan aimed to shift money from inpatient services to the community and reduce the use of inpatient beds by 35% - 50% over three years, alongside the closure of the last standalone learning disability hospital in England, Calderstones.⁴⁰ Transformation was based on 49 'Transforming Care Partnerships', comprising CCGs, NHS England commissioners, and local authorities. This was accompanied by £40 million of transformation funding from 2015/16 to 2018/19, to be matched by CCGs, and £20 million in capital funding.⁴¹

The [Government's Mandate to the NHS 2018-19](#) set an objective of achieving the 35-50% bed reduction by March 2019. The Government noted in October 2017 that the total number of people in inpatient units had fallen 14% since March 2015, and 164 inpatient beds closed in 2016/17, 'ahead of plan'.⁴² In 2016, the last standalone learning disability hospital in England was absorbed into a mental health trust, although the planned closure of the Calderstones site may not be completed until 2021.⁴³

However, as noted above, the 2019 *NHS Long Term Plan* provides that the target for reducing inpatient provision by 50% is delayed until 2023/24. This has been criticised by charities such as Mencap, who have described the continuation of people in inpatient care as a 'domestic human rights scandal'.⁴⁴

In February 2020, the Equalities and Human Rights Commission launched a legal challenge against the Secretary of State for Health and Social Care over the failure to move people with learning disabilities and autism into appropriate accommodation. The Commission said:

We have sent a pre-action letter to the Secretary of State for Health and Social Care, arguing that the Department of Health and Social Care (DHSC) has breached the European Convention of Human Rights (ECHR) for failing to meet the targets set in the Transforming Care program and Building the Right Support program.

³⁸ Public Accounts Committee, [Care services for people with learning disabilities and challenging behaviour](#), 27 March 2015, HC 973 2014-15, para 15

³⁹ Public Accounts Committee, [Care services for people with learning disabilities and challenging behaviour](#), 27 March 2015, HC 973 2014-15, page 5

⁴⁰ NHS England, [Building the right support](#), October 2015

⁴¹ NHS England, [NHS England to invest in building the right support for people with a learning disability](#), 20 June 2017

⁴² [PO 108577 \[on Health Services: Learning Disability\]](#), 26 October 2017

⁴³ 'UNION BOSSES: Calderstones Hospital closure date 'unachievable'', *Lancashire Telegraph*, 19 April 2018

⁴⁴ Mencap, [Government due to miss deadline for releasing people with a learning disability locked away in inpatient units, warns Mencap](#), 21 March 2019

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These targets included moving patients from inappropriate inpatient care to community-based settings, and reducing the reliance on inpatient care for people with learning disabilities and autism.

Following discussions with the DHSC and NHS England, we are also not satisfied that new deadlines set in the NHS Long Term Plan and Planning Guidance will be met.

This suggests a systemic failure to protect the right to a private and family life, and right to live free from inhuman or degrading treatment or punishment.

[...]

The DHSC has 14 days to respond to our pre-action letter. Alternatively, we have offered to suspend the legal process for three months if DHSC agrees to produce a timetabled action plan detailing how it will address issues such as housing and workforce shortages at both national and regional levels.⁴⁵

⁴⁵ Equality and Human Rights Commission, [Health Secretary faces legal challenge for failing patients with learning disabilities and autism](#), 12 February 2020

3. Employment

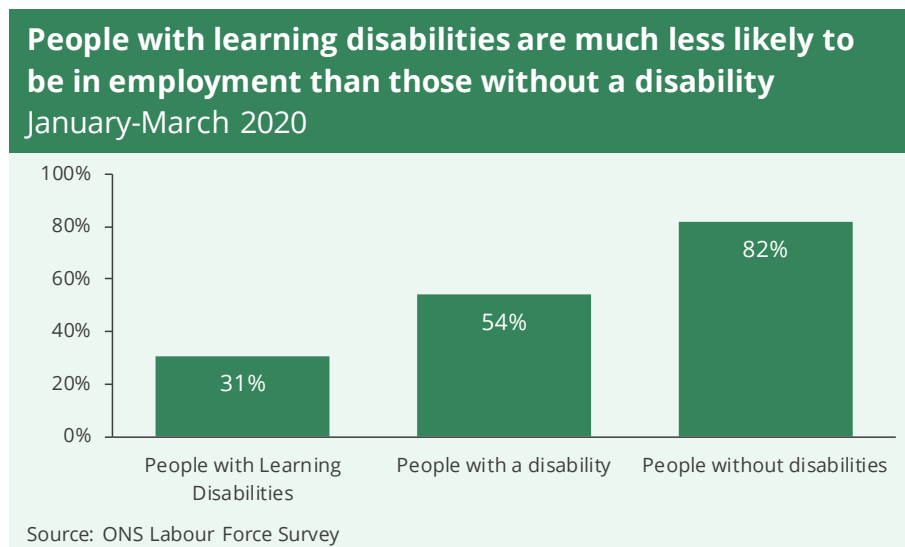
In the first quarter of 2020, there were 4.3 million people with disabilities in employment. Around 140,000 of these had a learning disability.

The Government is committed to “making a step change in the life chances of people with learning difficulties, and learning disabilities”, recognising that people who have learning difficulties “have often not been well supported in employment”.⁴⁶

The Government has stated that it will get 1 million more disabled people into work by 2027. To meet this target there would have to be 4.5 million people in employment with disabilities, a growth of around 7% on current levels.⁴⁷

3.1 Employment statistics

The chart below shows the employment rate for people with learning disabilities, and compares this with the rate for those with any disability and those who do not have a disability.



The employment rate for people with a learning disability is markedly less than that for those with any disability and those without a disability. While just over half of those with a disability were in employment in the first quarter of 2020, less than a third of those with a learning disability were also in employment. Over 80% of those without a disability were in work.⁴⁸

Public Health England has reported that only 6% of the 7,900 working age adults with learning disabilities in England who are getting long-term social care support were in paid or self employment. Over two thirds of those who were in employment were working for less than 16

⁴⁶ [PO 126722](#), 9 February 2018

⁴⁷ [Conservative Party Manifesto](#), May 2017

⁴⁸ ONS, [A08: Labour market status of disabled people](#), 19 May 2020

hours per week. They also report that paid employment rates for adults with learning disabilities “do not seem to be” increasing over time.⁴⁹

3.2 Increasing the number of people with learning disabilities in work

In November 2017, the government set out its strategy on how it intends to get a million more people with disabilities into employment by 2027 in the [Improving lives: the future of work, health and disability](#) White Paper. The strategy is partly based on supporting people with disabilities and long-term health conditions to find work, but also to provide investment to support these people to stay in work.

The main policies and proposals relating to employment support for people with disabilities are highlighted in the library briefing paper [People with disabilities in employment](#) (January 2020), and some of these are also referenced below. These initiatives are not aimed exclusively at people with a learning disability.

Personal Support Package

The Personal Support Package was rolled out from April 2017 onwards. The initiative offers tailored employment support for people with disabilities and health conditions, delivered through Jobcentre Plus.⁵⁰

This support includes **Disability Employment Advisers** whose role is to help people with disabilities to find suitable jobs, and work alongside work coaches to provide additional professional expertise.

The [Intensive Personalised Employment Support programme](#) launched in late 2019, and provides personalised support to those who are at least a year from moving into work. This programme is expected to benefit 10,000 people.⁵¹

People on this programme will have a dedicated support worker who will provide one-to-one support and training to help them get into work. They will usually receive this support for 15 months, as well as 6 months of on-the-job support if they find employment.

The Department for Work and Pensions worked with nine local authorities on a Proof of Concept for a **Local Supported Employment** scheme. This will support people with a learning difficulty or autism. The Proof of Concept ran until May 2019, and it is not yet apparent whether there will be a full trial of this scheme.^{52 53}

The Disability Confident Campaign

The [Disability Confident Campaign](#) was launched by the Prime Minister in July 2013, and aims to encourage employers to become more

⁴⁹ Public Health England, [People with learning disabilities in England](#), Chapter 2: paid employment, 28 October 2019

⁵⁰ DWP, [Welfare reforms and £330 million employment package start from April 2017](#), 31 March 2017

⁵¹ [PO 256951](#), 4 June 2019

⁵² [PO 4760](#), 27 January 2020

⁵³ BASE, [Supported Employment Proof on Concept](#)

confident in employing disabled people, by removing barriers and increase understanding.

Employers who sign up to the scheme are asked to commit to offer a disabled person an opportunity within their organisation.

As of December 2019, 15,560 employers had signed up to the Disability Confident scheme.⁵⁴

The Government has stated that the scheme “helps employers to improve in their ability to recruit, retain and develop disabled people”.⁵⁵

At a Westminster Hall Debate on the Disability Confident scheme, the Shadow Minister for Work and Pensions (Disabled People) stated that there is little evidence that the scheme is enabling more disabled people to find sustainable and supportive employment, and reported that the Government has stated that they are “not able to measure the number of disabled people moving into employment as a direct result of [the disability confident scheme]”.⁵⁶

Access to Work

The [Access to Work](#) scheme provides financial support for the extra costs of being in work which go beyond the “reasonable adjustments” that are required in law (see below). Access to Work is delivered by the Department for Work and Pensions through Jobcentre Plus and is available to those aged 16 years or over who live and work in Great Britain.

Specialist support is provided to those people with learning disabilities and other less visible disabilities through a Hidden Impairment Specialist Team.⁵⁷

For further information see the Library briefing on [‘Access to Work’ scheme for people with disabilities](#) (June 2016).

Work and Health Programme

The Work and Health Programme is an employment support programme which was launched in North West England and Wales in November 2017. The programme rolled out across the rest of England during early 2018.⁵⁸

The Programme provides support to help people find and keep a job. It is available, on a voluntary basis, to those with health conditions or disabilities, and to various groups of vulnerable people. The programme is compulsory for those who have been unemployed for over two years.

Up to November 2019:

- There had been almost 150,000 referrals to the programme, with the majority of these being people with disabilities.

⁵⁴ DWP, [Disability Confident: employers that have signed up](#), 5 December 2019

⁵⁵ [PQ 130481](#), 5 March 2018

⁵⁶ HC Deb, [Disability Confident Scheme](#), c133WH

⁵⁷ [PQ 126722](#), 9 February 2018

⁵⁸ DWP, [April 2018: Touchbase edition 126](#), 23 May 2018

- 92,500 individuals had started on the programme.
- There had been almost 10,000 job outcomes.⁵⁹

The Work and Health Programme replaces the [Work Programme](#) and [Work Choice schemes](#).

Further information on this programme is available in the Library briefing note [Work and Health Programme](#) (January 2018).

Organisations giving opportunities to those with learning disabilities

[Mencap](#) have provided a [list of the organisations](#) that provided work experience placements for people with a learning disability.

The Rethink Mental Illness charity provides a list of the organisations that they are working with [here](#).

The Department for Work and Pensions has also provided [case studies](#) of those organisations who have demonstrated good practice in employing disabled people.

NHS Learning Disability Employment Programme

In June 2015, NHS England and NHS Employers launched the [NHS Learning Disability Employment Programme](#) which aimed to increase the employment within the NHS of people with learning disabilities.

NHS England have published [tools and guidance](#) to support NHS organisations in meeting this objective.

3.3 Anti-discrimination legislation

The [Equality Act 2010](#) prohibits both direct and indirect disability discrimination in employment and recruitment.

Direct disability discrimination occurs where an employer treats a disabled person less favourably because they are disabled.

Indirect disability discrimination occurs where an employer applies a policy, criterion or practice which has the effect of putting a disabled person at a particular disadvantage as compared with non-disabled persons. Indirect discrimination may be lawful if it can be shown to be a proportionate means of achieving a legitimate aim.

Discrimination arising from disability occurs where an employer treats a person unfavourably because of something arising in consequence of their disability. It differs from direct discrimination in that the unfavourable treatment is because of something arising from the disability, not the disability itself. Further, unlike indirect discrimination the person does not need to show that the employer was applying a provision that puts (or would put) persons sharing that person's disability at a particular disadvantage. It is sufficient to show that they were treated unfavourably because of something arising from *their* disability. Discrimination arising from disability may be lawful if it can be shown to be a proportionate means of achieving a legitimate aim.

⁵⁹ DWP, [Work and Health Programme statistics to November 2019](#), February 2020

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

Reasonable adjustments

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

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

The DWP has published guidance on [Employing disabled people and people with health conditions](#). It states that:

- The costs of making reasonable adjustments to accommodate disabled employees are often low.
- The benefits of retaining an experienced, skilled employee who has acquired an impairment are usually greater than recruiting and training new staff.

Examples of reasonable adjustments included in the guidance and on the gov.uk page [Reasonable adjustments for workers with disabilities or health conditions](#) are listed below. This is not an exhaustive list of potential adjustments.

- Making changes to a disabled person's working pattern. Allow those who have become disabled to make a phased return to work.
- Doing things another way, such as allowing someone with social anxiety disorder to have their own desk instead of hot-desking, or allowing someone with a wheelchair to work on the ground floor.
- Providing training or mentoring. This will include training to non-disabled workers on how they can be more inclusive to disabled people.
- Either employing a support worker to assist a disabled worker, or arrange for a colleague to assist them with certain tasks.
- Making alterations to premises, like installing a ramp for a wheelchair user or an audio-visual fire alarm for a deaf person.
- Ensuring that information is provided in accessible formats, for example in Braille or on audio tape.
- Modifying or acquiring equipment, such as special keyboards for those with arthritis.
- Changing the recruitment process. Modify procedures for testing or assessment to ensure they don't disadvantage people with particular disabilities.
- Allowing extra time during selection tests.

[Access to Work](#) funding can be applied for towards the cost of making such reasonable adjustments.

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

4. Social security

Mencap notes that while disabled people, including people with a learning disability and their families, are more likely to live in poverty than the general population, they also face barriers accessing social security benefits and the levels of support often do not meet the extra costs they face. It states that applying for benefits can be challenging for people with a learning disability. Problems include:

- People having to wait months for assessments and decisions
- Assessments are often of poor quality, resulting in a high success rate at appeal
- People forced to undergo regular reassessments to continue to receive the support they are entitled to
- People with a learning disability often face “unreasonable expectations and inadequate support” as regards moving towards and finding employment, resulting in sanctions and further hardship⁶⁰

Mencap has set out a “vision statement” for a social security system to support people with a learning disability and their families to have a good standard of living. For this to happen, it argues that:

- The government and society should recognise social security as a necessary right and a form of income replacement to help alleviate poverty
- The extra costs that people with a learning disability face must be recognised and met in full by the social security system
- The social security system must provide people with stability and long-term security, and not force them to undergo continual reassessments
- People assessing and making decisions on social security claims must have better and more in-depth training and understanding in learning disability. This means decisions are right the first time, and people with a learning disability and their families get timely access to financial assistance
- High quality support – financial and otherwise – must be available to help people with a learning disability move towards, find, and stay in work, with long-term security for those who cannot work⁶¹

People with a learning disability may be entitled to a range of different benefits including:

- 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.
- ‘Income replacement’ benefits to cover day to day living costs. This includes benefits such as [Employment and](#)

⁶⁰ Mencap, [Benefits - what we think](#), April 2016

⁶¹ Mencap, [Social Security Vision Statement](#), July 2016

[Support Allowance](#), but increasingly support will be provided by [Universal Credit](#).

4.1 Personal Independence Payment

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

PIP was introduced for new claims from April 2013, and DWP is reassessing all existing working age DLA claimants for the benefit. Young people in receipt of DLA are also reassessed for PIP when they reach 16.

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 which differs from that used to determine eligibility for the DLA care components. PIP was intended to target support more closely on those most in need and significantly fewer people were expected to qualify for PIP than would have qualified for DLA, but the Office for Budget Responsibility has shown that PIP will not in fact deliver savings relative to DLA. In its January 2019 Welfare trends report, the OBR observed that while the Coalition Government assumed initially that PIP would ultimately cost 20% less than DLA would have done, by 2017-18 it was in fact costing around 15-20% more, with rollout only around two-thirds complete.⁶²

The Department for Work and Pensions is responsible for handling claims for PIP and making decisions on entitlement to benefit. Contracted assessment providers are however a key element in the claims process. Atos Healthcare holds the contracts for undertaking assessments in Northern England and Scotland; and in London and Southern England. Capita Business Services Ltd holds the contracts covering Wales and Central England; and Northern Ireland.⁶³ These are separate from the contract under which Maximus undertakes Work Capability Assessments for ESA and Universal Credit claims.

At November 2019, 335,700 Disability Living Allowance claimants in Great Britain – 22% of the total – were recorded as having "learning difficulties" as their main disabling condition.⁶⁴ Of the 2.5 million

⁶² OBR, [Welfare trends report](#), January 2019, p13

⁶³ For further information on PIP see Commons Library briefing CDP-2018-0020, [Claimant experience of the Personal Independence Payment process](#), 30 January 2018

⁶⁴ This is a broader definition than other Government departments' definitions of the population of people with learning disabilities – see Public Health England, [People with learning disabilities in England: Chapter 4: disability benefits](#), updated 28 October 2019

people entitled to PIP at April 2020, 159,400 – 6% - had had learning disability as their main disabling condition.⁶⁵

The DWP also publishes statistics on outcomes for working-age DLA claimants reassessed for PIP.⁶⁶ Compared with DLA claimants as a whole, people with learning difficulties reassessed for PIP up to October 2019 were more likely to have an increased award following a reassessment for PIP (54%, compared with 39%), and less likely to have their award reduced (4%, compared with 22%). However, 29% of those with learning difficulties had their award disallowed or withdrawn (for all those reassessed the figure was 25%).⁶⁷

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 – for background to these changes see Commons Library briefing CBP-7911, [Changes to the Personal Independence Payment eligibility criteria](#). The most significant change made by the regulations 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 learning disability. Disability organisations called on the Government not to proceed with the changes. Some questioned how the changes fitted with the Government’s stated commitment to “parity of esteem” between physical and mental conditions.⁶⁸

In its judgment on 21 December 2017 in [RF v the Secretary of State for Work and Pensions & Others](#),⁶⁹ the High Court ruled that the regulations introducing the March 2017 changes were unlawful because they discriminate against people with disabilities in breach of *Human Rights Act 1998* obligations, and declared that the Secretary of State did not have lawful power to make the regulations (i.e. they were “ultra vires”) and should have consulted before making them.

The Government subsequently announced⁷⁰ that it would not contest the High Court’s decision, and that it would also drop its appeal against the original Upper Tribunal decision (‘MH’) that had prompted the change to the regulations.⁷¹ The Secretary of State for Work and Pensions said that her Department would now “take all steps necessary to implement the judgment in MH in the best interests of our claimants, working closely with disabled people and key stakeholders over the coming months.”

⁶⁵ Source: [DWP Stat-Xplore database](#)

⁶⁶ DWP, [Personal Independence Payment: April 2013 to October 2019](#), 13 December 2019

⁶⁷ These figures are initial outcomes from reassessments, prior or any reconsideration, appeal action or award review.

⁶⁸ “Parity of esteem” refers to giving mental health equal priority to physical health.

⁶⁹ [\[2017\] EWHC 3375 \(Admin\)](#)

⁷⁰ [Written Statement HCWS414](#)

⁷¹ [MH v Secretary of State for Work and Pensions \[2016\] UKUT 0531 \(AAC\)](#)

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. Further details of the review process are given in a Deposited Paper.⁷²

On 11 February 2020, Justin Tomlinson, the Minister of State for Disabled People, Health and Work, provided the latest update on the number of PIP claims reviewed in a [written statement](#) to the House. Up to 5 January 2020, the Department had cleared 720,000 cases against the MH decision and 820,000 cases against the separate RJ decision (which concerned claimants at risk of serious harm as a result of their disability or health condition when carrying out an activity in the PIP assessment). In total the Department had paid £28 million in arrears to 5,900 claimants – with £17 million being paid in respect of the MH decision alone – and that it was on course to complete the exercise in 2020.⁷³

On 3 April however, the DWP's Permanent Secretary wrote to the Work and Pensions Committee announcing, among other things, that the Department was "pausing" the review of PIP claims, following the coronavirus outbreak. This is for an initial period of three months up to the end of June, but the Department would keep this under review, "depending on developments with coronavirus and demands on our services."⁷⁴

Disability benefits in Scotland

Under the *Scotland Act 2016*, responsibility for disability benefits (among other things) was devolved to the Scottish Government and Parliament. New benefits are to replace the existing extra-costs disability benefits in Scotland. Disability Assistance for Children and Young People will replace DLA, Disability Assistance for Working Age People will replace PIP, and Disability Assistance for Older People will replace Attendance Allowance.⁷⁵

New claims for Scottish disability benefits were expected to start from 2020-21, with existing benefit claimants transferring to the devolved benefits between then and 2025. On 1 April 2020 however, the Scottish Government announced that, due to the coronavirus outbreak, introduction of Disability Assistance for Children and Young People and Disability Assistance for Working Age People would be delayed.⁷⁶ A new timetable hasn't yet been announced.

The Scottish Government is still developing its plans for Disability Assistance, but it has given a number of commitments in relation to how it will differ from the existing reserved benefits. These include:

⁷² DWP, [Personal Independence Payment \(PIP\): Implementation of legal decisions MH and RJ: Frequently Asked Questions \(FAQ\)](#), DEP 2020-0061, February 2020

⁷³ [Written Statement HCWS104](#)

⁷⁴ [Letter from Peter Schofield to Stephen Timms MP](#), 3 April 2020

⁷⁵ See Commons Library briefing CDP-2019-0084, [Devolution of welfare](#), 8 April 2019; and Scottish Government, [Social security: policy position papers](#), February 2019

⁷⁶ Scottish Government, [Coronavirus \(COVID-19\) - update on devolved benefits: Cabinet Secretary speech](#), 1 April 2020

- Ensuring that the application process for Disability Assistance is “inclusive, accessible, provided in a range of formats, can be completed in a range of routes.”
- Not using private sector contractors to deliver disability assessments.
- Significantly decreasing the number of face to face assessments – people will only be asked to undertake an assessment where Social Security Scotland (the Scottish Government’s social security agency) has not been able to gather enough evidence to make a decision on entitlement.
- Giving people the right to be accompanied to an assessment, and to have that person participate in the assessment.
- Audio recording of assessments as standard.
- Introducing rolling awards of up to 10 years for people with conditions unlikely to change.
- Having independent advocacy workers to help disabled people applying for Scotland’s new social security benefits.⁷⁷

4.2 Benefit assessments

Disability organisations have long voiced concerns about the assessment processes for extra costs disability benefits such as PIP, and about the Work Capability Assessment (WCA) for Employment and Support Allowance and Universal Credit.

In November 2014, Dr Paul Litchfield’s [Fifth Independent Review of the Work Capability Assessment](#) also expressed concerns about the disadvantages faced by people with a learning disability during the WCA process. He raised concerns about the difficulties people with a learning disability may face in engaging with and navigating the process, including barriers to engaging with standard communications; a lack of easy read versions of materials; and interview practices that are not adapted to enable people with a learning disability to fully understand the questions being asked:

Many people with learning disabilities will answer questions literally and neither understand nor express subtleties of interpretation...Similarly, a number of people with learning disabilities will wish to please someone asking them questions and will consequently give the responses that they think are wanted rather than those which most accurately reflect reality.⁷⁸

Dr Litchfield made recommendations to improve the WCA process, including reviewing the learning disability training that the DWP provides to its staff and assessments providers.⁷⁹

In evidence to the Work and Pensions Committee’s inquiry into PIP and ESA assessments launched in September 2017, the charity Mencap said that its helpline had heard of many cases where people previously in

⁷⁷ Scottish Government, [Disability assistance in Scotland: response to consultation](#), 28 October 2019

⁷⁸ Dr Paul Litchfield, [An Independent Review of the Work Capability Assessment – year five](#), November 2014, page 60

⁷⁹ Dr Paul Litchfield, [An Independent Review of the Work Capability Assessment – year five](#), November 2014, page 60

receipt of the middle rate DLA care component had been denied PIP altogether; and where following a repeat Work Capability Assessment had had their ESA reduced or had been found 'fit for work', despite no change in the circumstances.⁸⁰ Other concerns raised by Mencap included:

- Despite some ongoing work to improve training, assessors often did not have a full understanding of learning disability.
- Family members and advocates not being allowed to speak up during assessments when not was clear that the person being assessed was saying things that did not reflect their real-life abilities.
- The need for fundamental reform of the Work Capability Assessment so that it captured an accurate picture of the barriers faced by disabled people and what kind of job the person could do.
- The “devastating effects” on disabled people’s lives of wrong PIP and ESA decisions, including the loss of passported benefits and people being subject to inappropriate conditionality.
- Ongoing concerns about the “Mandatory Reconsideration” process – many people felt that Tribunals seemed to understand their condition better, often because advocates were given the opportunity to speak and support the individual during appeals. Mencap was also worried that the Ministry of Justice’s plans for online appeals could deter people from appealing decisions and make it more difficult for Tribunals to understand the nature and impact of a person’s disability.
- Assessors should be more proactive in encouraging people close to the claimant, including care workers and family members, to submit evidence along with the claim, and professionals must be better educated about what types of evidence would be useful.
- An easy read version of the PIP2 claim form should be available, and people with a learning disability and their supporters should have access to staff with learning disability awareness on the phone to help with questions.
- All claimants should be given substantial advance warning of assessments, communications must make it clear that home visits can be requested, and claimants must be explicitly told that they can bring a companion with them and encouraged to do so. For those without a companion to accompany them, DWP should provide skilled advocacy service.

In its report on [PIP and ESA assessments](#) published on 7 February 2018⁸¹, the Work and Pensions Committee said that failings in the

⁸⁰ [Written evidence from Royal Mencap Society](#), PEA0398, November 2017

⁸¹ HC 829 2017-19

assessment and decision making processes for PIP and for ESA had resulted in the “pervasive lack of trust” that risked undermining the entire operation of both benefits. It set out a series of recommendations including:

- recording face to face assessments and providing a record and a copy of the assessor's report to claimants;
- measures to improve understanding about what constitutes good evidence to support PIP and ESA claim, and ensuring assessors use evidence effectively;
- improving the accessibility of the process at every stage, from the application form, to information about home visits and about accessing reconsiderations and appeals; and
- improving contractor performance through more effective use of contractual “levers” and ensuring assessors are given feedback, including from the appeals process.

In its [response to the Committee's report](#) issued on 23 April 2018, the Government made a number of commitments including:

- Producing an Easy Read version of the notes which accompany the PIP “How your disability affects you” form.
- Launching a series of videos which outline the PIP claim process in a simple and clear way, and explain the types of relevant information that are useful in support of a claim, in order to better prepare claimants for an assessment. The PIP assessment providers also supply information to claimants ahead of their assessment appointment via their websites and direct mail sent to the claimant.
- Addressing improvements to application forms by commissioning external research to identify whether, how and what aspects of the PIP (and ESA) claim forms could have the potential to cause distress; revising and amending the forms in light of these findings; and testing the revised forms with applicants to determine if improvements made result in the forms being more claimant-friendly and less likely to cause distress. This work is to comment in summer 2018.
- Working closely with the PIP assessment providers around requests for home visits to ensure their processes align with guidance and claimant needs are being met.
- Working with PIP providers to enhance GP engagement – all providers to foster a greater level of engagement and source information from a broader range of health and social care professionals.
- Pilot enhancements to the PIP telephony script to remind claimants to submit medical evidence and the types of evidence that are useful.
- The Department recognises that the complexity and potential costs of recording makes it difficult for

claimants—of PIP especially—to record their assessment. It intends “to make recording the PIP assessment a standard part of the process”. The Department would explore “potential options to test the recording of assessments, including video recording.”

- Gathering more information on companions accompanying claimants to PIP assessments. In recognition of the fact that a family member, friend, carer or other advocate to support claimants in the assessment, and can be “particularly helpful where a claimant has a mental, cognitive or intellectual impairment and may not be able to give an accurate account of their daily living and mobility needs.” DWP will consider how assessments where companions attend with claimants can be specifically examined in audit.

In a written statement on 5 June 2018, the Government announced further measures to “improve the experience” of those claiming PIP, including looking at how to enable more providers to deliver PIP by developing a DWP-owned IT system.⁸²

Repeat assessments

Since 29 September 2017, some Employment Support Allowance and Universal Credit claimants with the most severe health conditions and disabilities have been exempt from future reassessments. Claimants meet the “severe conditions criteria” if they have been assessed as having a “limited capability for work-related activity”; have a severe, lifelong disability, illness or health condition; and are unlikely to ever be able to move into work.

In August 2018 the DWP also issued updated internal guidance to ensure that people receiving the highest level of support under Personal Independence Payment, and whose needs are unlikely to change or may get worse, will receive an “ongoing award” of PIP with a “light touch” review at the ten-year point. The DWP is consulting with stakeholders to develop the light touch review process.

Further information can be found in Commons Library briefing CBP-7820, [ESA and PIP reassessments](#), 10 May 2019.

“Transforming assessments”

In March 2019 the then Secretary of State for Work and Pensions, Amber Rudd, announced that her Department had launched a “Health Transformation Programme” to develop a new, integrated service, supported by a single digital system, for Personal Independence Payment and Work Capability Assessments, from 2021. The integrated service is intended to provide “a more joined up experience” for claimants, but the two assessments will remain separate. However, she also announced plans to test the feasibility of a single assessment covering to determine eligibility for both ESA/UC and PIP.⁸³

⁸² [Written Statement HCWS733](#)

⁸³ [HCWS1376](#)

In a Written Answer in 8 October 2019, the DWP Minister Justin Tomlinson gave an update on progress:

In responses to the 2016 Improving Lives: Work, Health and Disability Green Paper consultation and through several other forums, stakeholders have raised concerns about the feeling of duplication across the current assessment processes. We have therefore been exploring options to reduce this, and make improvements to the customer experience. By testing the feasibility of a single assessment for Employment and Support Allowance/Universal Credit and Personal Independence Payment we can seek to understand if it will improve the assessment process for our customers, and ensure that it delivers high quality and accurate outcomes. The study is being informed by existing evidence and we have been gathering views and insight from key stakeholders to understand the issues around implementing this.

I do consider there are merits and we announced in March 2019 that we have launched the Health Transformation Programme to deliver a new integrated assessment service across all health and disability benefits. This will make the assessment process simpler, quicker, more user-friendly and more joined-up whichever benefit people are claiming. This integrated service will still be taking applications to individual benefits on a separate basis.⁸⁴

On 2 March 2020, Mr Tomlinson provided a further update on progress in creating a single assessment service with a single digital platform developed by the DWP. He noted that the Department would initially develop the new service on a small scale “in a defined part of the country, a Transformation Area”:

For claimants in this Transformation Area, assessments will be conducted by the DWP, rather than outsourced to providers. This will give us the flexibility to explore new ideas including:

trialling better ways of carrying out face-to-face assessments;

how to triage more effectively so that only those people who need a face-to-face assessment will have to undergo one;

how to make it easier for claimants to understand the evidence they need to provide and why;

how to remove the need for claimants to give the same information twice;

how to ensure that claimants are aware of the whole range of support available to them both from DWP and more widely.

He noted that the Department would continue to engage on this for an upcoming Green Paper.

In this written statement, Mr Tomlinson also notified the House that the DWP was issuing Prior Information Notices to advise the market that it is seeking to procure contracts to deliver PIP and WCA assessments from 1 August 2021 to continue the service once the current contracts end on 31 July that year. He noted that the new Transformation Area will start in Autumn 2021 and “operate alongside these contracts”.⁸⁵

⁸⁴ [PQ 293652](#), 8 October 2019

⁸⁵ [Written Statement HCWS138](#)

4.3 Universal Credit

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

Managed migration

Benefit and tax credit claimants who do not move onto Universal Credit following a change in their circumstances will transfer to UC by a process known as “managed migration.” Over two million households were expected to move onto UC by managed migration, of which around 745,000 would be claiming Employment and Support Allowance.⁸⁶

A managed migration pilot – “Move to UC” – which will involve around 10,000 claimants in the Harrogate area began in July 2019.⁸⁷ In light of the lessons learned from this, the DWP would then seek parliamentary approval for the main phase of managed migration, which was expected to get underway in late 2020 and be completed by September 2024.

Welfare rights and disability groups have expressed concern that vulnerable people – including people with learning disabilities – who fail to engage with the managed migration process could lose their financial support completely. The DWP has resisted suggestions that it transfer claimants directly to Universal Credit, or “pre-populate” UC claims using information it already holds on individuals, insisting that claimants themselves will be required to make a claim for UC when contacted at the managed migration stage.⁸⁸ It did however announce other changes to the managed migration rules including:

- extending the minimum notice period that legacy benefit claimants receive before they are required to claim for Universal Credit from one month to three months; and
- a one month “grace period” for all claimants, so that if a person misses the deadline to apply for UC but applies within a month of that deadline, they remain entitled to transitional protection (under the original plans, this would have been possible only in very limited circumstances)

The regulations for the managed migration pilot also allow for the three-month period to be extended in individual cases, “...if analysis shows that certain claimants require more time, e.g. someone who is vulnerable or has complex needs.”⁸⁹

⁸⁶ DWP, [Explanatory Memorandum for the draft Universal Credit \(Managed Migration\) Amendment Regulations 2018](#), 1 June 2018, p29

⁸⁷ For details see the DWP, [LA Welfare Direct Bulletin 7/2019 lite](#), 20 September 2019

⁸⁸ See the Work and Pensions Committee, [Universal Credit: managed migration](#), HC 1762 2017-19, 22 November 2018; and the [Government's response](#) (HC 1901 2017-19, 23 January 2019)

⁸⁹ DWP, [Explanatory Memorandum to the Universal Credit \(Managed Migration Pilot and Miscellaneous Amendments Regulations 2019](#) (SI 2019/1152), para 7.2

The DWP has said that in the managed migration pilot it does not intend to use its powers to terminate legacy benefits where a claimant has not made a UC claim, emphasising that its priority is “to ensure that claimants do not fall through the net during the process.”⁹⁰

As part of managed migration pilot, the DWP is also testing a new approach to assisting vulnerable claimants and those with complex needs – “Who knows me?” – based on the hypothesis that organisations with an existing relationship with the claimant are best placed to support them through the move to Universal Credit.⁹¹

The timetable for the final managed migration stage is however now unclear. Following the coronavirus outbreak, DWP has temporarily suspended the Move to UC pilot. T

UC and the Severe Disability Premium

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

Learning disability and the UC system

For some people with a learning disability, navigating the Universal Credit system may be a challenge, if they do not have an appointee to act on their behalf.⁹² Concerns include, amongst other things, people’s ability to cope with single monthly payments in arrears, making and managing claims online, and the possibility that people may be subject to inappropriate “conditionality” requirements. There is also concern that the removal of “implicit consent” in UC makes it harder for advisers and support workers to advocate for their clients.⁹³

⁹⁰ DWP, [Universal Credit: tests for managed migration: Government Response](#), HC 2499 2017-19, 5 July 2019, p2

⁹¹ See the [letter from Neil Couling, UC Programme SRO, to Frank Field MP](#), 11 June 2019

⁹² When a claimant is incapable of managing their own affairs because of mental incapacity or severe physical disability, the Secretary of State may appoint a person to act on the claimant’s behalf for benefit purposes. For further information see the DWP UC guidance chapter on [Appointees, Personal Acting Bodies and Corporate Acting Bodies](#), Version 8.0

⁹³ 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 the UC Full Service, the claimant must provide explicit consent before information can be disclosed to a

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.

The DWP should have in place procedures to identify Universal Credit claimants with complex needs – including those with learning disabilities – so that they can get the support they need throughout the “claimant journey”, and be subject to “conditionality” requirements that reflect their needs and circumstances. Identifying vulnerable claimants and those with complex needs can also be important in determining whether the person needs extra help with making and maintaining their claim, whether they would benefit from alternative payment arrangements, in deciding whether there is “good cause” for failing to comply with conditionality, or whether they should be offered home visits.⁹⁴ However, there are concerns that arrangements for identifying those needing support have not always worked as intended.⁹⁵

The DWP has produced guidance for its staff on the specific needs of people with learning disabilities and what this means for Universal Credit purposes.⁹⁶ It states:

A learning disability affects the overall Intelligence Quotient (IQ) and should not be confused with a learning difficulty. A person may:

- be very good at hiding their disability and may be too embarrassed to ask for help.
- be unable to read and write or retain information
- May agree with you to please you, despite not understanding what you have said
- struggle with basic tasks such as making appointments or finding documents
- never be able to learn the budgeting skills to be able to cope with monthly UC payments
- struggle to make or maintain their claim online and require additional support. A referral to Help to Claim can be considered.

A person will need the claimant commitment to be tailored so that it is realistic and achievable.

So what does this mean for DWP staff?

- Identify if the person you are working with has a learning disability or difficulty
- Make sure that the person gets the right support so that Universal Credit works for them

representative – although an exception has been made for Members of Parliament. For further information see the DWP UC guidance on [Consent and disclosure](#), Version 19.0

⁹⁴ For further information see the DWP UC guidance chapter [Complex needs overview](#), Version 14.0

⁹⁵ See Owen Stevens, [UC and complex needs](#), CPAG Welfare Rights Bulletin, August 2019

⁹⁶ DWP UC guidance chapter [Learning Disabilities or Learning Difficulties](#), Version 2.0

- Tailor support to the claimant's individual circumstances and refer for appropriate support as necessary
- Understand the claimant may be vulnerable and is treated correctly

The staff guidance states that when it has been identified that a claimant has a learning disability, consideration should be given to:

Communication

- Speak simply and clearly but do not be patronising
- Check whether you have been understood but be aware they may agree simply to please you
- Provide information in Easy Read format and language

Budgeting

- Refer for extra support by signposting to money guidance/debt advice
- Offer weekly or fortnightly payments
- Give extra help with advance and alternative payment arrangements including paying rent directly to the landlord

The Claimant Commitment – ask yourself:

- Is it reasonable and achievable?
- Is a specialist employment support provider needed?
- Are the number and type of job applications appropriate/applicable?
- Is support needed to prevent the claimant missing appointments?
- Is it tailored to meet the claimants needs/circumstances?
- Do they need a home visit?
- Is it necessary for an appointee to be considered?

Further information on arrangements for helping people unable to access UC via the standard online process can be found in the DWP UC guidance chapter [Assisted digital overview](#) (Version 12.0).

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”⁹⁷ – is available on the Citizens Advice website – see [Get help applying for Universal Credit](#).

5. Education

Special Educational Needs and Disability

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

The system introduced by the Act has been in place since September 2014, with transitional arrangements for those who already had support in place.

The [*Special educational needs and disability code of practice*](#) for children and young people aged between 0 to 25 years provides statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities.

The type of support that children and young people with SEND receive vary widely, as the types of SEND that they may have are very different. However, two broad levels of support are in place: SEN support, and Education, Health and Care Plans.

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

Parents can ask their local authority to carry out an assessment if they think their child needs an EHC Plan. A request can also be made by anyone at the child's school, a doctor, a health visitor, or a nursery worker.

The Local Offer

Since September 2014, all local authorities have been required to publish a 'Local Offer', which sets out education, health and social care provision for children and young people with SEN or disabilities in the area. The offer must include:

- the education and training provision available in FE and sixth form colleges, special post-16 institutions and other post-16 providers; and
- services available to support young people in preparing for adulthood and independent living, including:
 - finding employment
 - obtaining accommodation

- participating in society⁹⁸

Further information

Further information can be found in the Library briefing paper on [Special Educational Needs: support in England](#), CP 7020. Section 5 of the briefing provides research on the effectiveness of the reformed system.

Further education (FE)

The Government has issued separate [guidance to post-16 colleges and academies](#) (to be read alongside the [code of practice](#)) about implementing the new 0 to 25 SEND system, which sets out the new duties for FE providers. While EHC plans may cover eligible students up to the age of 25, the code of practice makes it clear that this does not mean that students have an automatic entitlement to education up to the age of 25.⁹⁹

As well as providing information on how FE institutions should work to fulfil their part of the reformed system, the code of practice highlights new statutory duties for the FE sector that are in place now the *Children and Families Act 2014* is in operation. For example, all FE and sixth form colleges must use their best endeavours to secure the special education provision that a young person needs, and they also, along with specialist post-16 institutions, have a duty to admit students if the institution is named in an EHC plan.¹⁰⁰

FE providers also have to comply with provisions in the *Equality Act 2010* (in the same way as HE providers). Details of this are set out below.

Higher Education (HE)

The relevant legislation in HE is the [Equality Act 2010](#), this Act absorbed and superseded the *Disability Discrimination Act* (1995, 2006), and the *Special Educational Needs and Disability Act* (2001). Chapter 2 of the Act contains the provisions specifically relating to further and higher education.

The Act states that disabled students should **not be treated less favourably** than other students and places HEIs under a **duty to make reasonable adjustments** to ensure that people who are disabled are **not put at a substantial disadvantage** compared to people who are not disabled in accessing higher education.

Section 149 of the *Equality Act 2010* contains the Public Sector Equality Duty which requires public bodies, including HEIs, to comply with general duties to eliminate discrimination, to promote equality of opportunity, and to foster good relations between people who share a protected characteristic and people who do not share it.

⁹⁸ Department for Education, [Implementing a new 0 to 25 special needs system: further education](#), April 2014, page 8

⁹⁹ Department for Education, [Special educational needs and disability code of practice: 0 to 25 years](#), January 2015 p.190

¹⁰⁰ Department for Education, [Implementing a new 0 to 25 special needs system: further education](#), page 7

Reasonable adjustments

The *Equality Act 2010* requires bodies to make reasonable adjustments for disabled people - this duty aims to ensure that disabled people do not face 'substantial disadvantage' in comparison with non-disabled people. Section 20 of the Act defines what is meant by the duty to make reasonable adjustments. 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), and the third covers providing auxiliary aids and services (such as providing special computer software or providing a different service). The duty is anticipatory.

The Equality Challenge Unit have published a document [Managing reasonable adjustments in higher education](#), 2010 which gives guidance to HEIs on their strategies around the duty to make reasonable adjustments.

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