

Learning Disability - policies and issues

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Section Social Policy Section

There are 1.5 million people in the UK with a learning disability. When also including families and carers of people with a learning disability, it is estimated around 6 million people in the UK are directly affected.

The availability and quality of services for people with a learning disability have recently come under scrutiny. It has also been evidenced that people with a learning disability experience worse outcomes than average, such as poorer access to health services and higher rates of premature mortality. The Government and NHS are taking action to address these inequalities.

The Government has recently mandated the NHS to reduce premature mortality rates for people with a learning disability following a Confidential Inquiry into this issue and the NHS has committed to improve the uptake of annual health checks and personalised health action plans. The Government and NHS England have also committed to an overhaul of inpatient and community services for people with a learning disability, following the abuse uncovered at Winterbourne View Hospital. This transformation would see a wide scale shift from caring for people in inpatient secure institutions to supporting people to live as independently as possible in the community.

This note examines the key issues and policy areas affecting people with a learning disability, and looks at what is being done to ensure people with a learning disability have equal rights, access and opportunities. The briefing summarises the main points of debate, recent developments, and work at local and national levels to improve services and outcomes.

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1 What is a learning disability?

A learning disability affects the way that someone communicates and understands information. This means that someone can have difficulties:

- understanding new or complex information;
- · learning new skills; and
- · coping independently

It is estimated that around 1.5 million people in the UK have a learning disability, and around 350,000 people have a severe learning disability.¹

A learning disability can affect children and adults, although children and young people with a learning disability may also have special educational needs.

The broad term 'learning disability' can cover a spectrum of conditions, from a mild learning disability where someone can manage independently but might take longer to learn new skills, to a profound and severe learning disability where an individual may need substantial care and support with every aspect of their life. With the right support, many people with a learning disability can lead independent lives.

Further information on severe, moderate and mild learning disabilities can be found on the NHS Choices page on What is a learning disability?

2 The social model of disability

The UK Government supports the social model as a way of understanding disability. This model, unlike the medical model, says that disability is not caused by an individual's health condition or impairment itself, but by the way that society treats and creates barriers for people with health needs. The barriers generally fall into three categories:

- the environment including inaccessible buildings and services
- people's attitudes stereotyping, discrimination and prejudice
- organisations inflexible policies, practices and procedures

Using the social model enables the Government and wider society to identify the barriers that prevent disabled people from fully participating in society or experiencing disadvantage compared to non-disabled people. The social model is supported by disabled people and their organisations, and encourages society to become more inclusive.²

NHS Choices, What is a learning disability? [last accessed 4 November 2014]

Gov.uk, Creating a fairer and more equal society, last updated 18 August 2014

3 Health and social care

People with a learning disability may need support from a range of health and social care services. This section details access to health and social care services, challenges around service provision, and what is being done to improve standards of care.

3.1 Access to healthcare: Reducing premature mortality

There is evidence that people with a learning disability experience poorer access to healthcare and worse health outcomes. One of the starkest inequalities is that people with a learning disability experience very high rates of premature mortality. Research has found that men with a learning disability die on average 13 years sooner, and women with a learning disability 20 years sooner, than those without learning disabilities.³

The Department of Health established and funded a Confidential Inquiry into the Premature Deaths of People with Learning Disabilities which was published in March 2013 by the University of Bristol. The inquiry explored why people with a learning disability have poor experiences of healthcare and found that the NHS is not being provided equitably to everyone based on need. It found that the most common reasons for the premature deaths of people with a learning disability were delays or problems with diagnosis or treatment; problems with identifying needs; and a lack of 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.⁴

The inquiry made 18 recommendations to improve health and social care for people with a learning disability to address these inequalities. These included introducing a named health professional to co-ordinate care across different agencies, proactive use of annual health checks and individual health action plans, and improving health professionals' adherence to the *Mental Capacity Act*.

In July 2013, the Department of Health published the Government's response to the Confidential Inquiry into premature deaths of people with learning disabilities. It set out actions to reduce premature mortality among people with a learning disability, and committed the Department of Health, NHS England, Public Health England and delivery partners to making significant improvements. Progress on these actions is monitored by the Learning Disability Programme Board.

In September 2014, the Government published its Premature Deaths of People with Learning Disabilities: Progress Update. This report found that progress has been made in several of the improvement areas. For example, as part of the negotiations on the GP contract for 2014/15, the Enhanced Service for the Learning Disabilities Health Check Scheme has been extended to include health checks for people from the age of 14. However, this is voluntary and GPs can decide whether or not to offer them to specific people. The report also highlights that a requirement for Health Action Plans to be part of the annual health check

Department of Health, Premature Deaths of People with Learning Disabilities: Progress Update, September 2014

Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD), March 2013, page 4

has been included in the enhanced service which began from 1 April 2014.⁵ The report finds nonetheless that further concerted national action is still needed to see more equitable access and outcomes.⁶

Additionally, the Government's Mandate to the NHS 2014-15 set a specific objective to reduce excess mortality for adults under 60 with a learning disability. NHS England is currently exploring, with CCGs, how to improve the uptake of annual health checks to monitor individuals' health regularly, as incentivised by the Directed Enhanced Service. However, uptake of annual health checks has so far been low: in 2012/13, 52 per cent of eligible people with a learning difficulties received a health check.⁷

NHS England has further information on its work on Reducing premature mortality in people with a learning disability.

3.2 Social care

Many people with a learning disability use social and personal care services to be able to live as independently as possible in their community.

Once someone is diagnosed with a learning disability, they will be given a needs assessment to determine what care they require. The 2014 Joint Health and Social Care Self-Assessment Framework will run from September 2014 to March 2015

An individual should be involved, along with their carer and/or family if consent is given, in drawing up a personalised care and support plan to choose services that meet their needs. This could include social care services such as help in getting dressed, washed and cooking, or managing finances. Many people will have a local care coordinator, to help them plan and organise a tailored range of services.

Mencap's *Face the facts* campaign into reported reductions in social care funding estimates that 142,500 people with a learning disability in England use social care services.⁸

The Care Act 2014 made changes to funding social care; information on how this is expected to work in practice is set out in the Standard Note Social care funding reform: FAQs (SN/SP/6863).

Self-directed support

Direct payments: Adults, including those with a learning disability, who qualify for state-funded care services may be entitled to receive payments instead of a care package from the local authority. The payments, known as direct payments, are then used by the recipient to arrange and pay for their own, independently contracted, care and support services.

Personal budgets: Personal budgets are an allocation of funding given to people after an assessment of their needs. People can either take their personal budget as a direct payment, or - while still choosing how their care needs are met and by whom - leave councils with the responsibility to commission the services. Or they can have a combination of the two.

Department of Health, Premature Deaths of People with Learning Disabilities: Progress Update, September 2014, page 9

Department of Health, Premature Deaths of People with Learning Disabilities: Progress Update, September 2014, page 22

Public Health England, The Uptake of Health Checks for Adults with Learning Disabilities 2008/9 to 2012/13

⁸ Mencap, 'Face the facts' cuts dossier, [last access 20 November 2014]

Under the *Health and Social Care Act 2001*, local authorities have a duty to provide direct payments for people who qualify for social care services. The *Care Act 2014* introduced a legislative basis for personal budgets for social care.

Further information is set out in the Library Standard Note on *Direct payments and personal budgets for social care* (SN03735).

3.3 Hospital care

People with a learning disability who also have a mental health problem and/or significantly challenging behaviours may spend time in a specialist hospital unit. There are different kinds of specialist hospital units, including:

- Specialist Assessment and Treatment Units
- General Psychiatric Units
- Secure Units

Admission to hospital

Voluntary admission to hospital can be made if someone has the *mental capacity* to consent, and a psychiatrist agrees it is in their best interest.

If someone lacks the mental capacity to consent, they can still be admitted to hospital as an informal patient under the *Mental Capacity Act (2005)* if the admission is in their best interests and does not deprive them of their liberty. Being an informal patient means someone is able to come and go, provided a doctor does not deem there to be a risk to themselves or others. Deprivation of liberty safeguards (DOLS) cover people who are in hospital or a care home, and do not have mental capacity. DOLS exist under the *Mental Capacity Act* to prevent deprivations of liberty without proper protection for people, including independent consideration and authorisation.

Compulsory admission, or 'sectioning' can take place if an individual has a mental disorder that requires them to be detained under the *Mental Health Act 1983*. Someone would usually be admitted under section 2 or section 3 of the Mental Health Act:

- Section 2 is a compulsory admission to hospital for up to 28 days, to allow for assessment
- Section 3 is a compulsory admission to hospital to enable treatment, initially up to 6 months but it can be renewed for up to a year

NHS England provides further information on legislation for admission: Going into hospital because of mental health difficulties or challenging behaviours: What families need to know.

After-care

People who have been detained in hospital under Section 3 of the *Mental Health Act* have a right to free 'aftercare' when they are discharged. Section 117 of the *Mental Health Act* imposes a duty on health and social care services to provide aftercare services, according to an individual's needs, such as supported housing, help managing money and regular meetings with a psychiatrist. For example, if someone was paying for their residential care prior to compulsory admission under section 3, this would

subsequently be paid for by the Clinical Commissioning Group after discharge, if in England.

S117 does not apply to certain sections of the Mental Health Act, including patients who have been detained in hospital for assessment under Section 2.

3.4 Winterbourne View and subsequent reviews of services for people with a learning disability

In May 2011, the Care Quality Commission (CQC) was informed that the BBC's Panorama had gathered evidence over several months to show serious abuse of patients with learning disability at Winterbourne View, an independent hospital that had been commissioned to provide services by a number of NHS organisations and councils. The Department of Health has provided a number of updates on actions to investigate and prosecute abuses at Winterbourne View and also asked the CQC to conduct a programme of focused inspections of 150 hospitals and care homes for people with a learning disability. The final reports from these inspections were published in May 2012.⁹ These reports found poor practice in some of the units, and common areas of concern included limited person-centred care, limited appropriate activities and a lack of monitoring and learning from incidents of restraint.

A Department of Health review of the events at Winterbourne View was carried out to draw conclusions on the basis of the findings from the serious case review and evidence from the other investigations and reports that had been undertaken. The final report of the Departmental review, setting out a programme of action to transform services, was published in December 2012 - Transforming care: A National response to Winterbourne View Hospital. The review was accompanied by the Winterbourne View Review: Concordat, which set out specific actions that organisations and key partners have committed to implement.

A key finding in the Department of Health review was that too many people with a learning disability were spending long periods of time in hospital care, due to a lack of appropriate services in the community. The review found that many people were being kept in hospital when they were clinically ready to be discharged back into community care:

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

People with learning disabilities or autism may sometimes need hospital care but hospitals are not where people should live. Too many people with learning disabilities or autism are doing just that.¹¹

The report set out significant milestones to be achieved by June 2014. These included:

All current placements will be reviewed by 1 June 2013, and everyone inappropriately in hospital will move to community-based support as quickly as possible, and no later than 1 June 2014¹²

By Summer 2015 NICE will publish quality standards and clinical guidelines on challenging behaviour and learning disability.

⁹ Care Quality Commission, Learning Disability reports [last accessed 5 November 2014]

Recent Ministerial statements on the Winterborne View investigations were made on 15 May 2012 (HC Deb c26-7WS) and 21 March 2012 (HC Deb c59-61WS):

¹¹ Department of Health, Transforming care: A national response to Winterbourne View Hospital, page 8

¹² Department of Health, Transforming care: A national response to Winterbourne View Hospital, page 9

By Summer 2016 NICE will publish quality standards and clinical guidelines on mental health and learning disability.

The Department of Health will revise statutory guidance and good practice guidance to reflect new legislation and address findings from Winterbourne View, to be completed in time for the implementation of the Care and Support Bill (subject to parliamentary approval).

CQC will take steps now to strengthen the way it uses its existing powers to hold organisations to account for failures to provide quality care.

A full timetable of actions can be found in the report's Annex. 13

Research published by a coalition of charities representing disabled people supports a preventative approach to care and supports the shift in care from inpatient services to supporting people in the community. The research found that for every £1 spend on support for people with moderate care needs, £1.30 will be saved by the NHS, local and central Government because people with a learning disability and their families are better supported, need less hospital treatment, and are able to access the community and employment.¹⁴

As part of the Transforming Care Programme, NHS England has also appointed two Learning Disability Network Officers to help people with a learning disability co-design and transform services. One of the officers will be someone with a learning disability, alongside a co-worker who together will engage with people with a learning disability to inform and shape services. It is expected that both officers will be recruited and in post by early 2015. 15

The Learning Disability Programme Board, chaired by the Minister for Care Services, Norman Lamb, will monitor delivery of the Transforming care: A National response to Winterbourne View Hospital programme.

However, a report Commissioned by NHS England and written by Sir Stephen Bubb in November 2014, *Winterbourne View - Time for Change*¹⁶, found that people with learning disabilities are still being placed inappropriately in long-term institutional care rather than being supported in the community. The report found that there are still more people being admitted to such institutions than are being discharged. The report's key recommendations were:

- To urgently close inappropriate in-patient care institutions;
- To introduce a Charter of Rights for people with learning disabilities and/or autism and their families;
- To give people with learning disabilities and their families a 'right to challenge' decisions and the right to request a personal budget;
- To require local decision-makers to follow a mandatory framework that sets out who is responsible, for which services and how they will be held to account, including improved data collection and publication;

¹³ Department of Health, Transforming care: A national response to Winterbourne View Hospital, page 56

Scope, Mencap, National Autistic Society, Sense, Leonard Cheshire Disability, Ending the other care crisis: Making social care funding work for disabled adults in England, January 2013

¹⁵ NHS England, New team to give voice to learning disability community, 10 November 2014

A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb, Winterbourne View - Time for change, November 2014

- To improve training and education for NHS, local government and provider staff;
- To start a social investment fund to build capacity in community-based services, to enable
 them to provide alternative support and empowering people with learning disabilities by
 giving them the rights they deserve in determining their care.

It is also reported that the Government will propose legislative change in early 2015, to transform care for people with learning disabilities placed in hospitals. A proposed Green Paper will consult on how to ensure people are able to live in the community wherever possible, and how they are able to challenge decisions about their care and inpatient admission.¹⁷

In January 2015, the Government published *Winterbourne View: transforming care 2 years on.* The report provides an update against the actions in the original report. In a Written Statement, Norman Lamb outlined the recommendations that have been achieved:

A significant number of the recommendations have been achieved. We now know how many people are in inpatient settings, where they are and who is responsible for them. NHS England has introduced Care and Treatment Reviews for everyone in inpatient settings, with a multi-disciplinary team from health and social care, alongside Experts by Experience. 181 people are benefitting from £7m DH capital funding to support people inappropriately placed in inpatient settings to move to more suitable housing. We have strengthened the accountability and corporate responsibility arrangements to assure the quality and safety of care services. A duty of candour which requires providers to inform service users where there are failings in care came into force for NHS providers last November, and will be extended to all other providers registered with the Care Quality Commission in this April. A fit and proper person's test which requires providers to ensure that Directors are fit to carry out their role came into force last November for NHS providers in NHS Trusts, foundation trusts and special health authorities. All other providers will be required to comply by this April. The introduction of the forthcoming statutory offences of ill-treatment or wilful neglect will also send a clear message throughout the health and care system that intentionally poor care will never be tolerated. We have new quidance on minimising restrictive interventions and work is underway to improve data about the use of restraint. A more rigorous registration, assessment and inspection approach is in place for learning disability services. The Care Act 2014 enshrines new principles for adult social care including the principle of individual wellbeing which encompasses people having control of their day to day life, suitable accommodation and being able to contribute to society. The Act requires local authorities to consider people's views, wishes and beliefs and focuses on the outcomes people themselves want to achieve. The Act also underpins and reinforces the importance of good quality, independent advocacy and will support people, their families and carers to raise concerns. 18

However, he also stated that not as much progress has been made as was intended:

The report is also clear, however, that we have not made nearly enough progress to transform services. This cannot be tolerated. We recognise that there is still much more to do to reduce the need for inpatient care. There are many people with very complex needs, in many different types of inpatient settings and we need to ensure the right decisions are made about their care, listening to individuals, their families and

¹⁷ Community Care, 'Minister to consult on changing law to transform learning disability care post-Winterbourne', 26 November 2014

Written statement - HCWS231 [on Winterbourne View: Transforming Care Two Years On report], 29 January 2015

carers. All partners involved in Transforming Care have agreed the need for a single programme to collectively drive forward the changes needed. A strengthened programme will be put in place, which takes into consideration the recommendations of Winterbourne View – A Time to for Change (2014) by Sir Stephen Bubb, and will drive a better co-ordinated approach to achieve faster and sustainable progress. The details of this approach can be accessed at: http://www.england.nhs.uk/ourwork/qual-clin-lead/ld/transform-care/.19

In February 2015, the Public Accounts Committee launched an inquiry into care for people with learning disabilities. The inquiry will examine progress made in moving people from inpatient care to community care, and how care is being improved in the community:

The Winterbourne View scandal revealed a system failing to protect the most vulnerable people in society and led to a shake-up of the care system for adults with learning disabilities. However, most of the June 2014 targets to improve care were missed. The number of people with learning disabilities increased by 37 per cent between 2007-08 (144,909) and 2011-12 (198,887).

Local authorities spent £5.2 billion on related community-based services and the NHS spent £500 million on about 3,250 people with a learning disability resident in NHS and private assessment and treatment centres such as Winterbourne View.

This inquiry will look into the placing of people with learning disabilities into private assessment and treatment centres - including progress made in transferring all people with learning disabilities in assessment and treatment centres into more appropriate and cost-effective community-based care.²⁰

Written statement - HCWS231 [on Winterbourne View: Transforming Care Two Years On report], 29 January 2015

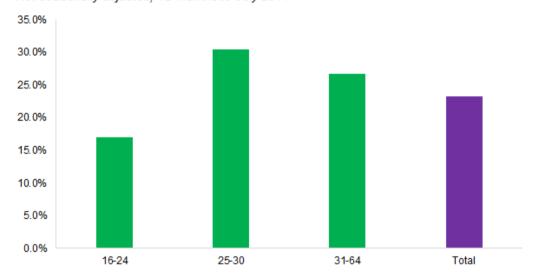
²⁰ Public Account Committee, Care for people with learning disabilities, February 2015

4 Employment

In the 12 months to July 2014, there were 103,645 people with a learning difficulty and/or learning disability in employment, this represented 23.2% of people aged 16-64 with this primary medical condition:²¹

Employment rate for people with a learning difficulty and or learning difficulties by age group

Not seasonally adjusted, 12 months to July 2014



Amongst specific age groups, the lowest employment rate was for those aged 16-24 (17%).

4.1 Improving access to employment for people with a learning disability

Work Programme

Disabled people may receive back-to-work support through the Work Programme, the Government's main welfare-to-work scheme. This scheme provides support, work experience and training for up to 2 years to help individuals find and stay in work.

Since 2010, 61,360 disabled people have been helped into work through the programme.²²

There have been concerns about the success of the Work Programme in supporting people with a learning disability. Some providers of the programme have said that the complex needs of disabled people cannot be met under the scheme, particularly for people in receipt of Employment and Support Allowance²³.

The Government have defended the success of the Programme, and said:

The 10% of people being helped through the Work programme is a significant improvement, and a significant number of people who go through Work Choice get into work. That is a very considerable record, and 116,000 more disabled people are in work this year than last year.²⁴

²¹ ONS, Ad-hoc analysis, 17 October 2014

Department for Work and Pensions, Disability Confident 1 year on: Breaking down the barriers to employment, October 2014

²³ 'Work Programme not doing enough for sick and disabled, providers say', BBC, 19 June 2013

²⁴ HC Deb 3 November 2014 c534

The Public Accounts Committee carried out an inquiry into the Work Programme in November 2014. The Chair of the Committee, Margaret Hodge MP, said:

Almost 90% of Employment and Support Allowance claimants on the Work Programme have not moved into jobs.

Evidence shows that differential payments have not stopped contractors from focusing on easier-to-help individuals and parking harder-to-help claimants, often those with a range of disabilities including mental health challenges.²⁵

Specialist disability employment programmes are also available:

Work Choice

Work Choice supports people with a more severe disability, by providing support tailored to individual needs. It is a voluntary scheme. Participants initially receive support intended to help them get work; once they have found work the programme provider works with the participant and their employer to identify support needed to help them start and stay in work and then progress in their job.

The programme was introduced in October 2010, and in 2013-14, over 20,000 people started on Work Choice, with more than 50 per cent achieving a sustainable job outcome.²⁶

Access to Work

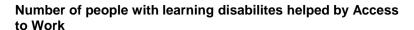
The Access to Work scheme provides financial support for the extra costs of being in work which go beyond the "reasonable adjustments" that are required in law (see section 4.2). Access to Work is delivered by the Department for Work and Pensions through Jobcentre Plus and is available to those aged 16 years or over who live and work in Great Britain.

The total number of people helped between April 2007 and June 2014 was 114,520, this includes the number of people who are "existing" customers in any one year (or part of the year) and the numbers of "new" customers who received help for the first time in the particular financial year (or part of the year).

The chart below shows the number of people who have been helped by the scheme whose primary medical condition is a learning disability:

²⁵ Public Accounts Committee, Work programme: report published, 6 November 2014

²⁶ HC Deb, 28 October 2014, c196





In 2013/14, 1,770 people whose primary medical condition was a learning disability were helped by the scheme – this is the highest number of people since 2007/08.

There was a drop in the number of people helped by the scheme between 2010/11 to 2012/13. The DWP have attributed these drops to various operational changes that were implemented in 2010.

Concerns about the awareness and uptake of Access to Work for people with a learning disability were raised in an independent review of employment support for disabled people, carried out by Liz Sayce, then Chief Executive of Radar.²⁷ The report found that less than five per cent of people using Access to Work had a learning disability as their primary condition.

Following this report, the Work and Pensions Select Committee launched an inquiry into Employment support for disabled people: Access to Work. The inquiry assessed the effectiveness of Access to Work for people with a learning disability and mental health problems, its effectiveness in helping disabled people to find and stay in work, and the adequacy on the ongoing support provided by the scheme, such as aids, adaptions and guidance from the DWP. The Committee is currently preparing its report.

Mencap responded to the Committee's call for evidence, and said that:

From problems applying initially, to issue maintaining their claims and a general lack of understanding by staff and a lack of accessibility throughout the claims process, access to work is often anything but easy to access.²⁸

For more information see the Library Standard Note, Access to Work.

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

²⁷ A review to the Government by Liz Sayce, Disability employment support fit for the future, June 2011

Mencap, Response to the call for evidence for the Work and Pensions Committee's enquiry into Access to Work, June 2014.

The DWP published its report Disability Confident 1 year on: Breaking down the barriers to employment in October 2014. It states that the Department has "made a great start to breaking down the barriers that stop disabled people getting work", and over 1000 employers have signed up to the campaign so far.

4.2 The Equality Act 2010 – discrimination and reasonable adjustments

Discrimination on the grounds of disability is unlawful under the *Equality Act 2010* and the United Nations Convention on disability rights. The *Equality Act 2010* means it is unlawful for an employer to discriminate against someone with a disability in areas including application forms, interview arrangements, and terms of employment, including pay.

The Equality Act 2010 also places a duty on employers to make "reasonable adjustments" for their staff so that a disabled person is not at a substantial disadvantage compared to a non-disabled person. The reasonable adjustment duty applies to recruitment practices as well as arrangements for existing staff members. The definition of what is "reasonable" will depend on factors such as the time and cost of making an adjustment. Reasonable adjustments might include:

- providing recruitment literature in large print
- providing in interview situations extra equipment at reasonable cost, removing movable barriers like furniture, or holding the interview in a different, wheelchair accessible room;
- allowing a guide or hearing dog into the workplace;
- · purchasing specialist equipment, such as an ergonomic chair;
- discounting disability-related sickness leave for the purposes of absence management;
- providing additional supervisory guidance / support;
- including a disabled parking space in the car park;
- allowing different start and end times to the working day.²⁹

As detailed above, the Access to Work scheme can provide additional financial support for adjustments which go beyond the remit of mandatory reasonable adjustments requirements.

²⁹ Equality Act 2010: Duty on employers to make reasonable adjustments for their staff

5 Welfare and benefits

People with a learning disability may be entitled to a range of income-based and disability benefits. These include:

Employment and Support Allowance

Employment and Support Allowance (ESA) replaced Incapacity Benefit for new claimants from October 2008. There are two forms of ESA: contributory ESA, for those who have a sufficient National Insurance contribution record; and income-related ESA, which is meanstested. To be eligible for ESA, a person must undergo a Work Capability Assessment and be found to have a "limited capability for Work". If they are also found to have a "limited capability for work-related activity" they are placed in the "Support Group"; otherwise they are placed in the "Work-Related Activity group" and may be required to under "work-related activity". This can involve participation in the Work Programme.

Further information is provided in the Library note on Employment and Support Allowance: an introduction.

The Work and Pensions Committee published an inquiry report, Employment and Support Allowance and Work Capability Assessments, in July 2014. The Committee's final report stated that the Work Capability Assessment (WCA) had such serious flaws that a fundamental redesign of the process was needed. The Committee said that ESA was not achieving its stated purpose of moving people into work who have been placed in the 'work related activity group', because tailored support covering the wide range of support needs and conditions of people in this group was not available. The Committee recommended that ESA should be redesigned so that employment support, and the conditionality claimants are subject to, is tailored to individual needs. The Committee also recommended that, if possible. paper-based assessments are used to place people in the support group as they are quicker. cheaper and less-stressful for claimants. However, the Committee recommended that paperbased assessments are not used to place people in the work-related activity group, as a decision to give someone a lower rate of benefit should only be taken after taking into account all possible evidence, including a face-to-face assessment. The Committee also recommended reducing the frequency of reassessments for people whose condition is unlikely to change.30

In response to the report, Mencap said:

The assessment is a cause of great fear and anxiety for people with a learning disability, whose only wish is to be able to live their lives like everyone else, but who are often prevented from doing so by an unfair and flawed process.

Wrong decisions are disturbingly commonplace, with almost four in ten appeals found in favour of the person claiming ESA. This process not only causes avoidable stress and worry for tens of thousands of people, many of whom are in vulnerable situations, but it also wastes huge amounts of the taxpayers' money - an estimated £66 million was spent on appeals last year alone.³¹

Dr Litchfield's fifth Independent Review of the Work Capability Assessment, November 2014, 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

Work and Pensions Select Committee, Employment and Support Allowance needs fundamental redesign, says MPs, 23 July 2014

³¹ Mencap, Mencap deems Work Capability Assessment "an unfair and flawed process, 23 July 2014

disability may face in engaging with and navigating the ESA 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.³²

Dr Litchfield made recommendations to improve the WCA process, such as reviewing the learning disability training that the DWP provides to its staff and assessments providers.³³

Sanctions

There are concerns about the sanctions that are imposed on people in the Work-Related Activity Group. ESA claimants in this group who fail to undertake work-related activity, such as participating in work-focused interviews, when required, may face a benefit sanctions – i.e. a reduction in the amount of benefit payable.

Statistics released by the DWP in March 2014 in response to a Freedom of Information request, showed the "adverse" ESA sanction decisions issued from January 2008 to June 2013, broken down by the Summary International Classification of Diseases. This revealed a consistently high sanction rate for ESA claimants with mental and behavioural disorders. Of the 10,210 sanctions imposed on ESA claimants in the first six months of 2013, 5,940 - 58 per cent – were imposed on claimants with mental and behavioural disorders.³⁴

A DWP analysis published in November 2012 stated that claimants with "mental and behavioural disorders" accounted for 40 per cent of the ESA Work-Related Activity Group "caseload".³⁵

Personal Independence Payment

PIP is a non-means-tested benefit for adults with disabilities who need help getting around and/or help with daily living activities.

Personal Independence Payment (PIP) is replacing Disability Living Allowance (DLA) for people of working age. It was first introduced for new claims in April 2013. New claims for DLA can now only be made for children under 16.

There have been concerns about the impact on disabled people of delays in moving people from DLA to PIP. A National Audit Office (NAO) report on PIP published in February 2014 found that "early operational performance has been poor" by the DWP, leading to delays and uncertainty for PIP claimants and a large backlog of claims. In response to the NAO report, Mencap said:

These delays are unacceptable are causing financial and emotional stress for thousands of disabled people waiting to hear if they will get PIP....

³² Dr Paul Litchfield, An Independent Review of the Work Capability Assessment – year five, November 2014, page 60

³³ Dr Paul Litchfield, An Independent Review of the Work Capability Assessment – year five, November 2014, page 60

³⁴ DWP Response to Freedom of Information request 2014-79, 18 March 2014

Employment and Support Allowance (Sanctions) (Amendment) Regulations 2012 Equality analysis, November 2012, Table 4

We are calling on the DWP to immediately halt the 'natural reassessment' process of existing DLA claimants.³⁶

The Work and Pensions Committee published a report on Monitoring the Performance of the Department for Work and Pensions in 2012-13 in March 2014, which found that the length of time disabled people had to wait to find out if they are eligible for PIP was unacceptable:

People should not be forced to wait six months or more to find out whether they are entitled to financial support towards the additional costs of living with disabilities and health conditions. Urgent action is required.³⁷

Mencap has also raised concerns about the implications of PIP for people with a learning disability. The charity is concerned that many people are expected to get a lower level of support under PIP than they would receive under the DLA system, as they will not meet the new criteria since one of the Government's aims with PIP is to focus support on those with the greatest needs.³⁸

The Government has not agreed to exemptions from reassessment for people with particular disabilities, but has said that decisions on the frequency of reassessments will take into account the nature of the person's disability and the likelihood of a change in their circumstances. It has also said that from some individuals, a face-to-face consultation may not be necessary.³⁹

The legislation governing PIP assessments does not make any special provision for people with a learning disability. However, the contracts between the DWP and the assessments providers stipulate that the training for health professionals undertaking assessments must have a broad training in disability analysis. DWP guidance for health professionals carrying out assessments states that assessors need to be particularly aware of the needs of those with "mental, intellectual or cognitive impairments" and the problems that such individuals might encounter with the assessment process, such as difficulties complying with the process and returning forms. Assessment providers must also employ "mental function champions" to give advice and support to their health professionals on health conditions and disabilities affecting mental, cognitive, intellectual and behavioural function.⁴⁰ However, Dr Paul Litchfield's fourth Independent Review of the Work Capability Assessment found that mental function champions "are not routinely" available in Great Britain.⁴¹

Further information is provided in the library standard note on Personal Independence Payment.

Carer's Allowance

A carer could be entitled to Carer's Allowance if they spend at least 35 hours a week caring for someone who receives the middle or higher rate care component of Disability Living Allowance, the daily living component of Personal Independence Payment, or Attendance Allowance. Further information is available on Gov.uk.

³⁶ Mencap, Response to government report on Personal Independence Payments, 27 February 2014

Work and Pensions Select Committee, Monitoring the Performance of the Department for Work and Pensions in 2012-13, paragraph 48

Mencap, Disability Living Allowance and Personal Independence Payments: Overview and Frequently Asked Questions, Updated: May 2014

³⁹ HC Deb 4 February 2013 c98-9W

⁴⁰ HC Deb 17 April 2013 c431-2W

⁴¹ An Independent Review of the Work Capability Assessment – year four, Dr Paul Litchfield, December 2013, page 80

Other benefits and funding sources

Other benefits that people with a learning disability could be entitled to include:

- Housing Benefit
- Motability Scheme
- Blue Badge scheme
- Help with Council Tax

We recommend that individuals have a benefits check with their local welfare benefits service or Citizens Advice Bureau who can provide tailored advice on benefits entitlement.

In addition to benefits and assessments, there are other sources of support available for people with a learning disability. For example, the Family Fund is a charity which provides grants to families in the UK caring for severely disabled children.

Responsibility for people who were supported by the Government's Independent Living Fund, which will be closed on 30 June 2015, will be transferred to local authorities. Further information is in the Library note on the Independent Living Fund.

6 Education and Special Educational Needs

6.1 Special Educational Needs

The Department for Education provides the following definition of Special Educational Needs (SEN):

xiv. A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her.

A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

- has a significantly greater difficulty in learning than the majority of others of the same age, or
- has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions

xv. For children aged two or more, special educational provision is educational or training provision that is additional to or different from that made generally for other children or young people of the same age by mainstream schools, maintained nursery schools, mainstream post-16 institutions or by relevant early years providers. For a child under two years of age, special educational provision means educational provision of any kind.

xvi. A child under compulsory school age has special educational needs if he or she is likely to fall within the definition in paragraph xiv. above when they reach compulsory school age or would do so if special educational provision was not made for them (Section 20 Children and Families Act 2014).

xvii. Post-16 institutions often use the term learning difficulties and disabilities (LDD). The term SEN is used in this Code across the 0-25 age range but includes LDD.⁴²

It is estimated that there are 1.8 million pupils in England with a SEN, of which 234,000 children have a diagnosis associated with a learning disability. There are concerns that children and young people with a learning disability, and SEN more broadly, are not receiving adequate support in the education system. For example, pupils with SEN are eight times more likely to be permanently excluded that pupils without SEN, and by the age of 19 young disabled people are three times more likely to not be in education, employment or training.⁴³

The new SEN system

The *Children and Families Act* received Royal Assent in March 2014 and provided for an overhaul of the system for identifying children and young people in England with SEN, assessing their needs and making provision for them.

In England, a dual system of SEN statements for children and Learning Difficulty Assessment for 16 to 25 year olds is being replaced by a new single system of birth-to-25 assessments and Education, Health and Care (EHC) Plans. The reformed system was introduced in September 2014, with transitional arrangements for those who already have plans in place. Transition to the reformed system is intended to be complete by April 2018.

⁴² Department for Education, Special educational needs and disability code of practice: 0 to 25 years, July 2014, p.15-16

Mencap, Hear our voice: the change we want to see 2015-2020, page 20

A brief overview of the SEN system is available on gov.uk. As it sets out, there is a process parents will go through with their school's SEN co-ordinator to address SEN issues their child may have. 'SEN Support' is provided by schools, and Education, Health and Care (EHC) Plans may be used for children with more advanced needs.

Further information can be found in the Library Standard Note on The reformed system for children and young people with Special Educational Needs in England.

Further education (FE)

The Government has issued separate guidance to post-16 colleges and academies about implementing the new 0 to 25 SEN system, which sets out the new duties for FE providers. While EHC plans may cover eligible students up to the age of 25, guidance on the legislation makes it clear that this does not mean that students have an automatic entitlement to education up to the age of 25.44

As well as providing information on how FE institutions should work to fulfil their part of the reformed system, the guidance 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.⁴⁵

The Local Offer

From September 2014, all local authorities must 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 society 46

Recent educational attainment rates

In October 2014, the Minister for Employment, Esther McVey, described improvements in attainment and employment rates for disabled people. With regards to SEN, the Minister said:

Attainment levels for pupils with special educational needs have increased since 2010-11 at both GCSE and A-level. The number of disabled students gaining their first degree has increased from nearly 32,000 to nearly 40,000 now.⁴⁷

⁴⁴ Department for Education, Special educational needs and disability code of practice: 0 to 25 years, July 2014 page 190

Department for Education, Implementing a new 0 to 25 special needs system: further education, page 7

Department for Education, Implementing a new 0 to 25 special needs system: further education, April 2014, page 8

⁴⁷ HC Deb 28 October 2014 c232