

## **Personal care bill becomes law**

A bill to provide free personal care to disabled and older people with the highest needs has become law, after government concessions were approved by peers.

Health secretary Andy Burnham last week described the personal care at home bill as the first of three stages of reforms that would lead to a national care service based on the principle of free personal care for everyone who needs it.

The government made two key concessions on the bill – delaying its implementation until April 2011, and agreeing that MPs and peers would have to approve its implementation after it became law.

Peers approved the new version of the bill today (8 April), and it later received royal assent.

The Personal Care at Home Act is now set to provide free personal care at home to an estimated 280,000 disabled and older people with the highest needs (although this figure includes about 170,000 people who already receive free personal care).

It will also provide intensive “re-ablement” support for around 130,000 people who need home care for the first time.

The second stage of Burnham’s care and support reforms, from 2014, will see those staying in residential care for longer than two years receiving free personal care.

**8 April 2010**

## **ELECTION 2010: ALLFIE and Trailblazers issue election calls**

Campaigners have called for action over the number of young disabled people who are not in mainstream education, employment or training.

The Alliance for Inclusive Education (ALLFIE) said political parties should stop ignoring the segregation and exclusion of disabled learners from mainstream education.

ALLFIE said 27 per cent of disabled 19-year-olds were not in education, employment or training, compared with nine per cent of non-disabled 19-year-olds, while 45 per cent of disabled children with statements of special educational needs were in special schools.

In its own election manifesto, ALLFIE called for a long-term plan to secure an inclusive education system in which “every learner has a legal right to participate in mainstream education regardless of impairment or health condition”.

It also wants: all disabled learners to have the right to individualised support; all education buildings to be accessible; mainstream courses to be accessible and include positive images of disabled people and their history and culture; compulsory disability equality training for all education staff; and all assessments and accreditations to be inclusive.

Tara Flood, chief executive of ALLFIE, said: “Inclusive education is a social justice issue because it creates a society that values all equally – not only does it benefit disabled students, but all students, because they learn the strength of diversity and equality, lose their fear of difference, and develop empathy for others.”

The Muscular Dystrophy Campaign has also issued an election manifesto, which includes a call for prospective MPs to help set up a new all party parliamentary group for young disabled people.

Laura Merry, a member of the charity’s Trailblazers network of young disabled campaigners, said: “Too often our needs are overlooked – I want MPs to care as much about these issues as I do and an all party parliamentary group is the perfect vehicle for change.”

MDC also wants prospective MPs to pledge to work with their local Trailblazer representatives to improve access to local education, transport and leisure services.

And the manifesto calls on them to pledge to help improve health services for people with neuromuscular conditions.

**8 April 2010**

### **ELECTION 2010: Parties ‘must ensure inclusive election campaign’**

Political parties have been told to reach out to disabled voters in the lead-up to the general election, with campaigns that are “truly inclusive and representative”.

The call came after the prime minister, Gordon Brown, finally confirmed that the general election would take place on 6 May.

The disability charity RADAR warned parties that the 11 million people living with injury, ill-health or disability, and their families and friends, were “a very big constituency”.

And it called for political parties to pay attention in their campaigning to the housing crisis, the “scandalous” delivery of social care and disability-related poverty.

RADAR also called for: campaign literature to be available in alternative formats and easy-read versions; public meetings to be held in accessible venues, with induction loops and sign language available; and disabled supporters and activists to be included in their campaigning.

Phil Friend, chairman of RADAR, said: “Parties and candidates who make an effort to connect with people living with injury, ill-health or disability will be able to tap a rich seam of voters.

“There are 11 million of us. We live in every single constituency. We can strongly affect the result in marginal seats, and so can our families and friends.

“We cannot be ignored or taken for granted by any party; if the politicians want our vote, their policies will have to address our concerns.”

**8 April 2010**

## **Equality bill set to become law, but work remains**

Disabled peers and other campaigners have welcomed the major improvements to the equality bill they helped to secure before it cleared its final parliamentary hurdle.

The bill is now set to become law after MPs approved amendments made in the Lords, many of them around disability rights. It is now just awaiting royal assent.

Three disabled peers – Baroness [Jane] Campbell, Baroness [Rosalie] Wilkins and Lord [Colin] Low – played a key role in persuading the government to accept the disability amendments.

Baroness Campbell said the bill – which streamlines existing equality laws – was “not in good shape” when it entered the Lords, when compared with the rights contained in the Disability Discrimination Act (DDA).

She praised the efforts of her fellow disabled peers, as well as the support given by the Disability Charities Consortium (DCC), former legal experts from the Disability Rights Commission and the disability charity RADAR.

She added: “It was a truly collective effort – something that the disability movement is renowned for and good at.”

Baroness Campbell said the number of amendments relating to disability that were passed by the Lords was “out of all proportion to the rest of the bill”, with 12 amendments either preventing “regression” from rights gained through the DDA – such as those around reasonable adjustments, accessible information and education – or securing new rights for disabled people.

The new rights include a ban on employers using health questionnaires to discriminate against disabled job applicants, stronger protection on reasonable adjustments, new laws on accessible taxis and new rights to auxiliary aids and services for disabled pupils.

Baroness Campbell said the “area of biggest disappointment” was that the bill’s new public sector equality duty does not provide strong enough protection for disabled people, despite some improvements secured by peers.

A government policy statement has indicated that the new duty will be “much weaker” than the current disability equality duty (DED), she said, while there is no way of ensuring that public bodies comply with the new duties.

She and other campaigners now face “an uphill struggle” with lobbying the next government on the regulations that will set out public bodies’ specific duties.

Marije Davidson, RADAR’s senior policy officer, said the act now “provides an opportunity to generate new energy and momentum behind disability equality”.

She said: “The new government needs to take forward implementation of the equality bill as a matter of urgency, including drafting and consulting on regulations related to the public sector equality duty and taxi accessibility.

“We will press for a robust enforcement of the rights of disabled people as well as raising awareness amongst disabled people of their rights.”

Scope said it was “delighted” that many of the changes it campaigned for as a member of the DCC found their way into the bill.

It described the bill as a “positive step forward” for disabled people, but warned that “much will depend on the guidance that accompanies the bill and how it is enforced”.

John Knight, director of policy and campaigns at Leonard Cheshire Disability (LCD), another DCC member, said it too was “delighted” with many of the key improvements.

He said it would now be vital “to make sure that the act works for disabled people up and down the country, and that disabled people are aware of their rights, and are able to challenge discrimination when they face it”.

LCD will release a report next week on how to ensure disabled people can use the Equality Act to challenge discrimination.

Most of the measures in the new act will come into force on 1 October, although the DED will not be replaced by the single public sector duty until April 2011.

**8 April 2010**

### **Tories back out of agreement on disabled candidates**

The Conservative party appears to have backed out of a cross-party agreement to publish reports on how many parliamentary candidates are disabled people.

The proposal was a key recommendation of a cross-party “conference” headed by the speaker of the House of Commons, which aimed to increase the number of disabled, female and ethnic minority MPs.

All three main parties backed proposals to produce regular reports on how many of their parliamentary candidates – including those who are not selected to stand for parliament and those who do not become MPs – are disabled, female and from an ethnic minority.

The proposal to publish reports on the diversity of candidates was also backed by an amendment to the government’s equality bill.

But in the final Commons discussion on the bill, the Conservative shadow minister for disabled people, Mark Harper, said that both the Liberal Democrats and Labour agreed that – because of difficulties in identifying disabled candidates – “it probably makes sense to start off with reporting on gender and ethnicity”.

He added: “We can see how that works and whether it drives the necessary change before we consider reporting in other areas.”

But a Liberal Democrat spokeswoman said: “I am not sure where he has got his information from, but categorically it is not true for the Liberal Democrats. We will definitely be monitoring disability.”

And Anne Begg, the disabled Labour MP who was vice-chair of the speaker's conference, said both Labour and the Liberal Democrats were already collecting such data and neither had raised any objections to reporting on disability.

She said: "I think the Tories are backtracking now. It does concern me. It is concerning simply because we have a long way to go."

Begg pledged that, if re-elected, she would focus on helping to correct the "enormous" historical imbalance in the number of disabled MPs.

She added: "In terms of gender and ethnicity we seem to have made big strides, but I think we have got a long way to go with disability. Where gay people were in 1992 is probably where disabled people are now.

"If I get back in then those are the kind of issues I am going to pursue from the perspective of the disabled person in a way I have never done before.

"When the political parties select the next cohort of candidates [after the election], we have to make sure they are from more diverse backgrounds."

No-one from Mark Harper's office was available to comment.

**8 April 2010**

### **Report makes 'compelling' case for 'diversion' from prison**

Two mental health charities have laid out a "compelling" case for treating offenders with mental health conditions in the community, rather than sending them to prison.

The report, by Rethink and the Sainsbury Centre for Mental Health, says such policies would save money at a time when public spending is under severe pressure.

The report lays out the interim findings of their research into how to build a financial case for "diversion" schemes, in which offenders are given community support programmes rather than locked up in prison.

It concludes that investing in “diversion” would save money in the criminal justice system and reduce reoffending rates.

It follows Lord Bradley’s review of people with mental health conditions and learning difficulties in the criminal justice system, which in April 2009 found a “growing consensus that prison may not always be the right environment for those with severe mental illness”.

In its response to the Bradley report, the government pledged to reduce the number of people with learning difficulties and mental health conditions in prison.

The new report is part of research – to be completed by November – that aims to find evidence to justify investing in diversion.

Paul Jenkins, chief executive of Rethink, said: “More than one in ten prisoners has a severe mental illness and most do not receive the help and treatment that they need.

“It’s not rocket science – providing the right support to offenders early on would save money in the long run.

“We could spend far less on appropriate community support than on prison places. At the same time, we would reduce reoffending rates which are often sustained as a result of mental illness.”

A review of published evidence for the report found that diversion can produce cost and efficiency savings in the criminal justice system, reduce re-offending and improve mental health.

The report concludes that, despite gaps in the evidence, the case for investing in diversion is “compelling”.

**7 April 2010**

**Blood campaigners attack government’s ‘cheap initiative’**

Campaigners have attacked the government for blocking new laws that would have improved support for disabled people who were infected with contaminated NHS blood in the 1970s and 1980s.

The contaminated blood (support for infected and bereaved persons) bill had been steered swiftly through the Lords by the former disabled people's minister, Lord [Alf] Morris.

But the government ensured that it failed to secure any parliamentary time in the Commons.

The bill would have implemented all of the recommendations of Lord Archer of Sandwell's independent public inquiry into the scandal.

Nearly 2,000 people with haemophilia have so far died after being treated with contaminated NHS blood and blood products. Of about 5,000 people with haemophilia, 95 per cent were infected with hepatitis C and a quarter with HIV.

Lord Morris's bill would have increased compensation for those infected, improved medical care, reviewed the support available, and set up a committee to advise on treatment.

TaintedBlood, a group set up by survivors of the scandal and relatives of those infected, said the government's move had "left hundreds of sick, dying and disabled people in despair" and "hammered in the final nail for all those who believe in honesty, decency and human rights".

Only days after ensuring the bill would not be debated in the Commons, the government announced that a review of the Skipton fund, which was set up to make payments to those infected with hepatitis C, would now be carried out this year instead of in 2014.

TaintedBlood said the government's announcement undermined Lord Archer's work and was "nothing more than a cheap initiative that brings no tangible benefit to victims who are currently dying at a rate of at least one per month".

Although Mike Dorricott, a TaintedBlood spokesman, said later that the Skipton fund announcement was "a step in the right direction", he said it was

“almost a kick in the teeth as far as Lord Archer and Lord Morris are concerned”.

Liz Rizzuto, chair of the Haemophilia Society, said: “The government statement brings not one penny of new support to arguably the most needy minority in Britain today.

“We hope that people across the country will join in our protest about this unsatisfactory response to the worst ever treatment disaster in the history of the NHS.”

TaintedBlood members are now awaiting the result of a judicial review brought by their committee member Andrew March into how the government reached its decision on compensation.

Gillian Merron MP, the public health minister, said: “The government has been listening carefully to the views of those affected, who have told us that our intended review date of 2014 will be too late for many of those affected.

“Therefore, the review will be brought forward to begin as soon as possible this year.”

Responding to the inquiry last year, the government refused to increase compensation for people infected with hepatitis C – instead announcing a review of the Skipton fund in 2014 – but doubled annual payments to those infected with HIV to £12,800.

A Department of Health spokeswoman said nearly £150 million had been paid out in compensation so far.

She added: “We do not believe that there is a need for legislation on the issues covered by the bill, because the majority of them are either already in place, or will be put in place, in one form or another.”

She said DH officials were already meeting twice-yearly with people with haemophilia and other members of the Haemophilia Alliance, and that the necessary health services were already available to people with haemophilia, with the DH currently considering its response to a review of prescription charges in England.

**6 April 2010**

### **Government 'must act on scooter safety'**

The government should collect better information about the number of accidents involving mobility scooters, according to a committee of MPs.

A new report from the transport select committee says anecdotal evidence suggests there are growing numbers of scooter-users and accidents involving scooters, despite "insufficient official data".

The government is in the middle of a three-month consultation on reforms aimed at modernising laws on mobility vehicles, including both powered wheelchairs and scooters, following "growing concern" about safety.

The consultation could lead to users of mobility vehicles having to undergo training, take a safety assessment and buy third-party insurance.

The committee's report says the government "must act" on the findings of its consultation, collect better data on the "number and nature of incidents involving mobility scooters" and clarify who is fit to drive a mobility scooter in a public place.

It adds: "Only by doing so, will issues such as the legal status of mobility scooters, the appropriateness of proficiency tests and the rights of users to take the vehicles on public transport be adequately addressed."

Louise Ellman MP, chair of the committee, said its members "welcome the independence that these vehicles can give people" but were "concerned about the many reported accidents and injuries involving the scooters".

The committee said it was concerned that the government had failed to act on many of the recommendations of a Department for Transport review in 2005.

In his evidence to the committee, transport minister Sadiq Khan said the government had believed at the time that the problem was "not as serious an issue as it could be now", with few reports of injuries.

He said the government had ensured that this year's national travel survey would include a category for accidents involving mobility scooters, in order to collect information about the extent of the problem.

**6 April 2010**

### **User involvement on autism board is 'woefully inadequate'**

Campaigners have criticised plans to appoint just one person with autism to a high-level board set up to monitor progress on the government's new national strategy on adults with autism.

The Department of Health (DH) has already appointed 21 people to the programme board, most of whom are from government departments, although there is also a handful of academics and representatives of social care quangos, local government and the voluntary sector.

This week, the government published a plan describing how it intends to make progress on the strategy over the next year. It says there will be an "open recruitment process" to appoint one adult with autism and one representative of carers to the board.

The delivery plan also says there will be progress this year on: delivering autism awareness training for frontline public sector workers; developing a new awareness-raising campaign to tackle stigma; improving access to services and support; helping adults with autism into work; and developing regional delivery plans.

But Russell Stronach, co-chair of the Autistic Rights Movement UK (ARM UK), said that although "bits and pieces" of the delivery plan were positive, there was still the same lack of detail that ARM UK criticised in the strategy itself.

He said that appointing just one person with autism to the board was "woefully inadequate", as people with autism had such a wide breadth of experiences.

He said people with autism must also be able to monitor regional progress on the strategy, as with the learning disability partnership boards set up through the learning difficulties white paper Valuing People.

Stronach said: “Who is going to be monitoring it independently? That should be us, users and carers, but the mechanisms aren’t there.”

ARM UK has already criticised the weak language in the strategy and “derisory” funding of £500,000.

The strategy aims to “make existing policies work better” for adults with autism, with the emphasis on avoiding “additional statutory requirements or financial burdens” on public services and business.

A DH spokeswoman said the strategy was developed “using the core principles of inclusivity and co-production, with extensive public consultation” and “sought the views of adults with autism themselves, their families and informal carers”.

She said the “careful selection” of board members ensured the DH would have “access to the right knowledge and expertise to provide direction and governance for the strategy”.

She added: “At both regional and local levels, we will encourage processes to be put in place to ensure that the views of adults with autism and their carers are sought and taken into account in the development of services locally.”

And she said further detail would follow through new statutory guidance and a three-year delivery plan by the end of 2010.

**7 April 2010**

### **Inquiry call over disabled woman’s death**

Campaigners have called for an inquiry into the death of a disabled woman whose direct payments had been withdrawn by her local council.

Two campaigning organisations held a vigil last weekend attended by more than 30 campaigners, friends and neighbours of Jennyfer Spencer.

They claim the wheelchair-user was one of many disabled and older people who have been found ineligible for support by Camden council, have had support packages cut or withdrawn, or “have been driven away by charges they can’t afford”.

They say many disabled people are now finding themselves “isolated and suffering routine neglect”.

But the council has defended its actions, insisting that Spencer had a “long history of refusing to engage with services”, while her direct payments were cancelled because the money was just being left in her bank account.

The council said care workers who were sent to Spencer’s flat after the direct payments were stopped were turned away, and she failed to turn up for meetings to discuss her care and housing needs.

The council said its savings threshold for providing free home care is higher than most London councils, at £30,750, while it provides care for those with “substantial” or “critical” needs.

The campaign for an inquiry into Jennyfer Spencer’s death is being led by the Campaign Against Care Charges (Camden) and the national disabled women’s charity WinVisible, with support from the CARAF Centre and the Black Women’s Rape Action Project.

They say Spencer spent seven years living in an inaccessible flat in Gospel Oak, north London and ended up “entirely dependent” on her neighbours, after Camden council stopped her direct payments in 2008.

The body of the former primary school teacher was found on 1 March, along with a letter addressed to a local paper detailing her battle with the council.

Although the death is “not being treated as suspicious”, a police spokeswoman said a financial investigation was underway to “see whether any offences have been committed”. She said there was likely to be an inquest into the death.

Spencer had apparently been trying to persuade the council to move her from a fifth-floor flat – which didn't even have a ramp at the front door – to a ground-floor flat for seven years.

Claire Glasman, a volunteer with WinVisible, said campaigners were “angry” because her death seemed to have been preventable.

She said: “It is just such a waste. Apparently she was a lovely person. She fought right up until the end.”

Jim Wintour, Camden's director of housing and adult social care, said the council had been “greatly saddened” by Spencer's death.

He said: “When a vulnerable member of society dies suddenly it is right that questions are asked and we will want to learn from this tragedy.”

But he said the council repeatedly tried to persuade Spencer to accept help. He added: “We care about our vulnerable residents and want to provide appropriate support, but we have to balance this with their own freedom and right to make choices.”

A Camden council spokeswoman said Spencer turned down five offers of ground-floor flats and “did not request a ramp, presumably because she had requested a transfer to a ground floor council flat”, and also did not turn up for two appointments with the council's mental health service for an assessment.

The council spokeswoman added: “She wasn't considered to have such mental health problems that we could have had her sectioned and forced care upon her.”

Friends have said Spencer's continuing health problems could have made it difficult for her to attend council meetings.

The council spokeswoman added: “No independent inquiry is planned at present although we will of course look for any lessons that can be learned as a result of this case.”

**7 April 2010**

News provided by John Pring at [www.disabilitynewsservice.com](http://www.disabilitynewsservice.com)