

# not the national information forum

But still working for the inclusion of disabled and other disadvantaged people  
by encouraging better information provision

News Briefing No. 37. September 2011

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## **FIXING BROKEN BRITAIN**

Gavin Poole, Director of the Centre for Social Justice (CSJ), has pointed out that the Centre has been researching an agenda for social reform for over six years. He identifies five key pathways to poverty other than simple monetary measure: family breakdown, educational failure, worklessness, addiction and debt. They have crippling effects in many of our communities, but none more so than family breakdown. CSJ believes that “fixing broken Britain must be the government’s number one priority”, and has published a detailed statement on the home page of its website at [www.centreforsocialjustice.org.uk](http://www.centreforsocialjustice.org.uk). CSG is a not-for-profit, independent ‘think tank’ with a distinguished advisory panel drawn from most sides of the political divides.

## **A QUIET REVOLUTION**

Have you noticed that the number of Co-operative Trust Schools has trebled in just over a year? They now make up the third largest association of schools in England. Modelled on the principles of the Co-operative Movement they offer independence with local accountability. This upsurge follows the 2006 Education and Inspections Act, and the schools are in principle supported by the Department for Children, Schools and Families. They have a membership structure to engage parents, carers, pupils, teachers, staff and the local community. While embracing co-operative values, they are happily free of religious bias.

For further information go to: [www.co-op.ac.uk/schools-and-young-people/co-operative-schools](http://www.co-op.ac.uk/schools-and-young-people/co-operative-schools), and for an overview see Warwick Mansell’s article in Education Guardian, 16 August 2011.

## **STANDARDS FOR LONDON’S LOW EMISSION ZONE TO CHANGE**

We have been asked to pass on the information that from 3 January 2012, larger vans, minibuses and other specialist vehicles will have to meet new Euro III standards for permitted particulate matter when driven within London’s Low Emission Zone, or face a daily charge of £100. The zone is roughly commensurate Greater London Authority area. Such vehicles first registered as new with the DVLA on or after 1 January 2002, will meet the standard and no action need be taken. Cars and motorcycles are not affected.

Transport for London has prepared an explanatory booklet. For this and further information call 0845 607 0009; e.mail: [lezlondon@tfl.gov.uk](mailto:lezlondon@tfl.gov.uk); or write to Low Emission Zone, POBox 4784, Worthing BN11 9PU.



## **UCanDoIT**

We have the annual report of this remarkable organisation, whose mission is to teach essential computer and internet skills to blind, deaf and disabled people in their own homes. Since 1998 UCanDoIT has supported, trained and signposted over 3,600 disabled people to greater independence, better communication, further education and work opportunities. Each person supported receives up to 13 tutorials. In all, over 40,000 tutorial lessons have now been given.

These include remote training sessions to 372 learners since the launch of this provision in 2007.

UCanDoIT provides training in Scotland and Wales, even in the North West of England. I expect Tom Dowling knows that!

UCanDoIT, Highfield House, 4 Woodfall Street, London SW3 4DJ; tel: 020 7730 7766; e.mail: enquiries@ucandoit.org.uk; website: www.ucandoit.org.uk

## **ACCESS TO JUSTICE**

The Spinal Injuries Association has mounted a High Court challenge to government plans to reform conditional fee arrangements (generally known as the 'No Win No Fee' system). The planned changes include provisions which would require claimants to pay some of their legal fees even if they win. With the support of Headway and Action Against Medical Accidents an application has been lodged seeking a Judicial Review.

SIA considers that the reforms are unlawful because the government has not carried out proper assessments of how the proposals would affect disabled people. It believes that access to justice is a fundamental right to protect vulnerable people and that this should be one of the government's highest priorities. The SIA newsletter *Forward* (August 2011) says: "For a great many people whose lives have been devastated through a catastrophic event such as a spinal cord injury, the 'No Win No Fee' system has opened up the opportunity, irrespective of means, to submit a legitimate claim. A newly-injured person who is facing up to a life of permanent disability should be entitled to obtain good quality, independent legal advice, without financial pressures impacting their decision to progress a claim."

The relevant intended legislation is contained in the Legal Aid, Sentencing and Punishment of Offenders Bill, available at [www.parliament.uk](http://www.parliament.uk). The bill has reached its committee stage, with a report due on 13 October. The committee is now accepting written evidence. Among other things, if enacted, the provisions include the abolition of the Legal Services Commission and the creation of a new offence (relevant to our last 'We Hate' piece) of threatening with an offensive weapon or an article with a blade or point thereby creating an immediate risk of serious physical harm.

## **BULLER FOR EVER?**

In his statement to the Commons on 11 August, the Prime Minister announced that gang injunctions will be used across the whole country for children and adults. Might these perhaps extend to the notorious Bullingdon Club, of which he, George Osborne and Boris Johnson were members? Or is the idea that we are all in this together simply rhetoric?

## **PAYMENT BY CHEQUE TO SURVIVE**

After a broad consultation, the Payments Council has announced (12 July) that the proposal to close cheque clearing by 2018 has been abandoned. "Cheques will stay as long as customers need them."

The Council is a voluntary membership organisation that "sets the strategy for UK payments". It has no fewer than 15 directors, 11 industry-appointed and 4 independents, plus an independent chairman.

## **ASSISTED DYING**

The case for a change in our law so that people do not have to suffer against their wishes at the end of life is gaining ground. At the AGM of the campaigning organisation Dignity in Dying three of its eminent patrons voiced their support for choice.

Rev Professor Paul Badham argued that religious belief need not be seen as incompatible with the option of assisted dying for terminally ill adults.

Sir Terence English, a distinguished heart surgeon, said that his views on the issue were very much in accord with those of his friend Lord Joffe. He thought that opposition often came from within the medical profession,

such as some palliative care doctors who fear their work could be negatively impacted by assisted dying. The group Healthcare Professionals for Assisted Dying planned to try to counter such concerns. Simon Weston, the Falklands war veteran, spoke passionately about the case for change and the scaremongering “hysteria” being used by some of those who oppose assisted dying. Nevertheless, his own experience of pain and depression had convinced him of the need for strict regulation.

A fuller account of these speeches can be found in Dignity in Dying’s magazine *Campaign* (issue 7, summer 2011), which also comments on Sir Terry Pratchett’s documentary *Choosing to die*, screened on TV on 13 June.

Dignity in Dying, 181 Oxford Street, London W1D 2JT; tel: 020 7479 7730; e.mail: [info@dignityindying.org.uk](mailto:info@dignityindying.org.uk); website: [www.dignityindying.org.uk](http://www.dignityindying.org.uk)

### **THE MS TRUST COMES OF AGE**

The Multiple Sclerosis Trust is celebrating its 18th birthday. Back in 1993, its founders – Jill Holt and Chris Jones – were frustrated that the needs of people with multiple sclerosis were not being met, specifically that:

- information, especially for those newly diagnosed, was woefully inadequate
- applied research was under funded
- NHS services were inadequate
- the image of MS was unduly negative.

Information has been at the heart of the trust’s subsequent work, particularly through a magazine *Open Door*, bringing news and details of research initiatives, with input from those who live and work with MS. Working closely with health professionals and people with MS and their families the trust has developed trusted, accessible and attractive books and factsheets. Of course, there is now a huge amount of information about MS, not least through the internet, and an important function of the trust, as it puts it, is to distil the hope from the hype.

The trust has also given high priority to funding practical research, and continues to raise money to support good quality, practical studies; often as pilots for larger trials. It has also commissioned research to prove the value of specialist nurses.

NHS services for people with MS remain less than adequate, and the trust has made great efforts to demonstrate these shortcomings, urging the importance of combining the clinical expertise of health professionals with the personal experience of people living with the condition and developing an accredited education programme for new MS nurses and therapists, along with a quarterly journal, *Way Ahead*, for health and social care professionals.

There remains a huge challenge: of the UK population, 16% have a neurological condition, yet the NHS spends only 3% of its budget on neurology, and Multiple Sclerosis gets just a tiny proportion of that.

For further information, contact: Multiple Sclerosis Trust, Spirella Building, Bridge Road, Letchworth Garden City, Herts SG6 4ET; tel: 01462 476700; e.mail: [info@mstrust.org.uk](mailto:info@mstrust.org.uk); website: [www.mstrust.org.uk](http://www.mstrust.org.uk).

### **MEASURING PRUDENCE**

There is general agreement on the need to cut government expenditure, but great discord on how fast and in what areas. The evidence of the recent riots and the underlying social malaise would surely suggest that far from reducing the police budget it would be sensible to substantially increase spending on the guardians of law and order so that they may be more proactive in preventing crime before the cost of mayhem overwhelms our communities.

### **SHOULD INFORMATION PROVIDERS BE IMPARTIAL?**

In *CILIPUPDATE* (August 2011) CEO Annie Mauger, speaking at a conference *The Future of Library Services in the Big Society* on 21 June, is reported to have pointed out that librarians are trained to deliver impartiality, neutrality and safety. And that libraries are an impartial source of information and are trusted, a principle that

cannot be ignored in a fair society. That is certainly the traditional view. But with society under attack from above and below, from government and from disaffected youth, can charities – charged with contributing to the public good – remain entirely neutral and above the fray? Is it not imperative in providing information to have an opinion? Perhaps it is wise to avoid recommendations, but should charities not come off the fence to warn of potential pitfalls and perils.

On another page, UPDATE quotes Catherine Bennett, from *The Observer*, who appears to have no such qualms: “And most perplexing – how do you account for a person such as Ed Vaizey [Minister for Culture, Communications and Creative Industries at the DCMS], who claims to be a great reader and watches, the picture of indifference, as British libraries are killed off or handed over to untrained volunteers for gradual dismembering? By rights, the simplest, most cautionary fiction should tell him that he will be despised for ever more. Unless we can trace his glib philistinism to a weakness for Jeffrey Archer.”

How’s that for neutrality?

### **SOCIAL CARE FUNDING**

This being a News *Briefing* we have hesitated to spell out the recommendations of the Dilnot Report. However it is worth mentioning that there is a short commentary, *Fairer Care Funding*, on the RNIB website ([www.rnib.org.uk](http://www.rnib.org.uk) – search for Dilnot Report). Of course, it does not follow that the government will accept the proposals.

### **ACCESSIBLE LABELLING**

Back in 2001 the National Information Forum gave one of its Getting the Message Across awards to The Co-operative Group to commend its introduction of braille labelling on Co-op brand medicine products. We praised this as “an excellent and [then] unique initiative”, and commented that the Co-op had “now opened the door to manufacturers and retailers to develop their own braille packaging”. The European Parliament is at last catching up. Prompted by the RNIB, Sense and the European Blind Union, 447 of its members have signed a declaration calling on the European Commission to launch a consultation on the feasibility of introducing a voluntary system to label products in braille and other accessible formats.

Lord Low is quoted in the RNIB magazine *NB* as claiming this as a landmark victory: “Access to information must be addressed, otherwise blind and partially sighted people have no independence, no choice, and no safety.”

### **DISABILITY INFORMATION NORTH OF THE BORDER**

Update, the Scottish organisation that provides disability-related information to organisations in the voluntary, public and private sectors and to individual members of the public, has launched SCOOP, a new online database available on subscription to member organisations. Details at [www.update.org.uk](http://www.update.org.uk).

### **THE HOPES BRING HOPE TO THE THIRD WORLD**

Elizabeth’s Legacy of Hope (EL of H) is a new charity inspired by twin sisters Sarah Hope and Victoria Bacon (who took the name of her husband, Richard Bacon MP). Sarah’s daughter Polyanna lost a leg in a traffic accident when she was just two years old. The twins’ mother Elizabeth died at the scene, and Sarah too was badly injured. Since then Sarah and her daughter have received wonderful care, so that Polyanna can now – albeit with difficulty - walk, jump, skip and play.

But the Hope family has recognised that in developing countries thousands of children with limb loss are not so fortunate. They suffer through the injustice of malnutrition, accidents, landmines, illness and violence. In memory of Elizabeth EL of H is now working to help some of those children, providing the prosthetic limbs and support they need to give them a free and happy childhood and a chance in life. The website, [www.elizabethslegacyofhope.org/](http://www.elizabethslegacyofhope.org/) has messages from patrons, including the actress Joanna Lumley.

### **LIBRARIES CHANGE LIVES**

The 2011 Libraries Change Lives Award was won by Kent Libraries and Archives innovative project *Making the Difference*, welcoming and working with adults with learning disabilities to develop services to meet their

needs, and helping them to lead more active lives in their communities.

There were two runners up. The *NEALIS Project*, a wide-ranging partnership has been working in North East England since November 2007 to improve library, information and reading services for blind and partially sighted people. *'Our Tyneside' Project*, run by Newcastle City Libraries and open to adults with learning disabilities, began in November 2009 with a focus on local and family history. Such was its success that *The History Club* was launched in April 2010 and has become a vital part of participants' and staff's lives.

Videos of all three projects are available at [www.cilip.org.uk/about-us/medalsandawards/libraries-change-lives/pages/finalists2011.aspx](http://www.cilip.org.uk/about-us/medalsandawards/libraries-change-lives/pages/finalists2011.aspx)

### **INCARCERATION LAID BARE**

Nick Hardwick, HM Chief Inspector of Prisons and former chair of the IPCC, has been making waves, and is to be admired for his straightforward honesty. Of a number of recent prison inspections, two - at Pentonville and Wandsworth – were unannounced. The Chief Inspector's reports make for fascinating reading. While that on Pentonville is not over-critical, that on Wandsworth is positively damning, summed up at the end of the introduction in two sentences: "The treatment and conditions of simply too many prisoners at Wandsworth was demeaning, unsafe and fell below what could be classed as decent. I did not detect willingness in the prison to acknowledge and address these concerns."

The last inspection in June 2009 had been "marred" by an attempt to subvert the process by moving 'difficult' prisoners between Wandsworth and Pentonville so that they were not present in either prison during their respective inspections. That contrivance did not recur in 2011, but "the prison's progress had halted and overall outcomes for prisoners were significantly worse."

It was accepted that the prison holds a challenging population with multiple problems, with many prisoners held for only short periods. Nevertheless, Wandsworth "compared badly with similar prisons facing similar challenges." The level of self-harm and the number of self-inflicted deaths were high. In 2010, some 700 documents were opened under the ['Assessment – Care in Custody – Teamwork' (ACCT) guidance], with a further 120 in the first two months of 2011. Typically, there were about 32 incidents of self-harm each month and about 60 ACCT documents were open at any given time. There had been 11 deaths in custody between January 2010 and the 2011 inspection; four of them apparently self-inflicted. [The ACCT plan is aimed at creating a safe and caring environment and preventing suicide]. But among the key areas of risk identified by the inspection was "the inconsistent quality of ACCT procedures". There was also concern that "poor staff-prisoner relationships, the lack of a predictable regime, deficiency of association, and insufficient activity contributed to feelings of isolation and alienation that might have led to self-harming behaviour."

Only 58% of prisoners said that they had a member of staff in the prison they could turn to if they had a problem. The inspection team observed "frequently indifferent and sometimes abusive staff interactions with prisoners", while the "formal application and complaints systems were overwhelmed and ineffective... The induction process was poor and many prisoners lacked basic knowledge about the routines and rules of the prison."

"Prisoners with any sort of specific individual need [such as disabilities] were particularly disadvantaged", while there was "no strategy to meet the needs of foreign national prisoners", many of whom "were held beyond the end of their sentence – one for three years."

"Most cells were shared and had inadequately screened toilets. First night cells were not cleaned of graffiti", some of which was seen to be racist. Time out of cells was very limited, association was often cancelled and when it did occur "there was little for prisoners to do." Inspectors saw little interaction with officers and exercise in the fresh air was limited to 30 minutes a day, weather permitting.

"Victims of bullying behaviour were not adequately protected", and responses and support were ineffective. "The segregation unit lacked direction. The regime was poor and there appeared to be little attempt to tackle

and resolve any of the underlying reasons for prisoners' behaviour." In short, the "prison did not respond adequately to the needs of the diverse population it held." In particular, "black and minority ethnic prisoners were disadvantaged in significant areas of the prison, and this needed to be addressed as a matter of urgency."

Mr Hardwick hoped that the Prison Service management would act decisively to reverse the prison's decline. We wonder if it is capable of doing so. This, of course, has necessarily been a summation of the introduction to a long report, the recommended full text of which is available at: [www.justice.gov.uk/downloads/publications/inspectorate-reports/hmipris/wandsworth-2011.pdf](http://www.justice.gov.uk/downloads/publications/inspectorate-reports/hmipris/wandsworth-2011.pdf)

### **DISABILITY WORLDWIDE**

The first ever *World Report on Disability* has been produced jointly by the World Health Organisation and the World Bank. It suggests that more than a billion people worldwide are currently experiencing disability. They generally have poorer health, lower educational achievements, fewer economic opportunities and greater poverty than non-disabled people. This is largely due to a lack of services and the many obstacles they face in their everyday lives.

The report presents the best available evidence about what works to overcome barriers to health care, rehabilitation, education, employment and support services, and ends with recommendations for governments and their partners to create environments that will enable disabled people to flourish.

The full report can be downloaded at [www.who.int/disabilities/world-report/2011/en/index.htm](http://www.who.int/disabilities/world-report/2011/en/index.htm). Print copies cost US \$40 from WHO Press, 1211 Geneva 27, Switzerland; e.mail: [bookorders@who.int](mailto:bookorders@who.int).

### **BRITISH LIBRARY ATTEMPTING TO BUY EUROPE'S OLDEST BOOK**

The BL is seeking to raise some £9 million to acquire the Saint Cuthbert Gospel. Produced in the late 7th century, the gospel was buried with the saint, the Bishop of Lindisfarne, apparently in 698, and was discovered when Saint Cuthbert's body was transferred from the island to Durham Cathedral in 1104. After passing through several hands it was finally donated to the British Province of the Society of Jesus in 1769, and has been on loan to the BL since 1979.

The original red leather binding is in excellent condition and the text, in Latin, is said to be the only surviving high-status manuscript from this historic period to retain its appearance. The proceeds of the sale will be used by the Jesuit Province to strengthen funding for its schools, help with the foundation of a new school in Africa, and restore the 19th century parish church of St. Peter at Stonyhurst.

The National Heritage Memorial Fund has made a grant of £4.5 million, and other funds have pledged generous contributions. An appeal has been launched at <http://support.bl.uk/Page/The-St-Cuthbert-Gospel>.

### **QUESTION TIME**

Is it not unfortunate that the BBC's 'Question Time' is off our screens just now? Rather like blocking a ventilator.

### **WE HATE NO. 45: WELFARE REFORM**

**Derek Kinrade**

*"...first, the treatment being meted out to thousands of people should be a moral offence to all of us; and second, our flexible labour market and increasingly brutal welfare system are now so constructed that even if you are doing well, it is perfectly possible that you could fall ill, and then find yourself just as terrified as the thousands who are currently being herded through the WCA [Work Capability Assessment] process."*

John Harris, *The Guardian*, 26 July 2011.

From time to time we have expressed hostility to some aspects of this legislation. Our primary disquiet has concerned the processes involved in applications for the new Employment and Support Allowance and the reassessment of people in receipt of Incapacity Benefit. It is perhaps time to reprise what began, I believe, as a

heartfelt theory, but which in its practical application is now in grave danger of becoming an iniquitous scandal. The theory began under a Labour government, albeit inspired by the advice of David Freud, an investment banker who was recruited by Tony Blair in 2006, but who subsequently joined the opposition Conservative team in February 2009, received a life peerage and is now a Parliamentary Under-Secretary at the Department of Work and Pensions. Unsurprisingly, the new coalition government embraced and has developed the reform programme with enthusiasm, sharing a view that welfare benefits tend to create dependency and that there is a moral imperative that anyone of working age found fit for work should, wherever possible, be helped to earn their living and not allowed (as it has been seen) to continue in perpetuity to receive a benefit based on incapacity: concepts encouraged by the popular media and readily accepted by many working taxpayers. Alongside this way of thinking has been the evidence of a steep rise in the overall burden upon the Exchequer arising from incapacity claims, a significant proportion of which were felt to be, if not fraudulent, at least undeserved. The original eligibility criteria for Incapacity Benefit were in theory very strict: embodied in a heavily criticised ‘all-work test’ designed to restrict benefit narrowly to people judged to be medically incapable of any kind of work, not merely their usual occupation. Nevertheless, over the years the numbers of beneficiaries remained remarkably high and continued to grow. Something, from Whitehall’s perspective, had to be done.

This perception is remarkably redolent of attitudes in the nineteenth century under the New Poor Law. Simon Fowler, in his authoritative study, *Workhouse* (National Archives 2007), points out that in the early 1870s, Albert Pell, Conservative MP for the Southern Division of Leicestershire, was convinced that so-called ‘out-relief’ (that is to say relief out of the workhouse) created a culture of welfare dependency. He had this to say:

“The administration of the Poor Laws is a matter of policy, not sentiment, and should be applied unswervingly in obedience to fixed principles, and not become the haphazard display of sentiment and counterfeit charity... [Otherwise] the incentives of industry are weakened; the fear of the consequences, such a cold, hunger and distress, is diminished or vanishes; and a distinct and pernicious inducement offered to the practice of deceit and fraud, and the total abandonment of conscientious, honest effort for self-maintenance unfolds.”

On 18 July 1876 this same Mr Pell moved:

“That it is desirable to take steps to check the irregular bestowal of out-door relief with a view to the gradual diminution of such an encouragement to pauperism and improvidence.”

So is history repeating itself?

We must start, I think, by accepting that a genuine effort to support disabled people into rewarding work is laudable, *but only if and to the extent that it is practicable*. Here the timing is awful, coinciding with a loss of jobs in both the public and private sectors, and high and rising levels of unemployment particularly among young, often disaffected, people, so that just now barriers to the employment of disabled people are greater than ever. A century and a half ago the solution was to offer impoverished people the ‘house’, there to exist on a meagre diet and obliged to work on domestic duties, picking oakum, or breaking stones for Britain’s roads. That option is no longer available, but the prospect for more attractive opportunities remains bleak.

However, our primary unease is centred on the arrangements for determining/reviewing fitness to work. This, as widely publicised, was contracted out to a French IT company, Atos Healthcare, for (we understand) £100 million a year. Criticism of the practical arrangements abounds. The work capability tests are said to have been narrow, simplistic, impersonal and insensitive. A recent report of a select committee on work and pensions accepts that the process has been flawed, prompting “fear and anxiety among vulnerable people”. The evidence for this is apparent in a high level of appeals, successful in around 40% of cases. The DWP says that it is now working closely with Professor Malcolm Harrington to make the medical test as fair and effective as possible, but this begs two questions: how will we know if and when fairness and effectiveness have been achieved, and what will happen to those found against under the previous testing, now admitted to have been poorly designed? It’s a mess and a scandalous one at that.

Conversely, of course, a sizeable proportion of people have either not appealed or have lost appeals. We

think that a modern Portia would say that while it is legitimate to cut benefits where it is fairly found that the claimant's only incapacity is laziness, beware that you do not harm those vulnerable people whose medical conditions are such that they have little, if any, prospect of securing gainful employment. Be merciful. This is morally dangerous territory and we think it may be better that the benefit of any doubt is given to the acceptance of borderline claims rather than taking an axe to thousands in genuine need. That conditions the political case.

The economic case is that the new arrangements are expected to save the government £1.1 billion by 2014/15. But savings on this scale are trifling when set against the outrageous waste of £6.4 billion already spent on the failed attempt to create a national electronic database of patient records and the massive outlay on a fortnight's Olympic sport, not to mention the huge cost of Trident and the questionable campaign in Libya.

All in all, surely time for a rethink.