

# not the national information forum

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

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*A Digest of Current Social Information*

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### **PUBLIC LIBRARIES AND SOCIAL JUSTICE**

Right now we face a great deal of social injustice. Yet our public libraries, one of the avenues for redressing inequality and disadvantage, are seen by some local authorities as a luxury and expendable. A new book by John Pateman and John Vincent, though regrettably expensive, is timely and welcome. *Public Libraries and Social Justice* points out that social exclusion is relatively neglected, with much of the library profession still in denial. Yet the need to address this agenda is becoming more urgent as the gap between rich and poor widens, and the future development and growth of public libraries and their relevance to the majority of their local communities depends on a recognition of the need to abandon outdated concepts of excellence, based on middle class values, and fully grasp the equity agenda.

The book examines the historical background to social exclusion and its strategic context in terms of government and professional policy. It looks at what social exclusion means in practice and suggests an appropriate service response. It proposes a 'manifesto' for change and considers ways in which local libraries can be transformed into needs-based services,

John Pateman, Information for Social Change UK, is Head of Libraries, Learning and Inclusion at Lincoln. John Vincent, a good friend, runs 'The Network', dedicated to tackling social exclusion in libraries, museums, archives and galleries.

In hardback the book costs £40 (online £36) and it is also available as an ebook. Sample pages are available at [www.ashgate.com](http://www.ashgate.com). Search for the title and scroll to extracts. To order, visit the website or contact Bookpoint Ltd, Ashgate Publishing Direct Sales, 130 Milton Park, Abingdon, Oxon OX14 4SB; tel: 01235 827730; e.mail: [ashgate@bookpoint.co.uk](mailto:ashgate@bookpoint.co.uk).

### **CHRISTMAS ROUND ROBIN LETTERS**

I have recently acquired a copy of Simon Hoggart's *The Hamster that Loved Puccini*, a cautionary tale of the folly of his *bête noir* of the Christmas post. I take it personally and have decided that in future it might be better for me to offer total honesty in Christmas greetings: like Samuel Johnson's comment "Little done ... my mind has neither been improved nor enlarged. I have read little, almost nothing, and I am not conscious that I have gained any good, or quitted any evil habit."

### **SPEAKING FOR OURSELVES**

This is a two-year oral history project, funded by the Heritage Lottery Fund,



to communicate the living heritage of people with cerebral palsy and aged over 50 to a wider audience. 16 volunteers, themselves disabled, have been trained to record life-story interviews. The recordings will form part of a collection held by the British Library Sound Archive.

For further information contact Project Co-ordinator, Speaking for Ourselves, Scope, 6 Market Road, London N7 9PW; tel: 020 7619 7228; website [www.speakingforourselves.org.uk](http://www.speakingforourselves.org.uk).

## **SURVIVING CANCER**

Macmillan Cancer Support reports that median survival rates, averaged across all cancers, have risen from one year to nearly six years since the 1970s. But while remarkable extensions have been achieved in respect of some cancers, very little change has been recorded in others. In some, survival times are still counted in weeks rather than years.

The research found that:

- Six of the cancers studied have predicted median survival times of more than 10 years
- The biggest improvement has been for colon cancer, with a 17-fold increase in median survival time from around seven months to 10 years
- Breast cancer median survival time has doubled since the 1970s and has been more than 10 years since at least the early 1990s
- Lung and brain cancer median survival times has barely risen: from 11 to 20 weeks and from 13 to 28 weeks respectively
- Pancreatic cancer median survival time has increased by just three weeks (from nine to 12 weeks).

Macmillan cautions that where improvements have been made, the time gained can pose a huge challenge in planning better care services.

For more details go to [www.macmillan.org.uk](http://www.macmillan.org.uk). Go to 'about us'; then 'media centre'; then 'The cancer survival lottery'. The release is dated 22 November and has a link to the research briefing paper. There is also a brief report at [www.bbc.co.uk/news/health](http://www.bbc.co.uk/news/health).

## **PATIENTS ASSOCIATION SLAMS CARE IN ENGLAND'S HOSPITALS**

Following critical reports in 2009 and 2010, The Patients Association has again drawn attention to some shocking accounts of poor hospital care across the country. The report, *We've been listening, have you been learning?*, focuses on 16 accounts of patient experience, but these are said to be drawn from many others sourced from the Association's helpline. Concern centres on four fundamental aspects of care: communication, access to pain relief, assistance with toileting and help with eating and drinking. The chosen cases show that patients are continuing to be failed in these key areas.

Speaking on Radio 5Live, the Association's Vice President, Angela Rippon, stressed the need for action rather than yet more enquiries and reports: the evidence is already clear.

The report, which can be downloaded from [www.patients-association.com](http://www.patients-association.com), is particularly concerned with the care of elderly patients. The Association's helpline is 0845 608 4455.

**Comment:** We referred to a range of criticism of hospital care for older people in Briefing 31 (March 2011). This report adds to that concern and is based on personal calls for help. But the evidence of only 16 cases, presumably chosen as particularly disturbing, is too small a number to extrapolate conclusions about the NHS as a whole, without knowing more about the database from which they were drawn. In England alone over 3 million patients are treated in the NHS every week. In this context even the 9,000 complaints received last year by the Health Service Ombudsman represent less than 0.006 per cent of those treated.

## **THE CARE QUALITY COMMISSION**

We referred to misgivings about the CQC as recently as October (issue no.38). It is in the news again. Devastating coverage appeared on the front page of *The Guardian* of 15 November, and in its letter page of

the next day. It was reported that the health regulator was being “urgently investigated” by the Department of Health. I was particularly interested to learn that the CQC is headed by Cynthia Bower, formerly CEO of the NHS West Midlands’ strategic health authority, where she was responsible for supervising the performance of the troubled Stafford Hospital.

A further article on page 12 concluded: “Rarely has a regulator inspired such a broad consensus that its performance, in scrutinising standards in the NHS and social care, is inadequate.”

In response, however, Richard Douglas, Director General of Policy, Strategy and Finance at the Department of Health, said that the article misunderstood a normal part of government business. It was only right that the DH, which funds and sponsors the CQC, should “periodically take a view about the organisation’s capability.” The review had the full co-operation and participation of the CQC. Just administrative routine then.

### **INCAPACITY BENEFIT REFORM: THE HUMAN COST**

As widely reported, The Centre for Regional Economic and Social Research at Sheffield Hallam University has published a report, *Incapacity Benefit Reform; the local, regional and national impact*. Written by Steve Forthergill and Christina Beatty, the report makes the following key points:

- Major reforms to the incapacity benefits system are underway. These include a tougher medical test, the re-testing of existing claimants and the time-limiting of entitlement to non-means tested benefit. The impact of the reforms has so far barely been felt.
- The report estimates that by 2014 the reforms will cut incapacity benefit claimant numbers by nearly one million, of which more than 800,000 will be existing incapacity claimants who will lose their entitlement. These figures are based on experience in the areas where the reforms have been piloted and on the DWP’s own assumptions about the impact of the reforms.
- The loss of entitlement is entirely the result of new benefit rules. It does not necessarily indicate that the health problems or disabilities that previously gave entitlement are anything other than genuine.
- Nearly 600,000 incapacity claimants will be pushed out of the benefits system entirely, either because they will fall foul of the time-limit on non-means tested entitlement or because they fail to qualify for other means-tested benefits.
- The reform of incapacity benefits will push up the numbers on Jobseeker’s Allowance by approaching 300,000. Combined with the new requirement on many incapacity claimants to engage in ‘work-related activity’, the increase in compulsory labour market engagement will be around 900,000.
- The highly skewed distribution of incapacity claimants across the country means that the older industrial areas of the North, Scotland and Wales, in particular, will be most affected by the reforms. The reforms will impact barely at all on the most prosperous parts of southern England.
- Although some incapacity claimants will re-engage with the labour market, there is little reason to suppose that the big fall in claimant numbers will lead to significant increases in employment. Incapacity claimants often face multiple obstacles to working again and their concentration in the weakest local economies and most disadvantaged communities means they usually have little chance of finding work.

The full report can be found at [www.shu.ac.uk/\\_assets/pdf/cresr-final-incapacity-benefit-reform.pdf](http://www.shu.ac.uk/_assets/pdf/cresr-final-incapacity-benefit-reform.pdf).

**Comment:** I am, of course, on-side with the authors of this report, but I think it has to be conceded that whereas the welfare state was intended as a safety net, some claimants are treating it as a hammock.

### **IS WELFARE BENEFITS REFORM UNRAVELLING?**

Channel 4 News Social Affairs Editor, Jackie Long, reports that the Coalition’s Employment Support Allowance (ESA) programme is being undermined by the weight of appeals, some repeated, against ‘fit for work’ findings. The number of appeals has almost quadrupled in two years, from 68,000 in 2009 to a projected 240,000 by the end of the current financial year. The cost so far is said to be £80 million and rising.

Nor is the programme succeeding in getting significant numbers of claimants back to work. Channel 4 has been told by a number of the organisations contracted to carry through the Coalition’s ‘Work Programme’ that they

have serious concerns about the numbers of people moving from ESA to work: in one example only 3-5 per cent rather than the anticipated 25 per cent.

For further details go to: [www.channel4.com/news/new-benefit-system-dogged-by-endless-appeals](http://www.channel4.com/news/new-benefit-system-dogged-by-endless-appeals).

**Comment:** DWP statistics indicate that around 21 per cent of those found 'fit for work' go to appeal. This takes no account of those who are not well enough to undertake an appeal or who lack the capacity or support to do so. Of those who do, the success rate is said to be 40 per cent (unrepresented) and 70% (with representation). I am unable to verify these statistics.

## DIGITAL INCLUSION

Martha Lane Fox, the UK's 'Digital Champion', is certainly single-minded and energetic in seeking to get more of us online, particularly those who are disabled. Race Online 2012, which she leads, has the strapline "We're all better off when everyone's on line". Using ONS statistics it says that 1.6 million people have been added to the online community since 2009, but that there are 8.4 million to go. At that rate there is no chance of achieving its objective in time for the 2012 Olympic Games.

But Ms Lane Fox is not deterred. On BBC's *You and Yours* on 17 November she regretted that 4.25 million disabled adults have never used the internet. She pointed to "an enormous benefit" for disabled people to be online, estimating that they could each save a net £200 a year by being connected. She said that she would "like to see more championing of the opportunity to transform disabled people's lives, and perhaps some bolder and bigger thinking around how we can solve some of these problems."

She was joined by Nigel Lewis, CEO of the charity AbilityNet. He offered an explanation of why disabled people make up such a large proportion (36.3%) of those still not online: "Often it's because it is not accessible to them. Either they can't engage with and use the standard computer out of the box, and so it needs adapting in some way, or the online services, the websites, are not accessible with their adaptive technology."

**Comment:** Obviously there are other reasons. The ONS statistics make clear that as the lower personal incomes fall, the greater the number of non-users. While there may be potential for long-term savings, the initial and continuing cost of the technology can be daunting. Disabled people are generally among the poorest members of our society, commonly on the breadline of poverty.

And neither they nor thousands of non-disabled people may want to join the technological revolution. What can be exciting for some, may be irritating for others. Alongside its undoubted benefits there are dangers and hassle associated with the internet; and not everyone is keen on e-mails, blogs and social interaction. It's fine to encourage and support, but I suspect that there will always be a sizeable proportion that prefers not to join in.

## THE SEVENTH AGE

In October, when I wrote my piece on the 'Seventh Age', I finished by saying that I would like to see a legal voluntary opt-out if and when people feel they have had enough, before what has been called "the indignity of decrepitude". I was then unaware that Yasmin Alibai-Brown had already expressed a similar view in *The Independent*. Noticing that in a recent poll 66% had said that assisted suicide should be legal, she is quoted as saying: "It's the law that's lagging behind, taking no account of the vast societal, environmental and scientific transformations of the past 50 years". She argued that medical advances meant that sick and old people could now be kept "ticking over" in a state of living death. They could be seen "in nursing homes – inert, staring into the void (what are they looking at with those cloudy, dreamy eyes?), cared for by kind or unkind strangers waiting for the bus of death to come and take them away".

Barbara Ellen in *The Observer* objected, troubled by the "unseemly rush to pronounce the lives of others 'not worth living' ". What arrogance, she argued, to assume they know the minds of those who can't speak for themselves.

**(Noticed, belatedly and with gratitude, in *The Week*, 23 April 2011)**

**Comment:** The point here, surely, is the word ‘voluntary’; a decision taken by the person concerned *before* their decline into impotence. Nobody, I hope, is suggesting killing off those who have already missed the chance for an earlier exit. I rather regret that the Voluntary Euthanasia Society decided to change its name to Dignity in Dying.

### **MENTAL HEALTH EMERGENCY TREATMENT INACCESSIBLE AND INEFFECTIVE**

Commenting on a new report, *Listening to experience*, Paul Farmer, CEO of the mental health charity Mind, said: “Mental health crises need urgent treatment, yet our investigation found that far from receiving the instant, 24-7 response we expect for physical health emergencies, people experiencing mental health emergencies can be faced with long waits, poor quality care and in some cases are unable to access help at all.”

Go to [www.mind.org.uk](http://www.mind.org.uk), and click on ‘news’ for an excellent summary, with a link to download the full report.

### **WE HATE NO. 48: DIVORCE**

*“A divorce is like an amputation; you survive, but there’s less of you.”*

Margaret Atwood, *Time*, 19 March 1973

*“Marriage is the chief cause of divorce.”*

Groucho Marx

A number of potential subjects for this feature have assailed my mind over the past month. Not least the shock revelation that the royal prerogative extends to Prince Charles, justified by a slender constitutional argument that if and when there is no heir apparent, the Duchy of Cornwall reverts to the throne. This anomaly requires the Prince to be consulted on any legislation that might affect the interests of the Duchy. And because of the controversial royal exemptions under the Freedom of Information Act (News Briefing no.16, December 2009) relevant correspondence with ministers is secret. I have concluded, however, that antagonism on this issue probably has had a sufficient airing elsewhere and that there must surely be a momentum for democratic change, if only in transparency.

Then my thoughts turned to the mounting disaffection between government policy and the populace at large, with protesters taking to the streets because, as the New Testament has it (four times), *“unto everyone that hath shall be given, and shall have abundance; but from him that hath not shall be taken away even that which he hath.”* Such reflections have been exacerbated by the news that the remuneration of directors of the top 100 FTSE companies has increased by nearly 50% in the past financial year. But we already saw this coming and inveighed against the trend in News Briefing no.8 (February 2009). I’m glad that the High Pay Commission is now on the case.

Another startling proposition was General Lord Dannatt’s view that the military can teach society about the importance of ethics and morality, and that young British soldiers must be able to kill and show compassion at the same time (*The Guardian*, 8 November). I remembered, however, that we had our say on this dubious morality in News Briefing no.19 (March 2010).

Finally, I was tempted to comment on the dismal performance of the ruling Coalition: most recently the continuing failure to reduce the deficit, and the unedifying confusion over the relaxation of border controls. Aren’t you just sick of the mantra that the previous government is responsible for all our ills?

Eventually, however, I decided to hate divorce, a subject of which I have some personal experience.

Let’s start with some facts. In 2008, the Office of National Statistics predicted that, if prevailing rates continue, 45% of marriages will end in divorce before their 50th anniversary, with almost half occurring before their 10th anniversary. The divorce figures for the six years to 2009 in fact showed a decline (from 153,065 in 2003 to 113,949 in 2009), but this may have been due to a drop in the number of marriages.

And by this time the incidence of divorce was already in full spate and overflowing. In 1858 only 24 divorces were recorded, but thereafter the annual figure gradually increased. In the 1950s the average annual count was

27,572; in the 1960s 36,217; in the 1970s (when I gained my own experience) 112,985; in the 1980s 150,144; in the 1990s 154,477; and in the 2000s 137,593.

The reasons given for divorce are various. The ONS statistics for 2009 break down as follows:

Adultery	16.3%
Unreasonable behaviour	47.8%
Desertion	0.4%
Consenting after 2 years separation	25.3%
Separated after 5 years separation	10.0%
Others	0.2%

These figures (which omit the thousands of couples who just ‘soldier on’) are surely shocking, yet have generally come to be seen – much like road deaths – as simply a fact of modern life. But the economic and emotional impact on couples can be devastating, along with divided loyalties and unhappiness for their children. Family breakdown is seen as one of the major causes of social disorder. Various mediation services are now available, but these are generally a last resort, when marriages are already on the rocks and conflict embedded, and seem to be aimed not so much to avoid divorce as to negotiate on questions of money and custody.

The road to divorce usually begins with an original mismatch of partners; and the need for advisory services pre-dates the marriage ceremony. Traditionally, the church – to some extent – fulfilled this role. But the form for the administration of the solemnization of matrimony in the Church of England’s Book of Common Prayer has a somewhat narrow view when it says that “it [marriage] is not to be enterprized, nor taken in hand, unadvisedly, lightly, or wantonly, to satisfy men’s carnal lusts and appetites, like brute beasts that have no understanding; but reverently, discreetly, advisedly, soberly ... duly considering the causes for which Matrimony was ordained”. These are said to be the procreation of children; a remedy against sin and (for those who lack “the gift of continency”) to avoid fornication; and the mutual society, help and comfort that one partner should have for the other, both in prosperity and adversity. I like the latter sentiments best, but if society, help and comfort are to be found wanting, it is by the time of the marriage ceremony already too late; the die is cast.

Let’s face it. The expectation that most marriages will survive a lifetime is precarious. It could be argued that the church is unrealistic in having couples – particularly young couples - give vows of undying fidelity. It might be said, at least from a male perspective, that couplings begin with sexual attraction; yet that is something which inevitably recedes with time, not to mention that younger and more alluring potential partners may appear along the way.

May I offer up my own blueprint of the essentials for a successful marriage, some more important than others? First, I put sexual compatibility. I really mean, in practice, male competence as a lover. Nowadays it is likely, at least in open societies, that this will have been tested (and perhaps found wanting) before marriage is contemplated. Second, a meeting of minds; ideally leading to co-operation: something like the liaison of Benjamin Britten and Peter Pears. Third, an understanding as to whether or not both partners want children. Fourth, some measure of agreement on day-to-day matters such as thrift, work and shared homemaking. Fifth, basic unanimity on religion and politics. Lastly (though I could go on), harmony in matters of taste and pleasure.

Marriage is too important and divorce too traumatic not to have guidance before tying the knot. The breakdown of a marriage is like the damaging of a pot. There may be no more than a hairline crack or it may shatter into a hundred pieces. We may try to restore it, but it can never again be perfect. What should be clear, however, is that at the outset some pots are more fragile than others. I give the last word to William Congreve. In his *Old Batchelour* (1693) he wrote: “*Thus grief still treads upon the heels of pleasure: Married in haste, we may repent at leisure.*”