

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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BETTER INFORMATION MEANS BETTER CARE

NHS England has sent a leaflet with this title to 26 million households. It concerns the intention to bring together personal information about the care you have received into a secure national database. This will allow those providing care and health services “to see how well they are doing, and where improvements need to be made”. The controversial aspect of the project is that information will not be restricted to care providers, but may be made available to others, such as those planning NHS services and approved researchers. The leaflet promises that, where this is allowed by law details that could identify individuals will first be removed. Randeep Ramesh (*The Guardian*, 20 January) is unconvinced. He asserts that drug and insurance companies, if approved, will be able to buy information, and that the removal of personal identification will not be sufficient to achieve complete anonymity.

The scheme is particularly sensitive as health services continue to be privatised, a view reinforced by Alice Bell in the following day’s *Guardian*. She points out that over and above social benefits, this collected knowledge has economic value, boosting the UK’s life sciences industry.

There must also be a legitimate doubt as to whether such a huge database of personal information will remain safe. The record of some government departments creates doubt. Yet the fact is that your records will be included unless you opt out. This means that unless you are proactive in taking steps to be excluded you will be deemed to be “happy” for your information to be shared. There is a presumption here that the great English public will not bother, but this may be misplaced. Media reaction has been distinctly equivocal, with the website www.thebigoptout.com particularly unconvinced. I will be opting out.

JOHN VINCENT: LGBT PEOPLE AND THE UK CULTURAL SECTOR: THE RESPONSE OF LIBRARIES, MUSEUMS, ARCHIVES AND HERITAGE SINCE 1950

For many years John and I have been on the national committee of one of the sub groups of the Chartered Institute of Library and Information Professionals, with a particular concern for community, diversity and equality issues. Over much the same period he was also a friend of the National Information Forum, also concerned with disadvantaged groups. I notice that in 1988 Ann and I devoted two chapters to homosexuality, transvestism and transsexuality in our *Sex Directory*.

John’s expertise on social exclusion has earned him enormous respect. I believe this book, the product of prodigious research, to



be unique in examining the complex and conflicting relationships between lesbian, gay, bi-sexual and transgender people and our cultural and heritage organisations. To set the work of libraries, museums and archives in context, John traces the development of LGBT rights in the UK. He goes on to examine some of the reasons for hostility and hatred against this minority group and critically explores provision that has been made by cultural and heritage organisations. He offers examples of good practice – not only from the UK, but from across the world – and draws up an essential ‘charter’ for future development.

To order, visit www.ashgate.com. It costs £50, but quote AUTHOR20 for 20 per cent discount

UNPRECEDENTED CALL TO REVERSE THE OBESITY AND DIABETES EPIDEMIC

With the support of 18 leading health experts Action on Sugar is working to persuade the food industry and government to reduce the amount of sugar in processed foods. At the same time to raise public awareness of the need to avoid products that are heavy in hidden sugars. A similar campaign succeeded in bringing down salt levels in our food. Action on Sugar now looks to achieving, over a few years, a 20 to 30 per cent reduction.

Further details at www.actiononsalt.org.uk/actiononsugar/

A QUESTION OF RIGHTS

Peter Salter

Latest quip from Ken Livingstone on LBC on 1 February 2014: “Anyone charged who does not go into the witness box is guilty as hell.”

This shows prejudice to me. I know inferences can be drawn when someone is silent under interview and defendants do need to be mindful of body language etc. But the fact remains that the prosecution has to prove its case beyond reasonable doubt.

I cannot find any figures about the percentage of those who do opt to go into the witness box and be subject to cross-examination, or whether the percentage varies between the most serious crimes and the less serious.

[I think Peter is right. Consider the fears of innocent defendants who don't want to subject themselves to the ordeal of cross examination. DK]

WHO CARES ABOUT EDUCATION?

The Who Cares Trust has brought out a new edition of this guide. They point out that despite improvements in recent years, children in care are still less likely to achieve academic success than their peers - only 15% of children in care achieve 5 A*-C grades including English and maths at GCSE, compared with 58% of all children. Narrowing this gap in achievement and encouraging young people in care to aspire and to fulfil their potential is a priority for those working with and caring for them.

Who Cares About Education? is described as a down-to-earth publication for children and young people in care about how to get the most out of their time in school. Its accessible, irreverent style means young people are more likely to read it - and to feel inspired, encouraged and empowered to achieve. The 2014 edition includes new advice and information on virtual heads, SEN, personal education plans and moving placements. Priced at £6.00, with discounts for bulk orders. Order online or contact Rosie Reynolds for further information.

Contact: Who Cares Trust?, Kemp House, 152-160 City Road, London EC1V 2NP; tel: 020 7251 3117; e.mail: rosiereynolds@thewhocarestrust.org.uk

AGE DISCRIMINATION IN THE NHS?

Macmillan Cancer Support claims that some older patients are not offered the right treatment. They want to ensure that older people are offered cancer treatment and care based on their needs, not their age.

www.macmillan.org.uk

THE BADGER CULL

The Badger Trust argues that DEFRA's figures are wrong. And that the department has been forced to suspend statistics on herds under restriction because of bovine tuberculosis.

www.badger.org.uk

GOOD NEWS ON THE MINIMUM WAGE

In *Briefing no.54*, February 2013, I pointed out that over the five years 2008-2012 the maximum national minimum wage had risen by only 8 per cent (this was by 46 pence, from £5.73 to £6.19). RPI inflation over the same period was 13 per cent. Thus had the minimum wage kept up it would have been £6.47. Good news therefore that George Osborne has called for an increase to £7 by 2015, for surely decent rates are crucial to making work pay.

A ROUND UP OF MAGAZINES AND OTHER MEDIA

Campaign, the magazine of Dignity in Dying, issue 1 of 2014.

This issue includes the result of a poll in which a majority of disabled respondents supported the case for a right to assisted dying when terminally ill. In October 2013 a new arm of the organisation was launched as Disabled Activists for Dignity in Dying (DADiD). Co-ordinated by Greg Judge, it provides a voice for disabled people who support Lord Falconer's Assisted Dying Bill. The poll found that 79 per cent of people with disabilities supported the proposals contained in the bill. Judge is quoted as arguing: "This survey shows that it is time for disability rights campaigning groups to shift to a neutral stance on the issue of assisted dying, reflecting the different and varied views of disabled people rather than dismissing the opinion of the majority as irrelevant." [See also my 'We Hate' piece. Ann Darnbrough, herself disabled, was a formidable champion of disabled people's rights.]

CILIP Update, January 2014

A survey by Chartered Institute of Public Finance and Accountancy has found that in 2012/13 there were 74 fewer libraries than at the end of the previous year. This is on top of a loss of 201 in 2010/11. From 2008/9 there has been a 20 per cent drop in the number of full time library staff.

An article headed 'Opening doors to people living with dementia' describes how Cumbria Library Service is working with Dementia Care Matters to make its services more welcoming and inclusive. It builds on research which shows that participation in activities based on the interests and abilities of a person with dementia can significantly improve their well-being and quality of life.

The Guardian

1 January: A letter signed by the heads of ten NHS organisations calls for a new page to be turned as we move into 2014. It urges the need to reach a more measured view of how the NHS is performing, rebalancing the "extraordinary achievements that NHS staff deliver every day and the need for improvement highlighted by the Francis report."

2 January: According to the British Medical Journal, the launch of NHS111 is likely to cost millions of pounds. It has been "riddled with teething problems since its inception on 1 April last year".

Margaret Drabble argues that medicine is artificially prolonging old age, but politicians deny us the help we need to die in dignity. [see *We Hate*, no 73].

3 January: David Cameron revealed to again be at odds with the European Court of Human Rights in his opposition to its ruling that whole life sentences without any prospect of release or review amount to inhuman or degrading treatment. Conservative leaders appear to be even more committed to reviewing the UK's relationship with the court.

A poll of GPs conducted by Doctors.net.uk has raised the idea of charging a fee for visits to Accident and Emergency units in an attempt to reduce unnecessary and frivolous use of the service. The survey has prompted debate as to whether the NHS mantra of care free at the point of need is sustainable.

Polly Toynbee inveighs against "serf-labour" and the vulnerability of immigrants from Eastern Europe.

4 January: Dr Martin McShane, NHS England's Director for People with Long-term Conditions, says that in England the soaring number of people with chronic conditions such as diabetes and dementia is already taking up 70 per cent of the NHS budget and more than two thirds of the amount spent on social care. Such costs will become unsustainable without major changes in the way that care is provided.

The funding provided to local authorities by the DWP to respond to emergency needs in low-income families is to be withdrawn after 2014-15. Such provision, set up to replace the national Social Fund, will

pass to the Department for Communities and Local Government. It appears that crisis relief will then at the discretion of local councils from their general funds.

Paddy Ashdown, the former LibDem leader, has spoken of a frightening mood of Jacobinism in England. He wonders if a collapse of beliefs and the dissolution of institutions, will lead to people finding an appeal in simplistic answers.

Christina Patterson points up that a poll (first reported on 2 January) for the Prince's Trust [no less] has found that hundreds of thousands of young people feel they have nothing to live for. One in three of those who hadn't had jobs for more than six months had seriously thought about suicide. She notices the failure of successive governments to get young people into work (the Prince's Trust is doing better), drawing one clear conclusion: that you can't have the same person slashing your benefits as trying to get you a job.

7 January: Tributes to Simon Hoggart, who died 5 January, aged 67, after a 43-month struggle against pancreatic cancer.

Cabinet divided over George Osborne's plan to impose a further £12bn cut in the welfare budget.

Criminal barristers and solicitors have demonstrated in England and Wales against government plans to cut back legal aid.

8 January: On the basis of leaked documents, Shiv Malik reports that the Cabinet Office is at odds with the Department of Work and Pensions over the action necessary to overcome difficulties in overhauling the Universal Credit project. It is said that the Cabinet Office has "accelerated the pull out of its elite team of IT experts from the project" and that the "DWP is now urgently searching for new IT specialists to keep the complex software project on track".

10 January: It is reported that the Department of Work and Pensions has made a fundamental error in preparing legislation for the 'bedroom tax'; one which has affected working-age tenants in social housing who have occupied the same home since 1996. As a result, thousands of tenants (how many is as yet unclear) have been wrongly identified as liable to the charge. Some may have been faced with eviction. The DWP intends to close what a spokesperson has described as a "loophole". Chris Bryant, the shadow minister for welfare reform, referred to "the chaos and confusion within the Department of Work and Pensions under Iain Duncan Smith" and called for the scrapping of the tax. "If they don't, the next Labour government will," he said.

11 January: The possibility that under Universal Credit housing benefit will be paid to tenants rather than to landlords has prompted fears of a surge in rent defaults. It is reported that landlords are increasingly disinclined to continue to let properties to people on benefits, quickening apprehension of a new housing crisis.

Alastair Sloan and Patrick Butler tell of a woman who committed suicide last year, leaving a note that having to pay the bedroom tax had made her life impossible. It has now been found that she would have benefitted from the loophole reported on 10 January.

Sentences have now been handed down to four nursing home staff found guilty of tormenting and abusing elderly residents with dementia at a Lancashire home.

13 January: The National Obesity Forum has published a report, *State of the Nation's Waistline*, which wants an intensive campaign to combat obesity, with GPs being more frank with overweight patients. A previous prediction suggesting that half our population could be obese by 2050 may have been understated. Public Health England recently estimated that 60 per cent of men, 50 per cent of women and 25 per cent of children could be obese by that date.

15 January: Dawn Foster draws attention to the impact of the 'bedroom tax' with thousands of people taken to court for arrears of council tax.

16 January: An article by eye surgeon Robert MacLaren describes how a clinical trial of a gene therapy has given people with a rare, inherited, disorder called choroideremia, causing blindness in middle age, hope of regaining some vision.

Research by scientists at University College London published in the journal *Neurology* appears to show that heavy drinking, at least in men, leads to significant deterioration in memory and function over the long term.

Seumas Milne describes the government of David Cameron as one of “naked class interest...waging war on the poor while slashing taxes for banks, corporate giants and the richest people in Britain, [with cuts that] have hit the most deprived, the disabled and women, hardest.”

17 January: A Guardian poll found that 83 per cent of responding doctors agreed that “Jeremy Hunt [Secretary of State for Health] is seeking to undermine public trust in GPs”. 88 per cent rejected his claim that the contract between Labour and GPs in 2004 was a key contributor to greater overcrowding in hospitals.

In a fascinating article Daisy Buchanan says that, according to the Health and Social Care Information Centre, last year nearly 762,000 people were referred for anxiety or depression treatment. In the same year the charity Calm reported that “suicide was the greatest killer of young men in Britain”, and that isolation was one of the greatest factors in this. As Ms Buchanan points out “we live in anxious times”.

Polly Toynbee offers advice to the Labour Party. “With growth returning,” she argues, “only a frontal assault can turn people against the complacent and inept nastiness of Cameron and Osborne economics.”

21 January: The Trussell Trust has begun to issue special packs of food that can be prepared by simply adding boiling water, intended for people lacking an energy supply or unable to afford the cost of conventional cooking. For the most destitute clients a ‘cold box’ of groceries not needing heating or hot water has been created.

A study by the University of Bath Institute for Policy Research has found that the cost of funerals rose by 80 per cent between 2004 and 2013, and estimates that more than 100,000 of the poorest people will struggle to pay for a funeral this year.

22 January: New ONS figures indicate that an increasing number of young adults (20-34 year olds) are still living with their parents, up by 25 per cent since 1996 to 3.3 million. Unemployment and housing failure are seen as the primary cause by one commentator.

23 January: Good to read that the great British public is weary of foreign wars and involving itself in other country’s troubles.

Also interesting, after my piece on social networking, to find the mother of Tallulah Wilson demanding action to stop the “poison” of self-harm and suicide-promoting blogs spreading online. Sarah Wilson called on major online firms to do more to protect children from the most “insidious aspects of the internet”.

25 January: Figures for December 2013 released by NHS England show the highest number of delayed discharges since records began in 2010, increasing the extent of ‘bed blocking’. It is suggested that this was caused by an increase in emergency admissions and delay in setting up out-of-hospital social care.

28 January: In September last Judge Peter Murphy ruled that a Muslim woman standing trial should uncover her face while giving evidence [Briefing 62, October 2013]. The court has now been told that the defendant will not be giving evidence in her own defence.

Jackie Ashley explains why efforts to limit the impact of care costs is unravelling, and that as things stand “most of us will have to pay more money before we receive government help than appeared to be the case a year ago.”

29 January: It is reported that an analysis of ambulance activity in England shows that the number of people over the age of 90 taken to hospital by ambulance in 2012/13 rose by 81 per cent on the figures for 2009/10. Labour sources, who carried out the analysis, infer that this is a consequence of cuts in social care funding having led to older people not getting the support they need at home.

Patrick Butler comments on the “inconvenient truth” that data on the use of food banks is indicative of the impact of welfare cuts, and a particular challenge to the espoused principles of Iain Duncan Smith.

The Nursing and Midwifery Council comes under heavy fire in respect of delay in resolving fitness-to-practice cases, over 400 remaining outstanding after two years.

30 January: A particularly reproachful issue. The following are merely a few of its critical reports.

Government resentment of European interference was intensified by a statement from the Council of Europe in Strasbourg ruling that the level of UK pensions, jobseeker's allowance and incapacity benefit is "manifestly inadequate". Iain Duncan Smith, Secretary of State for Work and Pensions, described the finding as "lunacy".

Government schemes to help first-time buyers are said to have triggered a substantial rise in house prices. Nationwide says that the average house price is now 4.6 times average earnings.

Home Secretary, Theresa May, is reported to want to bring in powers to strip foreign-born terror suspects of British citizenship if judged to present a threat to national security, a move fiercely criticised by Liberty.

Nicholas Watt, chief political correspondent, reports an analysis of government funding to local authorities which finds that our poorest communities are bearing the brunt of cuts. Randeep Ramesh adds that thousands of the poorest households in England face council tax increases of £80 a year.

A roundtable team in association with Marks and Spencer considers whether retailers should be doing more to promote healthy eating and combat obesity.

Ally Fogg finds no evidence that internet pornography is behind a vast wave of teenage sexual violence and abuse, and regrets that the House of Lords has stymied progress on reforming sex and relationship education. He accepts, however, that "it would be foolish to imagine that it is not influencing sexual norms and expectations."

Even Barack Obama is looking old (page 22).

31 January: You are unlikely not to have noticed that publication of a review of the proposed HS2 network has been vetoed, even though the Information Commissioner has decided that it should be released. The government is said to argue that "releasing the report would undermine the decision-making process, as interviews were given by officials and employees with assurances of confidentiality." [I wonder if this would this have been so, had the report been enthusiastically in support of the project?]

The Health and Social Care Information Centre reports that in the year to October 2013 there was an eight per cent increase in the number of young people admitted to hospital because of eating disorders. According to the support charity Beat, some 1.6 million people in the UK suffer from eating disorders. Health Editor Sarah Boseley considers the causes.

In a dramatic development, the Muslim defendant mentioned on 28 January above has admitted a charge of witness intimidation, despite previous denial. This after the jury had failed to reach a verdict. [But presumably she will continue to wear the niqab when sentenced].

Liberty (e.mail, 9 January, condensed)

The Government has been trying to introduce a law to punish "annoying" behaviour, replacing Anti-Social Behaviour Orders (ASBOs) with new "Injunctions to Prevent Nuisance and Annoyance" (IPNAs) – with harsher penalties thrown in for good measure.

With the support of our members, Liberty has been working with various charities and NGOs to build a broad alliance against the proposals, providing written briefings to peers, and holding meetings with various politicians and civil servants to voice our concerns.

After months of campaigning, the proposals were met yesterday with a resounding defeat of 306 to 178 in the House of Lords. Scores of peers backed an amendment advocated by Liberty and proposed by Lord Dear to replace the overly-broad and subjective phrase "nuisance and annoyance" with the term "harassment, alarm or distress."

IPNAs could have a chilling effect on freedom of expression. The right to protest is a vital part of any democracy, and sometimes we have to cause a nuisance to make our voices heard.

But with such sweeping and subjective language, almost anyone could fall foul of these new injunctions: carol singers, noisy children, buskers, charity collectors, trick-or-treaters...Do we really want to live in a society where minor irritations incur legal punishments?

Hopefully when the Bill returns to the House of Commons next month the Government will have

accepted that its proposals were flawed. But rest assured that Liberty will be working hard to oppose any return to the proposals (causing nuisance and annoyance where necessary).

NB, January/February 2014

Editor Olufunmi Majekodunmi announces NB Live 2014, a conference providing an opportunity to:

- discuss key issues with government
- be updated on the latest and key clinical topics
- share best practice across a spectrum of issues
- cope with new challenges
- debate the future of the eye health and sight loss sector.

The venue is Friends House, opposite Euston Station. Tickets cost £40.

Book at rnib.org.uk/nbmagazine

WE HATE NO.73: THE HIPPOCRATIC OATH

“Such is the brilliance of contemporary medical science, at least in our privileged realm, that we can be kept breathing long past the point where our existence is anything save miserable - miserable for us, miserable for our loved ones, and miserable for those who have been appointed by either by the state or a private health plan to minister unto us.”

Will Self, ‘A Point of View: The biggest decision’, an essay on BBC website, 13 January 2014

Hate the Hippocratic Oath? Surely not! Doesn’t this historic oath remain, in its various forms, at the heart of medical ethics? In particular do we not want our doctors to use treatments for our benefit in accordance with their ability and judgment, and to keep us from harm and injustice? Not least to refuse, if asked, to administer a fatal drug; or to suggest any such course?

But wait a moment: will these principles always be for our benefit? Hippocrates, we do well to remember, practised medicine around 400BC. Things have changed since then, especially over recent years. Notably we generally live longer and increasingly can be kept alive by sophisticated medical interventions. And sometimes kept alive beyond purely natural limits and in a pitiful condition. If we believe in the sanctity of human life, do we wish to see it reduced to an empty shell? Besides, our capacity to prolong life is rapidly generating a pressure upon health and social care which may not be sustainable. It is one of the great challenges of our times; yet one that we have been reluctant to face, or even discuss.

Novelist Margaret Drabble, however, has recently squared up to the issue, albeit mostly in personal terms. In *The Guardian* of 2 January she comments: “When it’s time to go, let me go, with a whisky and a pill”. Not everyone will share her viewpoint, but the fact that anyone should hold such an opinion inevitably raises the question of whether we should have a choice as to the time and manner of our passing. A right to death as much as a right to life?

I am not into encouraging suicide. The will to live is ordinarily so strong that we are entitled to think that opting out will normally be a matter of disturbance of the balance of the mind: something that must be heavily discouraged. Most of us can and will tolerate extremes of pain and discomfort, yet still wish to cling on to life. Nor is this determination necessarily related to the quality of our lives. We may value life even if it appears no longer to have any purpose. **But there can also be circumstances in which some of us may rationally want to die.** Margaret Drabble argues the case persuasively. She notices that old age can be “artificially” prolonged and describes as “grotesque” the fact that politicians continue to deny us the help we need to die with dignity. We are kept alive, she reasons, because doctors are “forbidden to give us what we want or need, and ... are too frightened to question the law”. Around three quarters of the population are in favour of legislation to allow people who are terminally ill to be given the help they need to die, if that is what they choose. But “politicians won’t let us, the bishops won’t let us, the health professionals aren’t allowed to let us”. So, says Drabble, “we shuffle on, until it’s too late to make any decisions at all, and we become helpless pawns in the politics of deferral, and utterly dependent on the humiliating procedures that for all our rational life we so wished to avoid”.

Readers will be aware that my own wife has just died, overcome by dementia, hypertension and loss of mobility. Ann, however, was previously an enthusiastic member of Dignity in Dying, and was able to express her contemplation of death in her last book, *A Rebellious Disposition*, published in 2007. In a series of personal reflections she revealed that her greatest fear was that she would be too old to be active in the future and

also might lack any choice surrounding her dignity in dying. In a subsequent chapter she enlarged her view: “I think it’s odd that those of us who consider ourselves thoroughly independent human beings in how we plan and manage our lives should be denied any choice about the manner and time of our deaths...While I don’t think about my death a great deal, I would be relieved to know that when the inevitable is about to happen and the end is nigh I would have some say in exactly how and when my demise is arranged. I certainly wouldn’t appreciate such an important decision about my life being taken away from me, and while I would appreciate palliative care in many circumstances, I don’t see it as an acceptable alternative when death is obviously on the immediate horizon”.

In practice, Ann was denied any choice. She was bedbound for the last 12 weeks of her life, and though the nurses, carers and doctors did their best, she detested the realities of care. Yet, emphatically, she did not choose to die. It was merely fortuitous that nature took its course relatively quickly, before palliative care had time to kick in, and she passed on peacefully, in sleep and with dignity. But equally, although I miss her intensely, I have no doubt that she was thus spared months of pain and humiliation.

Will Self has contributed a powerful personal essay on the subject, of which the opening quote is merely a taster. But curiously, it has been the story line of the BBC’s soap ‘Coronation Street’ that has brought this question even more sharply into public consciousness. In an episode screened on 20 January, around ten million viewers saw the much-loved Hayley Cropper pre-empt her death from pancreatic cancer by taking her own life. The representation was widely commended as being brave and moving, and prompted a widespread debate in the media. Julie Hesmondhaigh, a long-standing member of the British Humanist Association, who played Cropper, not only expressed her support for her character’s decision, but called for a change in the law in the real world. In a poll run by the Daily Telegraph nearly 93 per cent of 2,000 respondents thought that the right to die issue had been well-handled. The Sun similarly found overwhelming support among its readers, and has thrown its considerable weight behind Lord Falconer’s Assisted Dying Bill.

So, while it may go too far to hate the Hippocratic Oath, the time has come to reflect on whether it entirely meets the dilemmas of modern health care.

Derek Kinrade