

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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CARE QUALITY COMMISSION (CQC)

In our October and December issues I referred, briefly, to some misgivings concerning this health watchdog. The last word was given to Richard Douglas from the Department of Health who said that the department's role in reviewing the Commission's work was a normal part of government business. Since then things have moved on apace. First came the closure of a public inquiry into the failings at Stafford hospital. Its remit had been to consider the role of the commissioning, supervising and regulatory bodies and systems in detecting and correcting deficiencies in service provision. One of these bodies, of course, was the CQC. A final report will not be published until early in 2012, but media coverage of the remarks of Tom Kark QC, counsel for the inquiry, has been such as to suggest that its findings will be highly critical and "may stain reputations and possibly even end some careers".

This was quickly followed by a report from the National Audit Office: impressive, balanced and fair. Amyas Morse, head of the NAO, points out that the CQC had been working against a backdrop of considerable upheaval and had experienced serious difficulties. And that action is now being taken to improve performance. Nevertheless, as the report makes clear, the Commission has not so far achieved value for money in its regulatory function.

The CQC replaced three predecessors and took on greater responsibilities. Its budget was less than the combined budgets of all three of the earlier organisations. The report does not say so, but this was to be expected. Economies would be a normal part of such a rationalisation, and in practice there were under spends in the last two financial years. It seems that the heart of the Commission's problems was rather inadequate staffing, combined with an initial hurdle of registering care providers. The latter task was given priority over review and inspection work, so that there was a significant shortfall against planned targets for compliance activity. In the extreme case, the number of inspections and compliance reviews fell to a low of 511 in the second quarter of 2010/11 from a peak of 4,288 in the first quarter of 2009/10.

This pattern of work "increased the risk that unsafe or poor quality care went undetected". Inevitably the NAO report focuses on the serious abuse uncovered at Winterbourne View, the winding up of Southern Cross, the Mid-Staffordshire NHS Foundation Trust public inquiry, the Commission's own report on dignity and nutrition in NHS hospitals and its investigation

into Barking, Havering and Redbridge NHS Trust. In summary, criticism is centred on:

- lack of guidance for inspectors on how to decide when to initiate a review
- concern that some inspectors lacked appropriate knowledge and understanding of risk
- a shortfall of inspectors and compliance managers (229 and 19 respectively)
- a failure in the Winterbourne View case to respond to whistleblowing and to take timely action to deal with poor quality care.

This, of course, is only a brief review of some features of the NAO report. It can be found in full at www.nao.org.uk/publications.

DIVIDED BRITAIN

Not to be missed is the annual report of the National Centre for Social Research (NatCen), which among many other things explores the pervasive effect of private education in elevating the perceived status of a ruling class and creating a divide in both society and government. Top positions in our parliament, civil service and judiciary, it is argued, are increasingly dominated by a “segregated elite” that neither shares nor understands the views of the vast majority of the populace, thus perpetuating a kind of “social apartheid”.

Go to www.natcen.ac.uk for *British Social Attitudes 28*.

OPPOSITION TO WELFARE REFORMS

The disability newspaper *All Together Now!* reports that Anne McGuire MP, co-chair of the All-Party Parliamentary Disability Group and new shadow Minister for Disabled People, has claimed that plans to introduce a ‘universal credit’ would halve support for disabled children, and scrap the severe disability premium paid currently paid with income support. She is quoted as saying: “We believe there can be reforms made to the system, but this is the wrong way to do it, and we will do all we can to stop these changes.”

DIVORCE

My piece on divorce attracted some interest and, surprisingly, no dissent. Peter Salter invokes the definition of a bachelor as “a man who never makes the same mistake once”, attributable I think to Wentworth Dillon, 4th Earl of Roscommon. Chris Bazeley sends a Robin Williams quote: “Ah, yes, divorce – from the Latin word meaning to rip out a man’s genitals through his wallet.” And Cathy Mason conjectures that one of the reasons for divorce is the burden of repaying the cost of the wedding.

AFTER CAPELLO

There is some feeling that England’s next football manager should be English. Should we not be more concerned that the post has carried so absurd a salary? Football, for many people, has replaced religion, but it really isn’t that important: it’s only a game. Yet the potential fortunes of the English team gives rise to interminable, tedious and fruitless speculation in the media, while the most devoted Euro 2012 fans are prepared to travel thousands of miles into deepest Ukraine, at huge expense, to follow the team. To my mind the obsession that England may again win trophies should be balanced against the reality that on current form it is most unlikely. The rational probability is rather at what stage England will exit the various competitions. Even in our club football success is largely built on the importation, at great cost, of foreign players.

SPOTY

Continuing the sporting theme there is also some consternation that the nominees for Sports Personality of the Year were exclusively male. But the contest is so appallingly boring that it might be better to hand out awards for outstanding achievement in matters such as use of the whip, number of red cards received in the season, time spent in the sin bin, abuse to referees, alleged racial/sexual taunts to fellow sportsmen, no-balls bowled to order, feigned injury and managerial reluctance to resign.

DEMENTIA ALERT

The Department of Health, supported by the Alzheimer’s Society, has launched a new campaign across England to raise awareness of the early signs and symptoms of dementia. The campaign targets the families and friends of people at risk of dementia, who are likely to be the first to see the warning signs and can encourage the

person concerned to see their GP.

At present fewer than 50 per cent of people with dementia are diagnosed at a sufficiently early stage. Yet, says the DH, early diagnosis can significantly improve quality of life and provide patients with better treatment. The campaign officially closed on 18 December, but its relevance is imperishable.

Comment: It is ironic that this campaign has been followed by a report of an audit by the Royal College of Psychiatrists, in collaboration with a number of key professional bodies, which found that hospitals in England and Wales are failing to provide adequate care for dementia patients, and that only one in 20 hospitals insisted on compulsory dementia training for staff. Full report at www.rcpsych.ac.uk.

FUEL POVERTY

The government's obligation to eliminate fuel poverty by 2016 seems unlikely to be fulfilled. It is reported that fuel poverty (defined as having to spend 10% or more of household income to achieve adequate warmth and light) now affects over 5 million (one in four) households, a statistic much influenced by staggering increases in the prices charged by energy suppliers.

DISABLED PEOPLE ARE GETTING A BAD PRESS

The University of Glasgow's Strathclyde Centre for Disability Research has reported a significant increase in the number of negative stories about disabled people in national newspapers. It finds that over the last six years the proportion of stories about disability benefit fraud has more than doubled. There has been a shift from a largely patronising portrayal of disabled people to one where the predominant focus has represented them as scroungers. The Daily Mirror increased its use of unpleasant or disparaging language from 4.3 per cent to 8.8 per cent of articles, but the greatest change was found in the Daily Mail, the Daily Express and the Sun. Professor Nick Watson, of the Strathclyde Centre, said: "Much of the coverage in the tabloid press is at best questionable and some of it is deeply offensive."

Gleaned from 'All Together Now!'

GOVERNMENT RETHINK ON WITHDRAWAL OF MOBILITY BENEFIT FOR CARE HOME RESIDENTS

Some good news at last. On 1 December the government announced that after extensive consultation it had decided not to scrap the mobility component of Disability Living Allowance paid to around 78,000 disabled people living in care homes. This latest U-turn follows vigorous campaigning by disability charities. Prominent among those seeking to protect the allowance was Lord (Colin) Low of Dalston, who conducted an independent review of the proposal.

LEGAL AID

Kenneth Clarke has announced a six-month postponement (from October 2012 to April 2013) in the implementation of divisive and savage cuts in legal aid and the abolition of the Legal Services Commission. A Ministry of Justice spokesman is quoted as saying: "The government is committed to providing a legal aid scheme which targets resources at people who need legal support the most, and on the most serious cases." By such criteria access to free health care would be available only to the most seriously ill. A sign of things to come?

DISABILITY RIGHTS UK

Following the merger of the National Centre for Independent Living, RADAR and the Disability Alliance, the three organisations will share a common address: 12 City Forum, 250 City Road, London EC1V 8AF.

SELF-INFLICTED ILLNESS

My mind goes back to my National Service when I was put on a charge for what were called 'self-inflicted wounds' (in my case, sunburn). The fact is that a high percentage of the NHS budget is spent on preventable conditions brought on by excessive or inappropriate consumption. The latest example (widely reported) is that of young people with serious liver disease, caused by irresponsible drinking. Alcoholic liver disease, once rare in young people, has increased to disturbing levels. The evidence is such that, if the government is serious about

cutting costs, urgent and decisive action is needed to curb alcohol misuse: a menace both to society and to those who imbibe.

A CHRISTIAN COUNTRY?

The prime minister has said that “Britain is a Christian country and we should not be afraid to say so”. And that a return to Christian values could counter the country’s moral collapse. He blamed a passive tolerance of immoral behaviour for the summer riots, the financial crash, the expenses scandal and Islamic extremism. These views were tempered, however, by accepting and respecting that many people do not have a religion, and that he is “incredibly proud” that Britain is home to many different faith communities who do so much to make our country stronger”. He explained that what he was saying was that “the bible” has helped to give Britain a set of values and morals which make our country what it is today.

Given that he was speaking to Church of England clergy gathered to mark the 400th anniversary of the King James’s Bible, a certain amount of hyperbole is perhaps understandable, But few people of intellect can now argue that the bible, literally and in its entirety, is a sound guide to moral behaviour or that Britain is a Christian country in the sense of having an overwhelming majority of genuine adherents.

The difficulty for confirmed atheists, such as myself, however, is a recognition that even if God is a myth and a delusion, the values of much of the New Testament, embedded in our law, culture and language, can be a powerful force for good.

ON THE BUSES

We have previously criticised the information bypass on our buses, based on our own experience in London. An ‘Insight’ article in the RNIB’s magazine *NB* (December 2011) is therefore welcome. It refers back to a research study commissioned by RNIB in 2006, but now supplemented by a new survey. Naturally, this focuses on the difficulties experienced by blind and partially sighted travellers, but its conclusion that bus operators need to make changes is of even wider relevance. Hugh Huddy’s article refers to EU proposals in 2010 for new regulations for bus and coach operators, to include an obligation on all member states to implement mandatory disability awareness training for all bus and coach drivers. RNIB joined forces with Sense, Guide Dogs and a range of other charities to lobby the Department of Transport and the EU to seek the introduction of this new regulation. Although it was accepted in March 2011 that the new law should come into force in the UK in 2013, an option to postpone disability awareness training for up to five years was conceded. However, there is now (until the beginning of March) an opportunity (“a golden opportunity”) to submit views to the Department of Transport on the urgent need for mandatory disability awareness training. Guidance on how to do so can be found at www.rnib.org.uk/campaign (or phone 020 7391 2123).

A CODE OF PRACTICE FOR COMMUNITY DISABILITY EQUIPMENT

We are talking here of what has previously been called assistive technology, and specifically about the supply of potentially unsafe or inappropriate equipment. It is an issue being addressed by Brian Donnelly MSc who has founded and directs the company Community Equipment Solutions Ltd. Donnelly argues that “under-regulation” in this sector results in thousands of injuries and even fatalities. He advocates national minimum standards, a concept already adopted by the Welsh Assembly and welcomed by a number of key organisations across the UK.

The response of the Department of Health has been disappointing. According to the Community Equipment website, DH, while in part acknowledging some of the issues raised, has said that it does not advocate a national approach to minimum standards and that all the issues raised are the responsibility of local areas.

Donnelly has nevertheless set up and currently chairs a UK-wide group of organisations and professional bodies with an interest in improving the provision and safety of community equipment. A Code of Practice for England was launched at the King’s Fund in November.

Go to www.communityequipment.org.uk for further information.

RESPECTING THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

This September, the European Network on Independent Living (ENIL) launched a proposal for a European Parliament resolution on the effect of cuts on community-based services for people with disabilities in the European Union. The resolution, already supported by the European disability and anti-poverty movement, asks member states to respect their obligations under the UN Convention on the Rights of Person with Disabilities. If adopted, it would send a clear message that human rights must not be compromised by the need to make savings.

From the NCIL magazine, Independently, December 2011.

Comment: The concept of independence worries me. I know full well that pro-active disabled people find the idea of dependence repugnant and are determined to move away from a patronising model in which only the non-disabled determine social policy on behalf of disabled people. But there is a sense in which everyone is dependent on others, and I would hate a divisive doctrine that only disabled people may have a say in decisions affecting their lives. Better that people of like mind should work together as allies.

CHILD POVERTY

In a *Guardian* interview (14 December), Alison Garnham, CEO of the Child Poverty Action Group, is quoted as saying that the coalition government is in danger of emulating Margaret Thatcher's record on poverty. "It has been said her governments did two things for poverty: they increased it, then they pretended it did not exist. The coalition must avoid a similar, devastating legacy...what we've seen is the poorest families taking the biggest hit. The poorest 10 per cent has been hit ten times harder than the richest. It is not defensible."

But the government, or at least the prime minister and the work and pensions secretary, take a different view. Having to admit that George Osborne's autumn statement will mean another 100 thousand being added to the total of those deemed to be in child poverty, they call into question the way that it currently measured: related to household incomes of 60 per cent or less of the national median. This measure, enshrined in the Child Poverty Act and introduced by the Labour government, has been described by Ian Duncan Smith as an "approximate and by no means perfect measure of family wellbeing." Simply comparing relative incomes", it is argued, "leads to perverse incentives and does little to promote better life chances." Thus it appears that the legal measure of child poverty will no longer be a central goal.

How convenient. More at www.endchildpoverty.org.uk.

WE HATE NO.49: THE HIV/AIDS MENACE

"Si no puedes ser castro, ser cautos" (If you cannot be chaste, be cautious)

Spanish proverb

Twenty three years ago Ann and I devoted a chapter of our *Sex Directory* to this sexually transmitted infection - then a novel subject. We explained that AIDS starts with infection by one of a number of closely related human immunodeficiency viruses (HIV). The virus attaches itself to, and damages, certain lymphocyte cells, whose normal function is to promote an immune response against infection, causing their depletion in the blood and thus reducing the person's ability to resist infection. The number of people in the UK then carrying the virus was estimated as between 30 and 50 thousand. Fewer than 1,000 of these cases had then progressed to full blown AIDS, but a steep increase was predicted. 371 of these patients had already died.

The danger of an explosive rise in the incidence of HIV infection was clearly recognised. The call was for 'safe sex' and STI clinics and organisations such as Terrence Higgins Trust provided a range of services, and the risks attracted huge publicity.

This information from 1988 provides something of a baseline to evaluate the present state of affairs. And notably we now have a current report from the Health Protection Agency. The first thing to say is that treatment has greatly improved. On the HPA website Dr Valerie Delpach, consultant epidemiologist and head of HIV surveillance at the HPA, is quoted as saying that those infected with HIV, if diagnosed promptly, can look

forward to experiencing similar life expectancy to an individual without the infection. She explains that thanks to the development of anti-retroviral treatments and universal access to world class health care through the NHS, HIV is now a manageable illness for the vast majority of people affected in this country. What gives rise to concern, however, is that a significant number of people are unaware of their HIV status and are diagnosed late, sometimes too late.

The number of people living with HIV in the UK reached an estimated 91,500 in 2010, with approximately a quarter of them unaware of their infection. One in five people who visited an STI clinic did not accept an HIV test, prompting the HPA to advocate that no one should leave such clinics without knowing their HIV status. Indeed, in areas with a high prevalence of HIV, the HPA suggests that there should be universal testing of all new GP registrants and of in-patients admitted to hospital. As things stand, over half of people diagnosed in 2010 had come forward for testing only after the point at which treatment of their infection should ideally have begun. Two thirds of those who died in 2010 had been diagnosed late.

The HPA's annual report on HIV recorded 6,660 people newly diagnosed in the year, and said that infections probably acquired in the UK almost doubled between 2001 and 2010; from 1,950 to 3,640 (the latter total exceeding the number of those whose infection was probably acquired abroad: 3,020). And this rise was mainly due to infections acquired among men who have sex with men. One in every 20 gay men is now infected with HIV nationally (one in 11 in London). The HPA predicts that by the end of 2011 more than 100,000 people in Britain will be living with the virus. Yet the subject is one that has somewhat faded into the background.

In part the increase in people carrying the HIV virus is due to the effectiveness of drug treatments in keeping people with HIV alive and well, but this comes with a huge cost tag. Far better to avoid infection, essentially by always using condoms or, if that is unacceptable, renouncing sex altogether. We could learn a lot from the pandas.

Saving Lives UK, a public health awareness campaign, which began as a local initiative in a Birmingham Foundation Trust, is working to educate people about HIV, and to encourage testing. Not only are those unaware that they are carrying the infection missing out on the effective treatment now available and are at greater risk of developing AIDS, but they may be passing the infection on to others.

The website, www.savinglivesuk.com, provides access to a wide range of information about HIV. The HPA report is at www.hpa.org.uk/Publications/InfectiousDiseases/HIVAndSTIs/

Derek Kinrade