

national information forum

Working for the inclusion of disabled and other disadvantaged people
by encouraging better information provision

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For members of the National Information Forum*

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ASSISTED VOLUNTARY EUTHANASIA

In News Briefing no.12 we expressed disappointment at the failure of Charles Falconer's amendment to the Coroners and Justice Bill to give immunity from prosecution to relatives travelling abroad with a family member in order to secure them an assisted and gentle death. Things have since moved on a little. The dam is not yet breached but there are small signs of change. In a response to an appeal brought by Debbie Purdie, who has multiple sclerosis, five law lords have ruled that the Director of Public Prosecutions should publish the "facts and circumstances which he will take into account in deciding, in such a case as Ms Purdy's, whether or not to consent to a prosecution". We understand that the DPP has already decided that such guidance will apply equally to assisting suicides abroad and in Britain.

In addition to this, according to the Daily Telegraph, David Winnick MP has pledged to introduce a Bill to allow terminally ill people to end their lives with the help of loved ones in this country, rather than having to travel to 'suicide clinics' overseas.

There seems little doubt that majority public opinion is in favour of such a measure. A poll carried out by the organisation Dignity in Dying found that some two thirds of respondents supported a change in the law. We believe, moreover, that this is the feeling of most 'grass roots' disabled people.

ALL TOGETHER NOW!

We featured this newspaper for disabled people in News Briefing no.10, but feel compelled to praise it again. Unlike some magazines for disabled people, it adopts a positive tone, encouraging readers to push boundaries. The latest issue had Ann purring with pleasure, exclaiming out loud on its stunning presentation.

For further details, please contact All Together Now! Ltd, The Bradbury Centre, Youens Was, Liverpool L14 2EP; tel: 0151 230 0307; fax: 0151 220 4446; e.mail: news@alltogethernow.org.uk; website: www.alltogethernow.org.uk.

THE CARE DEBATE

Young disabled people tend to rebel against the concept of "care", which can have a cloying sense and connotations of being "looked after", whereas on the whole what they need is sufficient support to allow them to get going. We would like to suggest that opposition to the term should not stop with the



young, but can be extended to many older people. Of course there will be some whose problems are so acute that they have high levels of dependency and need to be cared for. But perhaps the word needs to be avoided as far as possible. At the recent DWP Annual Forum I had a brief chat with a woman who told me that she lived in a “care home”. She told me that she was nevertheless involved in a number of organisations and went out to meetings at least three times a week. This behaviour, she said, astonished both staff and other residents. I sensed that it caused consternation. I asked her what she would do if she became physically unable to be out and about. “Oh,” she said, “I would want to be out of it”. Even more recently, I met FC, an artist aged 86, whose memories go back to the Italian offensive of World War II and who still paints enthusiastically and is able to exhibit and sell the product of his endeavour. He confessed that while he continued to feel the breath of the grim reaper on the back of his neck, he dedicated some of his spare time to visiting care homes to deliver the message to the residents that they should find ways to stay active. Just so, for the danger of “care” is to succumb to inertia. So instead of “care” should we not substitute “support” and look to a National Support Service?

Note: In News Briefing no.12 we drew attention to the important DH consultation on ‘Shaping the Future of Care Together’, a Green Paper on proposals to reform adult care and support in England. The DH has now published a special issue to reinforce the importance of the consultation and explain the proposals.

www.dh.gov.uk/en/publicationsandstatistics/Bulletins/Socialcarebulletin/Browsable/DH_103537 for more.

OUTSIDERS

On 22 August, we were honoured to be invited to the 30th anniversary celebrations of Outsiders, held in the palatial Landmark Hotel. We have been advocates for this unique organisation for people with physical and social disabilities – the creation of Dr Tuppy Owens - from the outset. Essentially it is a club where people are accepted, whatever their looks, shape, disability, fears or shyness. Its activities include lunches, workshops, newsletter and contacts by post, phone and e.mail, which provide opportunities to make new friends, have fun and find love. The anniversary bash demonstrated the very real bond of friendship between members. This does not, of course, always lead to romantic attachments, but the sense of coming from the outside to a congenial inside is palpable.

Contact: Outsiders, 4S Leroy House, 436 Essex Road, London N1 3QP; tel: 020 7354 8291; helpline: 0707 499 3527; e.mail: outsidersclub@gmail.com; website: www.outsiders.org.uk.

ORGANIC FOOD

The Food Standards Agency (FSA) has caused quite a stir. At the end of July it published an independent review carried out by the London School of Hygiene and Tropical Medicine, based on a systematic examination of relevant literature, which found that “there are no important differences in the nutrition content, or any additional health benefits, of organic food when compared with conventionally produced food.” The FSA pointed out that it is neither pro nor anti organic food, but supports consumer choice. It recognises that there are many other reasons why consumers choose organic food, such as animal welfare or environmental concerns.

Nevertheless, such was the media reaction to the review that Tim Smith, Chief Executive of the FSA, felt it necessary to emphasise its validity in an open letter, which pointed out that the important message from the report was not that people should avoid organic food but that they should eat a healthy balanced diet and, in terms of nutrition, it doesn’t matter if this is made up of organic or conventionally produced food.

www.food.gov.uk/news/newsarchive/2009/ju for more.

THE CHIROPRACTIC CASE

The well-publicised libel action by the British Chiropractic Association against science writer Simon Singh has focused attention on the remarkable criteria governing British libel law. As we understand it, whereas in the USA plaintiffs must show that the defendant's statement is wilfully false and defamatory, here it suffices to establish that the defendant's statement is damaging to the plaintiff's reputation. There is a strong body of opinion, stimulated by this case, that this standard is antagonistic to the expression of reasonable discussion and criticism, and that the law has no place in scientific disputes. The campaign 'Sense about Science' has placed a statement on the internet expressing the view that it is inappropriate to use the English libel laws to silence critical discussion of medical practice and scientific evidence, along with an invitation to sign up to the statement. An impressive list of scientists and writers has already signed.

The statement can be found at <http://tinyurl.com/olm9gg>

Of course, the BCA's action can be seen as counter-productive. It has sharply focused scrutiny of the credibility and origins of chiropractic techniques, concerning which – not being scientists – we express no view.

A TRADE IN TRANSPLANTS?

Earlier this year, press reports alleged that organs from NHS donors were being allocated to patients from outside the UK able to pay for transplant operations. The reports gave rise to considerable disquiet and caused the then Secretary of State, Alan Clark, to commission an independent review. This was led by Elisabeth Buggins, former chair of the Organ Donation Taskforce, who published her findings on 31 July.

Ms Buggins confirmed that private operations had indeed been carried out, for payment, predominantly at two London hospitals: Kings College in Camberwell and the Royal Free in Hampstead. Both are run by Foundation Trusts, somewhat outwith the direct control of the Secretary of State for Health. The majority of the private patients concerned were from two EU territories: Greece and Cyprus. As the report points out, NHS Trusts are entitled to carry out private medical treatment, while the treatment of people from overseas is not uncommon and may well be the subject of full charge. Moreover, under reciprocal European law, citizens from other EU countries have a legal right, under limited but defined circumstances, to come to the UK for transplantation with UK donated organs within the NHS and to be treated with equal priority with UK-based citizens.

Nevertheless, the transplantation of organs donated after death is seen as a special case. They are a scarce commodity for which demand in the UK exceeds supply. The overriding concern must be that confidence in the integrity of the organ donation system could be eroded, "potentially exacerbating an already critical shortage of organs." While Ms Buggins found no evidence of wrongdoing in the way organs had been allocated to patients, she saw it as vital "that the system is not subject to any perception of bias, preferment or queue jumping." She commented that: "Financial gain by either an institution or individuals inevitably creates that perception." Further, that part of the willing donation of organs by NHS patients and their families is an expectation that the donated organ "should stay within the NHS rather than being used to treat a private patient." The report recommended, therefore, that as far as organs obtained after death from NHS patients are concerned "there should be no private clinical transplantation whatsoever in the UK for either NHS entitled patients or for those not so entitled." Ms Buggins saw this recommendation as "vital to maintain the integrity of the transplant system and the confidence of the public."

The Department of Health has broadly accepted the recommendations of the report, and is taking

the following steps to help to ensure public confidence in the fairness and transparency of the organ allocation system:

- seek agreement from devolved health administrations to ban all private clinical practice in the UK involving solid organs donated after death within the NHS from 1 October 2009
- monitor referrals from overseas
- support the development of a new liver allocation scheme to build greater transparency into the allocation process
- develop DH guidance for transplant centres to clarify the eligibility criteria for people from abroad
- raise with relevant EU colleagues the need to build capacity or expertise in developing transplant programmes in member states or the building of reciprocal agreements between neighbouring countries.

Kings College Hospital has welcomed the report as clarifying a difficult area.

The full report is at www.dh.gov.uk/en/News/Recentstories/DH_1

STRESSED BY THE RECESSION?

The NHS has launched a new helpline for people suffering from distress, depression or anxiety in the present economic downturn. It is staffed by health advisers who can assess callers and give them the resources they need to overcome their difficulties, which may include referral to other sources of help. **Contact 0300 123 2000 (M/F, 9am – 6.30pm; calls from landlines should be charged at the standard rate, but the cost from mobiles may vary).**

A HIGH PAY COMMISSION?

In News Briefing no.8 (February 2009) we ‘hated’ ‘Excessive Executive Expectations’. Two years earlier, in her memoir ‘A Rebellious Disposition’, Ann focused on the subject in a chapter headed ‘Money, money, more money. The deadly affluenza virus.’ It has taken some time, and we claim no credit, but at last there are loud calls for government intervention. The pressure group Compass wants excessive pay to be monitored and the Low Pay Commission to be matched by a similar High Pay Commission to curb greedy settlements. Influential MP Vince Cable has added his voice in *The Guardian* (17 August), pointing out that “the government is indirectly responsible for funding often outrageous quango pay”. And he thinks that “we should not be afraid to say adieu to investment bankers who think multi-million-pound bonuses are insufficient”. We would want to say ‘good riddance’, and not just to voracious bankers.

RESEARCH INTO TESTS TO DETECT FOETAL ABNORMALITIES

This is a controversial subject, but what is beyond doubt is that current invasive tests, such as amniocentesis, carry a risk that miscarriage could result. NHS-funded research, led by Dr Lyn Chitty, is now studying the viability of a number of approaches to non-invasive prenatal diagnosis (NIPD). *The Guardian* at www.guardian.co.uk (search for NIPD) and BBC News at <http://news.bbc.co.uk/1/hi/health/6320273.stm> carry articles. The latter quotes Dr Chitty as saying: “Most people think one of these technologies will eventually be refined enough to be useful in clinical practice.”

MENTAL CAPACITY

The Social Care Institute for Excellence has recently published a summary of the Mental Capacity Act. The Act, as they say, concerns the care, treatment and support of people aged 16 and over living in England and Wales who are unable to make all or some decisions for themselves. **To obtain a copy see the SCIE website at www.scie.org.uk**

EQUALITIES CONSULTATION

The Government Equalities Office has launched a consultation on policy proposals for specific duties under the Equality Bill. It is seeking input to embody the duties need to secure “a cohesive society in which the rights of individuals are protected and all can reach their potential”. A proforma for response is included and the consultation is open until 30 September. **Go to www.equalities.gov.uk**

RANDOM THOUGHTS ON DISCRIMINATION

Here in Peckham a new bar/restaurant has opened on the open top deck of the town centre’s multi-storey car park. It offers stunning views of the City, Campari cocktails, and an art gallery. It is attracting people – particularly young people – from far and wide. It is reached by a lift to the sixth floor, from which patrons must toil, if they can, by ramps to level 10. When the lift is working, it is accessible to disabled or older people at a push, but the less than ideal arrangements turned my thoughts (only thinking, not pontificating) to the realities of discrimination. For the fact is that if the venue was required to be perfectly accessible, it simply would not exist. The majority would be denied pleasure to avoid discrimination against a minority. Is there a case, then, to accept that in some circumstances our limitations may exclude us from certain places and activities? Particularly in relation to employment, where ability to do the job remains the employer’s primary concern; and where in practice discrimination usually has its natural meaning of choice. For myself, I have already given up thoughts of becoming Wimbledon champion.

My mind then turned to gender politics. Harriet Harman has roused the wrath of misogynists by declaring that “men cannot be left to run things on their own”. In some quarters, testosterone levels in response to this pronouncement have led to emotional overload, sometimes known as Peculiar Masculine Tension. The reality for women, as in the Peckham car park, is that ability to overcome barriers and the desire to do so are the overriding issues. Yet the statistics are so remarkable as to suggest that unfair discrimination is also a factor. As David Prosser pointed out in *The Independent*, only 16% of FTSE100 companies have a female board member, a figure falling to just 4% in Britain’s top 2000 companies. Perhaps Ms. Harman, who is MP for Peckham, would like to comment.

CAMPAIGNING FOR CHANGE

The Spinal Injuries Association (SIA) is inviting any of its members to join its Campaigning for Change Advisory Panel. The panel is responsible for responding to consultations from Government and other organisations. One of the concerns currently exercising the SIA (and anyone else with a sense of fair play) is the Government’s refusal to extend winter fuel payments to spinal cord injured (SCI) and other disabled people under the age of 60. It points out that payments are made to anyone at or over this age, regardless of their means. In 2006/07, payments of just under £8 million were even made to British pensioners living abroad, including £4 million to people living in Spain.

In April, SIA and Spinal Injuries Scotland met the Minister for Disabled People, Jonathan Shaw, to discuss this issue. Evidence points to this being a very important concern, and that disability benefits, such as Disability Living Allowance, are insufficient to meet the extra heating costs faced by many disabled people. Regrettably, the Minister made it clear that the Government would not change its position, pointing only to the Warm Front scheme to make homes more fuel efficient. This is a disappointing, negative response (surely raising the question of whether the purpose of the post is now genuinely intended to be “for” disabled people). As SIA says, the Warm Front scheme is open to people on a wide range of benefits. It fails to address the fact that many disabled people face extra heating costs or the specific medical needs for extra heating that SCI people require.

Based on an article in the SIA magazine ‘Forward’, June 2009.

KEEPING YOUR CHARITY AFLOAT

NCVO has published a guide for voluntary and community organisations on surviving the recession. Go to www.ncvo-vol.org.uk:80/recessionresources/index.asp?id=13230

EXPLORING THE PEAK DISTRICT NATIONAL PARK

Axess Film, a registered charity (and Forum member) has launched a new DVD, 'Access Passport'. It features John Harris, a paralympian, trialling new adaptations and innovations that the rangers of the Peak National Park Authority have developed for the benefit of people with disabilities or limited mobility to encourage them to enjoy an area of outstanding natural beauty.

It shows in short film clips how John enjoys the many aspects of a visit to the park, and assesses the level of difficulty of some of its highlight spots, even trying out abseiling from a 90° viaduct into a river. He encounters wildlife and birds of prey, tries out different types of cycles, and sees interesting examples of our industrial heritage.

This project, and similar initiatives, offer a 'passport' to the great outdoors, giving information to increase confidence in planning holiday trips. The response has already been terrific, with many people contacting the Peak offices and tourist information points to ask about this new guide.

For more information, please contact: Axess Film, 71A & 71C High Street, Heathfield, East Sussex TN21 8HU; freephone: 0800 028 3766; e.mail: axessinfo@btconnect.com; website: www.axessfilm.com.

SUPPORT FOR ASYLUM SEEKERS

The Refugee Council has a website in 19 languages (including English) with information on the asylum process and asylum support. Go to <http://languages.refugeecouncil.org.uk>.

CONSULTATION ON RECKLESS LENDING

The Office of Fair Trading has initiated a consultation on draft guidance on practices it regards as irresponsible lending. Go to www.offt.gov.uk/news/press/2009/93-09.

NEWS FROM THE INFORMATION COMMISSIONER'S OFFICE

Trade in personal data jeopardised employment prospects

The Information Commissioner's Office (ICO) has served enforcement notices on 14 construction firms following breaches of the Data Protection Act. Some organisations paid thousands of pounds to obtain unfairly personal information about construction workers without their knowledge.

An ICO investigation found that Ian Kerr of Droitwich, on behalf of The Consulting Association, held details on 3,213 construction workers and traded their personal details for profit. On 16 July Kerr was fined £5,000 for breaching the Data Protection Act. In the case of the construction firms, failure to adhere to the terms of the notices could lead to prosecution.

Since the ICO investigation, the Department for Business, Innovation and Skills is seeking views on draft regulations to outlaw the blacklisting of trade unionists.

Personal Information Promise

In response to major data losses, the ICO is urging heads of organisations and government departments to sign up to a Personal Information Promise. This sets out a number of key commitments that senior figures will make on behalf of their organisation to protect the personal information with which they are entrusted. We could not spot HMRC among the current list of

signatories, but hope we are mistaken!

PRESCRIPTION CHARGES

The Prescription Charges Coalition has called on the Prime Minister to set a firm timetable to fulfil his promise to provide free prescriptions for all people with long-term conditions. **To sign a petition, go to: www.prescriptionpromise.org.**

ROUGH GUIDE TO ACCESSIBLE BRITAIN 2009

An updated, improved edition of this guide has been published. All the locations have been tested by disabled reviewers. The guide is free to Blue Badge holders (otherwise free). **Order on freephone 0800 953 7070 or through www.accessibleguide.co.uk**

SEXUAL HEALTH IN SOUTHWARK

In News Briefing no.9 we said that there is currently much concern about the incidence of teenage pregnancies in this country. We might have added that there are some areas that are worse than others. The London Borough of Southwark is one of these. But the unfortunate statistics have been met with a positive response. The Sexual Health Centre in Camberwell, which opened on 23 November 2007, has recently attracted national interest. It provides a walk-in service with easy access to sexual health services for men and women, open Monday to Friday until 7.30 pm. On arrival, touch screens allow clients to register and indicate the reason for their visit. Services include:

- information on sexual health
- a wide range of contraceptive methods
- emergency contraception
- pregnancy testing
- information and referral for abortion
- testing and treatment for sexually transmitted infections
- HIV testing
- sexual health examinations
- free condoms for men and women.

Appointments can also be arranged for people with more complex needs, normally on referral from a GP or the centre's own doctors. All services are confidential and aim to be friendly and reassuring.

For further information contact the centre at 100 Denmark Hill, London SE5 9RS; tel: 020 3299 5000.

THE WORLD'S OLDEST BIBLE ONLINE

The Codex Sinaiticus, the earliest surviving Christian bible, has been made available at www.codexsinaiticus.org. To mark the electronic launch, the British Library has mounted an exhibition, 'From Parchment to Pixel'. It runs until 7 September and tells the story of the 1,600-year-old manuscript and the technological feat of reuniting its 800 pages.

From 'London CILIP', issue 20, August 2009.

A NEW EDITION OF 'DISABILITY RIGHTS HANDBOOK'

Despite DWP's attempts to simplify the benefits system, the Disability Alliance argues that the Government's ongoing welfare reform programme further complicates an already complex system. The replacement of Incapacity Benefit with Employment and Support Allowance is just one example. The 34th edition of the handbook (April 2009 – April 2010) provides updated authoritative guidance through the maze. It costs £25 including p&p (discounts on 5 or more copies; £10 for people claiming benefits). An accessible version is available on CD, May 2009

(£29 – concessionary rate £11). **Orders (with remittance) to Sales, Disability Alliance, 88-94 Wentworth Street, London E1 7SA or order online at www.disabilityalliance.org.**

This information and the current recession made us reflect on the continuing importance of welfare benefits. Is it perhaps time to accept an expansion of provision, and to desist from the pursuit of hugely expensive, potentially futile, attempts to move people from welfare to work? Is it possible that the contraction of work opportunities is more or less permanent and that as a society we have to contemplate and budget for adequate state provision for increased numbers of those unfit for or otherwise unable to earn their own living? And to think about how this might be funded from taxation?

WE HATE NO.21: OBESITY

“More die in the United States of too much food than of too little.”

J.K.Galbraith ‘The Affluent Society’ (1958)

“Should the gloomier scenarios relating to obesity turn out to be true, the sight of amputees will become much more familiar in the streets of Britain. There will be many more blind people. There will be huge demand for kidney dialysis. The positive trends of recent decades in combating heart disease, partly the consequence of the decline in smoking, will be reversed. Indeed, this will be the first generation where children die before their parents as a consequence of childhood obesity.”

House of Commons Health Committee report (May 2004)

Galbraith’s comment must surely hold good for the United Kingdom. Obesity now presents one of the biggest challenges we face. The cost to the NHS alone – put at £4.2 billion - is increasing in line with expanding waist lines. It is already a common experience to sit on a double seat on a bus and find that the person next to you spills over on to your seat.

It is not just that obese people look incongruous. The fact is that their well-being is in jeopardy. At the very least the effects will be debilitating; they will have trouble with breathing, walking or running, and will experience pain in their knees and back. At worst, they are at a substantially increased risk of a range of diseases. Type 2 diabetes, heart disease and certain cancers are linked to excess body fat. It is estimated that obesity is responsible for 9,000 premature deaths in England each year, and life expectancy is reduced, on average, by nine years.

Of course, obesity is not new. When I was a child in Toxteth a neighbour was infamous because she had to turn sideways to get through her front door. But what has changed is the incidence of the condition. Obesity has grown by almost 400% in the last 25 years, so that instead of the odd person (such as young ‘Fatty’ Bowman) almost 25% of our population is now obese. The number of hospital admissions with a primary diagnosis of obesity was seven times higher in 2007/8 than in 1996/7. And the numbers are still rising.

The causes are fairly straightforward. While genetic factors can affect appetite and metabolic rate, obesity is overwhelmingly attributable to overeating, an irregular pattern of meals, bad diet, and lack of activity. The step change in the incidence of obesity can fairly and squarely be traced to over-indulgence, increased reliance on convenience foods (particularly those with high levels of saturated fats and sugar), motorised travel and more sedentary lifestyles.

So there is every reason to hate obesity and to hate one’s own obesity. It is quite simple to measure: by dividing your weight in kilograms by the square of your height in metres. If the answer – known as your Body Mass Index – is 30 or more, then you are obese.

This information sheet has been compiled by Ann Darnbrough and Derek Kinrade. The views expressed do not necessarily represent those of the National Information Forum. Earlier News Briefings are available on the Forum's website: www.nif.org.uk.