national information forum

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

News Briefing No. 16. December 2009

A Digest of Current Social Information

For members of the National Information Forum

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THE WORST TREATMENT DISASTER IN THE HISTORY OF THE NHS

Our patron, Lord Morris of Manchester, has introduced a Private Member's Bill to give legislative effect to all of Lord Archer of Sandwell's recommendations on the contaminated blood disaster (News Briefing no.9, March 2009).

The Bill, if enacted, will establish a committee to advise on haemophilia; make provision in relation to blood donations; establish a compensation scheme for those treated with and infected by contaminated blood or blood products, extending to their widows, dependants and carers; and establish a review of available support.

The Bill received its first reading on 19 November and the current expectation is that it will be debated at Second Reading on 11 December. This is a tenacious parliamentarian who never gives up. It will be very interesting at this sensitive time to see how the Bill is received.

EQUALITY DENIED: BY THE NHS!

The RNIB magazine NB reports (November) that the long-standing failure of NHS professionals to communicate with patients with sight loss in accessible formats continues, notwithstanding the present Government's commitment to equality. Legislation imposing a disability equality duty on UK public bodies has been enacted, but it appears that all kinds of healthcare information is still not provided in formats that people with sight loss can read.

New research commissioned by the RNIB was conducted in the second half of 2008. The study included interviews exploring the experiences of 600 blind and partially sighted people and 500 healthcare professionals. It found little change since the provision of accessible health information was last considered ten years ago. Nearly three-quarters of blind and partially sighted people reported being unable to read the personal health information provided by their GP. A similar proportion did not receive accessible information from their hospital, either as an outpatient or inpatient. The implication was that private information could be obtained only with the help of a third party. The same story was generally true of pharmacists. 80% (4 out of 5) of respondents said that they could not read the information provided about their prescriptions for themselves.

The study – by the research organisation Dr Foster Intelligence – found that health professionals also faced problems. Seven out of ten admitted either that their organisation did not have a clear policy on the provision of accessible information or, if it did, they didn't know about it. Similar numbers felt that there was a lack of appropriate training, and 60% said that they lacked the means to produce accessible information. NHS computer systems were said to be inadequate to log patients' communication needs or to produce information in accessible formats.

A more detailed report can be found on pages 20-24 of the November issue of NB, including the preferred formats identified by respondents. For a copy of the full report, please e.mail campaigns@rnib.org.uk, or phone 020 7391 2123, indicating the format you require. The RNIB's guide, See it Right, has all you need to know about making information accessible for people with sight problems. Phone 0303 123 999 to order; price £30 (£22.50 for charities),

TESTING TIMES FOR ESA

In News Briefing no.15 we mentioned that there has been some concern about the practical arrangements for medical testing for the new Employment Support Allowance. Now an article in *Society Guardian* (28 October) has fleshed out that sense of unease. Melissa Viney reports that critics of the tests – carried out by doctors and nurses supplied by ATOS Healthcare under contract to the DWP – believe that they are target-driven and penalise genuinely ill people. She asserts that the points-based work capability assessment (WCA) relates to physical and mental functions and fails to include questions relating to energy, stamina, illness and malaise. It focuses on things such as reaching, bending and continence, and is stricter than the former Incapacity Benefit test.

This analysis seems to be borne out by the statistics. Between October 2008 and February 2009 only 5% of ESA claimants scored enough points to be deemed unable to work and thus receive the top rate of £105.55 a week, while 36% were found fit for work and placed on Jobseeker's Allowance of £64.30. A further 11% were found eligible for the 'work-related activity group' of £89.80, subject to being helped through compulsory work-focused interviews. The remainder of ESA claimants either stopped claiming benefits before the assessment was completed or were still being assessed when the statistics were being compiled. According to this source, these figures compare with some 83% of Incapacity Benefit claimants found unfit for work under the previous medical test.

Ms Viney goes on to give voice to a chorus of disapproval to which the Government appears deaf. Indeed the DWP insists that the WCA is "a fairer medical assessment, looking at what people can do, not only what they can't." Mike Baker, chair of the Disability Benefits Consortium, dissents. He fears that the consequences will be dire and that most claimants will effectively drop out of society and end up at the feet of informal carers or local last-ditch charities.

New Deal and Pathways programmes are also experiencing difficulties. *Third Sector* (8 September) has reported that several large charities have already parted company with welfare-to-work programmes because they are proving not to be financially viable. Rising unemployment has made the task of helping people on incapacity and other benefits into work unsustainable. Just, we might say, as we predicted.

We fear that our Welfare State may be beginning to disintegrate.

SHOULD WE COMMIT TO THE COMPACT?

In the 6 October issue of *Third Sector*, our old friend Sir Bert Massie challenged charities and voluntary organisations - particularly the larger ones - to sign up to the Compact. But does the

fact that such an exhortation is necessary imply some misgivings in the sector? We wonder if commitment to the Compact implies an acceptance of Government policy and threatens our independence. Just asking.

Ed: Established in 1998, the Compact describes an agreement between Government and the voluntary and community sectors in England. It is said to recognise shared values, principles and commitments and sets out guidelines for how both parties should work together (www.thecompact.org.uk).

THE EFFECTS OF SMOKING DURING PREGNANCY

Research published on 3 November in the *Journal of Epidemiology and Community* has confirmed a link between the smoking patterns of pregnant mothers and behavioural problems in their young children. The heavier and more persistent the smoking the more pronounced the effect. The findings were based on a study of more than 13,000 three-year-old boys and girls carried out under the leadership of Professor Kate E. Pickett of the Department of Health Sciences, University of York.

The results varied by sex, smoking levels, and whether or not conduct or hyperactivity problems occurred together or separately.

Details at http://jech.bmj.com

ASSISTED DYING: A DAMASCUS ROAD EXPERIENCE

Dr. Raymond Tallis, Liverpool-born humanist, professor of gerontology, poet and playwright has changed his mind on the question of physician-assisted dying. Previously, as chair of the Ethical Issues Committee of the Royal College of Physicians, he was with those who opposed Lord Joffe's Bill. He now feels that he was in thrall to numerous incorrect assumptions, and that the case for such a Bill is clear; that unbearable suffering, prolonged by medical care and inflicted on a dying patient who wishes to die, is unequivocally a bad thing. And that respect for individual autonomy is a sovereign principle.

The full, important reasoning is available at www.timesonline.co.uk.

LIBRARIES CHANGE LIVES

In July, the 2009 CILIP Libraries Change Lives Award, and a cheque for £5,000, was won by Across the Board, a project providing autism support for families, run by Leeds Library and Information Service. Presenting the award, Sir Andrew Motion, the former Poet Laureate, made the point that libraries were not just about book-based things, but about a mixed economy and a variety of provision. He acknowledged, however, that half the population still don't use libraries and that local marketing of their services needed to improve. The awards attracted 26 entries.

Further details at: www.cilip.org.uk/aboutcilip/medalsandawards/LibrariesChangeLives/lclafinalist09.htm

HOW MUCH CRIME IS RECORDED WHERE YOU LIVE?

The website http://maps.police.uk has crime mapping for police forces in England and Wales. It provides information on recorded crime and antisocial behaviour in any given neighbourhood and allows a comparison with other neighbourhoods on various types of crime. It is also possible to

access details of the priorities of local neighbourhood policing teams.

DISABILITY DISCRIMINATION: THE CONCEPT OF REASONABLENESS

Our short piece in News Briefing no.14 (Random Thoughts on Discrimination) has provoked a further response, this time from the Government Equalities Office but provided by the Office for Disability Issues. It is interesting and, dare we say it, reasonable.

"With regard to your comments about the accessibility of venues, Part 3 of the Disability Discrimination Act (DDA) was introduced to improve disabled people's access to goods, services, facilities and premises but it has now been extended to provide rights for disabled people in access to larger private clubs and the functions of public authorities.

"As you will know, the DDA requires those with duties under Part 3 to make reasonable adjustments to assist disabled people in accessing their services – for example by installing a lift if the service is provided from an upper floor.

"The concept of reasonableness is a key principle of the DDA, which recognised the need to strike a balance between the rights of disabled people and the interests of the service provider. Thus, the DDA does not require service providers to provide universal access to every aspect of their service and requires them only to do what is reasonable given all the circumstances. It is certainly not the intention of the Act that any service provider should go out of business or close down if major physical operations to improve disability access to a building cannot be made. The DDA recognises that, in some instances, major structural changes may not be practicable or affordable. Nevertheless, service providers are still required to consider providing their service by a reasonable alternative means.

"Similarly, the employment provisions in Part 2 of the DDA recognise the need to strike a balance between the rights of disabled people and the interests of employers. Employers are required to do what is reasonable given all the circumstances.

"Ultimately, however, only a court, or a tribunal in employment cases, can decide what is reasonable given all the circumstances of a particular case.

"You may find it of interest to know that Building Regulations are also written to a standard of reasonability, whether in respect of a new build, extension, change of use or alteration. However, the extent to which the Regulations apply (and the way in which they are applied) varies in each of the different types of building work in order to support the underlying need to be reasonable in each particular circumstance. Requirement M1 of Part M of the Regulations, for instance, is to ensure that people are able to access and use facilities within a building. The guidance in the supporting approved document demonstrates only one way in which this can be achieved.

"In unusual circumstances, such as you described concerning the bar and restaurant on the top of a multi-storey car park, the Building Control Body would need to assess both what is reasonable and what is necessary to demonstrate compliance with the requirements of part M. They might, for instance, take the view that the car park is the approach to the building rather than the whole car park being considered a bar and restaurant. In such a case, ramped access might be deemed to comply with the regulations as this is acceptable in approaching most buildings in common circumstances.

"Whatever decision they reached in determining compliance, it is the responsibility of the Building

Control Body to make that judgement, but ultimate responsibility for compliance rests with the client undertaking the building work in question."

AGEISM

I (DCK) expected that my personal comment in News Briefing no.15, somewhat defending ageism in the NHS, might provoke a salvo of criticism. Not so. Only Dr. Richard Lansdown has weighed in to agree with me about the undesirability of trying to keep people alive for ever, but at the same time to argue that we have to have some arbitrary age at which we say goodbye to anyone in government employment, because there are some people who will go on well past their sell-by date. Some, he writes, would call this ageism.

I stand by my view. I think that in matters of treatment, life and death we can take equality too far, and in this opinion I call in aid Alan Bennett. In his *A Life Like Other People's* he recounts how his Aunt Kathleen wandered away from the mental hospital in which she was a patient, and died from exposure in a nearby wood. He opines that the death that she and others like her die is preferable to the alternative of "sitting vacantly in a chair year after year, fed by hand, soiling themselves, waiting without thought or feeling until the decay of the body catches up with the decay of the mind and they can cross the finishing line together." He also argues that a life "varies in social importance". We set most value on the life of a child. Had a child been missing, the police search would have been more intense than it was for his elderly Aunt Kathleen, who lay undiscovered for six days. There is a parallel here. I hope that some sense of reasonableness can be brought into the legislation on age equality.

This led me to consider what is going on in this political enthusiasm for older people. Before the 2005 General Election, a telephone poll conducted by ICM Research for Age Concern found that 83% of over-65s said they would definitely vote, compared to 39% 0f 18-24 year olds. This perhaps explains why the Government is locked into the constitutional status quo and unwilling to upset traditional practices, and why all of the major parties spend so much time pandering to the 'grey vote', instead of concentrating on the needs of young people and harnessing their energy. This time, the young should wake up to the fact that their political apathy could mean that they will come second in the hierarchy of priorities.

FUEL POVERTY

According to the official definition a household is said to be in fuel poverty if it needs to spend more than 10% of its income on fuel to maintain an adequate level of warmth (usually defined as 21 degrees for the main living area and 18 degrees for other occupied rooms). The latest figures (those for 2007), published by the Department of Energy and Climate Change on 21 October, show that by this measure there were around 4 million households in fuel poverty across the UK, up half a million from 2006, many of them vulnerable with elderly members, children or someone with a disability or long-term illness. For England alone the total was 2.8 million, a rise of 0.4 million. And this despite improvements in the energy efficiency of housing. The main cause, of course, has been the rise in fuel prices.

Projected fuel poverty figures for England in 2009 envisage a further rise to 4.6 million. Such a rate of increase would mean that 12.5 million English households would be in fuel poverty by 2020, perhaps a majority of the population. These are very serious figures, and the problem is compounded by the fact that, according to Joseph Rowntree analysis, it is our poorest families that are most affected by the recession (see www.jrf.org.uk/media-centre for details).

When it comes to greater equality the combating of poverty must surely be the highest priority.

Details at www.decc.gov.uk/en/content/cms/news/pn120.

SOME CHARITY HEADS ARE PAID MORE THAN THE PRIME MINISTER

In the context of inequality, this is serious stuff. In The Guardian of 9 November, the Unite union is reported as claiming that an "insidious" and "excessive" City pay culture is creeping into some British charities. Of course, we have previously complained that excessive pay is permeating many executive areas, not least the public sector. But we think it is particularly regrettable in our charities. In her onslaught on modern maladies, A Rebellious Disposition, written over two years ago and before the present recession, Ann Darnbrough noticed that charities were not exempt from the financial spiral:

> "The defence for monstrous pay is that it is necessary to attract the right calibre of people. But does this argument stand up? Does outstanding performance necessarily follow financial reward, and is a devotion to high living the best qualification for leadership? Whatever happened to the idea of achievement through dedication as the ultimate prize? Unbridled remuneration simply creates a hierarchy of status, divorcing the leaders from the led. Don't get me wrong. I know that absolute equality is an impossible dream, not really a dream worth dreaming, and that financial incentives are needed as a spur to achievement. What I am saying is that there needs to be an overriding sense of proportion, a climate of what is reasonable rather than a free-for-all based on supply and demand."

And in the charity world, as Ann pointed out, "it's very off-putting to potential donors – what's their fiver worth to a cause that has such a skewed understanding of values?"

FROM THE E.H.R.C.'S EQUALITY NEWS ISSUE NO.16

"The Equality and Human Rights Commission's Disability Committee has published its strategic priorities, setting out how it will use its powers and responsibilities to tackle some of the major issues faced by disabled people.

"The strategy is working towards the Committee's vision of creating a society where disabled people participate fully and contribute to society as equal citizens. The work plan tackles legislative developments, including how the equality bill will affect disabled people and how to put into practice the United Nations Convention on the Rights of People with Disabilities as well as dealing with other key issues for disabled people.

"In order to achieve these priorities, the Committee will initiate a series of projects, act as a source of expert advice for all of the Commission's work, and consider how to use the Commission's regulatory powers to get results."

For the full strategy, see: www.equalityhumanrights.com/uploaded_files/disability_committee_work_programme_2009_10.pdf

THE WORLD'S LARGEST BIOGRAPHICAL ARCHIVE

The World Biographical Information System (WBIS) is a subscription-based database that provides brief biographical information on more than six million people from the 8th century BC to the present day. It includes over eight million digital facsimile articles from biographical reference works.

See: http://db.saur.de/WBIS/login.jsf

NEW ACCESS TO RARE AND OUT-OF-PRINT BOOKS

Cambridge University Press (CUP) has launched the Cambridge Library Collection, a project devoted to reissuing books of enduring scholarly value. Print-on-demand (POD), which is revolutionising the publishing industry, along with state-of-the-art scanning, can provide access to works that have hitherto been available only in libraries.

As well as re-publishing titles from its own backlist, CUP is able to utilise its unique relationship with Cambridge University Library to extend provision to a vast range of other books that are out-of-print and out-of-copyright.

See: www.cambridge.org/clc

DECLINING CHARITY SECTOR

In a written answer to a question from Jenny Willott, MP for Cardiff Central, the Charity Commission said that between March and September 2009, the number of registered UK charities fell from 188,901 to 178,720, a net reduction of 10,181 (5.39%). The number removed from the register (for various reasons) was 14,281.

HISTORY REPEATS ITSELF

We cannot resist repeating an unidentified quote from Thomas Paine that we spotted in the TPS Summer Newsletter:

> "We are oppressed with a heavy national debt, the burden of taxes, and an expensive administration of government. We have also a very numerous poor; and we hold that the moral obligation of providing for old age, helpless infancy, and poverty, is far superior to that of supplying the invented wants of courtly extravagance, ambition and intrigue."

THE SCROOGE AWARDS CHRISTMAS 2009

Notoriously (but not notoriously enough), only a small proportion of the money from some high street store sales of so-called "charity" Christmas card packs is actually donated to charity. The Charities Advisory Trust reports that in its 8th annual survey the 2009 award went to Cards Galore, where out of 36 designs on show 35 yielded less than 10% to charity. The Georgy Porgy award was shared between Harrods and Fenwicks, where over half their cards gave less than 10% to charity. Other stores fared better, but a better option for those who want to help charities is to buy from one of the temporary Christmas card shops, where the donation rate is 40 to 60% of the purchase price.

See: www.charityadvisorytrust.org.uk, click on Scrooge Awards

KITH AND KIDS 40TH ANNIVERSARY WORKSHOP

The charity Kith and Kids is to hold an afternoon workshop to update professionals and family carers on aspects of community care policy and law, along with the latest Government thinking on personal budgets for people with a learning disability. The event will be held on Wednesday, 24 February 2010 at the Directory for Social Change, 24 Stephenson Way, London NW1 2DB between 2-6 pm. Speakers: Luke Clements, a leading legal authority on community care, and Dame Philippa

Russell, chair of the Standing Commission on Carers.

Professionals and staff: £55
Parents/carers, voluntary advocates and self-advocates: £20

For further details please contact Sandra Rosen, Kith and Kids on sandra@kithandkids.org.uk. To book, go to: www.kithandkids.org.uk/html/events_conferences.html.

WE HATE NO.24: THE SUPPRESSION OF INFORMATION

Back in 1961, US President John F. Kennedy, addressing the American Newspaper Publishers Association, said: *"The very word 'secrecy' is repugnant in a free and open society…We decided long ago that the dangers of excessive and unwarranted concealment of pertinent facts far outweighed the dangers which are cited to justify it."*

Traditionally, British governments have seen it differently. The passing of the Freedom of Information Act 2000 was hard won and even then its provisions were strewn with 'get-out' clauses. Before the Act came into force on 1 January 2005, Heather Brooke, an American journalist, had discovered how difficult it was to extract information in Britain. The tendency for those in authority to 'clam up' made her angry and led to her writing *Your Right to Know,* published in 2004 in anticipation of the new legislation. When the Act came in she began to make requests: one on MPs' expenses, then their travel and then their second-homes allowances. And so began a long fight to overcome stiff opposition. Eventually the Information Commissioner ruled that MPs' claims for allowances (though not the associated documentation) should be released. Even this was resisted. The Commons Speaker, Michael Martin, against legal advice, appealed to the High Court and lost. The rest of the story – how after further delay the facts were leaked to *The Daily Telegraph* and published day-by-day – is well-known. What is even more telling is that when the official version was finally released in June 2009, despite most of the embarrassing farrago being by then in the public domain, it appeared in so-called redacted form, heavily and visibly censored!

The Forum, of course, has a special interest in information. We believe that its free flow is a conduit to the public good, and that, conversely, impediments to openness are not conducive to the well-being of society. There are still some people, however, who wish that the expenses scandal could have been avoided; that it has eroded the authority and standing of our Parliament. We have heard it said that parliamentarians who took advantage of the lax rules on expenses are no worse than the sins of society at large, such as petty smuggling, avoiding value added tax by making payment in cash, and similar dishonesty. But by that reckoning, surely any malpractice could be justified. We think that the public outrage over the greed of some parliamentarians has been cathartic. We see no reason to deny freedom of information other than on grounds of a genuine threat to national security; not just to spare the embarrassment of those in authority. Our leaders have taken the line, at least publically, of arguing for greater transparency and democracy, but there is still a disposition towards secrecy. This is epitomised in David Miliband's refusal to release evidence of the CIA's treatment of Binyam Mohamed to the High Court on the questionable ground that it would damage Britain's relationship with the USA. This dispute has brought the executive into direct conflict with our judiciary.

Alas, another, and wider, move to suppress information is on the horizon. This concerns the monarchy. From the outset it has been held that since the royal household is not regarded as a public authority it falls outside the provision of the Freedom of Information Act to supply information on request. Although certain bodies can be included within the scope of the Act if it appears to the Secretary of State "to exercise functions of a public nature", the royals have never been so

designated (an exclusion that may be thought remarkable given the wide range of public duties carried out by the monarchy at huge public expense). The website of the British Monarchy claims that it is nevertheless committed to transparency, and to making information available "where appropriate". But the effect of this, surely, is to release or not release information only as the guardians of the monarchy see fit.

Notwithstanding the general exemption, there remains the question of the status of correspondence with the royal household held by public authorities and therefore potentially within the scope of the Act. This, along with information that relates to the conferring of honours or dignities, is the subject of a special exemption under Section 37(1) of the Act. Moreover, an obligation under Section 1(1)(a) - to confirm or deny that the requested information is held by the authority - does not arise if the information is exempt or would be if it existed. At present, these are 'qualified' exemptions, that is to say they are subject to a public interest test, so that they apply only if the public interest in maintaining the exemption outweighs the public interest in disclosing the information. Under Section 201 there is also a provision that has the effect of 'disapplying' the exemption after 30 years, when the information is regarded as having become an historical record.

Ministry of Justice guidance on the exemptions has been that it is a fundamental constitutional principle that communications between the Queen and her Ministers and other public bodies are essentially confidential in nature and that there is therefore a fundamental public interest in withholding information relating to such communications. It is said that the sovereign has the right and the duty to counsel, encourage and warn her government and is thus entitled to have her opinions on government policy and to express them to her ministers. The guidance goes on to say that she is, however, constitutionally bound to accept and act on the advice of her ministers. Any communications which have preceded the giving of that advice remain confidential because of the need to maintain the political neutrality of the Queen in public affairs (its reality and appearance).

We have a problem with this guidance. Leaving to one side the fact that we have no codified constitution, we find it difficult to accept this curious interpretation of constitutional principle. It seems a perverse logic to argue that the political neutrality of the sovereign should be upheld by concealing the communication of her views to ministers; this implies that while we pretend to have to all appearances a politically impartial sovereign, she can in reality exercise political influence, but covertly, behind the scenes. Far from providing trust in the political neutrality of the sovereign, exercising purely ceremonial functions, this secrecy leaves hidden the extent and direction of the sovereign's power.

But now there is a new, even greater, bone of contention, for it has been announced that the Act is to be amended. The 30-year-rule will be reduced to 20 years, except that if the member of the royal family relevant to the correspondence is after this period still alive the exemption will continue to apply until five years after his/her death. **Here the overriding sting is that during the 20-year period the exemption will become 'absolute', so as not to be open to the public interest test and to preclude release altogether. In the event of an extension beyond the lifetime of the royal family member, the exemption will then continue to be 'absolute' in the case of the sovereign or heir to the throne, but 'qualified' for other members of the royal family.**

The reasoning behind this move is that the present safeguards within the Freedom of Information Act are "insufficiently robust to protect our current constitutional arrangements". The amendments are said to be designed "to ensure that our information access arrangements allow essential constitutional relationships and conventions to be preserved". We consider, on the contrary, that whereas Parliament is seeking to be more open, this change profoundly reinforces an essentially defensive position, retreating back to greater secrecy and away from transparency and freedom.

Whatever one's view of the merits of the monarchy, we suggest that the idea that it should be protected by a blanket ban on freedom of information profoundly undemocratic. Recent experience shows that there is a public interest in knowing exactly how taxpayers' money is being spent, and that open accountability and checks are as desirable in relation to the monarchy as they are in respect of the workings of Parliament. Moreover, it is surely in the best interests of the monarchy that it should be seen to have nothing to hide.

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.