

national information forum

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
For members of the National Information Forum*

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ASSISTED VOLUNTARY EUTHANASIA

We are disappointed at the failure of Charles Falconer's amendment to the Coroners and Justice Bill which would have given immunity from prosecution to relatives travelling abroad with a family member in order to secure them an assisted and gentle death. We understand that Jane Campbell's speech against the change was decisive in the vote.

50-year-old Jane, by any standard, is an exceptional person, living with spinal muscular atrophy, needing a ventilator to help her to breathe. In circumstances that might trigger a negative response in many other people, Jane exudes a positive zest for life and a passionate commitment to realise the rightful place of disabled people in society. She is, of course, to be admired for such optimism, such tenacity, such single-minded sense of purpose. Nevertheless, we disagree with her on two counts: firstly over what we perceive to be a mistaken tendency to view attempts to legalise assisted suicide for terminally ill people as a conspiracy directed towards disabled people; secondly, that her position effectively denies personal choice: a freedom that we are sure she passionately supports in other contexts. While she may choose to struggle to the natural end of life, others may not. As in the case of Edward Downes and his wife.

CARERS DIRECT

This is a practical information, advice and support service for carers operated by the NHS. It covers a guide to caring; financial and legal advice; guidance for young carers; work and study information; finding local support groups and services; advice on keeping healthy.

Freephone: 0808 802 0202 (calls from mobiles may be charged; lines are open 8am-9pm Monday-Friday and 11am-4pm at weekends and bank holidays).

Website: www.nhs.uk/carersdirect

ROBIN HOOD IN REVERSE

A new report by the think-tank Theos finds that the National Lottery is regressive. Whereas "lottery money is disproportionately garnered from lower socio-economic groups" it is then used for projects that "disproportionately benefit middle and higher income groups, effectively redistributing wealth from the poor to the rich". True, but are those who play the Lottery motivated by a desire to help disadvantaged people?



More at www.theosthinktank.co.uk

THE STATE OF SOCIAL CARE IN ENGLAND

In a recently published report, the Commission for Social Care Inspection (CSCI) has found that fewer than half of carers are given any support after being assessed by social services. Moreover, the report cited evidence that only 17% of new carers are actually even assessed. Carers often tell us that trying to access information and support can prove extremely frustrating. As one carer explained, "Sometimes I have been made to feel that my son's needs are either not severe enough, or too severe, or a burden on services. It seems that unless a family is at crisis point then help is not available." CSCI have advised that improvements are needed in one-third of councils to ensure that families are properly supported, The whole report can be read at www.csci.org.uk/about_us/publications/state_of_social_care_08.aspx.

From 'New Directions' (Crossroads Caring for Carers, Summer 2009)

THE ELDERS

Nelson Mandela has brought together and endorsed an independent group of eminent global leaders, who "offer their collective influence and experience to support peace building, help address major causes of human suffering and promote the shared interests of humanity".

A particular initiative is a demand for the realisation of equal rights for women and girls, which focuses on religious and traditional practices used to justify, condone and entrench discrimination. The Elders regard it as unacceptable to justify such discrimination as if it were prescribed by a higher authority. They believe that women and girls share equal rights with men and boys in all aspects of life and that those rights should be promoted and protected by all leaders, particularly religious and traditional leaders. They are totally committed to bringing about equality and empowerment of all women and girls.

The Elders have been founded and supported by Richard Branson and Peter Gabriel, and backed by many other distinguished people. The Elders themselves are Kofi Annan, Ela Bhatt, Lakhdar Brahimi, Gro Brundtland, Fernando H. Cardoso, Jimmy Carter, Graça Machel, Mary Robinson, Desmond Tutu, Muhammed Yunus. In addition, Nelson Mandela and Aung San Suu Kyui are honorary elders. Further details at www.theelders.org. Postal address: The Elders Foundation, PO Box 60837, London W6 6GS. E.mail via the website.

Thanks to Maurice Glassman for bringing this initiative to notice.

ACCESSIBLE INFORMATION AND COMMUNICATION

Museums, Archives and Libraries Wales (CyMAL) has produced its first *Equality Bulletin*, concentrating largely on accessible communication. Aimed primarily at libraries, the guidance will nevertheless be valuable for anyone providing information to people with access difficulties. It covers plain English, 'easy read' and RNIB guidelines, website and PDF accessibility, power-point presentations and communication between deaf and hearing people. There are links to more detailed guidance. **See:** <http://wales.gov.uk/docs/drah/publications/090612equalitybulletin1english.pdf>

PARTICIPLE

If you have not come across it already, you will find much food for thought on the website of the not-for-profit organisation Participle (www.participle.net). While recognising the towering achievement of Beveridge in addressing the social issues of his day, Participle advocates a new

perspective that takes account of the massive changes in British society, demographics, lifestyles and available resources. They have come up with a vision which instead of simply relying on a one-way relationship with the state that encourages people to focus passively on their needs rather than their abilities, looks to motivate deep participation and encourage social connections and contributions.

An example of Participle's work can be seen in our own borough of Southwark in a public-private partnership with the council, Sky and the DWP. Working with elderly people, Participle has developed a new service that harnesses the skills and resources of a 'circle' of older people: forging social connections, exploring new directions in life, and getting them to help one another by matching those who want assistance with small household tasks with those who, for a modest fee, want to provide it. Open to all, regardless of levels of need or income, Southwark Circle provides a model of how future services might look across Britain.

Contact: Studio 2, Swan Court, 9 Tanner Street, London SE1 3LE; tel: 020 7089 6950; e.mail: hello@participle.net.

TERMINOLOGICAL EXACTITUDE

We notice that Andy Gregg of the London Advice Services Alliance has real problems with the term 'ethnic minority', which he contends makes it sound as though the majority is not to be defined by its ethnicity when, in fact, the White majority is as ethnic as anybody else! He points out that we are all ethnic. That is why people have been so concerned to use the term 'minority ethnic' rather than the other way round.

QUANGO CONCERN

We read that there is a "sense of crisis" at the Equality and Human Rights Commission (EHRC). Jane Campbell and Bert Massie have become the fourth and fifth senior figures to quit the organisation this year and it has been announced that the number of commissioners will be reduced from 16 to 11. Harriet Harman MP has argued that a smaller commission with a sharper focus would "help the commission refocus its work", implying that at present its work is out of focus. We said in News Briefing no.11 that the effect of merging the equality provisions on disability, race and gender has made for neater legislation, but that the overall effect, perhaps, is to attenuate the distinctive characteristics and impact of the separate equality issues.

It is reported that the dissent among the commissioners has been prompted by Trevor Phillips' autocratic management style. We wouldn't know. Divisions may arise simply from differing perceptions of the way forward. What is for sure is that the EHRC is exceedingly expensive, with an annual budget of £70 million. At the time of writing, the National Audit Office has declined to fully sign off the accounts, critical of the payment of consultancy fees to former employees after they had left the EHCR with generous redundancy payments. We taxpayers are entitled to ask what we are getting for our money. How cost effective is the organisation? How does it compare to leading third sector campaigners? For example, Liberty, whose summer newsletter reveals a vital, focused, relevant agenda addressed by a committed staff. And, we guess, at a fraction of the cost of the EHRC.

SEEKING TRUTH

Have you ever felt, when watching the BBC's Question Time, that government ministers and their shadows appear to trot out the party line rather than their own opinions? That frequently their answers, if not wholly insincere, lack a ring of conviction. And that the studio audiences are not fooled. It seems to us yet one more example of bad politics. We now read (*Guardian*, 18 July) that James Purnell, who has resigned as work and pensions secretary (responsible for welfare reform)

and who will shortly join the ‘thinktank’ Demos, had previously been wrestling for some months with concerns about Labour policy, and considering leaving the government. He had come to believe that Gordon Brown’s continued leadership made “a Conservative victory more, not less likely”. A friend had advised him to be honest about what he thought. He is quoted as saying that British government can be a bit of conspiracy against ideas. Are we not also entitled to ask if it is also a conspiracy against honesty?

SHAPING THE FUTURE OF CARE TOGETHER

This Green Paper was published on 14 July. The first print run has already been exhausted but there is an electronic version on www.dh.gov.uk/en/publicationsandstatistics/. The consultation sets out the Government’s proposals for ways to reform the care and support system for adults in England. The aim is to build a National Care Service to run in parallel with the NHS, but not funded in the same way. The paper recognises that present arrangements for providing care and support can seem unfair; too many people face the prospect of having to use up their assets and sell their homes to pay for care and support.

The weaknesses in the present system are put under further strain by the growing pressures from greater life expectancy and changing demographics. By 2026, it is expected that an additional 1.7 million adults will need care and support. Radical reform is therefore vital. The Green Paper envisages a new system that is fair, simple and affordable for everyone, underpinned by national rights, but personalised to the needs of the individual. There is scope to respond up to 13 November, and 36 events will be held up and down the country to answer questions and garner views. The features of the proposals likely to attract the greatest interest are the suggested alternative funding options. These are clearly set out in the paper (though not with total certainty) but it may be helpful if we attempt to bring out the main possibilities.

To begin with it should be understood that most people entering residential care will have to pay for their accommodation costs, such as food and lodging – expenses that they would have to meet even if not in a care home. But the Government is proposing a deferred payment scheme, allowing both residential care and accommodation costs to be charged to a person’s estate after their death, rather than having to sell their homes.

There are three proposed funding options for care and support costs:

Partnership. This envisages a set proportion of basic costs – perhaps a quarter or a third – being met by the state; more for people who are not well off, up to 100 per cent for those unable to make any contribution. Individuals entitled to the basic level of state support would need to pay the remainder, estimated at around £20,000 to £22,500.

Insurance. This is similar to the partnership model, except that instead of paying a personal contribution, it would be possible to buy insurance to cover the cost.

Comprehensive. Here everyone over retirement age who has the resources to do so would pay into a state insurance scheme. Individual payments might total in the region of £17,000 to £20,000 – less for those already over 65 when the scheme is introduced.

Obviously, even having read the Green Paper, there will be a great many questions. This is difficult stuff to get one’s head around. One of the imponderables is what might happen if there is a change of government. Alexandra Norrish, Head of Social Care Strategy at the Department of Health, who ran a workshop at the DWP’s Annual Forum, nevertheless urges people to get involved, lest the whole thing be put back in the ‘too difficult’ tray.

SIX DOTS THAT CHANGE LIVES

In a feature article in *Library and Information Update* (Chartered Institute of Library & Information Professionals, June 2009) Helen Brazier, Head of the RNIB's National Library Service, reports on the RNIB's support for braille readers and why, despite technological advances, this medium is still needed and valued by many blind and partially sighted people. She tells us that 200 years after the birth of Louis Braille the system that he invented in 1825 is still used by around 18,000 people in the UK, around 5,000 of whom regularly read hardcopy braille. The RNIB is deeply committed to supporting these readers, providing the principal braille lending library service in the UK. RNIB is the largest publisher of braille in Europe, yet the sad fact is that less than two per cent of books published each year are ever transcribed into braille. The cost of transcription, writes Helen, amounts to a hefty £1,500 per title and the work can take several months to complete. She goes on to spell out how to help support braille readers, including:

making your reading groups inclusive

- check that your Disability Equality Scheme recognises the needs of blind and partially sighted people
- raise awareness with any publishers you know to emphasise that RNIB can make braille books much more quickly if they can get the digital files
- support braille readers to join specialist libraries such as the National Library Service, ClearVision and Torch Trust.

To find out more go to www.rnib.org.uk/reading or phone the RNIB helpline on 0303 123 9999.

TWO GREAT ORGANISATIONS FOR OLDER PEOPLE JOIN FORCES

The four national Age Concerns in the UK have joined together with Help the Aged to form new national charities dedicated to improving the lives of older people. At the time of writing, the previously distinct organisations retain their own websites.

INDUSTRIAL INJURIES

We have received the Annual Report 2008/9 of The Industrial Injuries Advisory Council. This must surely be one of the earliest advisory bodies, established under the National Insurance (Industrial Injuries) Act 1946, which came into effect on 5 July 1948, charged then as now with providing independent advice to the Secretary of State for Work and Pensions in Great Britain and the Department for Social Development in Northern Ireland on matters related to industrial injuries benefit and its administration. Year on year the Council has carried out its important staple task of deliberating on possible inclusion in a list of prescribed diseases. In the year under report, however, the Council has also considered with officials and ministers the Government's proposals for welfare reform. In December 2008, the Government announced its conclusion that there remains a strong case for continuing particular state support for people whose disability arises from work, and that the current framework in which the Industrial Injuries Disablement Scheme operates remains the most appropriate way to achieve such support.

In 2008/9 the Council recommended two additions to the prescribed list:

- Bronchiolitis Obliterans (associated with food flavouring agents, and
- Osteoarthritis of the knee in miners.

In the case of four other potential additions, two of which related to conditions possibly related to

asbestos exposure, insufficient evidence was found to recommend prescription.

The Council also considered, at the request of the Secretary of State, whether compensation through the Industrial Injuries Scheme was appropriate for people with pleural plaques (a thickening of the lining of the lung resulting from exposure to carcinogenic asbestos). This review covered:

- the current prevalence of pleural plaques
- the occupational causation of pleural plaques currently found in the population
- the likelihood of disability arising from pleural plaques
- the likelihood of disability arising from pleural plaques, and
- the likelihood of other more severe complications of asbestos exposure arising among those currently having plaques.

The Council, “against a tight deadline”, completed its consideration in September 2008, and submitted a response to the Secretary of State. The Annual Report does not reveal the Council’s findings, but we understand that it recommended against inclusion on the prescribed list.

Note: The House of Lords ruled in October 2007 that pleural plaques did not signify damage or injury sufficiently material to found a claim for damages in tort. Legislation was subsequently introduced in Scotland to ensure that this judgment does not have effect north of the border. In England and Wales, however, the Government has failed to make its position clear, temporizing on a decision which could result in a liability in the region of £50 million. On 21 July, Jack Straw, speaking in the House of Commons, said that the Government would give further consideration to the issue before publishing a final response “after the recess”.

PLAIN ENGLISH

The Plain English Campaign’s excellent magazine will no longer appear in print beyond issue 74, July 2009. It will, however, be available via a new website at www.global-shred.com. You are invited to log on to this site and send your e.mail address.

TOUCHBASE

The DWP magazine no.55, June 2009 summarises some welcome Budget announcements:

- additional funding for Jobcentre Plus and the Flexible New Deal. This will facilitate the guarantee of the offer of a job, work-focused training or meaningful activity to all young people aged 18 to 24 before they have reached the 12 month stage of their Jobseeker’s Allowance.
- A £1 billion Future Jobs Fund to which local authorities and other large organisations, such as social enterprises and voluntary sector bodies, can bid to create around 150,000 new jobs.
- An increase (from November 2009) in the capital threshold for Pension Credit (and for Housing Benefit and Council Tax Benefit for people who have reached the qualifying age for Pension Credit) from £6,000 to £10,000, aligning it with the threshold for those living in care homes.
- An extension of the increase in the Winter Fuel Payment. From winter 2009/10 the payment will be £250 for households with a person aged between 60 and 79 and £400 for households with a person aged 80 or over.
- An extra £260m over the next two years for Social Fund payments.
- Grandparents looking after children while their parents work will be credited with National Insurance contributions towards their State Pension.

A new disregard for permitted-work earnings of up to £92 a week (from April 2010 “at the earliest”) This will apply to Housing Benefit/Council Tax Benefit customers claiming contributory Employment and Support Allowance, Incapacity Benefit or Severe Disablement Allowance.

The magazine has many more positive messages. If you are not on the mailing list, you can contact

the Publicity Register using any of the following methods:

Online: www.dwp.gov.uk/advisers/publicity_register.asp

Letter: The Publicity Register, Freepost Plus RRUU-HSKS-ZEYT, LBM House, Atlantic Street, Altrincham WA14 5FY

E.mail: publicityregister@coi.gov.uk

WE HATE NO. 20: THE BURKA

“The problem of the burka is not a religious problem, it’s a problem of liberty and women’s dignity. It’s not a religious symbol, but a sign of subservience and debasement. I want to say solemnly, the burka is not welcome in France. In our country, we can’t accept women prisoners behind a screen, cut off from all social life, deprived of all identity. That’s not our idea of freedom.”

Nicolas Sarkozy, President of France, 22 June 2009.

British people, on the whole, have a deserved reputation for tolerance. We have welcomed a motley collection of people to our shores and have accepted, if not embraced, many cultural idiosyncrasies, recognising that we have numerous curious traditions of our own. There are, however, limits. We have frowned upon binding feet, female genital mutilation and forced marriage. Ann and I now wish to suggest that wearing the burka, if not of the same order of barbarity, is something that thinking Muslims should abandon.

President Sarkozy has really said it all, but let us take each of his points in turn:

Not a religious symbol

Here the Islamic authority must be the Qur’an. We are not scholars of that sacred text, but although we have tried we have been unable to find any stipulation we feel sufficient to justify the burka. We think that Surah XXIV/31 comes closest. Translations vary, but the thrust is that women should display only as much of their ornaments as is apparent and should draw their veils over their bosoms. We read it that display of femininity is to be reserved for family members and some others within their household, significantly including “children who know nothing of women’s nakedness”. The thought, surely, is that women should be modest outdoors and not parade their sexuality. We find it difficult to think that the Prophet or the revealing messenger had in mind the wearing of an all enveloping garment covering everything except the eyes. It is true that SURAH IV/34 says that men are in charge of women (because Allah made one sex to excel the other), and are instructed to admonish those who might be rebellious, and scourge them. But we beg leave to doubt if even those who accept such a position of authority have licence to impose unreasonable requirements.

A sign of subservience and debasement

It can certainly be argued that the Qur’an makes female inferiority and subservience explicit. The Muslim religion shows every sign of male domination, and we think that this is a great pity, not least for the males. When Ann visited Sudan some years ago she travelled by train overnight from Khartoum to Port Sudan with a male worker. They shared a carriage with four well-educated Sudanese men, robed and turbaned. In the waking hours they engaged in lively conversation and in the night all slept on bunks head to tail. It was a close and memorable journey, free from reserve. They treated Ann, who was dressed informally, in a relaxed and natural way. But when Ann disembarked at Port Sudan and made to shake hands with one of her travelling companions, he drew back. At the end of the platform, Ann was aghast to see four burka-clad wives emerging from a separate carriage.

It is often said that wearing a burka is reasonable if a free choice. But even where this is claimed, one has to question whether it is rather a conditioned choice, a response to input that it is the right

thing to do, a bizarre article of faith and symbol of allegiance. Or sometimes a deliberate profession of exclusion. We think that the garment – dubbed “a medieval style of tribal dress” by *The Week* - is so extreme as to be divisive, a statement of separation and a threat to community cohesion which puts women down. This is particularly sensitive in Britain, because female emancipation, such as we have achieved it, has been hard won. We have our own history of male supremacy, and brave women have fought over the years to seek equality, enshrined in law. The last thing we need is for anything that appears to put that progress in jeopardy. Women are no longer second-class citizens, and a tradition that suggests they need to be hidden offends cherished values.

We can't accept women prisoners behind a screen, cut off from all social life, deprived of all identity. That's not our idea of freedom.

When Alf Morris visited Saudi Arabia to give a keynote speech at a conference of disabled people, he was accompanied by his wife, Irene. Their flight was late getting into Riyadh. They were met by a member of the Saudi royal family and driven to the hotel where the conference was to be held, arriving barely three-quarters of an hour before its opening. Irene takes up the story:



Left to right: Derek Kinrade, Lord Alf Morris and Chris Hodgson, former chair of the Haemophilia Society.

“In the middle of our somewhat frenetic preparations, there was a knock on the door and a tall man in a sheikh's outfit – a thobe gown, ghuttera headscarf and rope – said that he had brought me a gift. I thanked him and he told me that his daughter would be with me in a minute or two to show me how to wear it. With time at such a premium I thought that was not my priority at the moment, but the girl soon arrived and unwrapped the parcel, revealing an abaya [burka]. She draped the garment around me, covering me from top to toe save for a see-through slit for my eyes. All the time I was thinking, uncharitably, ‘hurry up and go, it will be very rude of us to be late’. When she eventually left, I rolled up the dress, returned it to its box, put it in the wardrobe thinking it to have been offered as a memento of our visit, and got dressed in my own clothes: a mid-length black skirt and a black blouse which I thought would not cause offence.

“With very little time to spare, Alf and I went down the hotel's circular staircase to meet our host, Prince Salman bin Salman, a brother of the Crown Prince at the time... We found a line of sheikhs on one side and abaya-clad women on the other, standing as though on parade. When we got to the bottom of the staircase, they moved in. Alf was escorted away in one direction with the men, and I was shepherded off in another with the women. I was at a loss to understand what was going on, and I could see Alf looking towards me with considerable concern as he was led away. At the same time I sensed discomfort among the women I was left among, and it was explained that the ladies did not sit in the same place in the conference as the men. Then one of them said, “you're not wearing your abaya”. I told her that I didn't know I was supposed to wear it; that I thought it was a gift to take home as a souvenir.

“Remarkably – given that the conference was about rights, inclusion and integration – I soon discovered that while the proceedings went on in one hall with hundreds and hundreds of men, most of the females watched the proceedings on closed circuit television in another. Even then they didn't

know where to put me. I was placed on a dais at the back of the hall and a screen put round me. I asked if there was a problem, and if so what it was, explaining that I didn't want to sit there having travelled several thousand miles to hear Alf opening the conference. Reluctantly I was allowed to sit on the back row."

It would be difficult to imagine anything more un-British than this experience. Indeed, anything more degrading in any country. And difficult to reconcile 'covering up' with the religious view of humankind as having been divinely created. In Britain, no less than in France, women generally participate freely in intellectual discourse, social interaction and not least in sport, gloriously delighting in healthy, physical expression of their physique. The burka virtually precludes any such activity, setting its wearers apart as anonymous beings, alien to our most basic values and the principles of gender equality. Obscuring the face is particularly sad. It is the shop window of our personality, a means of expression and one of the most important ways in which we communicate with each other.

Ultimately this is not an issue of hatred; rather a plea that Muslim men should come, as soon as possible, to respect the status of women and encourage their rightful place not only in their own homes, but in our wider society. Women form around half of the population. Inhibition of normal participation in social and intellectual life, even if voluntary, is to lose a massive and distinctive contribution to the life of the nation.

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.