

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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THE CASE FOR CHANGE: WHY ENGLAND NEEDS A NEW CARE AND SUPPORT SYSTEM

In May the Government published *The Case for Change*, initiating a 'national debate' on reform of the care and support system. The opportunity to contribute will close in November, but will be followed by a Green Paper consultation in 2009. The debate centres on three questions:

- What more does the Government need to do to make the vision of independence, choice and control a reality?
- What should the balance of responsibility be between the family, the individual and the government?
- Should the system be the same for everybody or should the Government consider varying the ways it allocates government funding according to certain principles?

One of the organisations that has already responded is the National Centre for Independent Living (NCIL), whose views are thoughtfully presented in its September newsletter, *Independently*. It includes a letter from Ivan Lewis MP, the former Care Services Minister, in which he suggests that demographic change is just as big an issue in the UK as climate change. Already there are six million people looking after a relative or friend who needs to be supported for a decent quality of life. It is predicted that in 20 years time a quarter of our population will be over 65 and the number of those over 85 will have doubled. "The current system," he argues, "is simply not sustainable", and he flags up the opportunity to contribute to the debate at www.careandsupport.direct.gov.uk.

Connect, the impressive newsletter of LTCA (Long Term Conditions Alliance), which is unusual in exploring the political arena, devotes a centre-page spread of its Autumn issue to the review. Social care in the UK, it says, "is provided on the basis of a 'state-controlled' assessment of need, which is often less about what someone needs, and more about what is available to give them. Put simply, you can only get it if you really need it; and to get it, you really do have to need it. Unfortunately, for the vast majority of people... it is only available if they are willing to pay for it." The coverage incorporates the views of three of LTCA's members and takes a wide-ranging perspective, but is on common ground that for those who want to regain and retain their independence despite illness or injury the concern is about "how the individual can be supported to care for themselves, in settings that reflect what they want, as opposed to what the state would like to give them". Mark Platt, LTCA's Director of Policy and Public Affairs, finds, however, that "the



new political landscape for health (and social care) is now wider, and deeper. Nothing is off-limits, everything is open for debate, and everyone is being encouraged to participate.”

The full debate document is available online at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_084725. LTCA is at 202 Hatton Square, 16 Baldwin Gardens, London EC1N 7RJ; tel: 020 7813 3637; e.mail: info@ltca.org.uk. NCIL can be contacted on 020 7587 1663 or office@ncil.org.uk.

NATIONAL VOICES: USERS SHAPING HEALTH AND SOCIAL CARE

National Voices is a new umbrella organisation set up to bring together all national voluntary organisations representing users of health and social care, with the aim of giving them a stronger voice in policy development. It will campaign on behalf of patients, carers and service users from the conviction that they should be at the heart of policy development.

The new organisation held its first conference on 9 September, when over 130 organisations were represented. Its development has been supported by, and it shares its address with, LTCA (see previous article), which itself is an alliance of 100 national voluntary organisations but which recognises that it has hitherto represented only a portion of those who use health and care services.

Liz McSheehy, National Voices project manager, says that they look to “build on LTCA’s influence and achievements in the field of long-term conditions over the years, but also widening the scope to all voluntary organisations concerned with health and social care”. She believes that National Voices will “occupy a unique position in the health and social care voluntary sector” and will “work closely with, but be independent of government; and act as a critical friend to government and opposition alike.”

Membership rates vary according to the size of the member organisation, but encouragingly start from as little as £25 for those with an annual income under £50,000.

For further details phone 020 7813 3644 or e.mail info@nationalvoices.org.uk, or visit the website at www.nationalvoices.org.uk.

NAVEVO UNVEILS SAT-NAV FOR THE DISABLED DRIVING COMMUNITY

Navevo, a specialist GPS software developer, has announced the launch of BBNavevo, a sat-nav solution specifically designed to support disabled drivers and those caring for disabled people.

To assist Blue Badge holders in finding suitable parking locations and points of interest, Navevo has teamed up with Public Information Exchange (PIE), the UK’s leading publisher of disabled parking guides. BBNavevo covers 150 major cities and towns across the UK, including all the London boroughs. It includes all of the features found on a standard sat-nav, but has been enhanced to provide detailed information to support Blue Badge holders, including on-street disabled parking bays; disabled accessible car parks and local council Blue Badge concessions, as well as a wide range of points of interest to support people with disabilities. Standard features include NAVTEQ street level mapping covering UK and Republic of Ireland, 7 digit postcode routing and safety camera alerts.

Blue Badge car park and on-street parking database

BBNavevo’s database of Blue Badge car parks and on-street parking bays can save not only time but also take out the uncertainty when driving around and searching for a car parking space. Clear colour-coded and numbered icons are displayed on the mapping while driving, and it is easy to search for a car park/parking bay of choice and navigate directly to it.

To find the right type of car park for specific needs, most are graded from 1 to 3: Grade 1 being suitable for wheelchair users travelling independently; Grade 2 for wheelchair users travelling with assistance, and Grade 3 for wheelchair users or those with some degree of mobility, able to walk a limited distance. BBNav also provides information about any height restrictions above 2.2 meters, which can be extremely useful, for example if you are driving a converted vehicle.

BBNav also allows you to locate and navigate directly to over 10,000 on-street parking bays, including Blue Badge and red route bays. With clear icons on the map it's easy to identify the bays, as well as understand the waiting times or any restrictions.

In addition, BBNav's mapping is colour-coded to show local council rules applicable to Blue Badge holders, so users can easily identify whether they can park legally on yellow lines, pay and display or in residents' bays.

Note: Blue Badge data does not cover the Republic of Ireland.

Points of interest data in association with PIE

In addition to over 40,000 UK points of interest, BBNav offers a database of over 20,000 more, tailored specifically for people with disabilities. If visiting an unfamiliar town, BBNav will show where parking is permitted, where the public toilets with disabled facilities are and will even point out the nearest Shopmobility scheme. BBNav also provides details of accommodation with disabled facilities, as well as over 300 beaches with disabled accessibility.

BBNav's data displays the type of disabled access, with contact telephone numbers, making it easier than ever to plan a stress free trip. Anyone who fancies a detour, can do so with the knowledge that BBNav will be able to offer information to make the trip much easier.

"We have developed BBNav to make travelling far easier for the disabled driving community," says Nick Caesari, Navevo's CEO. "We have teamed up with PIE to ensure that we are delivering the most comprehensive solution available that uniquely addresses Blue Badge drivers' or their carers' specific needs."

Availability

BBNav will go on sale in October 2008 priced at £199.99 inc vat from www.bbnav.co.uk and selected retail stores.

For further information about BBNav, please visit www.bbnav.co.uk

YOUR RIGHTS TO FLY

Arthritis News (October/November 2008) reports that new regulations were introduced in July that give disabled and elderly air passengers with reduced mobility the right to be assisted when flying and using airports throughout much of Europe. New laws make airports responsible for providing wheelchairs and lifts in the airport and onto an aeroplane at no extra cost. Aeroplanes are now covered by anti-discrimination laws, which can also benefit people who have had an accident on holiday.

A new guide, *Your rights to fly*, published by the Equality and Human Rights Commission (EHRC) is a step-by-step guide for disabled and less mobile passengers. To order, download or view the guide visit www.equalityhumanrights.com/airtravel or call the national EHRC helplines (England: 0845 604 6610; Scotland: 0845 604 5510; Wales: 0845 604 8810).

PAYING FOR SOCIAL CARE

I attended the 50th anniversary conference of the Campaign for Nuclear Disarmament on 18 October (as an observer) and was surprised to see social care on the agenda. The explanation was simple. It seems that The Rt.Hon.Alan Johnson MP, Secretary of State for Health, had invited suggestions on how a shortfall of £6 billion on funding for essential non-medical care might be found. Unsurprisingly, a motion was passed unanimously at CND's conference to the effect that scrapping the Trident programme would meet the shortfall with money to spare. Maybe they have a point.

TURN2US

1 Derry Street, London W8 5HY; tel: 020 7396 6690; website: www.turn2us.org.uk

This new charity, founded by Elizabeth Finn Care, has been formed specifically to help people to find out about the charitable grants and state benefits to which they may be entitled. As well as obtaining information through the website, people can also be guided to apply directly to charities for financial help.

HEALTH AND SOCIAL CARE INFORMATION ACCREDITATION SCHEME UPDATE

The testing network for this scheme is now up and running. Forty information producers spanning the voluntary, commercial and public sectors are preparing to test the Standard, aid the development of the quality mark and take part in the production of case studies. These case studies will document the testing organisations' journeys to achieving certification and provide guidance to organisations that may be considering joining the scheme once it is launched next summer.

All 40 testing network organisations were present at a launch event in London on 4 September and were given the chance to meet the people behind the scheme development.

EMPLOYMENT RATES FOR ETHNIC MINORITIES

The Ethnic Minorities Employment Team of the Department of Work and Pensions has published an annual report updating statistics on how our ethnic minority population is performing in the labour market. The report runs to 38 detailed pages examining all facets of recent trends, but it is possible here only to bring out some of the highlights.

In summary, 2007 statistics showed 3.9 million working age ethnic minorities in Great Britain (GB), a figure that had grown by 80% in the last ten years and growing far more rapidly than the overall GB working age population. Ethnic minorities accounted for 14.8% of the working age population of GB and over two thirds were born outside the UK. Nearly 45% of them lived in London. The figures show the ethnic minority employment rate as 60.9% and the gap with the overall rate for GB as 14.1 percentage points.

Composition of the working age ethnic minority population

Indian:	20.1%
Black African:	12.6%
Black Caribbean:	10.3%
Black other:	1.0%
Mixed	7.4%
Pakistani:	13.9%
Bangladeshi:	4.7%
Chinese:	5.6%
Other Asian:	8.9%
Other:	15.6%

The 'Other' category has grown particularly quickly: six times more than in 1997, with many immigrants from the Far East (excluding China).

A curious paradox is that ethnic minorities are more likely to have a degree than the overall population, but also more likely to have no qualifications at all.

Employment rates

As mentioned above, the ethnic minority employment rate is now 60.9%, against the overall GB rate of 75%. But while all ethnic minority groups have lower employment rates than whites, this broad average covers wide variations, with particularly low rates for the Pakistani community (47.9%) and those from Bangladesh (41.9%), many of whom work only part-time. In all groups women have lower employment rates than men, but again this is most marked among Pakistanis and Bangladeshis (around 35%).

FIND THE HELP YOU NEED: A GUIDE FOR DISABLED REFUGEES AND ASYLUM SEEKERS

The Forum has relaunched an updated edition of this guide on its website (but not in print). Although aimed primarily at refugees and asylum seekers, specifying their entitlements, the guide will be useful to any disabled person, with sections on rights, discrimination, benefits, accommodation, employment, the NHS, community care, looking after a disabled person, equipment, education, voluntary organisations, information and legal services. It brings together this wide range of information as a single, downloadable file. Please have a look at it at www.nif.org.uk. Obviously, its effectiveness will depend on people – particularly refugees and asylum seekers and those serving them – knowing about the site, and we hope that members will give the site as much publicity as possible. It is not available in languages other than English, but we encourage community organisations, if necessary, to produce their own translations.

YOUR RIGHTS AT THE END OF LIFE

One aspect of the swelling numbers of older people needing care and support that the Government has so far avoided is the fact that some of us, while mentally competent, would in our last days like to have the option of an assisted death, subject of course to it being a voluntary decision and with a range of legal safeguards. Indeed we see it as a human right.

Dignity in Dying (formerly the Voluntary Euthanasia Society) has produced an excellent guide *Your Rights at the End of Life*. In its introduction, CEO Sarah Wootton begins by saying that Dignity in Dying believes that choice, control and access need to be at the heart of end-of-life policy making to ensure dignity at the end of life. The organisation whole-heartedly welcomes the Government's efforts to push for change in the area of end-of-life care and looks forward to seeing good policy translated into good practice. It believes that a dignified death means having choice, control and access to services: choice about where we die, how we die and who is present, control by planning for the end of life, and access to high quality palliative care tailored to individual needs, as well as access to support for carers and family members.

To make informed decisions about care and treatment at the end of life, she continues, we must have access to expert information on the choices available for end-of-life care, and the booklet aims to help people to get that information by looking at present rights in England and Wales.

Advance Decisions

Despite Dignity in Dying's undoubted aspiration to extend the law to allow assisted dying for mentally competent, terminally ill adults, the guide sticks strictly within current legal rights. It is

both thorough and authoritative, and those of us who do not wish to endure a long drawn out death (even with excellent palliative care) will be particularly interested in the section about making decisions about care and treatment, bringing out that even now we have the legal right to refuse medical treatment, even if we will die as a result. And that we can make an Advance Decision (sometimes known as a living will or advance directive) setting out what medical treatment we would like to refuse, should we lose mental competency or the ability to communicate.

Copies of the guide are available from Dignity in Dying, 181 Oxford Street, London W1D 2JT, tel: 020 7479 7730; e.mail: info@dignityindying.org.uk; website: www.dignityindying.org.uk.

FUEL POVERTY

The April/June 2008 newsletter of the European Anti Poverty Network (EAPN) focused on fuel poverty, headlining that “People in poverty shouldn’t have to choose between eating and heating!” The UK uses a definition that draws on the World Health Organisation’s analysis of adequacy: “A household is in fuel poverty, if in order to maintain a satisfactory heating regime [21 degrees C for a living room and 18 degrees C for other rooms] it would be required to spend more than 10% of its income (including housing benefit or income support) on all household fuel use.” Based on this definition the Government has calculated that 2.9 million of our people are in fuel poverty. However, the Consumer’s Association and Energy Watch have estimated this figure to be over 4 million and the number will surely rise given huge increases in energy prices, which having risen seem slow to come down now that wholesale oil prices have fallen. Energy Watch has said that Britain already has the highest number of avoidable deaths due to winter cold in Western Europe.

EAPN is calling for urgent EU action:

- To guarantee the right to energy, moving forward on a new horizontal EU framework on service of general interest;
- To recognise the complex causes of fuel poverty and the need for integrated strategies dealing with inadequate income, price regulation and energy efficiency.

Sad, therefore, that from 1 October the specialist watchdog Energy Watch has been subsumed within Postwatch and the Welsh, Scottish and National Consumer Councils to form Consumer Focus. Customer complaints about energy must in future be raised with Consumer Direct on 08454 04 05 06.

EAPN’s website is www.eapn.eu.

ARTHRITIS CARE

Long-standing member Arthritis Care was recently voted health charity of the year by the Medical Journalists’ Association. Several top health charities were nominated and the finalists included the British Heart Foundation and the Royal National Institute of Blind People.

Arthritis Care won on the strength of the presentation of health issues in campaigns like *People like us* – which used video diaries to demonstrate the impact of arthritis on people’s lives – for its usefulness to people living with arthritis, and for the quality of its service to health journalists. The award is significant because it comes from specialist medical and health editors in national television, newspapers and magazines, as well as publications for health professionals. “It is fantastic that it comes from the respected, authoritative communicators who influence health and public policy and are influential in reaching the public,” said Rachel Haynes, Arthritis Care’s director of public affairs. “By helping them, we’re doing our job of helping people with arthritis to get their voices heard.”

(from *Arthritis News*, no.139).

Note: Arthritis Care has also won two more awards from the British Medical Association for the

quality of its information. Kate Llewelyn, head of information services, comments “We pride ourselves on producing information that people with arthritis want. We ask people directly what issues affect them. We look at things from a lifestyle angle – after all arthritis is just one part of our lives, but one that can influence how we choose to live our lives. The fact that we keep winning awards for our information shows the success of our approach.” It could also be one from which other health charities could learn.

ACCESSING YOUR MEDICAL RECORDS

More people will be able to access their medical records by computer as part of a new service being offered to GP practices across the UK. Those practices that use the EMIS system will be offered a free trial of the online records system for patients. People whose GP practice is part of the trial can ask to sign up to the EMIS system. This could enable access to test results and other details of consultations.

(from *Arthritis News*, no.139).

COMBATING AGE DISCRIMINATION

The Government plans to introduce a wide ranging equality bill later this year to combine and extend the scope of many existing disability, age, gender and race laws. While age discrimination has been illegal since 2006, current laws apply mainly to the workplace. At the moment it is still legal to refuse insurance, loans, healthcare and car hire to someone because they are over a certain age.

The bill proposes to include a wide range of goods and services, particularly insurance and healthcare. One of the intentions is to stop insurance companies charging big increases in premiums once people reach a certain age if there is no increase in risk. Exemptions are likely to be that the risks of travel are too high or if doctors believe there are good medical reasons to refuse treatment.

The bill is expected to impose a duty on public organisations to ban discrimination and promote equality. There will also be requirements for public sector organisations to award more contracts to companies with a good record in equality. Services such as free bus passes are expected to continue. “Plans to make age discrimination illegal could make a huge difference to older people,” said Kate Jopling, head of public affairs at the charity Help the Aged. “But the timetable is still undecided. It is imperative that legislation is enacted without delay in the key areas of health and social care.”

The equality bill will cover England, Wales and Scotland.

(from *Arthritis News*, no.139).

WE HATE NO.13: REWARDING FAILURE

Derek Kinrade (with Ann Darnbrough)

Golden largesse for feeble performance has become, like lap dancing clubs, 24/7 drinking and casinos, an unsavoury part of the national scene. I refer, of course, to those extraordinary salaries and bonuses awarded to people who have loaned money irresponsibly or, conversely, have invested public money in banks palpably at risk. To people, moreover, who appear to be largely unaccountable for their actions. Obviously no-one has set out to fail. But fail they have: big time. No-one has put it better than Will Hutton (*The Guardian*, 14 October) who refers to “breathtaking business misjudgment, epic regulatory failure and a 20-year indulgence of now-defunct ‘free market’ principles”. What I hate most in such a context is the indiscriminate payment of excessive ‘rewards’ across the board.

But you may think that it is all very well to be wise after the event: in this case the credit crunch and meltdown of global stock markets. I take that point and rely instead on the remarks of my partner,

Ann Darnbrough, in her miscellany *A Rebellious Disposition*, published, please note, in 2007:

“Though lacking the skills of a trained accountant, I nevertheless have strong views about those sad people who dedicate their energies to acquiring personal fortunes, rather than benefiting the world around them; piling up riches by every this way or that, without thought for those struggling to make an honest living. Some may call it the politics of envy. I prefer to think that it is a basic principle of elementary morality.

“A recent Guardian survey found that over the previous 12 months boardroom ‘earnings’ had risen seven times faster than average earnings. More than 200 directors ‘earned’ more than £1m. Eight chief executives were said to have ‘earned’ more than £1m as a basic salary, quite apart from mind-boggling bonuses, perks and share options. The magic word ‘bonus’ seems to have high ‘earners’ salivating. In 2006, the total of bonuses to be paid out in the UK was estimated at £8.8bn.

“While some attempt has been made to lift the poorest members of our population out of absolute poverty, the disparity between those at the bottom and those at the top inexorably widens as the rich are allowed, indeed encouraged, to become immoderately richer.

Enough is never enough

“Naturally, we all want enough money to keep our lives going and to be able to do those things we enjoy. The trouble is that for so many people, enough is never enough...it all too often seems that once a person becomes rich their main object in life is to become richer. You might say they have caught the deadly affluenza virus that can be almost impossible to shake off.

“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.

“I believe a healthy nation, one that is prosperous in the best sense of the word, cannot be built on greed. A nation state based on the pursuit of affluence will surely die. True wealth is made up of the contributions of all its citizens to the common good: to each other as neighbours, to strangers around us through kindness and to the wellbeing of the state through fair and equitable taxation.”

Ann was not alone in challenging the culture of greed, but most of us closed our eyes and ears to the dangers of an economy built on excessive debt and weighted in favour of entrepreneurial adventurers. Information about the finances of banks and the ratio of deposits to lending now abounds in the media, but in non-specialist newspapers it was conspicuous by its absence before the bubble burst.

We have drifted into countenancing a society in which the rich get ever richer and the divide between those at the top and those at the bottom has widened to an obscene degree. I may have mentioned (but it is worth repeating) that while people on quite modest incomes pay National

Insurance contributions at 11%, high earners pay only 1% on income above £40,040 a year. Similarly, if you cast your eye on your gas or electricity bills, you will find that the price is higher for low consumption. This is surely indefensible.

I rest my case, save that those who have benefited from their mistakes still have an opportunity voluntarily to pay something back. But perhaps that is another impossible dream.

This information sheet has been compiled by Derek Kinrade. The views expressed do not necessarily represent those of the National Information Forum.