

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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CITIZENSHIP

The Borders, Citizenship and Immigration Act 2009 received the royal assent on 21 July. As we understand it (and this is not an easy Act to understand) its provisions include changes which, among other things, will allow the normal qualifying periods for naturalisation to be reduced by two years for applicants who satisfy “the activity condition”. This is where, to the satisfaction of the Secretary of State, the applicant has participated, otherwise than for payment [i.e. as a volunteer], in prescribed activities or is treated as having so participated. These and other changes are to be commenced at a future date by Order.

We think, and we are not alone, that there are dangers here. On the one hand that some applicants will suffer discrimination because, for personal reasons, they cannot involve themselves in prescribed activities; on the other because some applicants will simply see volunteering as means to an end, rather than as an expression of their public spirit. We think that charities taking on volunteers need to be alert to this possibility.

ACTION ON DEMENTIA

The latest issue of the Social Care Bulletin has reminded us that we have omitted to comment on the Government’s National Dementia Strategy (NDS). Which is a staggering omission, given that dementia now afflicts an estimated 700,000 people in the UK, a figure that is expected to double in the next 30 years. The cost to the UK economy is put at £17 billion, set to rise (if nothing is done) to over £50 billion. The principal key to redressing these depressing figures, of course, is early diagnosis, prevention and intervention. At present only about one-third of people with dementia receive a formal diagnosis or have contact with specialist services at any time during their illness. It is an alarming ‘black hole’ and to fill it the Department of Health has come up with an Implementation Plan, published on 22 July, to show how the Department will provide support nationally and regionally for all those involved in putting the NDS into practice. The proposals include the introduction of a dementia specialist into every general hospital and care home, and for mental health teams to assess people with dementia. Specialist dementia advisors are being piloted in 22 areas across the country to give people with dementia and their families ongoing support and to help them to access the care and support system. Several of the pilots are designed to reach people who don’t speak English, have learning difficulties or are from black and minority ethnic groups. A further 18 sites will test practical and emotional support networks for families and carers, and will give people a



say in developing local services.

Phil Hope, Minister for Care Services, has announced the publication of a new web-based dementia information portal. For details of this and the NDS go to: www.dh.gov.uk/en/socialcare/deliveringadulthoodsocialcare/olderpeople/nationaldementiastrategy/index.htm.

EQUALITY AND DISCRIMINATION

Harriet Harman QC, MP, Minister for Women and Equality, responds to our article ‘Random Thoughts on Discrimination’ in News Briefing no.13;

“The majority of the population believe that it is better to have a fairer and more equal society—one in which people’s lives are not blighted and marred by bigotry and discrimination, whether on grounds of sexual orientation or reflecting unfairness towards women at work, unfairness on grounds of race or unfairness caused by the different start that people have by virtue of where they were born. The Government make no apologies for that agenda and it is in the Equality Bill.

“As far as women in politics are concerned, it is important that we deliver for women in this country. Politics is not about us as politicians; it is about what we as women and men working together can do in respect of the lives of women and men in this country.

“The Equality Bill which is now in Committee will ensure that we tackle age discrimination—discrimination against older people on the grounds of their age will be outlawed—and pay discrimination against women. It will ensure that we make progress on a range of other issues, and it will also ensure that all public authorities, be they local government authorities, health authorities or Departments, and indeed Ministers, play their part in ensuring that this country is a more fair and equal society.

“Equality matters because it is right as a question of principle, and it is necessary as a matter of practice. It is essential for every individual. Everyone has the right to be treated fairly, and everyone should enjoy the opportunity to fulfil their potential. No one should suffer the indignity of discrimination—to be told, “You’re old, so you’re past it,” overlooked because of a disability or excluded because of the colour of their skin, or to face harassment because they are gay or be paid unfairly because they are a woman.

“Equality is not just the birthright of every individual; it is also necessary for the economy: a competitive economy is one that draws on everyone’s talents and abilities and is not blinkered by prejudice. It is also necessary for society: a more equal society is more cohesive and at ease with itself than one marred by prejudice and discrimination.

“We have already taken action to outlaw discrimination against disabled people, but prejudice still blights the lives of disabled people looking for work or a home or using services, so there are a number of new measures in the Bill. The new public sector equality duty will build on the disability equality duty that we introduced in 2005. We will use the powers under the new duty to require public bodies with more than 150 employees to publish annually the percentage of disabled people that they employ, so that we can build on good practice and see improvements year by year. It is a public policy imperative to include disabled people, so the public sector must lead the way.”

A NEW CHAIR AT RNIB

We were privileged to be invited to a reception on 25 June to bid farewell to Lord (Colin) Low as Chair of RNIB, held at the prestigious Locarno Suite in the Foreign and Commonwealth Office. It was a fitting venue to hear Baroness (Betty) Boothroyd pay tribute to one of the giants of the disability world. We have known and admired Colin’s work over many years, not least the academic

wisdom that has informed his thinking and the gentle stringency of its expression. We feel sure that he will continue to utilise these gifts to the full in the House of Lords, where they are sorely needed.

He has been replaced at the RNIB by the hirsute Kevin Carey, stepping up from the position of vice-chair. In an interview with *Third Sector*, Kevin, who lost his sight as young man, makes no bones about it being “horrible” to be blind, and thinks that more needs to be done to address blind people’s emotional and dislocational issues, not just practical help. Kevin is the founder director of HumanITy, a specialist on ICT accessibility with expertise in broadcasting, telecommunications and computing, with direct experience of social deprivation, underachievement, disability and ageing. He has advised the European Union and a number of UK government departments on eInclusion.

AGE-OLD CHALLENGES

The Department of Health’s ‘living well’ prevention package, which was launched on 22 July, aims to support older people in remaining healthy and independent for longer. It will promote best practice for preventing falls and managing fractures – which affect one in three women and one in seven men over 65 – and the benefits of foot-care services. The package also includes progress reports on hearing and remote care services, and updated guidance on intermediate care.

A public information leaflet for people aged 50 and over has been published, telling them about existing entitlements – including flu vaccination, sight tests and cancer screening – and how to find out what other services are available locally, how to access them, and what the benefits are.

In addition, the NHS Health Check programme will aim to help prevent heart disease, stroke, diabetes and kidney disease. Everyone between the ages of 40 and 74, who has not already been diagnosed with one of these conditions, will be invited to have a check, once every five years, to assess their risk and help them reduce or manage that risk. Phased implementation of the programme begins this year and is expected to be completed by 2012/13.

Prevention and early intervention works

Under the DH’s Partnerships for Older People Projects (POPP), East Sussex County Council has worked with the local Primary Care Trust and a wide range of partners to establish Independence First, a programme of services that proactively targets older people most at risk of admission to hospital or institutional care.

The programme, which focuses on mental health and memory loss, recognises that making preventative services available at an early stage is critical to providing effective support and reducing admissions to hospital or institutional care.

Pre- and post-intervention surveys show the older people involved were less likely to have used hospital services for an overnight stay in the previous three months, and were more likely to make better use of community services. The participants also felt that health and social care staff worked together better and they were happier with the services provided for them.

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POLIO PERSON OF THE LAST 70 YEARS

The British Polio Fellowship has made this unique award to Sir Bert Massie, recognising “an outstanding contribution to the quality of life of disabled people”. Over a long and distinguished career campaigning for the rights of disabled people, Bert has served as Chief Executive of

RADAR, and Chief Executive and Chair of the Disability Rights Commission. He is now Chair of Compact, set up to help relationships between the charity sector and the Government. The Fellowship commends, in particular, “his amazing energy and sense of humour”. But then he does hail from Liverpool.

HEALTH INFORMATION DENIED TO BLIND AND PARTIALLY-SIGHTED PEOPLE

New research commissioned by the RNIB has found that 95% of blind and partially-sighted people are never asked by NHS staff providing healthcare information which reading format they need. The RNIB campaign, ‘Losing Patients’, was launched in Sheffield on 17 July with the support of Sheffield Royal Society for the Blind.

The study also found that 72% of respondents said that they could not read information from their GP, and 81% were unable to read medicine instructions and safety notices. David Blunkett MP, a Vice President of RNIB, commented that visual impairment was not the problem; rather the “culture of giving ordinary print to people who can’t read it”. RNIB is working with local associations to encourage visually impaired people to exercise their legal rights and to feel empowered to ask for information in a format they can read.

Reported in ‘NB’, the sight loss and eye health magazine, issue 45, September 2009. Further information at rnib.org.uk/losingpatients.

EYE TESTS IN SCOTLAND

Free eye tests were introduced in Scotland three years ago, once more setting an example for the rest of the UK. The results are encouraging. The latest statistics show that the number taking up free tests rose from 1.63 million to 1.73 million in the year ended March 2009. There were also more referrals to follow-on care by a GP or hospital following tests. 72,660 people are now being referred for potentially sight-saving treatment. John Legg, Director of RNIB Scotland, said: “Policies such as the free eye test contribute to making Scotland one of the world’s leaders in eye health.”

Reported in ‘NB’, the sight loss and eye health magazine, issue 45, September 2009.

THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The September issue of NB, the RNIB’s sight and eye health magazine, carries a special article on the potential opportunities for beneficial implementation of the Convention.

CROSSROADS

This famous charity has changed its name from ‘Crossroads Caring for Carers’ to ‘Crossroads Care’, simpler and more reflective of the wider impact of its work.

MULTIPLE SCLEROSIS RESEARCH

Various media reported on 13 August that researchers at McGill University in Canada had successfully reversed a condition similar to multiple sclerosis (known as EAE) in mice. Researchers are reported as saying that the experimental treatment, called GIFT15, might, given early intervention, put multiple sclerosis (MS) and some other conditions into remission by suppressing the immune response, although clinical studies would be needed to test its efficacy and safety in humans.

Dr Susan Kohlhaas, Research Communications Officer at the MS Society, pointed out however that it is important to remember that EAE has been treated successfully before and is distinct from MS. “Determining whether this technique can apply to people with MS is the next challenge.” A press release is at www.mssociety.org.uk/news_events/news/press_releases/eae_reversed.html. Details of the research have been published in the journal *Nature Medicine*, issue 15, 9 August 2009 (restricted access).

VETTING AND BARRING

From 12 October new measures are to be introduced towards preventing unsuitable people from undertaking paid or voluntary work with children or vulnerable adults. A new body called the Independent Safeguarding Authority (ISA) will decide who should be barred. These decisions will be legally binding, and failure to comply could result in both the employer and the employee or volunteer being prosecuted and even going to prison.

Under the new scheme many more paid and voluntary roles will be covered than under earlier arrangements. The Government estimates that over 11.3 million people will ultimately have to be assessed!

From July 2010, all new employees, those moving jobs, and volunteers who want to work with children or vulnerable adults can register with the ISA, and from November 2010 this will be an obligation. Until applicants have been registered they cannot legally be employed. It is the potential employee's responsibility to register, but the employer is required to check that they are registered before they can legally take them on.

For more information, call 0300 123 1111 or go to www.isa-gov.org.uk.

PATIENT CARE IN HOSPITAL

The Patients Association (PA) has campaigned for many years to improve the quality of care provided by the NHS, prompted by accounts received from patients on a daily basis. In August it published a number of these accounts "to highlight the unacceptable experiences facing patients up and down the country on a regular basis". The report shows that while the failings at Mid Staffordshire may have been exceptional in terms of scale, the kinds of appalling treatment that occurred there could also be found across the NHS. Two of 16 first-hand accounts come from Stafford, and they sadly fail to stand out from others.

These accounts tell the story of two per cent of patients who consistently rate their care as poor. If extrapolated to the whole of the NHS from 2002-08 it would equate to one million patients. Very often these concern the most vulnerable elderly and terminally ill patients, with worrying instances of cruel and callous attitudes. According to PA, they reveal a denial of basic dignity; patients often left in soiled bed clothes, given inadequate food and drink, having repeated falls, suffering from late diagnosis, cancelled operations, bungled referrals and misplaced notes. They represent a sad indictment of the care they receive.

PA hopes the report will serve as a wake-up call for the Department of Health and the Care Quality Commission. It calls on the Government and the Commission to review as a matter of urgency the standards of basic care accorded patients in hospital, and demands stricter supervision and regulation of hospital care. Moreover, it intends to continue to publicise accounts until it can be confident that every patient is given dignity in their care.

The full report is available on www.patients-association.com. There is also an invitation to sign a petition calling for an independent inquiry to provide an answer to the following questions:

- How were the serious failings in care at Mid Staffordshire Foundation Trust able to continue for so many years?
- Can the public have confidence that the current and future systems of supervision and regulation will ensure safe hospital care for patients in the NHS and prevent this from ever happening again?

The Care Quality Commission, successor to the Healthcare Commission, publishes annual ratings

of healthcare services, including the performance of local NHS hospitals. Go to www.cqc.org.uk, locate 'find care services' and enter your postcode when prompted.

WELFARE TO DESTITUTION?

Support for our view that the DWP's 'Welfare to Work' initiative is misguided, at least under present conditions, has come in an article by Jenni Russell in *The Guardian* of 19 August. The poor, she argued, know it as 'welfare to destitution'. The idea that everyone except the very ill or disabled should be discouraged from leading a life on benefits faces two problems. First, that few jobs are available. Second, that such jobs as are on offer are precarious, temporary, part-time or have uncertain hours. "Leaving the security of benefits for jobs like these," says Ms Russell, "is like stepping out on to cracking ice." And our antiquated welfare system is not up to dealing with this instability. In practice, those at the bottom of the market who get work but are then laid off face "savage, searing experiences" in getting their allowances back. Small wonder that people are scared to leave what they know. Benefits may not amount to much, but if they stay put "at least they can be sure that their homes and essential bills will be paid for." The government mantra that work will always pay is unconvincing. We have yet to deal with this in reality.

Ian Duncan Smith suggests a way forward

Since we wrote the previous paragraph, the Centre for Social Justice has published a lengthy report *Dynamic Benefits: Towards welfare that works*. This has been well reported and we will not reiterate the detailed proposals here. The full report, with an executive summary, can be found at www.centreforsocialjustice.org.uk (**go to Publications**). We fear that it will be filed as "too difficult", but we think it is worth highlighting the thrust of the criticism of the present arrangements. The basic argument is that the benefits system is broken and needs to be redesigned in a way that recognises how claimants respond to how benefits are withdrawn if and when they enter into work that is almost inevitably low paid. In seeking to alleviate poverty, the current system has "entrenched and perpetuated its causes: the lack of employment and earnings", consigning people to long-term worklessness by making it pointless for them to return to work. To remedy this situation, claimants "must be given every incentive to participate in, and contribute to, future economic growth". Attempts by successive governments to address the problems of the welfare system have failed. Not only are worklessness and poverty rising, but an unwanted consequence is that the social security budget has also increased dramatically.

The report concludes that the structure of the system needs to change. "Work must be supported as the primary sustainable route out of poverty". The report therefore focuses on how to reduce, in an affordable way, the existing barriers to entering work and earning more. A detailed analysis highlights a key finding that there are significant disincentives to work, created by taxation and the way that benefits are withdrawn on entering work, so that "the first steps into the world of work for many in a low hours/low pay job are all but pointless".

The report goes on to point out that the situation is made worse by the complexity of the benefits system, with "51 different benefits of bewildering scope and complexity". This has entrenched benefit dependency, because claimants are afraid to change their situation, and even advisers are unsure whether to recommend they take a job.

The report is very thorough, perhaps too thorough for its own good, but we concur with its thinking. We urged much of this in News Briefing no 3 (August 2008), albeit in a single paragraph.

CARERS SUFFER BENEFITS CHAOS

In a report published on 9 September, the Public Accounts Committee (PAC) said that benefits for carers are "unnecessarily" complex and cause confusion. About one-fifth of carers in receipt of

benefits have had difficulties with some aspect of the application process, including understanding the information provided by the Department of Work and Pensions and what information they are required to provide. Complexity is also caused by the interaction of benefits for carers with those of the people for whom they care. The report says that the Department's communications with customers can be lengthy and difficult to understand.

The report goes on to say that carers who want to combine caring responsibilities with paid work are not receiving employment support tailored sufficiently to their circumstances. Part-time work is often the most practical option, but the Jobcentre Plus target regime does not provide sufficient incentive for personal advisers to help customers find part-time work.

Carers' needs, say the PAC, would often be met if provision was made for the needs of the person being cared for. This outcome requires effective co-ordination of services between the Department and other organisations in central and local government, as well as the voluntary and community sector.

Editorial note: This situation takes us back to the origins of the Plain English Campaign in 1979, launched because so many people found government forms incomprehensible. There remains a seemingly unbridgeable gulf between the academic attainments of those who design and promulgate systems and many of those most in need of help. This may go some way to explaining why of Britain's 6 million unpaid carers only an estimated 900,000 are in receipt of benefits. Pulse, the in-house magazine of HM Revenue and Customs (September 2009), reports a similar divide in that Department. Research carried out by HMRC's Individuals Customer Directorate compared the literacy and numeracy levels of members of the public with its own communicators, finding that the latter had significantly higher skills levels. This may be one of the reasons why, in 2006-07, some 80% of people entitled to receive just Working Tax Credit didn't claim it, including many over-50s who missed out on up to £200 a month.

The PAC report is at www.publications.parliament.uk/pa/cm20080.

WE HATE NO.22: E.MAILS

"E-mail has become the bane of some people's professional lives."

Randall Stross: 'Struggling to evade the e-mail tsunami', New York Times, 20 April 2008.

This is a qualified hatred. E-mails can be either a curse or a boon. In their favour, they offer a fast and mostly reliable means of conveying information. Detailed reports and pictures can be attached. Within an organisation, e-mails have the advantage that day-to-day communication is possible without the need for physical, simultaneous presence of sender and receiver. In the wider world – and we do mean world - the system is particularly useful for simple enquiries and rapid responses. Given the increasing unreliability, complexity and cost of postal services, e-mails are now a welcome alternative. They are, for example, perfect for distributing this News Briefing – and for feedback. Nor is the argument that this kind of communication is hostile to language sustainable. It is perfectly possible to be textually economical or literarily loquacious, according to context. Indeed there is a strong argument that our computers can be an aid to enhanced expression and creativity.

Unfortunately, however, e.mail transmission is open to attack in ways that have become all too familiar. Susceptibility to poisonous interference has spawned a whole new electronic vocabulary: words such as 'spoofing', 'bombing', 'worms' and 'viruses' describe ever-present dangers. A big problem is the pernicious dissemination of junk mail, so-called 'spam', sometimes targeted on a gargantuan scale. The technical simplicity of the e.mail system allows spammers to send millions

of e-mails every day. We found one advertisement on the internet offering the opportunity to send e-mails to over 10 million people at a cost of \$29. The consequence can sometimes be an avalanche that can engulf the unfortunate recipients, leaving them unable to cope. A term has been coined to describe their plight: e.mail bankruptcy.

It is bad enough to be overwhelmed with spam. But needless messages from our allies can be even more difficult to deter. Because of the essential simplicity of this kind of communication, with the opportunity to copy in all and sundry, messages tend to proliferate in a way that formerly, in pre-electronic days, afflicted only celebrities bombarded by fan mail. Nowadays you don't have to be famous. It is a familiar experience to take a holiday, a welcome break from work, only to return to a huge backlog of e-mails, mostly of minimal importance. And whereas letter post is now generally restricted to one daily delivery, unsolicited e-mails can and do arrive incessantly by day and night. Old-fashioned values tend to dictate that every message deserves a reply, but this can become impossible, prompting us to retreat behind automatic, palliative responses admitting that we have become victims of information overload.

Our heartfelt expression of hatred in this instance, therefore, is somewhat a call to exercise discipline: to communicate on a need-to-know basis, rather than simply sharing tittle-tattle.

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.