

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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“TELL DAVID CAMERON THAT IF HE SCREWS UP MY BELOVED NHS I’LL COME BACK AND BLOODY HAUNT HIM.”

These, reputedly, Claire Rayner wished to be remembered as her last words. We will miss her. She was in every sense a kindred spirit, but more forthright than we have ever dared to be. She was the keynote speaker at our 11th ‘Getting the Message Across’ annual awards, and in the following issue of our magazine *Innovations in Information* (Vol.12, no.3, 2006) we featured a Q & A feature with her. We will not repeat the whole of that article, but the last two questions are now particularly apt:



Claire with Ann Darnbrough in 2006

“Q: Do you believe in life after death?”

A: Certainly not

Q: How would you like to be remembered?”

A: As someone who made people laugh and was also on the useful side. And who lived to be a lively, with-it and happy 100 year-old, together with my husband and the pair of us dying in the same minute in some convenient manner. That would be perfect.”

Well we can’t have everything.

DO WE WANT A DISABILITY RIGHTS PARTNERSHIP?

Three organisations, the Disability Alliance, the National Centre for Independent Living and the Royal Association for Disability Rights, are consulting with their members on a proposal to create a unified organisation, to be known (provisionally) as the Disability Rights Partnership. The idea is to establish, by mid-2011, an integrated service for disabled people, led by disabled people and working with everyone who could be considered disabled, however they view themselves.

There is a lot to be said for mergers in these difficult times, but we are apprehensive that such an alliance smacks of sectarianism when we should all be pulling together. If equality and the big society mean anything we need to dismantle societal barriers, not create them.



HOSTILITÉ SEXUEL

As widely reported IFOP (the French Institute for Public Opinion) has published the results of a survey of the love lives of more than 1,000 French couples. It found that more than three quarters had bad sex lives. More than a third of women and one in six men admitted to making excuses to avoid sex. Surely that can't happen here. Vive l'entente cordiale!

WHO WON?

We recall that somebody said that it was a good election to lose. It is beginning to look as though that might be true. The problem with 'Your Country Needs You' is that it was tried in World War I, and look what happened to the volunteers.

WATERING DOWN EQUALITY

The RNIB (*NB* magazine, October 2010) reports that the Government's Equalities Office is consulting on what the new public sector equality duty will look like. *NB* says that the proposals in relation to disability have caused great concern among disability organisations as they place no requirement on public bodies to involve disabled people in the development of 'equality outcome objectives'. Moreover, public bodies are required only "to set a minimum of one objective in one equality area, meaning that many public bodies could have no objectives to improve disability equality if they chose to act on other areas". Nor do the proposals even contain a requirement for public bodies to act to achieve the objectives they have set out.

The consultation can be found at www.equalities.gov.uk/news/specific_duties_consultation.aspx, and closes on 10 November. See especially paragraph 3 of the draft regulation. If this is what the regulation intends we think it outrageous.

NOT TO BE MISSED

Phil Bradley in *Library and Information Update* has alerted us to a stunning internet site: www.legislation.gov.uk. It covers most types of legislation, offering information on UK laws passed since 1267, including new legislation. "A place," writes Phil, "to spend many happy hours".

SUPPORT NEEDED BY GRANDPARENTS

A new report from the Grandparents' Association has "found that 55 per cent of grandparents who are primary kinship carers experienced deterioration in their physical health, while 40 per cent had suffered mental health problems ... 'This research study concludes that when grandchildren 'at risk' can no longer be brought up by their birth parents, and instead are brought up 24/7 by their grandparents, these grandparents need considerably more recognition, support and services than they currently receive.'" (taken from: <http://www.cypnow.co.uk/bulletins/Daily-Bulletin/news/1033708/?DCMP=EMC-DailyBulletin>). Full details of the report - which is a charged-for publication - are at: <http://www.grandparents-association.org.uk/index.php>).

From John Vincent

PATIENT SAFETY

Following a short report in *The Guardian* ('57 NHS patients get wrong operation', 9 October) we perused the website of the National Patient Safety Agency and were astonished by the attention to detail and concern for the improvement of standards in the reporting of patient safety incidents. Did you know, for example, that in England in the period July 2008 to June 2009 there were 945,497 incidents, but that only 7,778 (less than one per cent) of these resulted in severe harm, and even fewer, 3,735 (less than 0.4 per cent), in death?

It would be reassuring to know that this mass of data, monitored quarterly, has a practical impact in achieving genuine reductions in avoidable incidents, rather than being simply interesting statistics.

ASSISTED DYING

The widely reported 'confession' of actor Michael Caine is significant in that it brings into the sharp focus of reality (versus dogma) the dilemma of having to witness the prolonging of the agony of a loved one experiencing extreme suffering when facing inevitable death. Keir Starmer, the Director of Public Prosecutions, has made clear that prosecution is unlikely in cases where a person has acted for compassionate, unselfish and

non-malicious reasons. Conversely, it might be thought that a readiness to accept the protraction of pain to satisfy a principle demonstrates a lack of compassion.

ACCESS TO TOURISM: ALL INCLUSIVE?

The Trailblazers Campaigners' Network (www.mdctrailblazers.org/campaigns/568), part of the Muscular Dystrophy Campaign, has published a report that draws attention to the fact that under the Disability Discrimination Act 1995 it is unlawful for a service provider to treat an individual unfairly on the grounds of disability. And that hotels, airports and airlines have a legally enforceable obligation to provide reasonable adjustments. Tour operators and travel agents, they point out, should also have adequate knowledge on the accessibility of their resorts and hotels used by their company abroad and provide accurate useful information before someone spends their hard earned cash on a holiday.

To test the extent of compliance, the Network launched an investigation into the accessibility of the hotels and attractions of the tourist towns of the UK and overseas. Over 200 young disabled people spent their summer surveying and investigating services, collating evidence in an attempt to tackle the challenges of enjoying an accessible holiday. Undercover, they looked at travel agents, hotels and tourist attractions across the UK. They filled out surveys, wrote blogs and used the internet and telephone, discovering that services are lacking and a lot can be improved both in the UK and for holidays abroad.

Key findings

Of the young investigators:

- 80 percent believed that holidays are more expensive as a direct result of disability
- 50 per cent said that the accessibility of hotels and tourist attractions in the UK was poor or very poor
- almost 80 percent felt that the standard of disability awareness among hotel staff members was poor or variable
- 90 per cent felt that most high street and mainstream travel agents have poor disability awareness and knowledge of issues affecting disabled tourists
- several reported landing in a foreign country to find their wheelchair had been broken by careless handling, leaving the traveller without any means to get around on holiday.

Action needed:

The Network calls on hoteliers, travel agents, airlines and owners of tourist attractions to:

- work with organisations like the Trailblazers Campaign Network to come up with solutions to the problems faced by young disabled tourists
- ensure high-quality disability awareness training is provided to staff members
- put accessibility at the heart of the travel and tourism industry and ensure that all members of staff are aware of the accessibility of the facilities with which they work
- install ramps, lifts and banisters to ensure accessibility throughout buildings
- increase the number of accessible rooms wherever possible
- ensure that accessible hotel rooms are spacious, well planned and, if en suite, have fully accessible bathrooms including walk-in showers
- keep a stock of adaptations and equipment useful to disabled people.

This is a slightly edited version taken from the Network's website, from which the full report can be downloaded. The Network should not be confused with the Trailblazers Equestrian organisation, nor the mentoring organisation run by Feltham Young Offenders Institution.

CHRIS BAZELEY OFFERS A SOLUTION

I was born in 1944 and caught polio in 1946 while it was still fashionable. I passed the following forty odd years teetering about on a succession of crutches and callipers skilfully constructed from various bits and pieces left over by the Marquis de Sade. When in 1990 I tripped on a frayed carpet and fell, breaking one of my two remaining working limbs, it was time to face the inevitable, and lower what was left into a wheelchair. This had the effect of severely limiting my theatre of operation. Suddenly the two local pubs in our village became inaccessible; one having wheelchair access to the bar but not the toilet, and the other having wheelchair

access to the toilet but not the bar which, the two hostelries being at opposite ends of the village, made for an exhausting Saturday night.

The same applied to many things in my life but arguably the most difficult to solve was holidays. In the past we have always managed to holiday independently, avoiding packaged and organized tours. We preferred to get as close as we could to “adventure” holidays. We looked at “wheelchair friendly” villas all around the Med only to be sorely disappointed when the brochures arrived to see flights of steps from car park to front door, or tiny shower rooms with even tinier toilets. We looked at several hotels in Venice advertised as wheelchair accessible to discover that our holiday would be restricted to around 200 yards in any direction due to the beautiful but insurmountable bridges. After many abortive attempts to find reliable and comfortable venues that suited our independent spirits, we were on the point of succumbing to the overtures of the local, but uninspired travel agent when my incredibly diligent wife found a contact email address on the internet, for a lady offering advice on cruises with a selection of companies.

We had tended to rule out cruises due to the perceived high cost and the alleged regimentation surrounding the whole concept. Our contact was able to put our minds at rest on several issues including “freedom dining” and accessibility. Her recommendation to book on P&O’s new cruise ship, the Azura, began to sound like a possible solution. When she provided a 16-night itinerary taking in all the places we longed to visit, and also removed the requirement to submit myself to the indignities that are a specialty of the airlines, we were convinced.

The cruise commenced in Southampton on a Sunday afternoon after a very enjoyable and dignified drive from our home in Gloucestershire. There was a well organised airport-like check-in and security system to negotiate but once that was done we slipped through a time warp into the golden age of great liners. The first hours on board were lubricated by a couple of glasses of excellent champagne and an impressive departure from the dockside with a brass band playing, streamers and Union Jacks waving and a gradually developing sense of camaraderie.



All the usual concerns I had about wheelchair access on board were very quickly and completely dismissed. I was able to go everywhere on board, my wheelchair did not restrict me in any way. I cannot remember seeing a toilet that was not mirrored by an accessible one alongside. The whole ship was spotless and our cabin exceeded all our expectations.

There were approximately 20 wheelchair accessible cabins. All these are outside cabins, with wide sliding doors onto their balconies. They are large, uncluttered and very well designed, being close to the spacious lift foyers for easy access to all decks. Cabins are all provided with tea & coffee facilities, a fridge, a safe, and a flat screen TV that accesses limited International channels received by satellite as well as on board information channels. These carry information about the ship’s position, speed and course, a weather forecast, diagrams of the ship and the various attractions and facilities, documentaries about the ports you will visit in the next day or two, menus from the various restaurants and the state of your onboard account. Cabins are serviced by a very discreet steward twice a day and we found a chocolate treat on our pillows every night when we returned from exercising our very agreeable new lifestyle.

All food, and tea and coffee etc. is included in the basic cost of the cruise. Extras are available such as onboard shopping and alcoholic drinks. Prices are comparable to your local shops, restaurants and pubs; a full English pint of ‘Old Speckled Hen’ being £2.70 as an example.

We enjoyed the various dining options on board, and availed ourselves of the excellent themed buffets in the evening, as well as the high quality ‘feature’ restaurants. We ate healthily and sensibly, and proved many of our friends wrong who promised us we would put on weight, because everyone did on a cruise! I did not expect to enjoy the ‘dress code’ aspect of the cruise, but it made the holiday nicely different to our usual daily routine.



The first two days were spent at sea, exploring the 13 bars, 7 restaurants and a multitude of other things to do, including two theatres, There was a huge cinema out in the open on the top deck which seemed a little brave of the ship's designers, until we turned the corner into the Straits of Gibraltar and emerged from under the cloud that is commonly northern Europe. Apparently, our day negotiating the Bay of Biscay was one of 'A Stiff Gale' although I would have been hard pressed to detect any ripples on the surface of my Gin and Tonic, and at no time during the whole cruise was I aware of any significant movement of the ship as the stabilization seemed perfectly able to cope with 8 foot waves.

I awoke at 4.00 am the following morning (Wednesday) to see the dark mass of the Rock of Gibraltar silhouetted against the night sky with only the reflection of the lights of Gibraltar Town on the surface of the calm waters to give some sense of dimension. I had woken my wife to see the view but the gentle sound of the water 12 decks below us was not enough to stir me into photographic mode and I fell asleep almost immediately. Fortunately my wife is made of sterner stuff and we do have a picture.

The first stop was Malaga in Spain, where I went ashore with no problem whatsoever. There is a team of crew members to offer assistance in a sensitive and efficient way at the gangplanks which were designed to be as safe and accessible as possible. There were accessible coaches laid on at most ports and taxis were also readily available. Generally the main town or city centres are around ten minutes walk and certainly in Greece, dropped kerbs are rare, so some form of local transport has to be part of your expenses. The exception was Katakolon in Greece where the ship practically docked in the fountain in the town square! A two minute walk was all that was required to get to a beautiful main street filled with exceptionally economic shops. There were so many bars and genuinely Greek restaurants that the day was far too short, despite the street being only around 300 yards long.



Accessible excursions were available at most ports, but our independent spirits did not allow us to book ourselves on these. The cost was also fairly high, but most of those who had taken the tours seemed satisfied and ready to do it again.

The next day was Corfu which was a delight, heightened by the attentions and care of a very accommodating local taxi driver. Dubrovnik in Croatia is beautiful but we felt the emotional scars of the recent wars have left a mark on the atmosphere in the city.

Venice is everything you have heard but a disappointment with regard to access. The much publicised chairlifts over some of the bridges are either not working and/or require a RADAR type key that has to be applied for some weeks before. The alternative; which is the Vaporetto water buses can only be compared to being shoved off and on a London Bus in a thunderstorm, but it is Venice and is not to be missed if at all possible. The next stop was a gentle unwind in Korcula in Croatia, the only place I was unable to get ashore. The ship is much too large to moor against



the jetty and tenders were used to ferry people ashore. The ship itself, being over 1,000 feet long and weighing in at around 116,000 tons, moored at anchor in the mile-wide waterway between the mainland and the island of Korcula. My wife went ashore but I spent the greater part of the day simply watching the rich, famous and beautiful parade past my balcony in their various luxury yachts – Oh, I did have a little support from free room service.

A further two days sailing took us back to a final day in Gibraltar before a gentle, and very warm, two days sailing back to the UK. The shock was waking up wreathed in thick, cold fog in Southampton docks. But what better way to grasp the thorny stem of reality again?

I would heartily recommend this type of holiday to anyone with any form of disability. The reassurance of having a huge first class hotel with 100% access, and filled with a surfeit of friendly, willing and extremely caring, yet discreet staff, make this a holiday that is exactly that! ‘A real holiday’.

STATE SUBSIDISED SEX?

According to *Forward*, the magazine of the Spinal Injuries Association (October 2010), “The Government has confirmed that it has no objection to disabled people using part of their council-funded personal budgets to pay sex workers”. We would be interested to clarify the authority for this statement and if confirmed whether it extends to the payment of trafficked prostitutes.

A CUT TOO FAR?

We have tried hard not to add to the controversy surrounding the coalition’s spending review. We might have said that while New Labour did indeed move from prudence to profligacy, much of the national deficit is attributable to its action to save certain banks which were ‘too big to fail’, and that at least some of this outlay should return to the Treasury in the fullness of time. We have been tempted to say that while we are all in it together, some are more together than others. And we might have said that we find it hard to accept harsh measures against those already poor from people on fat salaries with ministerial cars (but see Matthew 13/12).

But one measure surely demands outright censure. While we accept that a proportion of incapacity benefit claimants are feckless malingers who need to be weeded out, we think it unfair that there should be a wholesale attack upon those with genuine disabilities who might be thought theoretically to be just capable of work but who in the current climate have no realistic prospect of being taken on. Alf Morris has spent his long political career trying to raise disabled people from the status of second-class citizens. Is his work to be undone?

WE HATE NO. 35: SUPERSTITION

“The general root of superstition is that men observe when things hit, and not when they miss; and commit to memory the one, and pass over the other.”

Francis Bacon: *The Works of Francis Bacon* (1819), vol.2

Christopher Hitchens, writing in *Vanity Fair*, recalled that when Niels Bohr, the Danish physicist, hung a horseshoe over his door, some of his friends were appalled. Surely, they said, you don’t put any trust in such superstition. “No, Bohr replied, “but apparently it works whether you believe it or not.” This is amusing, but conceals a greater truth. The fact is that fortune or misfortune are entirely random, whatever you believe. It would be enlightening if we could know how many crashed cars had been ‘protected’ by a Saint Christopher medallion, what proportion of batsmen were dismissed on 111, or the incidence of misfortune suffered on Friday the 13th relative to other days

The credulousness associated with the number 13 is particularly interesting. A number of clubs based on this common superstition have been established, in some cases simply to poke fun at the myth. One such was set up by William Harnett Blanch (1836-1900), a Victorian gunsmith turned writer. He might have been expected to have had some sympathy with ‘providence’ in that as an infant he had been taken out in his pram when both his parents were killed by an accidental explosion in their gun shop. On the contrary, he grew up to be deeply antagonistic to superstition. So much so that he promoted an organised protest against such beliefs and, with

other journalists and writers, founded London's 'Thirteen Club'. For some years, they held an annual dinner at which traditional taboos were flouted. Details of one such, held in room 13 of the Holborn Restaurant on 13 January 1894 (unfortunately not a Friday), survive. Blanch, who had been elected President for the year, saw the occasion as an opportunity for something rather more vigorous and aggressive than previous celebrations. There were 13 tables, each with 13 diners. The members, wearing green ties and buttonholes of coffins with a skeleton and peacock's feathers, walked under a club ladder when summoned to dinner by the smashing of a large mirror, and sat down in front of crossed knives; they spilt salt from coffin-shaped salt-cellars, and were served by cross-eyed waiters. The famous artist Harry Furniss, who chaired the proceedings and left a detailed, illustrated account of them, clearly had misgivings about this bizarre jamboree, concerned that beliefs which in some places could have such cruel and brutal effects should be the subject of so jovial a charade.

Perhaps he had in mind such sinister (and common) beliefs as the 'evil eye', the notion that a targeted look can visit injury or misfortune upon those on whom it is directed; or sticking pins in dolls to curse an individual; or the casting of spells and other devices to bring harm to one's enemies. Today, there is even a website (www.pinstuck.com) that allows anyone so minded to send an anonymous curse by e.mail. Maxim Magazine thought that this "combines third-world vengeance with no-fuss high-tec communication".

But, on the whole, superstitious practices – too numerous to relate and already the subject of a vast bibliography – are just silly. Nor do they take us to the heart of the matter. Edmund Burke, in his *Reflections on the Revolution in France* (1790), put down superstition as "the religion of feeble minds", carrying the implication that an authentic kind of religion can be espoused by more elevated minds. And, in one of his famous essays, Francis Bacon (1561-1626), by no means an atheist, wrote of "the similitude of superstition to religion". Samuel Johnson's dictionary defined superstition as "false devotion, or religion", without attempting to distinguish false from true. Certainly there is a clear connection: even the apostle Paul (Acts 17.22) cautioned against superstition *within* religion, telling the Athenians (or at least the men folk) that they were "too superstitious". This strikes us as a harsh verdict. The Athenians might be thought to have been scientifically open-minded rather than ignorant when they inscribed an altar: 'To the Unknown God'. Later abhorrence of the superstitious practices of the Catholic church lay at the roots of the Protestant Reformation, while, in regarding atheism as preferable to superstition, Bacon (*ibid*) specifically deplored "pleasing and sensual rites and ceremonies; excess of outward and pharisaical holiness; overgreat reverence of traditions", and other things that had attached themselves to religious worship. Similar strictures have continued over time, but have generally stopped short of regarding religion itself – God worship – as superstitious. Yet religious faith relies on belief, sometimes irrational and against such evidence as we have, even contradicting the accepted laws of nature. One dictionary definition of faith is that of a "spiritual apprehension of divine truth *apart from proof*" (our italics). Perhaps the supremely irrational contortion is that of attempting to reconcile the concept of an omnipotent God with the fact of natural disasters. Believers can go to extraordinary lengths to square this particular circle. Thus William Hone (1780-1842), struck down by a paralytic stroke in church during worship, attributed his misfortune to the Almighty having suddenly suspended his mental and bodily functions. His statement went on: "Every infliction from His hand has driven me closer to Him, and been sanctified by His holy spirit to enlarge my views of His abundant mercies, and ne'er-failing Providence". No less fanciful are those survivors of a conflict who attribute their good fortune to the protection of God, unconscious of the implication that the same God allowed their colleagues to be annihilated.

We will admit, nevertheless, that religious faith deserves a place above other forms of superstition in that, even if erroneous, it may be a force for good and give consolation. And at least the philosophy may be rational. We hope that this has not been too aggressive. Here in Peckham some religious believers proclaim their message through megaphones. We think it only fair that two atheists should have their say.

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 and the 'We Hate' series are available on the Forum's website: www.nif.org.uk.