

not the national information forum

But still 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

ANN: A TRUE CHAMPION

(FEATURE REPRODUCED FROM 'ALL TOGETHER NOW!')

All her life, Ann Darnbrough has fought social injustice...*All Together NOW!* editor Tom Dowling reflects on her lifetime of helping others.



Ann Darnbrough is like a wise, wonderful, fun-loving aunt – with an almost permanent mischievous twinkle in her eyes.

By her own admission, she's been a bit of a rebel in her time, constantly speaking up for the underdog, and continually challenging bureaucracy.

And she hates the Honours' system – even though she herself has an OBE.

For more than half of her life, Ann, now 80, has been fighting to give disabled people a better deal in life – and encouraging others to do likewise.

“Information is now a commodity in such ample supply that many of us feel overwhelmed by it,” she told me when we last met a few years ago.

“We know what it is to experience information overload. But it is a revolution that has passed many people by.

“Alongside information affluence we have information poverty, and the paradox is that those who are information poor are frequently those who need information most!”

And that very much includes the millions of people in Britain who are faced with disability.

“That's why I was so delighted when the Liverpool ECHO started your *I*

Can Do That! disability page all those years ago (1983) – and when it developed into a stand-alone paper. It was a real breakthrough to have this kind of news, presented so positively, in a mainstream newspaper.

“But *All Together NOW!* is better, much better – jam-packed with life-enhancing news and information AND becoming increasingly available in mainstream venues.

Isolation

“People in deep hardship generally lack the skills and the initiative to seek out information, and any inquisitiveness they may have is often blunted by their crushing disadvantage.

“Their isolation is further compounded by the fact that those who have the information tend to wait to be asked for it. So it’s brilliant that *All Together NOW!* is banging the drum!”

Isolation and disability are things that Ann knows only too well.

As the only child of parents living in Madrid, Ann developed TB of the spine, while her mother, Ada, fell victim to cancer.

“My only clear memory is of crawling around the flat. I should have been walking, but doctors advised my parents that I should remain on all fours, rather than putting strain on my back.”

Aged three, she and her mum returned to England (her dad stayed in Spain) and each went into different hospitals.

“Mum never came out. She died when I was five.”

When Ann was discharged from hospital she had nowhere to go – a pattern that continued for the next ten years.

“I was never put into care, just looked after by families who my father could charm into taking me into their households.”

Constantly changing circumstances and living with new people helped her to cope with the challenges life threw at her.

“I quickly developed a strong sense of independence.”

Aged nine, she was back in hospital, again strapped to a leather frame for another two years. And if all that wasn’t enough to cope with, in her final year at school she had to have an emergency operation to remove an infected kidney.

“Fortunately, the operation coincided with the discovery of the antibiotic streptomycin, and the disease was stopped in its tracks, saving my life.

“Perhaps it was this seeming miracle that served to give me the further impetus to make the most of life’s opportunities – and to have fun.”

She’s certainly done that. Four years ago she also found time to write her autobiography, *A Rebellious Disposition*, published by Highshore Press.

Main passion

Outside her disability work, Ann has been an enthusiastic supporter/member of a number of charities including – Liberty, Dignity in Dying, the British Humanist Association, CND, Prisoners Abroad, Amnesty International, the Movement for the Abolition of War and Free Tibet.

She joined the anti-monarchy group Republic in November 1999, served as [a] director in 2009/10 – and is also a fierce defender of animal rights.

But since the early 70s her main passion has been improving the ways of getting information to underprivileged people.

For over 10 years she was the agony aunt of *Disability Now*, has chaired or been involved in the management of several disability charities, and has served as a member of five adjudication panels, including the Snowdon Award Scheme.

In 1972 she was appointed deputy general secretary of the Multiple Sclerosis Society.

“They provided information but it was largely confined to news of research. I felt that people with MS needed wider information such as financial benefits, aids and equipment, and leisure and holiday opportunities.”

So she launched a monthly bulletin newsletter.

Two years later she and her partner, Derek Kinrade, developed the work into what very quickly became a bible for so many disability organisations, the *Directory for Disabled People*.

There were even greater things to come.

When the United Nations set up the International Year of Disabled Persons they had overlooked the vital role

of information. [It] was not included on the agenda.

“When I complained I was invited to do something about it!”

Within months she and Derek – and others sharing the same commitment – had formed the National Information Forum to encourage UK organisations to come up with innovative ways of disseminating news and information.

“It was the only organisation whose prime concern was that every individual should have the opportunity to access the information they need to live lives of choice in our communities.”

The Forum has been Ann and Derek’s main focus ever since.

Sadly, however, time is now catching up...and Ann’s health must again be the top priority.

Earlier this year, when they decided to call it a day, the Forum’s trustees gave the *All Together NOW!* charity a fantastic donation to help us through extremely difficult times – and to develop the paper.

Derek said: “Ann’s single-minded dedication to the provision of information has impacted on the lives of untold thousands of disabled people.

“Now we really want to help *All Together NOW!* to carry on all the good work. We wish the paper every possible success.”

And we wish you both – and all the team at the Forum – every happiness. **Thanks!**

APOLOGY

One of our contacts and her team found my short piece on rape offensive. I think they found the language too explicit. I do not set out to offend and am sorry if anyone else was offended. Nevertheless, I do think that some rapes are more serious than others. And the idea of a 50% discount for an early guilty plea was ludicrous.

GOVERNMENT FOR THE PEOPLE?

Do you detect a whiff of arrogance from the Etonian side of the Coalition? Are you happy with the direction of travel? Is action to address the deficit being applied fairly? Here are some of the milestones that cumulatively give rise to concern (the task of filling up the list I’d rather leave to you):

- removal of 8,000 charities from the Charity Commission register since May 2010
- political polarisation (north v. south; urban v. rural) at its highest point since 1918
- the woodlands fiasco
- tuition fees in England to be increased, with inevitable impact on poorer students
- unfounded expectation that fees of £9,000 p.a. would be “exceptional”
- squeezing of welfare benefits and services, bringing thousands of disabled people on to the streets, not least in protest against the new Work Capability Assessment
- stalled NHS legislation widely criticised. Royal College of Nursing votes “no confidence” in Secretary of State for Health
- Care Quality Commission failure to spot horrific abuse in Bristol care home. On-site inspections said to have been reduced to almost zero
- savage cuts in legal aid (half a million people expected to lose out)
- criticism from the Archbishop of Canterbury (isn’t that Ed Miliband’s job?)
- dramatic rise in homelessness (8% rise in London’s rough sleepers)
- expensive involvement in military action in Libya, arguably escalating far beyond the protection of civilians
- pay gap widening beyond control and to Victorian levels
- gender pay differential (17.1%) has similarly widened in the past year
- Community and Local Government Committee third report concludes that government actions on localism give an overall impression of inconsistency and incoherence
- Oxford University lecturers have voted (283 to 5) “no confidence” in the policies of the Minister of State for Universities and Science.

In our February issue we wrote in praise of U turns when politicians find that they have taken a wrong turning, but repeated recourse to this manoeuvre suggests bad driving.

DEVASTATING EFFECTS OF WELFARE REFORMS ON PEOPLE WITH MENTAL HEALTH PROBLEMS

On 1 June *The Guardian* published an open letter from six leading people from the mental health sector: Paul Farmer (CEO, Mind), Paul Jenkins (CEO, Rethink Mental Health), Professor Bob Grove (joint CEO, Centre for Mental Health), Dr. Jed Boardman (consultant and senior lecturer, Royal College of Psychiatrists), Bill Walden-Jones (CEO, Hafal) and Billy Watson (CEO, Scottish Association for Mental Health). They claimed that the reform of the welfare system was already having “devastating effects” on the mental health of hundreds of thousands of people across Britain. Incapacity Benefit reassessments using “the deeply flawed Work Capability Assessment” were due to start next month, and the new Personal Independence Payment test would be trialled over the summer.

The prospect of Incapacity Benefit reassessment was already causing “huge amounts of distress”, with some cases of people taking their own lives following problems with changes to their benefits. The signatories were hugely worried that the benefits system is heading in a direction which will put people with mental health problems under even more pressure and scrutiny, at a time when they were already being hit in other areas, such as cuts to services. They argued that there “needs to be a shift towards a more sympathetic and supportive system that genuinely takes into account the additional challenges people with mental health problems face and can make a real objective assessment of their needs rather than placing them into a situation where their wellbeing is put at risk.”

HOUSE OF LORDS DEBATE TO CALL ATTENTION TO THE IMPACT OF GOVERNMENT POLICIES ON DISABLED PEOPLE

Given the sheer volume of parliamentary business it is difficult to keep an eye on everything that is happening. We therefore call special attention to a debate on 5 May, moved by Lord Low after success in a ballot, available on the www.parliament.uk site. We can, of course, give only a flavour of what was said.

Lord Low regretted that Lord Morris (of Manchester) could not be present. It was ironical that, in the 40th anniversary year of the coming into effect of his historic Act (The Chronically Sick and Disabled Persons Act 1970) the Lords was discussing the possible rolling back of so many of the gains for disabled people that it set in train. The question put was whether the coalition is living up to its pledge that fairness is at the heart of its programme of decision-making, so that those most in need are protected. Disabled people, said Lord Low, are “angry and fearful”. There is “a sense that Ministers are not listening”. The flagship policy of getting people off benefit and into work was welcome, but the devil was in the detail. He outlined the proposed changes and their devastating effect. Particular concern was felt over the reassessment of people on Incapacity Benefit: this was “deeply flawed”, with 40% of appeals succeeding. There had been widespread dissatisfaction with Atos Healthcare, the company handling the process. Ministers were failing to see the consequences of their policies. “Using the threat of loss of benefit in an attempt to force people who are not work-ready to work, or for whom there is no work,” he said, “is plain sadistic.”

Other peers raised particular concerns. Lord Addington thought that probably the most inept thing to have been heard was that the Equality Act is regarded as red tape. Baroness Campbell feared for the hard-won progress made to encourage and support independent living. Julian Fellowes (now Lord Fellowes of West Stafford), in a maiden speech, argued that limiting assistance to find work to one year in relation to Employment and Support Allowance could be seen as a false economy. Lord Rix said that, while he appreciated the current financial pressures facing the government, “there can be no excuse for allowing disabled people to suffer as a result”.

Baroness Wilkins made the point that “the government might not have intended disabled people to be the ones who suffer most under their policies, but that is most certainly their effect.” She pointed out that the Demos report, *Destination Unknown*, calculated that the impact of the emergency budget last June alone will mean that over the lifetime of this parliament disabled people and their families will lose a total of about £9 billion.

Lord Taylor of Holbeach, responding, assured the House that the government took its commitment to fairness seriously. The real impact of its policies on disabled people will be to empower them to establish the right and opportunity to work, to encourage accessibility and to provide greater choice and control over how public

money is spent to deliver independence and ensure that no one is ever written off because of disability.

Those who read the full debate will make up their own minds. For our part, we find the government line ‘a bald and unconvincing narrative’. The RNIB magazine NB has commented that there has been little movement on the part of the government in response to amendments raised at the committee stage of the Welfare Reform Bill.

We think that at least four distinct groups (of working age) are involved here, each requiring a different approach:

- those whose disabilities are such as to render them wholly incapable of work
- those whose disabilities are such that they are capable of some work, but find it difficult to secure employment
- those whose disabilities are not significant but who lack confidence and have become locked into a culture of dependency
- those who are simply work-shy and who play the system (benefit cheats)

ACCESS TO WORK

The number of new grants for adaptations and equipment under the Access to Work scheme fell sharply in the first three quarters of 2010-11. Funding is now being concentrated on equipment that employers are not legally obliged to provide, a policy that is difficult to reconcile with the drive to get disabled people into work.

CLOSURES

DEAC: The Disability Employment Advisory Committee has been abolished. It was set up in 2002 to provide ministers and officials with strategic advice on disability employment. Equality 2025, with a wider remit, is said to be available to fulfil this role.

COI: The Central Office of Information, set up in 1946, is to be scrapped in April 2012. A letter to The Guardian (26 June) described the abolition as “foolish vandalism”.

(Last October Francis Maude announced the so-called ‘bonfire of the quangos’. 192 public bodies would be scrapped or taken into ministerial or local government control. A further 118 organisations would be merged and another 171 substantially reformed.)

ILF: The government has indicated that it intends to close the Independent Living Fund in 2015. It was closed to new applicants on 1 May 2010.

SPINAL INJURY

A new website has been created to raise awareness of spinal cord injury among the general population, with information about the impairment as well as case studies, video testimonies and an online quiz. Go to www.everyeighthours.com

ASSISTED DYING

Sir Terry Pratchett’s film for BBC2, *Choosing to Die*, which showed Peter Smedley taking his own life at the Dignitas clinic in Switzerland, has shocked some viewers. But just why is there this great fear of death and desire to close our eyes to it? It is an everyday reality. And just why do so many people want to prolong their lives beyond the point of meaningful quality? What are they afraid of? I found the film absorbing, rational and moving, and Peter’s calm choice, having assessed his future with and alongside his wife, eminently sensible. Not everyone will want to make that decision, but I think it is high time that a free choice to die should be enshrined as a basic human right and not limited to those who can afford the cost of travel to Switzerland and the £10,000 charge.

THE INTERNATIONAL SYMBOL OF ACCESS



In the June issue of *Forward*, the magazine of the Spinal Injuries Association, wheelchair-user Max Reid has come up with a new alternative to the access symbol designed in 1968. He thinks that his suggestion looks as though the wheelchair user is about to go somewhere, to do something; and if help is needed, it will be asked for. Couldn’t agree more. Max says that if you like it, feel free to use it and publicise it. He has no intention of copyrighting it: “If it helps to change the image of disabled people from passive to active, that will be

reward enough for me.”

Max can be contacted at HalfmanHalfwheelchairAllmusic@gmail.com

MOBILITY SCOOTER INSURANCE

Mobility scooters and powered wheelchairs are currently excluded from the normal motor vehicle requirement to have insurance to cover against third party injuries and damage. But a recent accident, in which a scooter crashed into a Wigan pensioner, causing hip and thigh fractures, has reopened the argument for a change in the law. Such incidents appear to be on the increase and may involve the users of such vehicles in sizeable claims.

SOCIAL CARE CUTS RULED UNLAWFUL

In an important ruling, with wider implications, the High Court has found that Birmingham City Council (currently Conservative/Liberal Democrat) acted unlawfully in deciding to cut its provision of care for disabled people. The authority proposed that funding for social care should be limited to those in “critical” need, a move expected to stop care packages for around 4,000 adults. Mr Justice Walker held that the intended cuts failed to meet requirements of the Disability Discrimination Act 1995.

POSSIBLE LEGAL CHALLENGE TO WELFARE REFORM

The Disability Alliance, having taken legal advice, believe there is a “very credible case” for action against the Department of Work and Pensions over cuts in Disability Living Allowance expenditure.

WE HATE NO. 43: LITTER

Derek Kinrade

“It’s 56 years since the foundation of the Keep Britain Tidy campaign, and if you want to see how successful this well-meaning yet feeble organisation has been, take a look around us at the trash on our streets.”

Jeremy Paxman, launching the Clean Up Britain (CLUB) campaign, 23 June 2011.

Litter is an age-old problem, but modern consumer patterns are such that it is getting much worse. There are two drivers: those who discard the litter and those who provide it. And Paxman is right; Keep Britain Tidy (KBT) has been ineffective and the evidence is to be seen in the garbage deposited on our roadsides. But he is uncharacteristically gentle in saying that those who create offensive litter don’t do so deliberately. Well, that may not be their primary intention, but they are at the very least perverse, socially inept and irresponsible. I see it as only one step below vandalism. Their attitudes might be compared to those who play loud music late at night to the distress of their neighbours: a contemporary anti-social malaise characterised by a ‘couldn’t care less’ mentality. It isn’t confined to young people, but owes a great deal to a generation that doesn’t treasure fine food and eats on the hoof.

The other villains of this problem are those companies who over-package goods, not least by marketing food on plastic trays and wrappers, helping to create identifiable and enduring refuse on our streets, in our gardens and over our countryside. One can understand that they want to be household names, but it is sad that they should be content to be familiar as part of the proliferation of rubbish.

Litter and waste generally is an immense problem; witness the outcome of the government review of waste management reported in Parliament on 16 June. Discarded waste is unattractive, provides a breeding ground for disease-carrying insects and rodents, endangers animals who ingest plastic or cut themselves on broken glass and tins, and is very expensive to clean up. KBT reports a four-fold increase in litter in the last five years with over 30 millions tons collected every year. It costs £858 million annually to clean the streets of England, while the rat population of Greater London is now estimated at seven million: 12,500 per square mile. Legislation – the Environment Protection Act 1990 and the Clean Neighbourhoods and Environment Act 2005 – appears to be ineffective, and KBT’s ‘softly, softly’ approach (less about blame and more about the personal responsibility of individuals) has yet to yield results. While not wishing to be drawn into the criticism of KBT, I cannot resist observing that ‘Tidy’ sounds coy and genteel, and ‘Keep’ is entirely inappropriate. The KBT website is a mine of information, but its multi-layered seams and verbosity distract from genuine confrontation. The organisation launched an anti-litter campaign on 28 June called ‘Love Where You Live’. I see what they mean, but alas it

ignores the fact that many neighbourhoods are anything but loveable.

Websites for information (if not necessarily solutions):

- www.cleanupbritain.org
- www.keepbritaintidy.org
- www.cpre.org.uk
- www.cleanupuk.org.uk
- www.litteraction.org.uk (run jointly by CPRE and CleanupUK)