



THE PHOENIX

Campaign for Independent Living in Lewisham

June 2006

Message from Denise Smith, Chair, Campaign for Independent Living in Lewisham (CILL)

CILL has had some good news in the last few days – our first round application to The Big Lottery for funding for a Centre of Independent Living in Lewisham for five years has been successful and we have been asked to put in a further more detailed application. So far so good but we still have a long way to go and a lot of work to do. Earlier this month CILL was at Lewisham's very first Disability Forum (organised by Lewisham Disability Coalition - LDC) and LDC will be producing a report in due course. CILL will be at the Community Fair at The Goldsmiths Community Hall, Castillons Road, Downham on Friday 26 May from 10.30 a.m. to 2.00 p.m. so please come along and meet us.

Campaign Updates

Inaccessible New Shop Front in Catford – Although CILL has had no reply from LBL Planning (John Lloyd Stephenson) in response to our letter asking how DDA Part 3 is taken into account when planning permission is approved we have heard that Lewisham is now to undertake a review.

No GP Home Visits – This has been successfully resolved since CILL wrote to the practice. Following a visit from one of the doctors it has been agreed that the need for a home visit will be assessed whenever a visit is requested.

Lift at the Civic Suite – You may remember that a new platform lift was installed at the Civic Suite last year. Despite complaints from CILL that the lift was dangerous, LBL had made no progress in resolving any of the issues we raised. This week CILL was invited to a meeting at the Civic Suite to discuss the lift.

End of funding causes job loss to disabled man – A blind man who lives in Lewisham and who has worked for Action for Blind People in Southwark for the last 21 years is about to lose his job because Lewisham Council is stopping funding. CILL has written to Aileen Buckton (Executive Director Community – (Ills LBL) for clarification as to why this decision has been taken and to persuade her that this very small funding cut will be a false economy in comparison to the potential cost of funding to manage this person's care in view of the long term emotional distress that will be caused.

If there is an issue affecting you and your independent living please contact CILL for advice and support.

DISC (Disabled Interactive Social Club)

The very first social get together for the club was held on Tuesday 16 May at The Bridge Leisure Centre in Sydenham. The meeting started off in the function room at 7.00 p.m. and moved into the bar area later. This was a great opportunity for young disabled people to meet each other and to plan what DISC does next. Suggestions so far are disabled ski-ing, bowling, go-karting or a day out.

The next meeting will be in June so if you want to get involved please contact David Bourroughs at davidbourroughs@hotmail.com or by phone on 020 8659 6762.

Out and About

Out and About is one of CILL's Active Life Projects and is having its first meeting on Sunday 28 May at Ladywell Fields. A leaflet giving full details is enclosed.

Volunteering – Suki at Volunteering Centre Lewisham

It is Volunteers Week from 1 - 7 June and Volunteer Centre Lewisham will be holding a number of events during the week. We will have a stall in Lewisham Shopping Centre on Friday 2nd June to raise awareness amongst people in Lewisham about volunteering, featuring a prize draw. We are also having an art exhibition in our office from 1st June to 7th June exhibiting artwork about volunteering and community involvement, everyone is welcome to attend. If you would like to enter a piece of artwork send it to us before 22nd May 2006. If you are interested in volunteering and or would like more information please contact Suki on 0208 613 7113.

British Gas Rebates

Households buying Gas and/or Electricity from British Gas, where someone in the house is receiving certain benefits are eligible for rebates. The rebates are: Gas £60 a year paid in two instalments (£30 paid in the last quarter's bill in 2006 and £30 in the first quarter's bill in 2007). Electricity £30 a year paid in two instalments (£15 paid in the last quarter's bill of 2006 and £15 in the first quarter's bill of

2007). Eligible benefits are Disability Living Allowance, Carers Allowance, Child Tax Credits, Incapacity Benefit,

Severe Disability Allowance, Council Tax Benefit, Housing Benefit, Income Support, Income based JSA, Pension Credit, Attendance Allowance, War disablement Allowance, War Pension. To register 'phone 0845 601 2006 and you must have your British Gas and/or British Gas Electricity account number(s) available. **There is a short registration period so you need to register as soon as possible.**

Lewisham Libraries Home Library Service - Christine Dixon, Librarian

Do you know about Lewisham Libraries Home Library service? Would you like to receive the service? For many years we have offered a home library delivery service to those people who by reason of disability, illness, age or being a 'carer' cannot get into the library to select their own books. The service is completely FREE and we are very proud to offer it. Once registered with us, each member receives a monthly visit from a library staff member who delivers specially chosen books (in large or ordinary print), talking books, music CDs, videos and jigsaws. Individual requests are encouraged. We are starting to offer our Home Library users special days when we organise events in the library and transport them in. If you would like to receive the service – or you know of somebody else who would – all you need to do is ring me at Forest Hill library (0208 699 2063). I will then arrange for somebody to come and explain the service to you and register you.

RNIB Talking Book Service is a library of professionally recorded audio books, delivered through the post to your door. Types of books available

- Popular fiction, classic titles, non-fiction.
- Over 10,600 titles available (January 2006).
- Suitable for people of all ages.
- Books are mostly unabridged, read them as the author intended.
- Most books are contained on a single CD giving up to 24 hours of listening per disc!

The RNIB considers all requests from customers, its book selection group meets every month and works to provide you with the books you want to read.

You are eligible to join the service if you live in the UK and cannot read standard typescript (N12 or less) at normal reading distance using glasses. To join the service, contact RNIB Customer Services on 0845 762 6843 or email cservices@rnib.org.uk

New online resource will help further raise standards of interpreting for Deaf people

RNID, the national charity representing the 9 million deaf and hard of hearing people in the UK, and ASLI, the Association of Sign Language Interpreters have joined forces to launch the first ever professional development website for Sign Language Interpreters worldwide.

The website, www.pd4me.info, aims to make professional development resources accessible to all interpreters, including those who may not be able to access them for geographical, financial, or other reasons. This initiative aims to bring together resources, experience and good practice to raise the existing high standard of interpreting for deaf and hard of hearing people.

Cil funding crisis – Edited, Elizabeth Choppin, Disability Now May 2006

A funding crisis is threatening services run by disabled people across the UK, Disability Now research has confirmed. Half of the Centres for Independent Living (CIL) which responded to DN's random survey reported that all or part of their funding was under threat or has been in the last year. Of 12 respondents, eight said their work was undervalued and six reported their services were under threat.

In the wake of recent cuts and closures of CILs and user-led organisations, campaigners are concerned that the government risks not delivering on policies laid out in the Prime Minister's Strategy Unit report, Improving the Life Chances of Disabled People (ILC), which called for an organisation run by disabled people in each local authority.

GLAD on verge of collapse - Edited, Priya Kotecha, Disability Now, May 2006

London's leading organisation of disabled people appears to be on the verge of collapse, after all its staff were made redundant. The redundancies came after the Association of London Government (ALG) confirmed it had withdrawn Greater London Action on Disability's (GLAD) core funding.

GLAD had six months from last September to show "significant improvements" in how it was spending its grant, reportedly worth £300,000 a year. The money has now been ring-fenced for other disability services in the capital.

Disability campaigners said they were "saddened but not surprised" at GLAD's demise.

David Morris, disability policy and project manager at the Greater London Authority (GLA), said: "I think that it's something that's been expected for a long time. Disabled people in London have been very let down with the shenanigans that have gone on at GLAD."

Helpline and Information Service

The Association for Spina Bifida and Hydrocephalus (ASBAH) is marking its 40th anniversary with a fundraising drive to raise the £300,000 needed to launch a national Helpline and Information Service.

Assistant Director (Services), Mary Malcolm said: "Whenever people pick up the phone we want to make it as easy as possible for them. And while we provide the best possible service we can, we can't guarantee that there's always someone free to listen.

"A one-to-one conversation can do so much to allay people's fears and put their minds at rest. Knowing that there's someone at the end of the phone can be reassuring."

ASBAH's Helpline and Information Service will provide help and support on all aspects of spina bifida and hydrocephalus - from antenatal enquiries, health and social care, education.

Finger-spelling Fridge Magnets

Want a fun way to leave messages on your fridge? Want to learn finger-spelling?

British Deaf Association has created a set of fridge magnets, each of which has one letter of the alphabet for finger-spelling. For £5, you get a set of 50 letters, which you can use to write your personalised messages on your fridge (or other magnetic surfaces). They are great for people to practice their finger-spelling.

To order the magnets, send £5 plus 50p postage and packing (per set of magnets) to British Deaf Association London and South East, 69 Wilson Street London, EC2A 2BB Email: london@signcommunity.org.uk Videophone IP: 81.138.165.105 Text- phone: 020 7588 3529 Telephone: 020 7588 3520 Fax: 020 7588 3527 and you could be turning your fridge into a finger-spelling noticeboard! These magnets are fun to use with children, but we recommend that they are not suitable for children under 3 years old.

'I hoped our baby would be deaf' – Edited from The Guardian, March 2006

Most parents would be distressed to learn that their child had been born unable to hear. But for Paula Garfield and Tomato Lichy, it means daughter Molly can share their special culture. When a pregnant mother is asked if she would prefer a boy or a girl the response is pretty formulaic - "I don't mind as long as it's healthy." Which, put another way, means: "I don't mind as long as it's not impaired in any way." But what if the expectant mother or father actually preferred it if the baby wasn't "healthy", in the sense that we understand the word, but instead was profoundly deaf?

So, why? The answer for Paula Garfield and her partner Tomato Lichy, an artist and writer, lies in language. Lichy argues, "Being deaf is not about being disabled, or medically incomplete - it's about being part of a linguistic minority. We're proud, not of the medical aspect of deafness, but of the language we use and the community we live in. We're delighted that that is something our daughter can share as she grows up."

They continue to feel under pressure to explain and defend their actions. Garfield says, "We have Deaf friends and families. But these doctors, and many other people, generally know so little about the Deaf community, culture and language, yet they assume they know what is right for us. They have a perception that deafness is a physical failing that needs to be corrected. For us, it's just a different and equally valid way of being"

Decision eases Sativex access - May 2006

The government's has decided to issue an "open general licence" for importing the cannabis-based spray Sativex. The Home Office decision to simplify the licensing process means doctors and pharmacists only have to obtain a single import licence to supply or stock the medicine for all their patients, instead of applying for one licence per patient.

An MS Society spokesman said the decision would help reduce paperwork for doctors. He said: "Anything which helps to simplify the process is to be welcomed, but obviously we want to see people having equal access to the medication, whatever that may be."

Lost - audio description campaign success!

Lost fans complained straight away that the new television series of Lost that began on Tuesday 02 May wasn't audio described. Many visually impaired people were left very disappointed - after enjoying the first series, which was audio described, the long awaited second series was not.

Channel 4 said; "Following the recent feedback from you and some other users of AD, we have decided to recommence the audio describing of Lost."

The RNIB says, "Brilliant news! It really demonstrates that campaigning (or complaining) works - so please carry on!" If you're an audio description fan please join the RNIB's campaign to increase audio

description targets. Ofcom are currently carrying out a Television access services review. The RNIB also wants people to tell their MP how valuable audio description is. Email campaign@rnib.org.uk for a letter to send to your MP and tell us what you think about audio description targets.

Loophole to be closed – Edited from Disability Now, May 2006

Government plans to close a notorious loophole in mental health law. In March, the Department of Health announced plans to introduce safeguards into the Mental Capacity Act - passed in 2005 - to protect people who lack the capacity to give consent for treatment. The issue, known as the "Bournewood Gap", refers to a case in which HL, who cannot be named, was "informally" detained in Bournewood Hospital in Surrey for several months.

He could not appeal against his detention until being "sectioned" under the Mental Health Act.

The European Court of Human Rights found in 2004 that HL's human rights had been breached.

Strict new rules on passports – Disability Now, May 2006

Families with disabled children have been advised to apply early for passports because of strict new photograph guidelines. The rules were introduced by the UK Passport Service (UKPS) to meet new international standards. But the charity Contact a Family (CAF) said some parents were finding it difficult to secure approval of passport photos for their disabled children.

Passport pictures must now show the full face, with eyes looking forward and mouth closed, together with other requirements that can be impossible for some disabled children and adults.

The Home Office said exceptions were allowed for disabled people but increased the risk of being turned back by other countries' passport control. Consultations are continuing with disability groups, including CAF. Passport Adviceline, tel: 0870 521 0410

News from the MS Society

MS Specialist Nurses Under Threat

The MS Society fears that specialist MS nurse posts are under threat due to the cash crisis affecting the NHS. The Society will be joining the Royal College of Nursing to lobby the Government to put an end to the uncertainty over specialist posts.

New and improved travel insurance from 2 May 2006

Multiple Sclerosis Society Insurance Services has recently completed a review of its travel insurance for people living with multiple sclerosis, their family, carers and supporters of the Multiple Sclerosis Society. As a result of the review, Multiple Sclerosis Society Insurance Services has designed a new travel insurance. In nearly all cases:

- You will be able to purchase your travel insurance in just one call.
- You will get the cover you need regardless of age or medical conditions you declare.
- You will be pleasantly surprised by the competitiveness of the premiums.

There are many more benefits as well. Call today for your free no obligation quote on 0800 783 3157

Young Carers Fund

Are you a Young Carer? Or do you know someone who is?

The Young Carers Fund recognises the support provided by so many young people to relatives and loved ones who have MS. Many children take on caring responsibilities to help the family cope with the challenges that MS brings. For some, these responsibilities will increase to such a level that they cannot take part in many of the everyday activities of childhood such as going on school trips.

Through this fund, the MS Society can offer the opportunity to some young carers to fulfil a personal goal or wish and by doing so, to recognise their ongoing dedication and support. A copy of application forms and criteria for individuals are available to download and print – www.mssociety.org.uk

Sense launches new technology section

Assistive technology – everything from computers to liquid level indicators – can play an important role in helping deafblind people to maintain their independence. Four out of five deafblind people say that they use assistive technology – and yet many find choosing the right technology difficult and confusing. Sense's Technology Advisory Project has been set up to help deafblind people, and others who support deafblind people, to make the most of technology. The Technology Advisory Officer is available to answer queries. Details of products are now available on www.sense.org.uk/technology. Sense's website will also have a feedback facility where deafblind people can comment on products they have used.

You can contact Sense by email at: technology@sense.org.uk. Alternatively call the Sense information line on: 020 7272 7774 (voice) or 020 7272 9648 (text).

"Independent Living is not a service, it is freedom; it is liberation; it is equality for disabled people"

