



THE PHOENIX

Campaign for Independent Living in Lewisham

June 2007

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

Nationally there is a crisis about social care and locally Lewisham Council is undertaking a review of adult services. Yes, these are uncertain and difficult times for disabled people and all of us will have different issues that affect our lives. CILL believes that as disabled people we have the right to get our voices heard and our concerns taken seriously and that until our voices are heard we will **never** influence the services that shape our lives.

That is why I am very pleased to be able to tell you about a meeting CILL is managing in partnership with Lewisham Community Network (LCN) for disabled people to come along and have their say about anything that matters to their independent living.

The Lewisham Strategic Partnership (LSP) brings together representatives from the public, private, voluntary and community sectors to ensure that partners from all three sectors work together. Some of the aims of the LSP include improving all public services, focusing service delivery on the needs and aspirations of local people (including those who are traditionally excluded) and finding ways to encourage people to be involved in their communities.

As a community representative on the Lewisham Strategic Partnership I will take your views to the LSP because they need to hear how their services and decisions impact on our lives. I will also be taking your views to the wider voluntary and community sector via the LCN.

This is a great opportunity for disabled people to come together and speak up about the issues that matter to them. Our chance to get our voice heard and to put our concerns on the strategic agenda.

I hope to see you but if you cannot get there and you would like your views to go forward into our strategic report then email campaign@fsmail.net or write to us at CILL, 5 Silverdale House, Silverdale, London SE26 4SD.

**INDEPENDENT LIVING IS UNDER THREAT!
HAVE YOUR SAY**

**Come to a meeting at The Civic Suite, Catford SE6
On Tuesday 12 June 2007
5.30 p.m. to 8.00 p.m.**

Activities and Campaigns

People's Day – CILL met with representatives from Lewisham Council to discuss access arrangements at this year's People's Day. There will be different arrangements for stewards this year which should mean more awareness for the needs of disabled people and the top path in Mountsfield Park has been re-surfaced making access easier.

The big issue is accessible toilets and this year there will be four (two on upper and two on the lower levels) and where possible they will be sited on hardstanding within sight of the main toilet blocks (this may not be possible for 1 toilet on the lower level). Toilets will have working locks, anti-bacterial handwash will be available and programmes will show where all toilets are located.

People's Day is the largest event of its kind in South London and making sure it all goes smoothly is a huge task. Lewisham Council wants everyone to enjoy the day, Lis and Kellie are working really hard to make it happen, all you have to do is get out there and enjoy it.

Downham Leisure Centre – The follow-up visit to look at access at the new Downham Leisure Centre has been arranged. Full details will be in the next edition of The Phoenix.

Loampit Vale Leisure Centre – CILL was involved in a meeting to look at access for the proposed new leisure centre to be part of the development of Loampit Vale.

Lots of issues were looked at including parking and drop-off areas, signage, pool water temperature, pool hoist and chair transfer, accessible changing facilities and washrooms. As yet there are no drawn up plans so everything is being considered.

There will be further and wider consultation with other impairment groups and CILL will continue to lobby for one full access changing room (lavatory, shower, hoist and changing bed). Developments will be reported in The Phoenix.

Disability Equality Scheme (DES) Review – CILL has now met with Lewisham Council (Elizabeth Sclater and colleagues from Policy and Planning). Lewisham wanted to hear our views about the current scheme and also how we might work together over the next year to revise it for 2008-2011. This was a very, very positive meeting. CILL is now producing a short paper for Lewisham outlining our views and how we would like to see the DES develop. We will give specific details in next month's issue but for us a major issue is moving beyond consultation about decisions already made to involvement in the decision making process.

Advocacy and Independent Living Support Groups –

Monday 21 May	1 p.m to 4 p.m.	Lewisham Library, Lewisham High Street, SE13	Advocacy
Thursday 24 May	1 p.m to 4 p.m.	Ringway Centre, 268 Baring Road (opposite Coopers Lane, SE12	Advocacy
Wednesday 30 May	1 p.m to 4 p.m.	The Albany, Douglas Way, Deptford, SE8	Independent Living Support Group plus Advocacy
Monday 4 June	1 p.m. to 4 p.m.	Lewisham Library	Independent Living Support Group plus advocacy
Thursday 7 June	1 p.m to 4 p.m.	Ringway Centre	Independent Living Support Group plus Advocacy
Wednesday 13 June	1 p.m to 4 p.m.	The Albany	Advocacy
Monday 18 June	1 p.m. to 4 p.m.	Lewisham Library	Advocacy
Thursday 21 June	1 p.m to 4 p.m.	Ringway Centre	Advocacy

House of Lords approve Independent Living Bill

Lord Ashley of Stoke's Disabled Persons (Independent Living) Bill, completed its legislative passage through the House of Lords on 24 April. The Bill will now proceed to the House of Commons. Earlier this year over 150 MP's signed an early day motion in support of its provisions.

Lord Ashley's Bill was introduced in the House of Lords in November 2006 against a backdrop of increasing scarcity of social care support to millions of families. Last year 7 out of 10 local authorities admitted to only offering support to people whose needs were judged to be 'critical' or 'substantial', with 8 in 10 of the same authorities anticipating further tightening this year.

If enacted, Lord Ashley's Bill would provide a right for disabled people not to be placed in residential care against their will. The Bill would also safeguard the health and well being of carers and reduce dependency on social care provision by placing duties on local authorities and the NHS to increase opportunities for independence. Crucially the Bill would eliminate the post code lottery in the quality of social care and require agencies to pool funds to ensure better co-ordination of resources and cutting back on red tape.

Deaf Awareness Week: 7 - 13 May 2007

Volunteering England celebrated Deaf Awareness week with the first ever video introduction for British Sign Language (BSL) users on its website. Produced for Volunteering England (VE) in conjunction with the British Deaf Association (BDA), an introductory video aims to improve accessibility and outreach to the deaf community. It outlines Volunteering England's work and services for anyone working with volunteers and signposts potential volunteers to volunteer centres. When asked whether volunteering organisations were well prepared to work with and support deaf volunteers, 64% replied "not at all", 16% said, "just about", and only 20% said "yes".

To watch the video and for further case studies, visit: www.volunteering.org.uk/bsl

The RNID's 7 simple steps

During Deaf Awareness Week the RNID worked to raise awareness of the issues deaf and hard of hearing people face and encouraged people to take part in 7 simple steps. The steps are simple but they can make a big difference, such as learning new communication skills like fingerspelling or checking your own hearing.

Step 1: Don't SHOUT, just speak clearly

Take the time to communicate properly with someone with a hearing loss.

Deaf and hard of hearing people can feel isolated and excluded. Learning how to communicate with someone with a hearing loss can make a real difference to them.

Step 2: Check your hearing

Phone 0845 600 5555 (local rate) for a five-minute check-up Around 4 million of us are losing our hearing and not doing anything about it. Research suggests that this is because people feel embarrassed and are worried about what other people will think of them. We're working to change this view.

Step 3: Learn to fingerspell

It's as easy as A-Z! You can use fingerspelling to communicate with someone who uses British Sign Language (BSL).

Step 4: Watch your favourite TV programme with the sound off

Without TV subtitles, what would you miss out on? Research shows that one million people depend on subtitles while a further four million use them regularly. But not all programmes are subtitled.

Step 5: Turn your music down a notch

Protect your hearing – don't lose the music! If you listen to loud music or regularly go to clubs, gigs and festivals, you may be damaging your hearing

Step 6: Look out for the loop sign

How accessible are public places if you wear a hearing aid? Induction loops reduce background noise for hearing aid wearers so that sound can be heard more clearly.

Step 7: Get Involved

Campaign... join in... volunteer... donate... We need you! Don't stop now! Carry on raising awareness of deafness, hearing loss and tinnitus:

British Sign Language Charter

The British Deaf Association's British Sign Language Charter is a campaign to give real and practical meaning to BSL recognition. BSL Recognition does not mean anything unless it is backed by action. The BSL Charter aims to offer a 'roadmap' of how to start and carry out that action. Doing so will achieve three things:

- Firstly, it will enable Local Authorities to take a lead in meeting the terms of the Disability Discrimination Act and the Human Rights Act.
- Secondly, the adoption of the BSL Charter by Local Authorities will help to develop greater awareness of BSL.
- Thirdly, it will lead to greater inclusion of Britain's Deaf community in today's society, enabling them to benefit from the services on offer and also to contribute as citizens.

When a Local Authority signs up to the BSL Charter, they commit themselves to taking action to implement five initiatives:

Charter Pledge 1 - Improve access for Deaf people to local services and information

Charter Pledge 2 - Promote learning and high quality teaching of BSL

Charter Pledge 3 - Give all deaf children and young people the option of a bilingual education (BSL/English)

Charter Pledge 4 - Ensure key staff who are working with Deaf people meet minimum standards of BSL skills

Charter Pledge 5 - Consult with the local Deaf community on a regular basis.

Access guide provided by the Society of London Theatre

Councillor Mark Morris has informed CILL that every three months the Society of London Theatre produces a guide listing all theatre productions in London which have captioning, signing or audio description.

For a copy of the publication and other details contact Lucinda Harvey at 0207 557 6700, access@solttma.co.uk, www.officiallondontheatre.co.uk/access, Lucinda Harvey, Society of London Theatre, 32 Rose Street, London WC2E 9ET. It is also possible to just get on the mailing list for the publication.

Funding cuts could hit hard – edited from Disability Now, Sunil Peck, May 2007

Disabled people could be hit hard by funding cuts to the Department for Work and Pensions (DWP), say campaigners. The DWP, which funds disabled people's benefits, the Office for Disability Issues, and the Pathways to Work and Access to Work jobs programmes, is to receive a below inflation settlement.

A DWP spokeswoman told DN: "The departmental settlement applies across the DWP. How that settlement will be distributed is still to be decided at this time in the spending cycle."

London Underground launches groundbreaking accessibility information service to ease travel

London Underground (LU) is investing £1.5bn to improve access for customers.

Now, thanks to the expertise of Direct Enquiries, the Nationwide Access Register, LU can help customers plan their journey from street to platform, prioritising their search according to their individual needs. Routes available include both street-level to platform and interchanges (platform to platform). Details include the number of steps, lifts, escalators, walking distances, ramps and platform to train gap width.

Designed for people with specific access needs, including disabled people, parents with pushchairs and those carrying awkward loads Direct Enquiries also provides access information on nearby shops, tourist attractions, public buildings and other services.

This new resource will complement LU's existing access information, which includes the Tube Access and Getting Around London guides, as well as other products such as audio guides and large print and tactile maps, and will boost customer independence on the network.

If you have any further questions regarding Direct Enquiries, please contact Robin Hall via email at robin.hall@tube.tfl.gov.uk or phone on 0207 918 3524.

Ashley bill would also help young carers - edited from Disability Now, May 2007

Lord Ashley's independent living bill would offer new protection to children who care for disabled relatives, thanks to an amendment agreed during its committee stage. The private member's bill, which is backed by the Disability Rights Commission, aims to eliminate the postcode lottery in the quality of social care for disabled people.

The amendment during the bill's committee stage in the House of Lords in late March means social care agencies would not be able to allow a disabled person to rely on the care and support of a young person if it affected the child's health, well-being, or education and leisure opportunities.

Alex Fox, an assistant director for the Princess Royal Trust for Carers, said: "No parent wants to rely on the care of their child if they have a disability or develop a long-term health condition, but this is an increasing reality for many disabled parents who are refused support until they reach crisis point."

MS Society appalled at NICE Tysabri recommendation

NICE, the Government's drug watchdog, has recommended against the prescription of one of the most effective drugs so far developed to treat MS. Based on data from clinical trials and the cost of Tysabri, NICE has advised that the efficacy of Tysabri is not proven or that the cost is simply too much. The MS Society is urging its members to take part in NICE's consultation before a final decision is reached.

MS Society chief executive Simon Gillespie said: "The MS Society is appalled that NICE has recommended turning down one of the most effective drugs licensed so far for the treatment of aggressive multiple sclerosis (MS). But given NICE's track record on MS drugs, we are not surprised.

"In clinical trials, Tysabri has shown a significant reduction in relapse rates and a reduction in the risk of disability progression. This means the small number of people with MS who stand to benefit - probably around 2-3 percent of

everyone with MS - could face a better quality of life, stay in work and off benefits, and experience far less of the pain and isolation

"The UK is now alone in rejecting this drug. More than 10,000 people with MS in Ireland, Germany, the USA and elsewhere are already benefiting. NICE has decided people with aggressive MS in the UK are simply not worth it."

No respite for ministers until wards scandal is ended

Commenting ahead of publication of the Department of Health's mixed-sex wards report, Sophie Corlett, Mind's policy director, said, "We're very glad that the Department of Health is now acknowledging the scale of this problem. But there must be no respite for ministers until the grim conditions on our mental health wards have been vastly improved. Mental health wards should be the most safe and comforting of all places, yet at the moment, for many people they are the most fearful."

The Healthcare Commission's *Count Me In* census, released in March, found that a staggering 55 per cent of mental health patients surveyed last year were accommodated in mixed-sex wards, contrary to Government claims.

A National Patient Safety Agency report last year revealed the scale of rape and sexual assault on mental health wards - figures in themselves mask substantial under-reporting.

'Double discrimination' for black boys with autism - edited from Disability Now, May 2007

Autistic children from black and minority ethnic groups face "double discrimination", according to a new report*. The research, published last month by the National Autistic Society (NAS), shows parents of autistic children in black and minority ethnic (BME) groups are less satisfied with their child's education than white parents. The report finds that 62 per cent of parents from BME communities say they did not have a choice in the school their child attended, while 78 per cent feel that the local education authority had not given them sufficient support.

Joan Nelson, the mother of a black child with autism, said: "Black boys are penalised on several fronts; because their special educational needs cause them to have difficulty accessing appropriate education, because they are black, and because they are boys."

*Missing out? Autism, education and ethnicity: the reality for families today; for a copy visit www.nas.org.uk

Young volunteer leads the pilot evaluation for Mencap website - Yap

In 2005, Mencap worked with young volunteers with a learning disability to develop a lifestyle website, called Yap - a place where young people can find out what other young people like to do in their spare time. Now, young volunteers are leading on the Yap website evaluation.

Alice Clancy a young volunteer with a learning disability, from Devon worked with Dr Mary Kellett from the Open University Children's Research Centre to undertake and develop her own research into the Yap website. Alice wanted to find out what young people think about the website, and here are her findings in her own words:

The results: Having fun on the website came out very strong; Special login, games and speed of getting around were all quite good; Instructions, colours and sharing messages were all ok; Finding your way around was not so good

From the comments made by the website users, I have concluded that the pictures on the website are really important to them. They like the downloads and they like pictures of people and other places but if possible could the pictures be quicker to download. Also it would be good if there was more help to write the messages and if there could be longer messages. Some of the young people who used the website got lost. I think it needs to be made easier and simpler and an easier way to get back to the homepage when they get lost.

This work was supported by Mencap and Dr Mary Kellett from The Children's Research Centre, Open University.

Dyslexia Action and the British Dyslexia Association respond to The Mail on Sunday's article

The Mail on Sunday's article: "Dyslexic sues bank - because he can't read his statements", outlined the case of Mr Robert Neil, a man with dyslexia, who is suing his bank for not providing information about his account in a more accessible format. The article made the following statement: "If Mr Neil's actions succeed, it could force banks and businesses to review dramatically the way they deal with customers with any mental impairment."

Dyslexia Action and the British Dyslexia Association support the efforts of Robert Neil and The Mail on Sunday, to draw attention to the problems that some people with dyslexia and other learning difficulties, can have with printed matter. They also call on businesses to meet their responsibilities under the Disability Discrimination Act (DDA) which places responsibility on employers to enable access to premises and services by all staff and customers.

Dyslexia Action offers Workplace Consultancy to help employers and their staff with all the implications of dyslexia in the workplace. The British Dyslexia Association also offers bespoke training for employers.

Forum 'not run by disabled people' - Edited from Disability Now, May 2007

Campaigners have complained that a national forum set up to give people with learning difficulties a say in government policy is not led by disabled people. People First (Self Advocacy), a user-led learning difficulties group, said the National Forum for People with Learning Disabilities and its regional branches are controlled by people without learning difficulties.

Andrew Lee, director of People First, also claimed that forum members with learning difficulties carry out mainly non-paid roles, but co-ordinators and support workers without learning difficulties are paid. He said only those who will have the same support worker for two years may stand for election. Mr Lee said: "It's the system of election that we are criticising, not the national forum or the London regional forum."

But Karen Flood, co-chair of the national forum, insisted that the forums are user-led and democratically elected.

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