



# THE PHOENIX

Campaign for Independent Living in Lewisham

September 2005

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

CILL is about to make its first funding application and if successful we will be able to develop a publications service and a website. I will let you know how we get on.

Marcia Jones (CILL Vice-Chair) and I attended the Lewisham Community Empowerment Network meeting on 9 August and told everyone there about CILL and our aim to represent the voice of disabled people in Lewisham by raising awareness of real issues affecting us. We felt a lot of support from the Network and will we hope be able to work with them. At the meeting we found out about the Police Consultative Group and CILL will go to the next meeting to see whether that is something we need to be involved with.

The London Liberty Disability Festival will be held on 3 September 2005 – a one-day event in Trafalgar Square featuring performances by disabled artists, musicians and dancers plus a variety of stalls and displays – [www.london.gov.uk](http://www.london.gov.uk).

CILL also had its first donation this month from a supporter to help with administrative costs and as we now circulate THE PHOENIX to about 200 people this was greatly appreciated.

Please contact us if there is anything that you think we might be able to help you with.

## CILL Campaign updates

Many people were on holiday in August so there is not a great deal of change to report on the campaign front.

### CILL jumps in the deep end

Gary Evans (CILL Treasurer) and I will be meeting with Annette Stead (LBL Head of Leisure) this month to discuss improved facilities for disabled swimmers including raised water temperature.

### Direct Payments

CILL awaits information from Lewisham Council about the service being provided by Choices and the results of a review. We also have concerns about the information being given to clients about direct payments by a social worker and we are pursuing this with the Council. If you are experiencing problems with Choices or are having difficulty getting direct payments please get in touch with CILL and we will try to help.

### Inaccessible New Shop Front in Catford

CILL has asked the Head of Planning again about why planning permission for an inaccessible shop front was given.

### Cycle Paths But Not for All

CILL is also asking Lewisham Council for information about cycle paths in the Borough. Many are only fully accessible to standard 2 wheel cycles, so wheelchairs, mobility scooters and wheelchair cycles cannot use them.

### Council Budget Funding

Under the Achieving Access for All (disability equality) strategy 2004-07 Lewisham Council has provisionally set aside £3m from the 2005-08 budgets (£1m each year) to improve physical access to the public access areas of the council's buildings. Lewisham have identified and prioritised a rolling programme of works and set out generally what they plan to do each year. So far so good but CILL is making further enquiries as to how this will actually result in real improvements to specific buildings, whether local disabled people were consulted and the best way for disabled people to identify access difficulties to the Council.

### Bowley Close

CILL is looking at the poor service being received by disabled people from the clinics at Bowley Close which is now managed by Southwark PCT. There are serious difficulties with both the wheelchair and orthotics services and these are having a major impact on disabled people's quality of life. If you are or have been affected please contact CILL.

## Debenhams becomes first sued under disability access law

Disability Rights Commission, July 2005

Debenhams will become the first retailer to be sued under the Disability Discrimination Act (DDA) for failing to improve physical access to goods and services within its Derby store, the Disability Rights Commission (DRC) revealed.

Greg Jackson, a 43-year old wheelchair-user, is suing the retailer because he has been denied access to a section of the menswear department in the Derby store which can only be reached via a set of steps. The high street retailer, with 123 stores in the UK and Ireland and annual profits last year totalling £300.5m, failed to make improvements to the menswear section in Derby despite several requests from Mr Jackson dating back to January 2004. An independent report for the DRC shows that some 20 Debenhams stores pose similar access barriers.

Part three of the DDA places specific duties on shops and business that provide services available to the public to alter, adapt or remove physical barriers that make it unreasonably difficult for disabled people to receive fair treatment. The law, passed in 1995, gave businesses a nine-year breathing space to plan and prepare for changes that would benefit the UK's 10 million disabled people with a combined spending power of £80 billion. The equal access provision of the DDA came into force on October 1 2004. There are a total of 2.1 million service providers in the UK. An estimated 1.44m private sector service providers and 104,000 public sector providers will be affected by the 2004 duties.

## **Right to life-prolonging treatment upheld, but only if you can tell the doctor**

Disability Rights Commission, July 2005

A High Court ruling has created a Catch-22 situation for a disabled patient after upholding his right to life-saving treatment if he requests it, but allowing doctors to make the decision to remove it once he loses the ability to express his wishes or lacks capacity, says the Disability Rights Commission (DRC).

Les Burke, 45, who has Cerebella Ataxia is concerned that, because of his disability, he would reach a stage in his condition that meant he would no longer be able to swallow, talk or could loose capacity. At that point, doctors could decide to withhold, or withdraw, artificial food and water that would pro-long his life - even though he wants them to provide it. He would die of starvation and dehydration and he would be totally aware of what was happening to him.

When a patient lacks capacity it will be up to the doctors to decide what is in the patient's 'best interests'. The DRC is extremely concerned that 'best interests' could be based on a doctor's discriminatory attitude or negative stereotypical assumptions of a disabled person's quality of life.

The Appeal Court emphasised that disabled people should be "treated properly and in accordance with good practice, and that they will not be ignored or patronised because of their disability." (para 83). The DRC believes that without clear tests and considerations for doctors on the circumstances to give or withhold life-prolonging treatment that those laudable sentiments will remain just that.

## **Deaf and hard of hearing people failed by public transport services in London**

'Transport for All,' a comprehensive survey by the Royal National Institute of Deaf People (RNID) of over a thousand deaf and hard of hearing people's experiences of transport services in the Capital, confirms that all too often the system still relies entirely on the use of audible information and passengers ability to hear it.

With threats of terrorism high in the public's mind, there are real and pressing safety concerns felt by deaf and hard of hearing people, especially a lack of visual, real-time information to guide them in emergency situations.

The report also reveals a considerable lack of deaf awareness among staff working on tubes, trains and buses in the city. It is clear that even basic deaf and disability awareness training is seldom given to London transport staff. This means staff are unable to communicate effectively with over one million Londoners who live with deafness or hearing loss.

RNID is calling for:

- A review of emergency procedures on trains and the London Underground to ensure the needs of deaf and hard of hearing people are met, and suitable enforcement of such procedures.
- Provision of visual, real-time information on transport and in stations to ensure that accurate, accessible information accompanies information announced audibly.
- All passenger facing staff to receive deaf awareness training to a recognised standard.

## **Air travel accessibility survey**

The Department for Transport has commissioned a new research project about the experience of disabled flyers. The project will investigate how far the air travel industry complies with the Code of Practice issued by the DfT in March 2003 (entitled 'Access to Air Travel for Disabled People - Code of Practice'). The Code of Practice aims to improve the accessibility of air travel for people with disabilities by setting best practice for the industry.

Researchers at Transport Research Laboratory (TRL) will study journeys made by disabled air travellers to find out what their experiences of air travel are from booking the trip, departing from a UK airport, the flight and arrival back in the UK.

TRL looking to recruit 200 people who:

- have a disability; and/or
- required assistance at the airport and/or in flight; and
- have travelled on a UK based airline for at least one section of the journey.

If you have taken a flight between 01 June and 31 August 2005 and would like to complete a questionnaire about your trip, or take part in a 30-minute phone interview, please contact Ronit Tong, email [rtong@trl.co.uk](mailto:rtong@trl.co.uk) or telephone 01344 77 04 77.

## **Sickle Cell Society Telephone Help Line**

The Sickle Cell Society launches its first 24 hour National Telephone Helpline: 0800 001 5660

The free national telephone helpline service, believed to be the first of its kind for any black led charity in the UK will be supported by an interactive web presence which will enable families and individuals affected by sickle cell disorders to access information resources and support 24 hours a day. The service will be supported by the Society's team of medical advisers all of whom are experts in the field of haemoglobinopathies.

The new service will enable patients with sickle cell disorders and their families to self access the information they require to support them in the management of their condition. The service is available to everyone but will be specifically targeted at families with newly diagnosed infants, students living away from home for the first time and lone parents for whom 24 hour access to advice and support will help to reduce isolation and fear.

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