



THE PHOENIX

Campaign for Independent Living in Lewisham

November 2006

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

CILL has been successful in another funding application to support our Active Life Projects (ALPs). Our ALPs coordinator, Jenny Spencer, is now progressing all the projects and the next issue of the Phoenix will give full details. This month has seen both good and poor examples of involvement with disabled people and information about them follows but for me the best example of how to go about involving disabled people in consultation goes to Lewisham Hospital and the PCT for their planning of how to involve disabled people in their Disability Equality Scheme

Campaign Updates

'Equality for All' and the Disability Equality Scheme – CILL's Chair met with Rachael Turner, Head of Policy and Partnership, last week to discuss the issue of consultation. Rachael feels that we have misunderstood that 'Equality for All' and the Disability Equality Scheme (DES) are in fact different issues and that wide consultation around the DES did take place.

Last year CILL did take part in Lewisham Council's review of their equality policy and we accept Rachael's point that what we said then was taken into account in the DES but we were not approached this year with enough time to consult our members. The first we knew about any DES consultation was when we were called to a meeting, by Lewisham, to be held for Lewisham Disability Coalition (LDC) members. That meeting was four days before the consultation ended and neither the Chair nor any Trustees could get there but we did offer an alternative meeting date. That meeting did not happen because the earliest we could arrange a meeting for our members was after the end of Lewisham's DES consultation period. Rachael says that even though the consultation is over, the DES is ongoing and she has offered a meeting with our members.

For CILL the reality is that the DES consultation is over and the DES drafted. CILL is the organisation of disabled people who have first hand experience of independent living in Lewisham – an issue specifically addressed in Lewisham's survey – yet there was not time for our members to be consulted. CILL is credited as being consulted but that relates to the survey which the Chair sent in after the official end of the consultation. CILL's view is that disabled people needed to be involved not just in the consultation but in planning the best way to allow them to participate in consultation.

'Equality for All' will be a borough wide generic equalities scheme covering all statutory service providers in Lewisham, the consultation will be next year but the planning is happening now. Lewisham are using LDC as their 'strategic partner' in the planning process but we understood that is what happened with the DES. We are asking for wider consultation of User Led Groups in the planning process because no one group has all the answers and because we would like the consultation to be a success.

Since the Chair's meeting with Rachael, in the last few days, CILL has been asked to comment on the draft DES for the Council's Stronger Safer Communities Select Committee – this we have done and we are waiting to hear how the Committee's recommendations are considered by the Mayor and Cabinet.

Inaccessible New Shop Front in Catford – Still no word from John Lloyd Stephenson (LBL Planning) so we have reminded him.

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

Disability Forum

Another Disability Forum was held last Friday, 20 October. CILL has many concerns about the management of the Forum by LDC. Our understanding of the Forum has always been that it was to be an independent Forum facilitated by LDC with funding from Lewisham Council. In this way all disabled people of all impairments in the Borough would have an equal opportunity to come together and find out about and discuss any issue of concern to disabled people. At the same time LDC could bring to the Forum any issue on which they needed support to give strategic input to Lewisham in their role, for which they are funded, as Lewisham's strategic partner.

In this way Council funding would have the potential to impact directly and positively on every disabled person in this Borough in terms of information sharing, peer support, consultation and participation. However the reality is that only LDC members are invited to the Forum and the Forum itself is little more than an information session.

CILL's Chair brought nine people to the Forum (out of the 25 or so disabled people who were there), of those five had not been invited by LDC but we were told that everyone is welcome. The agenda was only available on the day (CILL's Chair was emailed a copy the previous evening after she spoke to LDC's Chair and told her that CILL intended to raise our concerns at the Forum) yet when we asked for a vote to adopt or change the agenda (which we believe is customary at open meetings) we were accused of hi-jacking the meeting. CILL's 'crime' was that we wanted an open discussion about the Forum's status and its role.

Apart from an interesting and valuable presentation from Hazel Fisher (see item below) there was little on the agenda apart from very basic information and there was also a rather uncomfortable slant towards the medical model of disability – a model the disabled people's movement rejected 25 or so years ago.

Apart from a couple of people only the CILL members interacted with anything that was said, blatantly disablist attitudes were not challenged by either LDC's Director or Chair and the overall flavour was of being patronised and controlled,

After the meeting CILL's Chair and Company Secretary again tried to elicit confirmation as to the Forum's status but both LDC's Chair and Director maintained that they did not understand the question. CILL was offered both a private meeting and an opportunity to influence the Forum by joining LDC's Forum Action Group but LDC have missed the point. We believe that the question of status and role has been tabled for the next Forum agenda and CILL's Chair will be asking for confirmation of this. At present the Forum is operating as an LDC service and that cannot be right. Take one example – consultation. CILL has been critical of Lewisham's consultation but if LDC was involved in planning the consultation process and took that to a widely advertised independent user led Forum for discussion and support surely that would be the beginning of true consultation, inclusion and participation for disabled people. Disabled people want it and Lewisham Council say they want it, so why isn't it happening. So that every one is very clear, this is what CILL says:

- **CILL will not be party to closed and secret discussion about the Forum**
- **CILL does not and will not seek to control the Disability Forum**
- **CILL believes that the Forum must be independent with the opportunity for all disabled people and their user led groups to participate, manage and control**
- **CILL believes that the Disability Forum should be the 'voice' of disabled people in Lewisham**
- **CILL wants to see an independent Disability Forum supporting LDC to meet its strategic advisory role**

PCT: Review of joint commissioning of services for adults with physical disabilities

Hazel Fisher from the PCT spoke at the Disability Forum about this forthcoming review. This review is really important for disabled people as it directly affects the services that we use or that are available. CILL will be asking to be involved in any consultation and if you would like to be involved contact us.

Parking at Lewisham Hospital

Deptford Action Group for the elderly (DAGE) are continuing their campaign to get free blue badge parking reinstated at Lewisham Hospital. The campaign is supported by local and national pensioners organisations and CILL. The Mercury Newspaper is also following the campaign.

There was a meeting at DAGE on 17th October 2006 between members of DAGE, Lewisham Pensioners Forum's Publicity Officer, Anne Roy, Denise Smith, Chair of CILL and Joy Ellery, Director of Knowledge, Governance and Communications, Lewisham Hospital, and Carl Shoben, Head of Communications.

Many issues were raised and Joy Ellery said that the Hospital valued patients/users views. She also said that the issue of parking is kept under constant review. DAGE had previously understood that parking charges were being used to deal with the Hospital's cash deficit but at this meeting it was said that charges were used to pay for security. Whatever charges are used for it does not address CILL's concern that disabled people who can only access the hospital by car are being charged to use the NHS at the point of entry and we support Anne Roy totally when she says that Lewisham Hospital are failing in its duty of care to Blue Badge Holders.

DAGE's Harry Haward concluded the meeting asking Joy to change the Hospital's current policy of charging Blue Badge holders and to report back on this within a month or a demo would be staged outside the Hospital by DAGE's members and any other interested groups and individuals. [If you want to know more about the campaign or to get involved please contact Tim Hamilton at DAGE on 020 8691 2849 or at \[tim@dage.ndo.co.uk\]\(mailto:tim@dage.ndo.co.uk\)](#)

New Building for Lewisham Hospital

At the meeting at DAGE and in response to other issues that were raised Joy Ellery highlighted recent improvements concerning their MRSA rates and stated that they were now one of the top hospitals in the UK for achieving the lowest rates of MRSA. Their new PFI building will provide nursing in four bed bays and is due to be in full use within a couple of months. The Hospital has also been classed as the capital's best for its children's services.

Disability Equality and Health

Lewisham Hospital and Lewisham Primary Care Trust will be producing a Disability Equality Scheme shortly and will be holding a consultation event on 8 November to get views from disabled people about their services. Not only are they running a well advertised open meeting to get disabled people's views they have also involved local user led groups in the planning of the event to make sure that the event is accessible and disabled people feel able to participate. This event will be a great opportunity for disabled people to have their say so if you want to help in shaping this scheme please get along to the meeting. Some information is enclosed about the Scheme and about the event.

Quercus

On 15th September, Stella Agunabor and Nick Harvey of the Quercus Project at Lewisham Council held a focus group at a **30+** meeting. This was one of a number that have been held with disabled people. The Quercus project aims to improve the environmental quality and "design out crime" in the northern section of Ladywell Fields. This involves diverting a section of the Ravensbourne River into the park. We were shown the draft plans and then asked for our views on a range of issues. The ensuing plans and results of the overall consultations were then on view at a Drop-in presentation at Lewisham Hall on 2nd Oct. 06. (Copies available).

Thank you to the Quercus project for coming to see and talk to us, we hope our involvement and input was useful. It was certainly good to know that disabled people and their needs have been taken into account in the design.

Accessible Housing Register

CILL is involved with the Greater London Authority's (GLA) accessible housing register advisory group. So that we can feed in to the group exactly how disabled people in Lewisham experience housing issues we would appreciate your input and a very short questionnaire is attached.

CILL 30+/'Drop-in'

Friday 27th October 2pm – 4pm "Accessible Housing"

An opportunity to use your experiences to influence the proposed London wide accessible housing register.

Friday 10th November. 2pm - 4pm "Introduction to Bowls"

Jill Tritton of Francis Drake Bowls Club, Hilly Fields will be doing a presentation comprising of a short film, Club member speakers, question time and a taster session.

Friday 24th November. 3pm - 4pm "So You Want to Recycle?"

Paul Hurwood, Lewisham Council's Waste Education Officer, will be consulting to get some feedback as to the practicalities of recycling for disabled people in Lewisham so that they can aim to make improvements where possible

UN treaty is victory for human rights

Edited from Disability Now, Elizabeth Choppin, October 2006

A United Nations (UN) treaty to protect the human rights of disabled people is one step away from being voted in by its general assembly.

The final text of the UN Convention on the Rights of Persons with Disabilities was agreed by a committee in August, after five years of negotiations. The aim is to secure the rights of disabled people in areas such as access to justice, education, health services and transport. Member states are expected to ratify the treaty in December.

Disability campaigners have welcomed the treaty as "a major victory" and a way to hold the UK government accountable over its disability policies. While the convention is not legally binding, campaigners hope the attention it brings will force member states to act.

After ratification, a UN monitoring body will judge whether governments are fulfilling their obligations, based partly on a report from disabled people's organisations in each country.

RNID warns against inadequate smoke alarms

During Fire Safety Week, (1 - 6 October), RNID, a national charity for deaf and hard of hearing people, urged everyone to make sure they have the correct smoke alarm for their needs. A staggering third of people with a hearing loss say they would have difficulty waking up to a conventional smoke alarm, especially since hearing aids are taken out at night. Almost a quarter (23%) say they would struggle to know if the alarm went off during the day.

Last year, BSI (British Standard Institute) published a national standard on smoke alarms for deaf and hard of hearing people. Smoke alarms that comply with the important new standard must meet demanding performance requirements for all parts of the system including the flashing light, standard audio alert and a vibrating pad, which is placed under the mattress or pillow to shake the user awake when the alarm detects smoke. RNID's BSI compliant smoke alarm has all of these features. For details on RNID's BSI compliant smoke alarm, or any other equipment designed for deaf and hard of hearing people, please contact RNID on Telephone 0870 789 8855, Textphone 01733 238020 or www.rnidshop.com.

Carers benefits unclaimed

Unclaimed benefits for carers now stands at £740 million. This major issue will, once again, be the central plank of Carers' Rights Day – the annual national day of action organised by Carers UK, which will be held on 8 December 2006.

The day is designed to raise awareness of the needs of the UK's six million carers, and to let as many carers as possible know of their rights and entitlements.

The 2006 Carers' Rights Day will focus particularly on the problems faced by older carers when claiming benefits and the complexity of the system. New research will be published which will focus on carers' awareness of the benefits.

Each year 2.3 million people become carers. Unpaid, they look after family, their friends and neighbours who cannot manage without help. Despite new legislation and efforts by the Government to ease their burden, carers still miss out on the help available to them, with the majority living in poverty and struggling to make ends meet. Yet the support carers provide saves the economy £57 billion each year.

ASBAH campaigns to prevent up to 1,000 terminations each year

ASBAH is the leading UK registered charity providing information and advice about spina bifida and hydrocephalus to individuals, families and carers and is actively campaigning the UK Food standards Agency (FSA), to introduce the compulsory addition of folic acid into UK flour products to prevent up to 1,000 terminations of spina bifida affected pregnancies each year.

Good evidence is now available from the United States, Canada, Chile and other countries, on the benefits to the population of flour fortification with folic acid, and the dramatic reduction of neural tube defects

It is now more than a decade since the UK's Medical Research Council completed a UK funded, world renowned study proving the lack of folic acid causes spina bifida. Many other countries have now followed the advice of COMA, the UK's Committee on Medical Aspects of Nutrition, and fortified flour.

There is now overwhelming evidence that the folic acid vitamin also prevents a large number of deaths from heart disease and stroke. There is an almost universal deficiency in the vitamin folic acid in most countries of the world.

ASBAH calls for the immediate implementation of COMA's recommendations and urges the FSA to take an interest in this issue.

National magazine for Deaf people launched at University

A national magazine for Deaf people and the signing community has been relaunched at the University of Wolverhampton.

The decision to relaunch the prestigious publication at the University is another feather in the cap for its student support. The Communication Support Unit currently provides 600 hours of support per week for deaf students.

Last week the University's pioneering support work for its deaf students received national recognition when its Communications Support Unit was nominated for a prestigious Times Higher Education Supplement 2006 award.

Joan Fleming, the University's Co-ordinator of Deaf Studies, said: "Sign Matters is the signing community's magazine, and the BDA is one of the oldest deaf organisations in the country so we are proud to host this launch event.

Alistair Wright, BDA Director West Midlands said, "The magazine is now the magazine of the signing community and not just of the deaf community, which is why we've changed the name and content to reflect that."

Off benefits, into uncertainty - Edited from Disability Now, October 2006

Concerns remain over government plans to push disabled people off incapacity benefit and into work. Campaigners are calling for problems to be addressed before the reform is rolled out. Elizabeth Choppin investigates In the coming years, the government hopes to shift one million disabled people off Incapacity Benefit (IB) and into work.

Campaigners are demanding to know if disabled people including those who cannot work, either on occasion or permanently will be supported in the process and if employers will be ready to take those who can work.

Proposed legislation would funnel over one third of the UK's 2.7million IB claimants into the job market via schemes such as Pathways to Work for disabled people.

Many campaigners fear the system will leave disabled people at the mercy of assessments by benefits advisors and medical professionals who do not fully understand their needs, leading to some being forced into work, often prematurely.

For those who are deemed fit for work, questions remain on whether employers are open to making adjustments and rooting out discrimination against disabled people.

Decisions are also still being made on levels of Employment and Support Allowance rates, which will replace IB and Jobseekers Allowance.

Mental health patients spend 12 times as long in hospital, yet the conditions of their wards are among the worst.

A survey for Mind's Building solutions report found that nearly a third of people (29 per cent) who had recently stayed in mental health wards were dissatisfied with their ward's state of repair, with 28 per cent unhappy about ward cleanliness. This backs up last year's Healthcare Commission finding that standards of cleanliness are markedly poorer in mental health hospitals compared to acute hospitals.

Mental health inpatients often have to spend many weeks in hospital, with average stays of around 58 days, nearly 12 times longer than patients with physical health problems. 56 per cent of recent inpatients surveyed rated their ward as unpleasant or very unpleasant. Mind is calling for standards on wards to be improved to ensure that all patients have a therapeutic and stimulating stay. The lack of activities leads to boredom, which causes frustration and slows recovery.

Mind's key recommendations

- Service-users should be involved in the design of new hospitals
- Wards should be maintained to the highest levels of cleanliness
- All patients should have access to green spaces
- All sleeping accommodation must be single-sex
- Urgent action must be taken to address levels of violence on wards
- Wards and their facilities need to be pleasant and stimulating, with a good range of activities.

Every Disabled Child Matters

A new campaign to get rights and justice for every disabled child calls on all supporters to sign up to the Every Disabled Child Matters campaign which is a partnership between Mencap, Contact a Family, the Council for Disabled Children and the Special Education Consortium.

Every Disabled Child Matters published 'Between a rock and a hard place', a campaign briefing which highlights that the government's ten-year childcare strategy is failing disabled children.

Jo Williams, Chief Executive of Mencap, said, "Disabled children have been left out for too long. Mencap's research has shown that 8 out of 10 families with disabled children are at breaking point'. The time has come for us to challenge politicians to show us that every disabled child matters as much as all other children." Sign up to the Every Disabled Child Matters campaign on www.edcm.org.uk,

Mini cab driver breaks the law

A contract hire mini cab driver called by the BBC to collect a blind woman Jane Vernon (39) and her guide dog after she appeared on BBC News 24 in London on Oct 13 2005, has been ordered to pay £1,400 for refusing to take the dog.

Mr Majekodunmi, who works for Niven & Co, a cab company contracted by the BBC, remained unrepentant saying he would still refuse to take guide dogs in his mini cab.

Jane Vernon, who is a Legal Officer at the Royal National Institute of the Blind (RNIB) said: "This experience was very upsetting indeed. I'd been working in the office all day and was asked to come out to do a live mid evening interview with BBC News 24. Afterwards, I was tired, and cold and just wanted to get home. The driver made me feel like I was a second-class citizen, like I didn't count at all."

Bill Alker, a spokesperson from RNIB said: "This kind of situation happens too often to blind and partially sighted people. It's absolutely wrong and must stop. Many drivers, cab company operators and the authorities that provide licences are together flouting a good law that was introduced to help blind and partially sighted people get about more independently."

If you are a man living with arthritis, Arthritis Care needs you

Arthritis Care is looking for men of all ages to join their People Bank, a bank of people with arthritis who get involved in different areas of their work.

Activities you could be involved in include:

- being interviewed for their publications, including Arthritis News
- interviews with external newspapers, magazines, television and radio
- providing feedback on drafts of their information booklets
- taking part in focus groups and photoshoots

People Bank members can opt to do as much or as little as they like and are vital to the work they do.

For an application form, or more information, email: PeopleBank@arthritiscare.org.uk.

Social care bosses fail on adult protection - Edited from Disability Now, John Pring, October 2006

Social services chiefs have failed to address the omission of vital information from their own "comprehensive" national standards on adult protection. Last year, DN told the Association of Directors of Social Services (ADSS) that its new standards failed to mention the criminal offences of ill-treatment and neglect of adults with learning difficulties and mental health problems.

Dwayne Johnson, chair of the ADSS's safeguarding adults network, said the organisation was now focusing on other issues, such as convincing the government to put its No Secrets vulnerable adult guidance on the same statutory basis as that for child protection and domestic violence.

No Secrets also fails to mention the two offences. Mr Johnson said the ADSS had "moved on" since its standards were launched last October and now needed to examine how to increase the number of successful prosecutions for abuse of vulnerable adults.

DRC could sue government over health - Edited from Disability Now, John Pring, October 2006

The Disability Rights Commission (DRC) is threatening to sue the government if it fails to address "shocking" inequalities faced by people with learning difficulties and mental health problems in primary healthcare.

The DRC has revealed the results of an 18-month formal investigation, which found that people with learning difficulties and mental health problems in England and Wales are more likely to experience major illnesses, develop serious health conditions at an earlier age and to die of them sooner.

The DRC told DN that the Department of Health and primary care trusts had one year to secure major improvements or face action under the Disability Discrimination Act's new disability equality duty, which comes into force in December.

The DRC said that "a wide range of current practices, identified by the investigation, could clearly breach this duty". The panel that led the investigation will reconvene in one year to check progress.

Health minister Rosie Winterton said the government had "already started to act", with £7million to improve the health of people with mental health problems and £42million allocated to help primary care trusts implement the learning difficulties white paper, Valuing People. She said: "We will be working with the DRC to develop a full response to their report, which will be available at the turn of the year."

Sativex at the last hurdle

Campaigners have welcomed an announcement that could see the cannabis-based spray Sativex licensed in the UK within a year. If successful, Sativex could be prescribed to treat other MS symptoms such as pain and given to people with arthritis and cancer if a doctor thinks it would help. An MS Society spokesman said: "It's time for cannabis-based medicines to be made available on the NHS."

European diabetes report may lead to driving ban

Edited from Disability Now, Elizabeth Choppin, October 2006

People with insulin-treated diabetes should be barred from driving emergency vehicles, according to controversial European guidance published in August.

Campaigners and disability groups were enraged after a report from the European Commission Working Group on Diabetes recommended people with insulin-treated diabetes should not be allowed to drive ambulances, fire engines or police cars.

The Driver and Vehicle Licensing Agency (DVLA) has not officially responded to the report yet but campaigners are concerned that the new guidance could lead to the introduction of a "blanket ban". Existing DVLA guidance states that drivers with insulin-treated diabetes should be dealt with on a case-by-case basis.

A DVLA spokeswoman said it was too early to comment on the impact of the report.

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

SUPPORTED BY CAPITAL COMMUNITY FOUNDATION – NEIGHBOURHOOD RENEWAL UNIT
CILL, 5 Silverdale House, Silverdale, London SE26 4SD email: campaign@fsmail.net

What is going on and How to contact CILL:

What and When:

What's On	When	Where
CILL 30+ Accessible Housing An opportunity to use your experiences to influence the proposed London wide accessible housing register.	27 October 2 – 4pm	The Clubroom 21 Marton Close Off Firhill Road Bellingham SE6 3SS
Out and About	29 October 1 – 3 pm	Ladywell Park Ladywell Road Ladywell SE13 (By the café)
Drop-in Introduction to Bowls Jill Tritton of Francis Drake Bowls Club, Hilly Fields will be doing a presentation comprising of a short film, Club member speakers, question time and a taster session.	10 November 2 – 4pm	The Clubroom 21 Marton Close Off Firhill Road Bellingham SE6 3SS
Out and About	12 November 1 – 3pm	Ladywell Park Ladywell Road Ladywell SE13 (By the café)
CILL 30+ So you want to recycle Paul Hurwood, Lewisham Council's Waste Education Officer, will be consulting to get some feedback as to the practicalities of recycling for disabled people in Lewisham so that they can aim to make improvements where possible. (3 – 4pm)	24 November 2 - 4pm	The Clubroom 21 Marton Close Off Firhill Road Bellingham SE6 3SS
Oot & About	26 November 1 – 3pm	Ladywell Park Ladywell Road Ladywell SE13 (By the café)

If you are interested in any of these events and would like to know more, if you need advice or support or advocacy or just have an issue about your independent living that you do not know how to deal with please contact CILL at campaign@fsmail.net or call 020 8776 6967.

GLA Accessible Housing Register Questionnaire

If you are or have been affected by issues relating to housing your experience can influence the London wide accessible housing register being set up by the Greater London Authority.

CILL will be holding a meeting at the Bellingham ‘drop-in’ on 27 October but if you cannot be there but want to feed in your views please let us have your replies to the following questions by 17 November 2006.

1. What is the best way of involving disabled people in identifying their own housing need?
We would like you to please consider issues like, self assessment of need and how best to communicate your needs to the relevant people.
2. What do you think are the gaps in existing services for providing information, advice and support for disabled people?
Consider the whole re-housing process: deciding to move, application, assessment, finding a property, bidding, suitability, adaptability, moving in.
3. Which types of information do you think are most useful? From whom would you like to receive support and advocacy?
For example do you think this is best undertaken by an independent organisation such as a local disability/community group or should it be provided by the Council?
4. Do you know of services that work well or poorly? If so why?
5. Please give any advice or suggestions about housing that you feel the AHR Project Team should take account of.

Contact details (optional):

Please return to CILL either by email – campaign@fsmail.net
or post – CILL, 5 Silverdale House, Silverdale, London SE26 4SD