



THE PHOENIX

Campaign for Independent Living in Lewisham

September 2007

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

Back in May Lewisham Council began their consultation on their review of adult social care. CILL has always understood that the social care budget cannot just be left to continue overspending year on year and we welcomed Mayor Sir Steve Bullock's decision to use Council reserves of £2m to support the current overspend while a review took place. Disabled and older people and carers were not involved in the review and when we were asked for our views at the start of the consultation we were alarmed at the proposals – changing eligibility criteria (by splitting the substantial band into higher and lesser, with lesser losing eligibility) and increasing charges. Also some services, shopping and housework, will have to be arranged and paid for privately.

We have huge concerns about the impact of the changes to quality of life and human rights. The review proposed various cost cutting measures but only those that legally require public consultation were put forward in the consultation documents. CILL also discovered that while the Council carried out service reviews for people with learning difficulties and for older people last year no service review for younger physically disabled people took place. Yet the present review of all services draws presumably on the findings of the earlier reviews.

CILL has been involved in the campaign we set up 'All Our Futures – Lewisham Crisis' throughout the summer and through our postcard campaign we asked for two things:

- ✓ A full equalities impact assessment on the proposed changes to provision.
- ✓ The involvement of disabled people's organisations in an immediate review of adult social care for physically disabled people.

The Pensioners' Forum has also been running a postcard campaign.

Lewisham Council's consultation will end shortly - in mid September - and they have stressed that no decisions have yet been made. We understand that once the consultation period ends a report of all the views expressed during the consultation (at meetings and in questionnaire replies) including an impact assessment will be considered and then Mayor Sir Steve Bullock and Cabinet will make the final decisions. If you have not already completed a consultation questionnaire please do so now. If you need a form or help to complete it you can get it from the Lewisham website at www.lewisham.gov.uk or by email at adultcare@lewisham.gov.uk or by calling their helpline number on 020 8314 7046. You can also get the questionnaire from any of our advocacy meetings and help to fill it in. As an organisation CILL will be completing a questionnaire in the next few days.

These changes will seriously and negatively impact on the quality of life of disabled people, older people and carers throughout this Borough. We must influence the report and impact assessment so that there is real understanding of our lives before final decisions are made.

Influence the changes by completing the questionnaire.

Lambeth Council backs down on changes to eligibility criteria

Plans to save money by taking services away from vulnerable adults in need of support by imposing more restrictive eligibility rules have been shelved.

Vulnerable adults who may need care or support are assessed by the Council. Lambeth provides services such as personal care, domestic help, day services and meals on wheels to people it thinks have 'critical' or 'substantial' needs. This will now not change.

Lambeth Council's Cabinet which met on 30th July also confirmed that it would not re-introduce the proposal to restrict eligibility to only those people with 'critical' needs during the lifetime of this administration.

If the plans had gone ahead only those people with 'critical' needs would have been eligible to receive services. Lambeth would have been one of a tiny number of councils in the country with such restrictive eligibility rules.

What does this mean? – Views of SOS Lambeth

Everyone getting community care services at present will now not have to be re-assessed to see if they fit into the 'critical' category. The 700+ people that the Council admitted would lose services will now not have these taken away.

We welcome this decision and believe that it is the only rational one the Council could have made in response to the overwhelming view of those who took part in the consultation. This clearly demonstrated

that the Council's adult social care services are regarded as a very high priority, not just by those who depend on them but also by large numbers of other residents.

Disabled and older people and their family carers have lost faith and trust in the Council. The Council must now work to restore its reputation as a borough that cares about and supports its most needy residents.

We ask the Council to now work with its partners in health and the voluntary and community sector and with service users and carers. It must make this an opportunity for a constructive debate on the future development and funding of services for vulnerable adults and their carers who need to be placed at the heart of all of its policies and programmes that are aimed at improving life for the residents of Lambeth.

SOS Lambeth is a campaign, coordinated by Lambeth voluntary and community organisations working with vulnerable adults, to protect vital social care services

Activities and Campaigns

Advocacy and Independent Living Support Groups – Funding for our Deptford Project has now ended but we now have some funding from Lewisham Council (to the end of March 2008) for a weekly meeting at The Bridge Leisure Centre in Sydenham. The meetings at The Bridge will be a chance for people to get together and have a chat and a coffee but there will also be an advocate there to talk to if you need information advice or support. There will also be a meeting at The Ringway Centre at Grove Park on 27th September where lunch will be available – please let us know if you will be coming along (for catering purposes).

Thursday 30 August	1 p.m to 4 p.m.	Ringway Centre, 268 Baring Road (opposite Coopers Lane, SE12	Advocacy
Wednesday 5 Sept	2 p.m to 4 p.m.	The Bridge Leisure Centre, Kangley Bridge Road, Sydenham, SE26	Independent Living Support Group plus Advocacy
Monday 10 Sept	1 p.m. to 4 p.m.	Lewisham Library, 199 Lewisham High Street, Lewisham, SE13	Advocacy
Wednesday 12 Sept	2 p.m to 4 p.m.	The Bridge Leisure Centre	Independent Living Support Group plus Advocacy
Thursday 13 Sept	1 p.m to 4 p.m.	Ringway Centre	Advocacy
Wednesday 19 Sept	2 p.m to 4 p.m.	The Bridge Leisure Centre	Independent Living Support Group plus Advocacy
Monday 24 Sept	1 p.m. to 4 p.m.	Lewisham Library	Advocacy
Wednesday 26 Sept	2 p.m to 4 p.m.	The Bridge Leisure Centre	Independent Living Support Group plus Advocacy
Thursday 27 Sept	1 p.m to 4 p.m.	Ringway Centre	Independent living Support Group and Advocacy Light lunch provided

Children with a learning disability banned from UK School Games

Over 300,000 children with a learning disability are not allowed to compete in the UK School Games, due to take place in Coventry from 23-26 August.

Elite athletes with a learning disability are currently excluded from the Paralympic Games and this has caused an unjust knock-on effect, preventing school children with a learning disability taking part in the UK School Games.

The UK School Games were introduced in March 2006, with the intention of bringing together the most talented young sports people across the UK to compete in an environment designed to replicate the feel of major events such as the Olympic Games and Paralympic Games.

Dame Jo Williams, Chief Executive, Mencap, said: "We strongly urge the government to find a solution, so that children with a learning disability have the chance to compete in next year's UK School Games."

RNIB accuses NICE of incompetence - risking blindness for 10,000 people

The Royal National Institute of Blind People (RNIB) has accused NICE (The National Institute for Health and Clinical Excellence) of massive incompetence that could lead to up to 10,000 people in the UK going blind unnecessarily.

NICE has announced, following an unprecedented public outcry, that it will not issue guidance on sight-

saving drugs as expected this Autumn but will now spend months considering its position before issuing a second set of preliminary guidance for consultation. This action by NICE means that final guidance on provision of sight-saving drugs for wet AMD will be delayed until next year.

In June, NICE published stringent preliminary recommendations denying anti-VEGF treatments to 80 per cent of patients with wet AMD (age-related macular degeneration) in England and Wales, and offering treatment to just one in five 'lucky' patients - but only after they've gone blind in one eye.

NICE received a record-breaking 20,000 responses from the public and health campaigners outraged at their recommendations to limit the use of anti-VEGF drugs (Macugen and Lucentis) to treat wet AMD, the UK's leading cause of sight loss.

Disabled Entrepreneurs Recognised

Leading disability charity Leonard Cheshire and easyGroup Chairman Sir Stelios Haji-Ioannou have launched an annual award for an exceptional disabled entrepreneur.

The 2007 winner of the Stelios Disabled Entrepreneur Award will be presented with a cheque for £50,000, generously donated by Stelios himself, at the British Chamber of Commerce's prestigious Chamber Awards ceremony at London's Victoria and Albert Museum 29 November.

Sir Stelios says: "I am very passionate about encouraging an enterprising spirit and decided to work with Leonard Cheshire to set up this award.

"With 50% of disabled adults out of work, helping to remove the barriers disabled people face to being in business is essential. Self employment is the only viable option for many disabled people as it offers flexibility and helps bypass much of the prejudice that sadly still exists in the workplace.

"I look forward to seeing the best of the entries and handing over this significant amount of money to a very deserving winner."

Disabled entrepreneurs wishing to apply need to demonstrate how the prize money would make a major difference to their business.

Six finalists will be shortlisted and on the night of the awards ceremony the winner will be personally given the cheque by Sir Stelios.

The deadline for applications is 14 September. Disabled people interested in applying can find out more information by visiting www.disabledentrepreneur.org.

Director General Bryan Dutton says: "Sir Stelios' award scheme will give a huge financial boost every year to one disabled entrepreneur allowing them the vital head start that all new businesses need."

Forest Hill Post Office

The Post Office is currently seeking feedback from customers who regularly use the Forest Hill branch on the following areas:

1. proposed opening hours at the new branch
2. access arrangements into the new branch
3. the facilities that are planned for the new branch.

The consultation closes on the 11 September.

I'm more than happy to discuss further. My contact details are Kerryn Pannell Strategic Programme Manager Policy and Partnerships Unit London Borough of Lewisham T - 020 8314 3941. E - kerryn.pannell@lewisham.gov.uk

'Leisure Volunteer Buddy Scheme'

The Leisure Volunteer Buddy is a new scheme that is to be launched at the Everyday Swim Event Weekend on 15th & 16th September 07 at the Bridge Leisure Centre.

Training for the volunteers has been provided by the Everyday Swim Co-ordinator and Volunteer Centre Lewisham with the support of Parkwood Leisure at The Bridge Leisure Centre, Wavelengths Leisure Centre, Ladywell Leisure Centre and Ladywell Arena and Leisure Connections at Downham Leisure Centre.

The aim of the Scheme is to provide a volunteer service to enable individuals and community groups to book a tour of the leisure facilities in their area; to assist them to discover the wide range of activities, events, programmes and initiatives that the leisure centres in Lewisham provide for the local residents. The volunteers will also assist in providing information and guidance on items such as the Lewisham Plus Card, the location and how to use facilities such as, changing rooms, gyms, swimming pools, sports halls and many other areas..

The Volunteer Buddy Scheme is asking for people to volunteer for a couple of hours a week or month to provide a friendly guide of local leisure facilities,

The benefits to the volunteer are, training, Everyday swim t shirt and free use of leisure facilities on the day they are volunteering to take part in an activity of their choice.

The scheme is looking for volunteers who have a couple of hours a week to spare, especially if you have experience of working with people in the community! (although this is not a requirement). Additional skills such as the ability to translate programmes or ability to sign would also be very warmly received!

The training of volunteers will take place on the following dates:

28th Aug - at Wavelengths and Ladywell Leisure Centres

29th Aug - at Bridge Leisure Centre and Downham Leisure Centre

If you would like more information or to express an interest in volunteering please contact: Jo Mechior - Everyday Swim Co-ordinator on mob: 07795690656, Sylvia Curtis - Lewisham Sport and Leisure Service on 020 8314 3793

Seven million suffer from noises in the head, new research reveals

One in seven people have experienced the symptoms of tinnitus – noises inside the ears or head – but 70 per cent of GPs surveyed have never had any training on the condition, new research from national charity RNID has revealed.

The charity found that 15 per cent of those surveyed – which equates to more than seven million people across the UK - had experienced tinnitus, often described as ringing, whistling, humming or buzzing in the ears or head, for more than a day.

Tinnitus can cause severe distress and suffering – disrupting people's work, relationships and sex lives. RNID has launched a new web service - www.tuneouttinnitus.org.uk - with information to help those with tinnitus understand the condition and advice on simple techniques and equipment to manage it.

London's Disability Rights Festival 2007

Liberty is a free festival that showcases the talents of Deaf and disabled artists and performers. This summer Liberty celebrates its fifth year with an exciting programme

Date: Saturday 1st September, Time: 1pm to 6pm Location: Trafalgar Square Admission: FREE Email: liberty@london.gov.uk Recorded information: 020 7983 4277 Minicom: 020 7983 4458, Website: london.gov.uk

Liberty is a festival for everyone and is organised to be inclusive and accessible. On the day the following facilities and services will be available at Trafalgar Square:

*Information points, *Disability Awareness trained stewards, *Programmes in large text and Braille, *BSL interpretation and Audio description, *Accessible toilets, *Lifts, *Induction loops at information points, *Wheelchair loan service, *Charging point for electric wheelchairs and scooters, *Assistance dogs area, *Organic Café, *Free mobility bus between Westminster Tube and Trafalgar Square from 12 - 7pm courtesy of Metroline, *Free parking nearby for blue badge holders. Limited availability, advance booking only 0207 983 6521

The Queen's Award for Voluntary Service

To celebrate her Golden Jubilee in 2002, the Queen announced a new annual UK National Honour to recognise and reward excellence in voluntary activities carried out by groups in the community. The Award is given in recognition of outstanding achievement by groups of two or more people in the United Kingdom, Channel Islands and Isle of Man (subsequently referred to as the United Kingdom), who volunteer their own time to enhance and improve the quality of life and opportunity for individuals or other groups in the community.

Successful groups will receive a certificate signed by The Queen. They will also receive a commemorative piece of crystal for display at their main place of operation.

If you have any queries about the Award or would like advice in completing the form, you can phone The Queen's Award for Voluntary Service Office on 0845 000 2002.

Further information about the Award and a nomination form can be found on the Award website: www.queensawardvoluntary.gov.uk Closing date for nominations - 30 September 2007.

Information

www.direct.gov.uk/disability - online public information including employment, financial support, independent living, disability rights, health and support

Malachi Mentoring Project – for people with mental health problems in Lewisham weekly meetings to reduce isolation and social exclusion, increase self esteem and self confidence, re-introduce to appropriate agencies Tel: 07946 419 920 Or email Malachimentoring1@yahoo.co.uk

Lewisham Shop Mobility - wheelchairs, scooters and escorts for shopping in Lewisham 7 day a week 10 to 4. Annual fee £10 or £2 a visit. You do not need a blue badge. Details/Bookings: Lewisham Shop Mobility Scheme, 29 Molesworth Street, Lewisham SE13 7HP or tel: 020 8297 2735

Eligibility for NHS Continuing Healthcare: Request for last remaining Retrospective Claims

The Department of Health has announced that any remaining "retrospective review" cases in relation to Fully Funded NHS Continuing Healthcare (formerly known as Continuing Care) should be raised with the relevant NHS body on or by 30th November 2007.

NHS Continuing Healthcare refers to the funding of the care of a person with long term care needs. If it can be demonstrated, by means of an assessment, that a person has a 'primary health need' then the

NHS pays all care costs. If the person does not have a primary health need then the patient may have to contribute to the cost of care.

In 2003 the Ombudsman found that the NHS had interpreted incorrectly Continuing Care policy guidelines in a number of cases, and some people had therefore been charged wrongly for their care. The NHS subsequently reviewed and corrected their existing systems and republished their Continuing Care policy guidance.

To ensure all relevant cases can be dealt with effectively, any remaining challenges to continuing care decisions made after 1.4.1996 and before 1.4.2004, should be lodged on or by 30th November 2007 wherever possible. Please note that all other cases (i.e. in relation to decisions taken after 1.4.2004) will continue to be dealt with in the normal way through the local Primary Care Trust.

If you think a decision affecting you needs to be challenged, you should contact Penny Pickering, Older Adults Services Manager at Lewisham Primary Care Trust on email penny.pickering@lewishampct.nhs.uk or 020 7206 3234

Further information about the Retrospective Review Process in London can be found on the NHS London website. www.london.nhs.uk

Parliamentary Joint Committee on Human Rights report – response by the Disability Rights Commission

Chairman of the DRC, Sir Bert Massie said in response:

'The most important point from the Committee is that many older and disabled people living in private or voluntary sector care homes are not protected by the Human Rights Act (HRA) and this legal loophole must be plugged.

'No part of the care sector should be beyond laws that protect human dignity and guarantee freedom from inhuman and degrading treatment. The abuse and neglect of older and disabled people in care can only be tackled if perpetrators are handed out the highest sanctions, whether it is in the NHS, local authority or privately run care homes.

'For too long a succession of bleak reports and stories have highlighted abuses within the system. The Government and the incoming Commission for Equality and Human Rights should be making this a number one priority for action.'

One for All – Persons with Disabilities' Initiatives in Development

We at Bangladesh Protibandhi Kallyan Somity (BPKS) are very excited to inform you about a seminar that we will host in Dhaka from Sunday 10th to Thursday 14th February 2008. The seminar – "One for All – Persons with Disabilities' Initiatives in Development" – will discuss an innovative and successful approach which many of you are already familiar with – the Persons with disabilities' Self-Initiatives to Development (PSID) approach.

BPKS has been working with the disabled people of Bangladesh using this approach – which promotes the vital involvement of persons with disabilities in the nation's development – for the past 11 years. We are holding this seminar to introduce and increase understanding of the PSID approach, and create a venue for discussion and exploration of the possibilities that the approach offers the disability movement beyond the borders of Bangladesh.

This is a must attend seminar for all people involved in the disability movement and for all others interested in contributing to this movement. It will be attended by professionals in the disability field, persons with disabilities (PWDs) involved in the disability movement, representatives of development organizations (particularly disabled peoples' organizations) and individuals with an interest in the disability field who want to contribute to the development of people with disabilities.

Further information about the seminar is at www.bpkssbd.org Abdus Sattar Dulal, Founder & Executive Director. Bangladesh Protibandhi Kallyan Somity (BPKS), Dhaka.

Mental Health Alliance gives final verdict on 2007 Mental Health Act

The new Mental Health Act will go down in history as a missed opportunity for legislation fit for the twenty-first century, the Mental Health Alliance said. Publishing its *Final Report on the Mental Health Act*, the 77-member Alliance said that the Act was much improved by Parliament but fails to modernise mental health law or to promote equality for people with mental health problems.

Alliance chair Andy Bell said:

"While other countries, often with less well-developed mental health services, are fundamentally modernising their mental health laws, our already outdated law has at best been mildly improved."

"The right to advocacy and the new safeguards for children are genuine steps forward. But the overall verdict of Alliance members is that the 2007 Act is a disappointment. Progressive measures such as giving people greater choice and rights to services, have been omitted."

Alliance vice-chair Rowena Daw commented:

"The refusal to include any test of impaired decision-making and the failure to give patients a right of appeal against the restrictions placed on them while on community treatment orders are fundamental

weaknesses in our legislation that will eventually have to be put right."

"But there is still hope. Many key aspects of how the Act will work in practice have been left to the Code of Practice. The Alliance will make every effort to achieve further improvements in the Code and to give service users and their families a voice in that vital process."

DNA vaccine' for multiple sclerosis

Scientists have reported that a newly developed DNA vaccine appears safe and may produce beneficial changes in the brains and immune systems of individuals with multiple sclerosis (MS).

The findings are reported in an article posted online that will appear in the October 2007 Archives of Neurology journal and refer to early tests carried out at the Montreal Neurological Institute with DNA vaccine BHT-3009.

The scientists will now continue to investigate the vaccine by carrying out a phase 2b trial - a randomised clinical trial in approximately 290 patients.

Alison Handford, Research Manager at the MS Society, said: "These are very early but encouraging findings and we welcome news that researchers are planning the phase 2b trial, which we hope will yield positive results."

Real change not short change

The physical and emotional impact of taking on a caring role can be hard enough. But carers are also faced with a devastating blow to their finances - particularly harsh when some are forced to give up work. The benefits system is failing to deliver the vital support carers need. Despite making such a huge contribution to society carers pay a heavy price for their commitments. New research from Carers UK shows :

- Half of carers are forced to give up work to care
- Two out of three carers have to cover extra costs of disability
- A third are facing severe financial hardship such as cutting back on food or unable to pay bills.

Carers UK believes the scale of the problem cannot be underestimated. We are calling for a radical rethink on how society values carers.

Carers benefits are not working. Carers want real change not short change.

Lewisham Plus Card - Leisure can cost less

The Lewisham Plus Card gives you access to leisure throughout Lewisham – for only £2 a year. With a Lewisham Plus Card, you can enjoy 25% off the full adult price of the following activities in any Lewisham Council-run leisure centre, park or site: swimming, fitness studios, squash activity classes such as aerobics, use of Ladywell Arena, tennis court hire, Beckenham Place Park golf course (for the last three hours of play), rental of an allotment.

If you receive a pension or have a disability, as well as the discounts listed above, you can use the following for free: swimming facilities, fitness studios (apart from the cost of your gym induction) and the Ladywell Arena athletics track.

You can apply for a Lewisham Plus Card if you are aged 16 or over and live or study in the London Borough of Lewisham and receive:

Benefits as a disabled person; or a freedom pass, council tax credit, family tax credit housing benefit, income support, rent allowance, disability living allowance, jobseeker's allowance.

If you care for someone who has a disability concession Lewisham Plus Card or a child with a disability, you can accompany them into the facilities for the same discounted price with the carer's card.

If you are over 60 we need to see either your state retirement pension, your full UK driving licence or your passport.

If you are an asylum seeker we need to see your ID card.

Students must provide their student ID card.

When applying for a card take with you:

- A passport size photograph of yourself
- Evidence that you are eligible for the Lewisham Plus Card (see the list above)
- A completed application form
- £2.

Any council-run library or leisure centre in the borough can process your application. You will be given proof of purchase so you can start using the leisure facilities straightaway. Your official card will then be sent to wherever you applied within four weeks.

For queries or copies of the application form in other formats contact the administration team, sport and leisure service on 0208 314 8499, or email sportandleisure@lewisham.gov.uk

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