



THE PHOENIX

Campaign for Independent Living in Lewisham

September 2008

A message from Denise Smith, Chair, CILL

You will have noticed that this is a special edition Phoenix and not the first email bulletin of Disability Review. There have been a few technical difficulties (sadly that's about the limit of my vast computer know how but thankfully others are working on it as I type). This means that Disability Review has been delayed by a few weeks but passwords will be issued very soon. Everyone at CILL is really sorry about the delay but we expect to be up and running in the next few weeks so thank you for your patience. Meanwhile I think that what is happening now is so important that we have issued this special Phoenix.

CARE AND SUPPORT – THE BIG DEBATE

At last we may see some action over the widespread crisis in social care with the launch of a national debate on the future of Care and Support announced by the Prime Minister on 12 May. The debate will continue to the end of the year with a Green Paper on care and support coming out in 2009.

Professionals and service users have known for a long while that social care is in crisis. Local authorities are struggling to meet costs through a mix of Government funding, council tax and individual contribution. The result has been charging policies and restrictive eligibility criteria that are adversely affecting some of the most vulnerable people in our society. Service provision that has become a postcode lottery so what you get and what you pay depend entirely on where you live. At the same time means testing has become a disincentive to saving and having a private or occupational pension. Then there are the many totally unaware that as they get older care costs are not met by the taxes and national insurance they have paid – that unlike the NHS, social care is not free. Many services are 'institutionalised' with people being expected to simply 'slot in' and take what is on offer and too often the focus is personal care only – washing, dressing, toileting and may be some shopping and laundry. All necessary but does not really embrace real quality of life. Often service users have little choice about basic issues that most people take for granted like what time you get up, when you go to bed, when and how often you can have a bath or a shave.

To be fair the Government had already acknowledged change was needed and had put in place an ambitious Transformation Programme to improve outcomes. Ultimately the move is towards the individual self assessing needs and choosing and controlling how they are met through a personal budget. The Government has made £52 million available to local authorities to help them

with transformation to services to provide better advocacy and information, more control and personalization of services (often referred to as self directed support) and better prevention. Back in June I attended the Self Directed Support Conference (organized by the London Direct Payments Forum) and the whole personalization agenda sounds really good and exciting. What it does not do for me is to address the fundamental issue of funding and I believe it's the money that will make or break transformation.

Just when I was starting to get negative about how 'transformation' could deliver without increased funding the Government started the care and support debate to look at how it is all going to be funded. The big reason for this is quite simple – the population is ageing and if services are under-funded now it's going to get worse in the future. In the next 20 years the number of people aged over 85 will double and aged over 100 will quadruple. Let me give you some figures for London: By 2026 the number of people aged 65 or over in Croydon and Enfield will rise by nearly a quarter. In Harrow and Hillingdon the number of over 65s is expected to reach 15%, in Havering and Sutton, 16% and, in Bromley, 17% - one sixth of the borough's population. Medical advances will mean that disabled people will live longer and healthier lives. A third of all men and half of all women over the age of 65 are expected to need long term care and support as they age. Younger disabled people will need support earlier. This will put huge pressure on care services and an estimated extra 1.7 million people will need support in 20 years time. Maintaining the current system will result in an annual £6 billion deficit. So what we have now will not work.

Care Service Minister Ivan Lewis is conducting a six-month tour of events debating the future shape of the care and support system in the UK. At those events professionals in the public health, social care and NHS services and third sector organisations will discuss their views on how best to develop a system for care and support that meets the needs of society into the future. I attended the London Stakeholders' event in July at which Care Service Minister Ivan Lewis said:

"It is essential that we hear Londoners' views on how we create a high quality, affordable care system for a rapidly ageing population in a way that promotes independence, choice and control for everyone. In 20 years' time the number of people living in Greater London over the age of 65 will have risen to over 1 million, and the number of people over 85 will have risen to over 140,000. So we need to decide now how the care and support system must adapt. The current system is simply not sustainable. I urge people to get involved - the debate affects us all."

Care and Support is being defined as the activities, services and relationships that help people to be independent, active and healthy, as well as able to participate in and contribute to society, throughout their lives. For me that is a welcome move towards citizenship and equality.

Many people have not yet realized how huge this issue is – we are talking major cross Government reform to put in place a system that will fund care and support that is likely to affect everyone in the UK. The scope of the debate is wide and will include all services related to personal care, some elements of housing support services for disabled and older people, and adaptations including the Disabled Facilities Grant, support for Independent living including the Independent Living Fund, and benefits that help with the extra costs of disability in later life.

The debate is trying to address three issues Firstly do we agree with the Government's vision of a system that builds on existing reforms, supports everyone as an equal member of our society and promotes choice and control, is targeted at those most in need and is affordable? No disagreement from me there but the next issue is more difficult – how do we pay for it? Should service users pay or their families or should everyone in society pay? Different countries fund their systems in a variety of ways – Japan promotes formal services, everyone contributes and people over 40 pay more. Germany supports informal family care and all working adults and employers contribute. In France all working adults contribute plus individuals buy private insurance. So far most people taking part in the debate favour contribution by everyone in our society but what do you think? Thirdly, once we have the money how should it be spent – local flexibility or national consistency, different levels of financial support based on the individual's income and assets or the same funding system for everyone? For me that is the most difficult issue to resolve. In my opinion local flexibility is one of the reasons for the present postcode lottery but I can understand disadvantages to a national consistency approach such as being unable to cope with local cost variations. I like the idea that financial support should be targeted at people with low income and assets but doesn't that leave people who have saved and contributed to pensions at a disadvantage? Is it going to be too difficult to achieve everything for everyone within one system or do we need two systems - one for people with long term conditions and one for people to prepare and cope with older age. Personally I would like to see free care and support for all those who need it delivered through one system and funded by taxation but I think that personal contributions will remain.

I am a Trustee at the National Centre for Independent for Independent Living (NCIL) and CILL is a member organisation. I attach a note of NCIL's position on proposed reform for you to have a look but basically NCIL want to see four objectives for a new care framework:

- it must be underpinned by equality and human rights;
- it must deliver an outcomes approach to services – an 'Every Adult Matters';
- it must provide universal entitlements to support; and
- it must include investment to transform services and ensure success.

I would encourage you to contribute your views to the debate either through a website www.careandsupport.direct.gov.uk or by attending any events in your area.

Also I'm really interested to know what you think so please click 'reply' or email campaign@fsmail.net and have your say. Do you agree with the aims set out by NCIL? Are they the most important ones for you? Are there other points you would like included?

By the time the Green Paper and proposals come out we are likely to be in the run up to the next General Election and call me a cynic but I do not see any party going into it with the promise of more taxation. I hope I am wrong and that 60 years after the first Labour Government brought us the NHS that New Labour press ahead to put in place a fair and sustainable care and support system. At the end of the day whether or not it happens may be down to you because if enough people start demanding change to an unsustainable system we might just influence our politicians.